



Health Services Safety
Investigations Body

Investigation report

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

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A note of acknowledgement

We 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. In particular, we would like to thank Ms H and her support staff for sharing their experiences.

About this report

This report is the third in a series considering the [self-administration of insulin by people with diabetes mellitus \(diabetes\) in community settings](#). Each report in the series has a focus on specific groups of people who, due to their circumstances, may be at increased risk of harm because of the way they self-administer insulin. A fourth report will be published to conclude the series, which will summarise themes from across the series and include a focus on diabetes-related devices and technology.

This investigation focused on people with a learning disability. A learning disability is defined by the Department of Health and Social Care (2001) as 'a significantly reduced ability to understand new or complex information, and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'.

The following are important to note when reading this report:

- The terminology used has been chosen while acknowledging that there are differing views across organisations and groups. It refers to people with a learning disability but with recognition that the term 'intellectual disability' is increasingly being used (National Institute for Health and Care Excellence, 2015). A glossary of terms is provided in [report 1 of this series](#).
- The term 'diabetes technology' is used to refer to continuous glucose monitors, insulin pumps and hybrid closed loop systems. An insulin pen device with associated software ('smart' or 'connected' pens) is also considered technology.
- Several of the issues identified as affecting people with a learning disability in this report were also identified in [previous investigations](#) in this series to be affecting other vulnerable groups. The findings are likely to be applicable to other groups of patients, not just people with a learning disability.

Executive summary

Background

This report is the third in a series considering the [self-administration of insulin by people with diabetes mellitus \(diabetes\) in community settings](#). HSSIB identified incidents where people with a learning disability and diabetes (requiring insulin) had been harmed when they had not been supported to administer their insulin safely. Incidents included where patients had not administered their insulin, or had administered it incorrectly.

Many people with diabetes administer their own insulin to manage their blood sugar levels, either by injection or using an insulin pump. Insulin pumps can be standalone meaning the person has to adjust all settings manually, or can be a combined monitor/pump device where some of the insulin delivery is automated (a hybrid closed loop system). However, a disability or impairment may affect someone's ability to safely administer their own insulin if they are not supported. This can lead to short-term and long-term health problems, which can be life threatening.

The investigation

The investigation explored factors contributing to this patient safety issue for people with a learning disability. Several of these factors were consistent with those found in relation to the patient groups in [report 1](#) and [report 2](#) of this series.

Findings

- People with a learning disability who require insulin have been harmed when they have not been supported to self-administer insulin safely. This includes harm when a person's health has deteriorated and from longer-term complications.
- There is potential underreporting of incidents associated with self-administration of insulin in community settings, meaning the patient safety issue may not be clearly recognised by healthcare services and oversight bodies.
- The factors that contributed to insulin-related incidents involving people with a learning disability were often similar to those that contributed to incidents involving people with other disabilities or impairments, suggesting unaddressed risks across multiple patient groups.
- People with a learning disability who require insulin are not always empowered or enabled to self-manage their condition where they may be able to do so. Recognition and implementation of adjustments to help people self-administer, and appropriately accessible education, are limited.

- A person's learning disability is not always accurately recorded in health records; this impacts on ongoing health monitoring and whether individual needs are recognised in support of insulin-related diabetes care.
- Limitations in the availability of wider learning disability specialist services affect the ability of non-specialist staff to seek advice to help them provide safe and effective insulin-related diabetes care.
- Limited education and practical support for application of the Mental Capacity Act 2005 by healthcare staff means its principles are sometimes misunderstood, including when caring for people with a learning disability.
- Insulin pen devices and diabetes technologies are not always designed in ways that support people with a learning disability to administer insulin.
- People with a learning disability may be less able to access modern diabetes technologies, with limited national data available to provide insights into uptake.
- Evidence gaps exist around how people with a learning disability manage their diabetes with insulin; these gaps relate to how best to support an individual to self-manage their insulin and diabetes, and the design of devices and technology.

HSSIB makes the following safety recommendation

Safety recommendation R/2026/094:

HSSIB recommends that the National Institute for Health and Care Research, in collaboration with relevant research and policy stakeholders, assesses the feasibility of research, and supports its commissioning, to address the gaps in knowledge around services, device and technology requirements for support of people with a learning disability to self-administer insulin for diabetes. This should be undertaken through co-development with people with a learning disability and aim to create new knowledge to inform delivery of safe and effective care for this group of patients.

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:

- Does your organisation have a process to ensure people with a learning disability are correctly identified and accurately coded in health records, to support long-term health monitoring, such as for diabetes?
- How does your organisation reliably identify patients with a learning disability and communicate the reasonable adjustments required to support their care, including at points of handover of care?
- How does your organisation ensure that the 'reasonable adjustments digital flag' supports effective transfer of information about patient needs, is up to date, and is reliably used by healthcare staff?
- How does your organisation ensure it is meeting its public duty for services to anticipate and make adjustments for people with a learning disability, to enable access to insulin self-management support where appropriate?
- How does your organisation support staff to understand who the person wants involved in their care – such as family members and carers – and enables them to have a role supporting the management of insulin?
- How does your organisation create the conditions for staff to empower and enable patients with a learning disability – through a person-centred approach and provision of accessible information – to self-manage insulin where appropriate?
- How does your organisation ensure that access to specialist learning disability advice is available to support staff to adjust care for patients to meet their diabetes and insulin-related needs?
- How does your organisation monitor and respond to issues that may impact on the ability of a person with a learning disability to safely self-administer their insulin?
- How does your organisation provide practical training and guidance to support staff to consider the mental capacity of patients with a learning disability to make decisions about their insulin self-management, when there are concerns their capacity may be compromised?
- How does your organisation ensure people with a learning disability who meet the criteria for diabetes technology are receiving support to access it, and are not being discriminated against because of their learning disability?

- Does your organisation actively encourage and support staff to report patient safety incidents associated with insulin self-management, including for people with a learning disability?

1. Background and context

This report is the third in a series considering the [self-administration of insulin by people with diabetes mellitus \(diabetes\) in community settings](#). This report focuses on people with a learning disability who live in the community, including in supported, residential or care settings.

HSSIB identified incidents where people with a learning disability and diabetes (requiring insulin) had been harmed when they had not been supported to administer their insulin safely (the patient safety issue of focus). The incidents included where patients had not administered their insulin or had administered their insulin incorrectly.

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 sufficient 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 (an injection under the skin), 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 (HCL) system. HCL systems involve a pump and continuous glucose monitor 'talking to each other' to automatically adjust the insulin dose (Diabetes UK, 2025a).

Insulin and patient safety

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.a). Insulin-related patient safety incidents are common and persistent across healthcare. HSSIB ([2025a](#); [2025b](#); [2026a](#); [2026b](#)) has

considered insulin-related incidents in acute hospital settings and on discharge of patients from hospital, and in community settings where a patient may have a co-existing disability or impairment.

1.1.4 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, 2025). To help mitigate this risk, there is national advocacy for people to self-administer insulin when they are able to do so (for example Care Quality Commission, 2016; Getting It Right First Time, 2020).

Self-administration of insulin

1.1.5 When safe to do so, supporting a person to administer 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.

1.1.6 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/carers.

1.1.7 Insulin administration by the patient themselves or by their family member/carers involves many considerations, as incorrect administration can result in complications and harm. These considerations were explored in [report 1 \(section 1.2\)](#) and include the need to understand (Diabetes UK, 2025b):

- 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.

1.1.8 Self-administration 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 management of their blood sugar levels and reduce the risk of both short- and long-term diabetes-related complications (see [report 1, section 1.1](#)).

1.2 Learning disability

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 medication), eating food, and getting washed and dressed. Disability and impairment were further explored in [report 2 \(section 1.2\)](#).

1.2.2 A learning disability is defined by the Department of Health and Social Care (2001) as 'a significantly reduced ability to understand new or complex information, and to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood'. Every person with a learning disability is different, and the effects of the disability can range from 'mild' to 'profound' (World Health Organization, 2022). A learning disability is a lifelong condition that is neither an illness nor a disease. It results from the effects of various factors on a person's brain when it is developing.

1.2.3 In England, there are approximately 1.3 million people with a learning disability (Mencap, n.d.a). The actual number of people with a learning disability may be higher but their disability may not have been diagnosed and/or recorded. People who are known to health and care services are often those with a more significant learning disability (Department of Health and Social Care, 2023).

Reasonable adjustments

1.2.4 The Equality Act 2010 requires public services to anticipate and prevent discrimination against people with a disability. Many people with a learning disability have support and communication needs that, if unmet, will put them at a disadvantage when accessing and receiving health and care services.

1.2.5 Reasonable adjustments are a way of making it as easy for people with a disability, and their family and carers, to access and receive health and care services as it is for people without a disability (NHS England, n.d.b). A tool to help healthcare professionals think through the reasonable adjustments that may apply is shown in figure 1.

Figure 1 TEACH tool for reasonable adjustments (Royal College of Physicians, 2022)

TEACH	Suggested action to consider
T = time	Clinical assessments may need more time, which may mean factoring this into working plans, breaking it down into manageable yet effective components, scheduling with carers, or completing assessments outside standard times.
	Consider noise, lighting, equipment such as bed height, personal belongings.

TEACH	Suggested action to consider
E = environment	
A = attitude	Consider more open visiting or sharing caring duties. Consider less frequent monitoring of vital signs or laboratory tests when the patient is stable.
C = communication	Use communication aids such as pictures, and ensure that communication is non-threatening and non-technical.
H = help	For example, ask for help from a learning disability specialist team.

Physical health and diabetes

1.2.6 People with a learning disability are more likely to experience other and multiple long-term conditions when compared with the general population (Hanlon et al, 2018). The 'Learning from lives and deaths: people with a learning disability and autistic people' (LeDeR) process has shown that adults with a learning disability on average die 19 years younger than the general population and that the rate of avoidable deaths is 'nearly double' the general population (data for 2024) (King's College London, 2026).

1.2.7 People with a learning disability are also at increased risk of diabetes; rates are estimated to be 2.46 times higher than that of the general population (Vancampfort et al, 2022) and evidence suggests that associated deaths are higher (Wing and Mathur, 2025). People with a learning disability also experience more long-term diabetes-related complications (Hanlon et al, 2018; King's College London, 2022; MacRae et al, 2015).

Mental capacity

1.2.8 This report includes reference to 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 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.

1.2.9 The Mental Capacity Act 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.

Further background information about mental capacity can be found in [report 2 \(section 1.2\)](#)

2. Exploring the patient safety issue

The focus of this investigation was identified through the initial [intelligence review](#) that was undertaken for the series overall. The review suggested that some patient groups are particularly vulnerable to harm associated with insulin, including some people with a learning disability. This investigation therefore focused on incidents where people with a learning disability and diabetes (requiring insulin) had been harmed when they had not been supported to administer their insulin safely (the patient safety issue).

This section describes evidence of the patient safety issue identified by the investigation. Evidence included the experiences of those affected, reports of incidents submitted to national databases and local patient safety investigations, and relevant national publications. A more detailed description of the investigation approach can be found in the appendix.

2.1 Ms H's experience

2.1.1 The investigation met Ms H at her home along with staff who supported her. Ms H had a diagnosis of type 2 diabetes and required insulin therapy because of a history of difficulty managing her blood sugar levels. Ms H had a diagnosed learning disability and was unable to read or write. She lived in a residential care home and had support for daily activities; she required prompting for these activities, including taking medications. Ms H was described by staff as “very active” and she told the investigation about her hobbies, which included football and going on holiday.

2.1.2 Ms H self-administered her insulin under supervision of staff. She told the investigation that “I am capable to do it myself – that’s what I want to do” and that it meant she did not have to “wait around” for a nurse to visit. This had given her greater independence and flexibility in her life. She was able to go out with her family and on holiday; before learning to self-administer she had not been able to go on holiday for 2 years.

2.1.3 Ms H told the investigation how she prepared and administered her insulin. This included selecting an insulin pen device and dialling up the dose. She described that, because she could not read, she selected the correct pen based on sight – “one is bigger and one is shorter”. Staff had also put coloured labels on the medications to help distinguish between the short- and long-acting insulins. Ms H said she then needed help to ensure she selected the correct dose on the pen, and staff would check this against her care plan.

2.1.4 Ms H also told the investigation that she had previously “got it wrong”. For an extended period, neither Ms H or supervising staff had realised that the cap on the needle was not being removed before attempting to inject the insulin. This meant she was not receiving the medication. The issue was identified when a practice nurse questioned why Ms H’s blood sugar levels were recurrently high, leading her to observe Ms H administering the medication.

Exploring Ms H’s circumstances

2.1.5 The investigation gained further insights into Ms H’s care from her support staff and the lead practice nurse in the local primary care network. They described how a community nursing team had initially supported Ms H with learning to self-administer insulin, and this was then taken on by her practice nurse. It took approximately 15 months of supervised, supported training involving Ms H and her staff before her administration could be managed. This period reflected the time needed to build the knowledge, skills and confidence of those involved.

2.1.6 Several factors enabled Ms H to be supported to self-administer insulin. The home where Ms H lived was described as proactive, with strong leadership and an attitude that meant patient-centred care was a priority. Ms H’s practice nurse had specialist knowledge and skills in diabetes management that enabled Ms H and her support staff to develop their competence. The practice nurse also supported staff through diabetes-focused training and the development of a treatment plan, with instructions about what actions to take in different situations.

2.1.7 The design of Ms H’s insulin pen devices and their accessibility were described as a barrier to her self-administering insulin. Because she was not able to read, identifying the correct pen and dialling the correct dose was a challenge. Through the care plan, Ms H’s support team had developed ways to adapt to these barriers, but they also acknowledged that any future change in insulin type may create a risk of incorrect administration if it was not recognised and adaptations made. This had been demonstrated during the period when Ms H had not been removing the needle cap, which followed a change to the insulin pen device.

2.1.8 More recently, Ms H had been provided with a continuous glucose monitor (CGM, see [report 1, section 1.1](#)) in line with national guidance (National Institute for Health and Care Excellence, 2023). A process had been established whereby CGM data could be uploaded and reviewed remotely by the practice nurse, providing additional oversight. Ms H was positive about the CGM because it meant she did not need to have regular blood tests and because the CGM would warn her when her blood sugar was low. These warnings were important as Ms H no longer reliably recognised when her blood glucose levels were low.

2.2 Patient safety incidents

2.2.1 The investigation reviewed patient safety incident reports, local investigations carried out by healthcare organisations, and coroners’ reports to prevent future deaths. The investigation noted that the number of reports to national incident databases about issues relating to insulin for people with a learning disability was lower than expected in comparison to evidence of harm heard from those affected, including patients, families and staff. This suggests potential underreporting of incidents, particularly in primary and community care, which has been highlighted in previous HSSIB (2025b) investigations.

2.2.2 Where incidents of harm to people with a learning disability had been reported, the investigation noted consistencies in the findings and learning points. Several of these findings were similar to those identified in [report 1](#) and [report 2](#) of this series, and included where insulin had been omitted (not administered), administered at the wrong time or dose, or the wrong type of insulin had been administered.

2.2.3 More specific to the care of people with a learning disability, the consistencies in findings and learning points across the incidents reviewed related to the following (examples are provided in table 1):

- People may not have been diagnosed with a learning disability and therefore were not under regular follow-up and review to identify changes in their health or deterioration (vignette 1).
- Assessment and documentation of a person’s mental capacity if they refused insulin was inconsistent, and the availability of routes of escalation to seek support varied (vignettes 2 and 3).
- Transitions of care between health and social care created risks to the safety of people with a learning disability, including variability in processes to ensure people and their families/ carers were competent and able to support diabetes self-management (vignette 2 and 3).

2.2.4 The investigation noted that most of the incidents involved patients whose insulin was administered using a pen device. As also highlighted in [report 1](#) and [report 2](#) of this series, the design of insulin pen devices was a factor in the incidents involving people with a learning disability. The investigation identified few incidents involving diabetes technology, but these did include incidents where patients with a hybrid closed loop (HCL) system had been harmed (vignette 4).

Table 1 Vignettes illustrating consistent themes across investigations

Vignette 1	The patient had a history of type 2 diabetes and a mild learning disability. She had stopped administering her insulin 22 months prior to being found at home, having collapsed and in
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	diabetic ketoacidosis (a serious condition caused by lack of insulin which causes acids to accumulate in a person's blood). She sustained severe organ damage as a result. A local investigation found that the patient was not registered as having a learning disability (rather a learning difficulty) and therefore was not receiving associated health monitoring – patients in this situation were described as 'forgotten' and 'incredibly vulnerable'. At the time of stopping her insulin, she was assessed to have mental capacity to make the decision but the assessment was not documented.
Vignette 2	The patient had a history of type 2 diabetes and a learning disability. He required support with insulin administration and blood sugar monitoring. The patient died at home as a result of diabetic ketoacidosis following discharge from hospital. A local investigation found that the patient's 'perceived challenging behaviour' overshadowed a focus on his insulin administration, which he refused to take. This led to missed doses and an escalation plan for this situation was not actioned. The patient was assessed to not have the mental capacity to make decisions about his health and social care needs.
Vignette 3	The patient had type 1 diabetes and a learning disability. The patient transitioned from child to adult residential services and was allowed to visit his family home unsupervised. During one of these home visits his health deteriorated and he died as a result of diabetic ketoacidosis. HM Coroner found that the patient was not capable of and not trained to manage his diabetes independently if he became unwell. His family had also not received training. Concerns were raised about transition planning from child to adult services and input from specialist diabetes services, escalation planning for deterioration, and assessment of mental capacity. No capacity assessments were undertaken in relation to the patient's decision to go home unsupervised and whether he was able to manage his insulin.
Vignette 4	The patient had type 1 diabetes and a learning disability. He was managing his diabetes with a HCL system. At a clinic appointment, a healthcare professional raised concerns about his ability to manage his system safely. The patient was subsequently found unconscious and suffered a brain injury as a result of hypoglycaemia. A local investigation found that the patient had turned off the alerting functions on the HCL system. The local investigation described concerns about the assessment of mental capacity to make decisions about the system, availability of accessible education, and support mechanisms.

2.3 National publications

2.3.1 The investigation reviewed relevant national publications and academic literature relevant to the patient safety issue. These included the reports of the 'Learning from lives and deaths: people with a learning disability and autistic people' (LeDeR) process. LeDeR reports highlight that physical health conditions are common amongst people with a learning disability (King's College London, 2024; 2026).

2.3.2 The investigation engaged directly with NHS England about the findings of LeDeR reviews and was told that a small number had noted concerns about insulin management in the death of a person with a learning disability, with only one out of 32,000 reviews where insulin was concluded to be involved in a patient's death. The investigation recognises that LeDeR focuses on deaths and so would not include review of other types of incidents. The investigation also identified other incidents where patients with a learning disability had died through complications of insulin management, where the incident had been concluded to be secondary to other diagnoses, such as a mental health problem (see [report 1](#)).

2.3.3 Research findings also provided insights into insulin-related incidents. People with a learning disability may not receive their insulin as often as they require it, resulting in missed target blood sugar levels and diabetes-related complications (Brown et al, 2017); complications may be acute (such as diabetic ketoacidosis) and/or longer term (such as visual impairment and kidney damage). National publications highlighted challenges faced by people in accessing the care and support they need to self-administer insulin. Services had not consistently adapted to the needs of people with a learning disability (NHS England, 2017) and opportunities had repeatedly been missed to make reasonable adjustments (King's College London, 2024; 2026).

2.4 Summary

2.4.1 The evidence demonstrates that people with a learning disability and diabetes (requiring insulin) are coming to harm where support for safe self-administration of insulin is limited. While there is limited evidence of death occurring because of the patient safety issue, the investigation saw and heard about significant harm. There is potential underreporting of the patient safety issue in community settings, as is known with other issues, limiting the availability of evidence to draw conclusions.

2.4.2 Across all the evidence, the investigation identified themes in the factors that contributed to patient harm. Several of these themes echo those identified in other non-insulin-related incidents seen by HSSIB ([2023](#)), and in the other reports in this series. They highlight a range of system-wide issues that impact on the care of people with a learning disability in general, and more specifically in relation to self-management of diabetes with insulin. The themes are explored further in section 3.

3. Contributors to patient harm

The investigation collated the evidence outlined in section 2, and engaged with local, regional and national stakeholders, including those affected by the patient safety issue. From this, common themes were identified across the factors that were contributing to harm to people with a learning disability who need to take insulin.

This section describes these themes and uses them to share local learning for healthcare organisations. It also highlights the need for wider national learning around future research to support care for people with a learning disability.

3.1 Themes associated with patient harm

Recognition of the need for, and the making of, reasonable adjustments

3.1.1 For people with a learning disability, reasonable adjustments (as described in 1.2) relate to support and communication needs that, if unmet, will put them at a disadvantage when accessing and receiving care. This includes understanding who the person wants involved in their care – such as family and carers – and enabling their involvement. The investigation was told by stakeholders at all levels of the healthcare system that services do not consistently provide reasonable adjustments to meet the needs of people with a learning disability. This has also been described in national publications (King's College London, 2024; 2026; NHS England, 2017).

3.1.2 Healthcare staff told the investigation that they recognised the importance of making adjustments for people with a learning disability, but were unable to do this in a reliable way. This could be because a person's learning disability was not recognised, their needs were not communicated, or because services did not have the ability to meet certain needs. Similar issues were found in [report 1](#) and [report 2](#) of this series in relation to other vulnerable groups, including people with a mental health problem ([report 1, section 3.1](#)).

3.1.3 Regarding recognition of a person's learning disability, a recurrent issue highlighted was the inconsistent, absent or incorrect coding of learning disabilities in patients' healthcare records. Patients may not have been coded as having a learning disability despite a diagnosis, or may have been coded as having a learning difficulty rather than disability. GPs also shared that they had some patients who they thought had a learning disability, but who had not been diagnosed because of delays accessing diagnostic services or the patient refusing an assessment.

3.1.4 Where patients were not coded as having a learning disability, the investigation saw how this impacted on a person's care, as demonstrated in vignette 1. Without a clear diagnosis coded in a patient's clinical notes, they may not be included in learning disability registers,

which means they may not be monitored or invited to annual reviews. Without a coded diagnosis, handover of information to other healthcare organisations to support ongoing reasonable adjustments may also be limited or lost.

3.1.5 While exploring the issue of reasonable adjustments, the investigation heard about the implementation of the 'reasonable adjustments digital flag'. The flag is designed to provide staff with information to support them to make adjustments and to ensure they undertake their duties under the Equality Act 2010 (NHS England, 2026). The flag is mandated for use in all care settings in England, but the investigation heard about delays to widespread adoption. This meant it was not always being used effectively, or, in some places, was not being used at all. The investigation heard that reasons for this included the poor quality of data in healthcare records and delays in the integration of electronic systems to enable data sharing.

3.1.6 Public services have a duty to anticipate reasonable adjustments for someone experiencing a disability and to ensure such adjustments are provided on an ongoing basis (Equality and Human Rights Commission, 2024). Despite this duty, the evidence suggested this was not happening consistently for people with a learning disability, due to issues such as a lack of recognition and consistent coding of the diagnosis, limited communication of needs between organisations, and limited availability of a specialist workforce (Health Services Safety Investigations Body, [2023](#)). These findings have contributed to the learning in section 3.2 and will contribute to the HSSIB investigation [Deterioration in adults with a learning disability in primary care](#).

Availability of services to support patient care

3.1.7 Throughout this series of investigations and in previous HSSIB reports, limited availability of services to support patients has been a recurrent finding. Specific to people with a learning disability, workforce challenges across community nursing teams ([report 2, section 2.3](#)) and in the allied health professions – such as occupational therapists and speech and language therapists – impacted on the making of reasonable adjustments.

3.1.8 Specific to specialist learning disability services, staff told the investigation that the support available was “not quite as accessible as it should be”. They further described limited routes through which to seek advice about the care of people with a learning disability who have a long-term condition, and an absence of defined pathways for accessing specialist support when a person’s health deteriorates. Similar issues accessing specialist support were found by the investigation for patients with a mental health problem ([report 1, section 3.1](#)), and issues around monitoring and responding to deteriorating health were also highlighted in [report 2 \(section 3\)](#).

3.1.9 Limited availability of learning disability services means that non-specialist care providers, including general practice, community and hospital services, are not able to access the support they need to help care for people with a learning disability. This affects the ability to make reasonable adjustments, and reduces the potential to empower and enable patients to manage their own insulin, which has several safety benefits (Specialist Pharmacy Service, 2023). This issue was also highlighted in [report 2 \(section 2.1\)](#), where community nursing teams told the investigation that it was “safer” for patients to administer their own insulin where appropriate but there was limited support available for people with a learning disability.

3.1.10 There is a recognised national shortage of specialist learning disability nurses (Department of Health and Social Care, 2024) and a ‘predicted collapse’ of the profession has been described (Mencap, 2025). This shortage is longstanding and has been highlighted in previous HSSIB ([2021](#); [2023](#)) reports is likely to be considered as part of an ongoing HSSIB investigation into [Deterioration in adults with a learning disability in primary care](#).

Training and competency for people to self-administer insulin

3.1.11 [Report 2 \(section 2\)](#) focused on competency to administer insulin. The investigation found that people with disabilities, including those with a learning disability, were not always being empowered or enabled to self-administer insulin where they may be able to do so. Staff described assumptions that someone would be unable to administer insulin because of their disability. The investigation also identified incidents where it had not been recognised that the person lacked competence or was not supported to develop competence.

3.1.12 The investigation was told about limited, but increasing, training opportunities that have been adjusted to support people with a learning disability to learn to self-manage their diabetes and insulin. These opportunities recognised that safe self-administration of insulin cannot be considered in isolation without also understanding the wider diabetes care, including aspects such as healthy eating, meal planning and monitoring of carbohydrate intake.

3.1.13 In [report 2](#), the investigation made two safety recommendations intended to support people with a disability to develop competency for insulin self-management. The safety recommendations focused on the development of service models that empower and support people to administer insulin in community settings, and the development of supportive guidance for patients, their families and carers to enable and assess competency in light of other disabilities and impairments. These findings have also contributed to the learning in section 3.2.

Application of the Mental Capacity Act in practice

3.1.14 Application of the Mental Capacity Act (MCA) 2005 to people's decisions around self-management of insulin was a recurrent issue raised in incidents involving patients with a learning disability. Staff also told the investigation of limited processes to support the assessment, review and recording of concerns about a patient's capacity to make decisions about their self-management.

3.1.15 Examples of incidents associated with the application of the MCA were also found for people with other disabilities including a mental health problem ([report 1, section 4.1](#)) and cognitive decline ([report 2, section 3.3](#)). Report 2 included a focus on mental capacity with suggested learning for national bodies, integrated care boards and local organisations. That report described how application of the MCA is complex, and that limited education for healthcare staff on how to carry out assessments in practice leads to the MCA being misinterpreted.

3.1.16 A past HSSIB ([2023](#)) investigation that looked at the care of people with a learning disability in acute hospital settings included a focus on supporting staff to assess mental capacity. In response, NHS England (2025) published guidance to support staff to fulfil their legal requirements around the MCA when supporting people with a learning disability. The guidance includes tools, and complements national guidance on decision-making and capacity assessment (National Institute for Health and Care Excellence, 2018). These findings have contributed to the learning in section 3.2.

Access to diabetes devices and technology

3.1.17 Diabetes technology in this investigation included smart insulin pen devices, continuous glucose monitors (CGMs), and insulin pumps (including hybrid closed loop (HCL) systems). The investigation was told by diabetes specialists that diabetes technology can support specialist oversight of people with a learning disability and allow for greater independence. However, across the three reports in this series, and as highlighted by Ms H's experience and vignette 4, factors associated with access to diabetes technology have contributed to patient harm.

3.1.18 Access to technology and devices has multiple dimensions including availability (whether people can have the technology) and design (the extent to which the technology can be used by people). The investigation saw issues with both the design of insulin pen devices and insulin pumps, and the availability of modern technologies – such as HCL systems – for people with a learning disability. Similar issues were identified in relation to people with a mental health problem ([report 1, section 4.2](#)) and other disabilities ([report 2, section 3.2](#)), including assumptions being made about patients' ability to use the device/technology.

3.1.19 Specific to people with a learning disability, assumptions about people's ability to use a device/technology were heard (see also Mencap, n.d.b). The investigation heard views at local and national levels that "it is too difficult" for people with a learning disability to self-manage,

particularly with modern technologies such as CGMs and HCLs. The investigation was further told that national work to consider HCL systems for eligible people with a learning disability had not progressed because patients would not be able to acquire the required numeracy and literacy skills, and because national courses were not adapted to the needs of people.

3.1.20 By contrast, the investigation also heard about services that had supported people with a learning disability to self-manage their diabetes and insulin. Examples included a national education programme that had been adapted to support “carb counting” and self-management using pen devices. Some services had also supported patients to manage their diabetes using an HCL system. The need for a strong social support network, adjusted training to meet individual needs, and regular access to specialist support was described. Stakeholders also highlighted the need for timely access to support, because technology can rapidly contribute to harm if it is not managed appropriately.

3.1.21 NHS England (2024) has published a 5-year strategy to ‘ensure equitable and fair access’ to HCL systems. The strategy describes the need for implementation ‘to avoid exacerbation of existing health inequalities’. The investigation heard that roll-out HCL systems was already exacerbating health inequalities – such as for people with a learning disability – because the healthcare system as a whole did not have the capacity, capability or attitudes to create the conditions for people to have the technology.

3.1.22 No data was found on the availability of diabetes technology for people with a learning disability, but the investigation heard from stakeholders that this group “missed out”. The Equality and Human Rights Commission (EHRC) (2024) told the investigation that organisational policies, including for the implementation of technology, must ensure they do not disadvantage people with a protected characteristic, which includes mental health problems and learning disabilities. To date, there has been no national evaluation of equity of access to HCL systems across different NHS regions to identify variation; the investigation understands that this is intended but not yet available.

3.1.23 The investigation has not examined diabetes devices or technology further here. However, due to the increasing use of modern diabetes technologies and evidence highlighting challenges with access to diabetes devices and technologies for people with various disabilities, this will be specifically explored in the final report in this series. These findings have also contributed to the learning in section 3.2.

3.2 Local-level learning

3.2.1 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 section 3.1, the investigation shares the following local-level learning for organisations that provide care to people with a learning disability with diabetes who require insulin.

- Does your organisation have a process to ensure people with a learning disability are correctly identified and accurately coded in health records, to support long-term health monitoring, such as for diabetes?
- How does your organisation reliably identify patients with a learning disability and communicate the reasonable adjustments required to support their care, including at points of handover of care?
- How does your organisation ensure that the 'reasonable adjustments digital flag' supports effective transfer of information about patient needs, is up to date, and is reliably used by healthcare staff?
- How does your organisation ensure it is meeting its public duty for services to anticipate and make adjustments for people with a learning disability, to enable access to insulin self-management support where appropriate?
- How does your organisation support staff to understand who the person wants involved in their care – such as family members and carers – and enables them to have a role supporting the management of insulin?
- How does your organisation create the conditions for staff to empower and enable patients with a learning disability – through a person-centred approach and provision of accessible information – to self-manage insulin where appropriate?
- How does your organisation ensure that access to specialist learning disability advice is available to support staff to adjust care for patients to meet their diabetes and insulin-related needs?
- How does your organisation monitor and respond to issues that may impact on the ability of a person with a learning disability to safely self-administer their insulin?
- How does your organisation provide practical training and guidance to support staff to consider the mental capacity of patients with a learning disability to make decisions about their insulin self-management, when there are concerns their capacity may be compromised?
- How does your organisation ensure people with a learning disability who meet the criteria for diabetes technology are receiving support to access it, and are not being discriminated against because of their learning disability?

- Does your organisation actively encourage and support staff to report patient safety incidents associated with insulin self-management, including for people with a learning disability?

3.3 National learning around supporting evidence

3.3.1 A challenge throughout the investigation was the limited research evidence about self-management of insulin for people with a learning disability. Evidence gaps include how services can best recognise and respond to people's varying and individual needs, including through the use of diabetes technology such as insulin pumps (Beresford and Kozłowska, 2022), and how to support safe self-administration of insulin and self-management of diabetes.

3.3.2 The investigation was told by people working in academia that these evidence gaps were contributed to by factors that affected the involvement of people with lived experience, including the attitudes of some researchers. Barriers to involvement included limited availability of accessible resources, strict inclusion criteria, and logistical issues such as transport. Concerns were also raised about seeking consent for participation in research and the potential for people to be exposed to harm through their involvement.

3.3.3 Limited involvement of people with a learning disability in research has previously been recognised, including in relation to data collection to understand equity in care delivery (Howard Dicks et al, 2025). The investigation was told that identifying opportunities to involve people with a learning disability is an active priority within the National Institute for Health and Care Research's (NIHR) (2022; 2024) inclusion strategy, with some relevant research already underway in relation to type 2 diabetes and an education programme. The investigation makes the following safety recommendation to support development of future NIHR priorities to address evidence gaps for safe and equitable care for people with a learning disability who require insulin.

HSSIB makes the following safety recommendation

Safety recommendation R/2026/094:

HSSIB recommends that the National Institute for Health and Care Research, in collaboration with relevant research and policy stakeholders, assesses the feasibility of research, and supports its commissioning, to address the gaps in knowledge around services, device and technology requirements for support of people with a learning

disability to self-administer insulin for diabetes. This should be undertaken through co-development with people with a learning disability and aim to create new knowledge to inform delivery of safe and effective care for this group of patients.

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5. Appendix

Investigation Approach

Terms of reference

Through engagement with patients, families, staff and organisations/providers of primary, community and secondary care, the investigation examined the following in relation to people with a learning disability and 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 progressed to engage with regional and national bodies.

Evidence gathering

The investigation engaged with and/or visited organisations/healthcare service providers. 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 coroners' reports to prevent future deaths (PFDs). The sources of evidence used in this investigation are described further in table A.

Table A Evidence gathering and engagement

Evidence source	Details
StEIS – serious incident search	Events submitted 1/01/2023 – 30/12/2025, n = 24,496. Filtered by description ('insulin'), n = 263. Further narrowed and reviewed by service area.
LFPSE – patient safety incidents	Events submitted 1/01/2024 – 30/12/2025, n = 489,859. Filtered by description ('insulin') n = 7,501. Further narrowed and reviewed by service area, date and medication involved.

Evidence source	Details
Reports to prevent future deaths (PFD) – search	Report dates 01/01/2023 – 01/12/2025. Filtered by keyword ‘insulin’, n = 14.
Literature review	A structured search was conducted across multiple databases, including the Cochrane Library, MEDLINE, and Google Scholar. Citation chaining was used to identify additional relevant evidence. A targeted search of national policies and guidance was undertaken to assess how system risks for people with a learning disability using insulin are addressed in practice.
Patient and family insights	Patient and family insights 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 provided specific 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.
Learning disability services	Specialist learning disability services and support services across England.
Integrated care boards	Leads of long-term conditions, nursing and quality representing health and care 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 following stakeholders who contributed evidence to the investigation. Stakeholders also contributed to the development of the safety recommendation.

- Breakthrough T1D

- Care Quality Commission
- Department of Health and Social Care
- Diabetes UK
- Equality and Human Rights Commission
- Getting It Right First Time
- Learning Disability England
- NHS England
- Primary Care Diabetes and Obesity Society
- other experts including academics in diabetes.