

NPDA Privacy Information for Young People with Diabetes

Why are we collecting information about your diabetes care?.....2

How do we keep your information private?2

Do we share your information with anyone else?2

How long do we keep your information for?.....3

How can you stop your information being used?.....3

Further information and how to contact us3

Why are we collecting information about your diabetes care?

The Welsh and English governments want to make care for diabetes better so that all children and young people with diabetes can live well with the condition. To see how well clinics in England, Wales, and Jersey are supporting children and young people with diabetes, the Welsh Government and NHS England have funded a charity called the Healthcare Quality Improvement Partnership (HQIP) to run the National Paediatric Diabetes Audit (NPDA). HQIP have put the Royal College of Paediatrics and Child Health (RCPCH) in charge of running it.

We collect information from all clinics for children and young people with diabetes in England, Wales, and Jersey every year. We do this to check progress towards better care and to help clinics work out where they are doing well, and where they could do better. You can see the full set of information we collect about each child or young person's care [here](#). This helps to support better care, better health for children and young people with diabetes, and better experiences for you and your family when you go to clinic.

How do we keep your information private?

You usually need to ask for permission to collect personal healthcare information from the person you are collecting it from, but it would be very difficult to ask for permission from the thousands of children and young people with diabetes included in the audit. For this reason, and because the NPDA does important work to improve diabetes care, we have special permission from the Confidentiality Advisory Group to collect your information from your diabetes team called 'Section 251 approval'. We make sure that the information is sent to use securely, is stored securely, and is only seen by specially trained people who have permission to work with it.

Do we share your information with anyone else?

Sometimes, researchers working at different universities ask for copies of information collected by the NPDA so they can do their own investigations into how care can be improved. We are only able to share this data with researchers who can hold the information safely and who are doing research that will help improve care for people with diabetes. When we share information with researchers, your personal dates (for example your NHS number or date of birth) are not passed on to them, so your privacy is protected. If you live in England and chose not to share your health information through the National Data Opt-Out, your data will not be used for research.

NHS England uses NPDA data to link with data from diabetes clinics supporting adults, which helps them to look into the care provided to adolescents and young adults. NHS England also uses our data to monitor how clinics are prescribing hybrid

closed loops (also known as artificial pancreases) and pay them back for the money they have spent on this treatment.

How long do we keep your information for?

We will keep your information for as long as we are responsible for running the NPDA. All data will be deleted or given back to HQIP very shortly after the RCPCH stops running the audit. Our current contract lasts until April 2027.

How can you stop your information being used?

If you live in England, you may have asked for your health data not to be shared through the National Data Opt-Out. This does not apply to the NPDA, so your data may still be shared with the NPDA.

Regardless of where you live, you can ask your diabetes clinic not to send your data to the NPDA. You can also contact the NPDA team at npda@rcpch.ac.uk.

If you live in Jersey, you can also email the clinical audit team at HSSClinicalAuditDepartment@health.gov.je.

Further information and how to contact us

If you would like more information about the NPDA, including how to make a complaint, please contact npda@rcpch.ac.uk or call us on 020 7092 6167.

This privacy statement was last updated in February 2025.