

South West



Congenital Anomaly Register



Paediatric Information Leaflet

RECORDING INFORMATION ON
CASES OF CONGENITAL
ANOMALY

**South West Congenital Anomaly
Register**

Congenital Anomalies

Every pregnant woman hopes that her child will be healthy and most children are. However, a few children do have problems (anomalies) such as cleft palate, spina bifida, or Down's Syndrome. These are sometimes called congenital anomalies or congenital malformations.

Some congenital anomalies are detected during pregnancy, some are found at birth, while others become obvious only as a child grows older.

Why is information collected about children with congenital anomalies?

The **South West Congenital Anomaly Register** collects information:

- To increase our understanding of congenital anomalies and help research into their causes, treatment and prevention.
- To look at trends - for example changes in the number of children born with congenital anomalies, or changes in the pattern of where they are born. Any problems can be investigated.
- To give health professionals information to help them advise families about their chances of having a child with a congenital anomaly.
- To help plan and develop NHS services.
- To monitor how good antenatal screening tests (serum screening and ultrasound scans) are at picking-up problems.

What is the South West Congenital Anomaly Register?

The South West Congenital Anomaly Register is a database of information on children born with suspected or confirmed congenital anomalies. It records all cases identified in the South West region.

What information is collected?

Information held by the Register includes:

- Descriptions of each anomaly.
- Details and results of any investigations carried out during pregnancy (for example, the results of any ultrasound scans).
- Possible risk factors in the pregnancy
- Details about mother and child including names and dates of birth.
- Mother's address and postcode.

How is information collected?

A member of staff from the hospital who treats you or your child, completes a notification to the Register when the anomaly is identified. Any information reported in the early stages can be improved or confirmed later by sending another notification.

Information is collected on paper and stored electronically on an NHS computer. This information is held securely by the **South West Congenital Anomaly Register** based at Institute of Child Health, University of Bristol. The public cannot access this data over the Internet.

Names are included so that information can be updated on the correct case and the same child is not counted several times.

Who sees the information?

There are very strict regulations controlling access to personal information - that is names and addresses. This information will only be available to members of hospital staff treating you and your child, and to those who work on the South West Congenital Anomaly Register.

Information is also sent to the National Congenital Anomaly Surveillance System, which collects information for the whole country. This is run by the Office for National Statistics.

Information that is used by researchers or published in reports does not contain anything to identify either mother or child, such as names and addresses.

Can I see the records on the Register?

Yes - you have the right to request a copy of the information held on you or your child.

To do this, please make your wishes known to a member of your healthcare team or contact the South West Congenital Anomaly Register. Contact details are provided at the end of this leaflet.

Will the database be secure and confidential?

The information recorded on the Register about you and your child is confidential. It is held in a responsible way which respects the rights and privacy of individuals.

The Register follows a strict policy on security and confidentiality which is available to the public. The Register conforms to the requirements of legislation on Data Protection and Freedom of Information.

Does my name or my child's name have to go on the Register?

We hope everyone will want to be included on the Register, to help us plan and improve services for future mothers and children. However, your details can be removed at any time. Please contact us if you want to request removal of some or all of your details from the Register.

How can I find out more about the South West Congenital Anomaly Register?

If you have any questions or concerns regarding the information that could be held on you or your child, or if you wish to have any information removed, please contact the Register. Contact details are provided at the end of this leaflet.

South West



Congenital Anomaly Register

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