



**SPAHA**

SCOTTISH PAEDIATRIC AND ADULT HAEMOGLOBINOPATHIES NETWORK

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## **Clinical Audit System (CAS) Information leaflet**

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#### **What is SPAH?**

The Scottish Paediatric and Adult Haemoglobinopathies (SPA) network is a national managed clinical network which aims to improve the clinical care and support for patients with sickle cell disease and thalassemia and their families, throughout Scotland. It does so through the development of guidelines and resources, and the provision of education and training for both health professionals and for patients and families themselves. Sometimes SPAH will contact you to ask what you think about haemoglobinopathy services or to update you on current research or other events you might want to be involved in.

#### **What is the purpose of the clinical audit system (CAS)?**

CAS is a computerised database for people living in Scotland who have a specialist condition. Information about you/your child will be entered onto the system, with the aim of improving treatment and services. The database will also hold information that will help professionals to better support you/your child. Any information that we use for planning services will not identify individual patients. We will only share information that can identify you/your child with other professionals they see or who they are being referred to.

#### **What sort of information do you collect?**

We will need to collect information about your/your child's diagnosis, condition, visits to clinics, any other conditions, and interventions as well as your/your child's name, date of birth and CHI (Community Health Index) number.

#### **Why have I/my child been chosen to take part in the scheme?**

You have been chosen because you/your child are looked after in clinics and hospital visits that are run by professionals working as part of SPAH.

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#### **Who manages the database?**

The overall managers of the database are the National Services Division (part of NHS National Services Scotland), which is the common name for the Common Services Agency of the Scottish Health Service. National Services Scotland and the 14 NHS health boards are joint data controllers. Professionals from the health board in your area will enter the information onto the database.

#### **Confidentiality**

We will keep the fact that you/your child are taking part in the scheme confidential and will handle your/your child's information in exactly the same way hospitals handle all other patient information. We will use an internal NHS computer network that will have no access to other networks outside the NHS in Scotland. The system will be password-protected and only those who are authorised will have access to it.

Your information will be held in line with the NHS Code of Practice (Scotland) 2012.

#### **Who has reviewed CAS?**

The Network Steering Group and the Scottish Government Health Directorate have reviewed CAS and it has been approved by the Caldicott Guardians (people appointed by the Scottish Government Health Directorate to make sure information about patients is kept secure).

#### **Processing your Information**

The network processes your information under a legal basis defined in the data protection legislation.

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### **The Right to Object**

When the network is processing your personal information for the purpose of the performance of a task carried out in the public interest or in the exercise of official authority you have the right to object to the processing and seek that further processing of your personal information is restricted. Provided the network can demonstrate compelling legitimate grounds for processing your personal information, for instance; patient safety or for evidence to support legal claims, your right will not be upheld.

You have the right to know what information we hold about you. To access this information, you will need to send a subject access request to your health board.

You also have the right to restrict how we handle your information, or alter or delete it, if you think it is not accurate.

### **Further Information**

Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH) through the website: [spah.scot.nhs.uk](http://spah.scot.nhs.uk)

If you have any concerns about data protection within National Services Scotland, please contact our Data Protection Officer at: [nss.dataprotection@nhs.scot](mailto:nss.dataprotection@nhs.scot) or you can ask at your health board how to contact your Board Data Protection Officer.

If you feel we have not kept to data-protection laws when handling your information, you can make a complaint to the Information Commissioner's Office (ICO): [www.ico.org.uk](http://www.ico.org.uk)

If you require an alternative format, please contact [nss.equalitydiversity@nhs.scot](mailto:nss.equalitydiversity@nhs.scot), telephone: 0131 275 600

British Sign Language, please contact Scotland BSL: [Contact Scotland \(contactscotland-bsl.org\)](http://contactscotland-bsl.org)