What young people want from their diabetes team: developing a patient reported experience measure (PREM) for young people with type 1 diabetes

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Abstract

The objectives of this study were: to explore whether a patient reported experience measure (PREM) questionnaire for carers reflected aspects of the clinic experience important to young people; and to develop a PREM for young people with type 1 diabetes (T1D) to measure their clinic experience.

A cross-sectional study design and focus groups were used. Questions from a PREM for carers and four open-ended questions were incorporated into a semi-structured interview administered to 77 young people with T1D across four paediatric diabetes clinics.

Eighty-two percent of young people rated help in managing high and low blood glucose as the most important aspect of their clinic experience. All items identified by parents as important were rated important by over two-thirds of young people, with the exception of ‘How important is it to be seen on your own?’ (40% rated this as important). Thematic analysis identified two superordinate themes: learning new information, and age appropriate structure and communication. Exemplary quotations from each theme were converted into questions and reviewed by six young people using cognitive interviewing. The final question set was reviewed by the National Paediatric Diabetes Audit PREM working group. The PREM was distributed to 177 paediatric diabetes units in England and Wales for completion between September 2012 and January 2013.

Exploring what is important for a young person about their clinic experience has supported the construction of a paediatric-centred measure. The young person PREM creates opportunities for improvement in care to help diabetes teams listen to patients and work with them to provide the best possible service. Copyright © 2015 John Wiley & Sons.

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Key words

young people; type 1 diabetes; patient reported experience measure

Introduction

Since the 2004 Children Act¹ there has been an increasing emphasis on services actively involving children and young people as well as parents/carers in the commissioning, development and evaluation of services.² Research suggests that clinical outcomes improve when people are invited to comment upon their clinical encounters³ and this creates opportunities for patients to compare the care they are receiving with others in different services.² The NHS constitution⁴ states: ‘NHS services must reflect the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate will be involved in and consulted on all decisions about their care and treatment.’ Domain 4 of the NHS Outcomes Framework highlights ‘ensuring people have a positive experience of care’.⁵

The National Paediatric Diabetes Audit (NPDA) is commissioned and sponsored by the Healthcare Quality Improvement Partnership and since April 2011 has been delivered by the Royal College of Paediatrics and Child Health. An inter-disciplinary working group was set up in December 2011 to consider how best to collect data on the experience of the 25,000 children and families receiving care from the 177 paediatric diabetes units (PDUs) across England and Wales.⁶ A patient reported experience measure (PREM) was developed and distributed to 185 PDUs in September 2012. This focused primarily on understanding the perspective of parents and carers but did not incorporate the voice of children and young people;⁷ 170/185 PDUs provided data, with 13,118 forms returned. (PDUs providing diabetes care for children are mandated to...
participate in the NPDA. The PREM is now part of the NPDA and is therefore also mandated. The Best Practice Tariff mandates an experience measure.8

Eighty-three percent felt they receive adequate diabetes advice and 74% said they would be happy to recommend their clinic to another friend or family.6

**Study objectives**

The objectives of the current study were: (1) to explore whether the first PREM questionnaire reflected a clinic experience that was important to children and young people; and (2) to develop a PREM for young people with type 1 diabetes (T1D) to measure their clinic experience.

**Methods**

**Procedure**

Quantitative and qualitative data were collected using a semi-structured interview. Clinicians on the working group were asked to complete the interviews with as many young people as possible over a four-week window. One clinic ran a group during an activity weekend. In two clinics a member of the diabetes team asked children and young people to complete the questionnaires during their clinic appointment. In one clinic an assistant psychologist used opportunistic sampling to interview young people waiting for their clinic appointment. No participants declined to take part.

**Participants**

Seventy-seven children and young people with type 1 diabetes (median age 12, range 6–17 years) from four UK diabetes clinics (University College Hospital London [UCLH], Birmingham, Harrogate, and Southampton) took part in the study. Twenty-nine were male and 28 were female. Some were chosen because they were deemed poignant or significant. Qualitative data from the focus group are referenced as ‘group’.

**Semi-structured interview**

Young people rated how important the themes covered in the original parental PREM were to them on a scale of 1–10. An example question is: ‘On a scale of 1–10 can you tell us how much being seen quickly/on time matters to you when you come to clinic?’ (1 = not important, 10 = really important). Scores for each question were clustered into three categories: not important (rated 1–3); neither important nor unimportant (rated 4–6); important (rated 7–10). One question was yes/no/not applicable: ‘If your mum or dad doesn’t speak English would you like the team to provide an interpreter for them?’

**Clinic experience**

Participants were also asked four open-ended questions:

- ‘Can you tell us up to three things that you like the most/look forward to the most when you come to clinic?’
- ‘Can you tell us up to three things that you dislike the most/don’t look forward to when you come to clinic?’
- ‘If you were in charge of running the clinic what would you do differently to make it better for the other people your age to attend?’
- ‘Is there anything else you want to tell us?’

**Analysing qualitative data**

Data were analysed using thematic analysis (TA). TA involves identifying patterns within qualitative information in order to discover emerging themes. This method can report experiences and the reality of participants (realist method); it can examine the ways in which experiences are the effects of a range of discourses operating within society,6 and, finally, it can also acknowledge the ways individuals make meaning of their experience (‘contextualist’ method)8. TA can be utilised both to reflect reality and to unravel the surface of ‘reality’.8 TA was used in this case as a constructionist and contextualist method. We were seeking to extract what patients’ experiences of care are and how important certain aspects are, which may or may not reflect reality.

The data were read in detail several times (by IG and TG) to code key words, phrases and associations in order to identify emerging themes. Subsequent readings acknowledged themes which described connected or closely associated issues. Once themes were established, a sub-sample of data was read and coded by DC to ensure the themes were clearly grounded in the data. Exemplary quotations were used to achieve trustworthiness. While the thematic framework was being analysed, the researchers actively looked for confirmatory statements. A table of themes and analogous quotations was produced. Themes were grouped into superordinate themes that shared commonality, and were organised to create a coherent thematic account. Exemplary quotations were chosen for their richness and how representative they were of the data. Some were chosen because they were deemed poignant or significant.

In the results (below), participants are referred to using gender and age. Qualitative data from the focus group are referenced as ‘group’.

**Constructing a PREM for young people**

The themes and corresponding exemplary quotations detailed in the results were used to create a bank of statements that preserved aspects of the diabetes clinic the young people identified as important; for example, for ‘age appropriateness’ a quotation ‘They talk to me and at my level’ was converted into ‘The team know how to talk to people my age and understand my situation’. The questions were then reviewed to remove redundancy or repetition, creating a final bank of 13 questions.
Cognitive interviewing
A very small number of children <11 years of age took part in the semi-structured interview data collection stage. As the median age for the sample was 12 years old, a focus group of six young people from UCLH (aged 11–17 years; two males and four females) were invited to review the 13 questions using cognitive interviewing. Young people were approached during two clinics and none declined to participate.

Cognitive interviewing explores whether the questions ask what we are intending to ask. Ease of understanding, appropriateness of language used and response options are discussed. Young people are invited to reword or alter the question if they want to. As the cognitive interviewing sample was aged 11–17 years, a pragmatic decision was made to recommend the final questionnaire for completion by those aged ≥11, although younger children who were willing to complete the questionnaire could do so. Following this process, the questions were reviewed by the NPDA PREM working group which includes diabetes consultants, psychologists, a young adult with diabetes, and parents of children and young people with diabetes.

Results
Importance of themes as identified by parents/carer s
Table 2 shows the frequency rating for each question with the equivalent parent/carer question from the original parent/carer PREM.

All questions were rated as important by over two-thirds of the sample. How to manage high and low blood glucose was rated as the most important aspect of clinic experience by 82% of young people. Only 40% of young people 13 years and above (n=30) rated being seen on their own as important.

<table>
<thead>
<tr>
<th>Importance rating for:</th>
<th>Not important (no. [%])</th>
<th>Neither important nor unimportant (no. [%])</th>
<th>Important (no. [%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seen quickly in your clinic</td>
<td>6 (8)</td>
<td>16 (21)</td>
<td>55 (71)</td>
</tr>
<tr>
<td>Seen on your own (13+ year olds)</td>
<td>8 (27)</td>
<td>10 (33)</td>
<td>12 (40)</td>
</tr>
<tr>
<td>Talking to different members of the team about different aspects of diabetes</td>
<td>12 (16)</td>
<td>8 (11)</td>
<td>56 (74)</td>
</tr>
<tr>
<td>Importance of receiving advice at any time of the day from your diabetes team</td>
<td>4 (6)</td>
<td>14 (19)</td>
<td>54 (75)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Being given information and knowledge to manage:</th>
<th>Not important (no. [%])</th>
<th>Neither important nor unimportant (no. [%])</th>
<th>Important (no. [%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>High blood glucose</td>
<td>2 (3)</td>
<td>11 (15)</td>
<td>58 (82)</td>
</tr>
<tr>
<td>Low blood glucose</td>
<td>1 (1)</td>
<td>12 (17)</td>
<td>58 (82)</td>
</tr>
<tr>
<td>Illness</td>
<td>4 (6)</td>
<td>12 (17)</td>
<td>55 (77)</td>
</tr>
<tr>
<td>Carbohydrate counting</td>
<td>6 (9)</td>
<td>9 (13)</td>
<td>55 (79)</td>
</tr>
<tr>
<td>Exercise and activity</td>
<td>7 (10)</td>
<td>14 (20)</td>
<td>48 (70)</td>
</tr>
<tr>
<td>The future and possible complications</td>
<td>5 (7)</td>
<td>10 (14)</td>
<td>54 (78)</td>
</tr>
<tr>
<td>How you feel about having diabetes</td>
<td>8 (12)</td>
<td>15 (22)</td>
<td>46 (67)</td>
</tr>
<tr>
<td>Diabetes at school</td>
<td>11 (16)</td>
<td>12 (17)</td>
<td>47 (67)</td>
</tr>
<tr>
<td>Receiving books and leaflets</td>
<td>8 (11)</td>
<td>15 (20)</td>
<td>53 (70)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Information about the following technologies:</th>
<th>Not important (no. [%])</th>
<th>Neither important nor unimportant (no. [%])</th>
<th>Important (no. [%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insulin pumps</td>
<td>6 (9)</td>
<td>8 (12)</td>
<td>53 (79)</td>
</tr>
<tr>
<td>Glucose monitoring</td>
<td>4 (6)</td>
<td>16 (24)</td>
<td>46 (70)</td>
</tr>
<tr>
<td>Blood glucose meters</td>
<td>8 (12)</td>
<td>10 (15)</td>
<td>49 (73)</td>
</tr>
</tbody>
</table>

Table 2. Frequency and percentages of importance ratings by young people for each question. (N=77 although 11 young people failed to answer all of the questions, therefore some missing data occurred)
Nineteen young people responded to the question: ‘If your mum or dad doesn’t speak English would you like the team to provide an interpreter for them?’ Twelve (63%) said they would like an interpreter present as their parents did not speak English.

**Qualitative results**

Two superordinate themes and six subordinate themes were identified, as shown in Table 3. These are described below.

**Learning new information**

This reflects how young people feel about learning information and gaining advice about diabetes, with four subordinate themes as follows.

Learning through processing and understanding clinical results. Young people expressed the importance of learning new things from the clinical process in order to increase their knowledge and enhance their practice of diabetes regimens.

‘Every time I come I feel I learn more about diabetes and how to control it better and change my lifestyle,’ (Female, 13).

‘[I] like to see my HbA1c and it being explained to me,’ (Female, 8).

Observing change and the effects. Young people connected observing changes (e.g. height, weight, HbA1c) with learning.

‘How good my bloods are to see if I have been doing well… How I have been doing overall and it being explained to me,’ (Female, 13).

‘[I] like to know how much I have grown,’ (Female, 9).

Change in HbA1c was described as an overall marker for ‘how you’re doing’ and how you experience being treated in the clinic appointment. Young people described the emotional impact of getting a ‘bad HbA1c’.

‘Satisfaction of good HbA1c which isn’t normally the case… Get told off for not writing down sugars [and a] bad HbA1c,’ (Male, 11).

‘Having a high HbA1c because then I get asked loads of questions when I’ve been handling it all well,’ (Group).

Learning new things from multiple members of staff and leaflets. A multidisciplinary team approach was seen as a positive way to gain knowledge from multiple perspectives which had an effect on young people’s confidence in the team to support them managing diabetes. Staff referring to other professionals for the relevant expertise and an extensive range of knowledge is important, as well as being able to ask questions and get feedback in order to expand their knowledge of diabetes and its associated responsibilities.

‘They are really on the ball here about my other problems like my feet and eyes; I know I’m getting the best care. I know that because they are so knowledgeable, they don’t tell you off: they look into it.’ (Female, 17).

Written relevant information as well as verbal information was important.

‘I like that you can get different advice from different members of staff like nurses and dietitians,’ (Male, 14).

‘I would also give out more relevant information, like leaflets. I know they have ones here but I’d like more in depth ones about drinking/piercing/travelling – more like official documents that are in depth that the doctors give you – ones that have official guidelines that I can trust with in depth information,’ (Female, 16).

‘I like to ask lots of questions about everything to do with diabetes and I also like it when they ask me about everything too,’ (Female, 10).

Learning new things through meeting other young people. It was important for young people to be offered the opportunity by clinic staff to meet other young people with diabetes which helped them learn how others cope as well as share advice.

‘I’d get two people the same age to get to know each other. I would do fun activities so people get to know each other. I would like this because then I would learn how others cope and if they had any tips,’ (Female, 15).

‘Talking sessions where I can talk to other kids and meet and talk to each other,’ (Male, 12).

**Age appropriateness**

This theme reflects the importance of age appropriate clinic structure and communication, with two subordinate themes as follows.

Clinic environment, waiting times and activities. Waiting times were described as negative although more tolerable when the clinic provided age appropriate activities to ‘occupy’ the young people while they wait.

‘I like the games there are to play, mostly the table football – it’s something to occupy me when I am waiting… I would make sure there were more games: some for small children and all ages but more for my age like a pool table or something,’ (Male, 14).

Young people described how time spent in clinic appointments impacted on missing school and being with friends. There was a mixed response as to whether young people experienced missing school as a positive or negative experience.

‘Make clinic time not during school time.’ (Group).

A clean and positive clinic environment was important to young people and impacted upon their mood.

‘It’s a nice environment here; makes me feel more positive as my last hospital was a bit of a dive. This makes me want to come… It’s better now it’s two sections,’ (Male, 17).

<table>
<thead>
<tr>
<th>Superordinate theme</th>
<th>Subordinate theme</th>
</tr>
</thead>
</table>
| **Learning new information** | • Learning through processing and understanding clinical results  
• Observing change and the effects  
• Learning new things from multiple members of staff and leaflets  
• Learning new things through meeting other young people |
| **Age appropriateness** | • Clinic environment, waiting times and activities  
• Communication |

Table 3. Superordinate and subordinate themes
Separate clinics for paediatrics and adolescents were seen as positive. Young people wanted ‘different clinics for different age groups’ with age appropriate activities, shorter waiting times as well as a quieter environment for the adolescents.

‘I like how they have split the rooms. I think it saves time and you don’t have to wait with the younger ones who can be really loud. I wait around less and have more to do like the Wii… Good environment because the staff are friendly,’ (Female, 15).

Young people emphasised the importance of consistency across staff: ‘[I] like seeing same staff; don’t like inconsistency,’ (Male, 16).

**Communication.** Young people emphasised the importance of age appropriate communication connected to sharing ideas and gaining more helpful advice.

‘People here are friendly; they find out my status of health. I like the doctors’ attitude; it makes me feel comfortable to talk to them. I think they have a really good approach for people my age [teenagers],’ (Female, 16).

Taking an interest and getting to know them rather than just diabetes was very important. When staff communicated in a way that was not experienced as age appropriate, it was associated with a disinterest in the appointment.

‘They are easy to talk to here, especially [Nurse X]: she is great. They really know how to talk to adolescents: they are straightforward, less formal and intense, much more friendly. You can talk to them and tell them the truth and they don’t shout at you; they are really responsive and they listen to me and we work through my problems and they actually act on them,’ (Male, 16).

‘Other nurses rushing past is scary; feels silly asking questions that the doctor might think is silly but is important to me,’ (Male, 10).

Young people wanted staff to ask questions rather than be ‘dictated to’. Highlighting problems was not experienced as helpful to young people.

‘Scary when they say I eat the wrong food,’ (Female, 9).

‘It’s so nice here, they have never dictated anything to me here, they ask me everything. They don’t go through and pick out the whole history or past and what you have done wrong. They are much more concentrated with finding solutions here. I don’t know how to say it; they are just much more solution focused than problem focused. I like that they don’t care too much about my sugars which is pretty cool,’ (Female, 16).

It was important to young people that staff promoted independence where possible, talking directly with the patient rather than parents. Young people appreciated being given clear information in a non-judgemental and non-critical way to help them make their own decisions. Being made to feel like ‘an expert’ was appreciated and was connected to not feeling ‘dictated to’.

‘They treat you like the expert here: you know what is best because you know your body. They make you feel comfortable: they don’t make you feel like you need to have a list of questions and then you have to just listen to the answer. It’s different: they really listen to you and want to help; they have so much knowledge and they listen to your worries, which is helpful. They talk to me and at my level. They give me all the information but let me make my own decisions. I can change my pump and make decisions on my own which helps me be independent and look after myself, not like the old hospital: I wasn’t allowed to do anything without asking,’ (Female, 14).

**Discussion**

The study highlighted what is important to young people in their clinic experience. Overall, young people highlighted the importance of a patient-centred, understanding and age appropriate approach as providing a positive patient experience.

Parents/carers and young people value similar aspects of clinical care. Access to information about blood glucose management was an important aspect of the clinic experience for young people. Young people highlighted the importance of learning new information from medical staff and other young people; when attending clinic, age-banded clinics and activities available during waiting times were also important. Effective communication was an essential part of a positive experience. Young people want their medical teams to take an interest in who they are and what is important to them, not just diabetes. They like to be provided with information and to be given options as to what to do with the information, to be included in decisions about their care. A dominant theme was that caregivers should listen and respond with care and consideration to age. The results mirror those of other previous studies.10

One limitation of the study was the different ways in which data were collected and the variable level of descriptive data across the four clinics. The interviews from the focus group provided less descriptive information than the individual interviews. In addition, the clinic that used the assistant psychologist generated a lot more detail than those interviews completed in the clinic by the clinician. Despite these challenges, the study highlights what young people feel are important drivers of their experience as patients. Providing a measure based on patient experience as well as giving patients an opportunity to comment from their perspective will improve clinical outcomes.2

The young person PREM has been distributed to approximately 25,000 children and young people aged 0–24 cared for by the current 177 PDUs in England and Wales.11 An alternative measure for children aged 6–10 years is being developed by the working group.

In order for the results of the PREM to provide a significant contribution to understanding how young people experience their diabetes care, a robust system to ensure rapid processing of the results must be established. This will require adequate centralised resources are in place to ensure data entry is accurate and fast and that analysis is fed back to units within a reasonable timeframe. To date this has not happened. It will only be possible for individual units to learn from the data if feedback is contemporaneous and there is a system in place to respond to unsatisfactory experiences. It is argued that responses to individuals who say they would not recommend the service (‘The Ultimate Question’12) should be immediate. Analysing PREM data and how units respond to the results of this should also inform commissioning decisions in the future.
Patient reported experience measures (PREMs) are an essential tool for services to enable them to audit and monitor their performance and facilitate positive service improvement. The use of PREMs allows patient care and experience to be compared and improved across care pathways. The study describes the development and delivery of the first national diabetes PREM for young people administered to 25,000 young people in England and Wales. This is the largest sample of young people with type 1 diabetes reporting on their experience of their diabetes care to date.

Key points
- Patient reported experience measures (PREMs) are an essential tool for services to enable them to audit and monitor their performance and facilitate positive service improvement.
- The use of PREMs allows patient care and experience to be compared and improved across care pathways.
- The study describes the development and delivery of the first national diabetes PREM for young people administered to 25,000 young people in England and Wales.
- This is the largest sample of young people with type 1 diabetes reporting on their experience of their diabetes care to date.

Acknowledgements
The authors would like to acknowledge the National Paediatric Diabetes Audit (NPDA) and the Royal College of Paediatrics and Child Health who approved the final manuscript, and the Healthcare Quality Improvement Partnership (HQIP) who fund the NPDA.

Commentary
Improving care for young people: ask them and they will tell you

I Girling, et al. What young people want from their diabetes team: developing a patient reported experience measure (PREM) for young people with type 1 diabetes. Pages 142–147.

Young people with diabetes are, first and foremost, young people. They are engaged in their day-to-day lives: maintaining friendships, achieving academic success and considering their longer-term goals.1 Diabetes self-care is a part of this wider picture. They attend clinic appointments to access support to stay safe and well; as the Girling et al. study suggests: ‘82% of young people rated help in managing high and low blood glucose as the most important aspect of their clinic experience’. But young people need this support delivered in an acceptable way that makes sense in terms of their daily lives. The recently published Young People’s Framework for Public Health again highlights the importance young people place on factors such as: confidentiality and a non-judgemental approach; the need to train staff to be young person friendly and provide age-appropriate services; and the need to think about young people as a separate group with their own voice and views.2

The Girling et al. study reports on the first large-scale, UK-based review of the experiences of young people attending diabetes clinics. Taking an existing carer-report experience measure, a national group of health professionals and young people developed a self-report version and this was administered to over 25,000 young people in England and Wales. There is a high concordance between parents’ and young people’s views of what is important within the consultation, and two main themes were for learning opportunities to be available and for these to be delivered in an age-appropriate way.

In looking at how all children and young people can be supported to access opportunities, the All Party Parliamentary Group for Children Inquiry Report 2012–2013 makes a wide-ranging consideration of health, education and social care systems and includes the recommendation for: ‘Representation of children and young people in shaping health services’.3 A key first step towards wider representation is to ask young people about their direct experiences of attending appointments and to shape local services that meet their needs. The Girling et al. study makes a significant contribution to this endeavour.

References
A patient reported experience measure for young people with type 1 diabetes

References