

National Paediatric Diabetes Audit

How are we doing? 2018-19

Thank you for participating in *How are we doing? 2018-19*, the NPDA's new national Parent and Patient Reported Experience Measure (PREM) surveys.

What are the PREM surveys?

The aim of PREM surveys is to gain an understanding of parents' and patients' perspectives and experiences of the care they have that they have received. The results of the surveys can be used to identify local and national areas of achievement and areas where improvements need to be made. PREM surveys enable patients and parents to provide structured feedback, to have their say in how their local services can better meet their needs, as well as affirm and acknowledge good care.

How have the PREM surveys been created?

The NPDA has already rolled out two previous successful national PREM surveys, collecting thousands of responses from parents and children and young people receiving care from paediatric diabetes units (PDUs). By the second round of PREM data collection, the questions of the PREM surveys needed to be refreshed since most services were now doing very well according to the results. The NPDA team commissioned the Picker Institute to do this work to help generate a wider range of responses, and 'raise the bar'.

How have the questions in the national PREM surveys been generated?

The first phase of the development of the parent and patient surveys was a series of workshops held with patients and parents, in which they were asked to talk about their diabetes care, what they valued, and what they would like to improve. These workshops were written up, and common themes were identified. Questions were then developed from these themes, and refined with the input of clinical members of the NPDA Board. The next step was 'cognitive testing' where children and young people with diabetes and parents/carers were asked how they interpreted the questions, to ensure that the questions measured what the researchers expected them to. Questions that did not 'perform well' were then removed or modified.

To ensure that the questions in the new national PREMs are fit for purpose, these were piloted amongst 12 units across England and Wales first and a "psychometric evaluation" of the results generated was performed. This included doing statistical checks to make sure that the questions generated a wide range of responses, so that if a PDU performs particularly well on a specific question, we can be confident that this is because their practice is better than other clinics in this area. The checks also

helped to identify redundant questions so that they can be removed to keep the survey as short as possible.

How long will the PREM run for?

The PREM survey will run for six months from the initial launch date to allow PDUs time to trouble shoot barriers to achieving a good response rate and choose when to intensify efforts to collect responses.

What do we get from participating in the PREM survey?

The NPDA team provide your PDU with a report that summarises the findings for your unit. The results will also be analysed at regional and national level to give a snapshot of parent and patient experiences of the services received in PDUs across England and Wales.

What is expected from PDUs?

To attempt to achieve as many responses as possible.

Are the PREMs mandatory?

All elements of NCAPOP commissioned national clinical audits including the NPDA and the PREM surveys are mandatory.

How will the NPDA support us to collect responses?

The NPDA will share a PREM pack in advance of the launch including promotional materials for display in waiting areas, a template email with links to the surveys, feedback from units who achieved a good response rate in the PREM pilot/previous rounds of PREM, and by offering a prize incentive for completion. The surveys will also be promoted via social media to relevant parent groups.

What incentive is there to motivate participation?

The NPDA will be providing a prize incentive for all respondents with the chance to enter a prize draw! Two winners will be selected for a £50 Amazon eGift vouchers each, one of whom will be a carer/parent, the other will be a child or young person.

The link to enter the draw will only be available after the PREM survey is completed, and personal email addresses collected will not be able to be linked to survey responses.

Full terms and conditions for the NPDA Prize Draw can be viewed on our information page.

<http://www.rcpch.ac.uk/npda-prem>

How many responses does our unit need to achieve?

The more responses you collect the richer and more representative the data collected about your service will be. The minimum number of responses necessary per unit to enable generation of a report is likely to be ten, with the Project Board making the final decision once all responses are in.

How can the pilot PREM survey be accessed?

The PREM survey is available on our website: <http://howarewedoing2018-19.co.uk>

A QR code is available as well which you will need to scan with a QR code reader app. This can be found in your iTunes or Google Play Store. The QR code can be found on the promotional materials provided.

How do users select our PDU in the pilot PREM survey?

- 1) Users will need to select the region within which your PDU is located.
- 2) This will provide a drop-down list of the available PDUs in that list where they will be able to find your clinic.

How will we know how many responses have been received?

Response numbers will be updated weekly on the RCPCH website via an Excel spreadsheet (please see the download box).

<http://www.rcpch.ac.uk/npda-prem>

Can we help parents and patients complete the survey?

No. In order to be able to provide honest feedback, it is **essential** that those completing the surveys are able to do so in privacy. PDU staff involved in approaching patients/parents to complete the survey should make sure that they keep a **reasonable distance** so that the respondents answers aren't able to be seen. We received several reports from parents completing the previous PREMs that PDU staff stood over them as they completed the survey which made them feel uncomfortable and affected their responses, and we are keen to avoid similar experiences this time. Please ensure that all staff members involved in approaching patients/parents to complete a survey are aware of their responsibility to ensure privacy.

The NPDA team is also available for you to speak to either via phone or email should you have any questions or concerns.

Thank you once again for your support and we wish you the best of luck in achieving a good response rate.

Best Wishes,

The NPDA Team