

Privacy information for young people with diabetes

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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 and Wales 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 and Wales 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 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 to collect your information from your diabetes team called 'Section 251 approval'. We make sure that the information is sent to us securely, is stored securely, and is seen only 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 details (for example your NHS number or date of birth) are not passed on to them, so your privacy is protected.

Your personal details are only shared with two trusted organisations: NHS Digital and the National Welsh Information Service. These organisations collect information about hospital

visits, and we send your details over so that they can give us back information about any time in hospital you may have had because of your diabetes. We use this information to work out how visits to hospital could be avoided.

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.

How can you stop your information being used?

If you don't want your care information to be used in the NPDA you can ask your diabetes clinic not to send it to the NPDA. If you want to delete any information we have already collected, you can contact the NPDA at npda@rcpch.ac.uk to find out how.

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.