

How are we doing 2018-19?

National Patient and Parent Experience Measures (PREMs) for users of paediatric diabetes units

Privacy Information

Why is the National Paediatric Diabetes Audit (NPDA) collecting information on parent and patient experience?

Every year, the NPDA collects data from all paediatric diabetes units in England and Wales about the health checks received and diabetes outcomes achieved by the children and young people. This information is very powerful as it shows individual clinics where they need to improve, and has driven dramatic improvements in care received and national HbA1c outcomes. By offering the 'How are we doing?' national PREM survey to children and young people with diabetes and their parents and carers, we are giving them a chance to let paediatric diabetes teams, their managers, and policy makers know what's important to *them* about their diabetes care.

Is the survey anonymous?

Yes. The survey doesn't collect any personal information that could identify you. If you make any comments that include your/your child's name or a staff member's name, this identifying information will be blanked out before the comments are included in clinic or national reports. If you choose to enter the prize draw, your email address will be requested but this will be collected via a different website, so it will not be able to be linked to your answers. In order to further protect your privacy and anonymity, we do not publish results from paediatric diabetes units where only a very small number of users have responded to the survey.

If you are completing the survey in clinic, clinic staff should give you space so that you can answer the questions privately. If you feel that clinic staff have not respected your privacy and that you have felt uncomfortable about providing certain feedback as a consequence, please contact the NPDA team either at npda@rcpch.ac.uk or on 0207 092 6167 so we can provide further guidance to your clinic.

What will happen to my answers?

Your answers are collected via an online survey managed by the Picker Institute. Once the data collection period has ended, the Picker Institute will return all the PREM survey responses to the NPDA team at the Royal College of Paediatrics and Child Health. The NPDA team will then analyse the responses and remove any identifying information before creating reports for individual paediatric teams, regions, and a national report to help services understand what they are doing well and what they could do better. The data will also feature in presentations at conferences, and may be shared with researchers subject to approval.

Who owns the PREM data collected?

The Picker Institute and the RCPCH act as the data 'processors', but the data 'controller' is the Health Quality Improvement Partnership (HQIP), the body funded by NHS England and the Welsh Government to commission the NPDA.

Where can I find out more about the PREMs and the NPDA?

The [NPDA website](#) offers a number of resources including:

- [Further information about the PREMs](#)
- [NPDA Online: Our interactive reporting tool that allows you to compare your clinic against others on a range of measures.](#)
- [National NPDA reports including versions for parents and carers](#)
- [Further privacy information](#)