



Scottish Paediatric Epilepsy Surgery Service

Information about the SPRESS Clinical Audit System

General Data Protection Regulation May 2018

What is the purpose of the Scottish Paediatric Epilepsy Surgery Service (SPRESS) Clinical Audit System?

The epilepsy surgery team seeks to provide high quality clinical care and to continually develop and improve the care provided. As part of this, SPRESS uses a database to collect information and outcomes in line with other epilepsy surgery centres in the UK. Patient data is routinely entered as a patient progresses through service from initial discussion at the multi-disciplinary team meeting.

All meetings and decisions will be in keeping with the standards and specifications of the current Service Level Agreement between NHS National Services Scotland, for and on behalf of the Scottish Government, and NHS Lothian, as provider of the service for paediatric epilepsy surgery.

What sort of information is collected?

The information we need to collect on the database will include patient information like your child's name, date of birth and CHI. It will include your child's diagnosis and referral to the SPRESS national multi-disciplinary team meeting (including the outcome of any multi-disciplinary team discussions). If your child is considered a suitable candidate for epilepsy surgery or requires further investigations, then the database will also record these. All outpatient appointments are recorded and if your child proceeds to surgery, then the outcome of the surgery and any post-surgery follow-up will be collected. Any patient undergoing surgery will also have their data updated yearly until 5 years post-surgery.

This data is extremely important in evaluating the quality of the service SPRESS provides and also contributes to how we plan to better support and prepare future families who are considering a surgical intervention for their child.

How is patient confidentiality guaranteed?

Your child's participation with SPRESS will be kept strictly confidential and all information will be handled in exactly the same way that hospitals handle all other patient information. NHS Lothian adheres to all current Data Protection legislation. We use a secure internal NHS computer network that is not accessible by other networks outside the NHS in Scotland. Only health professionals directly involved with SPRESS will have access to this secure drive. Any information extracted from the database (e.g. number of new referrals to multi-disciplinary team meetings) will not identify individual patients.

Who manages the database?

The database is administrated by the service coordinator and service data manager who collates all data and ensures that it adheres to all NHS Information Governance and Clinical Governance protocols.

What do I have to do?

When your doctor first discusses with you that they would like to refer your child to SPESS for discussion at one of our national MDT meetings, they should provide you with a copy of the SPESS information for patients leaflet or they may direct you to our website:

https://children.nhslthian.scot/departments-services/?_sft_category=epilepsy-surgery



Once you have agreed to a clinic appointment with the epilepsy surgery team, we will contact you to issue you a copy of this leaflet for reference. We can also be contacted to answer any questions about how data is collected and stored.

What if I have any questions about how this data is used or stored?

Please contact the service coordinator on the number below and we would be happy to answer any questions you may have.

SPESS Service Co-ordinator: 0131 312 0631

