



Driving improvements in paediatric diabetes care

Developing a Patient Reported Experience Measure
to understand the needs of children with diabetes



Summary

There are a number of surveys that routinely gather feedback from children and young people (CYP), but none specifically include diabetes care. The National Paediatric Diabetes Audit (NPDA) contains a patient experience survey element, but the extent to which it can inform service delivery and care improvement for CYP is limited. Therefore, this research aimed to develop and assess the validity of a new paediatric Patient Reported Experience Measure (PREM) for diabetes care, to be used in the NPDA. A PREM is a survey that allows patients to self-report on aspects of their care.

Challenges

There were three main challenges this research was aiming to overcome:

- Existing national patient surveys such as the CQC National Patient Survey Programme and the GP Patient Survey do not specifically ask about children's diabetes care.
- Concerns around the existing patient experience survey, and whether the questions were designed with children and young people in mind.
- One challenge with understanding paediatric care is whom to speak to – parents, children or both? At Picker, we know it's essential to hear from both.

What is important to parents may not be what matters to children, so we adapted the questions for the different groups.



Actions

Five focus groups were conducted with 25 participating diabetic CYP and their parents to explore recent diabetes care experiences. PREM questions were drafted with clinical insight from an advisory group, including paediatric endocrinologists. The PREM was cognitively tested with eight CYP and eight parents to make sure that the language was appropriate, and the questions were interpreted as intended. An online PREM methodology was then trialled with 12 paediatric diabetes clinics across England and Wales.

The online link and QR code was shared with young patients and parents via electronic bulletins, on posters in clinics and using other promotional materials, allowing the survey to be completed on people's own devices away from the clinic. Tablets were also shared within clinic settings.

All CYP and their parents under the care of a paediatric diabetes unit were eligible to participate. PREM validity was assessed by exploring patterns in the pilot data, including how individual questions were answered (for example the percentage of people failing to answer; how similar people's responses were) in addition to patterns in responses to different questions (inter-item correlations).

Impact

Changes were recommended to question wording to improve the survey, along with removing questions that were:

- highly correlated (indicating they may measure the same aspect of care); and
- largely unanswered.

The PREM is being implemented with a new set of scoring metrics that will allow diabetes care providers to understand the care experiences of their young patients and identify where they can make improvements. They will also be able to see how they perform relative to other NHS Trusts.

The improved PREM is now part of the NPDA in England and Wales that monitors care and outcomes for CYP attending paediatric diabetes units. As the PREM is repeated in future audits, it will allow an understanding of where new initiatives are having an effect, and drive continual improvements in care.

Testimonial

"Having a new PREM has enabled us to understand where children with diabetes need more support with self-care and any gaps in current service provision, both locally and nationally."

Holly Robinson, NPDA Manager, RCPCH



About Picker

We are a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care.

We work with NHS trusts, government bodies, charities, academic institutions, and commercial organisations, and are an approved contractor for the CQC.

Our eight Principles of Person Centred Care provide an internationally renowned quality improvement framework.

The Picker Principles



Fast access to reliable health advice



Effective treatment delivered by trusted professionals



Continuity of care and smooth transitions



Involvement and support for family and carers



Clear information, communication and support for self-care



Involvement in decisions and respect for preferences



Emotional support, empathy and respect



Attention to physical and environmental needs

About RCPCH

RCPCH's vision is a healthier future for children and young people across the world. Founded in 1996 and now with about 19,000 members in the UK and internationally, they play a major role in postgraduate medical education, professional standards, research and policy.

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