



# Children and young people with diabetes in Wales

## The Brecon Group Welsh Paediatric Diabetes Interest Group

We would greatly welcome your participation in the All Wales Paediatric Diabetes Register: a register held by the 'Brecon Group' of all children and young people with diabetes in Wales.

This leaflet tells you about the Brecon Group All Wales Paediatric Diabetes Register. If after reading this leaflet you would like more information you can find contact details on the back page.



Information Leaflet

### What is the Brecon Group?

The 'Brecon Group' is a group of paediatric healthcare specialists (including doctors, nurses, dietitians, psychologists) responsible for looking after children and young people with diabetes in Wales.

### What is the Brecon Group All Wales Paediatric Diabetes Register?

It is a set of information on children and young people who have been diagnosed with diabetes under 17 years of age, and have lived in Wales, from 1979 onwards.

### What is the purpose of the Brecon Group register?

The purpose of the register is to help us understand the numbers of children and young people with diabetes in Wales and monitor the quality of services across the country.

### What is the aim of the Brecon Group register?

The Group aims to continue collecting information on all children and young people diagnosed with diabetes of any type and to use this information to carry out research. The research will investigate the causes of diabetes looking at both environmental factors and genetic susceptibility. Also studies within the NHS will look into the quality of care and available services for children and young people with diabetes.

### Why is the register important?

Because information on all children from a defined area gives the best opportunity to study how the treatment of diabetes can be improved. Also if we can find the causes of the condition it may help in the prevention of diabetes.

### What information do we hold?

The register is held in a computer database that currently contains information on over 4000 individuals. For each child or young person personal information is taken from the Registration Form: New Patient Details. This includes details of their type of diabetes, date of diagnosis, presentation details, family history of diabetes, along with GP name, hospital and NHS number, past and current postcodes, address, date of birth, sex and ethnic group.

### How do we ensure confidentiality?

All paper based and computer records are kept under conditions of strict security, as required by all the relevant laws that relate to Human Rights, confidentiality of personal data & protection of personal data.

No personal information will ever be released to unauthorised individuals, groups or companies. The Brecon Group monitors the security and release of data. No individual will ever be identified in any published material.

### Is the data ever passed on to anyone?

Sometimes anonymous data that cannot identify any individuals may be given to appropriately authorised researchers (including researchers within academic institutions).

Information held by the Brecon Group Register may be used by your clinician/ authorised researchers to keep in touch with you and follow up your child's health status.

### Who will have access to the data?

An authorised restricted number of Brecon Group members, all of whom have been trained in confidentiality procedures: Brecon Group administrator/data manager, healthcare professionals, authorised and designated researchers.

### Can I have access to the data?

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

### What if I do not want information recorded or registered?

No personal details will be put on the computer and no reason is required. This will NOT affect you or your child's medical care in any way. We may store some very limited anonymous data about your child but it will be totally unidentified and no one would be able to trace or identify any individual from the data. It is possible to withdraw permission for registration at any time, either by contacting us directly or informing your hospital consultant or nurse who will contact us.

### What are we asking for?

We are asking for permission to collect, store and use your child's details, as described in this information leaflet, for diabetes research by the Brecon Group, in Cardiff and Vale University Health Board.

### How can I find out more about the register?

For more information regarding the register, talk to a member of your diabetes team at your local hospital or clinic.

✉ [Brecon.Group@wales.nhs.uk](mailto:Brecon.Group@wales.nhs.uk)

☎ 029 2074 3946

### What will happen to the data kept on the computer?

The data collected will be used to enable doctors caring for children with diabetes to improve the care that they provide and show how they compare with other centres. It will also be a very valuable asset for scientific study to learn more about diabetes in children and the best methods to improve their life and health. It may thus be used to guide Health Boards in the provision of better resources and also for presentation in scientific journals or at conferences. Individual children will never be identified.

### What about...?

- Participation in the register is entirely voluntary but the more people who participate, the more helpful the results will be in improving the care for children with diabetes.
- We hope that when you have given us full consideration, you will complete the Consent and Registration forms, which will be kept by your diabetes teams in your notes.

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