Health Services Safety Investigations Body

Investigation report

Insulin: supporting safe self-administration for patients in the community with a disability

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Mental health, Medication, Learning disabilities

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Before reading this report

This report includes consideration of the care of people experiencing mental health problems and mentions eating disorders, self-harm, suicide and death. Some readers may find the contents distressing. Information about how to access mental health support can be found on the NHS website.

A note of acknowledgment

The investigation team would like to thank the many people who contributed to this investigation. Patients, families and staff shared their personal experiences with us, including intimate and traumatic situations.

About this report

This report is the second in a series considering the self-administration of insulin by people with diabetes mellitus (diabetes) in community settings. Each report in the series focuses 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.

This report focuses on adults with diabetes who require insulin treatment, and who have not been supported to self-manage (including self-administer) insulin as intended alongside a disability or impairment. It also considers the scenario of family members or people in a caring role administering a person's insulin. The investigation did not consider all disabilities that may affect the administration of insulin, but learning may also be applicable to disabilities not described in this report; some disabilities may also be hidden or non visible. The final report in the series will consider people with a learning disability.

The investigation learned about the experiences of those affected by this patient safety issue by hearing from patients, families, carers and staff across primary and community care, and mental health and specialist diabetes services. Some of their experiences are described as vignettes in this report.

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 report 1 of this series and additional terms are described in this report.

Executive summary

Background

This report is the second in a series considering the self-administration of insulin by people with diabetes mellitus (diabetes) in community settings. Many people with diabetes manage and administer their own insulin, either by injection or using a combined monitor/pump device (a hybrid closed loop system). However, a disability or impairment may affect their ability to safely manage their own insulin if they are not supported. This can lead to short-term and long-term health problems, which can be life threatening.

HSSIB identified incidents where a person with diabetes or their family/carer had administered insulin incorrectly (the patient safety issue of focus). In these incidents, a disability – such as a visual or memory problem – had influenced how someone had administered insulin.

The investigation

The investigation explored the following areas in relation to the patient safety issue:

- supporting the development of people’s competency – that is, their skills, experience, knowledge and ability – to manage insulin
- recognising and responding when people’s circumstances change, such as deterioration in a disability
- assessment of people’s mental capacity to make decisions in relation to insulin.

The investigation’s findings are offered to support improvements in services for people with diabetes who require insulin and have a disability or impairment. Several findings may also apply to community services that support people with other long-term conditions.

Findings

- People with diabetes (who require insulin) are at risk of harm through the administration of insulin when pre-existing or new disabilities/impairments have not been recognised or adjusted for.

- People are not always empowered to become competent to manage their insulin, with assumptions made that a person is not competent to do so because of a disability/ impairment.
- Supporting people to safely self-manage their health, including insulin, requires integrated working across community services. Where this is limited, such as due to resource challenges or limited collaboration, people are put at risk.
- Efforts to empower and enable people to self-manage insulin are affected by the competing demands on, and the capacity and accessibility of the community services that provide this type of support.
- Designated and protected resource aimed at supporting the development of insulin self-management skills have shown benefits for patient experience and have reduced demand on community services.
- There is no national competency framework for the management of insulin by patients and families that supports community services to identify and make reasonable adjustments for a disability/impairment.
- Administration of insulin by staff in care homes (delegated administration) may reduce demand on community teams but is limited by barriers to implementation, including high turnover of care home staff.
- Some people with type 2 diabetes may be prescribed insulin without first optimising other diabetes treatments and/or exploring preferences. This means a person may be exposed to the risks of insulin unnecessarily.
- There are people with diabetes (who require insulin) whose circumstances mean they are not monitored for changes in a disability/impairment, including via long-term condition reviews in general practice.
- People may not engage with healthcare services to enable the regular monitoring of their condition. Engagement is affected by the ability of services to meet patient needs but may also represent other situations that require a response, such as in relation to patient safeguarding.
- Electronic systems in general practice may not alert users when people have not requested repeat prescriptions of insulin, removing a potential opportunity to identify patients who need support.
- Diabetes technology, such as insulin pen devices, are not always designed in a way that supports people to administer insulin when they have a disability/impairment, such as visual impairment or problems with dexterity.
- There are concerns about the future competence of the healthcare workforce to support the increasing numbers of people with hybrid closed loop systems.

- Healthcare workers may not identify when a patient's mental capacity to make decisions in relation to their insulin may be compromised, meaning a more in-depth assessment in line with the Mental Capacity Act (2005) may not occur.
- Limited education and practical support for application of the Mental Capacity Act (2005) by healthcare staff means its principles are sometimes misunderstood.
- Patients with diabetes (who require insulin) and who experience fluctuations in their mental capacity, are at risk of harm when services do not proactively plan for a time when the patient may lose the ability to manage their insulin safely.

HSSIB makes the following safety recommendations

Safety recommendation R/2026/084:

HSSIB recommends that NHS England/Department of Health and Social Care provides guidance to integrated care boards and community providers setting out expectations for service models that empower and support people to manage and administer insulin in community settings. This is to support recognition of models that have safely, effectively and equitably engaged patients, their families and carers, including through the use of modern diabetes technology for self-management.

Safety recommendation R/2026/085:

HSSIB recommends that NHS England/Department of Health and Social Care develops a tool for use in community settings to support the assessment of competency of patients, their families and carers to manage and administer insulin and care for people with diabetes. This should include recognition of a person's circumstances, the impact of disabilities and impairments, and potential adjustments to support administration where safe to do so. This is to support consistency in how competency is assessed for the safe management of insulin within the context of modern diabetes care.

HSSIB makes the following safety observation

Safety observation O/2026/085:

National bodies can improve patient safety by providing clarity on expectations around 1) how staff recognise that a patient's mental capacity may be compromised in relation to decisions about their self-management of insulin, and 2) the undertaking of a mental capacity assessment by the most appropriate person. This should include clarification on the practical application of the Mental Capacity Act (2005) to situations where a patient's capacity may fluctuate and where sharing confidential information to support patient safety may be appropriate.

HSSIB suggests safety learning for integrated care boards

HSSIB investigations include safety learning for integrated care boards where this may help organisations think about how to respond to a patient safety issue that relates to integrated care across a geographical footprint. Informed by the findings in this report, the investigation proposes the following safety learning.

Safety learning for integrated care boards ICB/2026/017:

HSSIB suggests that integrated care boards develop data-driven approaches to effectively identify the diversity of their populations' characteristics and social circumstances, and use this data to support community providers to design services that empower and enable people to be involved in a patient's care, including through supporting self-management of medications and conditions.

Safety learning for integrated care boards ICB/2026/018:

HSSIB suggests that integrated care boards, through future planning for neighbourhood health services, include consideration of how patients who may be at greater risk of harm from insulin administration due to their specific circumstances – for example co-existing disabilities, social isolation or receiving home-delivered medications – are proactively monitored to identify changes in their circumstances. This may include using technology such as remote monitoring.

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. Informed by the findings in this report, the investigation shares the following local-level learning.

- How does your organisation create the conditions for staff to empower and enable patients, their families and carers – through a person-centred approach – to self-manage insulin where appropriate?
- How does your organisation proactively identify the varying needs of people with diabetes in its local population, and ensure these are met to enable their management of insulin?
- How does your organisation promote patient-centred care and facilitate self-care models that empower and enable patients, such as those with diabetes?
- Does your organisation allocate specific resources to support patients, families and carers to develop competency to self-manage insulin, and ensure those resources are protected to empower and enable people?
- How does your organisation ensure that staff supporting the development of a person's competency have the required knowledge and skills to provide that training and education in relation to diabetes and insulin?
- How does your organisation support staff to identify and code a person's disabilities/ impairments that may influence their competency to self-manage insulin, and ensure these are considered and adjusted for when deciding whether a person is competent?
- Does your organisation have systems and processes to identify where patients have not requested their repeat medication prescription, or the frequency of the requests have changed, which may indicate changes in their circumstances?
- How does your organisation ensure long-term condition reviews reliably take place for patients who may be at a higher risk of deterioration due to their circumstances, for example those with multiple long-term conditions?
- How does your organisation identify and code patients – who may be more vulnerable to harm from insulin due to their circumstances – for increased monitoring? This may include patients who have their medications delivered to their home, who do not have family nearby, or who are housebound.
- Does your organisation provide practical training and guidance to support staff to consider the mental capacity of patients to make decisions around their insulin when there are concerns capacity may be compromised?

- Does your organisation provide practical guidance to staff to help identify when it is lawful, ethical and appropriate to share confidential information about a patient to mitigate risks to their safety, including with family members?
- Does your organisation have accessible routes via which staff can seek urgent support when they are concerned a patient's mental capacity to make decisions about their self-care may be compromised, particularly in high-risk situations?
- How does your organisation support staff to develop 'crisis plans' for patients who self-manage insulin to protect their safety at a later point when their capacity to make decisions in relation to their care may change?

1. Background and context

This report is the second in a series considering the self-administration of insulin by people with diabetes mellitus (diabetes) in community settings. This report focuses on people who have a disability which may affect their ability to safely manage their insulin including when self-administering insulin.

HSSIB identified incidents where people (people with diabetes themselves, or their families or carers) had administered insulin incorrectly. This is the investigation's patient safety issue of focus. In these incidents, a person's disability – such as a mobility or memory problem – had influenced how they had administered insulin.

This section provides background information specific to the topics discussed in this investigation and how the patient safety issue was selected. Broader background information about diabetes and insulin is available in report 1 (section 1).

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. 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 and the person may need insulin therapy.

1.1.2 Insulin can be administered by subcutaneous injection, commonly with an insulin pen device. 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 continuous glucose monitor ‘talking to each other’ to automatically adjust the insulin dose (Diabetes UK, 2025).

Patient safety and insulin

1.1.3 Insulin is a time-critical and high-risk medication. Early or delayed administration can cause harm or reduce its effectiveness (Specialist Pharmacy Service, 2025) and it can cause harm even if used as intended (NHS England, n.d.). Insulin-related patient safety incidents are common and persistent across healthcare (Care Quality Commission, 2025) and several organisations have described learning in support of insulin-related patient safety (for example, Specialist Pharmacy Service, 2026). HSSIB (2022; 2025a; 2025b) has considered incidents in acute hospital settings and on discharge of patients from hospital; these include a specific investigation into the risks associated with administration of insulin in inpatient settings.

1.1.4 Insulin-related incidents reported to national databases in England (see appendix) often involve incorrect administration. Incorrect administration includes omissions (insulin not administered), administering it at the wrong time or dose, or administering the wrong type of insulin. The risks associated with healthcare-led administration of insulin are well recognised (Getting It Right First Time, 2020; Lange Ferreira et al, 2025a) and in community settings contributing factors include the complexity of insulin regimens and poor electronic communications (Leeson, 2022). HSSIB (2025b) has previously examined electronic communications on patient discharge from acute hospitals which included several insulin-related incidents.

1.1.5 The wide range of insulin types, devices and regimens is recognised to pose a risk to patient safety because it increases the potential for incorrect selection and administration (Lange Ferreira et al, 2025a). To help mitigate this risk, there is national advocacy for people to self-manage and self-administer insulin when they are able to do so (for example, Care Quality Commission, 2016; Getting It Right First Time, 2020; Joint British Diabetes Societies, 2023; Specialist Pharmacy Service, 2023).

Self-management of insulin

1.1.6 Supporting a person to manage their own medication is an example of person-centred care. Person-centred care is where healthcare staff support a person to develop the knowledge, skills and confidence to effectively manage their own health (The Health Foundation, 2014). Effective person-centred care supports people’s independence, quality of life and positive outcomes (Giusti et al, 2020). In addition, when people take responsibility for their health, this reduces pressure on healthcare services.

1.1.7 Self-administration of insulin is where a person injects their own medication; it may also include a person using an insulin pump (see 1.1.2). A person's family member or carer may also be trained to administer insulin. The vast majority of insulin administration in community settings is done by the patient with or without support from a family member/carer.

1.1.8 Insulin management, which includes administration, by the patient themselves or by their family/carer involves many considerations, as incorrect management can result in complications and harm. These considerations were explored in report 1 (section 1.2) and include the need to understand (Diabetes UK, 2023):

- the type of insulin required, and the dose and timing of administration
- how the insulin is prepared and stored
- how the insulin is administered with a technique to ensure full absorption
- how to recognise and manage complications of diabetes and insulin.

1.1.9 Self-management of insulin has many benefits. It can empower the person, provide them with control, and support their independence (Specialist Pharmacy Service, 2023). A person in control of their own insulin management can also ensure they self-administer at the correct time and can adjust the dose depending on their blood sugar levels. This can support better control of blood sugar levels and reduce the risk of complications.

1.2 Disability and impairment

1.2.1 A disability is defined by the Equality Act (2010) as a 'physical or mental impairment with a substantial and long-term adverse effect on normal daily activities'. Where an impairment is temporary it is not classed as a disability but may affect a person's ability to do normal daily activities. Normal daily activities include communicating, following instructions (for example taking a medication), eating food, and getting washed and dressed.

1.2.2 Impairments can be categorised as follows:

- Physical impairment – relates to the condition and functioning of the body. Conditions such as arthritis or reduced dexterity can affect a person's ability to move.
- Mental impairment – relates to a person's mental health and/or cognition, and may affect thinking, memory and behaviour. Conditions such as dementia can affect a person's memory.
- Sensory impairment – relates to a person's senses and their ability to interact with the world around them. Conditions include visual impairment and deafness.

1.2.3 An estimated 16.8 million people in the UK had a disability in 2023/24, accounting for 25% of the population (UK Parliament, 2025). The most common reported impairments related to mobility, stamina/breathing/fatigue and mental health. For people of state pension age, additional reported impairments related to dexterity, hearing, vision and memory. The proportion of people reporting a disability is increasing; the increase is mostly in mental health and/or social/behavioural impairments.

Mental capacity

1.2.4 This report includes a focus on mental capacity. Mental capacity refers to the ability of a person to make a decision when they need to. Capacity is not fixed and can change over time, and depending on the nature of the decision. The Mental Capacity Act (MCA) (2005) is the law in England and Wales that sets out principles and the procedures for people who may lack mental capacity to make decisions.

1.2.5 The MCA (2005) requires that ‘a person must be assumed to have capacity unless it is established that [they] lack capacity’ (principle 1) and that ‘a person is not to be treated as unable to make a decision unless all practicable steps to help [them] to do so have been taken without success’ (principle 2). Supported decision-making requires healthcare staff to build a relationship with the person; understand what is involved in a particular decision; and consider what aspects of decision-making a person may need support with.

1.2.6 Steps are involved in determining whether someone has capacity to make a particular decision (NHS, 2024; Social Care Institute for Excellence, 2022):

1) Determining whether the person is able to make the decision, with support if required.

2) Determining whether there is an impairment or disturbance in the functioning of the person’s mind or brain.

3) Determining whether the person’s inability to make the decision is because of the impairment or disturbance.

The MCA (2005) describes that ‘a person is unable to make a decision’ if they are unable to do one or more of the following:

- understand the information relevant to the decision
- retain that information
- use or weigh that information
- communicate the decision.

1.2.7 In situations where a person is assessed as lacking decision-making capacity in relation to a given area, the MCA (2005) allows a decision to be made in the person's 'best interests' under certain circumstances (principle 4). A decision made in best interests is one that considers a person's wishes, feelings, beliefs and values, including any choices that they may have expressed in advance; it should also restrict their rights and freedoms as little as possible (principle 5).

2. Competency and safe management of insulin

Due to national advocacy for self-management of insulin (see 1.1.5) and because of the potential risks to patient safety (see 1.1.3), the investigation focused on self- and family/carer-management. To explore this issue, the investigation examined reports of relevant patient safety incidents and spoke to patients, carers and other stakeholders. More detail about the investigation approach can be found in the appendix.

By grouping the evidence gathered, the investigation identified two themes of focus:

1) supporting competency of someone with a disability/impairment

2) monitoring for and managing changes in a person's circumstances when they also manage insulin (see section 3).

This section focuses on the investigation's examination of competency of patients, their families or carers (collectively termed 'people' in this section) to safely manage and administer insulin where the person also has another disability/impairment. It includes consideration of empowerment and enablement, and the role of community nursing teams in providing support.

2.1 Competency

2.1.1 The investigation heard from healthcare staff that safe management of insulin requires "competency". A competent person – including patients, their families and carers – has the right combination of skills, experience, knowledge and ability to perform a task (Health and Safety Executive, n.d.). The investigation heard that competency includes the skill to undertake the task of administering insulin, and the memory and decision-making skills needed for management. When people were not supported to be competent to manage insulin or were considered competent when they were not, incidents were identified where patients had come to harm from the insulin administered.

2.1.2 The impact of incorrect or variable insulin administration in identified incidents included the following complications, some of which had contributed to patient deaths, such as in vignette A:

- hyperglycaemia (high blood sugar levels) – including diabetic ketoacidosis (DKA), a life-threatening condition in which acids accumulate in the blood
- hypoglycaemia (low blood sugar levels) – which can result in loss of consciousness and potential brain injury.

Long-term complications associated with diabetes were also seen, including visual impairment, kidney problems requiring dialysis, and vascular disease leading to conditions such as stroke.

Vignette A – patient safety incident

The patient had type 1 diabetes and a history of variable compliance with their insulin, evidenced through an abnormally high HbA1C (a measure of average blood sugar levels over the last 2 to 3 months). The patient was under the care of services for eye, heart and foot complications. They died following admission to hospital with DKA and concerns were identified that the patient had not been administering their insulin.

2.1.3 In the incidents reviewed by the investigation, factors that contributed to incorrect insulin administration included limited knowledge or skill, and a lack of ability to perform the task. Incidents included administration of insulin at the wrong dose or wrong time, or administration with a technique that resulted in the patient not receiving the full dose. Other incidents included administration of out-of-date insulin, and insulin being stored incorrectly which potentially affected its effectiveness.

2.1.4 For a person to become competent, they need to be supported through training and education to ensure they have the appropriate knowledge and skills to administer insulin, as well as manage the condition and any complications. There are multiple factors that may impact on a person's competence and the investigation was told by staff that these need to be recognised. It was also heard that diabetes itself can cause significant distress (see report 1, section 1.3.7) and without appropriate support patients may not be competent to care for themselves. This was demonstrated to the investigation by the incident described in vignette B.

Vignette B – patient safety incident

The patient was a young adult who had recently been diagnosed with type 1 diabetes. While living in a supported situation, they managed their insulin well. When their living situation changed they did not have the support they needed and were admitted to hospital several times because of DKA. They were later found to have died at home, potentially as a result of their diabetes management. Staff had attempted to ensure the patient understood that they needed to administer their insulin as prescribed.

2.1.5 Patients told the investigation about their experiences of learning to administer insulin after diagnosis of diabetes. They described “shock” at the diagnosis and variable training and education to develop skills and confidence. They were unsure if any pre-existing disability/ impairment was considered as part of their introduction to insulin. Where the disability/ impairment was physical and visible, the investigation heard that it was more likely to be explored. Healthcare staff described assuming someone “could” self-manage insulin, particularly if a disability/impairment was not apparent. Assumptions were also heard that someone “would not be” competent because of a disability/impairment. Vignette C summarises the experience of one patient which is described in more detail in report 1 (section 2).

Vignette C – family narrative

The patient had a diagnosis of type 1 diabetes. Over the years, her emotions influenced her management of her blood sugar levels and there were periods of time when she did not take her insulin or took too much. It was discussed whether the patient 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 because of assumptions that it would not be appropriate for her.

2.1.6 The investigation also observed community nursing teams (CNTs) working with people to develop competency. The CNTs took a “coached” approach, as observed during the visit described in vignette D, which involved consideration of the patient’s circumstances and any disability/impairment. The benefits of the self-management approach were evident from the perspective of patient health and wellbeing, and in terms of reduced demand for services.

Vignette D – investigation’s observation

The community nurse visited a patient with a diagnosis of type 2 diabetes. He described how in the past he had feared hypoglycaemia and had eaten lots of sugary snacks to prevent this. Since working with the self-management team, he had become confident

administering his insulin and managing his diet. He felt he needed the flexibility to manage his own insulin and not wait for a nurse, and that he was “getting there” with becoming independent.

2.1.7 During the investigation’s observations, CNTs described wanting to support people to administer their own insulin, saying it was “safer” than them being involved. However, they also described:

- limited ability to coach people
- having to adapt to the needs of increasing numbers of people with a disability/impairment
- increasing numbers of patients being prescribed insulin and referred for support
- increasing insulin prescribing rates due to rising numbers of people with type 2 diabetes (NHS England, 2022).

For some patients, CNTs also questioned the rationale for prescribing insulin and whether the risks and benefits to the patient had been fully considered.

2.2 Empowerment and enablement of people

2.2.1 The investigation was told that “disempowerment, lack of self-efficacy and lack of knowledge” meant people were not being empowered and enabled to manage insulin when they may be able to do so, regardless of any pre-existing disability or impairment. This meant the potential safety benefits of self-management, including by family members/carers, were not being accessed.

Empowerment and control

2.2.2 In the context of this investigation, empowerment means supporting someone to take control of and responsibility for their self-care and insulin management. The investigation was told by some patients, who did not self-administer insulin, that they had not been aware they might be able to do so. Healthcare staff described assumptions that some people would not be able to because of a disability/impairment, or would be unwilling, and so it had not been discussed. Assumptions were seen to be related to mental and sensory impairments, frailty and people’s age.

2.2.3 People shared perceptions that some staff might view older age as a disability. It was heard to be “easy” for older people to become disempowered when staff work in a “paternalistic” way (making decisions on the patient’s behalf) (Lange Ferreira et al, 2025a).

Paternalistic approaches do not align with person-centred care (Kilbride and Joffe, 2018) but these attitudes were heard to exist particularly where the healthcare system did not enable person-centred care because of resource constraints and demand.

2.2.4 The investigation found evidence that people are not always empowered to become competent to manage insulin. The investigation also found beliefs among staff that people are unwilling to learn to administer insulin. In contrast, people told the investigation that they wanted to learn but had not been supported to do so. This disconnect between staff beliefs and people's actual willingness has also been described elsewhere (SCARU, 2025). These findings have contributed to the local-level learning set out in 2.2.14.

Disempowerment on admission to hospital

2.2.5 CNTs told the investigation about situations where patients, who had been competent to self-manage insulin, were admitted to hospital and had "lost" their ability. Several patients also said that their independence had been "taken away" on admission to hospital, and when discharged they lacked the confidence to start self-managing their insulin again. Disempowerment of patients on admission to hospital is a known challenge and patients may not know they can continue to self-administer their insulin or may not be enabled to (Lange Ferreira et al, 2025b; 2026).

2.2.6 HSSIB's (2026b) investigation into supporting safe insulin administration in inpatient settings included consideration of safe self-administration. That investigation found that 'many' patients who safely self-manage insulin at home are prevented from doing so in hospital. Contributory factors include lack of local policies, reluctance of staff to enable patients to self-administer, lack of clarity about storage of insulin, and misconceptions about the regulatory stance. These findings have contributed to the local-level learning set out in 2.2.14.

Enablement and organisational support

2.2.7 In the context of this investigation, enablement means giving someone the ability to administer insulin and monitor their blood sugar levels using technology. The investigation was told that, even when people are motivated and likely able to manage insulin, they are not enabled to do so. Healthcare staff described that, in addition to assumptions (see 2.2.2), enablement is influenced by whether services can meet the needs of patients.

2.2.8 The investigation observed that much of the enablement support for insulin was provided by CNTs. CNTs described difficulties tailoring support to the multiple and varying needs of their local populations. The investigation saw these difficulties in practice for patients with different characteristics (such as age and disability) and social circumstances (such as education levels and economic status).

2.2.9 The investigation met patients who wanted to manage their own medications but were prevented from doing so by a physical or sensory disability (see 1.2.2). Barriers included the design of insulin pen devices not being accessible for people with a disability; for example, the investigation saw a patient with carpal tunnel syndrome who was no longer able to use an insulin pen device. The investigation also saw where CNTs had worked with patients with a disability/impairment to enable self-administration. A repeated example was where patients were physically able to self-administer, but their mental health or cognition issues meant they struggled to remember the dose or timing. Visual reminders – such as prompts on fridges – had been developed with the patients to help them.

2.2.10 The investigation observed people with multiple needs and these compounded their difficulties accessing self-management support. Examples included where people had a disability and:

- did not speak English; in one area visited “over 100 different languages” were spoken; a lack of language-specific resources meant people were less likely to administer insulin
- came from cultures whose values, beliefs and practices had not been considered by local services; this was heard to affect engagement with self-care programmes
- were experiencing homelessness; this is considered in report 1 (section 3.3).

2.2.11 The investigation examined why services were unable to provide tailored support to individuals. CNTs described how services had not “kept pace” with population changes. Potential “blindness” to certain issues was also described, such as levels of literacy; 18% of adults (aged 16 to 65) in England have poor literacy levels and may struggle with understanding long text (Department for Education, 2024). CNTs further described how demand for their services (see 2.3) meant they were “stuck”; they were unable to explore new ways of working, but without new ways they were not able to meet populations’ needs and reduce demand.

2.2.12 The investigation also engaged with integrated care boards (ICBs). The role of ICBs includes commissioning appropriate services, such as community nursing and diabetes services, to meet the needs of people in their area (Health and Care Act, 2022). ICBs described challenges achieving this role because of limited data about diversity and the nature of their populations’ needs, and financial constraints that affected their ability to support new ways of working. Similar issues have also been found by other HSSIB (2023c; 2026a) investigations. At the time of writing, national restructuring changes were also heard to be impacting on ICBs’ operational activities and ability to focus on supporting services to meet the needs of their patients.

2.2.13 The investigation found that community-based services to support the self-management of insulin were not always accessible. Demand on services prevented allocation of resources to understand local population needs and support service improvement. The Equality and Human

Rights Commission told the investigation that services need to anticipate reasonable adjustments for equitable access to care for people with a disability, and that organisations must consider the equality impact of policies to ensure they do not disadvantage people with a protected characteristic (Equality and Human Rights Commission, 2024). This investigation's findings have contributed to the following learning for ICBs which aligns with their future purpose to improve population health, reduce inequalities and ensure access to care (NHS England, 2025a).

Safety learning for integrated care boards ICB/2026/017:

HSSIB suggests that integrated care boards develop data-driven approaches to effectively identify the diversity of their populations' characteristics and social circumstances, and use this data to support community providers to design services that empower and enable people to be involved in a patient's care, including through supporting self-management of medications and conditions.

2.2.14 HSSIB investigations also include local-level learning where this may help providers/ organisations respond to a patient safety issue at the local-level. Informed by the findings in section 2.2, the investigation shares the following local-level learning for organisations that provide care to patients with diabetes who require insulin.

Local-level learning

- How does your organisation create the conditions for staff to empower and enable patients, their families and carers – through a person-centred approach – to self-manage insulin where appropriate?
- How does your organisation proactively identify the varying needs of people with diabetes in its local population, and ensure these are met to enable their management of insulin?

2.2.15 Throughout the investigation, a recurrent issue influencing organisational support for people with diabetes was heard to be a lack of a "community strategy". Services described a need for a strategy in light of increasing numbers of people with diabetes and people with complex needs. National stakeholders also described that a lack of strategy had influenced variability in community specialist diabetes service provision across the country, variability in access to diabetes technology, and concerns about training and education for the workforce.

Similar was heard by the investigation in relation to supporting people with a mental health problem in report 1 (section 3.2). The wider strategy for supporting people with diabetes in community settings will be considered further in later reports in this series.

2.3 Role of community nursing teams

2.3.1 The investigation observed that CNTs provided much of the community support for people to develop competency to manage insulin. CNTs described their key role in supporting the safety of patients who may be more vulnerable to harm due to their circumstances. Community diabetes nurse specialists also provided support in some geographical areas but this varied depending on local resources (see report 1, section 3.1).

2.3.2 All the CNTs who engaged with the investigation shared that local commissioning, local demand and service capacity all influenced the cohorts of patients they were able to support. For example, in report 1 (section 4.2), CNTs described not being commissioned to provide care where a person is able to self-administer insulin and is not housebound, but who may still be vulnerable due to a mental health condition. Service capacity and demand challenges also meant it was quicker for CNTs to administer insulin than coach someone through the process, limiting enablement.

2.3.3 Demand on CNTs is a known issue. There are many factors that contribute to this demand, including growth in the number of people living into older age and increasing numbers of people with healthcare conditions for which they need care (The King's Fund, 2016). Workforce challenges also limit the service capacity of CNTs (Care Quality Commission, 2025). CNTs described “picking up” insulin care that “could” be provided by others (for example carers, see 2.3.15) and questioned whether “unnecessary” insulin prescribing created unnecessary demand (see 2.3.19). Where patients were started on insulin in hospital, CNTs also said they “would expect the hospital … to support them, to be independent”. This expectation was not always met, and there was a perception that hospitals were under pressure to discharge patients meaning they were provided with limited support.

2.3.4 The investigation observed other factors that influenced CNT service capacity, including the need to travel long distances to provide care, and the limitations of electronic systems. Difficulties accessing electronic systems and/or clinical information meant staff had to find alternative ways to access information about prescription changes; this was explored as part of HSSIB’s (2025b) investigation into electronic communications on patient discharge from acute hospitals.

Self-management support

2.3.5 CNTs told the investigation that competency to manage insulin requires a “coached” approach that is tailored to a person’s individual needs. Flexibility is needed, as one person may need more support and time than another to become competent. The person undertaking the coaching also needs to have the required knowledge and skills in diabetes and insulin management, and in coaching techniques. However, HSSIB’s (2026b) investigation into supporting safe administration in inpatient settings found that ‘Education gaps persist at both trust and undergraduate levels, with no national minimum mandated standard for diabetes care or insulin safety education, training and competency assessments’. NHS England told the investigation that there are various education opportunities available for staff and work has taken place over the years to clarify the principles of insulin safety.

2.3.6 The investigation saw different support models for helping people develop competency. Some CNTs had a team, some had a ‘champion’ role (a dedicated individual), and others included it as part of their general work. The investigation shadowed one self-management support team and heard how staff “flexed” their support to meet individual needs, for example by adjusting the time spent with someone or the approach to educating them. This was seen in practice and people described feeling supported and safe. The team spent the necessary time with each person to develop competence or to recognise when a person may not be able to manage insulin.

2.3.7 Differing views were heard about whether a specific support team, or more community nurses, was the best model to support people to manage insulin. The investigation was unable to find evidence for which approach was most beneficial. The self-management support team shadowed was a team of two nursing staff and four assistants. The data they had collected demonstrated that by changing the care for 63 patients on insulin, and based on CNT visit patterns, they had saved approximately 46,719 visits per year.

2.3.8 The investigation found that safe management of insulin requires competency, and that providing designated resource to support people to manage insulin enabled person-centred care and had a positive impact on people’s experiences. This approach was not universal across England and was heard to be impacted by local commissioning arrangements and differing views about the most appropriate model to support people.

2.3.9 The investigation engaged with national stakeholders to explore the model that best supports people to safely manage insulin and heard that there was ‘limited evidence’ on which to draw conclusions. Stakeholders agreed that there would be value in sharing successful models of support across community providers to help them identify which model would fit best with their populations’ needs. The investigation was also told that, with increasing digitisation of the NHS (Department of Health and Social Care, 2025), any model must consider how

providers can support people to use modern diabetes technology, such as continuous glucose monitors and hybrid closed loop systems (see 1.1.2). These findings have contributed to the safety recommendation below.

Safety recommendation R/2026/084:

HSSIB recommends that NHS England/Department of Health and Social Care provides guidance to integrated care boards and community providers setting out expectations for service models that empower and support people to manage and administer insulin in community settings. This is to support recognition of models that have safely, effectively and equitably engaged patients, their families and carers, including through the use of modern diabetes technology for self-management.

Assessing competency

2.3.10 A recurrent issue faced when supporting the development of competency was knowing “when” someone is competent and confident to manage insulin. CNTs shared examples where someone was thought to be competent, but was later re-referred for support or admitted to hospital because of a complication. In those cases, CNTs questioned whether they had recognised the potential for a persons’ disability/impairment to influence their competence, and whether they had made the necessary adjustments to support the person. They also questioned whether the assessment of competency had recognised a person’s changing environments, for example a person administering their insulin without “someone checking over your shoulder” and when “out and about”.

2.3.11 The investigation explored the assessment of competency with CNTs and saw ‘checklists’ being used. These checklists were locally developed and the investigation was told there is no “nationally mandated checklist” for the assessment of competency of patients and families to safely manage insulin. CNT staff told the investigation they would consider whether the person had a disability/impairment when coaching them, but this was not prompted by the checklists seen and did not include consideration of what adjustments could be made to support people.

2.3.12 There are national sample policies and a competency framework for delegated administration of insulin – that is, administration by healthcare workers and others in non-regulated health and care roles (Diabetes UK, 2022). The investigation heard that this framework had been used to inform the design of local checklists. The framework does not include consideration of disability/impairment or the making of reasonable adjustments, and

was heard to be less applicable to patients and families because their circumstances were different. The investigation was unable to find a community-based competency framework for patients and families.

2.3.13 The investigation engaged with national stakeholders to explore the availability of competency documents for patients and families; resources were identified for inpatient settings (Joint British Diabetes Societies, 2023) but not in the community. The investigation heard support for a future national tool to help assess competency for safe self-administration/ management in community settings. Suggestions for the tool included that it is ‘up to date’ with modern diabetes care and technology, not overly prescriptive which may further negatively impact on workload, and should not be paternalistic (see 2.2.3). Any tool must include a focus on education around diabetes self-care and insulin management, and not just training on injection technique. These findings have contributed to the safety recommendation below.

Safety recommendation R/2026/085:

HSSIB recommends that NHS England/Department of Health and Social Care develops a tool for use in community settings to support the assessment of competency of patients, their families and carers to manage and administer insulin and care for people with diabetes. This should include recognition of a person’s circumstances, the impact of disabilities and impairments, and potential adjustments to support administration where safe to do so. This is to support consistency in how competency is assessed for the safe management of insulin within the context of modern diabetes care.

2.3.14 Informed by the findings in this section, the investigation also shares the following local-level learning for organisations that provide care to patients with diabetes who require insulin.

Local-level learning

- How does your organisation promote patient-centred care and facilitate self-care models that empower and enable patients, such as those with diabetes?
- Does your organisation allocate specific resources to support patients, families and carers to develop competency to self-manage insulin, and ensure those resources are protected to empower and enable people?
- How does your organisation ensure that staff supporting the development of a person’s competency have the required knowledge and skills to provide that training and education in relation to diabetes and insulin?

- How does your organisation support staff to identify and code a person's disabilities/ impairments that may influence their competency to self-manage insulin, and ensure these are considered and adjusted for when deciding whether a person is competent?

Carer-led administration in care homes

2.3.15 During the investigation's exploration of demand on CNT services, it heard that supporting patients in care/residential homes created "significant" workload. This included visits to administer people's insulin. CNTs highlighted the benefits to patients and their own services if carers were able to administer insulin.

2.3.16 There has been national recognition of the benefits of delegating the administration of insulin to non-registered health and care workers, including in care homes (Diabetes UK, 2022); a supporting framework exists for this (NHS England, 2019). CNTs told the investigation that delegated administration was "great in concept" but was poor in "execution". A key barrier described was that insulin administration was seen as a healthcare and not a social care task. National stakeholders also shared how care home teams have limited links with specialist diabetes services and so may feel unsupported to manage insulin (Breakthrough T1D UK, 2025).

2.3.17 The investigation encountered conflict between health and social care organisations about delegated administration in care homes. Contentious issues included responsibility for the patient, clinical oversight, training when there is a high turnover of staff, maintenance of competence, funding for extra support, indemnity cover and regulations (see Care Quality Commission, 2026). Perceptions that healthcare was moving work over to social care without funding or agreement were also heard.

2.3.18 The investigation found that these contentious issues around delegated administration of insulin in care home settings were creating barriers to its implementation. While these were not explored further in this investigation, examples were also seen where the delegated administration approach had been successful (see also Castro et al, 2021). From the CNT perspective, success was heard to require a "willing" care home team and "good governance". From the care home perspective, staff wanted support to build confidence and competence because they were not healthcare professionals.

Insulin prescribing practices

2.3.19 A factor that contributed to demand on CNT services was the increasing number of patients with type 2 diabetes who had been prescribed insulin. CNTs perceived that some of these patients may be prescribed insulin "unnecessarily" and this created risks that might be

avoidable. The demand meant CNTs had less time for patients who would benefit from greater levels of support – for example those with a disability/impairment – to develop their competency to manage insulin.

2.3.20 While the investigation did not focus on insulin-prescribing practices, concerns were heard from prescribers of insulin and diabetes specialists that other treatments for type 2 diabetes may not always be “optimised” before starting a person on insulin. Barriers to continuity in patient care in general practice (Health Services Safety Investigations Body, 2023b) and service capacity/demand challenges were described to limit a patient-centred approach to diabetes management. Concerns about “poor” control of blood sugar levels and potential complications were also heard.

2.3.21 The investigation heard about “deprescribing” projects which were looking to reduce or stop medications that were no longer beneficial or may cause harm. One such project on insulin management had shown the benefits of deprescribing unnecessary insulin, including reduced hospital admissions and reduced need for CNT visits (Getting It Right First Time, 2025). Getting It Right First Time (2025) is looking to broaden that project across England.

3. Changing circumstances and safe management of insulin

The investigation examined the issue of loss of competency and the circumstances in which a patient, their family or carer (collectively termed ‘people’ in this section) may lose competency. This can happen because of changes in a person’s circumstances, including a changing or new disability/impairment. This section presents the investigation’s findings in this area, and includes consideration of how people are monitored and how the assessment of mental capacity is undertaken in relation to decisions about a person’s insulin.

3.1 Changes in circumstances

3.1.1 Concerns were shared with the investigation that unrecognised changes in a person’s circumstances or deterioration in their health may impact on their competency to manage insulin. Incidents were identified where people had a new or worsening disability or impairment that resulted in incorrect administration of insulin. In several incidents, the change was only recognised after a patient had been admitted to hospital following a complication or after a safeguarding concern had been raised, such as in vignette E.

Vignette E – patient safety incident

The patient was known to have dementia, lived alone and was supported by a carer for their insulin administration. The patient's health deteriorated and they refused support. For several months the patient was unable to care for themselves, unable to cook, and was not mobile. They still administered their insulin but did not check their blood sugar levels. A referral for community nursing support found the patient unwell and unable to make decisions about their health.

3.1.2 Similar to the outcomes described in 2.1.2, the impacts of incorrect or missed administration of insulin were varied and included complications that resulted in admissions to hospital and contributed to patient deaths. In several incidents, the change in a person's circumstances involved their memory or their mental health deteriorating (see report 1). Deterioration in memory, such as in vignette E, affected people in different ways, including forgetting to administer insulin, forgetting how to adjust doses or manage complications, and not remembering to eat.

3.1.3 From a physical and sensory perspective, there were examples where a patient's dexterity and/or vision had deteriorated meaning they were less able to use insulin devices (as in vignette F) or see doses on dials. Similar issues have been highlighted by the Patient Safety Commissioner's (2025) study on safety of medical devices for people with sensory impairment.

Vignette F – patient safety incident

The patient was found in a chair, having slept there because they were unable to move. The patient required insulin for their diabetes and had been self-administering. However, due to a trapped nerve they had recently been unable to administer their insulin. They had developed DKA and were admitted to hospital with evidence of 'severe' physical harm.

3.1.4 Patients who were self-administering insulin and self-managing their diabetes told the investigation of their concerns for the future and "getting older". They described concerns about the ability of health and social care services to cope with an ageing population of people with diabetes and increasing disability. They described services as "unprepared" and being worried about a lack of "monitoring" of themselves.

3.1.5 Patients also shared concerns about the lack of knowledge within the health and care profession about modern diabetes technology. They described a "fear" of staff taking over their hybrid closed loop system (see 1.1.2) should they no longer be able to manage it themselves and/or required admission to a care home; similar has been highlighted by national

stakeholders (Breakthrough T1D UK, 2025). Concerns about staff knowledge of diabetes technology were echoed by many non-diabetes specialist healthcare staff. Some described having “no idea” about supporting someone with a hybrid closed loop system, and that they would “defer” to diabetes specialists. This is explored in 3.2.15.

Mental capacity and making decisions

3.1.6 In incidents where a patient refused insulin or declined admission to hospital for a complication of their insulin/diabetes, there was a recurrent issue around whether or not a disability/impairment was influencing the patient’s decision-making. This issue is illustrated in vignette G. Healthcare staff told the investigation about difficulties assessing mental capacity in situations where a patient’s decision did not align with what was recommended.

Vignette G – patient safety incident report

An ambulance crew attended a patient who had intentionally taken excess insulin. The patient was assessed and discharged at the scene. Within 24 hours a further 999 call was placed as the patient had deteriorated and was in cardiac arrest. Concerns were raised regarding the assessment of the patient’s mental capacity to make decisions in relation to their self-management of insulin in light of them taking an overdose of medication.

3.1.7 In report 1 (section 4.1), a repeated concern shared by families whose loved ones with a mental health problem had self-harmed with insulin, was how assessment of mental capacity had concluded that they (the patient) ‘had capacity’ and was therefore able to make “unwise decisions” that resulted in harm from their insulin. These concerns included those described in vignette H. In report 1, the investigation heard that the Mental Capacity Act (2005) was “difficult” to apply and “poorly understood”. This is explored in section 3.3.

Vignette H – family interview

The patient had previous episodes of self-harm through not self-administering insulin and administering too much insulin. On discharge from hospital, a mental capacity assessment found her to have capacity to make decisions about her self-management. Her family questioned the conclusion of that assessment and whether her underlying mental health problem was understood and recognised to be influencing her decision-

making. They further shared that her bright and articulate persona masked the severity of her internal struggles and her history of ignoring medical advice were considered as 'bad choices' and were not addressed.

3.2 Monitoring for deterioration

3.2.1 In several incidents, patients had been admitted to hospital when a disability/impairment had led to them losing the knowledge, skill or ability to safely manage insulin, or because they had lost their family/carer support. Reasons for hospital admissions included complications of diabetes, and/or complications of too little or too much insulin. The admission then prompted recognition that a person's circumstances had changed and that they needed support. These situations were "common" but were heard to not be anticipated or monitored for.

3.2.2 The investigation explored the role of different healthcare staff/carers in the care of someone with diabetes requiring insulin. The support network varied depending on the patient's circumstances:

- **Patient's general practice** – often the main healthcare contact for patients. Practices undertook yearly patient reviews (see 3.2.8) and provided appointments as requested. Practices also had oversight of repeat prescription requests (see 3.2.5). GPs told the investigation they had limited service capacity for home visits, and these may be delegated to a separate home-visiting service. Some practices did not prescribe insulin and, in those areas, insulin prescribing was managed via a specialist diabetes team.
- **Community pharmacy** – often involved in a patient's care when dispensing insulin. Pharmacies were able to track prescriptions where insulin had not been collected or delivered. Pharmacists described concerns about "delivery patients" (patients who had their prescription delivered to their home, see 3.2.7) and were rarely involved in self-management education unless a patient's insulin pen device had changed.
- **Community nursing** – may be involved in a patient's care depending on their needs. CNTs described how visits may be undertaken by nurses or care assistants, and because of high demand were increasingly focused on the required task. Opportunities for holistic assessment during a visit were described as having decreased.
- **Specialist diabetes teams** – involved in the care of some patients who require specialist support or depending on the set-up of local services. Availability of community specialist nurses varied geographically and a "postcode lottery" was described (see report 1, section 3.1). Specialist input was more common for patients with type 1 diabetes, but limited access to specialists meant some relied on their GPs.
- **Urgent and emergency care services** – may become involved in a patient's care following complications of their diabetes or insulin. Primary care staff described incidents where

patients had repeated complications with limited involvement of a patient's GP or a diabetes specialist.

- **Family/carer** – may support administration of insulin or be regular visitors to patients. The investigation was told that deterioration in a person's health is often noticed by family members and contact made with their GP.

3.2.3 When engaging with the staff/carers above, the investigation was told about the importance of communication between services to help identify patients who may be more "vulnerable" due to their circumstances and to provide a co-ordinated response. Several HSSIB (2023b; 2025b) investigations have previously identified where limited co-ordination has led to patient harm, including in relation to diabetes care through the lens of patients with mental health problems (see report 1, section 3).

3.2.4 In some of the areas visited, the investigation observed close liaison between different services such as a general practice, pharmacy and CNT. In particular, close liaison was seen where services were co-located, enabling clear lines of communication which were often face to face. For example, at one community pharmacy, the pharmacist was observed to "pop next door" to talk to a GP and a diabetes specialist nurse for advice about a patient they had concerns about. In contrast, the investigation heard about communication and co-ordination challenges where services relied on electronic communication and where interoperability between systems was lacking; this has previously been highlighted by HSSIB (2025b; 2025c).

Monitoring through medication management

3.2.5 The investigation heard that the regularity of a patient's repeat prescription requests could provide insights into how they were coping with their insulin administration. Requesting behaviours might indicate to general practice staff that they are not administering insulin as expected, signalling a possible change in circumstances or a disability/impairment. However, electronic systems may not make changes in requesting behaviours obvious and the investigation heard that systems might not "flag" when a person has not requested a prescription. General practice staff described that, among the many other tasks required, it was easy for a patient to "fall through the gaps", particularly in light of electronic systems that made it difficult for them to track insulin prescriptions.

3.2.6 Community pharmacies also have a role in monitoring patients when medications are dispensed. When a patient comes to a pharmacy to collect a medication, there is an opportunity for staff to "lay eyes on". The investigation heard that pharmacies provided an important "safety net", but that workforce challenges and closures (Community Pharmacy England, 2024) were impacting on continuity of care and opportunities to help safeguard patients.

3.2.7 Pharmacists also described concerns about patients who had their medications delivered or received them from other sources. A delivery means that a healthcare professional is not in direct contact with the patient and signs of deterioration may be missed; these patients were described as being more “vulnerable”. Some patients may also source prescriptions through other routes, such as online pharmacies, and HSSIB is undertaking a specific investigation into online prescribing.

Monitoring via annual reviews

3.2.8 Healthcare staff described the importance of the “annual review” of patients with diabetes who require insulin. There is an expectation that patients with long-term conditions, including diabetes, are reviewed annually by their general practice (NHS England, 2025c); they may also have additional specialist appointments depending on their circumstances. The annual review was described as a “safety net”, particularly for patients who had limited engagement with, or did not need care from, the support network described in 3.2.2. For someone who needs insulin, the review was described as including assessment of how they are managing their diabetes and insulin administration, and whether any pre-existing or new disability/impairment is affecting their care.

3.2.9 For some patients, the annual review may be their only contact with healthcare services, and therefore the only opportunity for staff to monitor for changes in their circumstances. However, the investigation heard from staff working in primary care that there is “a cohort of individuals out there who are perhaps not managing their condition [diabetes] as well as they could be … and we know they’re not having their annual reviews”. Examples were shared of patients whose health had deteriorated while awaiting their review and who required emergency admission to hospital following incidents with their insulin.

3.2.10 General practice staff described that attendance for a review required patient engagement; all the staff the investigation engaged with had patients who “never” attended. Depending on the patient’s circumstances, a more proactive approach may be taken including visiting them at home. Where patients were known to be vulnerable or were “housebound”, staff described identifying these patients via “coding” of their notes. They highlighted that this coding first required them to know that a patient was vulnerable and/or housebound.

3.2.11 General practices recognised that their review processes were mostly reactive, and all had patients who “had chosen” not to engage. However, the investigation also heard that non-engagement may also occur where services are unable to meet patient needs (such as in report 1, section 3.1) or because of situations that require a safeguarding response. Practices further described assuming that, if a patient had not engaged, they had chosen to make that

decision unless they [practice staff] had reason to think otherwise (mental capacity is explored further in 3.3). Non-engagement created challenges for practices and a need to balance risks of continuing or stopping medications without a review of the patient.

3.2.12 The investigation found that there was a cohort of patients living in the community, with diabetes requiring insulin, whose circumstances meant they were not being monitored on a regular basis. The patient's annual long-term condition review may be the only opportunity to recognise that their circumstances have changed. The challenges faced by general practices to respond to the needs of their population limited their ability to proactively monitor patients, reduce the potential for their deterioration, and prevent hospital admission.

3.2.13 At the time of this investigation, the Department of Health and Social Care's (2025) future plans for the NHS included intentions to support improvement in the proactive care of patients in the community. Notably, plans for neighbourhood health services described the need for integrated care boards (ICBs) to support and enable general practices to be more proactive in response to individuals' needs (NHS England, 2025b). Future plans also referred to the benefits of using monitoring technology in patients' homes (Department of Health and Social Care, 2025). Should these plans be implemented, they have the potential to mitigate some of the risks to patients found by this investigation. These findings have contributed to the safety learning for ICBs below.

Safety learning for integrated care boards ICB/2026/018:

HSSIB suggests that integrated care boards, through future planning for neighbourhood health services, include consideration of how patients who may be at greater risk of harm from insulin administration due to their specific circumstances – for example co-existing disabilities, social isolation or receiving home-delivered medications – are proactively monitored to identify changes in their circumstances. This may include using technology such as remote monitoring.

3.2.14 Informed by the above findings in section 3.2, the investigation shares the following local-level learning for organisations that provide care to patients who have diabetes requiring insulin.

Local-level learning

- Does your organisation have systems and processes to identify where patients have not requested their repeat medication prescription, or the frequency of the requests have changed, which may indicate changes in their circumstances?
- How does your organisation ensure long-term condition reviews reliably take place for patients who may be at a higher risk of deterioration due to their circumstances, for example those with multiple long-term conditions?
- How does your organisation identify and code patients – who may be more vulnerable to harm from insulin due to their circumstances – for increased monitoring? This may include patients who have their medications delivered to their home, who do not have family nearby, or who are housebound.

Diabetes technology

3.2.15 As described in 3.1.5, the investigation heard concerns about competency in relation to newer diabetes technology such as hybrid closed loop systems. These concerns related to the competency of the patients who need to use the technology and of the staff overseeing their care; a ‘confidence gap’ has also been described by researchers (Kelly et al, 2025). Patients who had these systems were “experts” in using their devices and feared what would happen if they lost the ability to manage them; they described that services needed to “plan ahead”.

3.2.16 Non-diabetes specialist staff told the investigation that they “wouldn’t touch” a hybrid closed loop system and that these were “the domain of diabetes specialist nurses” and manufacturers. CNTs also described that they were “not taking patients with these systems” but recognised this may change in the future. Diabetes specialists highlighted that it was important that only people with the necessary competency manage hybrid closed loop systems but also warned about future challenges as more patients use these systems.

3.2.17 At the time of the investigation, it was heard that a small proportion of eligible patients aged over 60 had hybrid closed loop systems but 60% of children with diabetes (around 22,200 children) had them (Royal College of Paediatrics and Child Health, 2026). Diabetes specialists described how technology was changing rapidly and some felt their knowledge was not “up to date”. They also described a small but growing proportion of people with type 1 diabetes using ‘do it yourself’ (DIY) closed loop systems. These systems are built by individuals for their own use and are not regulated. Breakthrough T1D UK (2019) – a UK-based charity supporting research into type 1 diabetes – has stated that it ‘cannot endorse the use of DIY tech systems’ but respected the rights of people to choose treatments that best fit their needs. The charity

also highlighted the importance of involving staff in the management of a person's diabetes, whether they use a DIY solution or not, but that 'there is a greater need for funded training for healthcare professionals around new technological developments'.

3.2.18 The investigation heard support for hybrid closed loop systems for patients who need them due to their multiple benefits. The investigation also heard concerns about "future proofing" the safety of patients by ensuring the workforce is competent and confident to support their use, including consideration of the NHS's role in DIY systems. NHS England (2024) has published a 5-year implementation strategy for the roll-out of hybrid closed loop systems which acknowledges specialist training requirements.

3.2.19 Across this investigation and in report 1 in this series, several findings have related to diabetes technology. These have included issues with the design of insulin pen devices, access to modern technologies, and support to use technology. Due to growing evidence around the emerging use and importance of diabetes technology, this will be explored further in the final report in this series.

3.3 Mental capacity and insulin-related decision-making

3.3.1 Throughout the investigation, healthcare staff raised the challenge of assessing mental capacity when people make decisions that may result in harm from their insulin. In several incidents, patients refused to administer insulin or intentionally administered too much. Concerns were stated about whether patients had the mental capacity (see 1.2.4) to make those decisions due to a disability or impairment, such as dementia and/or a mental health problem (as in the examples in report 1, section 2).

3.3.2 In response to the issues being raised about assessment of mental capacity, the investigation considered the application of the Mental Capacity Act (MCA) (2005) specifically to patient decisions associated with self-management of insulin. The investigation explored these situations with patients' families, healthcare staff, national stakeholders and from legal perspectives. Repeated examples were shared where the principles of the MCA (2005) were thought to have been "poorly applied" and patients were deemed to have the capacity to make decisions about their insulin that created a risk of harm.

3.3.3 Healthcare staff told the investigation that they had not been equipped with the knowledge and skills to apply the MCA (2005). While healthcare curricula include mental capacity and consent (for example, Nursing and Midwifery Council, 2023), training in how to apply the principles in practice, and to complicated and "ambiguous" situations, was described as limited; similar was heard in another HSSIB (2023a) investigation. In relation to patients who require

insulin, staff described having limited knowledge about the risks of different insulin types (see report 1, section 4.1) and the influence diabetes and other conditions (such as disordered eating, see report 1, section 3.3) may have on decision-making.

3.3.4 National stakeholders told the investigation that the MCA (2005) may be “misinterpreted” or “misapplied” by healthcare staff. Common misapplications include not recognising that capacity relates to a particular decision at the time the decision needs to be made. In practice, the investigation repeatedly heard reference to “the patient has capacity to make a decision” rather than it being in relation to a particular decision. The investigation also heard from staff that you should “assume capacity”, but legal insights highlighted that the principle of presumption of capacity does not mean that staff are ‘not able’ to consider whether a patient has capacity where there is reason to do so.

3.3.5 The investigation explored why application of the MCA (2005) was difficult for staff when assessing someone’s capacity in relation to insulin-related decisions. Factors highlighted included:

- limited education in the “nuances” involved when assessing patients with multiple diagnoses (including diabetes) and access to high-risk medications
- limited experience exploring whether patients can use and weigh up information, including the potential to “mix up” an ability to communicate information with evidence of weighing up (see report 1, section 2.2)
- a lack of recognition that assessment is complicated and may require staff to seek expert advice, particularly when the influence of a condition, such as diabetes or an eating disorder (see report 1, section 4.1), is unclear
- that the busy, high-demand environments in which staff work make it challenging to therapeutically engage with patients and their families. Contextual challenges meant some assessments were “brief”, made under a “pressure” to discharge the patient, and were sometimes “avoided” due to a “fear” of making the wrong judgement.

3.3.6 The investigation recognises that, through its narrow focus, the findings provide a limited view on the application of the MCA (2005). However, other HSSIB reports, other publications and ongoing national inquiries (for example, King’s College London, 2022; Scott et al, 2020) have highlighted similar issues about the safe and effective application of the MCA (2005) in different situations, particularly where decisions have the potential to cause significant harm. The National Mental Capacity Forum (NMCF) cited as a priority, better support for staff who have not had legal training to apply the MCA (2005) in different situations. The NMCF also highlighted limited education and training resources to enable this. In response, the NMCF and

others have provided guidance and supportive information to aid healthcare professionals to apply the MCA (2005) in practice (for example, 39 Essex Chambers, 2026; National Mental Capacity Forum, 2024).

3.3.7 The investigation found limited evidence of support for healthcare staff to practically apply the MCA (2005) in certain clinical situations, such as where a patient may have fluctuating capacity. Resources, such as those cited above, do exist to support understanding and application of the MCA (2005). However, resources were heard to be held in various locations and staff are not always aware of how to access them. These findings have contributed to the safety observation in 3.3.13 and local-level learning in 3.3.14.

Safety planning for patients at risk of harm from insulin

3.3.8 The investigation's consideration of the MCA (2005) also included situations where a patient's mental capacity to make decisions about their insulin may fluctuate. Report 1 (section 2.1) described the case of one patient whose family shared that, at the time her mental capacity (about decisions to administer insulin) was assessed she had the ability to make safe decisions. However, she would "inevitably" lose capacity when her emotions changed and there was no proactive safety planning for this. Healthcare staff told the investigation that these situations were "difficult" to manage because the patient required access to their insulin and in the community may not be under the immediate supervision of healthcare services.

3.3.9 The National Institute for Health and Care Excellence (NICE) (2018) recommends that advance 'crisis' planning is undertaken for anyone 'who is at risk of losing capacity (for example through progressive illness), as well as those who have fluctuating capacity (for example through mental illness)'. Healthcare staff recognised the importance of crisis planning for patients who had access to insulin, but also described reasons why the effective development of such plans was difficult. Reasons included time for therapeutic engagement, refusal by patients (with mental capacity) to engage in discussions or to involve family members, and being "helpless" to do anything when the patient had left their care. The investigation also heard some perceptions that services may feel "absolved" of responsibility for a patient's safety after they leave their care.

3.3.10 Healthcare staff and patients' families told the investigation that family members, friends and carers, if available, can be highly supportive of a patient's safety when at risk of self-harm from insulin; they may be able to help restrict access to insulin at the important moment. NICE (2018) describes the importance of collaboration with patients and their families in crisis planning, but the investigation heard from several families whose loved ones had been harmed by insulin, that they had not been involved. In these situations, refusal by patients (with mental capacity) to involve family members or allow information to be shared with them meant families were not aware of the risks. Healthcare staff described their legal and ethical duty to protect

patient confidentiality in these situations, but families felt that safety-critical information was being withheld. Similar to application of the MCA (2005), the investigation heard about “misinterpretations” in relation to when and what information about patients could be disclosed for their safety in different situations.

3.3.11 The investigation engaged with the UK Caldicott Guardian Council (UKCGC) around information sharing and was signposted to the Caldicott principles (National Data Guardian, 2020). These principles apply to the use of confidential information within health and social care organisations and when such information is shared with other organisations and between individuals. The UKCGC highlighted that, in line with principle 7, ‘the duty to share information for individual care is as important as the duty to protect patient confidentiality’. UKCGC further described that decisions in relation to information sharing will be individualised to the specific patient and information, and therefore staff should be supported through their employers, regulators and professional bodies.

3.3.12 The investigation also engaged with the Office of the National Data Guardian (ONDG) around the sharing of confidential information for patient safety and was directed to a consensus statement for information sharing and suicide prevention (Department of Health and Social Care, 2021). The ONDG described a “complex landscape of guidance” and differences in interpretation across organisations and professions. Healthcare staff may feel they are unable to share confidential information without a patient’s consent, but this is not an absolute rule and the ONDG encouraged staff to seek expert advice – for example from senior staff or their organisation’s Caldicott Guardian – because of the “nuances” of different situations. National stakeholders further directed the investigation to various guidance and information sources including: Zero Suicide Alliance’s (2025) guidance on consent, confidentiality and information sharing; NHS England’s (2026) guidance for sharing information with unpaid carers; and Making Families Count’s (2024) learning modules for working well with families in mental health crises.

3.3.13 The investigation found that the sharing of information in situations where patients are at risk of self-harm from insulin is complex and that staff may not have been equipped with the knowledge or given the support they need to help make decisions about sharing information under certain situations. The investigation has not made a safety recommendation in relation to information sharing due to the lack of clear guidance when people may be at risk of self-harm or suicide, and heard that there is a need for professional judgement in these situations. As mentioned in 3.3.7, resources to support decision-making are held in various locations and do not always provide clear practical advice. These findings have contributed to the safety observation below and local-level learning in 3.3.14.

Safety observation O/2026/085:

National bodies can improve patient safety by providing clarity on expectations around 1) how staff recognise that a patient's mental capacity may be compromised in relation to decisions about their self-management of insulin, and 2) the undertaking of a mental capacity assessment by the most appropriate person. This should include clarification on the practical application of the Mental Capacity Act (2005) to situations where a patient's capacity may fluctuate and where sharing confidential information to support patient safety may be appropriate.

3.3.14 Informed by the above findings in section 3.3, the investigation shares the following local-level learning for organisations that provide care to patients with diabetes requiring insulin.

Local-level learning

- Does your organisation provide practical training and guidance to support staff to consider the mental capacity of patients to make decisions around their insulin when there are concerns capacity may be compromised?
- Does your organisation provide practical guidance to staff to help identify when it is lawful, ethical and appropriate to share confidential information about a patient to mitigate risks to their safety, including with family members?
- Does your organisation have accessible routes via which staff can seek urgent support when they are concerned a patient's mental capacity to make decisions about their self-care may be compromised, particularly in high-risk situations?
- How does your organisation support staff to develop 'crisis plans' for patients who self-manage insulin to protect their safety at a later point when their capacity to make decisions in relation to their care may change?

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5. Appendix

Investigation approach

Terms of reference

Through engagement with patients, families, staff and organisations, including providers of primary, community and secondary care, the investigation examined the following in relation to people with a disability which may impact on their ability to safely administer insulin:

- 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 engaged 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 01/01/2023 – 30/09/2025, n = 23,413. Filtered by description (‘insulin’, n = 1924), n = 255. Further narrowed and reviewed by service area.

Evidence source	Details
LFPSE – patient safety incidents	Events submitted 01/10/2023 – 30/04/2025, n = 54,065. Filtered by drug involved (‘insulin’, n = 1,725) AND description (‘insulin’, n = 1,924), n = 2,334. 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.
Patient and family insights	Patient and family insights gained through interviews and observations during the course of the investigation.
Primary care	General practitioners, pharmacists and nursing staff from services across England, including staff involved in inclusion health and diabetes.
Community nursing teams	Community nurses and healthcare support workers from services across England, including staff who provide specific insulin self-administration support work.
Mental health care	Multidisciplinary mental health teams from services across England. Representation from community, crisis, liaison, physical health, homeless support, and patient safety teams.
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.

- Breakthrough T1D 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
- National Mental Capacity Forum
- NHS England
- Office of the National Data Guardian
- Primary Care Diabetes and Obesity Society
- Queen’s Nursing Institute
- UK Caldicott Guardian Council
- other experts including legal perspectives and academics specialising in diabetes.

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