

# Developing the National Paediatric Diabetes Audit Patient Reported Experience Measure



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There is an increasing interest in eliciting feedback from people with diabetes to highlight the aspects of care that require improvement. This feedback enables services to monitor their performance and to document the quality of care they provide and facilitate positive service improvement. It also creates an opportunity for people with diabetes to compare the care they are receiving with others in different services.

Measuring patient experience is essential within the NHS in order to empower people with diabetes and ensure that we are providing patient-focused services (Department of Health, 2011). The NHS constitution 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.”*

In addition, there is a commitment from the NHS to ensure that indicators of patient experience are included in national performance indicators. The fourth domain of the NHS Outcomes Framework highlights the importance of “ensuring people have a positive experience of care” (Department of Health, 2011).

Enabling the experience of people with diabetes to be captured, analysed and acted upon should result in a greater understanding of how they perceive the our service and, most importantly, it will help us identify necessary service improvements. Whilst we may not be able to always provide a “cure”, curiosity with respect to a patient’s experience of their care may increase opportunities to “relieve suffering.” It could be argued that whichever pharmaceutical or technological advance comes to our aid, a balance between quality of care and ability to cure should be our ultimate aim.

The National Paediatric Diabetes Audit (NPDA) is funded by the Healthcare Quality Improvement Partnership, in which the Royal College of Paediatrics and Child Health (RCPCH) has been responsible for the paediatric component since May 2011. A

multidisciplinary working group was set up in December 2011 to consider how best to collect data on the experience of 20 000 children and families receiving care from 185 paediatric diabetes units across England and Wales. This brief article describes the development of the Patient Reported Experience Measure (PREM) over a 9-month period.

## Development of the PREM Key principles of the PREM

It was decided that the PREM should:

- Be quick and easy to complete.
- Consist of no more than two sides of paper and include approximately five questions (+ or -2).
- Address generic issues, with future versions modified to address specific areas of interest.
- Run over a 4-month period to attempt to reach all patients attending the quarterly clinics.

## Survey of paediatric diabetes clinics

A total of 80% (148/185) of paediatric diabetes clinics replied to an electronic survey:

- 95% were interested in participating in the PREM.
- Only 22% had adequate IT support for an electronic version.
- 63% preferred a paper version.

Paediatric Diabetes Units were also surveyed to identify the different languages that were needed for translation purposes.

## Literature review

Existing measures appeared to be too long and based on satisfaction rather than experience. Research has shown that most people will say that they are satisfied with their healthcare (Fitzpatrick and Hopkins, 1983). However, the level of satisfaction does not capture the speed of the referral nor whether there was a clear negotiated care plan. Moreover, it does not provide with you information on whether the patients felt respected, involved in the decision-making process or allowed the opportunity to comment on the environment. It also tells us nothing about the effectiveness of interdisciplinary communication, which is a key aspect of safe and effective care for

Children With Diabetes, Inc. (2011) *Friends for Life UK 2011*. Children with Diabetes, West Chester, OH, USA. Available at: <http://bit.ly/QZgnbM> (accessed 19.09.12)

Department of Health (2011) *NHS Outcomes Framework 2012/13*. DH, London. Available at: <http://bit.ly/up3lKS> (accessed 19.09.12)

Fitzpatrick R, Hopkins A (1983) Problems in the conceptual framework of patient satisfaction research: an empirical exploration. *Social Health Illn* 5: 297–311

NICE (2004) *Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults: Clinical Guideline 15*. NICE, London. Available at: <http://bit.ly/gNUHei> (accessed 19.09.12)

people with diabetes. The PREM questions aimed to distinguish between satisfaction, which is subjective and non-specific, and experience. The questions were designed to reflect actual experience, avoid value judgement and “the effects of existing expectations.”

### Qualitative stage

Qualitative data on what makes a clinic experience positive was collected from a group of parents attending a “Friends for life” conference and focus groups run by the PREM working group members during clinics (Children With Diabetes, Inc., 2011). The results were cross-referenced with similar data from Diabetes UK and the current NICE guidelines (NICE, 2004). Initially, it was decided to focus on parental experience. Work exploring the experience of young people is currently underway. Seven themes were identified as strongly influencing the experience of care:

- The extent of awareness of entitlements in terms of the service and care received in order to make an accurate assessment of satisfaction.
- The level of access in non-crisis situations and how easy it is to communicate with healthcare professionals outside of designated appointment times.
- The consistency of the care and advice given at clinics.
- The use of technology in terms of what is available and whether it is being used effectively.
- The effectiveness of interdisciplinary communication (ensuring adequate referrals to specialists such as dietitians, psychologists and ophthalmologists).
- Structured Education – is access provided or offered?
- Is access provided to culturally appropriate advice?

### Question development and piloting

Questions addressing each theme were drafted by the PREM group and then reviewed by parents through the Children With Diabetes, Inc. website, as well as clinics in Southampton, Birmingham, Harrogate and London. Parents were asked to comment on the structure and wording of the questions, and how easy they were to respond to. Following this cognitive testing process, the questionnaire was revised and reviewed by the NPDA Board, which requested further minor modifications. The PREM working group project manager attended diabetes network meetings across the country to present the questionnaire to teams to gather additional thoughts and suggestions. All comments were

reviewed and, wherever possible, taken into account. The final version was reviewed by the RCPCH communications team.

### Dissemination of the PREM

Clinics have been invited to nominate a PREM “champion” to take responsibility for supporting the roll-out of the PREM within the clinic. The information leaflets, posters and final PREM will shortly be delivered to all paediatric diabetes units across the country. Diabetes UK is running a campaign to promote the PREM and let children and young people with diabetes, and their families, know that they can expect an opportunity to comment on their experience of the clinical care they receive.

### Discussion

The data will be made available to all teams via the NPDA website alongside the NPDA data set. Participants will have a chance to see the data and compare their experience to other clinics.

The PREM has been designed to help clinics think about the care they believe they are delivering and see if this corresponds with the experience from the view of the patients. It is designed to create opportunities for improvement of care and help us ensure we listen to our patients and work with them to provide the best possible service. In order to do this, we are going to need clinics to join us and find the courage to ask people what they think of the service they offer. The research suggests that clinical outcomes improve when people are invited to comment upon their clinical encounters. Rather than seeing the PREM as a threat, we invite all paediatric diabetes healthcare professionals to consider the PREM as an opportunity to continue to do their best for children, young people and families living with diabetes. ■

#### *Members of the PREM working group*

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