

Paediatric Diabetes Best Practice Tariff Criteria – for paediatric diabetes units in England

Frequently Asked Questions

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Background

The paediatric diabetes Best Practice Tariff (BPT) was introduced in England in 2012 with the aim of improving outcomes for children and young people with diabetes. At the time, standards of paediatric diabetes care varied quite widely across the UK. Compared with many European countries, outcomes in the UK were poor - in the 2009-2010 National Paediatric Diabetes Audit (NPDA) for England and Wales, less than 15% of children and young people achieved an HbA1C below 58 mmol/mol (7.5%), compared with over 50% of children in Germany in the same period. In 2010, only 10% of children and young people (CYP) with diabetes in Germany had an HbA1C > 80 mmol/mol (9.5%), compared with over 40% in the UK. Participation in the NPDA also included around only half of all paediatric diabetes units and estimates of the number of children and young people (CYP) with diabetes were just that; there was no reliable way of gathering reliable data on how many CYP with diabetes there actually were. Germany is deliberately used as a comparator as they faced similar problems with poor outcomes in the 1990s and as a result introduced nationwide standards on how paediatric diabetes care should be delivered. Over the next 10 years, they saw steady and sustained improvements in paediatric diabetes outcomes.

The BPT set out specific standards and criteria for delivering paediatric diabetes services in England, which units had to be able to evidence to claim the enhanced payment. Since the tariff was introduced in 2012, followed by peer review in 2013, there has been a year-on-year improvement in outcomes in England and Wales. Additionally, all diabetes units now submit data to the NPDA and it contains data on nearly 29,000 CYP with diabetes. The NPDA data from 2015-16 show that the percentage of young people with an HbA1C <58 mmol/mol has increased to 26.6% whilst those with poor control (HbA1C >80mmol/mol) has fallen to 17.9%. The median HbA1C has also fallen from 72 mmol/mol in 2009-10 to 64 mmol/mol in 2015-16; it took 10 years to achieve a similar fall in HbA1C in Germany after the introduction of standardised paediatric diabetes care.

In England, the BPT came with a substantial increase in funding for paediatric diabetes services, reflecting the actual costs incurred in delivering paediatric diabetes care. The tariff amount was arrived at by looking at the costs of delivering high quality paediatric diabetes care in Europe and also two high-performing units in England. For the first two years, the costs covered out-patient contacts alone and from 2014, also included any in-patient stays directly related to diabetes, excluding initial admission at diagnosis. The initial tariff payment was set at around £2900/patient per year and has not increased substantially since it was introduced. Health economics modelling estimate a

£184/person saving over 5 years if there is a drop in the HbA1C of 8 mmol/mol from an initial HbA1C of 72 mmol/mol; extrapolated over 29,000 this is a saving of >£5.3M in health care costs alone.

Why do we still need a paediatric diabetes tariff?

NHS England / NHS Improvement has been reviewing all the best practice tariffs from 2019 onwards. The clear evidence of improved outcomes has been acknowledged as providing substantial benefits, both on a short and long-term basis. As well as the potential in reducing health care costs, avoiding complications of diabetes will also result in lower costs to society as a whole as people will be working, paying taxes and not reliant on benefits long term. The BPT is a 'year of care' payment ie a fixed amount, per patient, per year, which allows commissioners and providers to clearly model their financial commitments for the future.

It is very clear from the NPDA data that there have been huge improvements in paediatric diabetes outcomes since the tariff standards were introduced. However, there are still a few units who are negative outliers in terms of outcomes (albeit far fewer than before the BPT). Up to now, the BPT has been very process-focused. In a cash-strapped NHS, it is likely that there will be an expectation that outcomes will also be looked at by commissioners in due course and those units which have been identified as negative outliers will be looked at more closely.

The trust has been receiving BPT but we have only had limited investment in our team. How do I make sure the money gets to the paediatric diabetes service?

This is a discussion you will need to have individually with your local general/business manager. If you don't, there is a real risk that it will disappear into the general black hole of NHS finances. It is also worth highlighting to the commissioners - after all, they are spending a large amount of money, so they need to be able to see where it went. If you are not able to fully demonstrate that your service is meeting all the BPT criteria, then the commissioners have no obligation to pay it. Does your trust want to lose that funding?

We still don't have a psychologist as part of the team. Will this affect our BPT funding?

Yes. Every team should have a psychologist (or equivalent, appropriately trained mental health professional) as an integral part of their team. This is so that children and young people have easy access to appropriate mental health support by someone who understands the specific impact diabetes has on a child's and their family's life. The person providing this expertise should have time for paediatric diabetes clearly identified and ring-fenced in their job plan. It is not appropriate to just refer to generic CAMHS services.

What's a 'senior member of the paediatric diabetes team'? Does a consultant general paediatrician count? What about diabetes specialist nurses or dietitians?

If they have formal training and expertise in managing paediatric diabetes, then yes. If they don't, then no. The person seeing the newly diagnosed child or young person must have specific training and experience in paediatric diabetes and they should be regularly seeing children and young people with diabetes in out-patient clinics etc.

I'm a single handed consultant with one paediatric diabetes specialist nurse. We really struggle to meet the standard to see all newly diagnosed patients on the next working day after their diagnosis once holidays etc are taken into account. What can we do about this?

Small units are going to have join with other units to provide cross cover. It will be up to individuals as to how this is organised and the networks should be able to help facilitate this.

The Best Practice Tariff (BPT) states that patients will have access to emergency advice on how to manage their diabetes 24 hours a day. It will again be up to individual units as to how this is delivered. Some may choose to work together cross covering several units at once, others may use other ways eg PDSNs provide emergency advice Mon-Fri 8-6 and paediatric registrar takes calls out of hours, using simple web-based guidelines for reference, as a first line. There must also be 24-hour access to expert advice, which must be provided by someone who is 'fully trained and experienced in managing paediatric diabetes emergencies'. Again, this may need to be provided on a regional basis, across networks for example.

How will we prove that we have achieved these criteria? The commissioners are going to want to know their money hasn't been wasted.

It is going to be vital that this information is collected in a way that allows the data to be analysed easily. There are many 'off the shelf' established software solutions to help with this and it will be again up to individual units as to how they robustly collate the information. With the current financial challenges faced by the NHS, it is going to be increasingly likely that commissioners are going to want to clear evidence that the tariff standards are being met. All units in England have been receiving tariff for at least 4 years now and so it would be expected that investment in systems to provide this information easily is now embedded.

As part of the National CYPD Quality Programme there will be an annual round of Self Assessment against 27 measures for MDTs and six for Health Boards/Trusts. These include the BPT criteria and the evidence used for the Self Assessment provides a basis for discussion with your trust management and commissioners.

Are insulin pump costs included in the Best Practice tariff? And what about the cost of insulin, testing strips, continuous glucose monitoring systems (CGMS), Flash blood glucose monitoring systems etc.?

No, all consumables are specifically excluded from the tariff. The BPT covers out-patient care as detailed in the criteria and in-patient stays specifically related to diabetes, from the date of discharge from hospital after the initial diagnosis of diabetes is made, until the

young person is transferred to adult services by the age of 19. It does not include the cost of insulin pumps, insulin pump consumables or the use of on-going, real time CGMS or Flash blood glucose monitoring and their associated consumables. It is expected that the cost of diagnostic (ie intermittent) CGMS or Flash blood glucose systems will be covered by the tariff. Emergency prescriptions for insulin and testing strips issued by the Specialist Team will be covered by the tariff but routine prescriptions for these will not. Usual practice is for these to be issued in primary care, not by the Paediatric Diabetes Team and so this will continue as before.

What happens to our patients in transition clinic? Do they still get the tariff or are they coded and funded under adult diabetes?

This will again depend on local variation and negotiations. If the transition clinic is staffed by people with expertise and training in paediatric diabetes as detailed in the criteria, then the tariff can be applied to young people attending that clinic aged up to the age of 19. Thereafter, they are classed as adults and so will be coded and funded under the adult diabetes tariff.

Does the doctor have to be present in every clinic for it to count for the tariff? The PDSN is really very good.

Yes, for a clinic to count as one of the four MDT clinics, an 'appropriately trained' doctor must be there. There is also the expectation that a PDSN and dietitian will be present for the majority of the time – clearly they are allowed leave, so using the AfC T&C to calculate their annual leave entitlement, then a singlehanded PDSN or dietitian should attend 44 clinics/year (or pro-rata if the clinics don't run every week), to allow that 4/pt/year to be offered. The expectation is that the doctor would be a consultant or SAS doctor or an experienced SpR intending to sub-specialise in paediatric diabetes. The SpR from the ward who's been to clinic once does not count!

The only exception to this would be if the PDSN was a recognized nurse consultant with their own patient list. Arguably, as they would be working at a doctor level, they should have appropriate PDSN support as well, anyway.

Why does every patient need 8 additional contacts a year? I've got patients that are doing really well and they won't thank us for hassling them unnecessarily.

These contacts mean any contact, whether instigated by the team or the family or anything to do with the child (eg the school): most families will have 8 contacts without really trying (the new meter, the letter for going on holiday, the query from school about the day trip etc). It includes e-mails, drop ins, calls to the ward out of hours etc. I have yet to meet this perfect patient who never needs any help from anyone. How good is 'really well'? Are they self sufficient or they actually just doing their own thing? Bearing in mind that still only 26% of children and young people with diabetes in the UK have an HbA1C of <7.5%, are these perfect patients really as good as you think? In reality, the families that are doing really well are probably liaising with the team themselves regularly.

I've seen the staffing levels document. They don't look right to me: there's far too much doctor time and nowhere near enough nursing time.

The staffing estimates are very much designed to be just that – estimates. They are the absolute minimum needed to be able to deliver just the clinical criteria in the tariff and do not take into account all the additional activity, training, CPD etc running a successful paediatric diabetes service requires. An increase of at least 50% more time will be needed to meet those requirements. They are also based around the concept of a fully staffed paediatric diabetes team.

All of the estimates are based around the bare minimum needed to deliver the tariff – I suspect that very few consultants have anywhere near enough time in their job plan to achieve the tariff requirements (and see the question about the MDT clinic definition above for further details).

This document is only designed as a 'starter for 10' to get dialogue going. The estimates (if the additional 50% uplift to cover other duties is included) do, however, broadly agree with the recommended staffing levels in the SWEET document.

What does 'evidence of structured education' mean?

This is very much up to local services to interpret. As there are currently no validated paediatric diabetes structured education courses, no specific course can be recommended. However, at the very least, this needs to be a check list of everything that is covered at diagnosis, plus additional check lists covered at various times of up date (eg starting primary school, when child starts doing their own injections, moving to secondary school, in mid-adolescence etc). Using the ISPAD guidance on structured education is a very good starting point.

What does a standard operating procedure mean in reality?

This means writing down and formally confirming what you do. The whole team probably knows what you do with the frequent DNAs, but is this written down anywhere? What about patients with a high HbA1C? What happens to children with diabetes under a child protection plan or in the care system? It doesn't have to be complex but it does need to be clear and documented.

What counts as 'annual' for the annual review? What happens if it's due on 1st April but the patient doesn't come to clinic until 5th May?

This kind of level of detail probably needs to be negotiated locally, but tolerances will need to be built into your service specification which will clarify all these areas. For example, for annual reviews, it might be reasonable to have a tolerance of, say, 15 months, and the expectation that 90% of patients will achieve that. There will then be more of an incentive for units to make certain all the parts of the annual review they

control have been done. Retinopathy screening is usually outwith the aegis of the paediatric diabetes clinic so teams should not be penalised if they cannot demonstrate 90% compliance with that.

What happens if, despite my best efforts, we cannot get everyone to come to clinic when they should and they just won't turn up for annual reviews etc?

Again, this is for building into the local service specification. Having had discussions now with numerous commissioners, 90% was felt to be standard level of compliance (which would mean that you would receive the tariff for the 90% of your patients that turned up, but nothing for the 10% that don't). Equally, it needs to be set quite high to ensure that services try to meet the criteria, otherwise there will be no incentive to make changes and thus lead to improved outcomes. Commissioners may also start to look at penalty clauses being built in, so failure to achieve 90% compliance could result in fines and ultimately the potential of losing the tariff altogether.

This should also encourage staffing to look at their models of working. If there are teenagers that persistently do not come during the day, would an evening clinic suit better? Or even doing a clinic in the school? Be innovative, be inventive!

How are commissioners going to check we are meeting the BPT criteria? And what about monitoring our outcomes?

This is another area for local agreement. Some commissioners may want data submitted quarterly, others less often (more than quarterly is realistically likely to be very difficult to achieve). The introduction of Self Assessment and Peer Review planned from 2018 (with participation expected to be a BPT requirement from 2019) will provide data which we expect will inform Trusts and commissioners when conducting local negotiations. The NPDA data is already available on the RCPCH open platform for commissioners to access if they wish and the proposed Self Assessment measures have been circulated to Trusts during November 2017.

Local negotiations may lead to outcome targets also being set after mutual agreement between commissioners and providers.

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