

POSITION STATEMENT

Title	Date
High Quality Care for Children and Young People with Type 1 Diabetes in the UK (Type 1 Essentials for Children and Young People)	April 2015
Key points	
<ul style="list-style-type: none">• The UK has the fourth highest number of children and young people in Europe with Type 1 diabetes, but is one of the worst performing countries in terms of blood glucose control;• The need to improve the delivery of paediatric diabetes care is widely acknowledged and work is underway in all UK nations to prioritise this area of care.• Children, young people and their families should know what care they should be getting. Diabetes UK have produced Type 1 essentials for children and young people to increase awareness.	
Introduction	
<p>There are about 35,000 children and young people under the age of 19 with diabetes in the UK. 96% have Type 1 (1).</p> <p>All children and young people with Type 1 diabetes and their families should have access to the best possible care and be involved in decisions that affect them.</p> <p>However, despite the UK having the fourth highest population of children and young people with diabetes in Europe, there is no standardised approach to care and the UK is one of the worst performing countries in terms of blood glucose control.</p> <p>There is agreement amongst healthcare professionals, supported by research, about the need to redesign services to provide children and young people with access to all aspects of paediatric diabetes care. Significant work is underway to achieve this.</p> <p>As part of this, it is key that children and young people with diabetes and their families know what care they should be getting. This is why Diabetes UK have produced Type 1 essentials for Children and Young People: a short guide which outlines the ten essential aspects of care and support that all children and young people living with Type 1 diabetes need.</p>	

Current situation

Children and young people with Type 1 diabetes should be offered an ongoing integrated package of care by a multidisciplinary paediatric diabetes care team.

The clinical, social and financial benefits of investing in services for children and young people with diabetes are clear (2). In the long term equipping young people with the care, education and support they need to self-manage and achieve wellbeing can help to reduce their risk of developing life threatening diabetes-related complications, through improved diabetes control. In the short term improved management can help enhance satisfaction with services, reduce hospital admissions for acute illness of complications and improve academic performance and attendance at school (2).

However, feedback from children, young people and their families, supported by audit and research, reveals significant gaps in the delivery of care and access to services. This is resulting in wide variation in DKA admission rates and glycaemic control.

The [National Paediatric Diabetes Audit](#) (2013-14) found:

- Only 16.1% of children and young people with diabetes over the age of 12 years had all care processes recorded;
- 15% of children were in diabetic ketoacidosis at diagnosis;
- Nearly 1 in 10 admissions to hospital of children and young people with diabetes is as a result of a hypoglycaemic episode¹.

In addition, a Diabetes UK survey found that 87% of children and young people had never had access to a psychologist (3) and the SWEET report, which looked at paediatric and adolescent diabetes in Europe, highlighted sub-standard education for children and young people and their families and poor evaluation of programmes across Europe (4).

Over the last ten years the need to improve the delivery of paediatric care has been recognised in the publication of both NICE and SIGN guidelines and national policy. It is now well understood that a full system approach is needed to improve.

Diabetes UK are supporting this drive for improvement and national consistency in care through the 10/10: Type 1 essentials campaign. A full explanation of the Type 1 essentials is available on our [campaign pages](#). Wherever possible these standards of care are based on NICE guidance and SIGN guidelines and were developed by Diabetes UK in consultation with families with diabetes and paediatric diabetes healthcare professionals.

¹ These figures are for England and Wales but these poor outcomes also reflect the position in Scotland and Northern Ireland.

At a national level the following initiatives are underway to support the delivery of best practice:

England

In England, a best practice tariff was introduced for paediatric diabetes in 2011/12 to incentivise the delivery of high quality paediatric care to all children with diabetes. This is a year of care tariff payable to paediatric diabetes units on completion of the predetermined criteria, which cover all aspects of high quality diabetes care.

Although the tariff is a very positive move, much more needs to be done – in particular to support standards of training in health professional education and education for self-management.

To support the drive for improvement and the implementation of the best practice tariff, paediatric diabetes units are expected to work together through membership of local paediatric diabetes networks. Together these networks form the National Children and Young People's Diabetes Network. Diabetes UK works closely with the networks.

Scotland

The need to improve and standardise the delivery of paediatric diabetes in Scotland is recognised and work is underway to achieve this. Better recording is in progress through [SCI-Diabetes](#), which has been extended to include paediatric diabetes and rolled out across all health boards. Diabetes UK are working as part of [The Childhood and Adolescent Scotland Group](#), which is assessing the current provision of paediatric diabetes care in Scotland to help address the challenges and improve outcomes.

Wales

The need to improve paediatric diabetes care is recognised in '[Together for Health: A Diabetes Delivery Plan](#)'. The national strategy includes actions health boards need to take to achieve progress in diabetes care. NHS Wales' commitments to the establishment of a Diabetes Paediatric Clinical Network and peer review of all paediatric diabetes units in Wales provides a good platform to achieve service improvement.

Northern Ireland

The need to improve and standardise the delivery of paediatric diabetes in Northern Ireland is recognised and addressed in the work of 'The Northern Ireland Paediatric Network'. Diabetes UK are working as part of the Network which monitors current provision and supports the Childhood Diabetes Register maintained by Queen's University Belfast recording the incidence of diabetes in young people across the 5 Health Trust areas. The Network also supports close working between the Health and Education services to improve diabetes care and the CHOICE self-management programme for families and children mainstreamed in 2015 and developed through funding from Diabetes UK.

Diabetes UK calls to action

It is now well understood that a full system approach is needed to improve the delivery of paediatric services. Research has shown that intensive management and psychosocial support can improve glycaemic control and this is best initiated through a family focused education package following diagnosis (5). It is also suggested that improvements in healthcare professional training could support improved outcomes (4).

Diabetes UK believes that the improvement of paediatric diabetes care should be prioritised, and that:

Local commissioners must:

- Commission a specialist paediatric diabetes service, which includes all aspects of paediatric diabetes care including diagnosis and initial management, ongoing care, transition services and inpatient care;
- Make sure that paediatric diabetes teams have the full complement of competent paediatric diabetes healthcare professionals, including provisions for staff cover. The ratio of children to Paediatric Diabetes Specialist Nurse (PDSN) must not exceed 70:1. More PDSNs and paediatric diabetes dietitians may be required in accordance with local need (6);
- Make sure that all staff delivering diabetes care receive appropriate training;
- Commission self-management courses for children and young people and their families;
- Ensure appropriate psychological support is available to support children and young people with diabetes and that clinicians are able to work in a multidisciplinary way with the specialist diabetes team;
- Make sure that the appropriate funding is available to allow children and young people to gain access to the right treatment in line with NICE guidelines – such as insulin pump therapy and continuous glucose monitoring as appropriate.

Paediatric Diabetes Units must:

- Make sure that children and young people with diabetes have timely access to high quality medical, nursing, dietetic and psychological support from a paediatric diabetes specialist team;
- Make sure that children and young people are getting all the necessary checks in line with NICE guidelines;
- Provide children and young people and their families with structured education at the point of diagnosis and as needed;
- provide children, young people and their families with 24 hour access to specialist support for emergency advice, including a telephone help line, which should be appropriately resourced;

- Work with children, young people and their families to ensure the care they deliver is centred on the needs of the child;
- Participate in the local paediatric diabetes network and the National Paediatric Diabetes Audit in England and Wales and in the Managed Clinical Networks in Scotland.

Conclusion

Children and young people with diabetes must have access to a comprehensive package of care, which meets their needs and supports them to manage their diabetes. Diabetes UK have produced the Type 1 essentials for children and young people to help them and their families understand what care they need and should be getting.

Diabetes UK is working with the relevant organisations in all four UK nations to support the improvement in the delivery of diabetes care, campaigning to make sure that the required standard is available throughout the UK.

Further information

Diabetes UK campaigns:

- [Type 1 essentials for children and young people](#)
- [Type 1 diabetes: make the grade](#)
- [4Ts](#)
- [Making connections \(Scotland\)](#)
- [Pump campaign \(Scotland\)](#)

NICE guidelines:

<https://www.nice.org.uk/guidance/cg15>

<http://www.nice.org.uk/guidance/ta151>

SIGN guidelines:

<http://www.sign.ac.uk/guidelines/fulltext/116/>

[British Society for Paediatric Endocrinology and Diabetes](#)
[International Society for Pediatric and Adolescent Diabetes](#)

References

(1) Royal College of Paediatrics and Child Health (2009). Growing up with diabetes: children and young people with diabetes in England, <http://bit.ly/growing2009>. Warner JT and O'Connell H (2009). Diabetes in children and young people in Wales: prevalence and outcome.

NHS Scotland (2009). Scottish Diabetes Survey 2009 <http://bit.ly/sds200>

- (2) Department of Health (2007) Making every young person with diabetes matter: report of the Children and Young People with Diabetes working group.
- (3) Diabetes UK (2009) A survey of views and experiences of children and young people who are Diabetes UK members: Access to and Quality care.
- (4) <http://www.sweet-project.eu/relaunch/>
- (5) NHS Diabetes (2013 -18) [National Paediatric Diabetes Service Improvement Delivery Plan](#)
- (6) Royal College of Nursing (2006) Specialist nursing services for children and young people with diabetes – a RCN guide.