

# “Join us on our journey”: A new model of care for children and young people with diabetes

Nicky Kime, Elizabeth Carlin

**The aims of this research were to develop a model of care that will deliver the aspirations of the policy document *Making Every Young Person with Diabetes Matter* (Department of Health, 2007) and improve the care provision for children and young people with type 1 diabetes in England. Children and young people with type 1 diabetes, their families and professionals across nine acute trusts throughout the Yorkshire and Humber region participated in talking group discussions and individual interviews to find out about their experiences of diabetes care provision. Findings show that there are certain aspects of the care pathway that need to be addressed. In particular, diabetes care, resources, education, psychological support, school or college and transition were found to be the main areas of concern. Recommendations have been made indicating how current practice needs to change if the care of children and young people with type 1 diabetes is to improve.**

The UK has the fourth largest population of children and young people with type 1 diabetes in Europe and the fifth largest population in the world (Diamond Project Group, 2006; Kanavos et al, 2011); at present there is no comprehensive, standardised approach to care. Over the past decade, UK standards and guidelines (Department of Health [DH], 2001, 2007; National Institute for Health and Clinical Excellence [NICE], 2004) have specifically focused on children and young people with diabetes, and substantial improvements within services have been achieved (Gosden et al, 2010). However, evidence from the recent *National Diabetes Paediatric Audit Report* (NHS Information Centre, 2011) shows that more than 85% of children and young people with diabetes did not achieve the NICE target of <58 mmol/mol (7.5%) HbA<sub>1c</sub>; this has remained unchanged over the past 7 years.

In the recently published *Atlas of Variation in Healthcare for Children and Young People* (DH, 2012), data show not only variations in care provision across the NHS and poor glycaemic control, but also alarming differences in diabetic ketoacidosis admissions across the regions. The report indicates that the delivery of care and education given to children and young people and their families may be a contributory factor towards such poor outcomes. Therefore, by ascertaining the current standards of care and the gaps in service and by acting on recommendations to improve diabetes care and education, it may be possible to eliminate these as contributory factors towards poor outcomes. However, in order to gain a true picture of the current services, and in particular the delivery of care and education, it is important that service provision is looked at from the point of view of all those using and involved

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## Article points

1. The research study “Join us on our journey” examined the delivery of diabetes care in the Yorkshire and Humber region.
2. Findings show that there are huge variations in diabetes care and support, and consequently many children and young people are not receiving the care they are entitled to.
3. Research findings highlighted certain aspects of the diabetes care pathway that need to be addressed, including continuity of care, resources to deliver consistent care, education, school involvement and effective transition to adult services.

## Key words

- Continuity of care
- Diabetes care provision
- Education
- Transition

## Authors

Nicky Kime, Senior Research Fellow, Carnegie Faculty, Headingley Campus, Leeds Metropolitan University; Elizabeth Carlin, PhD student, Sports and Exercise Science Research Institute, University of Ulster, County Antrim.

## Page points

1. The 3-year, multi-site research study “Join us on our journey” examined the current state of diabetes care provision in the Yorkshire and Humber region; the study comprised nine acute trusts across the region involving over 300 participants.
2. Talking groups were used to generate discussions with children and young people with type 1 diabetes, parents and professionals about their perceptions in relation to diabetes care provision in the region.
3. The main points for discussion were represented as “bus stops” along the “diabetes journey”, and each one was considered in terms of: what is currently happening; what is missing; and what needs to happen.

with the service, including children and young people, their parents and healthcare professionals.

A research project has recently been completed and launched at the 2012 *Diabetes UK Annual Professional Conference* in Glasgow that specifically involved children and young people with type 1 diabetes, their parents and healthcare professionals. This article reports on this research, which examined the current state of diabetes care to ascertain the baseline position, and establishes what needs to be done to improve diabetes care for the benefit of all those concerned.

## Method

A 3-year, multi-site research study, entitled “Join us on our journey”, was commissioned by NHS Diabetes to examine the current situation in the Yorkshire and Humber region, with the emphasis being on the delivery of diabetes care.

Nine acute trusts across the region involving over 300 participants took part. Process mapping was employed as the main methodology, incorporating three broad, overarching questions:

- What is currently happening?
- What is missing?
- What needs to happen?

Talking groups (a term coined by the children and young people to describe focus groups) were used to generate discussions with groups of children and young people (aged 6–25 years), parents and professionals about their perceptions, beliefs and attitudes in relation to diabetes care provision in the region. Individual interviews were employed on those occasions where people preferred not to, or were unable to, participate in a group discussion. The rationale behind using the process mapping approach was to map out the type 1 diabetes journey for children and young people who have the condition, which meant establishing what works well, what works less well, where the areas of inefficiency are to be found and how a particular area needs to improve. In keeping with the theme, “bus stops” along a “diabetes journey” were used to represent the different stages along the child’s and young person’s diabetes care pathway. These were aligned to the policy document *Making Every Young Person with Diabetes Matter* (DH, 2007; see *Box 1*).

The “bus stops” represented the main points for discussion, and all participants were asked the three key questions in relation to each “bus stop”. A written and verbal explanation to the study was given, informed consent obtained and confidentiality assured. The talking groups and interviews were recorded with the participants’ consent, and appropriate ethical and research governance approval was obtained. Data analysis was undertaken by members of the “Join us on our journey” research team using thematic analysis. Research participants verified the themes and thereby further established the reliability of the research findings.

## Results

The research findings indicated that there are certain aspects of the diabetes care pathway that need to be addressed; this article outlines the main areas of concern highlighted in the study.

### Box 1. “Bus stops” on the “diabetes journey” and their accompanying themes.

- Bus stop 1
  - Diagnosis and initial management
- Bus stop 2
  - Annual assessment of the continuing care plan and monitoring for complications
- Bus stop 3
  - Management of complications
- Bus stop 4
  - Structured education
- Bus stop 5
  - Mental health and emotional well-being
- Bus stop 6
  - Support of child and family
- Bus stop 7
  - Early years and school setting
- Bus stop 8
  - Promoting good health and healthy choices
- Bus stop 9
  - Sexual health and pregnancy
- Bus stop 10
  - Transition
- Bus stop 11
  - Benefits (e.g. Disability Living Allowance)

## Diabetes care

In general, all participants who accessed the paediatric diabetes service were extremely positive about their diabetes care and commented on how helpful and supportive the specialist diabetes teams were. Unfortunately, their experience of time spent on the hospital wards was less positive, with participants commenting on how general nursing staff seemed to be unsure as to how to treat children and young people with type 1 diabetes. Those young people who accessed the young adult diabetes clinics were not as happy with their care and made frequent comparisons between the care they had received in paediatric services and the current care they receive in adult services. Staff attendance in clinic and lack of continuity were major issues:

*“[...] at the children’s clinic I had thorough appointments and saw a doctor, nurse and dietitian. More recently my appointments are a complete waste of time, seeing a different doctor every time for a maximum of 5 minutes [...] I can’t remember the last time I saw a nurse or dietitian”*  
(young person, aged 22).

In terms of continuing care, most participants were unaware of a care plan and had not been told about potential complications of diabetes, especially long-term complications. Participants reported that access to 24-hour diabetes specialist care was not always available, and allocated clinic sessions and appointments were often too short. Diabetes teams had taken steps to improve the clinic, but many aspects of clinic organisation were beyond their control.

## Resources

Staffing levels, time and funding were the most talked about resources in discussions with professionals. These had important implications for the delivery of the individual diabetes services and the care provision available to children, young people and parents. Throughout the region staffing levels were such that diabetes teams were barely able to meet the demands of their caseloads. In most sites there were insufficient diabetes specialist nurses, only part-time dietetic support and limited, if any, psychological provision. Diabetes teams were performing as best they could with the limited resources available to them, but as the workload increased they felt under increasing pressure:

*“[...] it’s just that it feels like an elastic band at the moment and it’s fully stretched and ready to snap”*  
(healthcare professional).

Although not mentioned by the healthcare professionals, there may be other resource implications that need to be addressed besides staffing levels, time and cost. For example, inertia or a lack of motivation to change might represent a barrier for introducing improvements in diabetes care (Berwick, 2003; Grol and Wensing, 2004).

## Education

Children, young people and parents who had attended structured education sessions were in the minority; participants said they had learnt most about their condition from others with type 1 diabetes. All the professionals regarded structured education as an important component of diabetes management, but a lack of time and resources were the main reasons preventing staff from delivering structured education and reinforcing key aspects of continued education. A lack of awareness of type 1 diabetes among GPs and the public was also raised as an important issue.

## Psychological support

An acute lack of psychological support was evident region-wide, and few services had access to a psychologist:

*“It’s very difficult for us to be able to access psychological support in a timely manner for our patients, and that’s being polite about it”*  
(healthcare professional).

Many children, young people and parents had no-one to talk to about the impact of type 1 diabetes on their lives. Professionals stated that having a psychologist as part of the team would be ideal, in particular a health psychologist who was able to attend clinics as well as undertake more supportive and preventive work.

## School

Diabetes management in schools varied enormously across the region. In general, primary schools seemed to be more interested in managing children and young people with type 1 diabetes than

## Page points

1. Although all participants who accessed the paediatric diabetes service were extremely positive about their diabetes care, those who accessed the young adults diabetes clinic were not as satisfied with their care; a lack of continuity of care was a major issue.
2. In terms of resources, staffing levels, time and funding were the most talked about in discussions with professionals; these had important implications for the provision of diabetes care to children, young people and their parents.
3. All the professionals regarded structured education as an important component of diabetes management, but a lack of time and resources prevented this from being implemented.

## Page points

1. Improvements in the transition process are needed to ensure continuity of care, as this is a key issue in a young person's diabetes journey.
2. Children, young people and parents should have access to the same standard of care regardless of which hospital they attend and which service they use.
3. A standardised, structured education programme needs to be implemented within all diabetes services to ensure consistency, as education is an important and integral component of diabetes care.

secondary schools; regardless of the type of school, some schools were simply more helpful and willing than others:

*“Some schools will be very enthusiastic and say we will take on whatever the child needs; other schools will not take on as much so then you have to adjust the care that the child gets to accommodate what the school will take on” (healthcare professional).*

Greater consistency in school policies and practices was identified as a requirement for improved diabetes care, as well as more diabetes specialist nurses to support children and young people and parents in schools.

## Transition

Transition differed in each site, in terms of the length of the process and the age at which a young person moved through transition. Although it was regarded as a vital time in respect of a young person's diabetes journey and was known to have important implications for the ways in which young people continued to manage their condition, the transition process was often poorly handled. Young people and parents stated that too much was assumed by the diabetes teams regarding their knowledge of transition. They felt that more communication was needed between paediatric and adult diabetes services regarding young people's individual needs. When participants were in transition they were often unaware of what was happening and why:

*“I was originally told that because I was 13 I would be slowly put into the adult clinic [...] I'd spend half of my time in paediatrics and half of my time in adults to get me used to swapping over, but that never happened. I didn't know I was in a transition clinic” (young person, aged 22).*

In some sites both the paediatric and adult diabetes teams were actively trying to use the teenage clinics as preparation for transition and had implemented a specific pre-transition plan agreed upon through joint consultation between the young person and healthcare professional. One major weakness highlighted region-wide was the difference in record keeping between the paediatric and adult diabetes services, which had important implications for continuity of care.

## Discussion

This research is the first study of its kind that has consulted with over 300 children and young people with type 1 diabetes, their parents and professionals across such a wide geographical area in order to find out about diabetes care provision. Findings show that there are significant disparities in diabetes care that children and young people with type 1 diabetes receive across the region. These disparities indicate that there is an urgent need for change, in terms of both the care that children and young people receive and the ways in which diabetes services are delivered. Based on the research outcomes, recommendations have been made suggesting how current practice needs to change if the care and support of children and young people with type 1 diabetes is to improve.

First, every paediatric and adult diabetes team needs to include as a minimum a consultant, diabetes specialist nurse, dietitian, psychologist and administrator. Ideally, a diabetes educator and social worker need to be part of the team in order to ensure children, young people and parents across the region receive the care and support they are entitled to. A standardised, formalised staff training programme needs to be in place, and all ward staff should be trained in diabetes care. Record-keeping processes need to facilitate diabetes care rather than hinder it; a universal computer system across all diabetes services, both paediatric and adult, would enable this to happen.

Children, young people and parents should have access to the same standard of care regardless of which hospital they attend and which service they use. Children, young people and parents need to be actively involved in care planning and discussions around treatment regimens. Too much emphasis, in the authors' view, is placed on the medical aspect of diabetes, in particular HbA<sub>1c</sub>; although this is obviously important, a more holistic approach to diabetes care needs to occur, centred on the lifestyles of individuals and their families and incorporating glycaemic control. The annual assessment process and monitoring of complications should be reviewed across all services in order to ensure consistency. Procedures need to be instigated to ensure young adult diabetes care provision is comparable with that in paediatric services.

A mainstreamed, standardised, structured education programme needs to be implemented within all diabetes services across the region in order to ensure consistency and to send out a clear message that structured education is an important and integral component of diabetes care. Improvements are needed in awareness of type 1 diabetes among GPs and in understanding the difference between type 1 and type 2 diabetes among both professionals and the public.

A standardised, formalised protocol in respect of diabetes management within schools needs to be introduced to ensure consistency. This needs to be enforced through a joined-up approach between the education authority, health and social care, involving diabetes specialist nurses, dietitians, health psychologists, social workers and school nurses as well as children, young people and parents.

Every diabetes team should have a designated health psychologist working as part of the team. The psychologist should be readily accessible to undertake supportive and preventive work with children, young people and parents. This needs to be an integral aspect of diabetes care in paediatric and adult services.

Transition needs to be a planned process carefully worked out through joint consultation between young people and professionals. Ideally, it should be managed over at least 1 year, with both the paediatric and young adult diabetes teams involved. Young people and their parents need to be properly informed about the transition process well in advance, and there should be clear communication at all times involving young people, parents and paediatric and adult diabetes teams. At the end of the transition process there needs to be an explicit handover, which includes transfer of patient records, in order to ensure continuity of care.

## Conclusion

The focus of this research was on the delivery of diabetes care, and in particular the experiences of children, young people, their parents and professionals. It is apparent from the findings that there are huge variations in diabetes care and support across the region, and consequently many children and young people are not receiving the care they are entitled to. The research findings and wider

literature support the need for a redesign of diabetes services to improve the variations in care and diabetes outcomes, not only in the Yorkshire and Humber region, but also across the UK as a whole (Diabetes Control and Complications Trial Research Group, 1994; Epidemiology of Diabetes Interventions and Complications Research Group, 2001; Peyrot, 2009; Kime and Carlin, 2012).

In addition to practice recommendations, it is suggested that future research might include consultations with other caregivers, in addition to parents and healthcare professionals. For example, teachers, as caregivers in the school setting, would provide insights into the difficulties they experience when providing care for children and young people with type 1 diabetes. ■

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