

Frequently Asked Questions on Paediatric Diabetes Best Practice Tariff

Background

Standards of paediatric diabetes care vary quite widely across the UK. Compared with many European countries, outcomes in the UK are poor - in the 2009-2010 National Paediatric Diabetes Audit, less than 15% of children and young people achieved an HbA1C below 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 > 9.5%, compared with over 40% in the UK.

An RCPCH survey in 2008 estimated that there were 23,000 CYP under 18 with diabetes in England. This is an estimate as we do not, as yet, have any robust way of collecting this data and relied on individual clinicians reporting how many patients they had in their clinic. It does, however, mean that we have the fourth largest paediatric diabetes population in the world. It also means that there is potentially an enormous burden on the NHS and the economy as a whole in the long-term, dealing with the complications of this cohort of young people.

There is also increasingly the recognition that managing CYP with diabetes is not 'just a bit of sugar' and requires appropriately skilled and resourced services to deliver this care. This was officially recognised at the end of 2010 when out-patient paediatric diabetes services were given a separate treatment function code of TFC263, when previously they could only be coded either as General Paediatrics or Paediatric Endocrinology.

Paediatric diabetes services are almost entirely out-patient based and cost far more to deliver than they currently generate in income. At the request of NHS Diabetes, two paediatric diabetes services were costed up as reference centres: Northampton General was used as the DGH model and UCL as the teaching hospital model. These centres were chosen because their outcomes in terms of HbA1C etc were among the best in the UK. Both costings were found to be broadly similar and corresponded with similar costing exercises carried out in Oxford and Leeds - to provide good out-patient paediatric diabetes care costs around £3500 per child, per year. This is also in line with what European centres such as Rotterdam charge per year.

The reasons for poor outcomes in paediatric diabetes are multi-factorial but chronically under-resourced services are unlikely to be helping. There are many highly dedicated and motivated clinicians providing paediatric diabetes services but there are still some centres where the consultant leading the service has had no formal training (and in some cases, little interest) in paediatric diabetes. Not all centres have a paediatric diabetes nurse specialist, many have no access to appropriate dietetic support and hardly any have psychology as an integral part of their clinic. This is despite the fact that NICE guidelines recommending all of these have been in place now for nearly 8 years.

Why do we need a paediatric diabetes tariff?

The idea behind a specific paediatric diabetes tariff is to set certain minimum standards of care and offer an enhanced payment to those centres that meet those criteria. 2011-12 is the first year that paediatric diabetes has been formally recognised as a speciality in its own right and the payment by results criteria for this financial year can potentially reward this. The criteria are set out in the PBR guidance for 2011-12.

Currently, the basic payment for patients attending a paediatric diabetes out-patient clinic are £358 for a first out-patient attendance and £121 for each clinic attendance thereafter. If the criteria set out are achieved, then an additional payment of £148 per clinic attendance can be claimed. This is non-mandatory at present, so not all commissioners have agreed to fund it, even when all the criteria are met.

Is the extra payment a one off or does it apply to each clinic visit? And are there any restrictions as to which patients it applies (eg only newly diagnosed patients)?

If the additional funding is agreed, it applies to every MDT clinic visit, provided that all the criteria set out in the PbR tariff document are met. It applies to every patient who attends the paediatric diabetes clinic, regardless of how long they have had diabetes or what type of diabetes they have. It applies to every child and young person attending a paediatric diabetes clinic up under the age of 19.

Is there a limit as to how many clinic appointments this will apply to?

In theory, no. In reality, capacity issues will restrict the number of times a patient can be seen in a year. From a commissioning point of view, open-ended contracts such as this are not ideal as they are very difficult to budget for, which is why we are looking to move to 'year of care' model for the Best Practice tariff for next year.

The commissioners have agreed to fund the new PbR tariff. 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 quite a large amount of extra money (for a unit of 100 patients, this is potentially an additional £60,000 this year), so they need to be able to see where it went.

I think we meet the criteria for the tariff but I'm not sure about the psychology bit. What does that actually mean?

This has been left deliberately woolly for the moment as this is the area that most services struggle with. It is appropriate for the lead clinician or PDSN to make an informal assessment of psychological well-being (eg using the HEADSSS assessment tool) and a referral to CAMHS if one is felt necessary would count as 'access to psychology services'. In due course, the criteria are likely to become more robust and proscriptive, encouraging services to purchase dedicated psychology time from the additional funding. For the time being, just encouraging people to think about possible psychological issues will be a step forward in some centres.

What's a 'senior member of the paediatric diabetes team'? Does a consultant general paediatrician count?

If they have formal training 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. See below for further discussion of this.

I'm a single handed consultant with one paediatric diabetes specialist nurse. We will 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. Units also need to be aware that the current proposals for the Best Practice Tariff (BPT) (which we are hoping will apply from April 2012), there will also be an expectation 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. If the tariff is approved, the additional cost for providing this service will come out of the enhanced tariff the Best Practice Tariff brings.

How will we prove that we've 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. It is very important that all paediatric diabetes clinics are coded with TFC263 so that they can be easily identified by coders, which will help to some degree.

Are insulin pump costs included in the tariff for this year or the Best Practice tariff in future? And what about the cost of insulin, testing strips etc?

No, all consumables are specifically excluded from the tariff. The proposed Best Practice tariff covers out-patient care as detailed in the criteria, from the date of discharge from hospital after the initial diagnosis of diabetes is made, until the young person is transferred to adult services at the age of 18+. It does not include in-patient care, the cost of insulin pumps, insulin pump consumables or the use of CGMS and its associated consumables. 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 training in paediatric diabetes as detailed in the criteria, then the tariff can be applied to young people attending that clinic aged up to and including 18. Thereafter, they are classed as adults and so will be coded and funded under the adult diabetes tariff.

What's the difference between the proposed mandatory (national) Best Practice Tariff and the current non-mandatory PbR Top-up tariff?

The current top-up is non-mandatory, so the majority of commissioners may not have agreed to fund it. The proposed Best Practice Tariff (BPT) is a mandatory (national) tariff, so commissioners will **have** to fund it and find ways of funding it (there is no new money for any of this – it will have to come out of already very stretched existing resources). The other difference is that the proposed BPT will be a 'year of care' model, with a fixed amount being paid for every child and young person (aged 18 and under) attending a paediatric diabetes clinic (as defined in the tariff) per year. If a child is diagnosed mid-way through a year or moves up to adult services mid-way through a year, then it will be paid pro-rata. How this is paid is up to local negotiations, but we would recommend that you ask for it quarterly or at least 6 monthly, to allow services to develop.

With new tariffs such as this, commissioners have explained to me that it is fairly usual for them to release, say, 50% of the enhanced payment in advance to allow staffing levels to be increased so that it can be actually delivered. If, however, the criteria are then still not met, the money would need to be paid back.

Current negotiations are based around a tariff of £3500/pt/year, which is based on careful costings done at several different units in England and is pretty much in line with what European centres charge, too.

I hear that the new Best Practice Tariff is likely to be an 'all or nothing' tariff. What does that mean?

The rationale behind the BPT criteria is to improve paediatric diabetes care. The idea is that those services providing paediatric diabetes care will have to achieve all the specified criteria in the BPT or they will get no money at all. This is to encourage Trusts and commissioners to appropriately resource paediatric diabetes services to allow the criteria to be met. If the default position is for Trusts to continue to get the same amount of money as they do now, there will be no incentive to invest in the services and thus improve care.

We realise that not all services will be in a position to meet all the criteria from 2012, so if the Best Practice Tariff is agreed, there will be a staged approach to the implementation of the BPT in the form of a transition year (2012-13) to give the opportunity for all diabetes services to improve. The care provided during this improvement phase will be reimbursed on a pre-BPT basis with a

mandatory first outpatient attendance tariff and a follow-up outpatient attendance tariff. Following the transition year, it is intended that the BPT will be fully implemented in 2013-14.

It is very important that local general managers and commissioners are made aware of this so that appropriate arrangements can be made to ensure that local paediatric diabetes services are able to meet the criteria by 2013.

Is in-patient care covered under the Best Practice Tariff?

No, assuming the BPT is approved, it will only relate to out-patient activity, but will cover **all** out-patient activity. The four MDT clinics and additional eight patient contacts per year are the **minimum** numbers of out-patient contacts/ year. Under the PbR agreement, Trusts will get paid every time the patient attends a MDT clinic, which potentially could be limitless. This makes budgeting very difficult for commissioners.

Patients with poor control, difficult social circumstances, other medical problems will need more appointments and contacts than this, which is part of the reasoning for setting the tariff at fixed yearly rate that is substantially higher than is currently paid under the PbR agreements; the 'easier' patients will balance out the additional input required by the more 'difficult' ones. Current discussions are looking at around £3500/patient/year as this is what several different costing exercises in different Trusts around the country have consistently shown to be the average costs of providing paediatric diabetes care.

How do I make sure we are ready for the new tariff in 2012-13?

It is vitally important that all paediatric diabetes clinicians engage with their general managers and also link with the relevant commissioners to flag the potential changes coming. The networks and in particular the network co-ordinators can help with this, but these meetings need to be set up now. If the Best Practice Tariff is going ahead, there will be road testing in October 2011 and then the proposals will be published in draft in early 2012.

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 <15% 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. Clearly, if there is no psychology support easily available, then that will increase the amount of time the other members of the team will need to do their job. 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). I would recommend using the ISPAD 2009 guidance on structured education as 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 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 penalized 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). This still represents a huge increase funding compared to current levels. Equally, it needs to be set quite high to ensure that services try to meet the criteria, otherwise there will be no incentive to improve them and hopefully improve outcomes. Commissioners also made it clear that there are likely to be penalty clauses built in, so failure to achieve 90% compliance would 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!

If this tariff is approved, it will represent an enormous increase in funding for paediatric diabetes. The ultimate aim is to save the NHS large amounts of money in the long run. If we can improve diabetes control in children and young people, then we can prevent complications and all the costs they incur; not just the costs in treatment, but the costs in lost income, lost taxes, paying disability benefits etc etc.