

Every pregnant woman hopes that her baby will be healthy and most babies are.

However, a few babies do have problems (abnormalities) 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 baby grows older.

### Why is information collected about babies with congenital anomalies?

BINOCAR 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 babies 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 baby 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 BINOCAR Congenital Anomaly Register?

**The BINOCAR Congenital Anomaly Register is a database of information on babies born with suspected or confirmed congenital anomalies. It records all cases identified in the BINOCAR regions.**

### 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).
- Details about mother and baby 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 baby, 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 a computer. This information is held securely by the BINOCAR Congenital Anomaly Register. 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 baby 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 or your baby, and to those who work on the specific BINOCAR Congenital Anomaly Register.

Information is also sent to the National Congenital Anomaly Surveillance System, which collects information for the whole country. When this happens only the first three letters of the baby's name are sent.

Information that is used by researchers or published in reports does not contain anything to identify either mother or baby, 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 baby.

To do this, please make your wishes known to a member of your healthcare team.

## **Will the database be secure and confidential?**

The information recorded on the Register about you or your baby 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.

## **Does my name or my baby'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 babies. However, your details can be removed at any time.

## **How can I find out more about the BINOCAR Congenital Anomaly Register?**

If you have any questions or concerns regarding the information that could be held on you or your baby, or if you wish to have any information removed, please contact the registry at:

Contact Address      E Draper  
University of Leicester  
22-28 Princess Road West  
LEICESTER  
LE1 6TP

Tel:                    01664 561840  
Email:                msn@leicester.ac.uk

# **BINOCAR**

British Isles Network of  
Congenital Anomaly Registers

## **Information Leaflet**

RECORDING INFORMATION ON  
CASES OF CONGENITAL  
ANOMALY

**BINOCAR CONGENITAL  
ANOMALY REGISTER**