Practical steps for improving care and support for children and young adults living with diabetes

Practical steps to help ensure that every child and young adult living with diabetes in England receives high-quality care and support, regardless of where they live, are outlined in the GIRFT's national report for diabetes: children and young adults (CYA).

The report offers the most comprehensive national picture to date of how diabetes services for CYA aged 0-25 are organised, how care and outcomes vary, and what systems can do to adopt best practice and deliver equitable, modern care.

It brings together the findings from a far-reaching national review of all 42 Integrated Care Boards (ICBs); a joint initiative between GIRFT and the NHS Diabetes Programme. GIRFT clinical advisor Dr Dita Aswani (a consultant paediatrician at Sheffield Children's NHS Foundation Trust specialising in diabetes and weight management) authored the report following meetings with clinical leaders, managers, commissioners, regional network teams, charitable partners and patient advocates in each ICB, to interrogate their data together and agree local priorities.

Click to read the full GIRFT national report for Diabetes: Children and Young Adults >

Around 56,000 0-25-year-olds have type 1 diabetes in England and another 9,000 have early onset type 2 diabetes. The management of diabetes in childhood and young adulthood shapes future health, so providing high-quality care can support a person's safety, emotional wellbeing, independence and outcomes throughout their life.

Children and young adults living with diabetes make hundreds of daily decisions about insulin, food and activity, supported by their families and caregivers. This continual self-management makes reliable access to high-quality clinical care and psychological support fundamental to maintaining safety and preventing deterioration. Young adulthood (19-25) is recognised as a particularly vulnerable time, when reduced support from caregivers and increased expectation of independence can lead to rising HbA1c levels, more hospital admissions and a loss of confidence in self-management.

GIRFT's 138-page national report presents the findings of the review, highlighting areas of significant variation nationally, and featuring examples of best practice from teams across the country.

Overarching recommendations for ICBs

Three overarching recommendations are made for ICBs to help achieve a significant reduction in unwarranted variation:

- **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.
- **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.
- **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.

Actionable steps for ICBs, trusts and clinical teams

The overarching recommendations are supported by specific actions for quality improvement in six areas where unwarranted variation is most pronounced and where improvement can have the greatest impact on outcomes, safety and equity. Clinical teams and ICBs can select the actions that best fit their priorities and context to take forward. The six domains of unwarranted variation are:

- **Diabetes health outcomes (HbA1c)**
    - The GIRFT review found that median HbA1c values across paediatric diabetes units (PDUs) range from 54.8 mmol/mol to 70.5 mmol/mol, with no meaningful differences in case mix to explain this spread. This shows that units caring for similar populations achieve very different outcomes of care.
    - Variation was also found in areas such as the implementation of treatment intensification pathways, access to psychological professionals with diabetes expertise and access to specialist therapies and technology.
    - The report includes five actionable steps to reduce variation in diabetes health outcomes, including introducing consistent, equity-driven risk-based intensification pathways and implementing governance for unmet patient treatment-intensification needs.
- **Essential health checks**
    - Health checks enable early detection and timely treatment of complications, but the GIRFT review found variation in completion rates, with some paediatric diabetes units ensuring 98% of young people with type 1 diabetes receive all six key health checks in a year while others record 6% completion.

  - Fragmented care, inconsistent data capture and variation in emotional wellbeing and mental health screening were also noted.
  - Three actionable steps to reduce this variation are outlined in the report, including establishing clear responsibility and accountability for completing and recording essential health checks, and embedding routine psychological screening.

- **Emergency admissions**
  - Emergency admissions for diabetic ketoacidosis (DKA) and severe hypoglycaemia remain one of the most serious and preventable challenges in the care of children and young adults with diabetes, causing distress for young people and their families and placing pressure on urgent and inpatient services. For DKA at diagnosis, delays in detecting first symptoms are a key driver of presentation, particularly in younger children and underserved populations, highlighting the need for cross-system learning on early recognition and timely referral.
  - Although 98% paediatric services and 90% of young adult services have clear inpatient protocols for DKA, variation in the duration of admissions suggests these are not implemented or operationalised consistently.
  - Four actionable steps to reduce variation in emergency admissions are included in the report, including regular audit and thematic analysis of admissions data, and using inpatient episodes as opportunities to understand vulnerabilities and to strengthen support to prevent recurrence.

- **Access to hybrid closed loop (HCL) technology**
  - HCL technology is NICE-approved and cost-effective, improving glycaemic stability, reducing complication risk and enhancing quality of life for CYA living with diabetes.
  - Despite a national technology appraisal, centrally agreed pricing and significant investment in rollout by NHS England's Diabetes Programme, GIRFT findings show wide variation in uptake between areas and ICBs ranging from 37% to 79% across ICBs in 0–18-year-olds, including lower use in some areas without high levels of deprivation or ethnic diversity. This variation does not align consistently with population vulnerability and reflects a mix of system factors, including procurement and funding approaches and differences in workforce confidence and capability.
  - Six GIRFT steps outline how such variation can be reduced, including actions to ensure that the digital infrastructure required for HCL care is fit for purpose and to support inclusion in digitally enabled care.

- **Young adult care (19-25 years old)**
    - Greater glycaemic instability and higher emergency admission rates are well recognised in this age group. Among the variation GIRFT found were differences in transition models, the shift from BPT-defined paediatric care to less standardised young adult provision, the timing and process of transfer, and the use of digital tools and peer support.
    - Six steps are included to reduce variation in young adult care, including the design of young adult care pathways tailored to life-stage needs, and embedding digital self-management tools and relationship-based support such as youth workers and service navigators into young adult pathways.
- **Systems governance and workforce**
    - Effective governance and accountability are essential for safe, consistent and resilient practice, and require reliable, complete data. GIRFT found variation in how systems use data to assure care quality, with the highest and most hidden risks occurring at service boundaries where outcomes are not routinely visible across paediatric, young adult and adult services.
    - The report outlines five actionable steps, including establishing clear governance structures, accountability arrangements and clinical leadership for the 0-25 pathway, and strengthening data quality, intelligence and system-wide insight through routine, structured analysis of performance data.

Dr Dita Aswani, who led the national review, said: "The level of engagement from stakeholders in all 42 system reviews has been admirable. Despite pressures of financial instability and organisational change, colleagues discussed and interrogated the data with interest and played an active role in shaping their own local recommendations.

"What came through was optimism, drive, compassion, and a sincere desire to improve patient care and outcomes.

"I thank everyone for their time and preparation, honesty, engagement, and – now that the findings are shared and the report published - their energy in addressing their local ICB priorities."

Colette Marshall, chief executive of Diabetes UK, said: "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 in this report 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 look 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."