

You can ask to have your/ your child's details removed from the database at any time. Your medical care will not be affected.

Can I see the information that is held about me?

You are welcome to see what information is held about you on the database by contacting the SPEN manager at the address in this leaflet and you can ask for help in understanding what it says. If you require a copy of this information, there may be a charge for this in accordance with the Data Protection Act 1998.

How can I find out more about the database?

You can ask any of the health professionals involved in your epilepsy care or you can contact the SPEN at

Network Manager
Scottish Paediatric Epilepsy Network
NHS National Services Scotland
6th Floor
Meridian Court
5 Cadogan Street
Glasgow
G2 6QE
Tel: 0141 300 1378
E-mail: NSS.spen@nhs.net

This leaflet can be made available in other languages and other formats on request. Please contact the SPEN Manager at the address above.

For more information about SPEN please visit our website at:
<http://www.spen.scot.nhs.uk>



Scottish Paediatric Epilepsy Network

Clinical Audit System

Patient and Family Information Leaflet

What is the Scottish Paediatric Epilepsy Network (SPEN)?

SPEN is a national managed clinical network. Managed clinical networks (MCNs) are groups of health professionals from different services such as local health centres, small and large hospitals and specialist units. Sometimes MCNs also include voluntary sector organisations and local authorities. Patients and their families are also involved in MCNs.

For SPEN all of the people involved are connected to children's epilepsy services, e.g. epilepsy nurse specialists and doctors such as general paediatricians or paediatric neurologists.

What is the Clinical Audit System?

The clinical audit system is a database that can collect and store information about you/your child and your epilepsy. This means that your doctor or nurse can look at information about your epilepsy on the computer as well as in your paper case notes.

Who can look at the information?

The database is only for healthcare professionals (such as doctors, nurses and allied health professionals). Only people working for the NHS who are involved in your / your child's care will look at these records. Sometimes this will also mean the NHS administrative staff in SPEN.

No identifiable information about you will ever be passed to a third party without your express consent.

What is the information being used for?

The information will be used to:

- Make sure everyone receives a high standard of care;
- Share information about you/ your child with other health professionals who are involved in their care;
- To plan services and help research out understanding of the condition;

Sometimes we may contact you to ask what you think about epilepsy services or to let you know about research projects you might want to be involved in. Sometimes this might mean that information collected in the database is published in a report or research paper. Any published information will be completely anonymised so that you or your child cannot be identified.

Information collected in the database may benefit research and audit work which is primarily based outside of SPEN and the NHS, for example in Scottish Universities. Please be assured that we would not release any information which could identify you unless you had consented to its release. We may provide anonymised data for audit or research purposes, but this would not identify you in any way.

How will information about me/ my child be kept safe?

The information will be kept on NHS computers and will not be accessible from computers outside the NHS Scotland network. The system will be password protected and only health professionals and administrative staff involved in SPEN will have access.

What will happen now?

After your appointment your doctor or nurse will enter some information about you / your child into the database.

What if I don't want my / my child's information included in the database?

If you do **not** want your information to be held on the database please ask your doctor or nurse for an opt out form. Please complete the form and return it to your doctor or nurse. A copy of this will be kept in your case notes and a copy will be sent to the database manager. We will then ensure no information will be kept about you / your child on the database.