

How are the data kept up to date?

The information is as accurate and up to date as possible. This is done by checking the registry information with the NHS and other organisations.

Can I have access to the data?

Yes. You, your parents or the people who look after you have a right to see all the data that is held about you.

Do I have to be registered?

No. You, your parents or the people who look after you do not have to provide a reason why they do not want you to be registered.

What happens if I am not registered?

If you and your parents (or the people who look after you) do not agree to your personal information being put onto the registry, we will not collect details like your forename, surname or your full address details so that you cannot be identified. We will only collect a small amount of information like whether you are a boy or girl and details related to your diagnosis of diabetes such as your age, the date and the first part of your postcode where you lived when you were diagnosed.

Your treatment will NOT be affected if you decide not to take part in the registry.

Your identifiable details can be removed from the registry at any time by request. Your mum, dad or the people who look after you either have to contact us directly or inform your hospital consultant or doctor who will contact us on their behalf.

How can I find out more about diabetes?

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

Diabetes UK Central Office
Macleod House Tel: 020 7424 1000
10 Parkway Fax: 020 7424 1001
London, NW1 7AA
email: info@diabetes.org.uk
Website: www.diabetes.org.uk

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

How can I find out more about the registry?

For more information please contact:

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

Tel: 0191 282 1347
Fax: 0191 282 4724
email: tnu-tr.diabetesreg@nhs.net
Website: http://www.cypdiabetesnetwork.nhs.uk/
families-diabetes/



**East Midlands
diabetes registry
for children and young
people
Information Leaflet
for patients aged
10-15 years**



This leaflet tells you about the East Midlands diabetes registry for children and young people.

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 it?

The registry lists the details of children and young people aged less than 18 years who are diagnosed with diabetes and live in East Midlands region of England.

What are the aims of the registry?

- ◆ To collect information on all children and young people diagnosed with diabetes.
- ◆ To keep the information up to date.
- ◆ To use the information to find the best way to care for patients with diabetes.
- ◆ To use the information for research purposes. The research will investigate the causes of diabetes.

Why is the registry important to me?

- ◆ A registry will bring benefits to patients and service users by enabling effective planning of diabetes health care services.
- ◆ It will also give the best chance to study how the treatment of diabetes can be improved.
- ◆ It can also help to understand the causes of diabetes and how to prevent or even cure it.

What information will be collected?

Medical and personal information will be taken from your hospital notes. The personal information includes your name, address, date of birth and whether you are a boy or girl. The medical information includes details of your diabetes, for example type of diabetes and the date your diabetes was diagnosed.

What do I have to do?

You have to sign an 'assent form' to show you agree to your medical and personal details becoming part of the registry.

Will I have to do anything else?

Being part of the registry will not require any extra blood tests or investigations. The information we need is already part of your medical record. This means that you only need to sign the assent form to be included on the registry.

You, your mum, dad or the people who look after you will also need to sign a consent form to show they also agree that you can take part.

Everything can be done when you attend clinic for your scheduled appointment. The doctors and nurses who look after you can give you the forms and more information if you need it.

Once you have agreed to take part (given assent), information will be taken from your medical records and stored on a computer.

How do we ensure confidentiality?

All information is kept under secure conditions as required by law.

Personal details are only ever released to other research groups with the approval of the registry's Data Advisory Group. The Data Advisory Group look after the information and monitor the security, release and use of your details.