Does the Best Practice Tariff for paediatric diabetes create inequity of service provision and the death knell for any semblance of a UK-wide NHS?

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Type 1 diabetes is one of the most common chronic conditions in childhood. In the United Kingdom (UK), there are about 26,500 children and young people with type 1 diabetes. Paediatric diabetes outcomes in the UK are poor when compared to the rest of Europe, and are not improving. The data are extremely concerning – although the recommendation from the National Institute for Health and Care Excellence (NICE) is a glycosylated haemoglobin (HbA1c) target of 58mmol/mol (7.5%) or less, the mean HbA1c between 2003–2010 for children aged <18 years in England and Wales was 72mmol/mol (8.7%). No such national figure is available for Scotland but there is no reason to believe that it would be much different.

The Best Practice Tariff for paediatric diabetes

In 2009, huge differences were identified concerning how services for children with diabetes in England were staffed, delivered and supported. This resulted in the implementation of a Best Practice Tariff (BPT) in paediatric diabetes in England in April 2012. This BPT comprises 13 standards (see: www.diabetes.nhs.uk/networks/paediatric_network/best_practice_tariff_for_paediatric_diabetes/#), and the Department of Health has mandated that if services meet these standards, they must receive the set tariff (a funding increase) from their commissioners. Services that fail to meet the standards have a year to improve and are given support to do so. A firm belief underpinning the development of the standards is equity for all: ‘the same standard of care and access to services should apply no matter where you live.’

Potential impact on services

Due to the introduction of the BPT, investment has been made into paediatric diabetes services in England. However, the BPT has not been applied across devolved UK countries. This article provides views and experiences from health professionals working in paediatric diabetes services from each of the four UK countries.

England

In the north east of England, the effects of meeting the BPT standards are dramatic. Services are improving out of all recognition. The driver for change is the knowledge that the money for the BPT may have to come out of existing funds, but will be removed if the BPT is not satisfied. To put this in context, for one trust, this represents a loss of almost £1m a year, the potential for which has resulted in swift moves to appoint the necessary personnel. For example, having fought for over 28 years to get a clinical psychologist as part of the service, a part-time psychologist was appointed within months and is already making a difference. In addition, this service now has a specific nurse educator who is inputting structured education into every clinic session and arranging additional, specific training sessions for children and clinic staff. There is also a new dietitian and even a clinic organiser/data entry person. Improvements are already evident. The proportion of children with an HbA1c <58mmol/mol has risen from 20% in 2010 and 2011 to 24% this year thus far. This figure improves considerably for children diagnosed in the past three years, 35–40% of whom have an HbA1c <58mmol/mol, even after three years, and across all ages. The idea of the BPT was to move towards the German model of care and control, which took approximately 10 years to show substantial change, and the same will probably apply to the BPT.

Alongside the basic process measures to satisfy the BPT, there are wider ramifications resulting from the need for all clinics to network together, and the consolidation of a formal national network that is driving change. It is mandatory for all clinics to submit data to the national audit, which, of course, is public, and to participate in a peer review process. Thus, not only do clinics have to say what they are doing, but they also need to prove they are doing it. Chief executive officers of trusts are directly involved and responsible for this – which seems to be making a difference to getting things moving!

Scotland

The NHS in Scotland has taken an entirely different approach. Not only is there no purchaser-provider split but there is no structure to support service development linked to improved outcomes. However, in relation to diabetes in children and adolescents, the Scottish Government mandated in February 2012 that, from an almost standing start in most areas, 25% of children with type 1 diabetes should be on insulin pump therapy by March 2013. Hardware (pumps and a year’s consumables) were purchased in bulk and individual health boards drew up plans to implement the directive. For most, this has proved an impossible target but there has been some investment in new staff (albeit temporary) and the number of children on pumps has increased dramatically. The Scottish Diabetes Group reports directly to the Scottish Government and has oversight of services in Scotland via the health board Managed Clinical Networks (MCNs), but children’s medical services are not well represented in the MCNs and funding comes via the Women’s and Children’s Services route, which makes joined-up thinking about service provision troublesome. Nonetheless, the Scottish Government is taking an extremely keen interest and demands monthly progress reports towards its target. This scrutiny keeps
local health boards interested in service provision, at least in the short term. What happens when the 25% is reached is so far shrouded in mystery.

It is far too early to say whether this rapid implementation of insulin pump therapy will be of benefit but it is obviously a very different model of service development to that being employed via the BPT. One could argue that the latter is likely to be more sensitive to the needs of local services with decisions about where resources should be placed being made locally. However, this is simplistic and fails to take account of the very different model of provision of expensive interventions such as pumps and, increasingly, continuous blood glucose monitoring. A directive as challenging as the insulin pump mandate forces teams to focus on all aspects of care delivery. Thus, changes in provision extend well beyond just pumps. The task, of course, is to ensure that non-pump aspects do not suffer.

However, Scotland is a small enough country that some of the difficulties faced elsewhere in the UK are not an issue, and clinicians involved in young people’s care meet regularly to discuss priorities. An almost inevitable consequence of the BPT approach will be that there will be winners and losers. Thus, smaller units will be subsumed by larger ones. This is not necessarily a bad thing, but it is a less acceptable approach for Scotland with its significant geographical challenges. The hub and spoke approach being adopted in some English regions may be much more appropriate.

Wales

While services in England have been given what some may see as a lifeline, an unpublished telephone audit of services across the border in Wales identified that paediatric diabetes teams are struggling to maintain the provision of a diabetes structured education programme due mainly to totally inadequate dietetic support. NICE guidelines concerning children with diabetes and insulin pumps are based on the best available evidence but are still not being delivered in Wales. As found in England in 2009, there are varying standards of care across Wales, which may be due to clinics working in isolation, both from each other and, possibly more importantly, from their managerial systems, which ultimately determine funding. The NHS in Wales spends £5m/year on diabetes, but how and where this money is allocated is anyone’s guess. This massive sum should be sufficient to provide high-quality care but this does not seem to be effectively communicated to managers, who tend to have a short-term view of care outcomes based on acute services. Health boards seem to be failing to take on board, and really understand, what it is they are managing, seeing pennies and not people within a short-term context. It is also possible that health care professionals see themselves first and foremost as clinicians and are not as effective as they might be at communicating clinical priorities to those who hold the purse strings. Political masters need to be held to account for inadequacies of care, and not to simply point the finger at health boards. All these parties ultimately want the same outcomes, but how do we turn these good intentions to solid outcomes and improvements for children?

There needs to be increased transparency (particularly concerning where and how £5m/year is being spent on diabetes care), better information and evidence and, above all, better communication between key stakeholders. We are fortunate to have an established multidisciplinary clinical network for paediatric diabetes, the Brecon Group, founded in 1994 to advance the care and support of children with diabetes in Wales. However, although a very active group that has established a register in Wales, there is no managerial component to the network and hence new initiatives spread very slowly. The specific aims of the group when it was set up were to form a national view on standards of care, advise health service commissioners of care and act as a forum for audit (see: www.welshpediatrics.org.uk/diabetes-children-wales-%E2%80%93-work-brecon-group). However, as in England, clinics need to participate in peer review to address standards of care and ensure equality, and to actively promote feedback from families they treat. Outcomes of these processes could then be communicated effectively to managers to drive change and service improvement. This initiative is yet to cross the border from England into Wales.

Northern Ireland

Despite the production of the CREST report, which highlighted children and adolescent diabetes care as a priority area for action, diabetes services for children in Northern Ireland (NI) have failed to make significant progress over the past 10 years. Although some progress has been made, this has generally been as a result of the work of individual trusts or practitioners, leading to an ad hoc development of services with little overall strategic vision and a wide disparity in children’s diabetes care between service providers. One area of improvement has been a significant increase in the number of paediatric diabetes specialist nurses appointed. However, the absence of an overall strategic vision has led to a wide disparity in how each trust chooses to appoint such positions, with at least one trust continuing to appoint diabetes specialist nurses with combined responsibility for both adult and children’s services. Following consistent calls for a strategic review of the CREST report, the Minister for Health (NI) commissioned a policy group in 2012 tasked with evaluating this report and formulating a strategic vision to take diabetes care forward in NI. The report of this group is eagerly awaited and expected in September 2013.

Similar to Scotland, there has been a drive in the development of insulin pump therapy for children and adolescents in NI. In an effort to support the development of insulin pump services, a significant number of insulin pumps were purchased and distributed to each trust to assist with implementation of pump therapy. Unfortunately, no additional funding was supplied for staff time with the expectation that this service would be developed within existing resources. This has led once again to a wide disparity in the development of pump services throughout NI. In the absence of a target – such as that set by the Scottish Government or standards set within the BPT – these disparities are likely to remain for the foreseeable future.
In contrast to other devolved nations, NI does not have a single clinical database for all people with diabetes, which impacts significantly on NI’s ability to measure success of diabetes care at a national level. Although there has been a move to implement a single electronic paediatric diabetes care system across all trusts, differing versions of the system, inability to request national information without the assistance of the British Standards Agency and no link between the paediatric and adult systems continue to cause great difficulties.

The current review of CREST offers the opportunity for the NI assembly to provide a strategic vision for paediatric diabetes care over the next five years. Such a vision would have to be supported both financially and clinically in order to succeed. Furthermore, there is a need to embed appropriate robust measures to ensure targets are being achieved and a line of accountability in order to address poor performance.

Discussion
Investment into paediatric diabetes services in England due to the BPT is potentially in the best interests of children and young people with diabetes, and this has got to be a move in the right direction. Especially if we consider the increased investment in staff, e.g. psychologists, paediatric diabetes specialist nurses, to help ensure achievement of the standards. Currently, despite the need to justify the additional funding through a demonstration of improvement to outcomes, the focus is on process rather than outcome. Nevertheless, evaluating success with process measures is an important start and will provide a baseline against which to measure harder outcomes. In Scotland, the introduction of a single clinical database (SCI-Diabetes) for all patients with diabetes should help with this.

Nonetheless, how does the introduction of the BPT in England, but not in the other three devolved countries, equate with the underpinning philosophy of equity for all children and young people with diabetes and their families and the founding principles of the National Health Service? The introduction of this BPT has effectively created a postcode lottery in the UK in relation to paediatric diabetes care. It was probably inevitable that four devolved health systems would lead to different standards of care given the differing political stances of their political masters, but this should not undermine the basic premise of the NHS — equality of care for all.

Children’s diabetes services could reasonably be seen as a paradigm of wider NHS specialist provision and the social experiment underway with politically diametrically opposed policies north and south of the Border invites close scrutiny. It behoves all of us involved to pay close attention and to learn the lessons. The challenge now is to demonstrate swiftly any benefits from the BPT in England — the national diabetes audit should be able to do this now it has been taken over by the Royal College of Paediatrics and Child Health and made more relevant. It is vital that clinical and political leaders in the four home countries consider how the emerging evidence impacts upon the provision of services so that children and adolescents with diabetes in the UK can receive the best possible care.

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Declaration of interests
There are no conflicts of interest declared.

References

Drug notes
Find out how non-diabetes drugs impact diabetes patients. Visit the Practical Diabetes website and click on drug notes

Bromocriptine
Bumetanide
Carbamazepine
Cilostazol
Darbepoetin alfa
Diazoxide
Dipyriramole
Dronedarone
Duloxetine
Erythromycin
Labetalol
Lidocaine
Methyl dopa
Metoclopramide
Om acor
Prasugrel
Quinidine sulphate
Ranolazine
Spironolactone
Testosterone
Torcetrapib

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