

**This leaflet tells you about the North East England and North Cumbria registry for children and young people diagnosed with diabetes aged less than 18 years.**

On the back page you can find details of people to contact if you'd like more information or have any further questions.

**What is the North East England and North Cumbria registry for children and young people diagnosed with diabetes aged less than 18 years?**

The registry lists the details of children and young people less than 18 years of age that live in North East England or North Cumbria when they are diagnosed with diabetes.

**What are the aims of the registry?**

- ◆ To collect information on all children and young people diagnosed with diabetes and living in the North East England and 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.
- ◆ To use the information for research purposes. The research will investigate the causes of diabetes and work towards identifying risk factors, both environmental and genetic.

**Why is the registry important to you?**

Because information on all children and young people from a defined area gives the best opportunity to study how diabetes health care services can be improved. Analysing the information held on the registry may also identify what causes diabetes and lead to prevention or even a cure in the future.

**What information do we need?**

Upon consent, we collect both medical and personal information from your 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 diabetes diagnosis, for example, diabetes type, date of diagnosis and whether insulin treatment was necessary. We will also collect clinical results that were recorded around the time of your diagnosis, 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 age, your date of diagnosis, whether you are male or female and the first part of your post code. However, personal details that can be used to identify you 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 NHS 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 your data?**

A restricted number of staff working on the registry will have access to the data that we hold about you.

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

**Can you have access to the data?**

Yes. You have a right to see all the data that are held about you. You can request to see the data by contacting the registry team directly. Alternatively, you can ask the people providing your diabetes care to contact the team on your behalf.

**Are the data passed on to anyone?**

Yes, sometimes anonymous data that cannot identify any individuals is given to other researchers. Sometimes personal data are 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 to be registered?**

None of your personal details will be put on the computer without your consent. 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 personally identifiable details will be permanently removed from the registry.

Your 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

**Diabetes registry  
for children and young people  
aged less than 18 years  
at diagnosis and living in  
North East England  
and North Cumbria**

**INFORMATION LEAFLET  
(for patients 16+ years)**

