NHS England

GIRFT
GETTING IT RIGHT FIRST TIME

Diabetes: Children and Young Adults

GIRFT Programme National Speciality Report

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GIRFT is part of an aligned set of programmes within NHS England

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Foreword by Professor Tim Briggs

Children and young adults living with diabetes carry a lifelong condition through some of the most formative years of their lives - years of growth, learning, growing independence and significant transition. When care is timely, consistent and truly centred on the individual, it can make a profound difference to both their immediate experience and their long-term health. But as this GIRFT national report makes clear, too often the quality of that care and the outcomes that follow depends not on clinical need, but on where a young person lives, how local services are organised, and how well systems use the data and governance frameworks they already have.

GIRFT exists to reduce unwarranted variation by combining rigorous national analysis with the practical knowledge of clinicians, managers and patients. Across all 42 Integrated Care Boards, this review has drawn on national audit and activity datasets alongside local insight to build a clear, comparable picture of performance across the 0-25 age pathway. It identifies excellent practice in many places. But it also shows that variation is driven less by clinical complexity than by system design: diffuse accountability, inconsistent standards, workforce and infrastructure pressures, and a persistent failure to turn good data into sustained action.

The consequences of that variation are real and avoidable. They show up in glycaemic outcomes, completion of essential health checks, access to multidisciplinary support, uptake and optimisation of diabetes technologies, and rates of emergency admissions that should not differ so markedly by postcode. The report pays particular attention to the vulnerable window of young adulthood, and to the inequities that persist for people from socioeconomically disadvantaged communities and minoritised ethnic groups. Equal access is not enough: the NHS must be able to offer equitable outcomes, and innovation must narrow gaps rather than widen them.

The recommendations in this report are deliberately practical. They call for stronger ICS-wide leadership and clear accountability across the whole pathway; a unified data and intelligence function that gives systems a consistent, shared picture of performance; and measurable minimum standards that can be delivered reliably across neighbourhoods and provider settings. Delivering them will require genuine collaboration between paediatric and adult services, primary and community care, networks, voluntary organisations and industry partners. But accountability must be unambiguous at every level from ICB leadership through provider boards to frontline teams.

I am grateful to everyone across England who contributed to this work: the clinical teams, managers, commissioners, networks and patient representatives who engaged honestly with the data and the discussion, often under considerable operational pressure. As with every GIRFT review, the purpose is not to catalogue problems but to drive improvement at pace. The evidence and the will are there. By working together to implement these recommendations, we can make high-quality care for children and young people with diabetes the consistent expectation it should always have been.

Professor Tim Briggs CBE

GIRFT programme lead and NHS England National Director for Clinical Improvement, Elective Recovery and UEC

Foreword by Professor Partha Kar

Improving outcomes for children and young adults with diabetes remains a national priority. Since 2013, significant progress has been made in England through the introduction of the Paediatric Best Practice Tariff, the strength of national clinical networks, high-quality audit data, and a noticeable shift since the rapid adoption of innovative diabetes technologies. These developments have helped strengthen clinical care, improve benchmarking, and support meaningful quality improvement across services.

Despite these advances, important challenges remain. The GIRFT review of diabetes care for children and young adults highlights persistent and unwarranted variation in outcomes, especially in ages 19-25, access to technologies, completion of essential care processes, and emergency admissions. Too often, these differences are shaped not by clinical need but by variations in system design, governance arrangements, workforce capacity, and the use of data to drive improvement. Inequalities affecting socioeconomically disadvantaged communities, minority ethnic groups, and young adults transitioning between services remain a particular concern.

This review, undertaken across all 42 Integrated Care Boards, provides a comprehensive picture of how services are currently delivered and where opportunities exist to improve. It identifies six key domains where variation is most evident and sets out clear recommendations to strengthen leadership and accountability, improve data and intelligence, and standardise care across the 0-25 age pathway.

By addressing these issues collaboratively across systems, we can hope to build a more equitable, resilient, and effective diabetes service that supports every child and young adult to achieve the best possible outcomes.

Professor Partha Kar OBE

Joint adult diabetes clinical lead

Professor Kar is the NHS England GIRFT Type 1 diabetes and technology lead and a consultant in diabetes and endocrinology at Portsmouth Hospitals NHS Trust.

GIRFT clinical leads

Dr Dita Aswani

GIRFT Clinical Lead for CYA Diabetes

Dita is NHS England's GIRFT Clinical Advisor for Children and Young Adults' Diabetes, providing clinical leadership for the CYA diabetes workstream.

She is a consultant paediatrician at Sheffield Children's Hospital, specialising in paediatric diabetes, children's obesity and complications from excess weight. Her interests include reducing health inequalities and strengthening prevention and care for early onset type 2. She also contributes to national work through the NPDA and NICE.

Dr Fulya Mehta

National Speciality Advisor for Diabetes in Children and Young Adults

Fulya is NHS England's National Speciality Advisor for Diabetes in Children and Young Adults; providing programme oversight of the GIRFT/NHS Diabetes Programme CYA diabetes workstream.

She is a paediatrician working in Diabetes and General Paediatrics at Alder Hey Children's Hospital in Liverpool. Her areas of interest include improving transition and young adult diabetes care, improving access to diabetes treatment technology and tackling health inequalities.

Recognising the importance of partnership in driving improvement, Dita and Fulya lead this GIRFT workstream in collaboration with the NHS Diabetes Programme. The workstream aims to tackle variation in care and outcomes between and within trusts and Integrated Care Systems in England, with a particular focus on workforce, equitable access to technology, and the transition from paediatric to adult services. This work reflects the added value of the national paediatric and young adult diabetes clinical community working in partnership with patients, families, and system partners to enable shared learning and to develop recommendations that are both evidence-based and grounded in the lived experience of those most affected.

Introduction from Dita Aswani

A new diagnosis, marking the beginning of lifelong care, is a profound turning point. Sometimes no amount of healthcare expertise can prevent or alter what someone is facing, but we can shape how they face it, by the way we respond, for better or for worse.

When diabetes affects a child or young person, the onset can be abrupt, acutely life-threatening and entirely unforeseen. High quality care and support can ease the experience and improve the trajectory, and equity changes opportunity and outcomes.

Each healthcare professional has the potential to make their impact positive and empowering, by enquiring with intention about someone's reality, listening with sincerity to understand a world that may differ from their own, believing what they hear, explaining clearly, and offering every available choice without narrowing that choice through assumption or bias. Getting the basics right, every time and for every family, is the foundation on which all this rests.

These gifts lie in the hands of individual practitioners and should be delivered to a high standard whatever the context. But the care and support that patients and families receive, and the experience and outcomes that follow, are also shaped by the culture of the team, the structure of the organisation that creates the conditions for care, the strength of professional networks to uphold and drive standards, the ICBs that commission and govern services, and the lived experience and patient voice that influence policy.

Patients should be able to trust that the care package around them is what it should be, and clinical teams should be confident in providing that assurance. The whole system carries responsibility for elements of this; when any part is incomplete, individuals are compromised. There should be no lottery to this, no unwarranted variation. In the NHS, *everyone counts*.

The diverse stakeholder participation in all 42 system reviews reflects how many people across the system are invested in diabetes quality improvement: clinical leaders, managers, commissioners, regional networks supporting provider teams, charitable partners and patient advocates. These reviews were carried out during a period of increasing financial instability, sudden organisational change and personal difficulty for many colleagues in ICBs. Despite these pressures and their vast portfolios, colleagues discussed and interrogated the data with interest and played an active role in shaping their own local recommendations. Many teams demonstrated the improvements already achieved without additional investment, and there are scalable examples of these, in this report.

What came through was optimism, drive, compassion, and a sincere desire to improve patient care and outcomes. There is real hope for the future.

I had the privilege of chairing every single pre-meet and every review, and I want to offer a very warm thank you for everyone's time and preparation, honesty, engagement, and since then, their energy in addressing their local ICB recommendations. My biggest thanks go to the regional managers from National Children and Young People's Diabetes Network, who attended multiple reviews, and continue to provide wraparound support to all their teams and ICBs as they implement recommendations.

I am particularly grateful to Professor Tim Briggs and the GIRFT programme for collaborating with the NHS England Diabetes Programme, giving us, as a diabetes professional and lived-experience community, the opportunity to focus on this prevalent long-term condition through the vital lens of the youngest members of our society, those for whom the future is so important, and on whom we all depend. Without scrutiny, there is no progression.

This programme identifies three overarching recommendations that, with committed system-level action, would demonstrably reduce unwarranted variation.

Complementing these is a detailed roadmap of discrete, actionable steps for quality improvement across six domains of variation, steps that could be taken by any part of the system locally and, where possible, scaled through collaboration and support from clinical networks, charitable partners and GIRFT Academy.

Statement of support

Diabetes UK

Diabetes UK welcomes this GIRFT review of diabetes care for children and young adults and strongly supports its findings and recommendations. Diabetes presents relentless demands which interact with the challenges of growing up generally. Young people and their families tell us of how difficult it is to live with the physical and mental burden of the condition; managing blood glucose levels whilst socialising, taking part in sport, navigating education, work and other aspects of day-to-day life. However, these challenges can be overcome with the right foundations and approach.

We've seen great progress in diabetes care thanks to key improvements including dedicated clinical networks, availability of high-quality audit data, the widespread adoption of life-changing diabetes technology and introduction of the paediatric Best Practice Tariff (BPT). However, significant variation remains locally, and it is vital these resources and tools are consistently adopted across the whole country.

The report highlights the urgent need to reduce unwarranted variation across a number of key areas to ensure that every child and young person receives high-quality care and support, regardless of where they live. Its emphasis on strong system leadership, clear standards and pathways and meaningful use of data aligns with our 2026-30 strategy, particularly our focus on improving access to essential health checks, tackling inequities and stigma and enabling earlier, more effective intervention to end the avoidable harms of diabetes. Its focus on the value of lived experience also complements our ambition to empower young people to connect with their peers and amplify their voice through initiatives like our Together Type 1 programme.

Crucially, the report reinforces the importance of delivering holistic, proactive and tailored care. Children and young adults with diabetes require support that is adapted to their individual needs and life stage and can meet them where they are. The findings show how timely, co-ordinated care is essential to improving health outcomes and quality of life. This is true for all children and young adults with diabetes, and especially so for those who are at higher risk of experiencing poorer outcomes, such as those making the transition between paediatric and adult services and the rising number of young people with type 2 diabetes.

We particularly welcome the focus on equity and the recognition that personalised, culturally competent care and proactive support are key to closing gaps in outcomes for those from

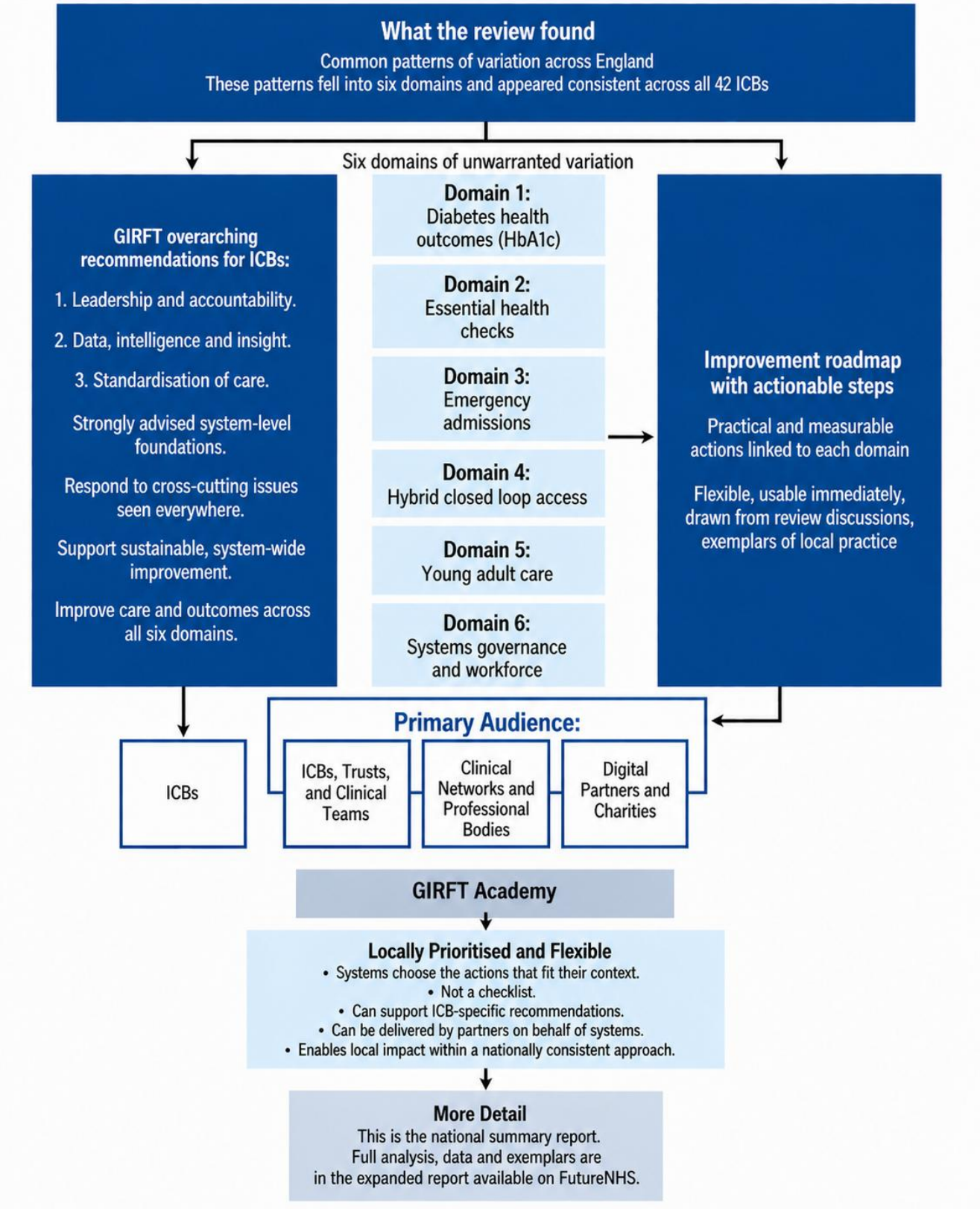
more disadvantaged groups. The recommendations provide a practical framework to deliver person-centred, preventative and digitally enabled care, in line with key shifts set out in the NHS England 10 Year Plan.

Diabetes UK looks forward to continuing to work with the NHS, partners and communities to support the implementation of these recommendations and to ensure that every child and young adult with diabetes is supported to live well now and in the future.

Colette Marshall

Chief Executive, Diabetes UK

Figure 1: How the review findings, recommendations and improvement toolkit are organised



How to read this report

This report brings together the findings from the GIRFT systems review of diabetes care for children and young adults (CYA) aged 0-25 across all 42 Integrated Care Boards (ICBs). The infographic on the previous page (figure 1) shows how the report is structured and how the findings link to the actions and recommendations.

The review identified consistent patterns of unwarranted variation and the system conditions required to address them. This report therefore presents:

1. **Three overarching GIRFT recommendations for ICBs** to address the structural foundations required to reduce unwarranted variation covering governance, accountability, data intelligence, commissioning and care pathway standards. These recommendations tackle the root causes of variation and create the system conditions needed for sustainable improvement.

2. **An improvement roadmap of actionable steps** serves as a **toolkit** for provider teams, clinical networks, charitable partners, and ICBs seeking to accelerate local improvement, supported by GIRFT Academy through the development of relevant resources. It is derived from detailed insights and examples of effective local practice identified across the 42 reviews, preserving learning that would otherwise be lost. The roadmap is not a prescriptive checklist: clinical teams and ICBs can select the actions that best fit their priorities and context, to take forward immediately, while partner organisations can adopt others to deliver scalable, efficient improvement across all settings.

Together, the recommendations set the system conditions, and the roadmap provides the practical steps, supporting ICBs and providers to deliver high-quality, equitable, age-responsive care across the 0-25 pathway.

Introduction

The GIRFT systems review provides the most comprehensive national picture to date of how diabetes services for children and young adults aged 0-25 are organised, how care and outcomes vary, and what systems need to do to deliver equitable, modern care. Covering all 42 Integrated Care Boards, it brings together data, pathway insight and frontline experience to assess how well current models meet the needs of a changing population.

Why the review was needed

Over the past decade, diabetes care for children and young people in England has strengthened significantly. The paediatric Best Practice Tariff (BPT), strong clinical networks, high-quality audit data and rapid adoption of NICE-approved technologies have driven meaningful improvement. The National Paediatric Diabetes Audit now provides near real-time insight into care processes, technology use and outcomes by deprivation, ethnicity and age.

Despite this national progress, there is marked and avoidable variation for cohorts of patients. Differences in completion of care processes, access to technologies, emergency admissions and diabetes health outcomes are evident both between and within ICBs, including between providers serving similar populations. Some variation is obscured where services sit across organisational boundaries and do not benchmark against one another. Other variation is visible in the data but remains unchallenged.

The case for a system-wide review is strengthened by the changing national picture: rising case numbers, increasing complexity, the sharp growth in early-onset type 2 diabetes, and rapid advances in technology and therapeutics all demand a more co-ordinated and proactive response. Expectations around equity and experience are rightly higher, and emerging approaches in screening and precision medicine mean that legacy models of care will not keep pace without deliberate system action.

What the review found

The review identified **six domains** where unwarranted variation is most pronounced and where improvement would have the greatest impact on outcomes, safety and equity:

1. Diabetes health outcomes (including HbA1c)
2. Completion of essential annual health checks
3. Emergency admissions
4. Access to and outcomes from hybrid closed loop therapy
5. Young adult care (19-25 years)
6. Systems governance and workforce capability

Across all six domains, the same underlying system weaknesses recurred. Variation was driven less by clinical complexity and more by **three cross-cutting structural issues:**

1. Leadership and accountability
2. Data, intelligence and insight
3. Standardisation of care

These system-level gaps were often compounded by fragmented pathways, particularly at transition, and variable workforce capacity and capability. Together, these insights form the basis of the **three overarching GIRFT recommendations for ICBs**, which address the root causes of unwarranted variation and provide the foundations for the **improvement roadmap of actionable steps** aligned to each domain of variation.

Specialty overview

Diabetes in childhood and young adulthood shapes decades of future health. Early glycaemic patterns have lasting effects ("metabolic memory"), meaning that timely intervention, treatment intensification, and follow-up continuity can alter a young person's entire trajectory.[1] High-quality care supports safety, emotional wellbeing, independence, and optimal outcomes.

Children and young adults carry a significant daily burden of self-management. Most of the actions taken to maintain glycaemic stability take place outside clinical settings, requiring young people, supported by families and other caregivers to make continual decisions about insulin, food and activity. Clear communication, practical education and psychological support are essential to sustaining safe care.

Young adulthood (19-25 years) is a particularly vulnerable period. Reducing support from caregivers and increasing expectations of independence can leave young people navigating complex care with less structure and safety, leading to rising HbA1c levels, increased hospital admissions and loss of confidence in self-management. Developmentally attuned pathways are essential to prevent avoidable deterioration.

Understanding diabetes in childhood and young adulthood

'Diabetes' refers to a group of different conditions with distinct causes, treatments and patterns of progression. All types of diabetes result in the body being unable to self-regulate blood glucose levels because the hormone insulin is absent, insufficient or not used effectively. Type 1 and type 2 diabetes are the predominant types seen in childhood and young adulthood, each with characteristic features (table 1). Type 2 diabetes diagnosed under the age of 40 is classified as early-onset type 2 diabetes (EoT2D), reflecting both the age at diagnosis and the fact that it behaves differently from type 2 diabetes in older adults - progressing more rapidly and accumulating risk earlier. There are also rarer forms, such as monogenic diabetes and diabetes secondary to other conditions. Specialist assessment and accurate classification is vital to avoid misdiagnosis and ensure individuals receive the right management.

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[1] *Rawshani A., Sattar N., Franzén S. et al., Excess mortality and cardiovascular disease in young adults with type 1 diabetes in relation to age at onset: a nationwide, register-based cohort study. Lancet. 2018 Aug 11;392(10146):477-486. doi: 10.1016/S0140-6736(18)31506-X. Epub 2018 Aug 9. PMID: 30129464; PMCID: PMC6828554.*

Table 1: Distinguishing features of type 1 and type 2 diabetes in children and young adults

Type 1 diabetes
An autoimmune condition in which the pancreas stops producing insulin
Requires lifelong insulin therapy from diagnosis
Incidence of cases steadily rising year on year, can present at any age, including infancy
Genetic susceptibility and environmental triggers; non-modifiable risks
Is permanent
Unusual to have diabetes-related complications at diagnosis
Early-onset type 2 diabetes
Driven by insulin resistance and progressive loss of insulin production
Managed with lifestyle measures, medications and sometimes insulin
Sharply increasing in incidence, especially from adolescence and young adulthood
Obesity, deprivation, ethnicity and feto-maternal factors; multifactorial, non-individual risk
Remission is possible for some individuals with intensive and sustained management
Diabetes-related complications are frequently already present at diagnosis

The 0-25 diabetes population

Children and young adults (0-25 years) represent a small proportion of the overall diabetes population, but a disproportionately large share of those living with type 1 diabetes. Early-onset type 2 diabetes, while still relatively uncommon in this age group, is increasing rapidly from adolescence into young adulthood.

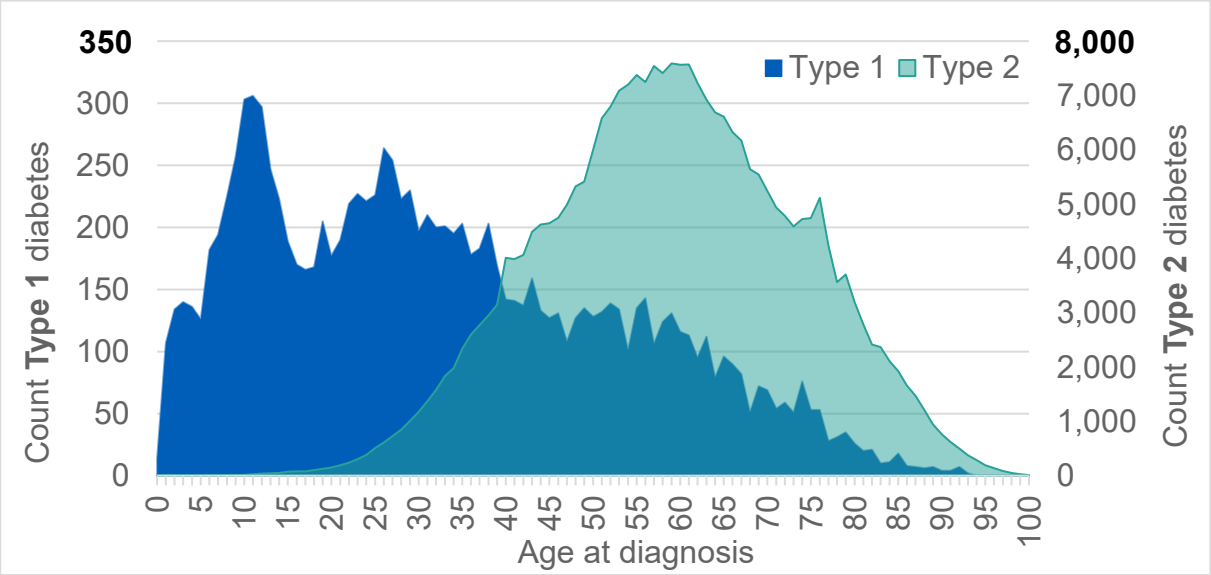
The care needs of CYA differ fundamentally from those of adults, reflecting their developmental maturity, dependence on family involvement, the life-stage risks that make management more challenging, and the way diabetes behaves in younger people. These differences mean that services must provide age-appropriate, developmentally aligned care and timely access to teams with the specialist expertise for each type of diabetes.

Table 2: The 0-25 diabetes landscape (England 2023/24)

Metric	Value
Total number of people with type 1 or type 2 diabetes	3.8 million
With type 1 diabetes	262,500
With type 2 diabetes	3.5 million
CYA (aged 0-25) share of type 1 and type 2 diabetes	1.7% of all people with diabetes
CYA share of type 1 (disproportionately large)	21% of all people with type 1
CYA share of type 2 (disproportionately small)	0.3% of all people with type 2

Source: Analysis of combined NPDA and NDA 2023/24 audit data

Figure 2: Count of new diagnosis in 2023/24 by age at time of diabetes diagnosis, note the difference in scale as type 2 diabetes is a more common condition.



Source: Analysis of combined NPDA and NDA 2023/24 audit data

Table 3: Number of children and young adults registered with type 1 and type 2 diabetes (England 2023/24)

Age group	Type 1	Type 2
0–12 years	12,805	190
13–18 years	18,375	1,540
19-25 years	25,005	7,420
Total	**56,185**	**9,150**

What defines high-quality care

High-quality diabetes care for children and young adults relies on input from a skilled multidisciplinary team (MDT) with expertise in paediatrics, young adult care and the behavioural and engagement needs of this age range, alongside specialist nursing, dietetics and psychology. Each discipline contributes essential components of safe day-to-day management, emergency preparedness and long-term health.

Structured education must be accessible and appropriately staged for cognitive maturity, building skills and confidence over time as children and young people move towards independence. Families, schools and other carers need practical, regularly updated training to support routine care and respond effectively to emergencies.

Addressing the psychosocial impact of diabetes is integral to holistic and non-stigmatising care. Support needs intensify during adolescence and young adulthood, when developmental pressures heighten emotional strain and make diabetes management more challenging. Access to peer support and psychological and mental-health professionals with diabetes expertise is critical to sustaining engagement and preventing deterioration.

A co-ordinated, age-responsive continuum of care is essential. Care should be seamless across paediatric, transition and young adult services, with clearly defined responsibilities and shared accountability. High-quality care also requires equitable access to evidence-based technologies and therapies, and equitable outcomes from their use, with support that intensifies proactively whenever risk increases.

An evolving field: technology, therapeutics and innovation

Diabetes care has transformed over the past decade. Continuous glucose monitoring, insulin pumps and hybrid closed loop systems now provide real-time data, semi-automation and cloud-based data sharing to enable remote review and timely intervention. These technologies improve glucose stability, reduce hypoglycaemia, ease the cognitive burden of self-management and enhance quality of life.

For type 2 diabetes, GLP-1 receptor agonists and SGLT2 inhibitors have expanded the range of effective therapies, offering benefits beyond glucose control, including weight reduction and reduced cardiovascular and renal risk.

In type 1, emerging innovations including screening tools, predictive biomarkers and immunotherapies signal a shift towards earlier detection and more precise, targeted care, offering opportunities to improve outcomes and reduce risk of harm where possible.

Workforce capability must keep pace with rapid advances in diabetes care. Sustained training, protected time for skill development and clear competency expectations are essential to ensure staff remain confident, safe and up to date.

Changing epidemiology and deepening inequalities

Early-onset type 2 diabetes incidence has increased sharply, rising by almost 50% in 0–15-year-olds in five years and continuing to accelerate into young adulthood.[2] A diagnosis earlier in life is associated with worse outcomes, with higher complication rates at diagnosis, greater cardiometabolic risk, and faster progression.[3]

This changing pattern is associated with a deepening entrenchment of inequality. Early-onset type 2 diabetes is disproportionally common in several minority ethnic groups, reflecting higher biological susceptibility at lower BMI thresholds and greater exposure to structural disadvantage. It is also more common in areas of deprivation, where CYA experience higher levels of early-life and environmental risk. Obesity is a particularly potent risk factor in youth. All these factors interact to drive earlier onset and a more aggressive disease behaviour.

Although national gaps are narrowing, inequities remain in type 1 diabetes with higher HbA1c levels, lower technology use and higher rates of Diabetic Ketoacidosis (DKA) at diagnosis in some ethnic and socioeconomic groups. While there may be some inherent biological differences between populations, these patterns cannot be explained by biology alone; even where populations have similar biological risk and comparable access to diabetes technologies, outcomes still vary markedly between places, highlighting the influence of system quality, consistency of care and responsiveness.

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[2] *National Paediatric Diabetes Audit, Type 2 Diabetes Spotlight Audit 2023/24, https://www.rcpch.ac.uk/sites/default/files/2025-08/npda_type_2_spotlight_report_2023-24.pdf*

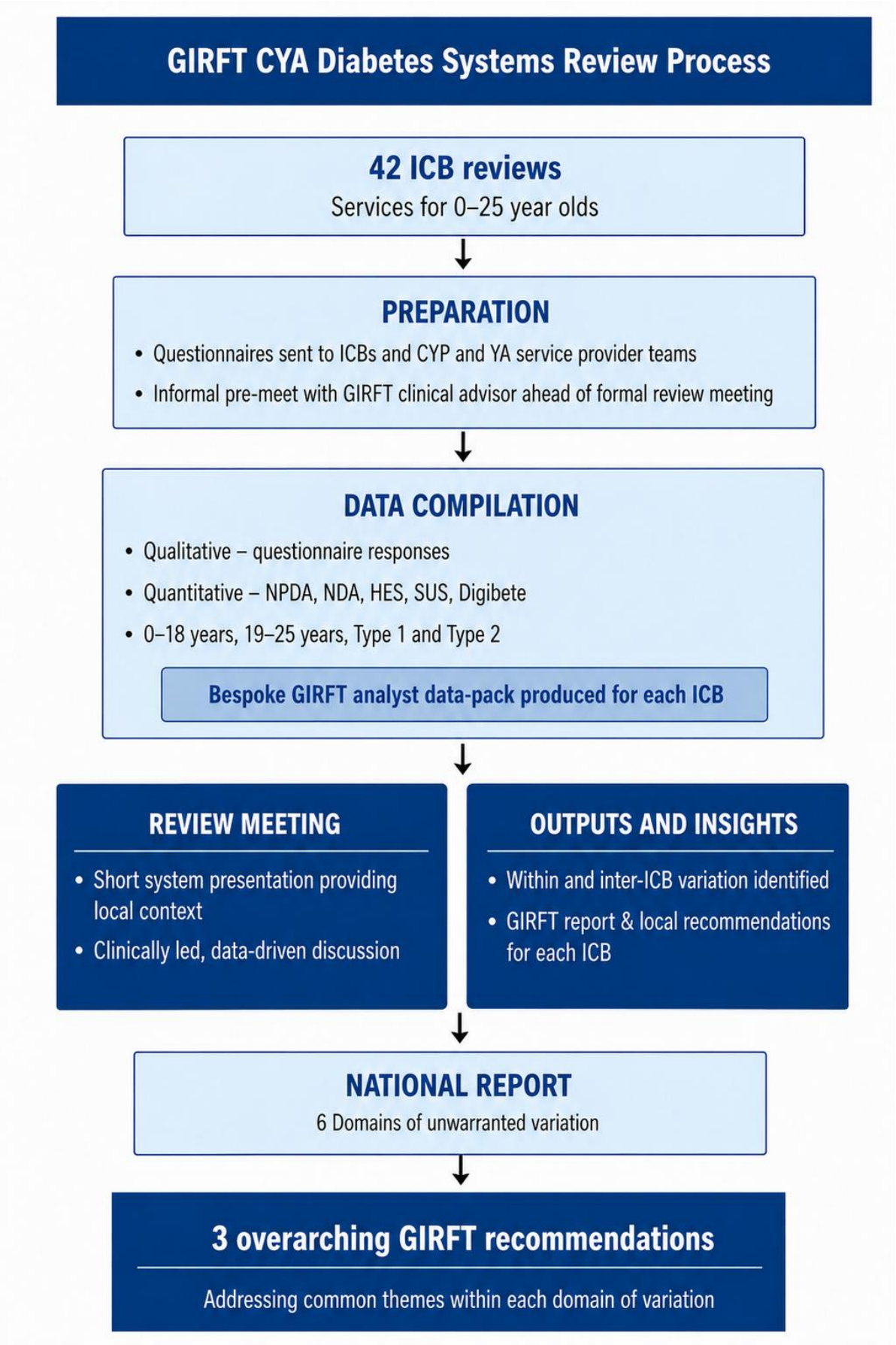
[3] *Lim LL, Misra S, Ke C, Srinivasan S, Ma RCW, Chan JCN, et al. Understanding the drivers and consequences of early-onset type 2 diabetes. Lancet. 2025;405(10497):XX–XX. doi:10.1016/S0140-6736(25)01012-8.*

What does this mean for Commissioners?

- Diabetes in 0-25s is a **critical long-term condition** where the **quality of early care determines lifelong health**.
- The major epidemiological shift in early-onset type 2 has clear implications for workforce expertise and for service design capable of delivering culturally competent care using **community and faith-anchored approaches** to reach groups most affected.
- Modern type 1 diabetes care requires **new models**, not simply more activity within existing ones. Systems must shift from episodic, clinic-based care to **continuous support enabled by digital and wearable technologies**.
- Precision medicine, screening and immunotherapies represent a **paradigm shift towards earlier detection** and more targeted intervention, requiring robust and clear system pathways.
- Care must shift from siloed paediatric and adult services to a **co-ordinated, age-responsive pathway** with shared responsibility across the whole journey.
- Commissioning and accountability must **move beyond ensuring equal access to include equitable outcomes.**
- Pathways must be designed with equity at their core, using **deliberate inclusive rollout strategies that prevent new developments from widening existing inequalities.**
- Workforce capability must **keep pace with digital, therapeutic and technological advances,** with mandated training and protected time for skill development.

The review process

Figure 3: Overview of the GIRFT CYA Diabetes systems review methodology



Findings, roadmap of actionable steps, and GIRFT recommendations

Rich engagement across the whole system enabled operational, strategic, financial, managerial and clinical leaders to interrogate their data together and agree on local priorities. This national report synthesises the collective findings across all 42 ICBs.

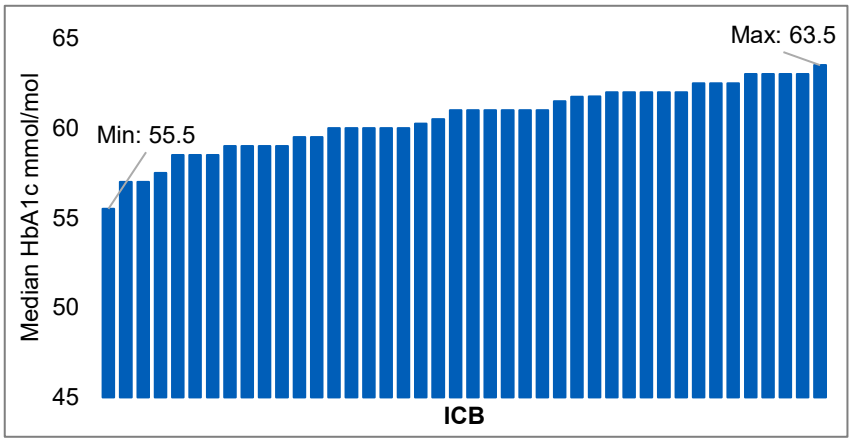
The sections that follow present the findings across six domains of unwarranted variation, the improvement roadmap of actionable steps aligned to each domain, and the three overarching GIRFT recommendations for ICBs. Together, these components provide a coherent, system-level approach to reducing unwarranted variation and improving outcomes for children and young adults with diabetes.

Overview of findings in six domains of unwarranted variation

Domain 1: Variation in Diabetes health outcomes (including HbA1c)

Diabetes health outcomes reflect how effectively systems support CYA to achieve safe, stable glucose levels over time. HbA1c remains the primary comparative measure between cohorts of patients and is a validated predictor of long-term diabetes health.

Figure 4: Variation in ICB median HbA1c for type 1 patients aged 0-18 (England 2023/24)



Source: NPDA 2023/24

Findings

- **Unwarranted variation in cohort HbA1c:** Significant variation persists between and within Integrated Care Systems (ICSs), even when accounting for demographics or technology uptake. Differences reflect system-level factors such as leadership, commissioning, capability and collaboration.
- **Place of care and service specification:** Care location influences review frequency, and access to MDT expertise, technologies and therapies. Outside paediatric secondary care, the absence of standardised specifications creates wide variation in the intensity and components of care.
- **Early-onset type 2 diabetes:** Many teams lack T2 specific pathways, workforce competencies and experience in using specialist therapies, and access to obesity and weight management services is limited.
- **Treatment intensification pathways:** 'High HbA1c' pathways are not always present or implemented, and variation in thresholds for additional input, and processes for intensifying care, leads to inconsistent responses to the same degree of patient-level risk.
- **Clinical and psychosocial risk indicators:** HbA1c is often the only indicator routinely used to trigger an intensification process. CGM metrics, admissions, WNB/DNA patterns and early complications are used inconsistently and rarely considered in combination to form a coherent picture of risk.

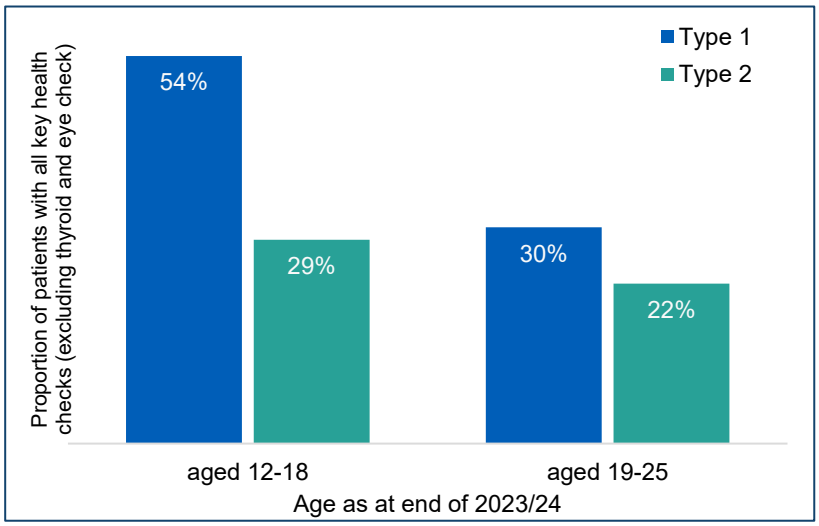
- **Access to technology**: Pump, CGM and hybrid closed-loop uptake varies widely due to commissioning, workforce and capacity constraints. The size of inequity gap for deprived and minoritised groups differs between places.
- **Workforce shortages and gaps in specialist expertise**: Rising caseloads, vacancies and limited MDT access reduce capacity for timely, intensified care and technology-enabled management. Insufficient protected development time constrains capability.
- **Service delivery challenges**: Limited administrative and operational support reduce routine clinical capacity for proactive review and treatment intensification, delaying intervention for those with high HbA1c or instability.
- **Governance of appointment systems, utilisation and follow-up:** Review frequency is often interval-driven rather than need-driven. Weak governance, inflexible systems and high DNA/WNB rates disrupt continuity and hinder proactive intensification.
- **Digital infrastructure, data quality and risk-stratification capability**: Incomplete NPDA / NDA submissions and limited analytical capacity hinder benchmarking and proactive care. Risk-stratification tools are inconsistently used.
- **Data missingness and reduced visibility of risk**: Missing data, often concentrated among higher-risk groups, reduces visibility of clinical, psychosocial and continuity-related risks. Systems rarely analyse data missingness itself.
- **Structural, racialised and socioeconomic disparities:** Racial and socioeconomic differences in HbA1c exist nationally, but wide variation between ICBs with comparable populations shows these gaps are not fixed and reflect how services are designed and whether care is adapted and delivered equitably**.**
- **Adapted and equity-informed practice:** Structured approaches to language-specific, culturally competent, faith-based or bias-aware practice are limited. Time, flexibility and training constraints lead to inconsistent personalised care**.**
- **Paediatric diabetes best practice tariff (BPT) minimum care standards**: Many services struggle to meet BPT standards, and few use the tariff to strengthen frontline capacity, limiting sustained improvement in diabetes outcomes.

1	Actionable steps to reduce variation in diabetes health outcomes
	a) Introduce consistent, equity-driven risk-based intensification pathways.
	b) Develop clinical pathways and workforce capability for type 2 diabetes in children, adolescents and young adults.
	c) Strengthen service delivery infrastructure.
	d) Implement governance for unmet patient treatment-intensification needs.
	e) Build capability for a culturally competent workforce skilled in inclusive practice.

Domain 2: Variation in completion of essential annual health checks (care processes)

Essential annual health checks are designed to prevent avoidable harm by enabling early detection and timely treatment of diabetes-related complications.

Figure 5: Completion of recommended health checks by age and diabetes type (England, 2023/24)



Source: NPDA and NDA combined data 2023/24

Findings

- **Low completion rates**:
  Delivery of essential health checks varies markedly between and within ICBs, with the lowest completion among young adults and those with early-onset type 2 diabetes, groups with the highest cardiometabolic and psychosocial risk.
- **Inequity**: Standardised, non-tailored approaches to health check completion, fail to meet differing needs amplifying an already heightened risk for those with clinical or psychosocial complexity or facing socioeconomic disadvantage.
- **Fragmented care**: Poorly co-ordinated pathways and the need for multiple appointments increase patient burden and leads to missed or duplicated checks, especially for young adults navigating varied routes through care.

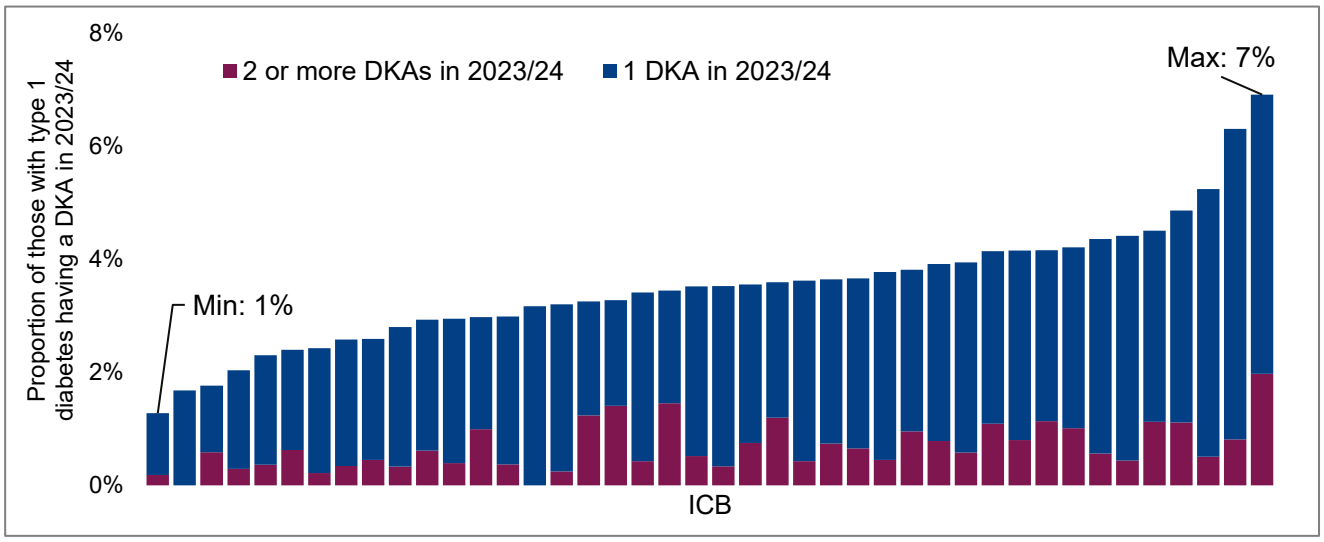
- **Missed opportunistic care**: Disconnected patient record systems and weak information-sharing mean overdue checks are not identified during other encounters, such as inpatient admissions, reducing opportunities to complete missed checks.
- **Responsibility for care processes:** Contractual responsibility is held by primary care. In practice, paediatric teams deliver checks for their patients; for young adults, checks can be shared across primary and specialist care creating ambiguity in ownership, gaps and duplication for both services and patients.
- **Data capture and audit accountability**: Separate record systems and inconsistent data entry and sharing mean completed checks are not always visible to primary care, or captured in national audits, obscuring true delivery and limiting accountability.
- **Retinal screening**: This is delivered by a separate screening service, with completion frequently differing from other essential checks; in paediatrics, capture in NPDA is limited by reliance on local data sharing and manual submission.
- **Emotional wellbeing and mental health screening**: Inconsistent wellbeing screening means the point at which expected diabetes-related distress becomes support-requiring may be missed, increasing the risk of unmet psychosocial need.
- **Education and self-management support**: Many young people are not routinely linked to approved digital diabetes resources that explain essential health checks and their purpose, and that validate lived experience of diabetes-related distress, supporting completion.

2	Actionable steps to reduce variation in essential annual health check completion
	a) Establish clear responsibility and accountability across the system for completing and recording essential health checks (including retinal screening).
	b) Provide patients with flexible, accessible and opportunistic pathways for completing checks.
	c) Embed routine psychological screening to ensure mental health needs are consistently identified, recorded and routed to staff with the expertise to assess risk, triage concerns and determine appropriate next steps.

Domain 3: Variation in Emergency admissions

Emergency admission rates for DKA and severe hypoglycaemia indicate how effectively symptoms are recognised, acted on and supported across the system, from first presentation through ongoing care. Many episodes are preventable, but not all are avoidable.

Figure 6: Variation by ICB of DKA (after diagnosis) rate for people with type 1 diabetes aged 0–18 years old (England)



Source: NPDA and NDA combined data 2023/24 linked to HES

Findings

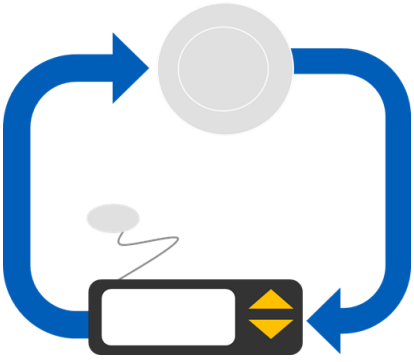
- **DKA at diagnosis**: GIRFT data show considerable variation between ICBs for DKA at diagnosis. Nationally, there are distinct patterns in incidence by age, deprivation and ethnicity.
- **DKA and hypoglycaemia after diagnosis**: Rates vary markedly between ICBs, including variation in numbers of individuals having recurrent episodes. Nationally, DKA peaks in young adulthood.
- **Responses to emergency admissions**: Admissions do not reliably trigger structured follow-up or communication with ongoing care teams. Variation in length of stay indicates differing inpatient management, discharge planning and co-ordination between teams.
- **Non-attendance and disengagement**: WNB/DNA patterns are not routinely reviewed, reducing opportunities to re-engage young people before deterioration and unplanned admission.
- **Out-of-hours advice**: Models for providing specialist advice outside routine hours vary widely between areas, with no consistent approach. This variation may influence how rising risk is recognised and acted on.

- **Digital support and self-management tools**: Nationally funded sick-day and ketone-management resources are not routinely embedded in care pathways, and uptake is not systematically monitored, limiting visibility of who is not receiving or using this support.
- **Case review, audit and thematic analysis:** Regular structured audit of emergency admissions is uncommon, and review is often limited to isolated cases and headline data. The lack of broader contextual analysis restricts system-level learning and improvement.

3	Actionable steps to reduce variation in emergency admissions
	a) Embed regular case review, audit and thematic analysis of emergency admissions for DKA and severe hypoglycaemia, as a core component of diabetes service evaluation.
	b) Identify individuals at increased risk of emergency episodes and intensify management accordingly.
	c) Use inpatient episodes as structured opportunities to understand vulnerabilities and strengthen support to prevent recurrence.
	d) Ensure a clear, safe plan is in place at the point of need.

Domain 4: Variation in access to and outcomes from Hybrid Closed Loop Therapy

Figure 7: Hybrid closed Loop



Hybrid Closed Loop (HCL) technology is NICE-approved and cost-effective, improving glycaemic stability, reducing the risk of complications and enhancing quality of life.

Findings

- **Unequal uptake across populations**: Overall uptake and gaps in use by ethnicity and deprivation vary widely between and within ICBs, indicating that inequities are structural and reflect local approaches, not inevitability.
- **Procurement and funding inequities**. Differences in procurement, approval processes and interpretation of NICE guidance create delays and inconsistent access across services.
- **Onboarding and optimisation in paediatrics**: Paediatric rollout has been rapid overall but with variation in timing of onboarding and optimisation practices. This affects equity within paediatrics and readiness for transfer to young adult care.

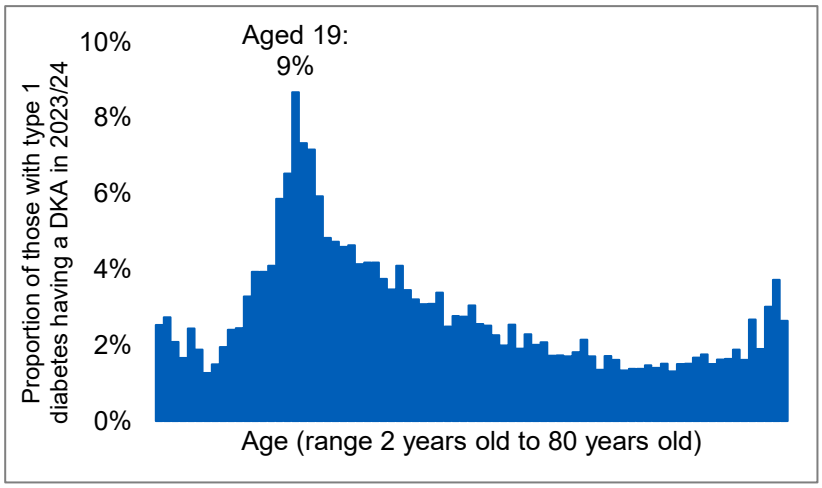
- **Under-resourced young adult services**. Adult services are not configured for the large numbers transferring from paediatrics on HCL, nor for onboarding eligible adults at pace, limiting consistent optimisation and management.
- **Workforce confidence and capability**: Experience with HCL varies across both paediatric and adult MDTs, with adult services generally having fewer trained staff. These differences create uneven expertise within each service and across transitions.
- **Training for non-specialist teams**: Emergency, surgical, inpatient and primary care settings often lack familiarity with HCL systems and their operation, creating uncertainty during acute illness when young people cannot safely manage devices themselves.
- **Infrastructure limitations**: Poor network connectivity and outdated NHS IT systems hinder cloud-based platforms, delaying onboarding, data upload and troubleshooting, and creating inefficiencies for staff.
- **Data capture**: Incomplete health inequalities data and inconsistent device recording limit reliable equity monitoring and affect reimbursement payments, which depend on accurate information on insulin regimen and technology use.
- **Out-of-hours support**: Models for providing clinical advice outside routine hours vary widely between services, which may affect continuation of HCL use or confidence in day-to-day self-management.

4	Actionable steps to reduce variation in access to and outcomes from hybrid closed loop therapy
	a) Embed early onboarding and optimisation of HCL in paediatric care to support safe transition to adult services and lifelong use.
	b) Build workforce confidence and capability across all services.
	c) Ensure digital infrastructure is fit-for-purpose to support safe and efficient HCL care.
	d) Strengthen system-wide safety nets for HCL users.
	e) Address inequalities and support inclusion in digitally enabled care.
	f) Plan for sustainable long-term commissioning and funding of HCL beyond the national support period.

Domain 5: Variation in young adult care (19-25 years)

Young adulthood (19-25 years) is a high-risk period where major life transitions occur just as family and service support changes. This is also the stage where greater glycaemic instability and higher emergency admission rates are well recognised.

Figure 8: DKA after diagnosis by age



Source: NPDA and NDA combined data 2023/24 linked to HES

Findings

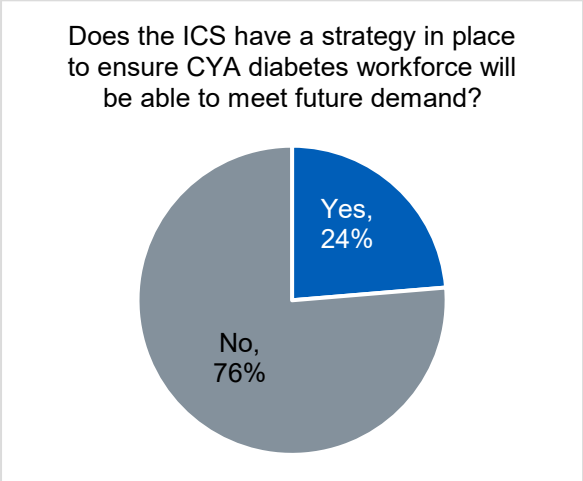
- **Transition and pre-transfer preparation:** Transition models vary widely in structure and duration, and limited capacity for joint appointments means some young people (YP) leave paediatrics with insufficient preparation or established relationships with their adult team.
- **Timing of transfer to young adult services**: Service structures and pressures usually determine the timing of transfer, rather than developmental readiness. Handovers can be incomplete and first adult appointments delayed, increasing the risk of disengagement and deterioration.
- **Change in minimum care standards from paediatrics to young adult care:** Paediatric BPT criteria define key care components and monitoring frequency, so transferring at a younger age, whether due to paediatric capacity constraints, provider service model structure or age cut-offs, results in an earlier step-down in intensity. Where BPT components have not been fully delivered beforehand, YP transfer with less optimisation and reduced readiness, increasing the risk of deterioration after transfer.
- **Developmentally appropriate service design**: Adult services are typically designed for older adults and often lack dedicated or adapted pathways to suit 19-25-year-olds.
- **Relational continuity and engagement support**: Many young adults lack access to non-clinical relational roles, such as youth workers who help sustain engagement.
- **Pathway clarity and co-ordination:** The review found that pathways into and through young adult services are often unclear or inconsistently described, making navigation difficult.

- **Place of care**: Care location is often driven by local capacity rather than individual's condition-specific requirements, leading to inconsistent access to specialist expertise, technologies and therapies.
- **Preventing loss to follow-up**: Automatic discharge after missed appointments and limited re-engagement mechanisms place young adults at high risk of being lost to follow-up, particularly those already vulnerable.
- **Flexible pathways into and out of specialist services**: The review found that standard pathways are often followed by default, with inconsistent adjustment for changing need, limiting timely return to specialist care.
- **Tailored care for type 1 diabetes**: Access to technologies is inconsistent, and where cloud-based data are available they are not reviewed in a standardised way, limiting optimisation and proactive support.
- **Urgent escalation for type 2 diabetes**: Pathway variation means young adults with type 2 diabetes often face delayed intensification of evidence-based therapies, and missed checks, despite having an aggressive condition.
- **Diagnostic ambiguity and maturity-onset diabetes of the young (MODY)**: Limited access to specialist assessment and testing increases the risk of misclassification, leading to inappropriate treatment and missed opportunities for cascade screening.
- **Psychological support in young adulthood**: Mental health needs peak in this age group yet screening and access to specialist psychological input are inconsistent and often unavailable at the point of need.
- **Safety during geographical mobility**: Temporary moves for education, work or housing disrupt continuity, and unclear cross-regional responsibilities make safe transfer of care difficult.
- **Digital tools and peer support**: NHS endorsed programmes and platforms are widely used in paediatrics, but not routinely embedded in young adult care pathways, leaving an available, funded resource underutilised and limiting their contribution to individual education and connection.
- **Addressing health inequalities**: Structural inequalities - socioeconomic disadvantage, digital exclusion, and constrained access to enabling support, can compound existing instability in young adulthood, further widening gaps in care and outcomes.

5	Actionable steps to reduce variation in young adult care (19-25 years)
	a) Design young adult care pathways that are intentionally tailored to life-stage needs.
	b) Align care intensity, service capability, expertise and place of care to young adults' clinical and psychosocial needs
	c) Ensure every young adult understands their care pathway and how to navigate it.
	d) Embed relational continuity, engagement and navigation support, and proactive processes to prevent loss to follow-up.
	e) Ensure seamless continuity of care during geographical mobility.
	f) Embed digital self-management tools and peer support into young adult pathways.

Domain 6: Variation in systems governance and workforce capability

Figure 9: GIRFT pre-visit survey 2024 and 2025



Effective governance and accountability are essential for safe, consistent and resilient practice, and they require reliable data for assurance and a workforce with the capacity and capability to deliver high-quality care.

Findings

- **Governance structures and accountability:** Leadership arrangements vary across ICBs, and many areas lack a clearly defined role with responsibility for the 0-25 diabetes pathway. Oversight remains split between 0-18 and 19-25 services, limiting visibility of changing risk at transition, and weak ICB-provider communication means emerging issues are not consistently shared, reducing system-level accountability.
- **Place of care decision-making criteria:** No standard criteria guide place of care after transfer, and decisions often reflect historical design or capacity. Data on place-of-care is

unreliable, limiting the system's ability to see this variation, with no mechanism to verify accuracy across providers.

- **System-wide risk management, reporting and escalation**: Risk processes are unclear or informal, with limited use of defined thresholds, triggers or escalation routes. Operational and service-delivery risks are not consistently surfaced or addressed through ICB governance.
- **Payment, oversight and assurance of the paediatric Best Practice Tariff**: Understanding and application of the BPT vary significantly. Data submission and funding flows are inconsistent and lack transparency, limiting assurance that BPT criteria are met, and that the tariff is paid correctly, and that it is used to deliver the intended minimum standards.
- **Cross boundary care**: Postcode-based commissioning creates inequitable variation, with differing access to education, technology pathways and specialist support for young people cared for by the same provider but registered with different ICBs.
- **Collaboration with networks and partners to support cross-system learning**: ICB engagement with regional and national networks and charitable organisations is inconsistent, limiting opportunities for shared learning, co-ordinated GIRFT implementation and co-produced service design with lived-experience partners.
- **Data quality, completeness and audit assurance:** Systems lack clear accountability for ensuring complete and accurate submission to national audits and missing or poor-quality data rarely triggers action. This reduces confidence in published data, and limits quality assurance and improvement.
- **Data integration, visibility, and analytical capability**: Paediatric and adult datasets are usually reviewed separately, limiting visibility of what happens to the same cohort after transfer and masking deterioration. Limited capability to link and interpret data from different sources, restricts the understanding of causes of unwarranted variation.
- **Workforce capacity, role adaptation and capability for modern care**: Workforce capacity and skill-mix do not match rising caseloads, increasing complexity, changing epidemiology or technological change. Limited cross-ICB planning and slow adaptation of roles to modern care models constrain resilience and contribute to variation in capability.
- **Cultural competence, inclusive practice and community partnership**: Teams aim for inclusive, culturally responsive care but lack time and system connections to apply tailored approaches consistently. Weak links with population-health and community partners limit alignment with local needs.

- **National accreditation and service assurance:** No national accreditation framework exists for CYP or young adult outpatient diabetes services, leaving ICBs without a consistent mechanism to assure standards or benchmark quality across pathways.

6	Actionable steps to reduce variation in systems governance and workforce capability
	a) Establish clear governance structures, accountability arrangements and clinical leadership for the 0-25 pathway, including transparent financial oversight.
	b) Implement a structured risk-management framework aligned to national diabetes care standards.
	c) Strengthen data quality, intelligence and system-wide insight across the 0-25 pathway, with clear processes for interpreting and acting on findings.
	d) Conduct regular workforce review at provider and commissioner level, with findings published and shared across the system to support transparency, planning and collective action.
	e) Expand and embed modern workforce models and novel roles that reflect today's clinical, technological and social care needs.

GIRFT overarching recommendations for ICBs

1. Leadership and accountability

Create a clear, ICS-wide governance and accountability framework for the 0-25 diabetes pathway, with explicit clinical leadership at ICB level and across all commissioned services. This framework should set out unambiguous lines of responsibility from ICB executives and clinical leads through to place-based leaders, provider collaboratives, trust boards, senior teams and frontline clinical staff.

2. Data, intelligence and insight

Commission and govern a unified ICS-wide data and intelligence function for the 0-25 diabetes pathway, providing a single, shared and accessible version of the truth that generates actionable insight. All partners must work from complete, benchmarkable data rather than fragmented local datasets. Providers should be required to submit accurate, complete and timely information to national audits as a core contractual responsibility, supported by administrative and digital infrastructure.

3. Standardisation of care

Define and implement nationally agreed, minimum standards of care for children and young adults with diabetes, grounded in evidence and clinical consensus. Standards should be specific, measurable and time-bound, delivered consistently across all neighbourhoods, and supported by the workforce capability and resources required to provide high-quality core care for all, with service resilience to intensify care proactively for those with greater need. Diabetes type, developmental maturity, and clearly defined clinical and psychosocial risk thresholds, not place of care, local service configuration or capacity, should determine the level and components of care. The same standard must apply for a given level of risk, whether care is delivered in specialist, community or neighbourhood settings, ensuring care is free from structural or cultural bias and that equitable outcomes are achieved for every child, young person and young adult.

These recommendations are closely aligned with, and provide a practical framework for delivering, key NICE guidance, including NG18 (Diabetes in children and young people),[4] NG17 (Type 1 diabetes in adults),[5] NG28 (Type 2 diabetes in adults),[6] and TA943 (Hybrid closed-loop systems for type 1 diabetes).[7] By strengthening leadership and accountability,

[4] *Type 2 diabetes in adults: management, NICE, 2015, https://www.nice.org.uk/guidance/ng28/resources/2019-surveillance-of-diabetes-nice-guidelines-ng17-ng18-ng19-and-ng28-6837997933/chapter/Surveillance-decision?tab=evidence*
[5] *Type 1 diabetes in adults: diagnosis and management, NICE, 2015, https://www.nice.org.uk/guidance/ng17*
[6] *National Institute of Clinical Excellence (2015). NICE guideline [NG28]. Type 2 diabetes in adults: management, https://www.nice.org.uk/guidance/ng28/resources/2019-surveillance-of-diabetes-nice-guidelines-ng17-ng18-ng19-and-ng28-6837997933/chapter/Surveillance-decision?tab=evidence*
[7] *Hybrid closed loop systems for managing blood glucose levels in type 1 diabetes, NICE guideline 2023, https://www.nice.org.uk/guidance/ ta943*

creating a unified ICS data and intelligence function, and standardising care to nationally agreed minimum standards, ICBs can systematically implement and evidence guideline-concordant care for all children, young people and young adults. The recommendations also reinforce the three system shifts - towards neighbourhood-level delivery, prevention-focused care, and digitally enabled pathways,[8] ensuring that transformation is aligned with wider NHS strategy as well as clinical guidance.

Implementation of the GIRFT recommendations will require co-ordinated effort across the system, but statutory accountability for progress sits firmly with ICBs. Progress should be supported through strong partnerships with national clinical networks (BSPED, ACDC, DTN, ABCD, NCYPDN), nationally commissioned audit programmes (NPDA, NDA), and partners providing digital self-management, structured education and peer- and community-based support, including DigiBete, Diabetes UK, Diabetes Africa and BT1D. These organisations contribute clinical expertise, audit insight and lived experience to strengthen pathway delivery.

[8] *Department of Health and Social Care, Fit for the Future: The 10 Year Health Plan for England, https://assets.publishing.service.gov.uk/media/6888a0b1a11f859994409147/fit-for-the-future-10-year-health-plan-for-england.pdf*

Main findings

Audience and purpose

The audience for a GIRFT national specialty report includes senior NHS leadership – the Department of Health and Social Care (DHSC), NHS England and NICE, alongside regional directors, Integrated Care Boards (ICBs) and ICB commissioners, trust and hospital executives, Royal Colleges, professional bodies, national and regional clinical networks, and specialty clinical and operational teams. The report also informs strategic charitable partners involved in research investment, system advocacy, and representing affected populations.

Given the way diabetes services are commissioned and funded, it is important to recognise the differing levels of accountability and influence across this audience. DHSC and NHS England set policy direction and, along with NICE, define minimum standards, issue evidence-based clinical guidelines and establish mandated metrics and expectations for performance. Regional teams and ICBs hold responsibility for commissioning, performance oversight and ensuring services meet statutory requirements. Provider organisations are accountable for safe delivery, workforce planning, and operational implementation. Royal Colleges, professional bodies, national clinical networks and charities influence standards, training, research priorities and system advocacy.

Although responsibilities differ, all parts of the system contribute to safety, quality and accountability. The GIRFT findings and recommendations are therefore structured to support action at each level, ensuring that commissioning decisions, funding allocation, service design and clinical practice are aligned to deliver safe, equitable and effective care.

The purpose of a GIRFT report is to identify unwarranted variation in clinical practice, outcomes, and resource use across England. It provides evidence-based recommendations to improve the quality and consistency of care, enhance patient experience, and support more efficient use of resources. A central focus is examining pathways of care and identifying where fragmentation, inconsistency or gaps in provision drive variation, and where redesign or standardisation can deliver meaningful improvement. Ultimately, GIRFT reports aim to strengthen collaboration between clinicians, managers, and commissioners, reduce unnecessary costs, and deliver high-quality, equitable care across the health system.

Methodology

The report follows the GIRFT programme model. For each of 42 system-level reviews, a bespoke data pack was developed drawing on national datasets covering care, outcomes and service use for children and young adults with diabetes. These included Hospital Episode Statistics (HES) and Secondary Uses Services (SUS) for emergency activity, the National Paediatric Diabetes Audit (NPDA),[9] the National Diabetes Audit (NDA),[10] and QISMET[11]-accredited DigiBete[12] usage data reflecting digital self-management support.

Quantitative data were combined with qualitative insights from extensive questionnaires completed by adult and paediatric clinical leads across 160 paediatric services, and 153 trust sites providing young adult care. These captured information on workforce, best practice tariff funding, clinic design, structured education, DKA and out-of-hours protocols, transition arrangements, WNB/DNA policies, and peer support. 41 ICBs also completed questionnaires detailing their integration with provider teams, forward plans, health inequality data, technology access, financial arrangements, and oversight and assurance processes. Together, these sources created rich, triangulated system-specific data packs.

Before each review, systems were invited to an informal meeting with the GIRFT clinical advisor to clarify the process and share priority areas. At the formal review meeting, systems provided a short contextual presentation before working through the data pack in a structured, clinically led discussion. Engagement was strong across every system, enabling shared interpretation of the data, exploration of variation within and between systems, and identification of the drivers of high and low performance.

Each system received a tailored GIRFT report and set of locally specific recommendations. The national report synthesises the common themes, challenges, and opportunities identified across all 42 reviews. The content and recommendations have been reviewed by relevant stakeholders and received strong support. Improvement will be driven through system-level action, supported by network-level co-ordination where appropriate, with additional trust-level activity as needed (for a visual summary see the review process section).

9 *Royal College of Paediatrics and Child Health, National Paediatric Diabetes Audit, https://www.rcpch.ac.uk/work-we-do/clinical-audits/npda*
10 *Royal College of Paediatrics and Child Health, National Diabetes Audit Programme, https://www.rcpch.ac.uk/work-we-do/clinical-audits/npda*
11 *QISMET, https://www.qismet.org.uk/accreditation/*
12 *DigiBete, https://www.digibete.org/*

Findings and recommendations

Six domains emerged where unwarranted variation is most pronounced and where improvement would have the greatest impact on outcomes, safety and equity. These domains reflect both the quality of clinical delivery and the wider system conditions that enable or constrain high-quality care.

Across these same domains, the review identified examples of strong local practice, demonstrating that equitable care and outcomes are achievable when services are well co-ordinated, supported by clear leadership, working to defined standards and making intelligent use of reliable data to identify gaps, prioritise quality improvement, and track progress.

Domain 1: Variation in diabetes health outcomes (including HbA1c)

Variation in diabetes health outcomes reflects how effectively systems support CYA to achieve safe, stable glucose levels over time. HbA1c remains the gold-standard biomarker of long-term glycaemic exposure, and in paediatrics the NICE target of <48 mmol/mol[13] is deliberately set low because early glycaemic stability has lifelong protective effects.

When HbA1c remains above target, the risks of acute complications such as diabetic ketoacidosis and longer-term risks of retinopathy, nephropathy, neuropathy, and cardiovascular disease, accumulate.[14] The higher HbA1c rises above target and the longer it remains elevated, the greater this cumulative burden of risk.[15] Even short periods of raised HbA1c contribute meaningfully to lifetime exposure, and levels above 75 mmol/mol are associated with a markedly higher likelihood of complications.

HbA1c reflects average glucose levels over the preceding 2–3 months, and for most people without conditions affecting red blood cells (such as some haemoglobinopathies), it is the key long-term marker of overall diabetes health. However, it does not capture short-term glycaemic instability or variability. Continuous glucose monitoring (CGM) metrics such as Time in Range (TIR) provide real-time insight into daily glucose patterns, identify rising risk

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[13] *NICE NG18, Diabetes (type 1 and type 2) in children and young people: diagnosis and management, https://www.nice.org.uk/guidance/ng18/chapter/recommendations*

[14] *Lachin JM, Nathan DM; DCCT/EDIC Research Group. Understanding Metabolic Memory: The Prolonged Influence of Glycemia During the Diabetes Control and Complications Trial (DCCT) on Future Risks of Complications During the Study of the Epidemiology of Diabetes Interventions and Complications (EDIC). Diabetes Care. 2021 Sep 21;44(10):2216–24. doi: 10.2337/dc20-3097. Epub ahead of print. PMID: 34548284; PMCID: PMC8929187.*

[15] *DCCT Research Group (1993) 'The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus.' N Engl J Med, 329(14):977–86. doi: 10.1056/NEJM199309303291401*

earlier, and support timely treatment intensification. Falling TIR offers an immediate signal of instability, often long before HbA1c begins to rise. CGM use in type 1 is almost universal in CYP but not all YA have access to it, and for those with type 2 diabetes, only a subset meet eligibility criteria under NG28.[16,17] In contrast, HbA1c can be measured for everyone, making it the only universal, population-level marker of glycaemic exposure across services.

Optimising HbA1c and TIR as soon as possible after diagnosis is especially important in children and young people. Early exposure to elevated glucose has lasting effects through 'metabolic memory', and because CYP live with diabetes for many decades, their cumulative exposure to high glucose is substantially greater.[18,19,20] This makes intensive early support, close monitoring, and timely treatment adjustments essential to protect long-term health.

Although many other indicators of diabetes health exist, including emergency admissions, weight trajectory, blood pressure and psychosocial health and wellbeing, these are not consistently used in benchmarking service performance for CYA. Consequently, unwarranted variation is most visible in differences in HbA1c trajectories between services and ICBs, highlighting where system design, capability, access and support are not operating equitably. Reducing this variation is essential to ensure that all CYA benefit from the same high-quality care and long-term health, regardless of where they live or which service they attend.

Unwarranted variation in cohort HbA1c

Marked variation in cohort HbA1c exists both between and within ICBs.

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[16] *National Institute of Clinical Excellence (2015). NICE guideline [NG28]. Type 2 diabetes in adults: management, https://www.nice.org.uk/guidance/ng28/resources/2019-surveillance-of-diabetes-nice-guidelines-ng17-ng18-ng19-and-ng28-6837997933/chapter/Surveillance-decision?tab=evidence*

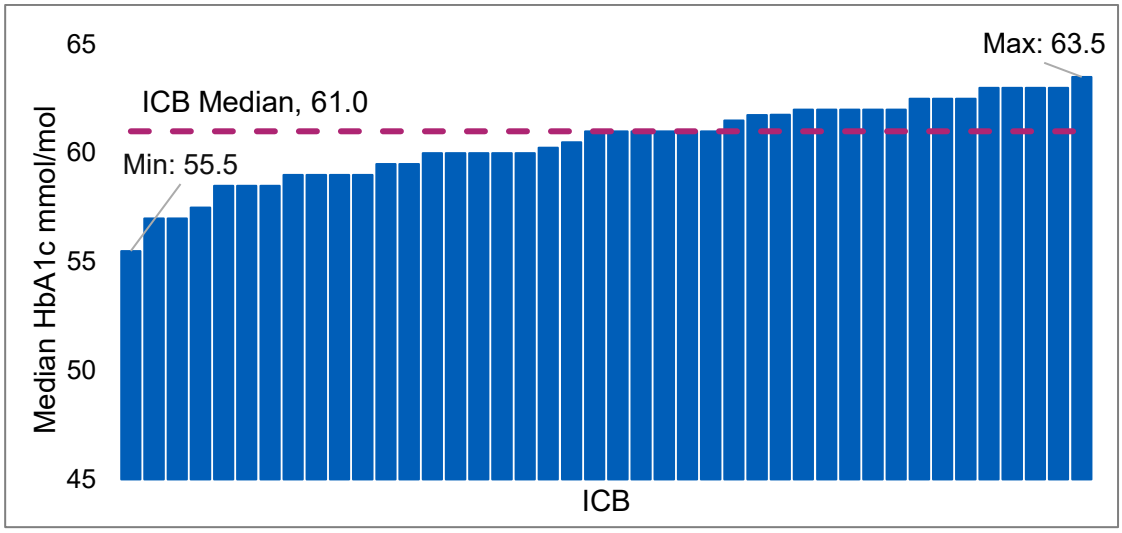
[17] *NHS England, National Diabetes Audit dashboards, https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-diabetes-audit/dashboards*

[18] *Lachin JM, Nathan DM; DCCT/EDIC Research Group. Understanding Metabolic Memory: The Prolonged Influence of Glycemia During the Diabetes Control and Complications Trial (DCCT) on Future Risks of Complications During the Study of the Epidemiology of Diabetes Interventions and Complications (EDIC). Diabetes Care. 2021 Sep 21;44(10):2216–24. doi: 10.2337/dc20-3097. Epub ahead of print. PMID: 34548284; PMCID: PMC8929187.*

[19] *DCCT Research Group (1993) 'The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus.' N Engl J Med, 329(14):977–86. doi: 10.1056/NEJM199309303291401*

[20] *Nathan DM et al.; DCCT/EDIC Study Research Group (2005) 'Intensive diabetes treatment and cardiovascular disease in patients with type 1 diabetes.' N Engl J Med, 353(25):2643–53. doi: 10.1056/NEJMoa052187*

Figure 10: Variation in ICB median HbA1c for type 1 patients aged 0-18



Source: NPDA 2023/24

While demographic factors, social complexity, access to technology and workforce capacity all contribute, they do not fully account for the scale of differences observed. NPDA 2023/24 data illustrates this clearly: median HbA1c values across paediatric diabetes units (PDUs) range from 54.8 mmol/mol to 70.5 mmol/mol, and 55.5 to 63.5 mmol/mol across ICBs (figure 10), despite comparable case mix in many areas. Some services achieve strong outcomes despite challenging demographics, demonstrating that variation is not inevitable and cannot be explained by population factors alone.

System-level factors are therefore key drivers. These include leadership, accountability, commissioning decisions, service design, operational capability, and critically, the strength of collaboration between managerial functions and frontline clinical expertise. When these elements are co-ordinated, services deliver more consistent and equitable care; where they are fragmented, predictable weaknesses emerge across models of care, MDT access and technology optimisation, driving variation in HbA1c trajectories.

Place of care and service specification

Paediatric diabetes specialist care services follow a nationally defined service specification. There are no equivalent minimum care standards outside this age range. NICE recommends that all CYP aged 0–18 with type 1 or type 2 diabetes receive specialist MDT input within paediatric secondary care. In practice, however, paediatric provision often ends at 16, depending on the remit of the paediatric unit and local service rules. This creates variation in where young people receive their care and the standards available to them, with consequences for those with type 2 diabetes.

For type 2, NDA linkage to SUS outpatient data suggests that 27% of CYP aged 0–18 with type 2 diabetes are not managed within secondary care. While reduced contact frequency may limit the completeness of this dataset and therefore how confidently it can be interpreted, the proportion remains far below what would be expected for a condition requiring regular specialist input. This indicates unwarranted variation in access to defined standards of care.

Consequences include delayed detection and treatment of co-morbidities, missed opportunities for early intervention, and reduced access to specialist-prescribed medications such as GLP-1 receptor agonists. These therapies should be proactively considered and escalated in line with clinical need, but treatment inertia often reflects the configuration of the care setting rather than lack of clinical expertise. This creates delays in responding to the aggressive progression of early-onset type 2 diabetes.

Enhanced care models such as T2DAY (Type 2 Diabetes & the Young) offer valuable opportunities for active case finding among those age 18–39.[21] This includes identifying 16 to 18-year-olds who may be lost to follow up or unknown to specialist services, enabling timely referral back into specialist care and reducing the risk of prolonged unmanaged hyperglycaemia.

For type 1 diabetes rapid access to CGM, insulin pumps, and hybrid closed-loop systems is dependent on specialist MDT input. For insulin-treated type 2 diabetes, timely access to CGM and data review is also frequently tied to specialist care. CYA who are inappropriately placed outside specialist services may lose access to these technologies, despite clear clinical need and eligibility.

For young adults aged 19-25 years, the care setting should be determined by clinical risk and complexity. In practice, however, placement usually follows routes shaped by historical service design and local capacity, rather than a consistent assessment of clinical need. As a result, young adults may be managed in primary, community, or secondary care irrespective of level of risk, leading to highly variable access to MDT input, specialist therapies, diabetes technologies, and regular follow-up.

[21] *NHS England, T2Day: Type 2 Diabetes in the Young, https://www.england.nhs.uk/2023/08/nhs-rolls-out-world-first-programme-to-transform-diabetes-care-for-under-40s/*

This variation in place of care directly determines the care components and expertise available, the frequency of review and opportunity for treatment intensification, therefore contributing to the observed variation in HbA1c.

Early-onset type 2 diabetes

Although absolute numbers remain small, the prevalence of type 2 diabetes in children, adolescents and young adults is rising rapidly. Presentations are often complex, with overlapping metabolic, psychosocial and social-determinant factors that require co-ordinated, multi-disciplinary input. Access to specialist children's obesity and weight management services is highly variable, and in many areas unavailable. Many paediatric and young adult teams report limited experience and confidence in managing early-onset type 2 diabetes, reflecting the relative newness of this clinical area and the absence of consistent pathways or defined competencies. Structured training in early-onset type 2 diabetes and participation in peer-support or clinical learning networks are not prioritised or job-planned in many services, contributing to wide variation in capability across teams,[22,23,24] and therefore in the quality and intensity of care available to young people.

Treatment intensification pathways

Most PDUs have defined treatment intensification pathways, often referred to as 'high HbA1c' policies, to address persistent hyperglycaemia (figure 11). However, pathways are not universally in place, and where they do exist, they vary considerably in thresholds for action, and processes used to intensify care and support. Equivalent pathways are far less commonly embedded in young adult services.

Even when pathways are defined, they are not always feasible to implement, typically due to workforce constraints, limited multidisciplinary expertise, or weak operational integration. These delivery gaps are not routinely captured through evaluation, audit, or service-level safety governance, meaning that failures to deliver intensified support to those who need it, do not translate into escalation of service risk, or appear on risk registers.

Services and systems therefore lack mechanisms to monitor whether intensification is delivered as intended, or whether it is effective. As a result, clinical and mental-health related

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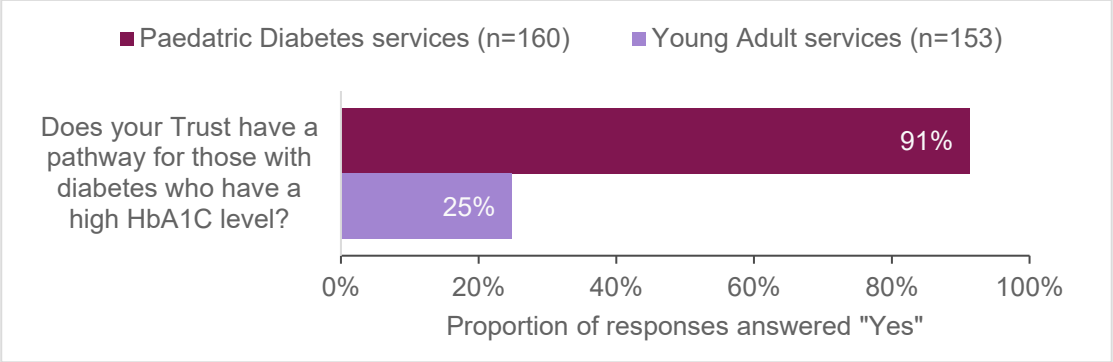
[22] *NHS England, elfh, https://learninghub.nhs.uk/catalogue/Managing-Type-2-Diabetes-in-Children?nodeId=6552*
[23] *Eden, Early Onset Type 2 Diabetes, https://www.eot2deden.com*
[24] *National Children and Young People's Diabetes Network, https://www.cypdiabetesnetwork.nhs.uk/national-network/type-2-national-working-group/*

risks associated with missed or delayed intensification remain unquantified. When intensive input cannot be provided, CYA may experience prolonged hyperglycaemia without timely therapeutic adjustment, contributing to the high proportion and wide variation in the proportion of patients with an HbA1c above 80 mmol/mol across PDUs (figure 12).

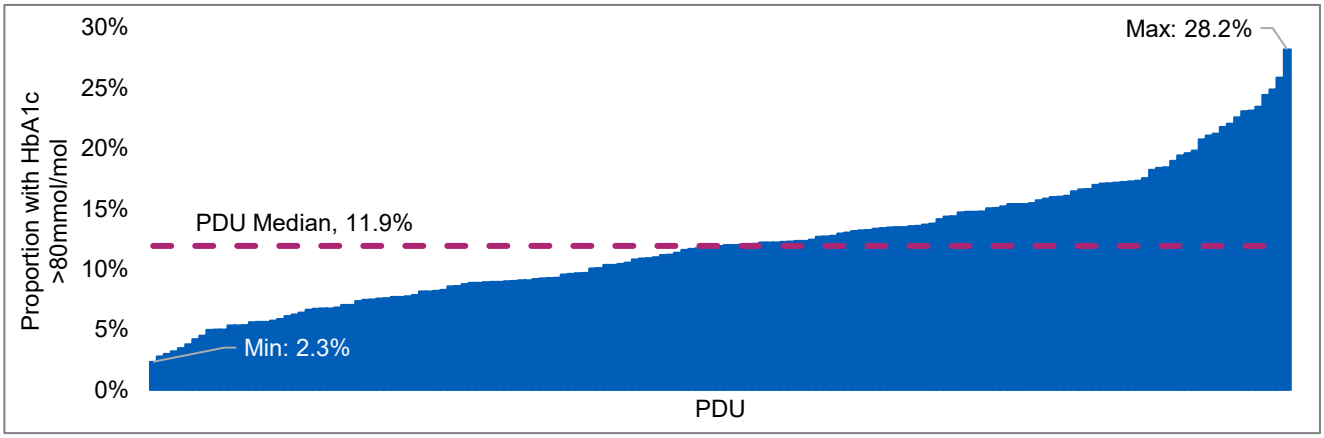
Thresholds for identifying and responding to risk also differ between paediatric and adult services, creating misalignment at transition and resulting in inconsistent treatment intensification for young people moving between services.

Figure 11: High HbA1c pathways, source GIRFT Provider questionnaire



Source: GIRFT pre-visit questionnaires (2024 and 2025)

Figure 12: Variation by PDU of the proportion of type 1 diabetes with a HbA1c of >80 mmol/mol



Source: NPDA 2023/24

Clinical and psychosocial risk indicators

In most services, treatment-intensification pathways are triggered by HbA1c alone, rather than a broader and more holistic assessment of vulnerability or emerging risk. Other indicators, including CGM-derived metrics, diabetes-related admissions, WNB/DNA patterns, or early signs of complications are used variably between teams and are not routinely considered in combination to form a coherent picture of risk.

This reliance on a single biochemical measure, with inconsistent use of wider clinical and psychosocial indicators, means that early deterioration is often recognised late and responses to the same degree of patient-level risk differ markedly across services.

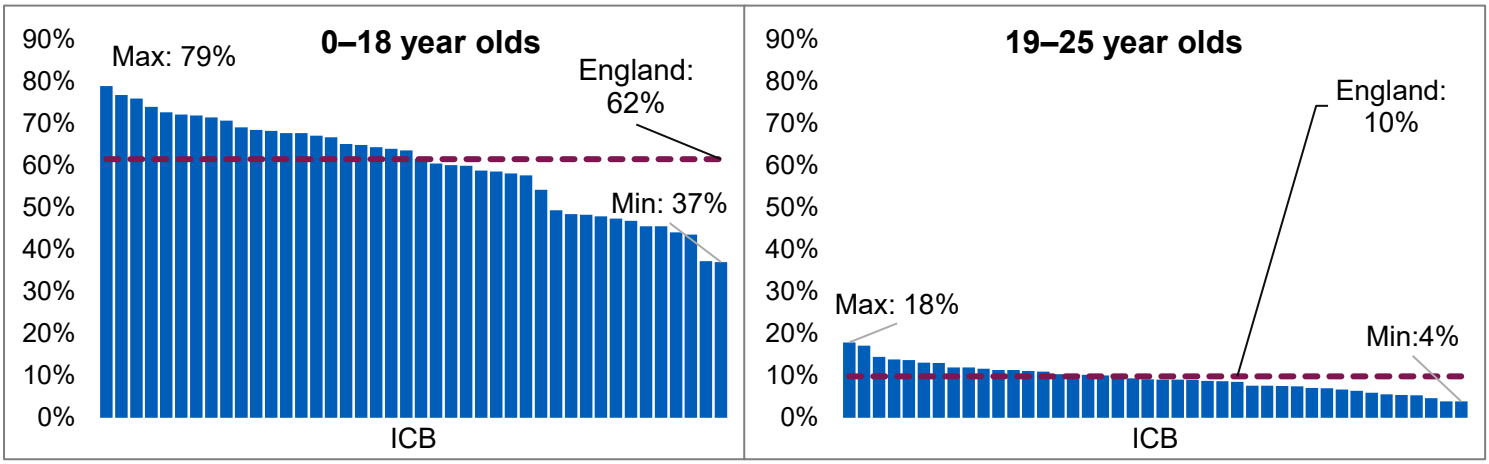
Access to technology

Use of insulin pumps, continuous glucose monitoring (CGM), and hybrid closed loop (HCL) systems can significantly improve diabetes health outcomes. However, access remains inconsistent across and within ICSs (figure 13). Variation reflects a combination of structural constraints, the need for tailored support to overcome digital and social barriers, and differences in team processes and clinical approach.

Commissioning arrangements, workforce training gaps, and service capacity constraints create limits on availability and uptake. Many CYA also face digital exclusion, low health literacy, financial pressures, or language, communication and culturally informed support needs, which require services to provide tailored, responsive support to enable equitable uptake. Equity is further shaped by team approach. In many services, the process for identifying eligible CYA, proactively discussing technology options to support adoption is inconsistent. Clinical confidence, service practices and implicit bias can influence who is reached, who is encouraged to use technology, and who ultimately benefits.

These interacting factors operate within every service, leading to inequitable access and contributing to variation in technology use and, in turn, cohort HbA1c.

Figure 13: Variation in HCL usage in the type 1 population across ICBs, 2024/25



Source: NPDA and NDA combined data. England. 2024/25

Workforce shortages and gaps in specialist expertise

Rising caseloads (a 14% increase in type 1 for 0 to 18-year-olds and a 36% increase in type 2 for 0 to 25-year-olds since 2018/19) have not been matched by corresponding MDT capacity. Shortages in diabetes specialist nurses, psychologists, and dietitians and wider MDT functions limit the capacity for services to provide early intensive support, timely review and proactive intervention when it is most needed (figures 14 and 15).

Figure 14: PDUs: Workforce and staffing (WTE per 100 patients)

		Paediatric Diabetes Specialist Nurse	Consultant	Dietitian	Psychologist	Youth Worker	Administrative Support	Other (HCA, social work)	Total all disciplines
Units with caseload < 150 (51 units)	**CYPDN Workforce Calculator: minimum recommended staffing per 100 patients**	1.7	0.5	0.8	0.5	0.8	0.8	0.4	5.50
	Median from questionnaire	1.6	0.4	0.6	0.3	0.0	0.4	0.0	3.5
	GAP	**-0.1**	**-0.1**	**-0.2**	**-0.2**	**-0.8**	**-0.4**	**-0.4**	**-2.0**
	Min	0.6	0.0	0.0	0.0	0.0	0.0	0.0	1.6
	Max	4.4	3.4	2.2	1.0	1.1	0.9	1.9	9.6
Units with caseload >= 150 caseload (114 units)	**CYPDN Workforce Calculator: minimum recommended staffing per 100 patients**	1.6	0.5	0.75	0.4	0.4	0.7	0.3	4.65
	Median from questionnaire	1.6	0.3	0.5	0.2	0.0	0.4	0.1	3.1
	GAP	**-0.1**	**-0.2**	**-0.3**	**-0.2**	**-0.4**	**-0.3**	**-0.2**	**-1.5**
	Min	0.2	0.1	0.2	0.0	0.0	0.0	0.0	1.5
	Max	2.6	4.0	1.2	0.7	0.6	1.3	0.7	6.8

Source: GIRFT pre-visit questionnaires (2024 and 2025). 152 units, 30,361 patient caseload. National CYP Diabetes Network (CYPDN) workforce calculation tool[25]

Financial pressures mean that in some areas vacancies are held, frozen or removed from establishment when staff leave. Over time this erodes MDT capacity and reduces services' ability to respond to rising complexity, deliver technologically enabled care or plan for future demand.

Young adult services face even greater challenges. With no dedicated tariff or minimum service specification, staffing levels, skill mix and access to specialist input vary widely (figure 15), constraining the system's ability to deliver equitable, developmentally appropriate care and timely intensification.

[25] *National CYP Diabetes Network, Workforce Webinar - Aim 3 National CYP Diabetes Network - 26th February 2024 - National Network CYP Diabetes Workforce Standards, https://www.cypdiabetesnetwork.nhs.uk/national-network/workforce-webinar-aim-3-national-cyp-diabetes-network-26th-february-2024/*

Figure 15: Young adult services: Workforce and staffing (WTE per 100 patients)

	Paediatric Diabetes Specialist Nurse	Consultant	Dietitian	Psychologist	Youth Worker	Administrative Support	Other (HCA, social work)	Total all disciplines
Median	0.2	0.1	0.0	0.1	0.0	0.1	0.0	0.6
Mean	0.3	0.2	0.0	0.1	0.1	0.1	0.1	0.9
Min	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Max	1.7	3.3	0.5	0.7	1.1	0.8	1.0	6.6

Source: GIRFT pre-visit questionnaires (2024 and 2025). 114 units, 18,848 patient caseload

Capability is also constrained by misaligned banding structures and insufficient protected time to undertake available training. The pace of innovation in diabetes care demands ongoing professional development, yet opportunities for structured learning, clinical network engagement and updating expertise are often not job-planned or routinely supported, and there is rarely an expectation to demonstrate the maintenance of specialist competence. Together these factors make it harder for teams to stay current in areas such as type 2 diabetes, technology and intensification pathways.

Service delivery challenges

Where administrative and operational support is limited, essential non-clinical tasks, such as appointment management, service co-ordination, audit requirements and procurement processes fall to clinical staff, reducing the time available for proactive review and treatment intensification. This constrains the service's ability to intervene early for those with rising risk or high HbA1c and to review service performance data to inform quality improvement.

Governance of appointment systems, utilisation and follow-up

Review frequency is commonly driven by routine intervals rather than clinical need, creating rigidity in how and when young people are seen. Limited operational bandwidth means services often cannot offer additional or earlier appointments when a young person's HbA1c is rising or instability emerges, reducing opportunities for timely intensification.

High DNA/WNB rates further reduce effective clinical capacity, yet many services lack the systems needed to understand or address the underlying causes. GIRFT questionnaire data shows that 8% of paediatric services did not have a DNA/WNB policy, and 11% of paediatric services and 51% of young adult services do not collect information on repeat

DNAs/WNBs,[26] limiting insight into whether non-attendance reflects logistical, emotional or systemic barriers. Without this visibility, services cannot reliably meet minimum contact standards, make best use of available appointments, or identify safeguarding risks associated with repeated non-attendance.

These weaknesses are amplified at service transitions, where missed first appointments may go unrecognised or unflagged to clinicians, increasing the risk of deterioration at this point and reducing the likelihood that existing deterioration is identified and acted on promptly.

Digital infrastructure, data quality and risk-stratification capability

Incomplete or inconsistent NPDA / NDA submissions limit the ability to benchmark HbA1c outcomes, understand variation or identify inequities in diabetes care. Many services are required to use parallel ICB or Trust built systems that do not interface with national datasets, meaning teams must enter and submit the same information twice. Duplication increases the risk of inconsistency, data loss and gaps in longitudinal records, limiting the ability to build a complete picture of risk or glycaemic outcomes.

Poor IT infrastructure and limited analytical capacity further restrict the ability to turn available information into timely, actionable insight for proactive case-finding or service improvement. Alongside these data-quality and infrastructure issues, risk stratification tools are not yet used consistently or integrated into routine MDT workflows. Unlinked patient-level data means that key signals, such as HbA1c trends, WNB/DNA patterns, emergency admissions and technology use, cannot be combined, limiting early identification of compounding risk and the ability to target support effectively.

Together, these weaknesses reduce the system's capacity to intervene early and contribute to variation in HbA1c outcomes between places.

Data missingness and reduced visibility of risk

Missing patient data also affects the interpretation of cohort HbA1c outcomes. Benchmarking is typically based only on those with a recorded HbA1c, meaning that services with high levels of missing data may appear to perform well despite a substantial proportion of their population not being represented. Because young people without a recent HbA1c are more likely to have weaker engagement or emerging risk, incomplete data can create a

[26] *GIRFT pre-visit questionnaires (2024 and 2025)*

misleadingly favourable picture and make comparisons between places unreliable. Without adjusting for data completeness, it is difficult to determine whether apparent variation reflects true differences in glycaemic outcomes or simply differences in who is being measured.

Many systems focus on analysing recorded data rather than examining what is absent, creating blind spots in risk identification. Effective data use must begin with understanding patterns of missingness - what is not recorded, for whom and why.

Missing data on care processes, WNB/DNA patterns, and recent contacts can itself be a marker of deteriorating glycaemic stability. Missing information on technology use, and missing cloud-shared CGM or pump data where young people are on technology, and indicators of social or neurodevelopmental complexity, reduces visibility of wider clinical and psychosocial risks, limiting the ability to intensify and tailor support.

Structural, racialised and socioeconomic disparities

Nationally, racial and socioeconomic differences in mean HbA1c persist. Higher values are recorded in some ethnicities and among CYA living in deprivation – for example 63 mmol/mol in White CYP and 71 mmol/mol in Black CYP and 60 mmol/mol versus 66 mmol/mol respectively[27] between least and most deprived groups. Although disparities have narrowed in some regions, progress is uneven and insufficient to close national outcome gaps.

Structural inequalities shape the conditions in which care is delivered and the ease with which it can be accessed. They influence the level of support required and the extent to which services must adapt to enable equitable access.

In areas of higher deprivation or where racialised groups experience barriers related to language, communication, cultural mismatch, digital exclusion or systemic bias, families encounter additional obstacles to engaging with care. These barriers can constrain attendance, technology use and safe self-management unless services provide tailored, responsive support. This increases the need for flexible, culturally competent and poverty-proofed pathways.

These same structural pressures affect diabetes teams, who often operate with limited capacity, inflexible systems and pathways not designed to support the level of individualised

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[27] *RCPCH, National Paediatric Diabetes Audit (NPDA) 2025 Report on Care and Outcomes 2023/24, 2025, https://www.rcpch.ac.uk/sites/default/files/2023-07/npda_report_on_admissions_2015-2020v2.pdf*

care required. This restricts the ability to provide proactive follow-up and equitable intensification work for those with rising risk.

For many CYA, structural disadvantage is compounded by wider social complexity such as unstable housing, reduced support networks or involvement with multiple agencies. Safeguarding activity, while present across all socioeconomic and ethnic groups, is more frequently concentrated in services supporting populations facing greater adversity. This work is essential but resource-intensive, consuming substantial clinical and administrative time and reducing the capacity available for proactive follow-up and intensification. In turn, this can contribute to variation in outcomes.

Adapted and equity-informed practice

Many services lack structured approaches to tailoring care for populations with language barriers, low health literacy, differing health beliefs, faith-related considerations or experiences of systemic bias. Time, flexibility and training in culturally competent or equity-aware approaches are required; without these, services struggle to deliver personalised care consistently.[28,29]

Paediatric diabetes best practice tariff (BPT) minimum care standards

The paediatric diabetes BPT sets nationally defined minimum standards that underpin good diabetes health outcomes. GIRFT reviews found variable delivery of these standards across services, particularly in completion of essential health checks, minimum MDT review frequency, interim contacts between clinics, timely treatment intensification in response to rising risk, and access to the full specialist multidisciplinary team (including support from a psychological professional). Inconsistent delivery of these core components directly undermines efforts to improve HbA1c and wider outcomes, particularly for children and young adults with complex needs or persistently high levels.

Where standards were not reliably delivered, few services were able to use the tariff to strengthen frontline capacity, meaning that the BPT did not consistently translate into the intended investment in MDT time, capability or resilience.

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[28] *Diabetes Africa, Cultural competence in diabetes management: why is it important?, https://diabetesafrica.org/cultural-competence-in-diabetes-management-why-is-it-important/*
[29] *Diabetes UK, Tackling Inequality Commission report, https://www.diabetes.org.uk/sites/default/files/2023-11/366_Tackling_Inequality_Commission_Report_DIGITAL%20(1).pdf*

1	Roadmap of actionable steps to reduce variation in diabetes health outcomes
	Introduce consistent, equity-driven risk-based intensification pathways ▪ **Embed a structured, holistic framework within intensification pathways** so teams proactively identify, record and respond to all forms of rising risk. This should include systematic assessment of psychological, social, cultural and neurodevelopmental factors that may affect engagement, stability or safety. ▪ **Ensure timely access to psychological professionals trained in diabetes-related distress** and vigilant to risks associated with insulin misadministration, disordered eating and other safety concerns, to support emotional wellbeing, engagement and early intervention. ▪ **Use consistently agreed indicators across three domains** – clinical risk (such as complications, emergency admissions), glycaemic risk (such as HbA1c, TIR) and engagement risk (such as missing care processes, WNB/DNA), with clear thresholds that trigger defined intensification steps, increased support and structured follow-up. ▪ **Align risk-based thresholds across all settings**, defining when intensification should occur and when movement between primary, community and specialist services is required. This enables consistent intervention and reduces inequities linked to care location ▪ **Ensure all service areas take responsibility for identifying eligibility for specialist therapies and diabetes technologies using nationally agreed criteria**, so access does not depend on patient or family advocacy and is not influenced by healthcare bias. Monitor compliance through routine audit of eligibility checks and referral activity, disaggregated by age, deprivation, ethnicity and diabetes type.
	Develop clinical pathways and workforce capability for type 2 diabetes in children, adolescents and young adults ▪ **Develop clinical pathways for early-onset type 2 diabetes.** Ensure consistent, evidence-based pathways across paediatric, young adult and primary care settings, with timely access to appropriate therapies, structured education, and treatment intensification aligned to the needs and risks of EoT2D. ▪ **Build workforce capability for early-onset type 2 diabetes.** Define clear staff competencies, mandate completion of required training and ensure teams have the knowledge, confidence and MDT support to manage EoT2D, including competence in pharmacological treatment, obesity-related comorbidity and psychosocial complexity.
	Strengthen service delivery infrastructure ▪ **Ensure administrative support is sufficient to protect clinical time** with clear expectations for minimising the proportion of specialist time spent on non-clinical tasks. Support should be adequate in both capacity and banding so clinical staff are not routinely diverted into logistical or administrative work.

	▪ **Ensure MDTs have sufficient operational capacity to deliver minimum care standards** reliably, and provide timely intensification when risk increases, without compromising core care for others, or reducing the ability to respond promptly to emergencies.
	Implement governance for unmet patient treatment-intensification needs ▪ **Implement prompt reporting and risk-management escalation processes** whenever intensification pathways cannot be delivered as intended, including where required interventions, specialist MDT input, or the necessary operational capacity are unavailable. Risk-management escalation should trigger immediate risk-mitigation actions, senior oversight, and system-level review of capacity or process gaps.
	Build capability for a culturally competent workforce skilled in inclusive practice. ▪ **Embed ongoing practice-based training** in poverty-proofing, cultural competence, neurodiversity, accessible communication, and faith-based considerations with clear expectations for completion. Ensure learning directly shapes pathway design, appointment structures, and follow-up, and is treated as a core part of routine practice rather than a one-off exercise.

Domain 2: Variation in completion of essential annual health checks (care processes)

NICE sets out a defined group of core annual health checks, often referred to as key care processes or delivered collectively as a 'Diabetes Annual Review' - to support early detection of complications, guide treatment decisions, and protect long-term health and quality of life. From age 12, the required processes expand (see table 5) to include assessments such as retinopathy screening, reflecting the increasing cardiovascular, renal, and microvascular risks that emerge during adolescence and continue into adulthood. Although diabetic foot complications and retinopathy remain uncommon in younger age groups, introducing these assessments early helps establish lifelong habits of vigilance, normalises regular screening, and reinforces the importance of protective behaviours such as attentive foot care.

The National Paediatric Diabetes Audit (NPDA)[30] and National Diabetes Audit (NDA)[31] track completion of these core processes using standardised national data, enabling services and ICBs to benchmark performance, identify gaps, and drive improvement.

High-quality diabetes care also relies on a broader set of holistic elements that support safe self-management, emotional wellbeing and long-term health. These include structured education, psychological wellbeing assessment, smoking cessation support, immunisation advice, oral health guidance, and for older adolescents, sexual health and pregnancy planning. Clinically important components, such as insulin regimen reviews and dietetic input for carbohydrate counting, are also essential for effective management and quality of life. Although NICE does not specify their frequency, they should be routinely available as part of person-centred care. Unlike the core annual processes, many of these holistic elements are not consistently audited across all age groups, limiting visibility of variation and unmet need.

[30] *Royal College of Paediatrics and Child Health, National Paediatric Diabetes Audit, https://www.rcpch.ac.uk/work-we-do/clinical-audits/npda*
[31] *NHS England, National Diabetes Audit Programme, https://digital.nhs.uk/data-and-information/clinical-audits-and-registries/national-diabetes-audit*

Table 5: Essential annual health checks

Type 1	Type 2	Type 1 and 2
12–18 years	**12–18 years**	**19 years and over**
6 key health checks	**6 key health checks**	**8 key health checks**
HbA1c	HbA1c	HbA1c
Blood pressure	Blood pressure	Blood pressure
BMI	BMI	BMI
Urinary albumin	Urinary albumin	Urinary albumin
Foot check	Foot check	Foot check
Thyroid	Cholesterol	Cholesterol
		Creatinine
		Smoking status
Plus retinopathy screening*	Plus retinopathy screening*	Plus retinopathy screening*

*Annual or every 2 years depending on risk level

In paediatric diabetes services, specialist multidisciplinary teams typically co-ordinate and complete all care processes, often during an annual review. After transition to adult services, responsibility for delivering these checks usually shifts to primary care where some elements are incentivised through the Quality and Outcomes Framework (QOF).[32] Where specialist teams remain involved, delivery may be shared across settings, and many adult services are increasingly using their contacts to complete outstanding checks. Retinal screening is the only essential care process consistently delivered by an externally commissioned provider across all ages, operating as a standalone service with its own referral and recall system.

Despite their central importance and improvements in recent years,[33] completion rates remain below optimal levels and vary widely by age, diabetes type, and local system performance.

Each missed check represents a lost opportunity for prevention, early identification and timely treatment of complications. Improving delivery of both the core annual processes and the wider holistic elements of care is essential to improving long-term outcomes for people with diabetes at every age.

[32] *NHS England, Quality and Outcomes Framework (QOF) guidance for 2025/26, https://www.england.nhs.uk/gp/investment/gp-contract/quality-on-outcomes-framework-qof-changes/*
[33] *RCPCH, National Paediatric Diabetes Audit (NPDA) 2025 Report on Care and Outcomes 2023/24, 2025, https://www.rcpch.ac.uk/sites/default/files/2023-07/npda_report_on_admissions_2015-2020v2.pdf*

Case study: National diabetes paediatric audit care completion

George Eliot Hospital NHS Trust

George Eliot Hospital NHS Trust achieved a 92% care process completion rate for children with diabetes, significantly above the regional (67%) and national (63%) averages by embedding efficient, low-cost workflows into routine practice.

A healthcare support worker trained in phlebotomy was integrated within clinic appointments, allowing routine blood tests to be completed during visits. This reduced the need for multiple appointments, improved patient experience, and enhanced operational efficiency without incurring additional cost. The team prioritises completing most annual review components in Q1–Q3, using Q4 to catch up on any outstanding elements. This proactive scheduling ensures timely and comprehensive care for all patients.

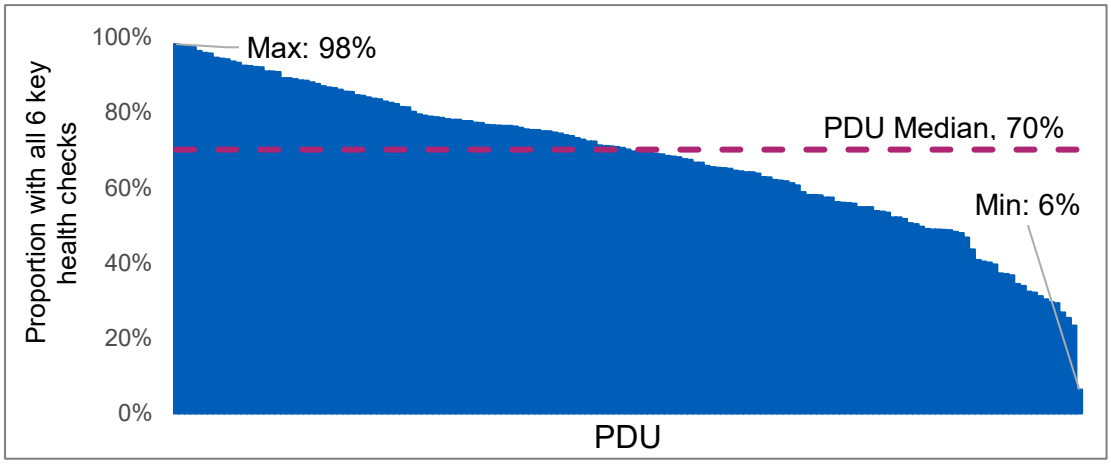
Success has been driven by strong team ownership of data, integration of processes into daily clinic routines, and a consistent focus on access and equity. This approach has not only improved audit performance but also delivered better outcomes and experiences for children and families.

Click here to see the full case study.

Low completion rates

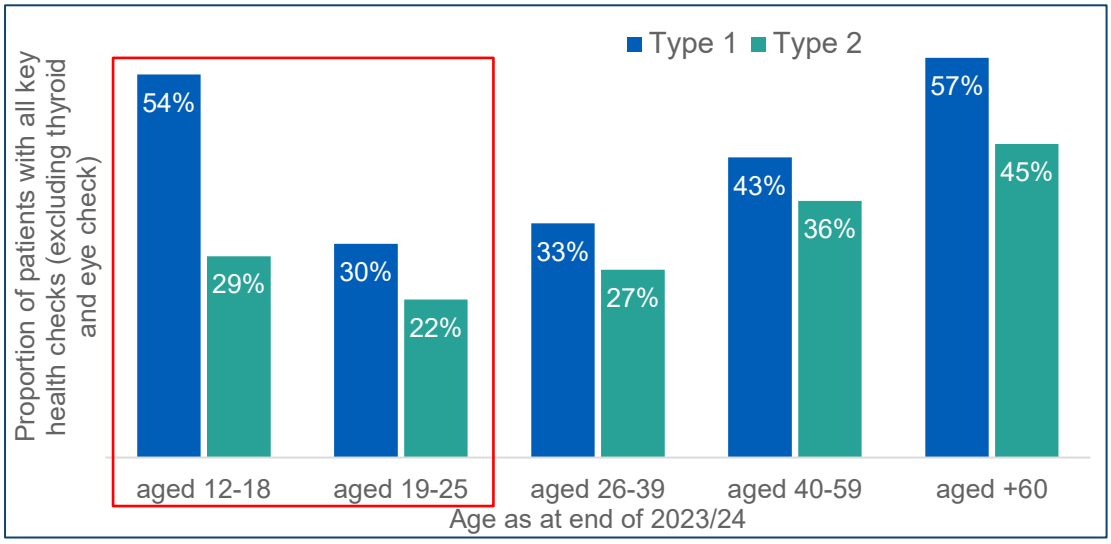
Paediatric audit data show a wide range in performance, from PDUs achieving near-universal completion of 98%, to others where as few as 6% of young people with type 1 diabetes patients are recorded to be receiving all six key health checks in a year (figure 16). Completion rates are consistently lowest among young adults aged 19-25 (figure 17) and among those with type 2 diabetes – two groups with the greatest clinical vulnerability. The 19-25 age range represents a life stage characterised by significant flux, during which glycaemic stability can be more easily disrupted for all young adults. For those with early-onset type 2 diabetes, this period is further compounded by the inherently rapid progression of the condition and the silent development of complications. Low completion in these groups increases the likelihood that early signs of deterioration will be missed.

Figure 16: Variation in proportion of type 1 patients receiving all 6 essential health checks, aged 12+ years, by Paediatric Diabetes Unit (PDU) 2023/24



Source: Published NPDA

Figure 17: Proportion of patients with completion of recommended key health checks in 2023/24 by age and diabetes type (excludes thyroid checks and eye checks)

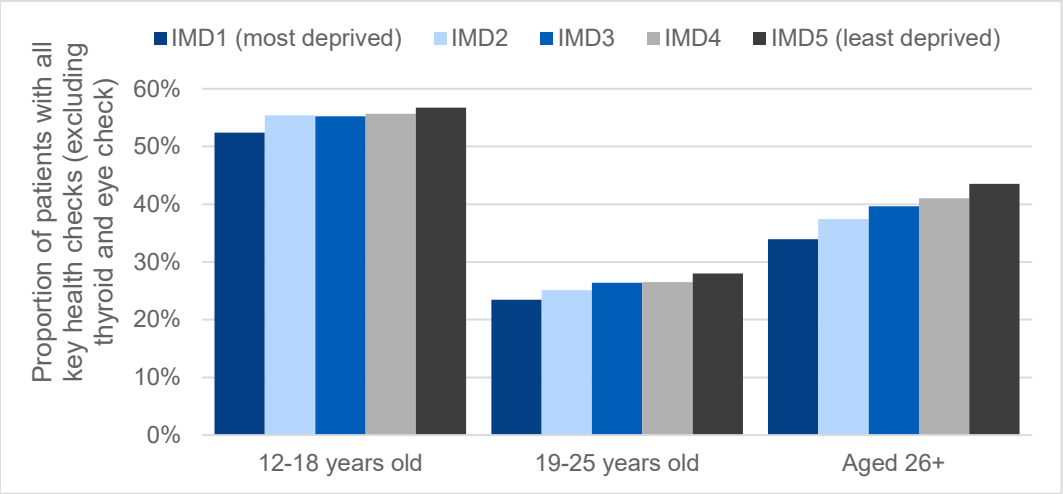


Source: NPDA and NDA combined data 2023/24

Inequity

Socioeconomic deprivation, minority ethnic background, and structural barriers, such as digital exclusion and limited access to culturally responsive services, contribute to marked inequities in completion of essential care processes. Among those aged 12–18 with type 1 diabetes, completion is 52% in the most deprived areas compared to 57% in the least deprived (figure 18). Early-onset type 2 diabetes is disproportionately concentrated in these same communities, compounding risk through both the aggressive nature of the condition and reduced access to routine checks. These structural barriers intersect with the developmental challenges of adolescence and young adulthood, widening gaps for those already experiencing disadvantage. When access to essential checks depends on navigating complex systems or on individual health literacy, inequalities deepen further.

Figure 18: Proportion of type 1 patients with completion of recommended key health checks in 2023/24 by deprivation quintile (excludes thyroid checks and eye checks)



Source: NPDA and NDA combined data 2023/24

Case study: T2DAY Project

South Yorkshire ICB

The South Yorkshire ICB's T2DAY pilot, launched at Burngreave Surgery in February 2024, aimed to improve engagement in diabetes care for young adults (18–39) with early-onset Type 2 diabetes (EOT2D), especially those from deprived and ethnically diverse backgrounds. The Foundry Primary Care Network, serving a high-need population, was chosen for the pilot. A Health and Wellbeing Coach (HWC) was central to the approach, supporting patients through data-driven outreach, holistic assessments, and personalised clinic invites.

The project responded to evidence showing EOT2D is more aggressive and common in deprived and ethnic minority communities, where care engagement is typically lower. The T2DAY pilot saw an increase in eight and nine care process completions by 95% and 76%, respectively. It improved access to medication reviews, transitions between services, and proactive care planning. The HWC role proved vital in building trust and tailoring support.

Key learning includes the value of personalised, culturally aware engagement and the need to promote the HWC role and awareness of the T2DAY programme among communities and clinicians.

Click here to see the full case study.

Fragmented care

Pathways for completing annual health checks are often fragmented and poorly co-ordinated. Even within paediatric services, where care is delivered by specialist teams, families may need to attend multiple appointments across different services to complete the full set of checks. This creates unnecessary burden, disrupts education and employment, and increases financial strain through travel and childcare costs.

For young adults, fragmentation is even more pronounced. The shift toward taking on more responsibility for organising their care often coincides with uncertainty about where checks should be completed, with options varying between primary, community and secondary care and rarely communicated clearly. This fragmentation increases the likelihood that essential checks are delayed, missed altogether, or duplicated.

Missed opportunistic care

Disconnected patient record systems and weak information-sharing across primary and secondary care mean that overdue checks are often not identified, even during encounters where completion would be feasible, such as inpatient admissions, urgent care visits or contacts with other specialties. Limited visibility across settings makes it difficult for teams to know which essential checks have been completed and where gaps remain, reducing opportunities to make every contact count.

Inpatient admissions represent a particularly valuable but frequently missed opportunity to complete overdue checks, including HbA1c and retinal screening. Gaps arise from limited communication between inpatient and outpatient teams, incomplete access to system-wide health records, and unclear responsibility for completing essential checks. In the absence of interoperable systems, a patient-held record could help ensure essential information is available at the point of care, but these do not currently exist in formats that are reliable or routinely usable across services.

Responsibility for care processes

While primary care holds contractual responsibility for delivering diabetes care processes for all registered patients, in practice specialist paediatric diabetes teams carry out these checks for children as part of the established model of care. For young adults, elements of routine care may shift back to primary care, sometimes from as early as age 16. Without explicit, system-level agreement on who is undertaking what at each stage, gaps and duplication become more likely.

This lack of clarity also leaves young people unsure who is overseeing their diabetes management. Local variation adds further complexity: while most routine checks sit within primary care, some assessments, such as foot examinations in certain areas, are delivered specialist teams. For adults under secondary care, the picture becomes even more complex, as they may still require primary care appointments for prescription review, creating uncertainty about who is accountable for ensuring that annual checks are completed and recorded.

Although contractual responsibility sits with primary care, operational delivery for essential checks is, in practice, shared across primary care and specialist teams, while commissioners are accountable for ensuring that the system is configured to enable checks to be completed reliably. Without clear ownership and a defined division of labour, confusion, duplication and missed essential checks become more likely and are less easily identified.

Data capture and audit accountability

Oversight and accountability for essential checks are undermined by the absence of reliable, shared data across the system. Incomplete or inaccurate records compound the risk: where data entry is known to be inconsistent, low recorded completion rates are often dismissed as recording issues rather than treated as potential signals of genuine under-delivery. This masks real gaps in care and provides no assurance that checks have been completed.

Care processes completed in specialist services are not always recorded for the National Diabetes Audit or shared with primary care, and responsibility for recording and transferring this information is not always clearly understood. This makes it difficult to determine whether all checks have been completed for a cohort of patients.

ICBs are responsible for ensuring that services in their area submit data to the NDA. Submission is mandatory: it is directed by Secretary of State under section 254 of the Health and Social Care Act 2012,[34] and mandated through the NHS Standard Contract.[35] Despite this, 13 of the 41 ICBs that completed the questionnaire reported that they do not use national audit data to identify unmet need within their local diabetes population,[36] limiting their ability to address inequities.

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[34] *NHS England, Directions and mandatory requests for information, https://www.england.nhs.uk/long-read/directions-and-mandatory-requests-for-information-item-8-1/?utm_source=copilot.com*
[35] *NHS England, NHS Standard Contract, https://www.england.nhs.uk/nhs-standard-contract/?utm_source=copilot.com*
[36] *GIRFT pre-visit questionnaires (2024 and 2025)*

Without consistent visibility of what has been completed and where gaps remain, system-level accountability becomes difficult to enact, and opportunities to use data to drive improvement are constrained.

Retinal screening

Retinal screening is distinct among diabetes care processes because it is delivered through a separately commissioned service, with its own pathways, recall intervals and data flow arrangements, as part of the National Screening Programme. As a result, retinal screening data are generated and transferred differently from the datasets used for other care processes, each with its own limitations. These differences mean that reported completion rates for retinal screening and for other care processes cannot be interpreted at face value or assumed to be directly comparable.

Although retinal screening data, for all people aged 12 and over, flow directly from the Diabetic Eye Screening Programme into the NDA, paediatric benchmarking is based on the NPDA. Paediatric units manually enter all care process information, including retinal screening, and this depends on local data-sharing arrangements. Gaps can arise at the point of data entry or during data transfer, whether due to incomplete input, difficulties retrieving screening data, or both, meaning no single part of the system is solely responsible. This can result in missing records and an unreliable picture of genuine uptake, often appearing lower than other care processes.

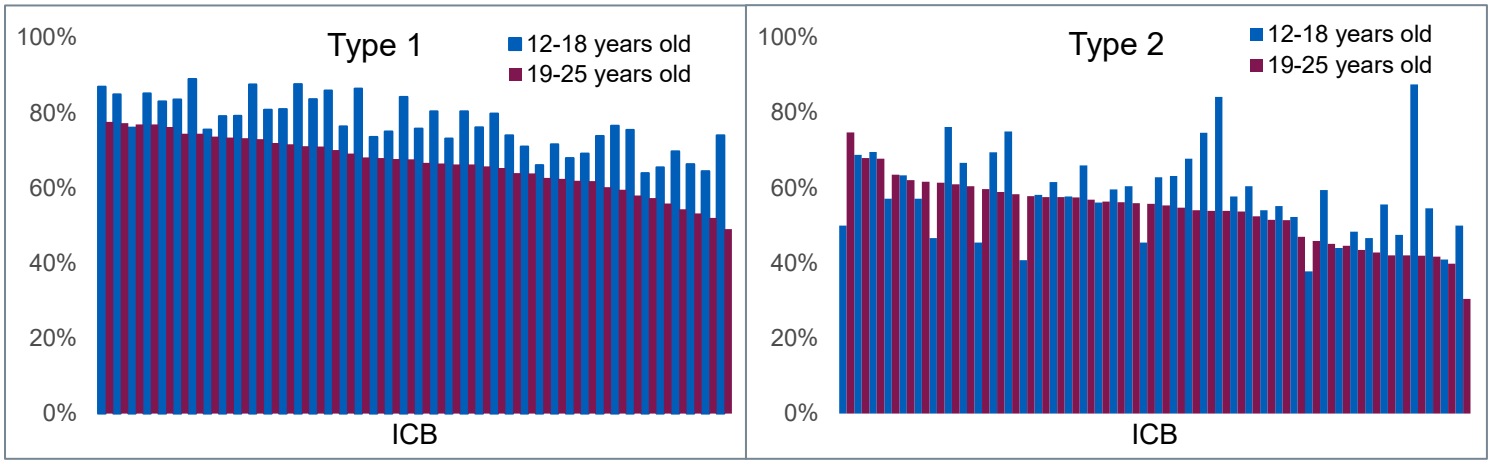
In adult services, retinal screening data flow directly into the NDA, as do care processes completed in primary care, whereas other essential checks delivered in secondary care require manual audit submission. This can make retinal screening appear comparatively higher, while other care processes seem lower, due to gaps in secondary care data capture. Taken together, these structural differences in data flows mean that reported completion rates may appear higher or lower simply because of how information is captured and transferred, rather than reflecting true performance.

Interpretation is further complicated by variation in recall intervals: some young people are screened annually, others biennially based on risk stratification, and recall schedules can change for an individual over time. Without matching each person’s expected recall interval to their actual screening date, population level percentages cannot show whether recorded completion is appropriate for that cohort, making local performance difficult to interpret.

These factors should not be used to discount low recorded completion rates, nor to make firm assumptions about comparisons between retinal screening and other care processes. Instead, they highlight the need to interrogate the underlying reasons for variation and ensure that data capture is complete and reliable.

Combined NDA and NPDA data at ICB level shows considerable variation in eye check completion (figure 19): for 12-18-year-olds with type 1 diabetes, ICB completion ranges from 64% to 89%. Completion in young adults (19-25) is lower than in children for all but one ICB, ranging from 49% to 89%. As more 19-25-year-olds would be expected to be on an annual recall than their paediatric counterparts, lower completion in this age group may be of even greater significance. Completion for those with type 2 diabetes is lower than for those with type 1 diabetes: 38% to 88% for 12-18-year-olds and 31% to 75% for 19-25 year-olds.

Figure 19: Variation in retinal screening by ICB for type 1 and type 2 diabetes (ages 12–18 and 19-25)



Source: NPDA and NDA combined data 2023/24

Case study: Improved outcomes for young people aged 16–25 with type 1 diabetes

Sheffield Teaching Hospitals NHS Foundation Trust

Sheffield Teaching Hospitals redesigned their diabetes services for young people through close collaboration between adult and paediatric diabetes teams. The paediatric and adult services achieved the best national engagement rates (97.4%) and excellent outcomes despite high levels of socioeconomic deprivation (over 29% of Sheffield's young people live in the most deprived quintile).

Over five years the trust aligned services so young people experience wrap-around care and avoid falling through the gap between paediatric and adult care. The trust aims to

complete all nine care processes in the same appointment. In 2024, 71% of young people with type 1 and 64% with type 2 completed all care processes.

In terms of overall trends there were a number of achievements:

- HbA1c levels improved year-on-year from 2022–2024 with 42.1% with HbA1c <58 compared to the national average of 24.9%.
- For the first time, females achieved better outcomes than males.
- The HbA1c gap between the least and most deprived quintiles was reduced to 5 mmol/mol (vs 9 nationally).
- 68.8% of YP now use hybrid closed-loop insulin therapy.

Click here to see the full case study.

Emotional wellbeing and mental health screening

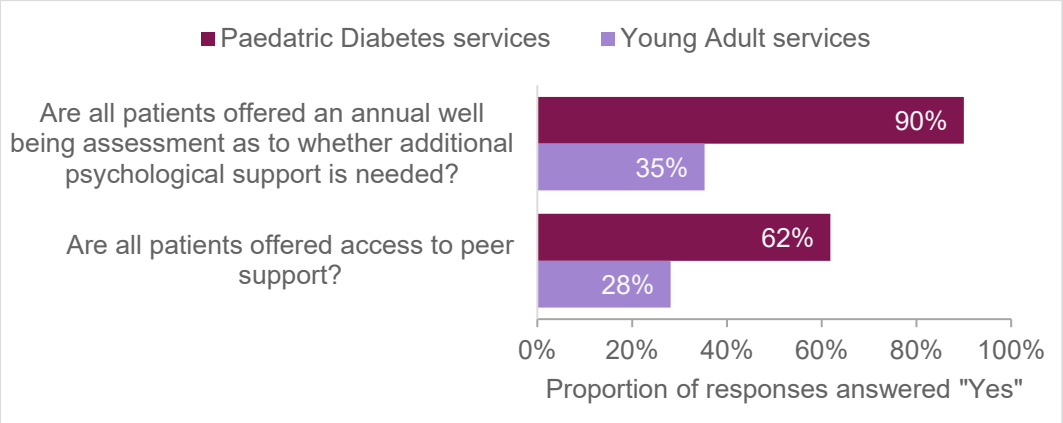
Children and young adults living with diabetes carry a substantial emotional burden. The demands of daily self-management, vigilance around blood glucose changes, social stigma and navigating food choices that can feel restrictive or out of step with peers all contribute to heightened vulnerability, particularly during adolescence and young adulthood. Many also carry an unspoken but persistent fear of future complications, which can intensify during periods of transition or instability.

Psychological need is rising sharply in the general population, with one in five CYP now experiencing a diagnosable mental health disorder.[37] For those with diabetes, this background prevalence combines with condition-specific pressures, making routine assessment of psychological need essential. Every review and contact should be holistic and include consideration of wellbeing. Annual structured screening provides a universal, cohort-wide route to identifying emerging distress and hidden need. Where screening is absent or inconsistently delivered, recognition of the need for specialist input often relies on self-advocacy or visible crisis, limiting opportunities for early identification and creating inequity.

[37] *NHS England. Mental Health of Children and Young People in England 2023, https://www.england.nhs.uk/2023/11/one-in-five-children-and-young-people-had-a-probable-mental-disorder-in-2023/*

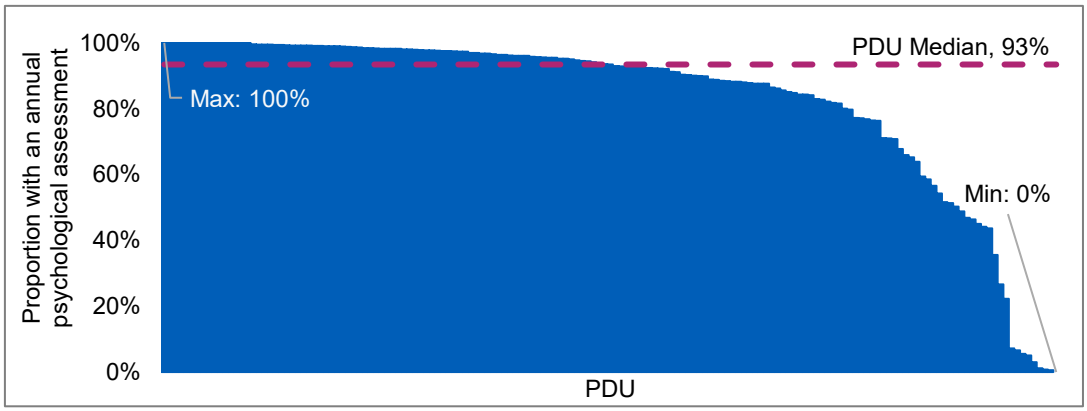
Most paediatric diabetes services offer an annual wellbeing assessment (figure 20), but delivery is variable, as are the tools and methods used, and some units report no patients receiving this check (figure 21).

Figure 20: Variation in proportion of paediatric and young adult services that offer an annual wellbeing assessment and access to peer support



Source: GIRFT pre-visit questionnaires (2024 and 2025)

Figure 21: Variation in proportion of type 1 patients completing an annual psychological assessment, aged 12+ years, by Paediatric Diabetes Unit (PDU) 2023/24



Source: NPDA 2023/2024

Where screening is completed, unmet need becomes immediately visible: 28% of those with type 1 and 39% of those with type 2 are identified as requiring additional psychological support.[38] Screening therefore plays a critical role, not only as a route into services, but as a way of validating emotional experience and identifying risk early.

Unaddressed psychological distress can undermine engagement, continuity and glycaemic stability.[39] In some cases, this includes complex behaviours such as insulin omission, chaotic dosing or disordered eating, which carry serious clinical risk and are frequently driven by distress rather than a lack of knowledge or motivation. These behaviours are often subtle

[38] *RCPCH, National Paediatric Diabetes Audit (NPDA) 2025 Report on Care and Outcomes 2023/24, 2025, https://rcpch.github.io/NPDA-Extended-Analysis-2023-4/#psychological-assessment*
[39] *Royal College of Paediatrics and Child Health (RCPCH). National Paediatric Diabetes Audit (NPDA) Report on Care and Outcomes 2023/24: Full Audit Analysis, Section 3.7 Psychological Assessment. Available at: rcpch.github.io*

and easily missed without specialist expertise. General CAMHS provision is not configured to recognise or manage these presentations. It does not routinely assess for diabetes-related distress, the cognitive effects of glycaemic variability, or the interaction between emotional wellbeing and metabolic control. CYA should have access to psychological professionals with expertise in diabetes, integrated within diabetes services to ensure these risks are identified and addressed early.

Despite the scale of need, psychological provision within diabetes services remains extremely limited. GIRFT data show that while paediatric services are more likely to have access to psychology, median provision is still only 0.2 WTE per 100 patients, falling to 0.1 WTE in young adult services,[40] far below recommended levels,[41] and many teams have no specialist provision at all. National workforce shortages mean rapid expansion is unlikely in the short term, making early recognition even more important. Screening should not be contingent on the immediate availability of psychological provision, or the presence of a psychologist within the team; it is a core component of holistic diabetes care.

Unmet psychological need in childhood often escalates in young adulthood, when emotional distress increases and expectations for independent diabetes self-management rise. Without early identification, difficulties that were manageable in paediatric care can become destabilising, contributing to deteriorating glycaemic stability and disengagement from services.

Relational roles such as youth workers, family support practitioners, named key workers and peer support networks provide vital support, emotional safety and non-judgemental contact. They are often well placed to notice early signs of distress, and in some cases their input may be sufficient to prevent escalation. However, they are not clinically trained to assess or treat psychological disorders. Their contribution complements but cannot replace access to psychologists with expertise in diabetes-related distress and mental health.

Given the rising prevalence of mental health disorders among all CYA, and the limited availability of specialist provision, consistent wellbeing screening and early identification of need are essential components of safe, holistic diabetes care.

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[40] *GIRFT pre-visit questionnaires (2024 and 2025)*
[41] *National CYP Diabetes Network, Workforce calculation tool, https://www.cypdiabetesnetwork.nhs.uk/national-network/wp-content/uploads/sites/14/2024/03/Workforce-calculation-tool.pdf*

Case study: Mental health screening of young adults with diabetes

St Helen's Hospital (Mersey and West Lancashire Teaching Hospitals NHS Trust)

The clinical team embedded the CORE-10 screening tool into routine practice to assess levels of psychological distress. This brief, 10-item tool supports a bio-psycho-social model of care that covers anxiety, depression, trauma, and risk to self, offering a standardised way to identify those who may benefit from psychological support.

Of 134 young adults screened in 2023/24, 72% scored below the threshold for concern, while 28% recorded moderate to severe distress highlighting the importance of screening within this age group. By stratifying responses, the service can respond holistically, avoid over-medicalisation and tailor its response: offering self-help resources, coaching, or direct referral to psychological services depending on need.

Implementation of CORE-10 helps the service align with national guidance on mental health integration in diabetes care, while building psychological safety into routine reviews. It enhances staff understanding of the psychological dimensions of diabetes, fosters a culture of openness, and improves patients' engagement in their own care

Click here to see the full case study.

Education and self-management support

Many young people lack a clear understanding of the purpose and importance of annual health checks, particularly when information is delivered in clinical language or framed around fear of complications. This can imply inevitability rather than opportunity for early detection, reversal or treatment, and can undermine motivation to complete care processes.

Youth-oriented, co-produced digital platforms and apps like DigiBete[42] and T2Digibete[43] provide education and self-management support in an accessible, emotionally attuned format. Because support is available in-app, young people can engage in the moment they feel most ready or motivated. Funded by NHSE and clinically approved, these platforms provide relatable lived-experience content, clear explanations of each component of annual health checks, and interactive tools that build developmentally appropriate understanding, confidence and participation in care. They also help young people understand that some

[42] *DigiBete, https://www.digibete.org/*
[43] *T2Digibete, https://www.youngtype2.org/*

degree of diabetes-related distress is expected, validating emotional experience, and making wellbeing screening feel relevant and safe rather than punitive or crisis-driven. When positioned as part of the universal offer within the diabetes pathway and reinforced by trusted clinical relationships, these tools can reduce apprehension, promote agency, and encourage completion of annual checks.

These tools are well utilised and embedded in paediatric care, but despite being freely available, young adult services often fail to signpost or embed them, leaving many young adults without the access they need at the very stage when they face the greatest pressures, life transitions and high geographical mobility.

2	Roadmap of actionable steps to reduce variation in essential annual health check completion
	Establish clear responsibility and accountability across the system for completing and recording essential health checks (including retinal screening) ▪ **Produce a responsibility and accountability matrix** across primary care, community services, and specialist teams that specifies, for every essential health check, who holds primary responsibility for ensuring the check is completed and recorded once, regardless of where it is delivered. ▪ **For each check, set out who would normally complete it by default** within the usual pathway, while making clear that checks may be completed in other settings opportunistically when this is more accessible for the young person. ▪ **Embed these responsibilities in local operating procedures** so all teams understand their role, even when multiple services contribute to routine care. ▪ **Assign a named team with the accountability for monitoring of outstanding or overdue checks,** acting on abnormal results, communicating with the young person, ensuring follow-up is completed and the loop is closed. ▪ **Enable all relevant teams, including diabetic eye screening, to access and update shared records** showing completed checks, results, non-attendance and outstanding or overdue checks. Configure systems so that updates made in any service are visible to all others without manual duplication. ▪ **Specify audit responsibilities for each service,** making clear who should submit national audit data for each essential health check, based on where the check is delivered. When checks are completed in secondary or specialist care, that service should either submit the audit data directly or provide it to primary care in an agreed format and timeframe so that it can be uploaded exactly as received, without interpretation, for timely national audit extraction. ▪ **Provide dedicated administrative support at an appropriate skill level** with accountability for complete, accurate and timely data submission held at the correct managerial level, including routine performance checking, so clinical time is protected.

Provide patients with flexible, accessible and opportunistic pathways for completing checks

- **Fix accountability for completion while allowing flexible delivery**, so checks can be completed in the most accessible and timely setting for the young person.
- **Create a clear, efficient pathway for completing essential checks** tailored to the main care setting, enabling multiple checks to be completed in a single encounter wherever possible, with flexibility to complete checks across different settings when required.
- **Reduce duplication and maximise opportunistic completion through system-wide agreements** on roles, processes and data sharing, supported by real-time access to patient information, and by completing outstanding checks at every touchpoint.

Embed routine psychological screening to ensure mental health needs are consistently identified, recorded and routed to staff with the expertise to assess risk, triage concerns and determine appropriate next steps.

- **Establish a regular, standardised process for annual psychological screening** using agreed risk indicators and thresholds, with clear plans for how identified needs will be managed.
- **Ensure timely access to psychological professionals trained in diabetes-related distress** and vigilant to risks associated with insulin misadministration, disordered eating and other safety concerns, to support emotional wellbeing, engagement and early intervention.

Domain 3: Variation in emergency admissions

Emergency admissions for diabetic ketoacidosis (DKA) and severe hypoglycaemia are dangerous and remain one of the most serious and often preventable challenges in the care of children and young adults with diabetes. These events carry significant life-threatening risk, cause considerable distress for young people and their families, and place substantial pressure on urgent and inpatient services.

At diagnosis DKA is associated with acute complications and longer hospital stays, and evidence shows that presenting in DKA can have lasting consequences, including diminished preservation of remaining insulin-producing cells and potential long-term effects on cognitive functioning. For the NHS, emergency admissions for DKA and severe hypoglycaemia also carry substantial financial cost.

Across England, emergency admission rates vary widely. This variation reflects differences in how systems recognise early warning signs, support young people to manage rising risk, and respond when acute deterioration occurs.

High rates of DKA at diagnosis often reflect missed opportunities for early symptom recognition, while DKA and severe hypoglycaemia after diagnosis more commonly indicate gaps in structured education, continuity of care, or timely intensification of support.

Reducing this variation is essential to preventing avoidable harm and improving long-term outcomes.

DKA at diagnosis

DKA at diagnosis remains the only major metric in paediatric and young adult diabetes care where sustained improvement has not been observed, despite repeated national awareness campaigns aimed at improving early symptom recognition among families, schools and clinicians, and supporting timely referral.[44,45] However, the UK does have lower rates when compared with many countries,[46] GIRFT data show a near 2-fold difference in DKA rates at diagnosis between ICBs, ranging from 27% to 51% of 0–18 year olds presenting in DKA at diagnosis of type 1 diabetes (NPDA 23/24) (figure 22). This substantial variation highlights

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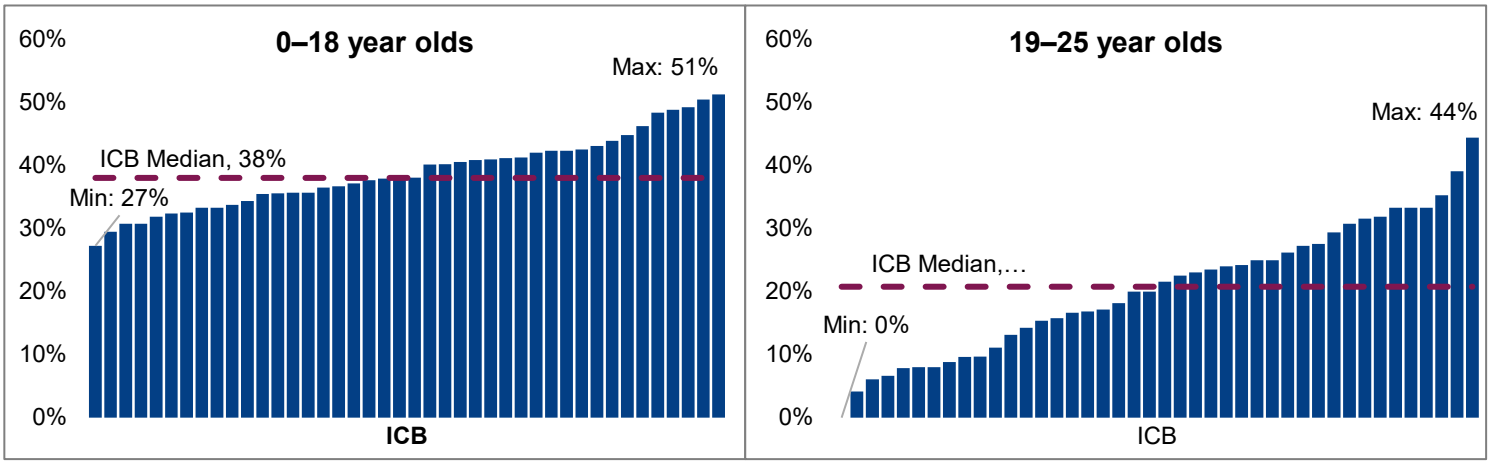
[44] *Diabetes UK, 4 t's Diabetes UK resources, https://www.england.nhs.uk/midlands/wp-content/uploads/sites/46/2021/02/CH_DIABETES-UK-4TS-links-and-resources.pdf*

[45] *National Children and Young People's Diabetes Network, DKA prevention at diagnosis, https://www.cypdiabetesnetwork.nhs.uk/national-network/dka-prevention-at-diagnosis/*

[46] *Usher-Smith JA, Thompson M, Ercole A, Walter FM. Variation between countries in the frequency of diabetic ketoacidosis at first presentation of type 1 diabetes in children: a systematic review. Diabetologia. 2012;55(11):2878–2894. doi:10.1007/s00125-012-2690-2. PMCID: PMC3464389.*

system-level differences and signals underlying inequalities. The variation is even more marked for 19 to 25-year-olds.

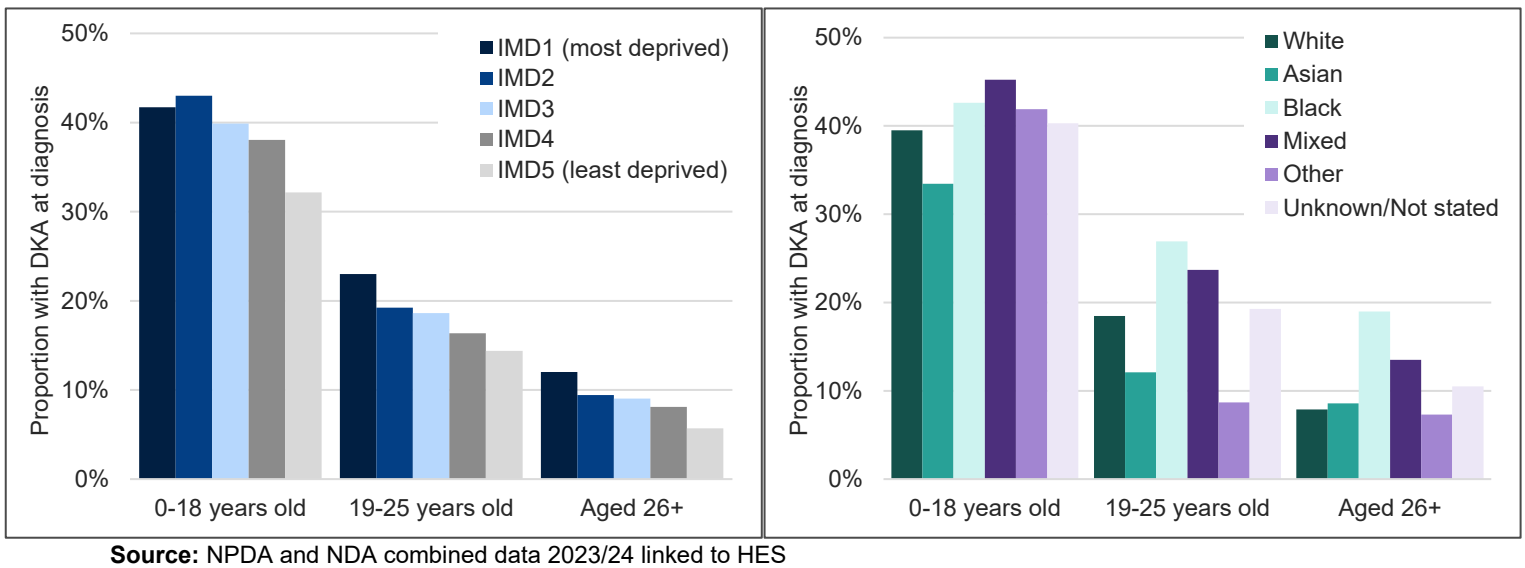
Figure 22: Variation by ICB in the proportion with DKA at diagnosis of total people diagnosed with type 1 diabetes in 2023/24



Source: NPDA and NDA combined data 2023/24 linked to HES

Geographical and population-level disparities are also evident. National data show that CYA in the most deprived quintile (IMD 1) are more likely to present in DKA at diagnosis than those in the least deprived quintile (IMD5) (figure 23). Those of black ethnicity are more likely to present in DKA at diagnosis than those of white ethnicity, while those of Asian ethnicity are less likely (figure 23).

Figure 23: DKA at diagnosis by age and deprivation/ ethnicity, the proportion with DKA at diagnosis of total people diagnosed with type 1 diabetes in 2023/24

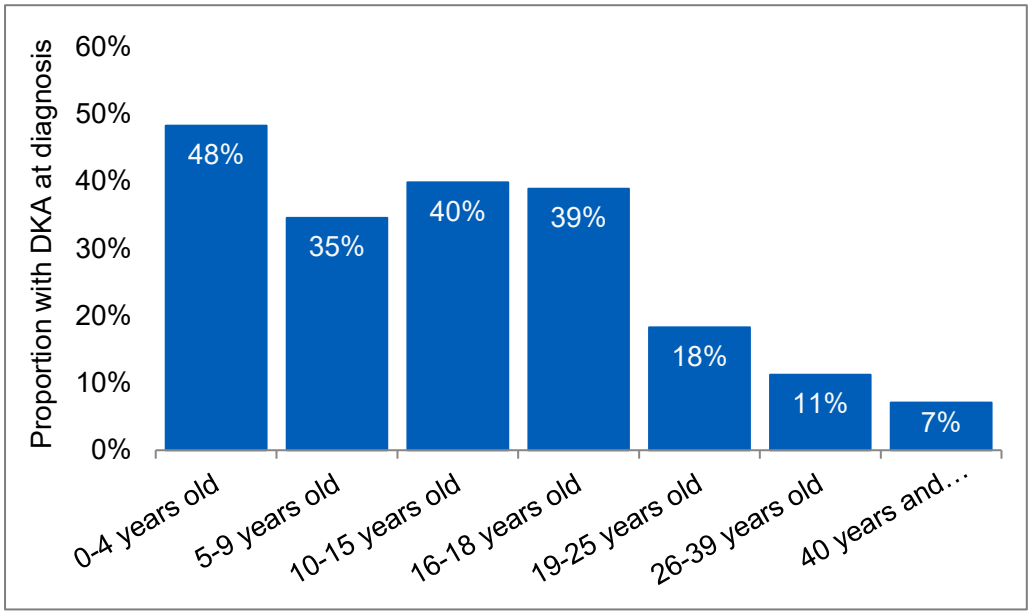


Source: NPDA and NDA combined data 2023/24 linked to HES

Children under four have the highest rates of DKA at diagnosis, with nearly 50% presenting in DKA (figure 24); in this age group symptoms may be unexpected, subtle, or misattributed,

which can affect recognition, clinical suspicion, confirmatory testing and same-day referral.[47] Adolescents also show higher rates of DKA at diagnosis compared with adults. Several factors may contribute to this pattern, including developmental changes, fluctuating independence and variability in how symptoms are recognised or acted upon, with early features sometimes masked or attributed to common experiences such as tiredness, stress or minor illness.

Figure 24: DKA at diagnosis by age, proportion with DKA at diagnosis of total people diagnosed with type 1 diabetes in 2023/24



Source: NPDA and NDA combined data 2023/24 linked to HES

System-level contributors include difficulties navigating the healthcare system, challenges securing timely GP appointments, and the use of virtual consultations that may miss critical visual cues or delay point of care testing. More consistent local data review is needed to understand these drivers and target improvement efforts appropriately.

Importantly, not all cases of DKA at diagnosis are preventable, and presentation in DKA does not necessarily indicate a missed opportunity in primary care. Some children progress rapidly, some present atypically, and in some situations the clinical picture evolves in ways that make recognition genuinely difficult. Improvement efforts therefore need to focus on reducing avoidable delay while recognising the limits of preventability.

Addressing this requires place-based, multi-agency collaboration across primary care, specialist services, community settings and public health, supported by inclusive communication strategies delivered in trusted community environments and equity-focused

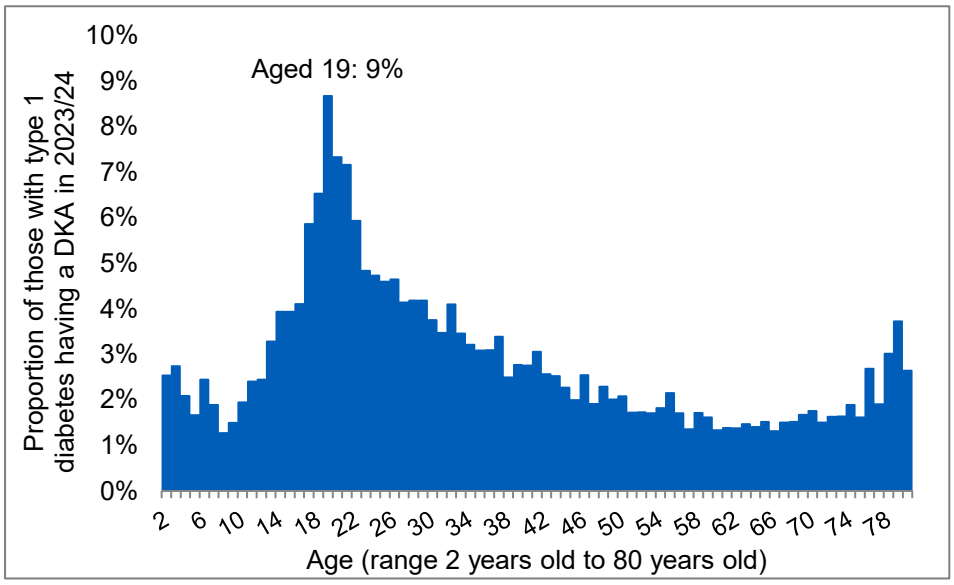
[47] *RCPCH, Report on hospital admissions of children and young people with diabetes 2015-2020, 2023, https://www.rcpch.ac.uk/sites/default/files/2023-07/npda_report_on_admissions_2015-2020v2.pdf*

commissioning. These approaches should ensure that information, routes to urgent assessment and access to timely diagnostic testing are proactively tailored to the needs of the most vulnerable populations.

DKA and hypoglycaemia after diagnosis

DKA and severe hypoglycaemia after diagnosis typically reflect unmet clinical or psychosocial needs, gaps in structured education for prevention of acute deterioration, or lack of timely intensification support. These episodes peak in young adulthood (figure 25),[48] a period characterised by transitions between services and changes in routine that can disrupt continuity of care.

Figure 25: DKA after diagnosis by age



Source: NPDA and NDA combined data 2023/24 linked to HES

Repeated episodes are a particularly strong indicator of unmet need, signalling persistent barriers to engagement, inconsistent follow-up, difficulties accessing timely support and the availability of proactive follow-up once the acute episode has resolved.

Responses to emergency admissions

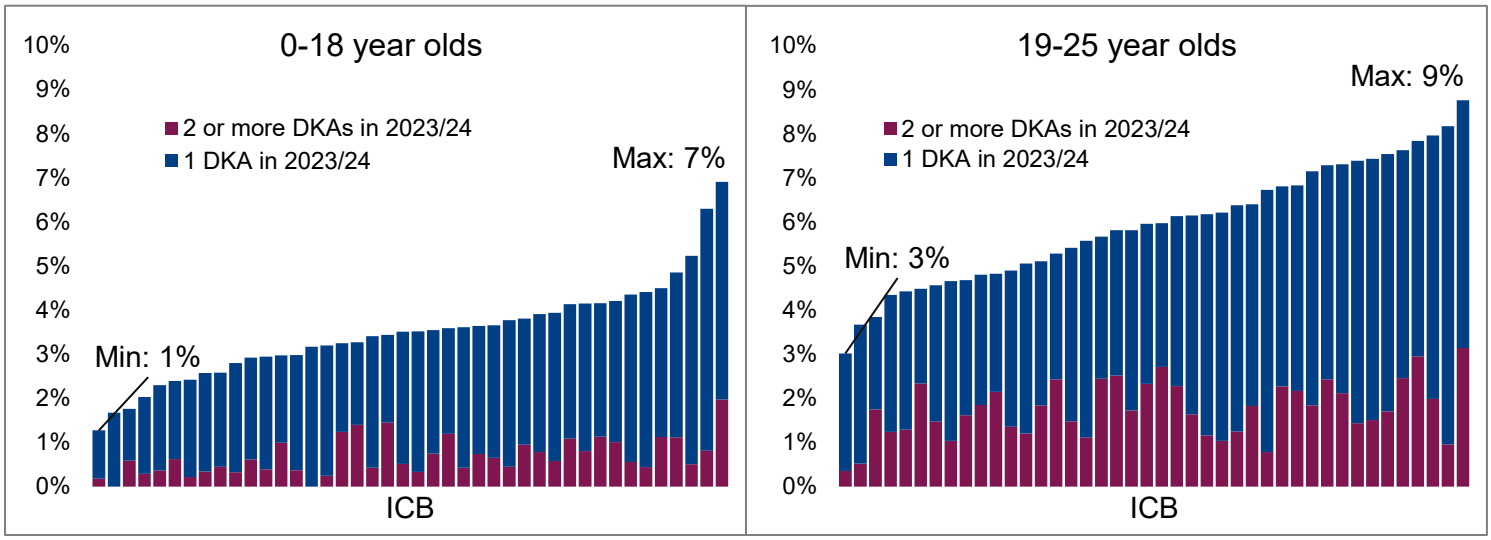
In many areas, admissions do not reliably trigger a structured response that explores underlying causes, addresses barriers to engagement or ensures timely follow-up once the acute episode has resolved. Yet each admission provides a critical opportunity to identify

[48] *Holman, N., Woch, E., Dayan, C., et al. (2023). National trends in hyperglycemia and diabetic ketoacidosis in children, adolescents, and young adults with type 1 diabetes: A challenge due to age or stage of development, or is new thinking about service provision needed? Diabetes Care, 46(7), 1404–1411. https://pubmed.ncbi.nlm.nih.gov/37216620/*

vulnerabilities, missed care processes, gaps in support or periods of disengagement, and to reconnect young people with routine care. These opportunities are not used consistently.

The HSSIB report on safe insulin administration highlights wider system issues, including fragmented communication, inconsistent handover processes, and limited data integration, that can undermine continuity between inpatient and ongoing care teams.[49] Variation in admission rates (figure 26) and length of stay between ICBs suggest that the reliability of inpatient response, discharge readiness, and co-ordination across the interface varied considerably.

Figure 26: Variation by ICB in the rate of DKA occurring in 2023/24 rate for people with type 1 diabetes



Source: NPDA and NDA combined data 2023/24 linked to HES

Although 98% paediatric services and 90% of young adult services report having clear inpatient protocols for DKA,[50] variation in duration of admission indicates that these are not implemented or operationalised consistently. Recent analysis also shows significant variation in hospital length of stay between ethnic groups that cannot be explained by clinical factors alone.[51]

Following discharge, timely follow-up (ideally within days) is needed to reinforce education, review psychosocial needs and provide technology support. For young people with more complex circumstances, co-ordinated multi-agency input may be required.

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[49] *Health Services Safety Investigations Body (HSSIB) (2026) Insulin: Supporting Safe Administration in Inpatient Settings - Investigation Report, https://www.hssib.org.uk/patient-safety-investigations/insulin-supporting-safe-administration-in-inpatient-settings/investigation-report/*

[50] *GIRFT pre-visit questionnaires (2024 and 2025)*

[51] *N Chackalaparambil Philip, A Manta, K Persad, P Kempegowda, OC24 - Ethnic disparities in outcomes of diabetes-related emergencies: a multicentre observational study, European Journal of Endocrinology, Volume 193, Issue Supplement_1, September 2025, lvaf168.043, https://doi.org/10.1093/ejendo/lvaf168.043*

Case study: Ethnic variation in length of stay for diabetes emergencies

Findings from DEKODE Database

Analysis of pooled DEKODE data from 26 NHS hospitals identified consistent ethnic variation in hospital length of stay for diabetes emergencies. Asian and Black patients experienced longer admissions than White patients, even after adjusting for clinical severity, highlighting opportunities to improve equity in inpatient and discharge pathways.

The study utilised data from the DEKODE programme, examining adults admitted with DKA, hyperosmolar hyperglycaemic state (HHS), or severe hypoglycaemia between 2020 and 2023. Multivariable regression was applied, adjusting for age, sex, diabetes type, comorbidity and biochemical severity, with each emergency type analysed separately.

For DKA, Asian and Black ethnicity were independently associated with longer length of stay (Black ethnicity: adjusted $p<0.001$). In HHS, Asian patients had significantly longer length of stay (adjusted $p=0.014$), along with significantly longer time from resolution to discharge. For hypoglycaemia, no independent ethnic difference was identified. Black and Asian adults present younger and with more severe emergencies than White patients, yet these differences persisted despite similar in-hospital mortality and intensive care admission rates.

The findings suggest that upstream and post-discharge factors, rather than inpatient care delivery, drive observed disparities. National audits do not routinely report outcomes stratified by ethnicity, and without this analysis, health inequalities may be missed. Ethnicity-aware risk assessment, routine stratified audit, and investigation of discharge pathway barriers are essential to reducing disparities in length of stay and improving equity in diabetes emergency care.

Click here to see the full case study.

Non-attendance and disengagement

High rates of non-attendance recorded as ‘Was Not Brought’ (WNB) for children and ‘Did Not Attend’ (DNA) for adolescents and young adults may be associated with later emergency

presentations. These missed contacts frequently reflect unmet needs, early disengagement or barriers to accessing care, and may signal increasing risk of deterioration.[52]

Systems should routinely review clinic attendance patterns and missed elements of care – including essential checks, structured education, and psychosocial assessments – to identify individuals who are more at risk of complications including acute admission. Repeated WNB/DNA or frequent cancellations should trigger a structured response, such as flexible rebooking, community outreach and multiagency assessment where appropriate. GIRFT reviews found that many areas lack robust mechanisms to reconnect with young people who have disengaged, despite this group being at heightened risk.

Effective outreach may include personalised digital messaging, text reminders, phone calls, liaison with schools or universities, and collaboration with youth workers or family support teams. Using the communication channels that young people rely on, typically direct messaging platforms, can help restore contact and reduce barriers to re-engagement. As neighbourhood health models develop, there is the potential to embed diabetes outreach within these structures, creating more accessible, community-based touchpoints. These strategies aim to restore contact, understand underlying barriers and ensure that young people receive timely support to prevent avoidable harm.

Out-of-hours advice

The review found no standardisation of out-of-hours protocols, and wide variation in how clinical advice outside routine hours is organised across England. In paediatrics, models often depend on the size and configuration of the diabetes workforce, may be variably remunerated, and in some areas rely on goodwill, making them difficult to sustain. The type of advice available also varies, with some services offering specialist diabetes input and others relying on general paediatric or medical rotas. In some regions, several units contribute to a shared rota, while in others each service provides its own cover.

Increasing use of diabetes technology and wearables also means that out-of-hours advice now requires greater technical expertise, yet current service models do not consistently reflect this need. This diversity represents another area of operational inconsistency that may influence patterns of emergency admission. The priority is ensuring that young people and families are regularly updated on sick day and emergency management, and that they

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[52] *Children's Hospital Alliance. Was Not Brought Artificial Intelligence Tool: Findings from the Evaluation* https://childrenshospitalalliance.co.uk/wp-content/uploads/2023/07/EvaluationOfTheWasNotBroughtProgramme.pdf

understand how to access appropriate advice, whatever model operates locally. Clear communication about routes to help, and how and when to use them, is essential to maintaining safety and preventing avoidable deterioration.

Digital support and self-management tools

Tools such as DigiBete and T2Digibete provide clinically endorsed guidance on sick day rules, ketone management and early deterioration, alongside essential medicines-safety information, and clear prompts on when urgent clinical advice is needed. These nationally funded platforms are well embedded in paediatric pathways, but uptake is markedly lower among young adults, the group at highest risk of acute complications and emergency admissions. Limited access to, or low engagement with, these resources may reduce the ability to manage rising risk independently, particularly when geographical mobility increases, routine contact is missed or timely clinical advice is unavailable.

Ensuring that digital self-management tools are embedded within routine pathways is therefore an important component of safety-netting. Services should take responsibility for introducing these tools consistently, monitoring engagement and integrating digital support into structured education, follow-up and outreach activity so that young people know what is available and how to use it confidently. Routine review of digital-engagement metrics can help identify gaps in provision and ensure that these nationally funded resources are used to their full potential.

Case review, audit and thematic analysis

Emergency admission rates show substantial variation across England, yet detailed review of these events is inconsistent. At provider level, over half of young adult services do not routinely examine their own emergency admission data: 54% of 153 services do not review DKA admissions, and 66% do not review admissions for hypoglycaemia.[53] At system level, oversight is similarly variable. 14 of 41 ICBs answered “No” to the question: “Outside of finance and contracting, do you use NPDA / NDA and DKA admission data to have regular conversations with clinical representatives from services to identify where there are opportunities for improvement?”.

Where review does occur, it often focuses on single admissions rather than drawing together findings across multiple episodes. As a result, services may miss wider patterns linked to

[53] *GIRFT pre-visit questionnaires (2024 and 2025)*

completion of care processes, HbA1c trends, technology use, WNB/DNA patterns, structured education, digital tool engagement or demographic and inequality data. Without this broader thematic analysis, structural risks, recurring drivers of deterioration and service gaps remain hidden.

A more co-ordinated, data-driven approach is needed. Emerging tools, including AI-driven risk-stratification models, offer opportunities for proactive case-finding by highlighting individuals at increased risk of preventable emergency episodes. Alongside this, services should undertake routine audit of emergency admissions to assess compliance with agreed standards and identify unwarranted variation. Systems should then ensure that insights, from individual case review, AI-supported risk identification and whole-system thematic analysis, are linked directly into high HbA1c and treatment intensification pathways, as well as wider system-level improvement plans. Digital audit programmes such as DEKODE (Digital Evaluation of Ketosis and Other Diabetes Emergencies)[54] provide structured methods for reviewing the quality of inpatient care, benchmarking performance, and supporting consistent improvement.

3	Roadmap of actionable steps to reduce variation in emergency admissions
	Embed regular case review, audit and thematic analysis of emergency admissions for DKA and severe hypoglycaemia as a core component of diabetes service evaluation. ▪ **Ensure there is immediate and proportionate learning from each individual admission.** Complete a brief review of every admission to identify clinical or operational learning. Share this promptly with the team most closely involved in the patient's care (e.g. diabetes team, GP, urgent care team). Keep this rapid learning process separate from audit and thematic analysis to ensure timely action. ▪ **Implement a quarterly audit cycle reviewing all diabetes emergency admissions.** Assess compliance with agreed standards for DKA and hypoglycaemia management, including inpatient care processes and discharge criteria. Benchmark performance, document findings, and maintain an action log with named leads, specific actions, timelines and follow-up checkpoints to ensure changes demonstrably influence practice across all care settings. ▪ **Undertake a quarterly thematic analysis of all emergency admissions** to identify recurring patterns, contributory factors and structural risks, and link these themes to wider indicators such as care-process completion, HbA1c trends, technology use, WNB/DNA patterns, structured-education uptake, digital-tool engagement and inequality data. Produce a documented action log

[54] *Rengarajan et al, DEKODE – A cloud-based performance feedback model improved DKA care across multiple hospitals in the UK, 2025, Wiley Online Library, https://onlinelibrary.wiley.com/doi/10.1111/dme.70004*

with named leads, specific actions, timelines and follow-up checkpoints, to ensure thematic findings are shared across relevant services and demonstrably influence practice across all care settings.

- **Review DKA at diagnosis separately from post-diagnosis episodes.** For DKA at diagnosis, examine delays in symptom recognition, testing and referral. For post-diagnosis episodes, review gaps in structured education and assurance of understanding, loss of follow-up continuity, and unrecognised or unacted upon vulnerability factors. Record actions and review impact of improvement activity.
- **Strengthen early recognition of new onset type 1 diabetes.** Provide regular training for primary and urgent care teams on early symptoms of type 1 diabetes and monitor whether this improves timeliness of testing and referral. Ensure clear pathways for same-day referral to acute paediatrics and specialist diabetes teams. Use clinical prompts and decision-support tools to support earlier recognition in busy clinical environments. Track training uptake and evaluate whether pathway use and referral times improve.

Identify individuals at increased risk of emergency episodes and intensify support accordingly

- **Use digital or AI-supported tools** to integrate key risk indicators, including missed care processes, high HbA1c, low TIR, WNB/DNA patterns, psychosocial factors, uptake of structured education, digital self-management tools, ethnicity and deprivation. Generate a risk-flagged list and ensure each flagged individual is offered proportionate, targeted support or proactive review within an agreed timeframe. Monitor whether this targeted support is associated with improved engagement or greater glycaemic stability over time.
- **Apply standardised risk flags in the shared record** whenever a young person has a significant clinical risk or psychosocial or neurodevelopmental vulnerability that could delay recognition of deterioration. Maintain system-level processes to keep these flags visible, accurate and current across all services, ensuring emergency teams can access critical information during acute episodes, enabling planned intensification of support before deterioration occurs.
- **Monitor structured education and digital self-tool engagement metrics** (e.g. log-ins, module completion, competency checks, and access to sick-day rules) to identify individuals who are not engaging with, or may not fully understand, available support. Ensure they receive tailored support and confirm their understanding of key self-management guidance.

Use inpatient episodes as structured opportunities to understand vulnerabilities and strengthen support to prevent recurrence

- **Treat every emergency admission as a structured, documented assessment**, identifying missed appointments, incomplete care processes, psychosocial vulnerabilities, communication barriers and education needs, and recording the actions required to address them.
- **Ensure each young person is discharged with a strengthened support plan,** including an updated care plan, clear deterioration-management instructions and rapid follow-up arranged within an agreed timeframe.

- **Ensure inpatient teams promptly notify the usual diabetes team and the GP of every admission,** sharing key information in a clear, documented format so that the causes of the episode are understood and any required changes to follow-up, education or care plans are made.

Ensure a clear, safe plan is in place at the point of need

- **Ensure patients have clearly documented instructions for accessing urgent advice** between scheduled reviews, including when their usual team is available and who to contact for support outside these hours. This information should be visible in the care plan and shared across relevant services.
- **Provide key therapy information in reliable written or electronic formats**, updated promptly and consistently across all platforms and records whenever details change. This ensures that any healthcare professional involved in an emergency episode can access accurate information without relying solely on the young person or carer.
- **Systematically offer and integrate digital self-management tools** (e.g. sick-day rules, ketone-management guidance) into routine care, ensuring staff reinforce their use so young people can recognise early deterioration and act quickly.

Domain 4: Variation in access to and outcomes from Hybrid Closed Loop therapy

Hybrid Closed Loop (HCL) systems represent a major advancement in type 1 diabetes management, using continuous glucose monitoring data to automate adjustments to insulin delivery, thereby reducing the cognitive and emotional demands of self-management. Clinical benefits include an average HbA1c reduction of 7 mmol/mol at 12 months, a 13.4% increase in time in target glucose range, and fewer episodes of hypoglycaemia and DKA.[55] These improvements support better sleep, reduce diabetes distress, and help individuals participate more fully in education, work, driving, physical activity and family life. For parents and carers, features such as alarms and remote monitoring provide reassurance, helping to alleviate overnight vigilance, particularly for younger children or when young people are away from home. HCL systems can also be adapted to different life stages and circumstances, for example using pregnancy-specific blood glucose targets, adjusting alerts for younger children, or supporting greater independence during adolescence and transition to adult care.

National progress has been driven by two distinct pillars: the NICE Technology Appraisal for HCL (TA943)[56], which provides evidence-based approval and eligibility criteria prioritising groups for whom HCL therapy offers the greatest benefit and highest return on investment; and NHS England's substantial support, including centrally negotiated pricing, national supply-chain frameworks, a five-year implementation strategy, and dedicated programme funding to help systems meet their legal obligations under the appraisal. Together, these measures have transformed access to diabetes technology, enabling rapid expansion, embedding HCL as standard care for eligible groups, and promoting equitable provision across England through nationally co-ordinated procurement.

Despite this strong foundation, differences in local commissioning, workforce readiness and operational infrastructure continue to shape how effectively HCL is adopted and optimised. These challenges are not universal, and many areas have achieved high usage, but where they do occur, they limit access for underserved groups and young adults in transition, and place pressure on the long-term sustainability of HCL delivery. To realise the full benefits of this innovation, systems need a confident and adequately resourced workforce, structured

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[55] *Ng, SM, Wright NP, Yardley, et al., 2024. Long-term assessment of the NHS hybrid closed-loop real-world study on glycaemic outcomes, time-in-range, and quality of life in children and young people with type 1 diabetes, BMC Medicine*

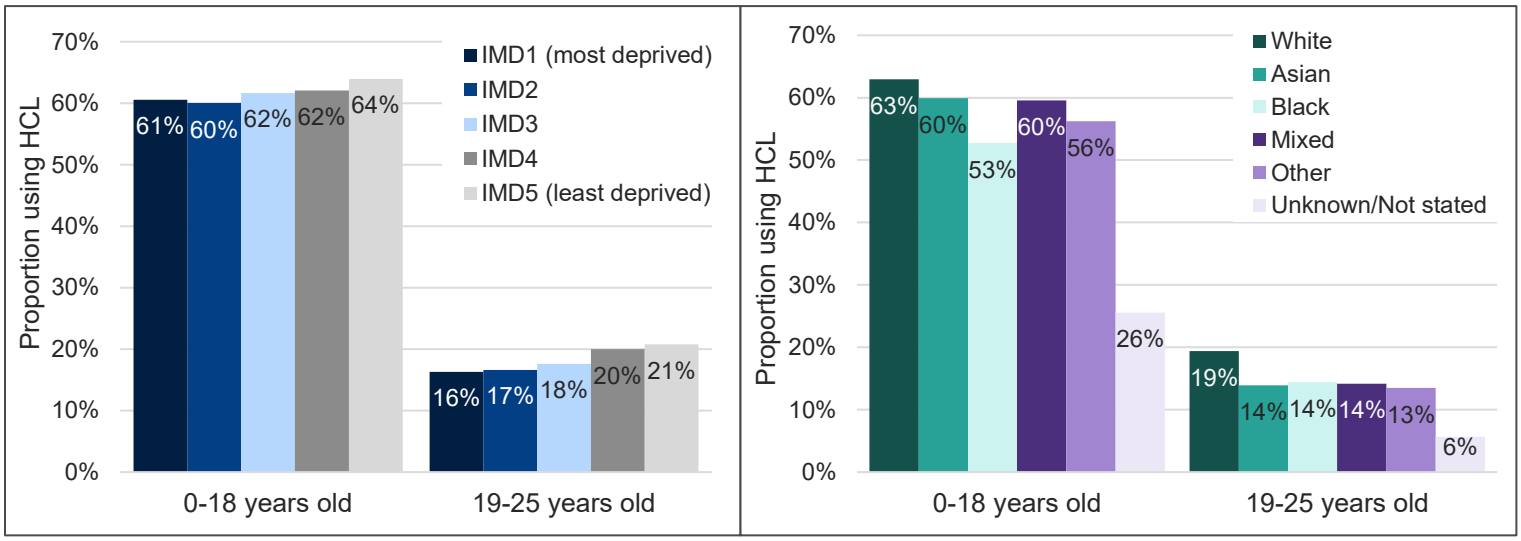
[56] *NICE TA943, Hybrid closed loop systems for managing blood glucose levels in type 1 diabetes, https://www.nice.org.uk/guidance/ta943*

onboarding, reliable digital infrastructure (including the capability to run and use HCL data systems and the clinic workflows that support them), improved data capture, and clear aligned commissioning and procurement.

Unequal uptake across populations

Access to HCL varies significantly across regions and populations (figure 13), with lower uptake in more deprived groups and among minority ethnic communities (figure 27).[57] In some highly deprived populations, disparities are minimal, demonstrating that inequities are not inevitable and are strongly influenced by local approach, pathway design and implementation. There is also variation between providers within the same ICB, serving a similar population, even under a shared implementation plan.

Figure 27: Distribution of HCL usage as at end of 2024/25 by age and deprivation/ ethnicity



Source: NPDA and NDA combined data 2024/25

Equity cannot be achieved through reactive, request-based support; it requires proactive, system-wide processes that offer HCL to all eligible individuals as a universal starting point, with tailoring to accommodate different needs and circumstances. When these processes are absent, unconscious bias and assumptions about people's best interests can influence who is offered technology, leading to selective provision and unequal access.

Systems should routinely review uptake data disaggregated by age, ethnicity, socioeconomic status and care setting. Digital and financial barriers, including digital exclusion and the

[57] *Diabetes UK, UNBIASED: Breaking barriers in diabetes technology,* https://www.diabetes.org.uk/about-us/our-impact/tackling-inequity/unbiased

personal costs associated with using an NHS-funded device (such as compatible smartphones to enable all functionalities, data plans and connectivity) must be addressed.

Case study: Tackling inequality in accessing diabetes technology for children and young people living in low-income households

North East and North Cumbria ICS

In North East and North Cumbria (NENC), partners came together to address digital and health inequalities by improving access to diabetes technology for children and young people (CYP) from low-income families. The initiative, led by Gateshead Health NHS Foundation Trust and the CYP NENC Diabetes Network, refurbished donated phones and laptops, pairing them with SIM cards to support diabetes technology use (e.g. CGM apps).

A no-means-testing, poverty-proofed approach ensured dignity and accessibility. Devices were securely refurbished and matched to families referred by local diabetes teams, with set-up support provided. In the first year (March 2023–2024), 310 referrals led to the distribution of 232 phones and 66 laptops - 60% of which went to families in the most deprived areas (IMD deciles 1-3).

This initiative helped CYP manage their diabetes more independently and confidently while also addressing digital exclusion. It also offered environmental benefits through sustainable technology reuse. Strong collaboration across NHS and voluntary sectors, including Vodafone's donation of 500 SIM cards, contributed to its success.

Click here to see the full case study.

Case study: Reducing inequalities in access to HCL systems for CYPs with type 1 diabetes

South East England CYP Diabetes Technology Team

The South East CYP Diabetes Technology Team implemented a 12-month regional programme aimed at addressing inequalities in access. Funded by NHS England, this 'roving' multidisciplinary team worked across 23 Paediatric Diabetes Units (PDUs) and six ICBs, combining audit data, workforce assessments and patient engagement to inform targeted interventions.

Baseline data revealed major disparities in HCL access, ranging from 10–80% across the region (average 39%). Key barriers included limited workforce capacity, inconsistent procurement processes, unclear financial arrangements, and variation in local clinical confidence and visibility of inequalities. Patient feedback highlighted additional challenges such as anxiety, lack of information and cultural or digital access barriers.

The team employed the COM-B behaviour change model to tailor strategies to each PDUs needs. Interventions included:

- Clinical training in HCL onboarding and optimisation.
- Shared decision-making and co-production of educational resources.
- Development of HCL operational pathways, risk management frameworks and patient education tools.
- Visibility and communication initiatives, including newsletters, inequality awareness resources and IMD (deprivation) tagging in digital patient systems.
- Business case support for sustainable workforce planning.

After one year, regional HCL use increased to 53%, with most units achieving 50–60% access rates. Deprived and high-need populations saw above-average improvements, demonstrating a measurable reduction in inequality. However, some centres with procurement constraints or staffing shortages remained below 20% access.

This pilot highlights the effectiveness of a region-wide, multidisciplinary approach in improving equitable access to diabetes technology. Sustained impact will depend on embedding workforce investment, visibility of inequalities and continuous optimisation of HCL systems within routine care.

Equitable implementation of HCL requires inclusive onboarding and commissioning that anticipates likely barriers from the outset, with tailored approaches for individuals facing language, literacy or educational challenges.

Case study: Improving equity and outcomes through a high-throughput hybrid closed loop initiation pathway

University Hospitals of Derby and Burton NHS Foundation Trust

University Hospitals of Derby and Burton NHS Foundation Trust children's diabetes team addressed significant challenges in HCL technology access following site merger and new guidance implementation. The service faced wait lists exceeding 18 months, inequalities between sites in technology access, and poorer health outcomes at one location.

The team implemented a workstation pump start model, allowing 20 patients to be onboarded daily. A Plan-Do-Study-Act (PDSA) cycle was used to implement, assess and refine the pathway using existing resources, capitalising on multidisciplinary team working and the QI embedded approach within the team.

The implementation successfully increased and equalised technology access across both sites. At Derby, pump use increased from 49% to 89.8% with median HbA1c improving from 57.5 mmol/mol to 53 mmol/mol. At Burton, pump use rose dramatically from 21% to 93.4% with HbA1c improving from 61 mmol/mol to 54 mmol/mol. Wait lists were cleared and newly diagnosed patients commenced HCL within three months of diagnosis. Patient and carer feedback was overwhelmingly positive, with families reporting life-changing improvements.

Future plans include using the PDSA approach to reassess the process as patient demand evolves to ensure continued relevance and effectiveness for a smaller cohort, alongside regional and national process sharing to support broader service improvement in paediatric diabetes technology provision.

Click here to see the full case study.

Case study: Removing the barriers in Hybrid Closed Loop (HCL) approval for high-risk young people with type 1 diabetes

Stockport NHS Foundation Trust

Stockport NHS Transition Young Adult (TYA) diabetes team removed all trust-specific eligibility criteria for hybrid closed loop technology, automatically approving any young

person meeting NICE guidelines. The team identified 13 high-risk young people (defined by HbA1c >95mmols, poor MDT engagement, frequent A&E attendances, recent DKA admissions, and irregular insulin use) and supported them through a tailored onboarding pathway including baseline blood tests, flexible MDT reviews, pump education sessions, frequent follow-up and six-monthly group sessions.

Results were substantial: HbA1c reduced by 54% on average, with no diabetes-related hospital or A&E attendances post-implementation and MDT appointment attendance reaching 92.3%. The work demonstrates that strict eligibility criteria may be detrimental to health outcomes and therapeutic relationships. Most high-risk young people adapted more effectively to diabetes management through HCL than through multiple pre-pump education sessions, with frequent, flexible contact proving key to success. The team emphasises that HCL should be accessible to all young people without additional barriers, and that holistic, non-judgemental care is crucial for this vulnerable cohort.

Click here to see the full case study.

Procurement and funding inequities

Variation in procurement processes across ICBs contributes to uneven device availability and delays in HCL rollout. GIRFT reviews identified avoidable inefficiencies, such as individual funding requests for newly diagnosed 16-18-year-olds despite NICE TA943 eligibility, annual reapplications for patients to have continued device funding, outdated Blueteq forms not aligned with NICE TA 943 eligibility criteria, and variable interpretation of the NICE TA. These practices create unnecessary bureaucracy and inequitable access. National and regional procurement frameworks already exist; consistent local engagement with these mechanisms can improve efficiency, streamline access, reduce variation and ensure cost-effective purchasing.

Onboarding and optimisation in paediatrics

Paediatric teams have achieved rapid and broad coverage of HCL therapy in a short timeframe. However, there is wide variation in both the timing and the process of onboarding. Some centres now initiate HCL from diagnosis during the first admission, recognising that this supports equity and gives young people the longest possible period to build confidence, stability and effective self-management before transfer to YA care.

Elsewhere, onboarding occurs later, in some services at a planned timepoint and, in others, varying by individual clinician or patient circumstances.

Processes also differ in the structure and content of early education, the extent of developmental tailoring, and the frequency and methods used to support people in the initial stages of using HCL.

Young people who have been established on HCL for several years are more likely to transition to adult care with lower risk of destabilisation. In contrast, later or inconsistent onboarding and optimisation can mean young people reach transfer without being fully stable or confident in using their system. This increases pressure on already stretched young adult services and reduces their ability to provide the support young people need at a critical time.

Earlier and more consistent onboarding and optimisation in paediatrics, planned with the capacity pressures of adult services in mind, gives young people the time and support needed to achieve stable, effective use before transfer and reduces avoidable pressure on receiving teams.

Case study: CYP Diabetes Team start all CYP with new T1 diabetes on HCL at diagnosis

University College London Hospitals NHS Foundation Trust

University College London Hospitals has successfully implemented HCL technology as first-line treatment for all CYPs diagnosed with type 1 diabetes. The service established a care pathway enabling patients to commence HCL therapy within days of diagnosis and to be discharged from hospital using the technology, addressing the challenge of ensuring equitable access while managing existing pump users and newly diagnosed patients requiring time for treatment decisions.

The implementation required ensuring availability of pumps and sensors, developing a first-year care pathway led by nursing and dietetic teams, delivering multidisciplinary staff training, including ward personnel, maintaining ready equipment supplies, and establishing standardised procedures for diagnosis and follow-up.

From 2021 to 2023, 54% of newly diagnosed CYPs elected to start HCL at diagnosis. Since 2023, this increased to 100%, with all new type 1 patients discharged on HCL systems. Median HbA1c levels have remained consistently below the national average

throughout this period, and no increase in length of hospital stay was observed. Staff knowledge and confidence in HCL technology and diabetes management increased across all professional groups.

This model demonstrates that offering advanced diabetes technology at diagnosis is clinically effective and operationally feasible within an inpatient setting. The approach has successfully reduced health inequalities by providing universal access to technology independent of socioeconomic factors, without reliance on industry representatives for patient training.

Click here to see the full case study.

Under-resourced young adult services

Rapid expansion of HCL use in paediatrics means increasing numbers of young people are entering adult services already established on advanced technologies. This growing cohort, combined with the next phase of prioritisation in the five-year implementation strategy, is placing significant pressure on young adult pump services. Although 41 ICBs responded that they support continuation of the technology prescribed in paediatric care following transfer to adult care,[58] under-resourced teams cannot consistently deliver the frequency of clinical review required for optimal outcomes. They also lack the capacity to respond to additional reviews at the point of need, which is essential for maintaining safety during a period of heightened vulnerability. Future-proofing young adult services for modern diabetes care requires deliberate succession planning, redesigned pathways and sufficient capacity for data review, device optimisation and sustained patient support.

Case study: The effect of a dedicated diabetes YA service on HCL

Stockport NHS Foundation Trust

Stockport NHS Foundation Trust's Young Adult Diabetes team streamlined hybrid closed loop approval for 19 to 25-year-olds, addressing long waiting lists, limited pump showcases, outdated pathways and restricted specialist nurse working hours. In 2024, the

[58] *GIRFT pre-visit questionnaires (2024 and 2025)*

team actively populated pump discussion lists with eligible young adults, and in 2025 gained authority to host independent pump showcases and group starts.

Results were dramatic: young adults aged 19-25 discussed for HCL at MDT meetings increased from two in 2023 to 52 in 2024, with HCL uptake rising from 26% to 88% within 16 months. The work demonstrates that rapid HCL adoption is possible and sustainable, even with a single diabetes specialist nurse, disproving the belief that patients need years of 'good enough' diabetes management before commencing HCL.

Patient feedback emphasised the importance of timely access, with one young adult describing years of depression from being told to wait and finally feeling listened to when immediately accepted. The team emphasises that delaying transition to modern approaches maintains the mental burden of diabetes, increases complication risks, and may cause patients to miss opportunities. Young adults eligible for HCL should experience minimal delays, with disciplined urgency enabling successful transition of large groups from multiple daily injections to HCL.

Click here to see the full case study.

Workforce confidence and capability

Effective use of HCL depends on the confidence and capability of specialist diabetes teams across both paediatric and adult services. The rapid pace of technological development means that all MDTs require protected time and structured, regularly updated training to maintain skills in onboarding, troubleshooting and optimisation. Many adult teams report limited baseline experience with HCL systems and associated digital platforms, while paediatric teams are working to keep pace with evolving devices and software within limitations of existing job plans.

Joint training[59] that brings paediatric and adult teams together offers opportunities for cross-system learning, consistent optimisation approaches, smoother transition and shared messaging for families. It is also more cost-effective, reducing duplication of training content and effort across services. As HCL becomes routine in paediatrics, adult teams need the capability to support young people who are already experienced users of advanced

[59] *DTN-UK, Hybrid Closed Loops (HCL) Educational Videos, https://abcd.care/dtn-education/hybrid-closed-loops*

technologies, while paediatric teams require continued managerial support to sustain high-quality optimisation from the outset.

Realising the full clinical benefit of pumps, CGM and HCL, and the system's return on investment depends on specialist MDT input for onboarding, optimisation and sustained use. Services without the training, capacity or structured follow-up needed to provide this support often see lower or inconsistent gains, even when device uptake is high. Without the clinical time and expertise required to help families use these tools effectively, technology-enabled care can widen inequalities rather than reduce them. Equitable access therefore relies not only on consistent commissioning and device availability, but also the specialist support needed to help CYA use these technologies safely, confidently and to their full potential.

Training for non-specialist teams

As HCL use expands across all care settings, non-specialist colleagues such as primary care clinicians, inpatient ward staff, surgical teams and emergency departments need a basic understanding of how these systems work. Without this foundational knowledge, variation in how non-specialist teams respond to HCL is a likely contributor to inconsistent care. This includes familiarity with the core components and knowing when to seek advice from specialist teams or when it may be safest to revert temporarily to manual insulin delivery. Embedding these core safety principles into routine HCP training will ensure safe, consistent care and reduce reliance on families in high-pressure situations.

Infrastructure limitations

When asked "Do all of the trusts clinics have on site facilities to download information from insulin pumps, continuous glucose monitors and blood glucose meters in time for the results to be discussed at their clinic appointment?" most services responded positively, paediatric services (yes 98%) and young adult services (76% yes, and 17% some). However, review discussions highlighted that although industry platforms for CGM, pump and HCL data are generally robust, their performance is often compromised by poor connectivity, slow network speeds and outdated IT systems within NHS hospital and community settings. These limitations mean that data upload and cloud-based tools for reviewing glucose, insulin and device data, often fail to load or function reliably on NHS networks. When systems cannot run in clinic, staff and families are unable to set up or activate devices, complete onboarding, configure alerts, personalise settings, or synchronise data to make safe dose adjustments. This prolongs review time, slows optimisation, reduces clinic efficiency and delays decision-

making, with implications for patient safety. Fit for purpose infrastructure, including stable, high-speed Wi-Fi, modern hardware and reliable connectivity, is crucial for these technologies to work as intended.

Data capture

Reliable data capture is essential for understanding inequalities in uptake and outcomes from HCL use. Incomplete demographic information and inconsistent submission to national datasets limit the ability to monitor equity, evaluate improvement and determine NHS England reimbursement contributions to systems. GIRFT reviews highlight frequently missing ethnicity data, which restricts meaningful segmentation and hinders analysis of health inequalities.

Robust and routine data collection is needed to track implementation, measure outcomes and inform funding decisions. Services should develop local systems that capture a single core dataset, integrate device information with clinical records and ensure accurate submission to the NPDA, NDA and ICBs. Processes are also required to keep device information current, reflecting changes in pump or CGM models, software versions and connectivity status, so that clinical records and audit data remain accurate.

Information governance (IG) compliance must underpin all data-sharing arrangements, with agreements in place between providers, ICBs and national bodies, and processes that meet NHS data-security standards while enabling timely flow of information. Efficient, aligned data processes minimise administrative burden while supporting high-quality audit, reimbursement and service evaluation.

Out-of-hours support

Young people using HCL technology may encounter issues outside routine clinic hours. Without timely advice, problems can escalate, leading to device discontinuation, safety concerns or avoidable admissions. Systems should work with technology providers and diabetes teams to establish reliable out-of-hours advice lines or shared regional rotas to ensure consistent access to support.

Families need clear guidance on emergency protocols and basic troubleshooting, including how to recognise and respond to device alerts, manage interruptions in insulin delivery, switch to back-up insulin regimens if required, and understand when and how to escalate concerns. Most importantly, they should know who to contact, at what point, and for which types of problems, with simple, unambiguous instructions that reflect local arrangements.

Families should also be equipped with handheld information (printed or digital) summarising device settings, insulin doses, and recent glucose trends, which can be shared with unfamiliar healthcare professionals when digital platforms are inaccessible.

4	Roadmap of actionable steps to reduce variation in access and outcomes from Hybrid Closed Loop Therapy
	Embed early onboarding and optimisation of HCL in paediatric care to support safe transition to adult services and lifelong use ▪ **Establish HCL as the recommended first-line therapy for CYP with type 1 diabetes,** ensuring onboarding is initiated as early as clinically appropriate. Record onboarding dates, waiting times, and completion of structured optimisation steps to ensure timely initiation and monitor equity. ▪ **Ensure CYP who choose injections or stand-alone pump therapy receive equivalent quality of care** with documented education, structured review schedules and access to appropriate support for their chosen therapy, so they are not disadvantaged in review frequency or outcomes.
	Build workforce confidence and capability across all services ▪ **Implement joint paediatric-adult MDT training programmes**, using structured and standardised education packages, covering device functionality, optimisation, data interpretation and troubleshooting, to ensure consistent capability and messaging across transitions. ▪ **Provide protected time for regular technology-focused learning**, ensuring teams across all services can keep pace with evolving systems and maintain up-to-date skills. Maintain a training register documenting attendance, completion and required refresh cycles.
	Ensure digital infrastructure is fit-for-purpose to support safe and efficient HCL care ▪ **Provide stable, high-speed Wi-Fi, modern hardware and reliable IG compliant access to cloud-based data platforms and apps** across hospital and community settings. Audit connectivity, device compatibility and access rights at least annually to ensure clinicians can review data and make safe dose adjustments without delay during both in-person and remote reviews.
	Strengthen system-wide safety nets for HCL users ▪ **Equip non-specialist healthcare teams** in community, primary care, urgent care, surgical and inpatient settings with basic familiarity of HCL systems, supported by clear guidance and decision-support tools. Training should clarify when HCL can be safely continued, when temporary reversion to simple insulin management is safer, and when to escalate to specialist teams. ▪ **Ensure primary care prescription records retain essential items for emergency use in case of technology failure**, including back-up insulin, pens, needles and ketone testing supplies. These items should be kept in date and reviewed at least annually or after any therapy change.

- **Provide patients with written, up-to-date emergency plans**, covering technology failure, sick-day rules and when to seek urgent help.
- **Give clear guidance on accessing urgent clinical and technical support** so device, connectivity or algorithm-related issues can be resolved safely, continuity of technology can be maintained where appropriate, and unnecessary escalation to urgent or emergency care is avoided. Services should ensure that CYA and families understand the appropriate routes for advice and support, within and outside routine hours.
- **Monitor call volumes and outcomes for technology-related queries** to assess service safety and identify recurring themes. Use this intelligence to strengthen onboarding and optimisation processes, and to inform preventative actions to reduce avoidable escalation to urgent or emergency care.

Address inequalities and support inclusion in digitally enabled care

- **Apply NICE TA criteria consistently across all services**, with documented decision-making processes to ensure access is not influenced by healthcare bias (such as assumptions about motivation or capability), or by the greater advocacy confidence of some families. Audit approval rates and waiting times by demographic group.
- **Use disaggregated data** (age, ethnicity, deprivation, language, SEND, neurodiversity and other relevant characteristics) to identify and act on disparities in uptake, discontinuation or outcomes, and monitor progress. Review these data at least quarterly and document actions taken.
- **Ensure financial or digital barriers** never prevent CYA from taking up or safely using HCL by providing access to compatible phones, data, connectivity and other essential digital equipment. Assess and document digital-access needs at onboarding and routine reviews, recording unmet needs and actions taken.
- **Increase optimisation support for groups who currently experience, or are at risk of experiencing, reduced benefit from HCL.** Use defined metrics to identify where benefit is suboptimal so that HCL implementation narrows, rather than widens, inequalities in long-term diabetes outcomes.
- **Ensure CYP can use their HCL systems confidently and inclusively** in nurseries, schools and colleges, by equipping staff with practical training and clear guidance. Make explicit that these devices constitute essential medical equipment and must be permitted even where general phone restrictions apply, in line with statutory duties to support pupils with medical conditions.

Plan for sustainable long-term commissioning and funding of HCL beyond the national support period

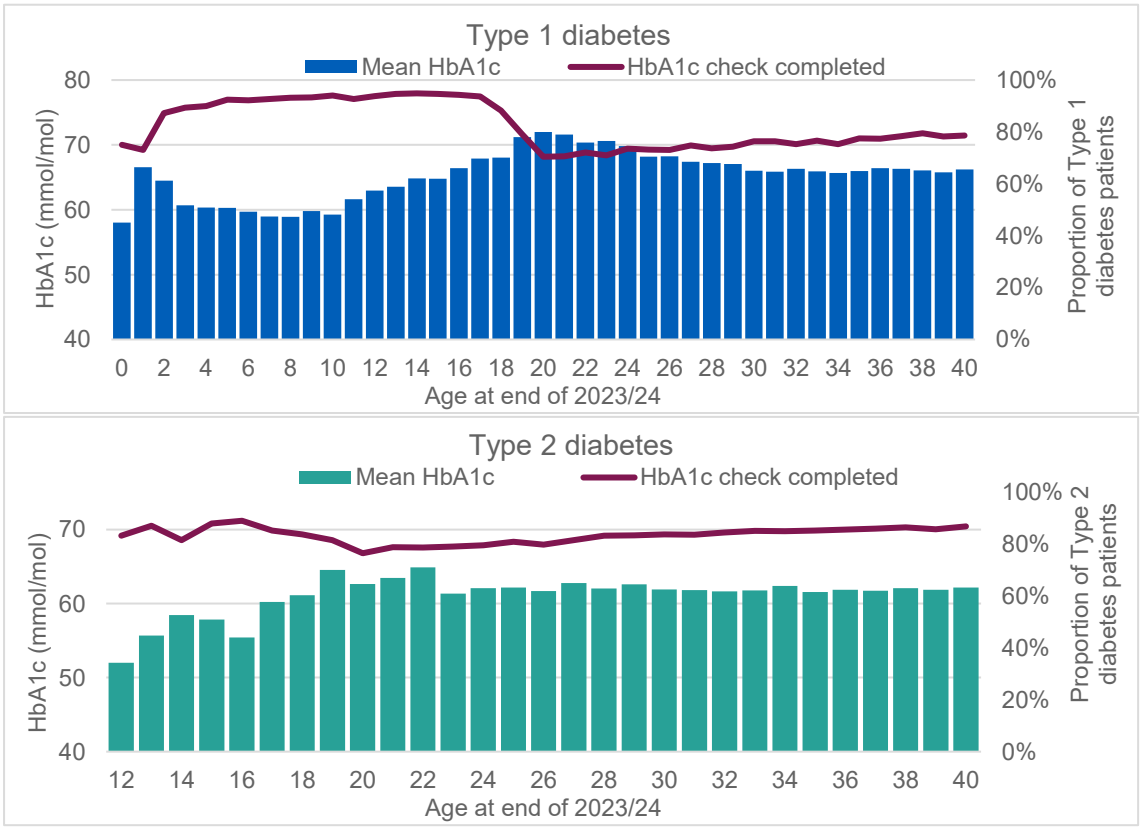
- **Ensure ICBs develop and publish a sustainable commissioning and financial plan for HCL therapy beyond March 2029**, when national funding ends. Plans should model future eligible cohorts, identify recurrent budgets to meet NICE TA requirements, and set out provision for consistent onboarding, optimisation and ongoing support across all services. Progress should be reviewed annually through documented updates to financial plans and activity forecasts.

Domain 5: Variation in young adult care

Young adulthood (16–25 years) is a pivotal and vulnerable phase for individuals living with diabetes. It coincides with major life transitions including leaving education, entering employment, gaining financial independence, adjusting to new living arrangements, all while taking on greater responsibility for self-management. During this period, support from carers typically reduces and the transfer from paediatric to adult services introduces substantial changes in service design and expectations. This shift can disrupt continuity, leading to loss of contact, challenges with glycaemic stability, and increased risk of emergency admissions and long-term complications.

Young adults aged 19-25 represent a high-risk cohort, with lower care process completion (figure 17), and higher average HbA1c than children (figure 28). In addition, diabetes-related hospital admissions (figure 25) rise during adolescence and young adulthood. This pattern does not reflect age-related decline (outcomes for older adults are better), indicating that factors beyond biology, including how current service models are organised and accessed during this life stage, may contribute. Matching care to individual risk and complexity is therefore critical to support glycaemic stability and prevent long-term complications.

Figure 28: Average HbA1c in 2023/24 by diabetes type and age alongside HbA1c health check completion rates. (Excludes HbA1c measures taken with 90 days of diagnosis date)



Source: NPDA and NDA combined data 2023/24

With flexible, inclusive and psychologically informed service design, care can be made more continuous, equitable and empowering. Young adults should be supported to thrive, not left to fall through the gaps, or rely solely on self-advocacy to access the care they need.

Transition and pre-transfer preparation

Transition is intended to be a phased and supported journey of preparation that begins within paediatrics and continues over a meaningful period of time, gradually introducing young people to the teams, expectations and processes of adult care. Ideally, between ages 16 and 18, young people should attend co-ordinated clinics involving both paediatric and young adult teams, allowing them to build early relationships, understand how adult services work, and develop confidence in managing their condition with increasing independence. The pace of this journey should be flexible and personalised, guided by emotional readiness rather than fixed age thresholds. When the transition period is too short, inconsistently delivered, or insufficiently focused on relationship-building, young people may reach the end of paediatric care without being fully prepared for the expectations and autonomy of adult services, increasing vulnerability at the point of transfer.

In practice, transition models vary widely, particularly in the extent to which young people have structured contact with the young adult MDT before transfer: 85% of paediatric services said their trust has a transition policy, but only 78% of those said their policy aligns with NHS England's service specification for diabetes transition.

Timing of transfer to young adult services

Transfer marks the point at which responsibility moves from paediatric to adult services. Ideally, transfer should occur when the young person has been adequately prepared, is developmentally ready and when the adult service is able to receive them, ensuring a seamless handover and rapid continuity.

In reality, transfer timing is often shaped by service pressures rather than individual readiness. Young people may be discharged from paediatrics before they feel equipped to navigate adult care, and adult teams may not have the capacity or processes in place to receive them promptly. This can result in weak or incomplete handovers and delays to first appointments. These factors heighten the risk of disengagement and clinical deterioration at a critical time when consistent relationships and clear support are not firmly established.

Change in minimum care standards from paediatric to young adult care.

Paediatric BPT criteria define minimum care standards such as access to MDT input (including psychological support), structured education, and an expected frequency of clinic follow-up, and interim contacts. Local pathways differ in the age at which paediatric diabetes services end, with some areas transferring YP at 18, and others as early as 16. Transferring at a younger age, whether due to paediatric capacity constraints, provider service model structure or age cut-offs, brings an earlier step-down in care intensity. Separately, where BPT components have not been fully delivered in paediatric services, YP transfer with less optimisation. Both factors reduce readiness for adult care and increase the risk of deterioration after transfer, contributing to variation in outcomes during early adulthood.

Although the BPT is intended to support delivery of minimum standards up to age 19, these standards are rarely maintained once young people move to adult services before that point. Receiving adult teams are frequently unable to provide the required MDT access, psychological input, appointment frequency or interim contacts, even in late adolescence. This creates avoidable variation in the level of care available at a time when young people are most vulnerable to deterioration in glycaemic stability.

Developmentally appropriate service design

Standard adult diabetes services are typically designed around the expectations and priorities of older adults, and therefore often do not align with the developmental stage, life pressures or support needs of 19-25 year olds. This misalignment creates barriers to engagement and contributes to poorer outcomes.

Many adult services also lack the capacity to provide cohorted or dedicated young adult provision, meaning young people are absorbed into pathways built for much older populations. This limits the ability to tailor expectations, pace and communication to the realities of young adulthood.

Services need to adapt to the pressures of this life stage – exams, employment transitions, caregiving responsibilities and fluctuating emotional resilience – rather than expecting young adults to fit rigid adult service structures. Flexible scheduling, drop-in clinics, virtual options and peer-informed group sessions all contribute to developmentally appropriate care. Systems should routinely evaluate appointment formats and seek feedback to ensure services reflect young adults' preferences, clinical risks, and life-stage realities.

Case study: Promoting enhanced accessibility and support for young adults

Mersey and West Lancashire Teaching Hospitals NHS Trust

In response to rising complications and disengagement among young adults with diabetes, St Helens and Knowsley Teaching Hospitals (STHK) implemented a targeted accessibility initiative in September 2023. The programme introduced a dedicated mailbox and an urgent access clinic, designed to provide rapid, flexible support outside conventional appointment structures. The mailbox, monitored daily (excluding weekends), offers timely guidance between appointments. A standard operating procedure ensures efficient triage, with urgent cases referred to the rapid access clinic within two weeks. The clinic operates virtually or in person, integrated into existing schedules with no additional staffing, offering 12 sessions monthly.

This model addresses key challenges: increasing mental health needs, barriers to traditional care access, and the growing complexity of diabetes management due to advanced technologies. It provides an additional entry point for young adults with reduced participation or who require support before their next scheduled review, helping to reduce avoidable hospital admissions and long-term complications.

Patient feedback highlights improved confidence, engagement and satisfaction, with comments noting the supportive nature of staff and the value of feeling heard and supported. The initiative is promoted through the young adult diabetes care leaflet, ensuring awareness and ease of access.

Key achievements include:

- Improved access and timely intervention through 12 monthly clinic sessions.
- Enhanced patient engagement and reduced emergency service pressure.
- Increased satisfaction and self-management confidence among young adults.

Lessons learned emphasise the importance of age-appropriate communication, service flexibility and safeguarding patient data. The model demonstrates how low-cost, integrated solutions can improve outcomes and experience for young adults with diabetes, offering a scalable approach for other systems seeking to strengthen continuity and responsiveness in transitional care.

Click here to see the full case study.

Relational continuity and engagement support

Relational continuity is a critical component of effective young adult care, yet many services lack the structured roles that help young people stay connected as they move through adult pathways. Roles such as youth workers, family support practitioners, named key workers and peer networks provide emotional safety, practical guidance and age-appropriate advocacy. They help young adults understand new expectations, navigate increasing independence and maintain engagement during a period of unstable life circumstances and competing demands.

In many systems, however, these roles are not formalised or consistently integrated into MDTs (figure 15). Only 37% of young adult services ensure patients have a named key worker.[60] Without this relational support, young adults can struggle to maintain continuity even when individual clinicians are stable and committed.

These roles also provide the practical scaffolding that enables young adults to access care, supporting appointment management, prescription collection, and completion of essential annual health checks with minimal burden.

Embedding relational roles as core elements of young adult diabetes care supports smoother transitions and creates a more relationally attuned service model. When delivered through trauma-informed approaches, they further enhance emotional safety, reduce re-traumatisation and strengthen young people's ability to remain connected to care, particularly for those with complex or adverse life experiences. Their stabilising and preventative function also helps reduce escalation of diabetes related distress and lowers demand on scarce specialist psychological professional resource.

Pathway clarity and co-ordination

As young adults move toward greater independence, they often encounter uncertainty about where and how their annual diabetes health checks will be delivered. Some elements of routine care sit in primary care, others in specialist services; without clear co-ordination this can lead to delayed, missed or duplicated tests, and confusion about who is overseeing their care. Pathways may also vary between areas or depending on which part of the system a

[60] *GIRFT pre-visit questionnaires (2024 and 2025)*

young adult is registered with, adding further complexity at a time when predictability is essential.

Clear, well-co-ordinated pathways help young adults understand where each element of care takes place, how these will be arranged and who is responsible for each element of care. Transparent expectations reduce cognitive load and support consistent, reliable care during a period of significant life transition.

Place of care

Decisions about care location are often shaped by local capacity, workforce pressures and historical service configurations, rather than individual clinical need or psychosocial risk. As a result, young adults may be placed in primary, community or specialist settings that do not always match the complexity of their condition or the level of support required.

For this age group, care must be both accessible and delivered with the specialist expertise needed to manage clinical vulnerability, psychosocial complexity, and the demands of emerging independence. Follow-up frequency and review intensity vary not only between settings but also within the same setting across different localities. In some areas, primary or community services offer fewer reviews and limited MDT input; in others, they provide more regular contact than specialist clinics. This system-driven variation means that access to technology, specialist therapies, monitoring, optimisation and timely treatment intensification can differ markedly depending on where a young adult is registered.

Aligning care location with individual requirements is essential for delivering safe, equitable, and responsive young adult diabetes care.

Preventing loss to follow-up

Many young adults become lost to follow-up during or after transition, particularly when life circumstances are unstable and competing demands make attendance difficult. Discharge policies that are automatically triggered by missed appointments can be punitive and disproportionately affect those with the greatest clinical and psychosocial vulnerability.

Preventing loss to follow-up requires services to avoid automatic discharge and instead prioritise maintaining contact through flexible, non-judgemental approaches. GIRFT questionnaire data shows that 51% of young adult services do not collect information on

repeat DNAs.[61] Proactive strategies, such as active case finding of missing patients and targeted outreach by youth or community workers, are especially effective for high-risk groups, ensuring that young adults who disengage are identified early and offered a route back into care.[62]

Offering alternative appointment formats, and support at times and locations that fit young adults' lives can help sustain engagement.

Flexible pathways into and out of specialist services

Adult diabetes pathways are often rigid and poorly aligned with the fluctuating realities of young adulthood, where clinical and psychosocial needs can change rapidly. Pathways must therefore allow young people to move back into specialist care when their level of need increases, rather than being constrained by system inertia.

Vulnerability is multidimensional and dynamic. Risk stratification should consider HbA1c trends, DKA episodes, psychosocial factors, social determinants, and eligibility for technologies and specialist therapies. Patterns of reduced attendance or missing data on care metrics should also be interpreted as indicators of increased need, not as non-compliance.

Systems should ensure that young adults receive the level of support that matches their evolving circumstances.

Tailored care for type 1 diabetes

Young adults with type 1 diabetes face needs that are particularly common and consequential during this life stage, including pregnancy planning, driving safety, recreational drug use and managing the emotional demands of intensive self-care. These require timely proactive clinical assessment and access to diabetes technologies such as CGM, insulin pumps and HCL systems. Access should be driven by clinical need, rather than self-advocacy, digital fluency, or the ability to navigate complex systems. Healthcare professionals must take the lead in identifying eligibility and ensuring equitable provision.

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[61] *GIRFT pre-visit questionnaires (2024 and 2025)*
[62] *T Balafshan, H Sullivan, S Keigan, Amanda Wilson, Ifeoluwa Oyedeji, Revolutionising young adult diabetes care: a patient-centred transformation to improve access, engagement and outcomes in one of England's most deprived areas, Future Healthcare Journal, Volume 12, Issue 2, Supplement, 2025, 100431, ISSN 2514-6645, https://doi.org/10.1016/j.fhj.2025.100431.*

Meaningful technology use depends on referral to services that can onboard effectively and have the capability to view and interpret cloud-based data and therapy metrics routinely, enabling timely adjustments and ongoing support. This is essential to ensure that high-cost technologies deliver maximum personal benefit. 21 of 114 trusts reported they had no dedicated young adult service[63] leaving many eligible young adults without access to specialist care or advanced technologies (figure 13).

Systems should audit records to identify eligible individuals and address gaps such as missing HbA1c data. Primary care has a vital role, as it is often the point of contact for young adults who have disengaged from or never entered specialist services. It is therefore well placed to identify unmet need, initiate referral and support continuity of technology use or those managed outside secondary care.

Urgent escalation for type 2 diabetes

Early-onset type 2 diabetes is particularly aggressive, with complications often present at diagnosis. Effective care must be equity-driven, recognising biological risk is compounded by socioeconomic disadvantage and that delays in treatment intensification widen existing inequalities.

Young adults with type 2 require prompt access to health checks, rapid diagnostics, proactive treatment intensification and structured education, including support for weight management. Yet only 41% of young adult services provide an individualised education programme for those newly diagnosed, indicating that even specialist services are not consistently delivering the full range of evidence-based support.

Care closer to home is appropriate only when neighbourhood settings can provide MDT input, including diabetes specialist nurses, dietitians and psychological support, and have the diagnostics, monitoring infrastructure and clinical expertise to initiate and optimise therapies such as GLP-1 receptor agonists and SGLT2 inhibitors. In many systems these therapies are initiated only in secondary care, creating delays for young adults managed primarily in general practice. Digital-first recall systems and monitoring pathways can further disadvantage those who cannot access or navigate them, increasing the risk of missed reviews and delayed treatment intensification.

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[63] *GIRFT pre-visit questionnaires (2024 and 2025), excludes specialist paediatric only trusts*

Primary care is often the first or only point of contact for young adults who have disengaged from specialist services. Clear referral routes, timely access to specialist clinical advice and system-level support to complete overdue health checks are essential to ensure that unmet need is recognised early and care escalation is not delayed. Primary care should be enabled, not expected, to manage this complex, high-risk group in isolation.

Treatment intensification should not be reserved for crisis points. Systems must ensure that young adults can access timely, expert-led care, wherever they are registered.

Diagnostic ambiguity and maturity-onset diabetes of the young (MODY)

Diagnostic ambiguity between MODY, a form of monogenic diabetes, and type 2 diabetes is common in young adults. Without access to teams who can interpret atypical presentations, assess family history and arrange genetic testing, individuals may receive inappropriate treatment for years and miss opportunities for cascade testing. Although MODY accounts for only 1–2% of all diabetes cases, an estimated 80–90% of individuals are initially misdiagnosed.

This highlights a critical gap in young adult care: the need for clearer referral pathways, timely specialist assessment, and greater awareness of when monogenic diabetes should be considered. Limited access to diagnostic testing, particularly from primary care, can delay accurate classification. Ensuring timely testing enables personalised treatment, avoids prolonged use of ineffective or unnecessary therapies, and supports family members through appropriate genetic counselling and cascade screening.

Psychological support in young adulthood

Young adulthood is a recognised period of psychological vulnerability, with higher rates of anxiety, depression, and emotional distress. For those living with diabetes, these pressures are intensified by increasing self-management demands, the loss of familiar paediatric support structures and the reduced day to day involvement of caregivers.

Only 35% of young adult services offer an annual wellbeing assessment.[64] Irregular screening means emerging difficulties are often missed until they escalate. Access to support is frequently limited, delayed or delivered by professionals who may not recognise diabetes related distress, or the risks associated with fluctuating capacity for self-

[64] *GIRFT pre-visit questionnaires (2024 and 2025)*

management. Trained psychological professionals with diabetes expertise bring essential understanding of the condition's cognitive, behavioural and emotional demands, expertise that general mental health services often lack. Their limited availability leaves many young adults with unmet needs and worsening distress. Embedding dedicated mental health professionals within diabetes teams is therefore critical, particularly during transitions, periods of disengagement, or when complex social circumstances intensify the burden of self-management.

Safety during geographical mobility

Moves for education, employment or housing frequently disrupt communication, monitoring and continuity of care. Delays in registration, referral and transfer of clinical information are common, and young adults may struggle to access essential medications, technologies and supplies when moving between regions. These risks are compounded by variation between ICBs in prescribing processes, technology ordering systems, and local eligibility criteria, creating uncertainty and gaps in care. To ensure safety, ICBs must establish shared responsibility between 'home' and 'host' providers, with clear protocols for cross regional referrals, timely record sharing, and continuity of prescriptions, monitoring and structured education.

Digital tools and peer support

Consistent access to endorsed digital resources is especially important during young adulthood. Platforms such as DigiBete[65] and YoungType2.org[66], widely used in paediatrics, remain underused in this age group despite their distinct value at a time when other support structures are changing. Limited time, capacity and operational support mean many services do not routinely embed these digital tools into routine young adult care pathways, leaving young adults unaware of resources that provide personalised education, emotional support, culturally tailored content, and direct connection to the clinical information used in their care. Features such as the 'Connect' button link young people to local events, peer networks and support opportunities in their area, and early signposting can reduce isolation and strengthen engagement.

[65] *DigiBete, https://www.digibete.org/*
[66] *T2Digibete, https://www.youngtype2.org/*

Only 28% of responding young adult services said they offer access to peer support.[67] Peer support programmes such as Diabetes UK's Together Type 1[68] offer relatable role models and youth-focused support in every region. However, integration with clinical pathways is often inconsistent, largely because clinical teams have limited time and capacity to make proactive connections, rather than any gap in the support available. Strengthening collaboration between services and these established programmes would ensure more young adults benefit from what is already in place.

Case study: DigiBete implementation to enhance CYA service engagement and communication

Royal United Hospitals Bath NHS Foundation Trust

The trust implemented the DigiBete platform to improve engagement and communication with young adults aged 18–25 years with diabetes, a critical transition period when engagement often declines and traditional communication methods fail to reach this digitally-native population effectively.

The team created a young adult clinic homepage featuring useful links, clinic information and team details. The clinic access code was integrated into transition handouts and initial letters sent to all 18 to 25-year-olds in the service. Ongoing engagement is supported through systematic verification of clinic code access during appointments, with the broadcast feature used to share updates and advertise Together T1D local events and artwork workshops.

The implementation has established a sustainable digital communication channel, reducing reliance on verbal instructions or paper-based communication. Integration into transition processes ensures systematic onboarding, while the broadcast feature enables efficient communication and connects young people with peer support and creative opportunities. The model demonstrates how digital platforms can enhance accessibility and engagement in routine clinical pathways.

[67] *GIRFT pre-visit questionnaires (2024 and 2025)*
[68] *Diabetes UK, Together type 1, https://www.diabetes.org.uk/support-for-you/community-support-and-forums/type-1-youth-programme*

Addressing health inequalities

Young adults facing socioeconomic disadvantage, digital exclusion or limited support experience disproportionate challenges during a life stage already marked by heightened clinical and psychosocial risk. Instability in care structures during transition and transfer can further disrupt access to monitoring, specialist input and essential technologies, amplifying existing inequalities. These structural vulnerabilities contribute to lower completion of care processes, delayed treatment intensification and widening gaps in outcomes for young adults from deprived or ethnic minority backgrounds. Tailored interventions must therefore address systemic and structural barriers through inclusive, culturally sensitive care that recognises and responds to the diverse needs of young adults.

Neighbourhood health factors, transport, proximity to services, digital connectivity and the availability of community-based support, strongly shape whether young adults can access routine care. Moving care closer to where young adults live is beneficial only when neighbourhood-based services are equipped with MDT expertise, diagnostics and technology, or have clear reliable pathways into specialist care when required. Greater use of digital tools, including remote interim reviews and virtual consultations, can help bridge the gap where geography or circumstance would otherwise prevent timely access, provided that young adults have the connectivity, devices and the confidence to engage with them. Without this combination of local capability and digital enablement, shifting activity out of hospital risks maintaining or even widening inequalities rather than reducing them.

5	**Roadmap of actionable steps to reduce variation in young adult care (19-25 years)**
	Design young adult care pathways that are intentionally tailored to life-stage needs ▪ **Define and publish a young adult pathway specification** that sets out the core minimum standards, core components of care for each diabetes type, including review schedules, expected MDT involvement and the level of treatment intensity required to match the clinical and psychosocial risk profile of young adults aged 19-25. ▪ **Provide appointment options that meet the needs of young adults.** Offer flexibility with appointment scheduling and multiple review formats, including in-person, telephone and video, to accommodate different circumstances. Monitor uptake and waiting times across formats to ensure access is equitable and responsive, without assuming extended hours alone will improve outcomes. ▪ **Ensure same-week review availability** for young adults requiring rapid support, with simple access routes such as drop-in or direct booking without complex navigation. Track utilisation and timeliness to ensure responsiveness.

Align care intensity, service capability, expertise and place of care to young adults' clinical and psychosocial needs

- **Define the required intensity and standards of care for young adults** at different levels of clinical and psychosocial complexity and by diabetes type, including the MDT expertise, specialist technologies, therapies, diagnostics and digital / IT infrastructure (such as cloud-based data platforms). These requirements should determine the appropriate place of care, ensuring that service capability is aligned to need rather than local configuration. Apply them consistently across the ICB so that every young adult receives care in a setting equipped to deliver the level of support their risk profile requires.
- **Define and communicate thresholds for escalation, de-escalation and movement between services**, ensuring they are applied consistently and all changes in place-of-care decisions are clearly documented in the shared patient record.
- **Equip community and primary care teams delivering young adult care with the required training,** named specialist contacts and agreed routes for advice and joint reviews needed to deliver safe, high-quality care close to home. Clear pathways should ensure that when a young adult's needs exceed local capability, timely access to specialist expertise is available without delay.

Ensure every young adult understands their care pathway and how to navigate it

- **Give each young adult a personalised written or digital care overview** that maps their care and sets out expected review frequency and required care processes, where different elements of care take place and how services co-ordinate, named contacts for routine reviews and prescriptions, accessible points of contact for urgent advice and crisis management, the actions the young adult needs to take independently, and what to do if their care is delayed.
- **Use a standardised onboarding conversation or checklist** at entry to adult services to confirm understanding of roles and responsibilities, escalation routes, and how to use their care overview to navigate appointments and contacts in practice.
- **Provide a single, reliable point of contact** (email, phone, or portal) for queries about appointments, prescriptions and care co-ordination**.** Monitor response times and query themes to identify system gaps.

Embed relational continuity, engagement and navigation support, and proactive processes to prevent loss to follow-up

- **Assign each young adult a named navigator, youth worker, or key worker** who provides consistent relational continuity and support for practical navigation of appointments, care processes, and prescriptions, with a developmental focus to build confidence over time in the ability to manage care in adult services independently.
- **Implement a proactive follow-up protocol for missed appointments,** including repeated contact attempts using multiple channels, flexible rebooking options and alternative review formats. Record all attempts and outcomes and

include clear safeguarding escalation where repeated non-attendance or inability to contact indicates potential concern.

- **Run regular (e.g. monthly) case-finding reports** to identify young adults overdue for reviews, prescriptions or essential checks, with documented follow-up actions and escalation where needed.

Ensure seamless continuity of care during geographical mobility

- **Create a standard transfer-of-care process** for temporary or permanent moves, including transfer of prescriptions and technology supplies, transfer of monitoring data, named contacts in both 'home' and 'host' services, and confirmation of next review date.
- **Ensure the home service retains clinical responsibility until the receiving service formally confirms acceptance** and has scheduled the young adult's first review. Where the young adult does not attend the arranged review, the receiving service must follow the agreed non-attendance and safeguarding protocol, with clear documentation and escalation where required.
- **Provide young adults who move back and forth between locations** for education, employment or housing with a concise information pack outlining how to access prescriptions, technologies, structured education and clinical advice while away from home, and the named contacts co-ordinating their care.

Embed digital self-management tools and peer support into young adult pathways

- **Embed NHS-endorsed digital tools** (e.g. DigiBete) within standard operating procedures, with clear pathway steps, workforce responsibilities, and documented demonstration and onboarding.
- **Record digital tool uptake and use** (e.g. app activation, platform registration, frequency of log-ins and use of key features) as part of the care process checklist, and review patterns at MDT or governance meetings to identify groups who are not engaging and may need additional support.
- **Establish routine integration between clinical teams and peer-support organisations,** with agreed referral routes and scheduled touchpoints (e.g. quarterly). Provide each young adult with information on accessible peer support options (e.g. Together Type 1, DigiBete Connect) and incorporate these into care plans, especially before periods of reduced in-person contact (e.g. university terms, employment transitions).

Domain 6: Variation in systems governance and workforce capability

Effective governance is essential to delivering safe, equitable and high-quality diabetes care for children and young adults. Because pathways span multiple settings, age transitions and providers, system-level oversight is required to ensure services are co-ordinated, adequately resourced and aligned with national standards. Integrated Care Boards (ICBs) play a critical role in reducing unwarranted variation, improving equity of access and upholding consistent care quality through clear accountability.

Across many systems, governance is weakened by fragmented commissioning arrangements, unclear accountability and inconsistent use of data. Siloed reporting between paediatric and adult services obscures risks at transition, and limited visibility of comparable outcomes across age groups makes it difficult to identify gaps or assure continuity of care. Variable application of the paediatric BPT and inconsistent monitoring of compliance further limit assurance that minimum standards are being delivered.

Workforce pressures compound these issues. Many teams lack the capacity, skill-mix and cross-system planning to meet rising demand, adopt new technologies and provide developmentally appropriate support.

Escalation of risk routes are often unclear, reducing opportunities for timely reporting and system-wide learning. Although national audit tools are well-designed, their potential is underused due to fragmented review processes and limited co-ordination across trusts and ICBs.

Strengthening governance, improving data oversight, aligning funding with service needs and embedding robust assurance processes are essential to support CYA and drive improvement across the pathway.

The RightCare diabetes toolkit,[69] developed specifically for children and young adults' diabetes care, provides a practical framework for system leaders to support oversight, benchmark against standards, and reduce unwarranted variation.

Governance structures and accountability

Governance arrangements for children and young adults (CYA) with diabetes remain fragmented across many ICBs. Oversight is typically split between paediatric (0-18) and

[69] *RightCare, Children and young people diabetes toolkit, 2025, https://gettingitrightfirsttime.co.uk/wp-content/uploads/2025/11/Children-and-young-adults-diabetes-toolkit-2025.pdf*

young adult (19-25) services, with few designated clinical or managerial leads spanning the full age range. This structural divide reduces continuity at transition points and limits routine sharing of learning across services, making it harder to identify and address risks that emerge at service boundaries.

ICBs should identify leads with strategic responsibility across the full age spectrum to support service development, workforce planning and performance monitoring. Formal structures should bring together paediatric and adult clinical leads, operational managers and commissioners to review performance and outcomes on a scheduled basis. Without integrated oversight, variation persists and system-level accountability is weakened.

Place of care decision-making criteria

Clinical pathways for CYA diabetes vary widely across and within ICBs. Risk-based criteria for determining place of care after transfer from paediatrics, referral routes and integration points for specialist therapies and new technologies are often unclear or inconsistently applied. As a result, decisions are frequently shaped by historical service design, capacity, or diabetes type alone, rather than by whether the setting can deliver the components of care required for the young person's level of need. In some areas, where a young person first presents effectively determines where they remain, with limited review of whether that service continues to be the most appropriate.

Standardised, risk-based pathways are essential to ensure that place-of-care decisions are driven by clinical and psychosocial need rather than default patterns of service use. This requires reliable, routinely collected data on place of care and movement between services, so that ICBs can monitor variation, identify mismatches between need and capability, and ensure young people receive care in settings with the expertise, resources and support necessary to meet their needs.

System-wide risk management, reporting and escalation

The review found that processes for identifying and responding to service-level risk are often unclear, informal or absent, and there is no consistent tiered risk-management framework for the 0-25 pathway. Reporting is not based on defined triggers or agreed escalation routes and rarely leads to structured follow-up or transparent feedback loops. In several areas, staff were aware that risks had been placed on a register but were not kept informed about planned actions, progress or reasons for inaction. System-level risks, such as workforce fragility, service gaps at transition, or persistent variation across providers, were also

identified, but these were not consistently escalated or addressed through ICB-wide governance processes. This limits the system's ability to escalate concerns effectively, act on emerging risks before harm occurs and ensure that actions are completed.

Payment, oversight and assurance of the paediatric Best Practice Tariff

There is significant variation in how the paediatric diabetes BPT is understood and applied across and within ICBs. Key elements are frequently misunderstood, including the misconception that it applies only to type 1 diabetes, the all-or-nothing nature of the payment, and the fact it does not cover technology or prescription costs. Approaches to calculating the tariff also differ, with some areas still using historical activity rather than current caseloads, leading to misalignment between funding and need.

Data to evidence compliance with BPT minimum care standards is not supplied or reviewed consistently, and commissioners often lack routine processes to verify delivery of the required components of care. As a result, there is limited assurance that standards, such as annual care process completion, timely follow-up, interim contacts, treatment intensification and access to the full MDT including psychology, are being met. Even where services achieve full compliance, this does not always translate into strengthened frontline capacity or resilience.

Funding flows from ICBs to trusts are not always transparent, and clinical leaders often have no visibility of what proportion of the BPT income reaches the service. This obscures whether the funding is sufficient to deliver the required MDT offer. In many areas, the BPT does not reliably follow the young person when they move between services after age 16, despite the tariff being intended to support paediatric-model care up to the young person's 19th birthday. Because funding flows and service boundaries vary, receiving teams may not receive the investment required to deliver BPT-aligned care. This results in markedly different levels of support for young people. A 16½-year-old discharged early from paediatrics may enter an adult or young adult service without equivalent MDT access, psychological support, appointment frequency, or treatment intensification, while a peer retained longer in paediatrics, may continue to receive the full BPT-aligned offer for an extra 2 years. During late adolescence, the period of highest clinical risk, care can depend more on local service design than on clinical need. Ensuring that BPT-funded standards reliably follow the young person, rather than dropping away at service boundaries, is critical to sustaining safe, equitable care.

Where BPT standards are not met, mechanisms for challenge, escalation of patient safety risk or co-ordinated support are limited. Teams may raise concerns internally but receive little response, and there is no consistent pathway for alerting the ICB when a service cannot sustain minimum standards. Without clear escalation processes, transparent financial governance, and routine oversight of compliance, services are left managing risk in isolation, and the system loses opportunities to intervene early and mobilise support (table 6).

Table 6: GIRFT CYA diabetes ICB and provider questionnaire - BPT

(please note some totals do not add up to 100% due to rounding)

Ref.	Question	Objective	Yes	No	Don't know	Not answered
ICB Q9 (n=41)	Are all of the paediatric diabetes services in your ICS funded based on the latest numbers as per BPT guidance?	To verify that each provider is being awarded the tariff for current patient numbers ensure that BPT funding reflects current patient numbers, rather than historical activity, ensuring that funding reflects the true size and complexity of the caseload. This is to ensure that services across the system have the financial resource required to deliver the minimum standards of care.	44%	39%	17%	0%
ICB Q11 (n=41)	Have you got mechanisms in place to annually review BPT data?	To ensure that the ICS can routinely monitor and evidence compliance with BPT minimum standards of care	37%	61%	Was not an option for this Q	2%
Provider Q32 (n=160)	Has your trust secured BPT for the paediatric diabetes service?	To confirm that the provider is actually receiving the BPT payment it is eligible for and whether there is assurance and oversight of this process.	62%	19%	18%	1%
Provider Q33 (n=160)	Is the actual income accrued into your paediatric departmental budget sufficient for your unit to provide the required workforce to deliver the service?	To confirm that the BPT income received by the organisation is being passed through to the paediatric diabetes service in sufficient proportion, including its share of any pooled or shared costs, to enable the service to deliver minimum care standards, and therefore functioning as intended.	9%	48%	43%	1%

Provider Q34 (n=160)	Are you aware of who is the trust's contact in the ICB regarding the BPT?	To ensure services have a clear, identifiable point of contact in the ICB for all matters relating to the BPT, and that communication, assurance and escalation routes between the provider and the commissioner are understood.	38%	61%	Was not an option for this Q	1%

Source: GIRFT pre-visit questionnaires (2024 and 2025)

Cross boundary care

Cross boundary care disparities affect both paediatric and young adult services. Variation between neighbouring ICBs in commissioning policies, funding flows, eligibility criteria for technologies or structured education, and care pathways, particularly for transition and transfer from paediatrics, means that two patients attending the same specialist diabetes clinic can access different levels of support simply because they live in different postcode areas.

These inconsistencies stem from misaligned commissioning arrangements across ICB boundaries. A single specialist provider may serve patients from multiple ICBs, but differences in local policies create avoidable variation and undermine equity between patients even within same service.

This variation also places a significant burden on clinical and administrative staff, who must navigate multiple sets of processes, documentation requirements and approval routes for different ICBs. Managing these parallel systems increases workload, introduces delays and impacts on service efficiency.

Strengthened co-ordination between neighbouring systems is essential to ensure that children and young adults receive a consistent offer, regardless of postcode, and to reduce the operational complexity faced by staff.

Collaboration with networks and partners to support cross-system learning

Clinical networks, including the National Children and Young People's Diabetes Network (NCYPDN)[70], AIM improvement subgroups, and the National Paediatric Type 2 Working Group,[71] play a pivotal role in benchmarking outcomes, standardising care, reducing

[70] *National Children and Young People's Diabetes Network, https://www.cypdiabetesnetwork.nhs.uk/*
[71] *National Children and Young People's Diabetes Network, Type 2 National Working Group, https://www.cypdiabetesnetwork.nhs.uk/national-network/type-2-national-working-group/*

variation, supporting workforce development and co-ordinating implementation of GIRFT recommendations.

Embedding these networks within local governance structures ensures that services and commissioners work to a shared direction and benefit from collective expertise. Bringing paediatric and young adult teams together in joint network forums would create shared spaces for planning, learning and integrated service design. This would help bridge the structural divide between 0–18 and 19-25 services, support smoother transitions, and promote continuity of care.

There is also significant opportunity to strengthen early paediatric optimisation on hybrid closed loop (HCL) systems ahead of transfer, reducing pressure on adult teams and improving outcomes. Networks can facilitate the spread of training packages and practical resources, enabling services to build capability without duplicating effort. Involving young adults with lived experience and linking with organisations such as Diabetes UK, BT1D, and local community or faith-based groups, ensures that service development is co-produced, informed by patient voice and aligned with broader psychosocial needs.

Data quality, completeness and audit assurance

Although 100% of paediatric diabetes services participate in the NPDA, many teams face persistent challenges in collecting, validating and submitting high-quality data. Where administrative or analytical support is limited, audit work falls to clinical staff, reducing capacity for direct patient care. Services with dedicated administrative support consistently produce more complete and validated submissions, highlighting inequity in the system's ability to generate reliable data.

Across the pathway, systems lack clear governance for ensuring accurate, complete and timely submissions to national audits. There is no consistent accountability at trust or ICB level for verifying returns, challenging missing data or supporting teams to prepare submissions. Only 29 of 41 ICBs reported reviewing whether services are uploading data to the NPDA and NDA specialist service collections.[72]

In several areas, teams acknowledged that datasets were incomplete and assumed performance would appear better if full data were available, but there was no mechanism to evidence or test these assumptions. As a result, poor-quality or missing data does not

[72] *GIRFT pre-visit questionnaires (2024 and 2025)*

reliably trigger action, assurance or follow-up. This undermines the ability of systems to track progress or confirm whether improvements are being made. Missing or unvalidated data should be treated as a governance risk in its own right, signalling that essential information for oversight is absent.

System-wide data collection should capture core metrics on care processes, therapies, outcomes, attendance, admissions and place of care. Without defined accountability for data quality, validation and audit assurance, systems cannot build the insight required to identify risk, prioritise improvement or provide credible assurance of performance.

Ethnicity recording remains variably complete, with some PDUs reporting very high rates of 'not stated' ethnicity (maximum 37%).[73] Clear, sensitive communication about why this information is collected is essential to build trust and support fairer care.

Ultimately, inconsistent data quality and weak audit assurance create a structural barrier to equity: without reliable information, systems cannot see where inequities lie, whether they are widening or narrowing, or whether interventions are working.

Data integration, visibility, and analytical capability

The review process brought together aligned paediatric and young adult datasets at ICB level, creating a level of cross-pathway visibility that systems do not routinely have. In current practice, paediatric and adult datasets are reviewed separately, and adult data is rarely disaggregated for 19 to 25-year-olds. This masks the sharp deterioration that occurs after transfer and obscures the later recovery in metrics such as care process completion and HbA1c. These improvements do not mean the issue resolves itself; they highlight how much stronger population-level outcomes could have been had the deterioration at 19-25 not occurred. Importantly, this recovery is not universal at an individual level, as some young adults do not re-engage, and the consequences of early deterioration persist into adulthood.

Fragmented data practices and inconsistent use of national audit datasets further weaken visibility. Paediatric services submit to the NPDA, adult specialist services to the NDA specialist services audit, and the NDA also extracts data from primary care. For 15 to 25-year-olds, a complete population view requires data from all three sources. Figure 29 illustrates how, at age 17, young people with type 1 diabetes are distributed across GP

[73] *Royal College of Paediatrics and Child Health, National Paediatric Diabetes Audit, https://www.rcpch.ac.uk/work-we-do/clinical-audits/npda*

records, NPDA and NDA SS, with no single dataset providing a complete picture. The NDA's Adolescents and Young Adults with Type 1 Diabetes and Young Type 2 Diabetes reports[74,75] combine these datasets annually, but without comparison to other age groups, limiting the system's ability to see where performance drops or recovers.

Systems also lack routine mechanisms for shared interpretation of data across age groups and diabetes types. Limited analytical capacity constrains the ability to link datasets, identify emerging risks or understand the drivers of variation. Only 28 of 41 ICBs reported using NPDA and NDA dashboards to identify unmet need, indicating inconsistent use of available intelligence.

Strengthened analytical capability is essential to ensure that audit insights are routinely reviewed, translated into action and used to drive improvement. Unified oversight should track outcomes across transitions and provide shared visibility for commissioners and providers. Routine review of NPDA and NDA data should include age-specific analysis and admissions data to identify preventable events such as DKA and lost to follow-up, and should be interrogated through a health inequalities lens to guide equity-focused interventions.

NHS England's Diabetes Actionable Insights dashboard, delivered through the Federated Data Platform (FDP),[76] brings together data on care processes and treatment targets, down to GP practice level, giving ICBs a consistent view of local performance and enabling targeted improvement.

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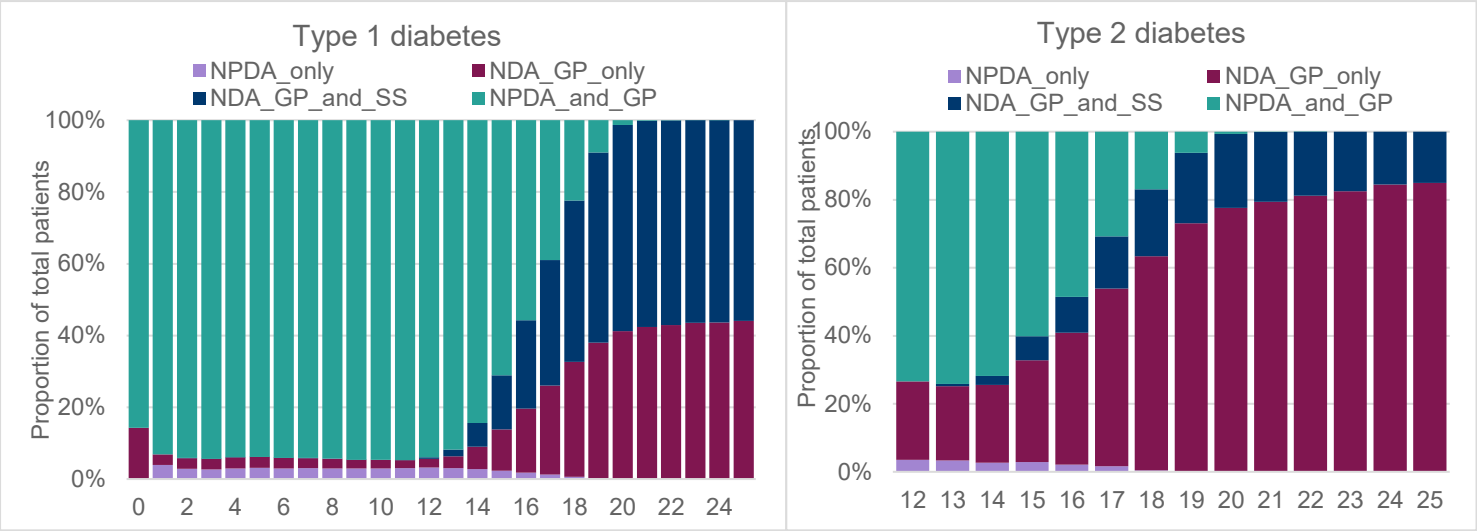
[74] *NHS England, Adolescent and Young Adult Type 1 Diabetes Audit (AYA), 2017-21, https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit-aya/nda-aya-2017-21*
[75] *NHS England, National Diabetes Audit 2021-22, Young People with Type 2 Diabetes – Overview, https://digital.nhs.uk/data-and-information/publications/statistical/national-diabetes-audit-yt2/young-people-with-type-2-diabetes-2021-22*
[76] *NHS Federated Data Platform, Diabetes Actionable Insights Dashboard, https://england.federateddataplatform.nhs.uk/workspace/module/view/latest/ri.workshop.main.module.5481ae50-6336-491b-ad5f-539ed1802eda*

Figure 29: Variation in dataset presence by age



Source: NPDA and NDA combined data 2023/24

Workforce capacity, role adaptation and capability for modern care

The workforce supporting CYA diabetes care must evolve to reflect rising caseloads, increasing complexity and rapid technological change. Diabetes technologies require significant workforce input for onboarding, optimisation and troubleshooting. Technology it increases, rather than reduces, the need for skilled staff who can support safe effective use while maintaining personalised, developmentally appropriate care.

The growing prevalence of EoT2D increases demand for staff trained in weight-management, behaviour-change support and the safe use of specialist therapies. Many teams reported limited access to structured weight-management services for this age group, creating gaps for young people with obesity, insulin resistance or complex metabolic needs.

GIRFT reviews highlight services operating below recommended capacity and with outdated skill mixes. Only 9 of 40 ICBs confirmed having a workforce strategy for CYA diabetes; 3 of the 40 submitted a return but left this question blank.[77] Workforce analysis should include banding reviews, adequate administrative support and stable staffing models that minimise repeated induction cycles and maintain continuity for young people. Rotational roles can strengthen resilience and professional development but require structured supervision and continuity planning.

[77] *GIRFT pre-visit questionnaires (2024 and 2025)*

The sharp deterioration in outcomes seen at age 19 coincides with a significantly smaller workforce per 100 patients in young adult services (figures 20 and 21). The system is least resourced at the point of greatest need, limiting proactive support, early intervention and technology onboarding. While some outcome metrics improve later in adulthood, this recovery is not universal at an individual level, and outcomes would almost certainly be stronger had services been able to deliver consistent, intensive support during early adulthood.

Headline staffing figures often mask underlying fragility as they do not reflect skill distribution, banding structures, or the vulnerabilities of small teams that can be easily destabilised by turnover, sickness or vacancies. Recruitment and retention challenges, limited opportunities for progression into specialist roles, and high administrative burden reduce real clinical capacity. Multi-site working and travel time further dilute availability for complex cases.

Large tertiary centres carry substantial volumes of highly specialised activity in rare and complex diabetes, peri-operative support, paediatric intensive care, that are not reflected in headline staffing metrics or BPT allocations. This unrecognised workload stretches already fragile teams and widens inequity between services with different case-mix profiles.

Developing the workforce requires strengthening existing roles and introducing new ones. Technology assistants, youth workers, social prescribing link workers, and family support roles can enhance psychosocial and relational support, technology onboarding, and self-management confidence. Roles should reflect local population needs and cultural context. Where recruitment is difficult, shared posts across systems or networks can help retain expertise.

Future-proofing services demands forward-looking workforce planning, including horizon scanning for developments such as early detection pathways, immunotherapies and emerging care models. Regular training and upskilling are essential to maintain safe, evidence-based care, and to support delivery in the most appropriate settings, including virtual platforms. Workforce leaders have a responsibility to work with medical schools, training programmes and the royal colleges to ensure that diabetes-specific competencies for CYAs are embedded across curricula.

Safeguarding supervision and multi-agency co-ordination add further specialist workload, particularly for insulin dependent diabetes, where unmet needs carry acute and dangerous consequences. Teams must manage clinical risk while educating social-care colleagues

about the time-critical nature of insulin administration, the risks of omission and the emotional load of caring for a young person who requires constant vigilance.

National safety investigations, including those by HSSIB,[78] consistently show that safeguarding concerns often arise from system-level weaknesses, such as gaps in information-sharing, unclear escalation routes, and insufficient capacity. When structural disadvantage and psychosocial complexity coincide, services face a profound imbalance between need and resource.

Without a workforce that is adequately staffed, appropriately skilled and able to adapt roles to modern models of care, systems cannot deliver minimum standards consistently, intensify treatment for those who need it or maintain stability for others.

Cultural competence, inclusive practice and community partnership

Addressing inequalities requires a workforce that is not only adequately staffed and technically skilled but also equipped to personalise care and work effectively with diverse communities. GIRFT review discussions highlighted strong commitment to inclusive, culturally responsive practice, but also consistent reports of time pressure and limited capacity to apply these approaches reliably.

Stigma relating to weight, diabetes type, socioeconomic circumstances, neurodiversity or cultural identity, is a recognised barrier to engagement. Reducing stigma requires strength-based communication and training in trauma-informed practice, adolescent development and neurodiversity-aware tailoring. Without protected time for reflective practice and skills development, teams struggle to embed these approaches consistently, and young people may disengage at points of highest need.

Poverty-proofing services[79] is essential to ensure that care remains accessible for families facing financial hardship. This includes designing pathways that minimise avoidable costs, offering flexible appointment models, and ensuring universal approaches incorporate targeted support for those most affected by deprivation. Embedding these principles into routine practice ensures tailored support does not depend on individual staff effort.

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[78] *Health Services Safety Investigations Body, https://www.hssib.org.uk/*
[79] *Poverty Proofing, Paediatric Diabetes Workforce Guide, https://children-ne.org.uk/wp-content/uploads/2023/11/PDiabetes-Workforce-Guide.pdf*

Partnerships with trusted local organisations, including voluntary-sector groups, youth services, schools and faith-based organisations can strengthen engagement and improve outcomes, particularly for communities facing structural barriers to care. These partnerships require system-level support and shared objectives; they cannot rely on individual enthusiasm or informal local links.

Case study: Urdu family support worker

Mid Yorkshire Teaching NHS Trust

Local Health and Wellbeing, working with Mid Yorkshire Teaching Trust's paediatric diabetes team, secured funding through the Equitable Provision of Diabetes Technology fund to employ an Urdu-speaking family support worker.

Introduced in May 2023, this role aimed to address inequalities in technology uptake among children and young people with diabetes from ethnic minority backgrounds in Dewsbury, where usage of insulin pumps and continuous glucose monitoring was significantly lower compared to white peers. The support worker played a vital role in engaging families, improving understanding and encouraging use of diabetes technology.

As a result, there was a marked increase in uptake of insulin pumps and real-time CGM, particularly among both ethnic minority children and those from the most deprived backgrounds, leading to measurable improvements in glycaemic control. By 2025, 77.8% of ethnic minority CYP and 80.3% of those from the most deprived group were using Hybrid Closed Loop technology.

Additional initiatives, such as 'Walk and Talk' sessions, further promoted physical activity and peer support. Positive parent feedback highlighted the support worker's impact in easing transitions at diagnosis and providing ongoing reassurance. The success of the intervention led to the role being made permanent, demonstrating how targeted investment and culturally tailored approaches can significantly reduce health inequalities.

Click here to see the full case study.

Case study: Supporting technology-enabled diabetes care: The role of the Band 3 Technical Assistant

Sheffield Children's NHS Foundation Trust

At Sheffield Children's NHS Foundation Trust, a Band 3 Technical Assistant plays a vital role in supporting the delivery of modern diabetes care, ensuring that both newly diagnosed and existing patients can access and effectively use diabetes technologies such as insulin pumps and continuous glucose monitoring systems.

The assistant manages account setups for platforms including Dexcom, Glooko, DigiBete, Tandem Source, and Omnipod, and provides onboarding support at diagnosis. Within clinics they assist with downloading data from devices such as insulin pens, BG meters, and pumps (including T:Slim and Omnipod), ready for clinical review and informed decisions between families and the diabetes team. They maintain accurate and up-to-date patient records on technology use on platforms such as Twinkle and Glooko.

Their responsibilities also extend to device ordering, troubleshooting connectivity issues, arranging sensor deliveries, and supporting families with software updates and account access. The role requires strong communication and problem-solving skills, especially when addressing barriers to technology use among families facing deprivation or digital access challenges.

Typical time allocation per patient is approximately three hours for diagnosis-related setup, two hours for data and device management, and additional time for troubleshooting and supporting families in need.

This role illustrates how evolving diabetes services increasingly rely on flexible, tech-enabled workforce models. By embedding digital support roles within multidisciplinary teams, trusts can future-proof services, enhance access to life-changing technologies, and adapt dynamically to emerging therapies and care delivery innovations.

National accreditation and service assurance

Adult inpatient diabetes services benefit from an established accreditation scheme that supports consistent standards and external quality assurance.[80] No equivalent national

[80] *Royal College of Physicians, Diabetes Care Accreditation Programme, https://www.dcap.org.uk/*

accreditation framework exists for children's or young adult outpatient diabetes services. In the absence of a structured, nationally recognised programme, service quality is assessed through local governance, GIRFT reviews and national audit data, rather than through a comprehensive, standardised assurance mechanism. This contributes to variation in pathways, workforce models, technology support and psychosocial provision across ICBs.

A national accreditation approach would provide clear benchmarks for service expectations, strengthen accountability and support ICBs to commission against consistent standards. It would also offer a structured route for recognising excellence, identifying gaps, and guiding investment in areas such as workforce capability, cultural competence, technology optimisation and transition pathways.

6	Roadmap of actionable steps to reduce variation in systems governance and workforce capability
	Establish clear governance structures, accountability arrangements and clinical leadership for the 0-25 pathway, including transparent financial oversight ▪ **Publish a single governance map** for all 0-25 services, setting out commissioners, accountable officers, decision-making groups and escalation routes across paediatric, transition and young adult care. ▪ **Define responsibilities and clinical leadership across the pathway**. Agree and document responsibilities for safety and outcomes in paediatric, transition and young adult care; embed these in terms of reference; and identify named clinical leads from primary care, community, paediatric and young adult services who hold these responsibilities, with minimum attendance expectations and documented clinical advice. ▪ **Ensure transparency and clarity of BPT funding**, through annual reporting of allocations, the eligible patient numbers underpinning BPT calculations, and a clear assessment of service delivery against minimum standards.
	Implement a structured risk management framework aligned to national diabetes care standards. ▪ **Establish a structured oversight and escalation framework.** Implement a regular oversight meeting cycle with a standard agenda covering performance, risks and safety concerns, and define clear triggers for unmet minimum standards with a consistent escalation route across all providers. ▪ **Create a co-ordinated partnership network** with regular touchpoints and a shared workplan to support learning from best practice, implementation of GIRFT recommendations and alignment with national strategic direction. ▪ **Introduce national accreditation for CYP and young adult diabetes services** to provide external assurance, benchmark standards and drive systematic improvement across the pathway.

Strengthen data quality, intelligence and system-wide insight across the 0-25 pathway, with clear processes for interpreting and acting on findings.

- **Introduce provider-level accountability for audit submission and data quality.** Assign responsibility to trust providers (not clinical teams) for validation, completeness monitoring and submission accuracy, supported by supported by dedicated administrative or analyst capacity. Require routine outputs such as completeness reports, validation checks and submission logs.
- **Implement a standardised coding framework across providers** including SNOMED for presymptomatic type 1 diabetes, complications, care processes, therapies and technology use, so that key clinical information is recorded and shared in a uniform way.
- **Establish structured data review cycles with defined actions.** Use a standard review template at service and ICB level covering trends, variation, deterioration, data completeness and required actions. All variation should be interpreted alongside data completeness to avoid missing data masking risk.
- **Implement a shared pathway-wide dashboard**. Align paediatric, young adult, primary and secondary care data oversight through a single dashboard tracking glycaemic trends, care process completion, emergency episodes and technology use across service boundaries, age transitions, and diabetes type, at sufficient granularity to avoid masking variation.
- **Expose disparities and inequalities in care and outcomes** by disaggregating data by age, ethnicity, deprivation, language, SEND, neurodiversity and other relevant characteristics.
- **Use AI-enabled risk stratification tools** to combine risk indicators for glycaemic instability such as missed appointments, emergency care, psychosocial flags and missing data, and to identify interacting and compounding risks, and prioritise quality-improvement activity. Insights should also be used to highlight unwarranted variation across services.

Conduct regular workforce review at provider and commissioner level, with findings published and shared across the system to support transparency, planning and collective action

- **Undertake an annual workforce review** covering capacity, capability, skill mix and caseload trends, benchmarking findings against national workforce planning tools and identifying any risks to meeting minimum care requirements. Produce a documented output using a shared template across providers and commissioners.
- **Assess administrative and operational support annually** adjusting provision to ensure clinical time is protected for patient care and quality improvement activity.
- **Ensure workforce planning includes activity not captured in caseload numbers** such as presymptomatic type 1, type 2 at-risk groups, regional referrals and PICU admissions, rare diabetes pathways, and perioperative support, and quantify this annually to inform capacity modelling.

Expand and embed modern workforce models and novel roles that reflect today's clinical, technological and social care needs

- **Introduce and embed novel and relational roles within MDTs** such as technology assistants, youth workers, social-prescribing link workers, family support workers, digital navigators and behavioural or psychosocial practitioners, to deliver cost-effective support and undertake tasks that do not require specialist expertise, freeing clinical capacity. Ensure these roles have defined competencies, supervision structures and measurable outputs (e.g. families supported, technology onboarding completed, interventions delivered).
- **Develop flexible, system-wide workforce models across ICBs and 0-25 pathways** that enable neighbourhood-based MDTs, shared deployment of scarce expertise, and improved recruitment and retention. Ensure capacity is available across key functions, including psychological care, technology onboarding and optimisation, transition co-ordination, health-inequalities work, structured education, language and communication support, urgent clinical advice and safeguarding, with clear expectations for delivery and annual review of performance against these expectations.

Six domains of unwarranted variation and alignment with national policy

Six domains of variation	Alignment with the three shifts	Strategic cross-cutting themes
1. Diabetes health outcomes	From sickness to prevention	Tacking inequalities; Prevention & early intervention; Precision risk stratification; Improved mental health support
2. Completion of essential health checks	From sickness to prevention	Prevention & early intervention; Early detection; Shared patient records; Personalised care, improved mental health support
3. Emergency admissions	From hospital to community	Screening; Early detection; Proactive care; Integrated neighbourhood teams
4. Access to Hybrid Closed Loop Therapy	From analogue to digital	Digitally enabled care; wearable technologies; AI supported decision making; Reducing inequalities
5. Young adult care (19-25 years)	Supports all three shifts	CYP & young adults as priority populations; Integrated and personalised care; precision risk stratification; strengthening transition pathways
6. Systems, governance and workforce capability	Enabler across all three shifts	Quality and safety; AI enabled analytics; Best Practice Tariffs

Overarching GIRFT recommendations

1. Leadership and Accountability

Create a clear ICS-wide governance and accountability framework for the 0-25 diabetes pathway, with explicit clinical leadership at ICB level and across all commissioned services. This framework should set out unambiguous responsibility from ICB executives and clinical leads through to place-based leaders, provider collaboratives, trust boards, senior teams and frontline clinical staff.

It should define how accountability operates across the whole system, with agreed escalation and review processes so that risk flows upwards and support flows downwards. Teams must be equipped to identify rising risk, act on data, escalate concerns confidently and receive timely organisational backing to deliver safe, high-quality care. All accountable partners should have access to the data required for effective oversight and assurance and decision-making.

2. Data, Intelligence and Insight

Commission and govern a unified ICS-wide data and intelligence function for the 0-25 diabetes pathway, providing a single, shared and accessible version of the truth that generates actionable insight. All partners must work from complete, benchmarkable data rather than fragmented local datasets. Providers should be required to submit accurate, complete and timely information to national audits as a core contractual responsibility, supported by administrative and digital infrastructure.

The system must maintain visibility of data missingness, missed care and rising risk, and use disaggregated clinical, psychosocial and vulnerability indicators to identify those at greatest need to support anticipatory prevention. Data should be available in real-time to provide immediate operational and clinical insight, with intentional visibility across transitions and other service boundaries so that care gaps, deterioration and inequity are exposed rather than obscured. Teams should be accountable for regular interrogation of service data to drive iterative PDSA cycles, testing changes, evaluating impact and embedding effective improvements into business-as-usual practice.

3. Standardisation of Care

Define and implement nationally agreed, minimum standards of care for children and young adults with diabetes, grounded in evidence and clinical consensus. Standards should be specific, measurable and time-bound, delivered consistently across all neighbourhoods, and supported by the workforce capability and resources required to provide high-quality core care for all, with service resilience to intensify care proactively for those with greater need. Diabetes type, developmental maturity, and clearly defined clinical and psychosocial risk thresholds, not place of care, local service configuration or capacity, should determine the level and components of care. The same standard must apply for a given level of risk, whether care is delivered in specialist, community or neighbourhood settings, ensuring care is free from structural or cultural bias and that equitable outcomes are achieved for every child, young person and young adult.

Standards should set out clear service specifications for each diabetes type, age and level of risk, including MDT provision with embedded psychological support, treatment-intensification thresholds, review frequency, equitable access to specialist therapies and technologies, prescribing and monitoring requirements, out-of-hours advice, peer support, mental health and wellbeing screening, structured education, delivery of all care processes, and standardised safety-netting and emergency pathways. Patient facing information should be a core component, aligned with NICE guidance, accessible across literacy levels and languages, and available through digital and handheld tools. This information should be co-produced with patients, families and charity partners.

Benefits summary

Notional financial opportunities

Disclaimer: *This analysis provides a focused estimate of the potential fiscal value of specific paediatric diabetes improvements; it does not constitute a comprehensive cost-benefit analysis. It should be noted that the clinical drivers for these interventions (health check engagement, and technology uptake) are highly interrelated. Consequently, the modelled benefits, for short term savings through avoided DKA admissions, may overlap across improvement categories and should be viewed as illustrative of the scale of impact rather than additive.*

Furthermore, this analysis is likely to underestimate the total benefit of the modelled improvements. Downstream healthcare savings beyond those modelled, such as reduced primary care contacts and lower costs associated with early microvascular complications, are not fully captured here. Indirect benefits such as reduced school absence and carer productivity gains represent additional areas of potential financial benefit not captured in the analysis below. Analysis for those with type 2 diabetes has also not been included.

Short-Term Financial Opportunities

Improvement	Target Activity Opportunity	Short-Term Financial Opportunity
0–18-year-olds/ Paediatric Diabetes Units (PDUs)		
Increase health check completion rates to the mean completion rate across all PDUs (patients 12+).	145 PDUs to increase health check completion rates among patients 12+ to top decile of 91.1%, based on NPDA 2023/24 values [81] **Assumptions:** • Baseline DKA admission rate for regularly attending patients is 2% and among patients experiencing barriers to engagement is 10%[82] • Cost of DKA admission is £2,867[83]	Estimated savings at each PDU ranges from £0 to £72.1k a year Total estimated savings across 145 PDUs: £2.2m

[81] *RCPCH: 2023/24 National Paediatric Diabetes Audit (NPDA) data*
[82] *RCPCH: National Paediatric Diabetes Audit (NPDA): Report on hospital admissions of children and young people with diabetes, 2015-2020*
[83] *NHS England 2023/24 National Cost Collection Data Publication HRGs PK67A and PK67B*

Increase the uptake of Hybrid Closed-Loops (HCL) (patients 0-18).	HCL uptake in 37 ICBs to increase to the mean HCL uptake rate to top decile of 72.6% **Assumptions:** • HCLs result in a 7 mmol/mol reduction in HbA1c[84] • Risk of DKA admission increases 6% per 1 mmol/mol increase in HbA1c[85] • Cost of DKA admission is £2,867 • HCL uptake rates and baseline DKA rates from GIRFT analysis of combined 2024/25 NPDA and NDA data	Estimated savings at each ICB ranges from £0 to £9.0k a year Total estimated savings across 37 ICBs: £107.5k
Reduce avoidable DKA admissions at diagnosis (patients 0-18).	Compare the rate of DKA admission at diagnosis among patients 0-18 at the worst-performing ICB to the best-performing ICB (DKA admission at diagnosis rate 27%). **Assumptions:** • Cost of DKA admission is £2,867 • Assume numbers of new diagnosis are same as in 2023/24 • New diagnosis counts and DKA at diagnosis rates from GIRFT analysis of combined 23/24 NPDA and NDA data linked to HES	Estimated savings at each ICB ranges from £3.9k to £53.7k a year Total estimated savings across 41 ICBs £1.2m
19-25-year-olds		
Increase health check completion rates to the mean completion rate across all PDUs (patients 19-25).	42 ICBs to increase health check completion rates among patients 19-25 to the mean PDU completion rate of 68%. **Assumptions:** • Baseline DKA admission rate for regularly attending patients is 2% and among patients experiencing barriers to engagement is 10% • Cost of DKA admission is £1,749[86] • Health check completion rates and ICB sizes from GIRFT analysis of combined 23/24 NPDA and NDA data	Estimated savings at each ICB ranges from £11.2k to £84.6k a year Total savings across 42 ICBs: £1.5m
Increase the uptake of Hybrid Closed-	42 ICBs to increase HCL uptake to the estimated eligible population 60%.	Estimated savings at each

[84] *Ng SM, Wright NP, Yardley D, Campbell F, Randell T, Trevelyan N, Ghatak A, Hindmarsh PC. Long-term assessment of the NHS hybrid closed-loop real-world study on glycaemic outcomes, time-in-range, and quality of life in children and young people with type 1 diabetes. BMC Med. 2024 Apr 24;22(1):175. doi: 10.1186/s12916-024-03396-x. PMID: 38659016; PMCID: PMC11044460.*

[85] *Elliott J, Jacques RM, Kruger J, Campbell MJ, Amiel SA, Mansell P, Speight J, Brennan A, Heller SR. Substantial reductions in the number of diabetic ketoacidosis and severe hypoglycaemia episodes requiring emergency treatment lead to reduced costs after structured education in adults with Type 1 diabetes. Diabet Med. 2014 Jul;31(7):847-53. doi: 10.1111/dme.12441. Epub 2014 Apr 8. PMID: 24654672; PMCID: PMC4264891.*

[86] *NHS England 2023/24 National Cost Collection Data Publication HRGs KB02G, KB02H, KB02J, KB02K*

Loops (HCL) (patients 19-25).	**Assumptions:** • HCLs result in a 7 mmol/mol reduction in HbA1c • Risk of DKA admission increases 6% per 1 mmol/mol increase in HbA1c • Cost of DKA admission is £1,749 • HCL uptake rates and baseline DKA rates from GIRFT analysis of combined 2024/25 NPDA and NDA data	ICB ranges from £2.3k to £29.3k a year Total savings across 42 ICBs: £156.8k
Reduce avoidable DKA admissions at diagnosis (patients 19-25).	Compare the rate of DKA admission at diagnosis among patients 19-25 at the worst-performing ICB to the best-performing ICB (DKA admission at diagnosis rate 4.2%). **Assumptions:** • Cost of DKA admission is £1,749 • Assume numbers of new diagnosis are same as in 2023/24 • New diagnosis counts and DKA at diagnosis rates from GIRFT analysis of combined 23/24 NPDA and NDA data linked to HES	Estimated savings at each ICB ranges from £1.1k to £22.8k a year Total estimated savings across 41 ICBs £356.8k

Long-Term Financial Opportunities

These two estimates are based on published cost savings estimates in type 1 diabetes. The costs savings in these papers have been uplifted using the Consumer Price Index (CPI) Health domain change from 2016 to 2026, which may not be reflective of trust NHS cost increases. The papers also both focused on adult populations which means they are likely and underestimate of potential costs savings in a younger population. They are intended only to be indicative of the magnitude of cost reduction potential based on the HbA1c profiles of the 2023/24 0-25-year-old type 1 diabetes population.

Improvement	Target Activity Opportunity	Long-Term Financial Opportunity
Improve HbA1c by 4 mmol/mol in each patient (Baxter et. al 2016)	Patient level reduction in HbA1c by at least 4 mmol/mol **Assumptions costs saved:** • Assumes HbA1c reductions by at least 4 mmol/mol with differing costs depending on initial HbA1c (<=59 mmol/mol, 59-64	Estimated total England savings over 25 years for 0–18-year-olds: £116.6m, and 19-25-year-olds: £79.1m

	mmol/mol, 64-75 mmol/mol, >75 mmol/mol) based on analysis from 2016[87] • Inflation of costs between 2016 and 2026 of 40.4%[88] • Estimate of patients in each HbA1c category from GIRFT analysis of combined 23/24 NPDA and NDA data **Assumptions QALYs gained:** • For a 1 mmol/mol decrease in HbA1c, 0.056 lifetime QALYs are gained (equivalent to 0.61 lifetime QALYs gained per 1% unit decrease in HbA1c), from another study (Mc Ewan et. al 2026)[89] • Assumes is linear relationship with QLAY gained and HbA1c mmol/mol, and no difference depending on starting HbA1c	Total: £195.7m Estimated total England QALYs gained for 0–18-year-olds: 6,884, and 19-25-year-olds: 4,252 Total QALYs: 11,136
Improve HbA1c by 8.6 mmol/mol in each patient (McEwan et. al 2016)	Patient level reduction in HbA1c by at least 8.6 mmol/mol **Assumptions:** • Assumes HbA1c reductions by at least 8.6 mmol/mol with differing costs and QALYs gained depending on initial HbA1c based on analysis from 2016[90] • Inflation of costs between 2016 and 2026 of 40.4% based on ONS CPI Health Index 06 • Estimate of patients in each HbA1c category from GIRFT analysis of combined 23/24 NPDA and NDA data	Estimated total England lifetime savings for 0–18-year-olds: £161.6m, and 19-25-year-olds: £102.0m Total: £263.7m Estimated total England QALYs gained for 0–18-year-olds: 23,702, and 19-25-year-olds: 15,364 Total QALYs: 39,066

[87] *Baxter M, Hudson R, Mahon J, Bartlett C, Samyshkin Y, Alexiou D, Hex N. Estimating the impact of better management of glycaemic control in adults with Type 1 and Type 2 diabetes on the number of clinical complications and the associated financial benefit. Diabet Med. 2016 Nov;33(11):1575-1581. doi: 10.1111/dme.13062. Epub 2016 Apr 15. PMID: 26773733.*
[88] *Office for National Statistics (ONS) Consumer Price Inflation INDEX 06: Health change between Jan 2016 and Jan 2026*
[89] *McEwan P, Bennett H, Fellows J, Priaulx J, Bergenheim K. The Health Economic Value of Changes in Glycaemic Control, Weight and Rates of Hypoglycaemia in Type 1 Diabetes Mellitus. PLoS One. 2016 Sep 15;11(9):e0162441. doi: 10.1371/journal.pone.0162441. PMID: 27632534; PMCID: PMC5025276.*
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Glossary

Carbohydrate counting

This is a method to work out how much carbohydrate is in the food or drink you are about to have, so you can match it with the right amount of insulin.

Co-morbidities

The simultaneous presence of one or more additional health conditions in a patient at the same time as their primary condition (e.g. diabetes). The conditions may be related (sharing risk factors) or entirely separate, but together they influence a person's overall health, treatment needs, and outcomes.

Complications

Health problems arising from diabetes, particularly if blood glucose levels remain consistently high over prolonged periods of time. These may include damage to nerves, eyes, kidneys, blood vessels and the heart.

Continuous glucose monitoring system (CGMS) / Continuous glucose monitor (CGM)

A device that tracks glucose levels in real time throughout the day and night. It uses a small sensor placed under the skin to measure glucose in the interstitial fluid and transmit this data to a receiver or smartphone. CGMS provides trend information, alerts for high or low glucose levels (alarms), and often includes a follow function that allows carers or family members to monitor readings remotely.

CYA (Children and Young Adults)

Individuals aged 0-25 years, encompassing children, teenagers, and young adults who receive diabetes care within specially commissioned NHS services.

CYP (Children and Young People)

Individuals aged 0-18 years, usually referring to those eligible for paediatric diabetes care.

Diabetic ketoacidosis (DKA)

A serious complication that occurs when the body does not have enough insulin. It results in a build-up of ketone chemicals, through the breakdown of fat into acids that build up in the blood. DKA mainly affects people with type 1 diabetes, can develop very quickly, and requires hospital admission, often to intensive care. It can lead to severe dehydration, unconsciousness, diabetic coma and death if not recognised and treated quickly.

Diabetes

Diabetes is a group of long-term conditions in which the body cannot self-regulate blood glucose effectively. There are two main types – type 1 and type 2

DigiBete

A QISMET-accredited digital self-management platform and app for children, young people and families living with type 1 diabetes, covering those up to the age of 25. Developed in partnership with Leeds Teaching Hospitals NHS Trust, DigiBete provides age-appropriate structured education resources for individuals from diagnosis through to young adulthood. As an independent commercial provider access to its services is subject to local commissioning and the securing of NHS contracts.

DNA (Did Not Attend)

Traditional term for when an adult patient does not attend a scheduled healthcare appointment. It is often seen as an autonomous decision of choosing not to attend.

Early-onset type 2 diabetes (EOT2D)

Type 2 diabetes which tends to develop before the age of 40. It tends to be more aggressive and carries a higher risk of complications already being present at diagnosis compared to cases that begin later in life.

GLP-1RA (Glucagon-Like Peptide-1 Receptor Agonist)

Injectable medicines used to treat type 2 diabetes and sometimes obesity, helping lower blood glucose, stimulate insulin release, reduce appetite, and increase satiety.

Glycaemia

The level of glucose in the blood; too low is hypoglycaemia and too high is hyperglycaemia.

Glycaemic

An adjective relating to blood glucose.

HbA1c

A blood test that shows average blood sugar over the past two to three months by measuring glycated haemoglobin. It provides a long-term picture of glucose stability. An HbA1c of 48 mmol/mol or less is the target range aimed for in children. Targets vary by age and circumstances. Lower HbA1c reduces the risk of complications; higher HbA1c increases risk.

Hybrid Closed Loop (HCL)

A smart diabetes management system combining a continuous glucose monitor (CGM) with an insulin pump. It automatically adjusts insulin delivery based on glucose levels. Sometimes called ‘artificial pancreas’ technology, it supports decision-making and improves long-term outcomes by reducing diabetes-related complications.

Hyperglycaemia

When blood sugar is too high, associated with symptoms such as tiredness, thirst, frequent urination and blurred vision. Persistent hyperglycaemia can be serious.

Hyperosmolar hyperglycaemic state

A life-threatening medical emergency and a serious complication of diabetes, primarily affecting people with type 2 diabetes, characterised by extremely high blood sugar levels, severe dehydration, and high blood concentration (hyperosmolality), without the significant buildup of ketones seen in diabetic ketoacidosis.

Hypoglycaemia

When blood sugar is too low. It must be treated immediately, as the brain relies on glucose. Severe hypoglycaemia can cause confusion, loss of consciousness or seizures.

ICB (Integrated Care Board)

A statutory NHS organisation responsible for planning and commissioning health services in a local area.

ICS (Integrated Care System)

A partnership bringing together NHS organisations, local authorities and other partners to plan and deliver joined-up health and care services.

Immunotherapies

Treatments aiming to modify the immune system. In diabetes, these are therapies being tested in clinical trials to prevent or delay type 1 diabetes.

Insulin pumps

Wearable devices providing continuous subcutaneous insulin infusion (CSII) as an alternative to multiple daily injections. Pumps may be tubeless (patch pumps) or tethered via tubing.

Macrovascular
Relating to large blood vessels; macrovascular complications include heart disease and stroke.

Maturity-Onset Diabetes of the Young (MODY)
A rare inherited form of diabetes caused by a single gene mutation. Typically presents before age 25 and may not require insulin depending on the gene involved.

Metabolic memory
Early periods of poor glucose control can cause lasting damage to blood vessels and nerves, even if control later improves. This highlights the importance of early good control.

Microvascular
Relating to small blood vessels; microvascular complications include retinopathy, nephropathy and neuropathy.

National Children and Young People's Diabetes Network (NCYPDN)
A major national audit collecting data from every paediatric diabetes clinic in England and Wales funded by NHS England. It benchmarks the quality of diabetes care for children and young people by comparing it against NICE (National Institute for Health and Care Excellence) guidance.

National Diabetes Audit (NDA)
A national initiative by NHS England collecting comprehensive data on diabetes management and outcomes across all age groups in the UK, used to benchmark and improve service quality.

National Institute for Health and Care Excellence (NICE)
A UK public body providing evidence-based guidance on treatments, medicines and health services.

NICE Technology Appraisal (TA)
Formal NICE approval of a treatment, requiring NHS organisations to fund and provide it within three months of publication.

National Paediatric Diabetes Audit (NPDA)
A national audit benchmarking paediatric diabetes care across England and Wales against NICE guidance.

Nephropathy
Kidney damage caused by diabetes, which may progress to chronic kidney disease or renal failure.

Neuropathy
Nerve damage caused by prolonged hyperglycaemia, leading to numbness, tingling, pain or weakness.

Paediatric Diabetes Unit (PDU)
A dedicated clinical service or multidisciplinary team within a hospital clinic, hospital ward, or similar hospital department that diagnoses, treats, and manages children and young people with diabetes mellitus.

Retinopathy
Damage to retinal blood vessels due to diabetes, potentially leading to vision loss.

SGLT2 (Sodium-Glucose Co-Transporter 2 Inhibitor)
A class of oral medications for type 2 diabetes that increase glucose excretion via the kidneys.

System
A set of connected healthcare organisations, services and processes working together to deliver care.

Type 1 diabetes
A lifelong autoimmune condition where insulin-producing cells are destroyed, requiring lifelong insulin therapy. Not caused by lifestyle factors and often develops in childhood or young adulthood.

Type 2 diabetes
A metabolic condition characterised by insulin resistance and relative insulin deficiency, increasingly seen in young people. Associated with lifestyle and genetic risk factors and may be managed with diet, medication, or insulin.

WNB (Was Not Brought)
A term used when a child or young person does not attend an appointment, recognising that parents or carers hold responsibility for enabling attendance. It highlights that non-attendance may reflect wider needs, pressures or vulnerabilities withing the family context.

YA (Young Adult)

In NHS diabetes services, individuals aged 19-25 years, often supported through transition or young adult clinics.

YP (Young Person)

Sometimes used interchangeably with CYP, but specifically refers to individuals aged 11-18 years.

YoungType2

A QISMET-accredited digital self-management platform supporting young people up to the age of 25, their families and communities, to learn about and live well with type 2 diabetes. Developed by DigiBete in partnership with Leeds Teaching Hospitals NHS Trust, YoungType2 provides structured education resources covering treatment, lifestyle, emotional wellbeing and wider community support. Access to its services are subject to local commissioning and the securing of NHS contracts.

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Finally, a personal tribute. I wrote the final drafts of this report by my Dad’s side in his last days. He always believed that money should never be wasted, and that resources are precious. He had meticulous attention to detail, and a work ethic built not by boundaries, but by doing things properly, with no compromise acceptable. Although he did not get to read this report, his principles of equity, integrity and high standards shaped every part of it.

Dita Aswani

The GIRFT programme

Getting It Right First Time (GIRFT) is a clinically led national programme designed to identify and minimise unwarranted variation in treatment and care delivered. It undertakes clinically led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive timely and effective investigations, treatment, and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal, they can, when accumulated across an entire trust – and even more so across the NHS as a whole – deliver substantial benefits.

The GIRFT methodology was conceived and developed by consultant orthopaedic surgeon Professor Tim Briggs who undertook a pilot review of elective orthopaedic surgery to address a range of observed and undesirable variations in practice. In the 12 months after the pilot programme, it delivered an estimated £30m to £50m savings in orthopaedic care – predominantly through addressing unwarranted variation and reducing average length of stay. Professor Briggs was appointed to lead the programme for the NHS, working with frontline senior clinicians across surgical and medical specialties and cross-cutting areas including diagnostics, day case surgery, outpatient services and clinical coding.

The programme has the backing of the Royal Colleges and professional associations and has a significant and growing presence on the NHS Model Health System portal, with its data-rich approach providing the evidence for providers, systems and regions to benchmark against expected standards of service and efficiency. In addition, GIRFT runs the National Consultant Information Programme (NCIP) which hosts an online portal on the Model Health System that provides NHS consultant surgeons with a single point of access to their NHS practice and patient outcomes data, supporting clinical quality and patient safety.

The GIRFT model has now been applied in more than 50 different areas of clinical practice. It consists of five key strands:

1. **Data gathering** – a broad data gathering and analysis exercise, generating a detailed picture of current national practice and outcomes.

2. **Peer reviews** – direct clinical engagement via visits or virtual meetings between clinical leads and trust teams; an opportunity to examine trust behaviour in the context of the national picture, enabling teams to understand where they are performing well and what they can do better.
3. **National report and Academy resources** – production of national reports that draw on data analysis and discussions with provider teams to identify opportunities for improvement, locally, regionally and nationally, alongside - clinical resources such as best practice pathways and guides.
4. **Support to deliver** – the implementation phase where the GIRFT team supports trusts, commissioners and integrated care systems to deliver the improvements recommended.
5. **Research** – GIRFT fellowships support resident doctors, nurses and allied health professionals to develop their research and clinical improvement skills, delivering research projects and GIRFT identified improvements in their host provider, system or region.

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