

This leaflet tells you about the North West England (excluding North Cumbria) diabetes registry for children and young people.

What is the North West England (excluding North Cumbria) diabetes registry?

The registry lists the details of children and young people aged less than 18 years of age that live in North West England (excluding North Cumbria) when they are diagnosed with diabetes. North Cumbria is included in the North East England and North Cumbria diabetes registry.

What are the aims of the registry?

- ◆ To collect information on all children and young people diagnosed with diabetes and living in North West England (excluding North Cumbria).
- ◆ To keep the information up-to-date.
- ◆ To use this information to make sure that the best quality care and treatment is given to patients with diabetes.
- ◆ Use the information for research purposes. The research will investigate the causes of diabetes and work towards identifying risk factors, both environmental and genetic.

What are we asking of you?

We are asking for your consent to collect and store your child's medical and personal details within the registry database.

What are the benefits for you and your child?

Giving your consent would allow us to use your child's data for diabetes research and to help plan diabetes healthcare services. Thus, the registry will help provide the best treatment for people with diabetes and may ultimately lead to finding a cure.

What information do we need?

Upon consent, we collect both medical and personal information from your child's hospital notes. The personal information includes: NHS number; addresses and postcodes; date of birth, sex and ethnic group.

The medical information includes details of your child's diabetes diagnosis, for example, diabetes type, date of diagnosis and whether insulin treatment was necessary. We will also collect clinical results, for example, blood sugar levels/ ketones/acidosis and other results such as HbA1cs/cholesterol/triglycerides.

What happens if you do not give your consent?

If you do not give your consent we will still extract some information like your child's age, the date of their diagnosis, whether they are male or female and the first part of their post code. However, personal details that can identify your child will not be collected.

How do we ensure the data is kept accurate and up-to-date?

We will make sure the information we hold is as accurate and as up-to-date as possible. We will do this by cross checking our records with information held by the Health & Social Care Information Centre and the General Register Office. The General Register Office is a national organisation that provides health information for the whole of England and Wales.

How do we ensure confidentiality?

All information is kept under conditions of strict security as required by law in the Data Protection Act (1998). No personal information is ever released to unauthorised individuals, groups or companies. A Data Advisory Group act as guardians of the information and monitor the security, release and use of data.

To protect your interests all research in the NHS is looked at by an independent group of people called a Research Ethics Committee. This registry has been approved by Newcastle & North Tyneside 1 Research Ethics Committee.

Who will have access to the data?

A restricted number of staff working on the registry will have access to the data about your child.

All registry staff have been trained in confidentiality procedures to ensure that your child's data are protected at all times.

Can you have access to the data?

Yes. You have a right to see all the data that is held about you and your child.

Are the data passed on to anyone?

Yes, sometimes anonymous data that cannot identify any individuals is given to other researchers. Sometimes personal data is given to approved outside researchers but information is only released under very strict security and only with the permission of the Data Advisory group.

What if you do not want your child to be registered?

No personal details will be put on the computer without your consent if your child is under 16 years old. You do not have to give a reason if you do decide to say no.

What happens if you give your consent now and then change your mind in the future?

It is possible to withdraw permission for registration at any time either by contacting us directly or informing your hospital consultant or GP who will contact us. All of your child's personally identifiable details will be permanently removed from the registry.

Your child's medical care will NOT be affected if you decide not to take part in the registry.

How can I find out more about diabetes?

Contact Diabetes UK (previously called the British Diabetic Association, BDA)

Diabetes UK Central Office

Macleod House
10 Parkway
London
NW1 7AA

TEL: 020 7424 1000
FAX: 020 7424 1001
EMAIL: info@diabetes.org.uk

WEBSITE: www.diabetes.org.uk

You can also contact your local team that delivers your care.

How can I find out more about the registry?

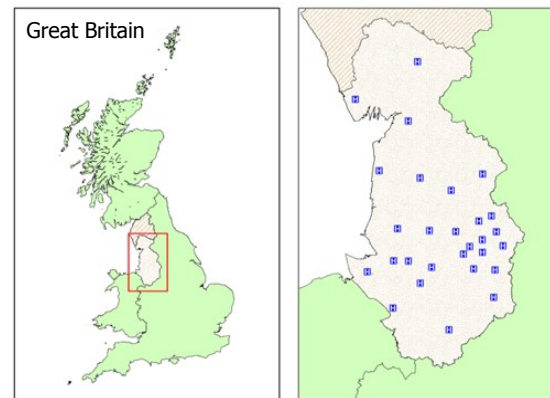
For more information regarding the registry contact:

Diabetes Registry Co-ordinator
Newcastle University
Sir James Spence Institute
Royal Victoria Infirmary
Queen Victoria Road
Newcastle-upon-Tyne
NE1 4LP

TEL: 0191 282 1347
FAX: 0191 282 4724
EMAIL: tnu-tr.diabetesreg@nhs.net

**North West England
(excluding North Cumbria)
diabetes registry for
children and
young people
aged less than 18 years at
diagnosis**

**INFORMATION LEAFLET
(for parents and carers)**



— North West England (excluding North Cumbria) registry boundaries



— Location of units providing treatment for children and young people with diabetes

