

# Further reflections on the caseload in Leeds, the impact of the Best Practice Tariff and the implications for future working practices

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**This paper is a follow-up to an article originally published in 2012. It considers the children and young people with diabetes who attend the Leeds Children's Diabetes service. It discusses the reasons why there are a growing number of referrals to the service and the changing diversity of the caseload, which has an increasing proportion of ethnic minority groups and a high number of children who are living in areas of deprivation. It also considers the mix of skills needed to deliver the service and the impact of the Best Practice Tariff. The paper concludes that in order to provide a sustainable service for the future, core commissioning groups and managers need to work together to meet the needs of an ever-growing caseload.**

Diabetes continues to be a major threat to health, affecting 3.2 million people in the UK (Diabetes UK, 2014). A significant increase has been observed among the numbers of children developing diabetes, and the latest figures from Diabetes UK (2014) estimate there to be about 35 000 children and young people with the condition. Ninety-six per cent of these children have type 1 diabetes, 2% have type 2 diabetes and another 2% have monogenic or rare forms of the condition. Nationally, the current prevalence in children aged 0–14 years is 24.5 per 100 000. A study of the population in Yorkshire predicted the overall incidence of type 1 diabetes to rise to 39 per 100 000 per year by 2020, with the distribution of new cases across age groups predicted to be 20% 0–4 years, 37% 5–9 years and 43% for 10–14-year-olds; forecasted incident rates for south Asians are 20.1% (Harron et al, 2011).

On average, life expectancy is reduced by 23 years for young people with type 1 diabetes and by 10 years for those with type 2 (Department of Health [DH] Diabetes Policy Team, 2007), although recent studies are showing significant

improvement for people with type 1 diabetes born later in the 20<sup>th</sup> century. Cardiovascular disease accounts for 44% of fatalities in people with type 1 diabetes (Morrish, et al, 2001). The total cost directly and indirectly associated with diabetes in the UK stands at £23.7 billion per year and is predicted to rise to £39.8 billion by 2035 (Hex et al, 2012). The All Party Parliamentary Group (APPG) for Diabetes suggests that the cost to the NHS is £1 million per hour (APPG for Diabetes, 2013).

## Caseload profile

It is now 3 years since a profile of the caseload in Leeds was first undertaken (Sewell, 2012). The patient population has increased from 345 in April 2011 to 437 children and young people when the caseload was re-examined in April 2014. The numbers admitted to the caseload in Leeds have been steadily rising, with 56 new cases being diagnosed in 2011/12, 48 in 2012/13 and 60 in 2013/14, demonstrating at a local level the increase in incidence that has been predicted nationally. Sixteen of the children are under the age of 5 years. Diabetes in this age group poses unique challenges for the

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## Article points

1. The Leeds Children's Diabetes service has an ever-growing and changing caseload with a large number of children and young people living in areas of deprivation.
2. The service is attempting to provide the best possible care to its challenging caseload by improving structured education, targeting services to people with the greatest need and providing more psychological support.
3. Managers and core commissioning groups will need to work together with clinicians in order to provide high-level care to this growing patient group.

## Key words

- Caseload profile
- Diversity
- Future planning
- Sustainable service
- Workforce planning

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### Page points

1. The Leeds service sees 16 children under 5 years old who have diabetes. This group is at high risk of complications and requires intensive support.
2. In 2011, 12% of the caseload was from ethnic minority groups. This has now increased to 22%.
3. With 59% of the children on the caseload living in areas of deprivation, care needs to be directed to the areas of greatest need.

children, their families and the diabetes team. The former require intensive support and care with the use of technologies, such as insulin pump therapy and continuous glucose sensing, in order to deal with the complexities of day-to-day diabetes management and to minimise the risk of diabetes-related complications. These children are at greatest risk as complications become more likely with increasing age and duration of diabetes (Zoungas et al, 2014).

The number of cases of type 2 diabetes has increased since 2011, when there were just eight cases, to 18 children with the condition in 2014. Thus, we are seeing the increase in referrals that was predicted by Fagot-Campagna (2000). This is due, in part, to the rise in obesity levels (Springer et al, 2013). Treatment involves integrating modification of lifestyle factors, such as diet and exercise, along with medication (Copeland et al, 2013). Therefore, in Leeds, a monthly dedicated type 2 clinic has been introduced. This provides children and young people with input from all members of the multidisciplinary team, including psychology and dietetics, to tackle the multifaceted issues associated with this problem.

About 22% of the caseload is made up of ethnic minority groups, compared to 12% in 2011. Children and young people from these populations have particular problems, with a higher incidence of type 2 diabetes and poorer control (Diabetes UK, 2010). It has been suggested that ethnicity plays a larger role than deprivation in determining HbA<sub>1c</sub> (Thompson et al, 2011; 2013). The diabetes team, therefore, will need to consider how they may approach different ethnic groups in order to deliver effective and equitable diabetes care. Perhaps future teams may need to ensure that there is recruitment of staff from the different ethnic groups represented in the caseload in order to offer a greater understanding of the culturally diverse patient population.

Latest figures following the 2011 UK census indicate that 23% of all children in Leeds are living in poverty (Leeds City Council, 2012). Indices of deprivation are an important tool for identifying areas of greatest need and look at income, employment, health, education, housing and crime rates (Leeds City Council, 2010). Leeds has some of the most deprived areas in the country as measured by the indices, with several inner-city areas giving cause for concern (Leeds Church Institute, 2010). It is, therefore, no surprise to see that 59% of children

living with diabetes in Leeds reside in areas of high deprivation. This is hugely significant as social deprivation is strongly associated with poor glycaemic control (Zuidwijk et al, 2013). In these areas there are higher levels of obesity, physical inactivity, unhealthy diet and smoking, all of which are linked to the risk of developing serious diabetes-related complications (APPG for Diabetes and Diabetes UK, 2006).

Hine et al (2011) indicated that social deprivation and low levels of education were associated with low uptake of diabetes self-care and poor success with intensification of insulin regimens. People with a higher socioeconomic position generally have a greater array of life chances and better health (Marmot, 2010). In his review, Marmot states that inequalities need to be tackled by employing “proportionate universalism”; that is, having actions of a scale and intensity that is proportionate to the level of disadvantage. Therefore, consideration needs to be given to directing services and resources in the areas of greatest need. For example, a dedicated social worker for families who are experiencing difficulties would be able to help them manage complex social issues that impact on their ability to manage diabetes (Martin et al, 2012).

Patients have had a legal right to choose where to receive their care since 2009 (NHS, 2014). Patients from outside Leeds account for 21.3% of our caseload compared with 17.3% in 2011. Some children and families travel a considerable distance to access our service which brings unique challenges for all concerned. Clear communication is required with all parties to agree roles and responsibilities regarding what the team in Leeds is able to provide. For example, we may be unable to undertake community visits or attend meetings in the child’s school if it is too far away. Difficulties may arise when there are safeguarding issues, and it may be better for the child and family to have more immediately accessible local support.

### Inpatients

In 2011 less than 1% of the caseload was in hospital at any given time; this remains the case to date. Often this is at diagnosis. At diagnosis, an unacceptable number of children are still presenting with diabetic ketoacidosis (Lokulo-Sodipe et al, 2014), and there needs to be an improved public and professional

awareness of the symptoms of diabetes so that prompt diagnosis and referral can be made. This is the case in Leeds and the team uses the Diabetes UK 4 Ts campaign (Diabetes UK, 2012) to raise awareness among the public and professionals alike.

When a child is admitted at diagnosis, referral to the diabetes team needs to be prompt. Edge et al (2011) highlighted that communication with the team out of hours can be challenging and highlighted the importance of having link nurses on the wards and in accident and emergency. These challenges are recognised by the Leeds team, as there is a limited availability of medical hours and a current need for consistent named diabetes link ward nurses on each shift. These are areas that the medical staff, team leader and clinical educator are working to address with business managers, ward leaders and matrons.

Children may be admitted to the ward electively for re-education following poor adherence to treatment regimens, which is particularly prevalent during adolescence (Taddeo et al, 2008). They stay for 4–5 days and attention is given to optimising blood glucose levels to allow them to learn about diabetes and be supported in all aspects of management, thus giving them space to focus on the condition and relieve the burden and responsibility of managing diabetes 24/7. Although one could argue that an intensive education programme can be delivered on an outpatient basis, the children and young people and their families still have to care for the diabetes overnight and parents tell us this is the time they find most worrying. A hospital stay can relieve this burden for a short period. Families who have experienced this report that it was beneficial and gave them an opportunity to re-evaluate and refocus attention on their diabetes management.

As Leeds is a large regional centre, children with diabetes attend from other centres for planned surgery or day case admission, with the team liaising with the child's local diabetes team to provide a care plan for the ward. Other children whose primary diagnosis may not be diabetes (e.g. cystic fibrosis-related diabetes and steroid-induced hyperglycaemia) are referred to our service. These children may then be assimilated into the caseload if the diabetes continues. They are exceptions to our patient populations under the terms of the Best Practice Tariff (BPT; NHS Diabetes, 2012) and are not, therefore, accounted for in the funding

for service provision. This needs addressing, as on average there are 3–4 referrals each month, and the nursing team may spend 1–2 hours each week providing education and care for these children.

Geography impacts on the workload of all team members. Our inpatient base is at a separate site in the city, and travelling to and from the site needs coordination and careful planning if patients are to be seen in a timely manner. The future may see the team being relocated (again), although this will need careful consideration as the team currently has a space for education and outpatient work that is fit for purpose. This space was hard won – children and young people and their families supported the team to develop this resource with charitable donations. Both our peer-review reports have described the accommodation as an asset to the functionality of the team. A protected environment conducive to learning is important (International Society for Pediatric and Adolescent Diabetes, 2009). The International Diabetes Federation (2009) states: “The quality and availability of the physical space and educational resources affects learning”. Therefore, as education is the cornerstone of diabetes care and structured diabetes self-management education is key to a successful outcome (Martin et al, 2012), any relocation would need to include provision of appropriate accommodation.

### Education

The latest National Paediatric Diabetes Audit Report highlighted that children in England and Wales have exceptionally poor glycaemic control, with only 18.4% achieving the target HbA<sub>1c</sub> of 58 mmol/L (7.5%) or less, while 23.9% have an unacceptable level of glycaemic control (Royal College of Paediatrics and Child Health [RCPCH], 2015). Other areas in Europe have a more comprehensive service provision for children and young people with diabetes (Danne et al, 2001). For the past decade, Germany has had a national programme of structured education and they have seen a significant improvement in metabolic control along with a decrease in hypoglycaemic events (Rosenbauer et al, 2012). The DCCT (Diabetes Control and Complications Trial) Research Group (1993) and the EDIC (Epidemiology of Diabetes Interventions and Complications; 2005) study provided strong evidence that good control

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### Page points

1. Education is the key to good glycaemic control and the Leeds team has been working on an improved structured education programme.
2. The Best Practice Tariff has enabled an increase in staff.
3. Increased psychological input has been welcomed as people with chronic conditions are more likely to develop depression and this can have an impact on diabetes management.

reduces the complications of diabetes and improves outcomes. Rosenbauer et al (2012) highlighted that the improvement in control could be attributed to the intensification of treatment, improvements in the quality and delivery of patient education, and a well-motivated multidisciplinary team. Leeds has a well-motivated and skilled multidisciplinary team which is committed to improving outcomes for children and young people. The Leeds children and young people's diabetes team works constantly to improve the quality and consistency of the structured education programme, in particular from diagnosis and during the first year of diabetes. It is recognised that a "good start", based on treatment, intensive education and ongoing support, results in prompt reduction of HbA<sub>1c</sub> and maintains optimal control (NHS Diabetes, 2013). Thus an important tracking effect is produced and maintains an optimum quality of life (Edge et al, 2010; Viswanathan et al, 2011). Since implementing this more intense educational approach we have seen some improvements in HbA<sub>1c</sub> results, with figures for January–March 2014 showing an average of 25.6% of the caseload achieving or bettering the target HbA<sub>1c</sub>.

### Best Practice Tariff (BPT)

Since 2013, the multidisciplinary team has expanded and now includes two whole time equivalent (WTE) dietitians (one is currently on maternity leave and is backfilled by 0.6 WTE), one WTE psychologist, 1.5 WTE paediatricians with expertise in paediatric diabetes (although this is woefully inadequate and negotiations are ongoing to improve this as more medical hours are required) and 0.5 WTE play therapist. In order to provide a transition service for young people aged 16–19 years, the number of children and young people's diabetes nurse specialists (CDNS) clinical hours has increased to 6.36 WTE. There are 0.9 WTE hours for clinical education, research, transition development and management. There is now a ratio of one WTE CDNS for 69 children and young people compared with one WTE for 83 children and young people in 2011. However, there has been no increase in secretarial or administrative support and this needs addressing.

An increase in staffing was enabled via the Best Practice Tariff (BPT) payment of £3189 per patient per year for every child or young person attending

the Leeds Children's Diabetes Service and fulfilling the requirements of the mandatory tariff (NHS Diabetes, 2012). (The value for 2014/15 is set at £2988.) The income to the trust over the year is in excess of £1 305 756. However, once the service bills have been paid, any money left goes straight to the organisation and is not reinvested in the children's diabetes service. One way to ensure transparency would be for the organisation to provide an annual account of how the money from BPT has been spent and how much, for example, is spent on staffing, equipment or other resources.

One of the challenges the nursing team faces is ensuring all families are offered the additional eight contacts per year as specified by the BPT criteria (Randell, 2014). Some families in greatest need of support, such as the under 5s or those living in areas of high social deprivation, receive a significantly high number of contacts each year. This, along with inpatient work and referrals for advice and technologies (e.g. on continuous glucose sensing), has an impact on the ability of the CDNS to fulfil this criterion for all families. In addition, some families have a high capacity for diabetes self-management and would prefer to be the ones to initiate contact between clinic visits, although one could argue that unless we contact and seek out the opportunity to promote good diabetes management the status quo will continue. However, if we are working in partnership with families (DH Diabetes Policy Team, 2007) then that level of contact and communication is negotiated and agreed.

The increase in psychology hours has been welcomed. People with a chronic long-term condition are 2–3 times more likely to develop depression (Fellow-Smith et al, 2010). Failure to recognise psychosocial and psychological distress leads to ineffective or inappropriate efforts to intensify therapy. This, in turn, may worsen the distress (Cameron et al, 2007). Rates of psychological distress are high and this can persist into adulthood (Northam et al, 2005). Thus one of the criteria is to ensure all children and young people have an annual psychology assessment. More problematic is how to do this. Cameron et al (2007) suggest a self-administered questionnaire along with other clinical tools and interviews. In Leeds, children and young people over the age of 11 and their parents are invited to complete a psychological

screening tool in the clinic once a year in order to screen for distress. This is in the early stages and the team is looking at effective ways to ensure that it is administered effectively. Early indications suggest that a significant number of our caseload would benefit from psychological support, and that children and young people with the poorest control could be described as self-harming by omitting treatment. Martin et al (2012) suggest that contact with a psychologist should be mandatory. There is a definite need for more psychology hours in the form of therapeutic intervention, individual support from diagnosis, group work and the planning of effective ways to teach young people and their families.

The team in Leeds constantly reviews the service and responds to the needs of those children and young people visiting us. Our patients have reported high levels of satisfaction with the service they receive (RCPCH, 2015). It is not known, however, whether this has been as a result of the BPT or if the report would have been positive anyway. The team will continue to audit this.

It is worth noting that the BPT does not provide funding for those over the age of 19 years when transition to adult service takes place. Young people between the ages of 16 and 19 years are cared for by a dedicated transition service. However, the journey post 19 years is not so clear. More work needs to be undertaken to collaborate effectively with our adult colleagues. One way forward is to develop a provision that straddles the services for both children and young people and adults, providing dedicated holistic care from 16 to 25 years.

## Discussion and the future

Along with the BPT (Randell, 2014), the National Paediatric Diabetes Peer Review programme (<http://www.nationalpeerreview.nhs.uk>) has been welcomed by the team in Leeds as a way to drive up standards of care nationally. In addition, qualitative research into the lived experience of children and young people and their families strengthened the need to improve services (Kime and Carlin, 2012). There have been numerous changes since 2011, with additional staffing, structured education and more use of insulin pump therapy (47.5% of children and young people attending the service in Leeds now use an insulin pump) and technologies to support care. On top of this, there has been a significant increase

in the number of patients admitted to the caseload, necessitating an increase in the number of clinics and contacts. Team members have to continually re-evaluate working practices in order to accommodate this increase. Home visits have reduced but contacts via email, text and telephone have increased, as has nurse-led, dietetic and psychology contact in the centre. Work with schools continues and the team is working closely with the local authority to support school staff in an efficient and effective way, such as with a yearly workshop.

It is vital that staff caring for children and young people with diabetes are appropriately trained (Waldron et al, 2012). Staff in the team are encouraged to maintain their continuing professional development and this year has seen staff attend the children and young people Master's module at York, the transition module and the non-medical prescribing module, the latter being essential to fulfil the role of CDNS. More challenging is ensuring that ward staff have the necessary knowledge and skills to care for diabetes. As well as formal courses, another option may be to have a rotational post with a link nurse spending 6 months working with the team. This would see expertise taken back to the ward environment and provide a step on the path for a career in diabetes care.

More recently, negotiations have been underway to secure a band 5 development post (fixed term for 1 year and review) as the first step on the diabetes nursing career ladder. Further work is required to ensure succession planning and a career pathway in diabetes nursing from band 5 to band 8 in order to maintain a highly skilled workforce and provide excellent care.

Although there have been many developments since 2011, the team must continue to develop and remain at the cutting edge of diabetes care if the outcomes are to improve for children and young people and their families. Having nationally recognised accredited programmes for professionals and patients (NHS Diabetes, 2013) would go some way to achieving this. If a reduction in the average HbA<sub>1c</sub> can be achieved and maintained through intensive treatment, support and education, then this would minimise the risk of future diabetes-related complications and also reduce the cost to the NHS. One way to increase support and care is to have a reduced ratio of CDNSs to patients. For example,

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the Family Nurse Partnership (FNP) Programme operates on a 1:25 nurse-to-client ratio and this has a robust evidence base to improve health, social and educational outcomes in the short, medium and long term (FNP, 2014). One wonders if this model could transfer to diabetes and whether an approach of regular visiting within the first year or two post-diagnosis would promote good outcomes. Perhaps this is worthy of further investigation. Although expensive, the costs would be offset by saving on the amount spent treating diabetes-related complications.

Whatever the future holds, delivering a high level of care will carry costs, so local managers and core commissioning groups will need to work together to ensure service provision meets the needs of this vulnerable population in the coming years. ■

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