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## **Title page**

### **Title of paper**

'Join Us On Our Journey': exploring the experiences of children and young people with type 1 diabetes and their parents

### **Abbreviated title**

'Join Us On Our Journey': type 1 diabetes care

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# **‘Join Us On Our Journey’: exploring the experiences of children and young people with type 1 diabetes and their parents**

## **Introduction**

Young people in England have one of the highest incidences of type 1 diabetes mellitus (T1DM) in Europe. At present, over 26,000 young people have the condition<sup>1</sup>, which represents the fourth largest population in Europe and the fifth largest population in the world.<sup>2,3</sup> More worrying is the fact that young people in England have one of the worst records for glycaemic control in Western Europe. Over 85% of young people with T1DM were recently identified as not achieving NICE recommended HbA1c levels of <58mmol/mol (7.5%) and this figure has remained unchanged for the past 7 years.<sup>4</sup>

Recent evidence has shown that, in addition to poor glycaemic control, there are alarming differences in diabetic ketoacidosis admissions throughout the country and the quality of care and education that children and young people with T1DM receive is hugely variable. Compared with our European and global counterparts this care is below the highest European and global standards.<sup>5</sup> Furthermore, inconsistencies in quality of care is highlighted as a possible contributory factor towards poor outcomes. Poor quality diabetes care results in an increased risk of short- and long-term clinical complications, as well as compromised social and psychological wellbeing, leading to increased health care costs.<sup>6</sup> Therefore, it makes sense to ascertain current standards of care and identify gaps in service provision, before making recommendations in terms of how diabetes care needs to improve for the benefit of children and young people’s health outcomes.

However, in order to gain a clearer and more accurate picture of current care, it is important that service provision is examined from the point of view of all those involved with the service. This includes not only health care professionals, but most importantly, children and young people with T1DM and their parents. Increasingly, greater attention is being directed at gathering information from children, young people and families based on their experiences and involving them in decision-making, since they are the key stakeholders of the health service.<sup>7,8</sup> Indeed, recent policy documents stress the contribution that children, young people and families have to make in shaping the future of health care in the UK.<sup>9,10</sup> Therefore, although this study in its entirety explored the views of children and young people with T1DM, their parents *and* health care professionals, the experiences of children, young people and parents are reported here. The main research aims were:

1. To develop a model of care that will deliver the aspirations of the policy document ‘Making every young person with diabetes matter’.<sup>11</sup>
2. To improve the care provision for children and young people with T1DM in England.

## **Methods**

The research, entitled ‘Join Us On Our Journey’, was a 3-year, multi-site study. Nine acute trusts across the Yorkshire and the Humber region were involved and overall 300 participants throughout the region took part. Of these, 257 comprised children, young people and parents. The research employed a qualitative approach and process-mapping, using talking groups (a term coined by the children and young people to describe focus groups), was the main methodological component. The rationale behind using a process-mapping approach was to map out the T1DM journey for children and young people who had the condition, which meant establishing what worked well, what worked less well, where the areas of inefficiency were to be found and how a particular area needed to improve. In the case of diabetes care provision for children and young people, this approach enabled the complete journey, from diagnosis through to transition from paediatric to adult services, to be explored. 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 (see Table 1). The

talking groups used the 'bus stops' as a basis for generating discussions and all participants were asked three key questions in relation to each 'bus stop':

1. What is currently happening?
2. What is missing?
3. What needs to happen?

So, as an example, for 'bus stop' 3, participants were asked:

1. What currently happens in terms of managing complications?
2. What is missing?
3. What needs to happen?

### Recruitment

Children and young people aged 6-25 and their parents participated in the research. Given that children and young people necessarily had to have T1DM to participate, they were recruited in a purposeful manner from each of the caseloads within the nine acute trusts, via the consultants. A total of 116 children and young people took part spread across the age range. At the same time, parents were also asked to participate; a total of 141 parents took part. The talking groups involving children and young people were age-banded and conducted separately from each other and from those involving parents. Four age bands were identified: 6-11; 12-14; 15-17 and 18-25; talking groups were conducted in each one, varying in size from 4 to 8 participants. Similarly, parents/carers of children and young people from the four age bands were grouped accordingly and separate focus groups conducted.

Appropriate national and local ethical approval was obtained. A written and verbal explanation to the study was given, informed consent obtained and confidentiality assured. The talking groups were conducted by members of the research team and recorded with the participants' consent. The data from the talking groups was analysed using a thematic approach. This process involved generating categories and coding data so that common themes and links could be identified, whilst at the same time ensuring the data remained faithful to, and accurately reflected, the participants' comments.<sup>12</sup> At least two researchers were involved in the data analysis process, thereby reducing interpretation bias. In addition, research participants verified the themes as a means of establishing the reliability of the research findings.

### Results

The key themes to emerge from the findings were diabetes care, education, communication and support, school and transition. These are explained below.

#### Diabetes care

Those participants who accessed the paediatric diabetes clinics were extremely positive about their diabetes care. The few concerns that participants had were focused on long waiting times, short consultation times and the re-scheduling/cancellation of appointments. In addition, access to 24-hour diabetes specialist care was reported as not always being available, especially at weekends. In general, participants were satisfied with the care they received from their diabetes team, but less positive regarding the care they received from nursing staff on the wards who seemed to be unsure as to how to treat children and young people with T1DM. In particular, they had little knowledge of treatment around carbohydrate counting and insulin dosages.

Those who accessed the young adult diabetes clinics were not as satisfied with the care they received and made frequent comparisons between the care they had experienced in paediatric services and the current care they received in adult services. Staff attendance in the young adult

clinics was a major issue. Many participants felt there was no continuity because they saw a different consultant every time they attended clinic; young people commented on how unhelpful and repetitive it was to have to recite their full medical history afresh to each new consultant they encountered. Participants reported that the adult consultants did not really know them or understand their diabetes.

“...at the children’s clinic I had thorough appointments and saw 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 [YP], 22).

Children, young people and parents had little knowledge of a care plan or any idea what was meant by a care plan. Very few participants had been given information following diagnosis about what would happen next, either in the short- or long-term. Few participants had been told about complications, especially long-term complications, nor were they always involved in discussions relating to alternative treatments, e.g. pump therapy.

#### Structured Education

Most participants who accessed paediatric diabetes services felt that they had learnt the majority of what they knew about their condition from others with T1DM. They stated that they would welcome the opportunity to attend a structured education workshop similar to the DAFNE course<sup>13</sup> offered as part of adult services. Children and young people who had attended structured education sessions were in the minority, but commented on how helpful they were.

“I was invited to a carb-counting class to help me understand how to read labels and be confident with carb-counting. This class was really helpful” (YP, 17).

A lack of awareness of T1DM amongst the public and GPs was highlighted as a major concern amongst participants. It was noted that most members of the public seemed to be unaware of the difference between T1DM and type 2 diabetes mellitus (T2DM), and GPs were slow to detect the symptoms of diabetes, which led to a delay in diagnosis.

“I went to the doctor on three occasions and was told each time nothing was wrong. On the third occasion I was told I would be reported to social services for being an over-protective parent!” (Parent of 16 year old).

In addition, participants thought that ward staff needed more education on T1DM as they were often unaware of how to treat the condition. In general, there was a lack of education provided by diabetes staff in relation to healthy lifestyles, sexual health and pregnancy. Many parents and young adults conducted their own research on the internet, in order to find out what they needed to know.

#### Communication and support

Those participants who accessed paediatric diabetes services reported having a good relationship with their diabetes team. In general parents felt that communication was not a problem, since they were able to contact their diabetes specialist nurse at any time about their child. However, those children and young people who had a greater understanding of their diabetes wanted to have more input into their care, be involved in decision-making and be given more responsibility. They felt their diabetes was controlled by their doctor and their parents rather than by them. Many children and young people, even those of a younger age, stated that they often felt ignored in consultations and the adults tended to talk to one another as if they were not in the room.

"I don't like it when they all talk about me at the same time...they talk about me as if I'm not there (YP, 8).

A lack of psychological support was reported by most participants. Children and young people felt isolated among their peers and thought they would benefit from the opportunity to talk to others of the same age who also had T1DM. Those who had attended a diabetes camp or a programme such as 'Getting Sorted'<sup>14</sup> commented on how helpful they had found it, because everyone had the same condition and, therefore, having diabetes was perceived as 'normal'. Whilst some parents had access to a parents' support group many parents had no support. Young people spoke about how psychological support would help them cope better with their diabetes, especially as they did not feel able to talk to their consultant. Likewise, parents commented on how the support from a psychologist or counsellor would help them to deal with the shock of diagnosis and assist them in the on-going management of the condition. Participants stated that they would benefit from a psychologist in attendance at clinic as there was often no one to talk to at this time.

"I find it hard to cope sometimes and get extremely stressed, down about things, where counselling would help" (YP, 23).

### School

Diabetes management in schools and the quality of care varied enormously, particularly between primary and secondary schools. In general, children in primary schools had a more positive experience than young people in secondary schools. The young people attending secondary school stated most of the school staff did not know how to deal with them because they had type 1 diabetes and, therefore, they had more negative experiences than positive ones.

"Teachers complain about me having to have snacks and have drinks and go to the toilet" (YP, 15).

The majority of school staff were unfamiliar with type 1 diabetes and, therefore, had little knowledge of what a child or young person needed. Diabetes specialist nurses did attend school when a child was newly diagnosed to agree a care plan, but parents felt the majority of the on-going education and care was left to them. Many parents and young children in particular, relied heavily on the goodwill of a school volunteer to help them, usually the receptionist, rather than the enforcement of school policies, which were often not in place. Participants emphasised the need for consistency in terms of policies and practices within schools and colleges, for example, policies relating to classroom management, the storage of insulin/medical kits and the provision of a safe place for children and young people to take their insulin.

### Transition

Young people and parents commented on how the period of transition from paediatric to adult diabetes services was a vital time in a young person's diabetes journey and this had important implications for the ways in which young people continued to manage their diabetes. The general feeling was that young people and parents needed to be better informed of the process. Participants did not necessarily know what the transition process meant and when they 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, but 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 (YP, 22).

Participants felt that more communication was needed between paediatric and adult diabetes services regarding young people's individual needs, rather than assuming that all young people

moving into adult services were a homogeneous group. Those young people who had been through transition thought a year or more was appropriate for the transition process, since this enabled the young person to spend time with the paediatric and adult diabetes teams and, therefore, build up a comfortable rapport.

## **Discussion**

The focus of this research was on the delivery of diabetes care and in particular the experiences of children and young people with T1DM and their parents. It is the first study of its kind to consult with over 250 children and young people with T1DM and their parents about diabetes service provision across Yorkshire and the Humber, one of the largest regions for diabetes care in the UK. The findings provide a valuable insight into the key issues confronting families, whilst reinforcing, yet again, the disparities in care that exist for children and young people throughout the region<sup>5</sup>. These disparities in care indicate that there is an urgent need for change, both in the way that diabetes services are delivered and the care that children and young people receive.

The research findings presented here substantiate what has been stated in the diabetes literature over the course of the previous decade, namely that there is a need for a redesign of diabetes services, in order to improve the variations in care and diabetes outcomes throughout the whole of the UK. Even though there have been numerous publications and reports highlighting this issue<sup>15, 16, 17</sup>, it is still the case that shortfalls in care exist. Whilst a significant number of children and young people receive a high standard of care from highly skilled and trained health care professionals, there are others who, because of inadequate service provision, are failing to receive the highest levels of diabetes care available.

A crucial factor in service improvement is the participation of children and young people with T1DM and their parents. Therefore, if the needs of this population are to be met, it is vital that we listen to them and involve them in any decision-making processes centred on service redesign. Furthermore, it is imperative that we continue to gather information on their experiences, in particular those of children and young people, as part of a wider philosophy of service user involvement. Only by doing this will we achieve the best outcomes for children and young people with T1DM and their families.

## **Key points**

Young people in England have one of the worst records for glycaemic control in Western Europe. Over 85% of young people with T1DM have been identified as not achieving NICE recommended HbA1c levels of <58mmol/mol (7.5%).

The quality of care and education that children and young people with T1DM receive is hugely variable throughout the country. Inconsistencies in care provision are highlighted as a contributory factor towards poor clinical outcomes and increased health care costs.

Key findings from this research reiterate the need for change in the way diabetes care is delivered, particularly in relation to communication and support, schools, structured education and transition.

Children and young people with T1DM and their parents need to participate in decisions centred on service redesign as part of a wider philosophy of service user involvement.

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