

The case for investing in children and young people's diabetes services

Health Policy team

This information bundle on diabetes presents interventions to improve the quality of paediatric diabetes care and patient self-management through data collection, quality improvement measures, diabetes networks and investment in technology. This information was presented to NHS England to inform the development of their long term plan.

Last modified

18 November 2019

Post date

24 October 2018

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What is the problem?

- The most recent [National Paediatric Diabetes Audit \(NPDA\)1](#) shows that paediatric diabetes services were providing care for just over 26,000 children and young people with diabetes in England in 2017.
- Of these, 95% have type 1 diabetes, 2.5% have type 2 diabetes and the remainder have other rare forms of the condition.
- If not properly managed, children and young people with diabetes are at risk of developing significant clinical complications such as kidney failure requiring dialysis and / or transplantation, limb amputations as a result of peripheral vascular disease, blindness or are diagnosed with premature cardiovascular complications leading to premature death. All of these come at considerable cost to the individuals, their families and financially to the NHS. These complications are avoidable with good care and management of the condition.
- There has been a slight increase in the prevalence of type 1 diabetes amongst children and young people in the past few years. Numbers with type 2 have risen significantly, with an increase in those receiving treatment within paediatric diabetes units of 41% since 2014, coinciding with the obesity epidemic².

- Despite the prevalence of type 1 diabetes being spread equally across different ethnic and socio-economic groups, black and ethnic minority groups and those living in deprived areas of the country have poorer outcomes. They are also at significantly greater risk of developing type 2 diabetes.
- Although there has been considerable improvement in outcomes for children with diabetes over the last 8 years, England still significantly lags behind most of Europe and there remains excessive variability across the country.

Numbers

Building on national (NPDA) and international evidence, regional diabetes networks and a Best Practice Tariff payment mechanism, introduced by the Department of Health in 2012, there has been a highly significant improvement in glycaemic outcome, as measured by HbA1c values (a marker for glycaemic control over the previous 10 weeks), for children and young people with diabetes. This has been steadily reducing towards the national target of 48mmol/mol (6.5%) since 2009 and currently stands at 66.9mmol/mol. By extrapolating from studies performed in adults with diabetes, these improvements in the HbA1c outcome will reduce the risk of developing the long term complications outlined above by around 40%. However, England still lags significantly behind other nations with implications for longevity and quality of life. The consequences on healthcare resources of poor diabetes control in childhood are well documented (see above).

In order to maintain the current momentum gained towards meeting the current NICE Quality Standards³, reduce the variation in the quality of care and outcomes currently seen across the country and bring our performance into line with other international counterparts, it is of paramount importance that NHS England continue to invest in children and young people's diabetes care. Interventions considered to be of great importance are listed below. Their continuation, with further refinement where necessary, will ensure that by 2025 England will be amongst the top performing countries in the world for outcomes for children and young people with diabetes.

What are the interventions required?

NPDA

The NPDA provides quantitative benchmarking data between paediatric units and the ten managed clinical networks in England and helps to provide peer support and information exchange to encourage data driven improvements in the diabetes care delivered by the participating diabetes teams (currently 100% participation).

The NPDA also includes a Patient / Parent Reported Experience Measure (PREM). The PREM questionnaire allows parents and patients to provide direct feedback on their experiences of care. The PREM audits performed in 2012, 2013 and 2015 captured the experiences of between 7,500-13,100 children and young people and their parents in each round. These questionnaires have been updated in 2018 and a further PREM audit is planned. The results from these audits have been essential to inform service improvements and redesign.

The contract to provide the NPDA for three years from May 2017 was £977,794, which is

shared between NHS England and the Welsh Government.

Best Practice Tariff (BPT)

Paediatric Diabetes is currently locally commissioned by Clinical Commissioning Groups (CCGs) against the BPT specification. The BPT was introduced in 2012 and has been fully in place since 2013-14. It includes 14 criteria for hospital Trusts to receive full funding of £2,927 per patient receiving a full year of care. The cost of £2,927 per patient is reflective of the actual care required per child per year.

If the paediatric diabetes services / units were funded directly and received full tariff, as cancer services do, the improvements in standards and delivery of care would be achieved very much quicker and areas of national concern could be addressed more easily. The current NHS England payment of BPT for the provision of paediatric diabetes services allows for variation of the money available to the diabetes services because of the differences in Trust overheads (these are taken at source from BPT income). This in turn leads to geographical differences in the standards of care provided to families with the inevitable detrimental effect on outcomes.

The RCPCH wants NHS England to set a standard overhead charge nationally for Trusts when accepting BPT or pay the tariff direct to services / units as per the cancer model.

National Diabetes Quality Programme (NDQP)

87% of paediatric diabetes units have so far committed to participation in a voluntary, three-year National Diabetes Quality Programme, managed by the RCPCH at the request of the National Children and Young People's Diabetes Network. This Programme will consist of Quality Assurance in the form of self-assessment against quality measures, external verification and peer review visits along with the development of quality improvement collaboratives.

The rationale for establishing NDQP is based on evidence from colleagues in [Sweden](#), where they have very successfully reduced their HbA1c levels in recent years through a programme of developing countrywide quality improvement collaboratives and peer review.

In 2017-18, a pilot quality improvement collaborative, made up of ten diabetes teams from across England, showed positive early findings. The NDQP is currently funded by the diabetes units themselves subscribing to the collective national scheme at a rate of £29 per patient per year based on 2016 patient numbers.

The NDQP, alongside the NPDA data, will enable units to demonstrate their compliance with criteria to justify receipt of their BPT payments and for CCGs to ensure that the funding given to providers is used effectively to ensure high quality care for their population.

The costs of running the NDQP is £850,000 and is funded by individual units via BPT, therefore there is no direct cost for NHS England to take on.

Networks

The National Children and Young People's Diabetes Network is made up of the 10 regional

diabetes managed clinical networks in England. They were established in 2010, principally to improve the quality, experience and outcomes of care for patients / families living with diabetes. At their heart, they promote greater integration and engagement across services, establish methodologies to deliver change and implement, measure and evaluate improvements. Through peer review, there is an evidence-base that demonstrates successful improvements and interventions that have changed services and practice and enabled major change at minimal cost.

The return on investment for supporting the national and regional managed paediatric diabetes networks in England needs to be costed. We understand that the networks charge either by per patient levy or a fixed amount of £5,000 per unit. Overall, this is estimated to be around £750-850,000 per year.

Technology

Diabetes related technologies are developing at a rapid pace. These include insulin pumps, real-time Continuous Glucose Monitoring (CGM) and Flash Continuous Glucose Monitoring (FCGM). They all have proven benefits and NICE approval. A third of children and young people in England now use an insulin pump to manage type 1 diabetes but considerably less patients are using either form of CGM. Inequalities of access still remain for some groups of patients including ethnic minority groups, those living in deprived areas and places where funding is limited by CCGs and Trusts, leading to a postcode lottery.

NICE have set an HbA1c target of 48mmol/mol (6.5%) for the good reason that at or below this level the chances of developing the well known complications of diabetes are minimised. It is a widely held view that reaching this target is only achievable if diabetes related technologies are used by patients.

In Sweden, and other countries, they have achieved excellent HbA1c outcomes (national mean HbA1c of 54 mmol/mol versus England mean of 64.4 mmol/mol). They have chosen to invest heavily in technology to assist patients to self-manage their diabetes, with particular emphasis on increasing the use of continuous glucose monitoring. Clinical colleagues in Sweden, and other European countries, are aiming to allow all their patients access to the use of pumps and / or CGM if clinically appropriate.

The cost for providing equipment to all paediatric diabetes patients who would benefit from an insulin pump and / or CGM in England needs to be modelled. It is estimated that the purchase of a pump alone is approximately £3,000 per patient (four year warranty), plus an additional £1.5,000 per patient per year thereafter for consumables. The cost of real time CGM is approximately £3,000 per year. Flash Glucose Monitoring is less than £1,000 per year. Insulin pumps and continuous glucose monitoring now come as integrated systems. The newest pumps with integrated CGM (automatically increase or decrease insulin delivery) are coming into clinical practice now with an annual cost of approximately \$4,700 (£870 for insulin pump, £1,500 for pump consumables, £23,50 for Glucose Sensors).

Self-management education

The delivery of ongoing self-management education, by highly trained health care professionals, is an essential component of high quality care. This education must include carbohydrate counting from diagnosis. The NPDA data shows variation in effective provision at a clinic level. A number of programmes are being developed by the regional networks and

supported by the young people's diabetes research charities JDRF and Diabetes UK. Successful patient / family self-management education will result in better-informed young people moving through their transition into young adult services with the hope that they will require less support from these services in the future.

The cost for providing universal education and self-management programmes is included in the BPT. RCPCH wants to see education and self-management resources, such as the video web platform [DigiBete](#), supported and rolled out by NHS England as part of their digital strategy to ensure that every patient has access to education in a convenient, accessible way.

- [1.](#) RCPCH (2018) National Paediatric Diabetes Audit Report 2016-17 Care processes and outcomes RCPCH: London
- [2.](#) Office for National Statistics (2017) National Child Measurement Programme 2017 ONS: London
- [3.](#) NICE Quality Standard 125, and Diabetes (type 1 and type 2) in children and young people: diagnosis and management NG18 August 2015