

Privacy information for young people with Type 2 diabetes - Type 2 diabetes spotlight audit

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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.

Each year, the NPDA collects information from all clinics for children and young people with all types of diabetes in England and Wales. 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.

From this information, we have seen that more and more children and young people with Type 2 diabetes are being looked after by children and young people's diabetes clinics, and that some children and young people with Type 2 diabetes are not getting all of the health care checks they should.

A group called the National Children and Young People's Diabetes Network (NCYPDN) have come together to try to agree on the best way to care for children and young people with Type 2 diabetes. This will help make sure that children and young people with Type 2 diabetes are accessing the best care for their diabetes no matter which clinic in England and Wales they attend.

Helping to support the work of the NCYPDN, the NPDA has been given permission to collect specific information on Type 2 diabetes care, so that we can check how children and young people with Type 2 diabetes are currently being cared for in England and Wales, and to learn about some of the results of this care. This information is being collected through the NPDA Type 2 diabetes spotlight audit.

You can see the full set of information collected about each child or young person's care in the Type 2 diabetes spotlight audit [here](#).

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 difficult to ask permission from the hundreds of children and young people with Type 2 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.

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 NPDA.

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.