

# Driving UK paediatric diabetes care forward through national quality initiatives

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**Compared to Europe, the UK has a higher mortality rate and significant variations in paediatric diabetes health outcomes. The National Children and Young People's (CYP) Network, Best Practice Tariff and National Peer Review Quality Assurance Programme were developed to improve services received by CYP and, as a result, health outcomes. We aimed to assess the impact of the quality initiatives in the North West region. Data were collected from paediatric diabetes units and extracted from the 2010–16 National Paediatric Diabetes Audits. Staffing levels and mean HbA<sub>1c</sub> values before and after the national initiatives were compared. There was a significant increase in the number of administrative staff ( $p<0.001$ ), consultants ( $p=0.03$ ), dieticians ( $p<0.01$ ), specialist diabetes nurses ( $p<0.01$ ) and psychologists ( $p=0.01$ ) across the network. There were statistically significant improvements in HbA<sub>1c</sub> levels and in mean HbA<sub>1c</sub> year-on-year since the initiatives were implemented. Since the introduction of national quality initiatives, there have been improvements in service redesign and staffing levels for CYP services across the North West region of UK.**

Type 1 diabetes mellitus (T1DM) is a common condition in childhood. It poses serious health risks and is associated with devastating long-term complications and a 20-year reduction in life expectancy (McKnight et al, 2015). The prevalence of T1DM is higher in the UK than in most other European countries and the incidence is increasing each year; the National Paediatric Diabetes Audit (NPDA) reported an increase from 22.6 new cases per 100,000 in 2013/14 to 26.5 new cases per 100,000 in 2014/15 (Royal College of Paediatrics and Child Health [RCPCH], 2016). Despite its increasing prevalence, paediatric diabetes outcomes and organisational structures in the UK were poor and HbA<sub>1c</sub> figures were considerably worse when compared to similar countries. In 2010, the median HbA<sub>1c</sub> for children and young people (CYP) in the UK

was 73 mmol/mol (8.9%), and less than a third of young people aged 12 and above had received all of the key care processes recommended for this patient group (RCPCH, 2016). In comparison, the mean HbA<sub>1c</sub> in Germany and Austria was 65 mmol/mol (8.1%) (Rosenbauer et al, 2012; Bohn et al, 2016). In comparison, the mean HbA<sub>1c</sub> in Germany and Austria was 65 mmol/mol (8.1%) (Randel, 2012; Bohn et al, 2016). In 2015/16, the NPDA showed an improved national mean HbA<sub>1c</sub> of 67.8 mmol/mol (8.4%) (RCPCH, 2016). It has been estimated that a 4 mmol/mol (0.4%) reduction in mean HbA<sub>1c</sub> would save the NHS £995 million over the next 25 years, demonstrating that modest improvements in glycaemic control can generate huge reductions in the cost of diabetes complications in people with type 1 and 2 diabetes (Baxter et al, 2016).

**Citation:** Ng SM, Moore HS, Carson ME, Maiden J (2018) Driving UK paediatric diabetes care forward through national quality initiatives. *Diabetes Care for Children & Young People* 7: DCCYP012

## Article points

1. UK quality initiatives aim to improve service provision and clinical outcomes for children and young people with diabetes
2. Staff levels, services and HbA<sub>1c</sub> levels have improved since the introduction of national initiatives.
3. National quality initiatives have had a positive impact services and outcomes.

## Key words

- Best Practice Tariff
- HbA<sub>1c</sub> levels
- National Peer Review Quality Assurance Programme (DQUINS)
- National quality initiatives
- Quality

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Table 1. Staffing levels in the North West CYP Diabetes Network paediatric units

Unit	Administration		Consultant		Dietician		Nursing staff		Psychologist	
	Before	After	Before	After	Before	After	Before	After	Before	After
Alder Hey Children's Hospital	1.4	1.4	1.2	1.2	2.0	2.0	5.4	5.4	1.1	1.1
Blackpool Victoria Hospital	0.2	0.2	0.7	0.7	0.8	0.8	2.0	2.0	0.0	0.0
Royal Bolton Hospital	0.2	0.2	0.23	0.23	0.5	0.6	1.8	1.8	0.1	0.5
Trafford General Hospital	0.0	1.0	0.3	0.35	0.6	1.5	3.5	5.0	0.2	1.0
Manchester Childrens' Hospital	0.0	1.0	0.3	0.35	0.6	1.5	3.5	5.0	0.2	1.0
Countess of Chester Hospital	0.0	0.0	0.25	0.25	0.4	0.4	1.6	1.6	0.0	0.0
Macclesfield District General	0.0	0.15	0.1	0.1	0.1	0.23	1.0	1.5	0.0	0.2
East Lancashire Diabetic Service	0.0	0.8	0.4	0.6	1.0	2.8	3.8	6.3	0.0	1.2
Royal Preston Hospital	0.0	1.0	1.0	1.3	0.2	0.65	1.7	2.9	0.0	0.0
Leighton Hospital	0.0	0.0	1.0	1.0	0.26	0.26	2.2	2.2	0.0	0.2
Salford Royal Hospital	0.4	0.4	0.3	0.4	0.4	0.4	2.0	2.0	0.1	0.1
Ormskirk and District General Hospital	0.0	0.8	0.2	0.6	0.4	1.0	1.6	2.0	0.08	0.2
Whiston Hospital	0.5	0.7	0.5	0.5	0.5	0.5	2.3	2.3	0.0	0.2
Stepping Hill Hospital	0.0	0.8	2.0	3.0	0.1	0.6	1.2	2.0	0.0	0.4
Tameside General Hospital	0.0	0.6	0.15	0.35	0.4	0.6	1.0	1.6	0.0	0.4
Fairfield General Hospital	0.0	0.0	2.0	2.0	0.4	2.54	4.6	4.6	0.0	0.0
Rochdale Infirmary	0.0	0.0	2.0	2.0	0.4	2.54	4.6	4.6	0.0	0.0
North Manchester General Hospital	0.0	0.0	2.0	2.0	0.4	2.54	4.6	4.6	0.0	0.0
Royal Oldham Hospital	0.0	0.0	2.0	2.0	0.4	2.54	4.6	4.6	0.0	0.0
Wythenshaw Hospital	0.0	0.1	1.0	1.0	0.1	1.0	1.0	2.0	0.2	0.6
University Hospitals of Morcambe Bay	0.0	0.7	1.44	1.44	0.2	0.2	3.2	3.0	1.0	0.6
Arrowe Park Hospital	0.0	0.2	0.2	0.3	0.2	0.6	1.0	1.8	0.1	0.2
Royal Albert Edward Infirmary	0.0	0.05	0.25	0.4	0.2	0.2	0.75	2.0	0.2	0.2
Warrington Hospital	0.0	0.38	1.25	3.25	0.1	1.0	1.6	2.0	0.0	0.2
<b>Total</b>	<b>2.7</b>	<b>10.48</b>	<b>20.32</b>	<b>24.8</b>	<b>11.06</b>	<b>25.2</b>	<b>55</b>	<b>62.7</b>	<b>2.908</b>	<b>6.7</b>
Difference	7.78		4.48		14.14		7.7		3.79	
Mean	0.12	0.46	0.87	1.06	0.48	1.08	2.46	2.89	0.14	0.31
p-value	<0.01		0.05		<0.01		<0.01		<0.01	

### National quality initiatives

To standardise UK diabetes healthcare and improve outcomes for CYP with diabetes, several

national quality initiatives have been conceived and implemented in recent years. These have included the National CYP Diabetes Network, the Best

Practice Tariff (BPT) and National Diabetes Peer Review Quality Assurance Programme (DQUINs).

### National Children and Young People's Diabetes Network

The National CYP Diabetes Network was formed in 2009 with the support of NHS Diabetes. This consisted of 10 regional CYP diabetes networks comprising of multidisciplinary healthcare professionals looking after CYP with diabetes with essential managerial support to the networks. The aims were to develop national standards of care, share good practice, improve quality standards, advise health commissioners and act as a forum to ensure equity.

Since its inception, the National CYP Network has supported paediatric diabetes units (PDUs) struggling to drive change to achieve service improvements and actively promotes feedback and collaboration with families with diabetes. This initiative has resulted in:

- Individual school healthcare plans for all CYP nationally
- A single database for all CYP with diabetes
- NPDA data submission from all PDUs,
- Improvements in shared guidelines and operational policies to reduce the disparity between service providers.

In 2013, in collaboration with NHS Diabetes and the Department of Health, the National CYP Network produced a 5-year national paediatric diabetes service improvement delivery plan aimed at achieving better health outcomes for CYP with diabetes by improving the quality of planning, service redesign and commissioning.

### Best Practice Tariff

The BPT was introduced in April 2012, comprising of 13 national mandatory standards to be met by each PDU, with a tariff of £3,189 per individual per year to be paid to the PDUs that achieved all the requirements (Randell, 2012). These standards have since been slightly revised, see *Box 1*. PDUs failing to meet the mandatory standards of care were supported by the regional and national networks to deliver these standards within a year. Since April 2013, services that have not met the BPT standards have not been able to claim any funding from local commissioners to provide their CYP diabetes

#### Box 1. Abbreviated 2017–19 Best Practice Tariff criteria (<https://bit.ly/2QlkwYt>)

- On diagnosis, a young person's diabetes is to be discussed with a senior member (doctor or paediatric specialist nurse) of the paediatric diabetes team within 24 hours of presentation.
- All new patients must be seen by a member of the specialist paediatric diabetes team on the next working day.
- Each unit can provide evidence each patient has received a structured education programme, tailored to their needs and their family's needs, at initial diagnosis and ongoing updates throughout their attendance at the paediatric diabetes clinic.
- Each patient is offered a minimum of four clinic appointments per year with a multidisciplinary team (MDT), including a paediatric diabetes specialist nurse, dietitian and doctor.
- Each patient is offered additional contact by the diabetes specialist team for check-ups, telephone contacts, school visits, troubleshooting, advice, support, etc. Eight contacts per year are recommended as a minimum.
- Each patient is offered at least one additional appointment per year with a paediatric dietitian with training in diabetes (or equivalent appropriate experience).
- Each patient is offered a minimum of four haemoglobin HbA<sub>1c</sub> measurements per year.
- All eligible patients must be offered annual screening. Retinopathy screening must be performed by regional screening services. Where retinopathy is identified, timely and appropriate, referral to ophthalmology must be provided.
- Each patient must be annually assessed by their MDT for whether they need care from a clinical psychologist and access to psychological support, which the MDT itself should be able to provide.
- Each provider must participate in the annual National Paediatric Diabetes Audit.
- Each provider must actively participate in the local paediatric diabetes network.
- Each provider unit must give patients and their families 24-hour access to advice and support. This should also include 24-hour expert advice to fellow health professionals on the management of patients with diabetes admitted acutely.
- Each provider unit must have a clear policy for transition to adult services.
- Each unit will have an operational policy, which must include a structured 'high HbA<sub>1c</sub>' policy and a 'did not attend/was not brought' policy.

service. As a result, local commissioners have been asked to consider making alternative provider arrangements for CYP with diabetes in their area.

The BPT has provided not only clinical goals but financial incentives for improved care for CYP with T1DM. While limited resources and staff shortages initially made these standards unachievable, NHS providers and commissioners took notice and investments were made in paediatric diabetes care.

### National Quality Assurance Programme

In 2013, a DQUINs were implemented in all PDUs. The units underwent self-assessment followed by external certification of assessments by peer review visits. The programme was based on the fundamental principles of being clinically led, confirming the quality of service via comprehensive

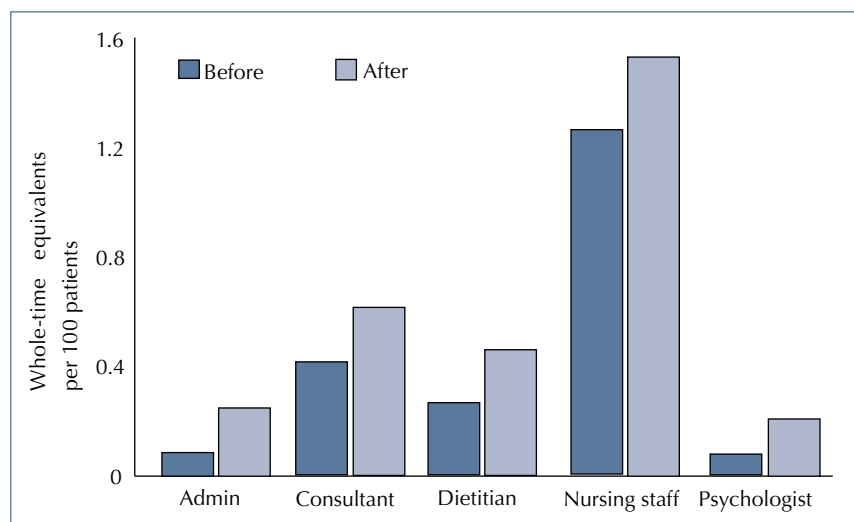


Figure 1 Average staffing levels before and after the introduction of the North West Children and Young People's Diabetes Network, Best Practice Tariff and DQUINs.

peer review and user and patient involvement, and publishing reports providing accessible information about the quality of the services (National Peer Review Programme, 2013).

### Aims

The aims of this study were to assess the impact of the National CYP Diabetes Network, BPT and DQUINs and to explore trends in paediatric diabetes care within all PDUs in the CYP North West Diabetes Network.

### Method

The North West CYP Diabetes Network is the largest regional CYP diabetes network in the UK. Data were collected from each PDU in the region and extracted from the NPDAs from 2010/11 to 2015/16. We compared staffing before and after the national initiatives, mean HbA<sub>1c</sub> values and the percentage of patients with HbA<sub>1c</sub> <58 mmol/mol (7.5%). Data were analysed using paired student T-tests.

### Results

Data on staffing levels before and after the implementation of the BPT and DQUINs were collected and received from all 24 PDUs within the CYP North West Diabetes Network, see Table 1. There were significant increases in full-time equivalent administrative staff ( $p<0.001$ ), consultants ( $p=0.03$ ), dieticians ( $p<0.01$ ), specialist

diabetes nurses ( $p<0.01$ ) and psychologists ( $p=0.01$ ) across the network after the BPT and DQUINs were introduced, see Figure 1.

Data relating to CYP HbA<sub>1c</sub> levels were extracted from the NPDA for the years 2010/11, 2011/12, 2012/13, 2013/14, 2014/15 and 2015/16. There was a statistically significant improvement in the percentage of patients with HbA<sub>1c</sub> <58 mmol/mol (7.5%) when compared year on year, with significant improvement between 2010/11 and 2015/16. The mean HbA<sub>1c</sub> was also significantly improved for each year and compared to baseline at 2010/11 prior to the national initiatives, see Figure 2.

### Discussion

Since the formation of the national CYP diabetes network, the introduction of the BPT and the implementation of DQUINs, there has been a dramatic and significant improvement in PDU staffing levels across all groups, from consultants to administrators, in the North West region. In practical terms, this means that each group can spend more time dedicated to the care of CYP with diabetes. More diabetes specialist nurses will ensure better care and education is delivered to CYP with diabetes and improved resources, such as home visits, support for school and education, the delivery of age-appropriate structured education and acting direct points of contact for GPs and families. Dieticians were now able to deliver group education and hold one-to-one consultations with patients, as well as taking part in multidisciplinary clinics. Clinical psychologists, who were not part of the diabetes teams in the past, are now being appointed within PDUs to deliver a holistic service encompassing psychosocial aspects of diabetes care in CYP.

Setting standards for paediatric diabetes care and appropriate staffing levels are critical to delivering a good service and improving health outcomes. Provider NHS trusts have made huge investments in PDUs, with the main driver for change being the knowledge that the BPT will be removed if mandatory standards are not met.

Over the past 6 years, the North West CYP Diabetes Network has also seen a significant and continued improvement in our mean HbA<sub>1c</sub> levels and increases in the percentages of patients with HbA<sub>1c</sub> <58 mmol/mol (7.5%) over the past 5 years. In 2015, 176 PDUs were audited in England and

Wales and 24% of CYP were found to have  $HbA_{1c}$   $<58$  mmol/mol (7.5%) (RCPCH, 2016). This mirrors results seen in Germany and Austria. Rosenbauer and colleagues examined trends in the metabolic control of children and adolescents with T1DM over a 15-year period. They found an improvement in  $HbA_{1c}$  levels across all insulin regimens, leading them to conclude that it was the development of the multidisciplinary care team and improvements in the structural quality of diabetes care and patient education that had led to the improved results and outcomes (Rosenbauer et al, 2012).

Investments and national initiatives to improve paediatric diabetes care are in the best interest of CYP with diabetes. While we are seeing significant improvements, there are fewer than one in six CYP achieving  $HbA_{1c}$  values of  $<48$  mmol/mol (6.5%), which has been identified as providing the best future outcomes. A significant proportion of CYP have levels that are much higher than this. In 2015, 21% of CYP in England and Wales had a mean  $HbA_{1c}$  values of  $>80$  mmol/mol (9.5%) (RCPCH, 2016). There remains a wide variation in outcomes between PDUs that are achieving BPT. There must be a link between diabetes strategies and frontline quality improvements for CYP with diabetes. This needs to be provided by national leadership and direction from both clinical and political leaders to champion excellent diabetes care in the UK.

While many national initiatives have shown quality improvements, the NHS has been faced with budgetary constraints in recent years. Unfortunately in 2016, as a result of the reorganisation of health care under NHS England's Organisational Alignment and Capability Programme, the DQUINs National Peer Review Programme lost its funding. A programme called the Quality Surveillance Team was formed to continue the progress (Waldron and Campbell, 2015) and in October 2017, the RCPCH launched its new CYP Diabetes Quality Programme of Peer Review and Quality Improvement Collaborative across PDUs in England and Wales. Devised and supported by the National CYP Diabetes Network, comprising 11 constituent regional networks, the programme is clinically driven and aims to further transform outcomes for the approximately 29,000 CYP living with type 1 and, increasingly, type 2 diabetes (RCPCH, 2017).

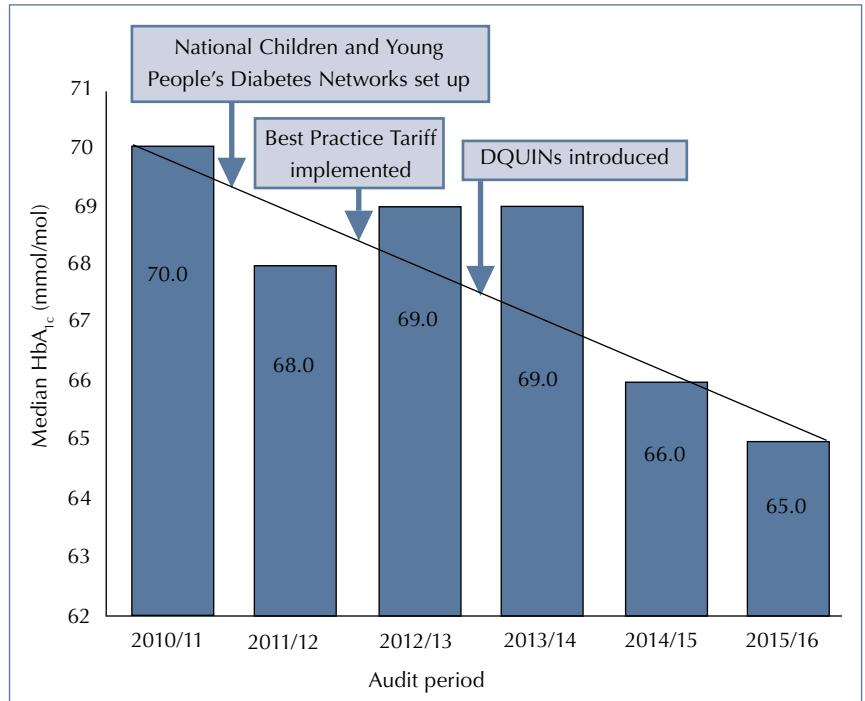


Figure 2. Average  $HbA_{1c}$  levels of children and young people with diabetes before and after the introduction of various national initiatives.

While national initiatives in paediatric diabetes care has been at the forefront of drivers for change in past years, there are concerns that such standards and focus only applied to CYP under the age of 19 and did not include preparing young people for the move to adults services. There are now clear gaps between PDUs and adult diabetes units, and more work needs to be done to address the transition from child to adult services, including incentives such as BPT in adult diabetes.

Patients and families must be at the forefront of any quality improvement initiatives and the success of national initiatives is dependent on collaboration between clinical networks and national organisations to improve the quality of care for CYP with diabetes.

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