

# Developing a best practice tariff in paediatric diabetes: Can we improve services and outcomes for children and young people with diabetes in England?

Tabitha Randell

**There has been no change in average HbA<sub>1c</sub> in children and young people in England and Wales over the past 10 years, whereas other European countries have shown marked and sustained falls. With HbA<sub>1c</sub> clearly demonstrated to influence long-term outcomes, there is a pressing need to try to improve this. As the delivery of paediatric diabetes services across England varies enormously and funding has not historically matched the actual costs of delivering these services, a best practice tariff for paediatric diabetes outpatient care has been introduced from 1 April 2012. Its aim is to standardise care by setting strict criteria for the delivery of paediatric diabetes services and increasing funding for those centres meeting these standards. This article describes the processes in its development and adoption.**

There are around 23000 children and young people aged under 19 in England with diabetes (Royal College of Paediatrics and Child Health, 2009), and their management is typically provided by paediatricians based in secondary care (National Institute for Health and Clinical Excellence [NICE], 2004). Managing diabetes during childhood and adolescence is particularly difficult, as any young person with diabetes or family member will probably agree. Compared with other countries in Europe, diabetes outcomes in England are poor; whereas other countries such as Germany have shown marked improvements over the past 10–20 years, our outcomes remain largely unchanged. The median HbA<sub>1c</sub> in England and Wales from 2003–2010 was 72 mmol/mol (8.7%), using data collected for the *National Diabetes Audit Paediatric Reports* (NHS Information Centre, 2003–2010). Contrast this with the fall in average HbA<sub>1c</sub> in Germany, from 72 mmol/mol (8.7%) in 1995 to 65 mmol/mol (8.1%) in 2009 (Rosenbauer et al, 2012), then to 61 mmol/mol (7.7%) by 2011 (Lange, 2011). Poor long-term diabetes

control has been clearly demonstrated to increase the risk of complications (Diabetes Control and Complications Trial Research Group, 1994); thus, improving diabetes care in children and young people has to be a priority for the NHS.

In 2009, under the aegis of NHS Diabetes, clinicians and healthcare professionals involved in the care of children with diabetes and passionate about improving outcomes established clinical networks for paediatric diabetes across the whole of England. Each network covered a clear geographical area (mapping the areas covered by the strategic health authorities in place at that time), and every team providing paediatric diabetes care in that area was invited to participate. An initial aim of these networks was to scrutinise how paediatric diabetes services were provided and to reach consensus on how standards could be raised. One thing that rapidly became clear was that there were huge differences in how services were staffed, delivered and supported across the country, and it was felt that this was something that had to change; the same standards of care and access to services should apply

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## Article points

1. Outcomes for paediatric diabetes in the UK compare poorly with those in Europe, and standards of care vary widely across the country.
2. Best practice tariffs have been developed by the Department of Health to standardise care for various inpatient conditions and reward centres who adhere to those standards.
3. Development of a best practice tariff for paediatric diabetes was seen as a way of ensuring high-quality care across the whole of England by setting stringent minimum standards criteria for how those services should be delivered and funding those centres that met the criteria appropriately.

## Key words

- Best practice tariff
- Improved outcomes
- Paediatric diabetes
- Standardised, high-quality care

## Author

Tabitha Randell, Consultant in Paediatric Diabetes and Endocrinology, Nottingham Children's Hospital, and Clinical Lead for Paediatric Diabetes, NHS Diabetes.

*“One thing that rapidly became clear was that there were huge differences in how services were staffed, delivered and supported across the country, and it was felt that this was something that had to change; the same standards of care and access to services should apply no matter where you live.”*

no matter where you live. Developing those universal standards of care became one of the main priorities of NHS Diabetes and the networks.

### **Funding paediatric diabetes outpatient activity in the NHS**

Outpatient activity in the NHS is funded in the main using the “payment by results” (PBR) tariff. These are fixed payments set by the Department of Health for new and follow-up appointments, and vary according to the specialty. Funding of paediatric diabetes services has long been an issue, with paediatric diabetes outpatient attendances being coded as general paediatric activity or, occasionally, as paediatric endocrinology. In adult services, diabetes clinics have always had a separate code, in recognition of the fact that it is a separate specialty. From hospital statistics, it was impossible to determine who was doing what and where in paediatric diabetes, and as this activity was coded as general paediatrics it was paid for as such. This meant a single payment for each outpatient appointment attended by a child or young person, with no remuneration for home visits, school visits, telephone calls, e-mail traffic, or similar items. This in no way reflected the actual costs of delivering paediatric diabetes care.

NHS Diabetes thus looked at accurately costing paediatric diabetes services. These were formally calculated in two reference centres with acknowledged high standards of care: Northampton General Hospital as a representative of a district general hospital; and University College London Hospital as the teaching hospital exemplar. Despite using quite different models of care, the costings from both centres showed that the average price for providing outpatient care for 1 year for a child or young person with diabetes was around £3500. This contrasted starkly with the just under £500 per individual per year that centres received under the PBR general paediatric tariff, if children or young people attended clinics four times a year. This was also something that NHS Diabetes and the networks felt strongly was in need of change.

### **Developing a best practice tariff in paediatric diabetes**

The first big change came at the end of 2010, when the Department of Health announced a separate treatment function code for paediatric diabetes. This allowed all paediatric diabetes outpatient activity to be separately coded and so accurately captured.

This change was driven by NHS Diabetes’ extensive lobbying and negotiating with the Department of Health to have paediatric diabetes recognised as a specialty in its own right. With the ability to code paediatric diabetes activity accurately, the next step was to negotiate enhanced funding, designed to reflect the real costs of delivering high-quality paediatric diabetes care. NHS Diabetes identified the need to have clinicians leading this work and released funding to support this. The author successfully applied for the role of Clinical Lead for Paediatric Diabetes Tariff and Dr Fiona Campbell was appointed as the Clinical Lead for Paediatric Diabetes Networks in December 2010; in January 2011, negotiations were started with the Department of Health to develop the tariff.

As well as being an opportunity to increase the funding available for paediatric diabetes, a primary aim was to use the tariff as a tool to set minimum standards of care for paediatric diabetes services. Using the work started by the SWEET Project (2012) and drawing on the recommendations in the International Society for Paediatric and Adolescent Diabetes (2009) *Clinical Practice Consensus Guidelines* on managing diabetes in children and young people, the networks drew up these minimum standards. These were then set out in the 2011 PBR tariff (Department of Health, 2011), which applied from 1 April 2011. The centres complying with these standards were able to apply to local commissioners for an enhanced payment on top of the basic outpatient PBR tariff; unfortunately, the top-up payment was non-mandatory and it is estimated that less than half of all centres who were potentially eligible for the payment actually received it. For those centres that did receive it, however, it more than doubled the income they had previously been receiving.

With the top-up payment being non-mandatory, in those areas where it was not paid there was no incentive for trusts to invest in children’s diabetes services. Indeed at the same time these negotiations were going on, the NHS was being faced with the largest reorganisation of service provision and changes in funding since its inception. Huge financial savings were needed in every area, and many trusts were starting to look at services that cost more to provide than they generated in income; there was the potential that paediatric diabetes services would fall into this category. What was needed was a mandatory tariff that would reflect the real costs of delivering a paediatric

diabetes service, while at the same time setting robust standards as to how that service should be delivered.

In 2010 the Department of Health introduced best practice tariff (BPT) payment schemes for certain inpatient stays. These detailed minimum standards of care for specific conditions and attracted enhanced, mandatory payment for those centres meeting the standards. It was felt that paediatric diabetes services would be well suited for the development of a BPT, even though these are almost entirely outpatient based and a BPT had never been applied to an outpatient area before.

From March 2011 to January 2012, intensive negotiations on establishing the BPT went on. The author met staff from every paediatric diabetes unit in England, as well as commissioners from primary care and business managers from the provider trusts to discuss and reach agreement on what those standards of care would be. Fiona Campbell and the author also had regular meetings with the Department of Health, and an initial set of standards along with the proposed cost of the tariff were agreed in September 2011. These were then sent out by the Department of Health to a large number of stakeholders (commissioners and service providers) for sense checking. This is a process designed to see if the standards are appropriate and to ensure that there are no perverse incentives in introducing them. With sense checking completed successfully, the Department of Health then sent out the final standards and final proposed cost of the tariff to reference organisations to road test at the end of 2011. While these discussions were ongoing, every network was visited to make sure that all centres were aware of what the tariff criteria were likely to be and to ensure that they started local negotiations to be ready to meet them from 1 April 2012.

### BPT in paediatric diabetes – standards and exclusions

Having passed the road test, the agreed BPT standards were published in early 2012 and became applicable from 1 April 2012 (Department of Health, 2012).

These standards are as follows:

- On diagnosis, a young person with diabetes is to be discussed with a senior member of paediatric diabetes team within 24 hours of presentation. A senior member is defined as a doctor or paediatric specialist nurse with “appropriate training” in paediatric diabetes. Guidance as to what constitutes

“appropriately trained” is available from the British Society of Paediatric Endocrinology and Diabetes (2012) and the Royal College of Nursing (2012).

- All new individuals must be seen by a member of the specialist paediatric diabetes team on the next working day.
- Each provider unit can provide evidence that each individual has received a structured education programme, tailored to the child or young person’s and his or her family’s needs, both at the time of initial diagnosis and as ongoing updates throughout the child or young person’s attendance at the paediatric diabetes clinic.
- Each individual is offered a minimum of four clinic appointments per year with a multidisciplinary team (MDT), comprising a paediatric diabetes specialist nurse, dietitian and doctor. The doctor should be a consultant or an associate specialist or specialty doctor with training in paediatric diabetes or a specialist registrar training in paediatric diabetes, under the supervision of an appropriately trained consultant (see above). The dietitian should be a paediatric dietitian with training in diabetes (or equivalent appropriate experience).
- Each individual is offered additional contacts by the diabetes specialist team for check-ups, telephone contacts, school visits, e-mails, trouble-shooting, advice, support, and similar items. Eight contacts per year are recommended as a minimum
- Each individual is offered at least one additional appointment per year with a paediatric dietitian with training in diabetes (or equivalent appropriate experience).
- Each individual is offered a minimum of four haemoglobin HbA<sub>1c</sub> measurements per year. All results should be available and recorded at each MDT clinic appointment.
- All eligible individuals should be offered annual screening as recommended by current NICE guidance. Retinopathy screening should be performed by regional screening services in line with the national retinopathy screening programme, which is not covered by the paediatric diabetes BPT and is funded separately. Where retinopathy is identified, timely and appropriate referral to ophthalmology should be provided by the regional screening programme.
- Each individual should have an annual assessment by their MDT as to whether input to their care

### Page points

1. What was needed was a mandatory tariff that would reflect the real costs of delivering a paediatric diabetes service, while at the same time setting robust standards as to how that service should be delivered.
2. It was felt that paediatric diabetes services would be well suited for the development of a BPT, even though these are almost entirely outpatient based and a BPT had never been applied to an outpatient area before.
3. Having passed the road test, the agreed BPT standards were published in early 2012 and will be applicable from 1 April 2012.

***“Ultimately, we would hope to see reductions in HbA<sub>1c</sub>, fewer acute admissions for diabetes-related emergencies such as diabetic ketoacidosis and a lower rate of development of complications in young adulthood.”***

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by a clinical psychologist is needed, and access to psychological support as appropriate.

- Each provider must participate in the annual *National Diabetes Audit Paediatric Report*.
- Each provider must actively participate in the local paediatric diabetes network. A minimum of 60% attendance at regional network meetings needs to be demonstrated.
- Each provider unit must provide individuals with diabetes and their families with 24-hour access to expert advice on diabetes management. This should also include 24-hour advice to fellow healthcare professionals on the management of people with diabetes admitted acutely, with a clear escalation policy as to when further advice on managing diabetes emergencies should be sought.
- Each provider unit must have a clear policy for transition to adult services.
- Each unit will have an operational policy, which should include within it a structured “high HbA<sub>1c</sub>” policy, a clearly defined “did not attend/was not brought in” policy taking into account local safeguarding children board policies and evidence of patient feedback on the service.

The tariff has been set at £3189 per individual per year for those centres that achieve the above standards. It only covers outpatient care and does not cover inpatient stays or the cost of insulin or other consumables such as insulin pump equipment. Those centres that were not able to meet all the criteria by 1 April 2012 are able to claim the standard PBR tariff (Department of Health, 2012) of £119 per individual per outpatient clinic appointment attended. The current aim is to make the BPT an “all or nothing” tariff by 2013 as an incentive for trusts and commissioners to ensure their paediatric diabetes services meet the criteria by 1 April 2013. Concerns have been raised that this may lead to centres having to stop providing paediatric diabetes services, but it is hoped that this will not be the case. More legitimate, perhaps, are concerns that if it is possible to pay for a cheaper service, albeit of a lower standard, there will be little incentive for commissioners and trusts to make the necessary investment to ensure paediatric diabetes services are fit for purpose.

## Future plans

As this is the first outpatient BPT, the Department of Health will be subjecting its implementation and outcome to rigorous scrutiny. First, it will be

necessary to collect data to demonstrate that the increase in funding is justified. Next, there is a need to review the criteria and be ready to modify them in due course, potentially making them more stringent. After all, the aim of the tariff is to improve outcomes and thus save money, albeit in the long term. Finally, it will be necessary to continue to look at how paediatric diabetes services are provided in the UK and what other changes can be made to improve outcomes further. These include development of a national curriculum for training paediatric diabetes service providers, reviewing structured education programmes already available elsewhere to see if they can be adapted for and applied to the UK population and subjecting transition and young adult services to a similar level of scrutiny as has happened with paediatric services during the development of the tariff.

## Summary

By introducing a BPT in paediatric diabetes it is hoped that we will see improved outcomes in children and young people with diabetes. Setting minimum standards of care for these services and ensuring that centres are appropriately resourced to deliver these standards should mean that no matter where a young person with diabetes lives in England, he or she will receive the same high-quality service. Ultimately, we would hope to see reductions in HbA<sub>1c</sub>, fewer acute admissions for diabetes-related emergencies such as diabetic ketoacidosis and a lower rate of development of complications in young adulthood. None of these changes are going to happen overnight and it may be several years before sustained improvement can be demonstrated, but ultimately that is the goal. ■

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