

South West



Congenital Anomaly Register

## The South West Congenital Anomaly Register (SWCAR)

SWCAR was set up in January 2002. It aims to collect data on all birth anomalies in the South West from Cornwall to Wiltshire. It includes anomalies identified at any stage of development: in utero, at delivery, and up to 18 years.

SWCAR aims to provide accurate data on incidence of anomalies, diagnosis and outcome, to aid research, audit and planning of services in the South West.

[www.swcar.org.uk](http://www.swcar.org.uk)

## Why a South West Register?

Prior to 2002 the South West Region did not have its own register for children with congenital anomalies.

Anomalies were reported through a national notification scheme to the Office for National Statistics (ONS) using the SD56 form. The national scheme does not collect data for elective terminations of pregnancy on babies with anomalies, or spontaneous loss before 24 weeks gestation.

In addition there are registers for specific conditions e.g. CRANE the cleft lip/palate database and NDSCR the National Down Syndrome Cytogenetic Register. Some local units also conduct their own monitoring systems.

However, there has been an acknowledged under-reporting of congenital anomalies nationally through ONS with correspondingly low anomaly rates for the South West.

Other regional registers exist in: Oxfordshire, Buckinghamshire and Berkshire (CAROBB); North Thames; Wessex (WANDA); West Midlands; East Midlands and South Yorkshire; Merseyside and Cheshire; Northern Region (NORCAS); Glasgow and Wales (CARIS). Some have been operating for over a decade. Their value has been demonstrated by improved detection rates.

The South West Congenital Anomaly Register has been operating since 2002 and all anomalies in the region are now reported directly to SWCAR. We pass data to ONS every month. Anomaly rates are published on our website and regular feedback is provided to reporting hospitals.

## Aims

Through accurate, prompt and complete collection of data SWCAR aims to:

- Describe the pattern of congenital anomalies in the South West
- Report notifications to Office of National Statistics so that accurate increased rates can be passed to local Public Health Offices indicating possible anomaly clusters.
- Provide baseline population data for use in assessing effectiveness of interventions to detect and prevent anomalies.
- Provide data as a resource for research, audit and service planning.
- Disseminate data and information as appropriate
- Provide easy access to anomaly rates for the Region, Strategic Health Authorities and for individual hospitals via the SWCAR website: [www.swcar.org.uk](http://www.swcar.org.uk)

## Benefits of Improved Reporting

- Audit of prenatal diagnosis including antenatal ultrasound and amniocentesis
- Evaluation and monitoring of new prenatal tests
- Provision of data for healthcare policies and planning
- Provision of data for the investigation of anomaly 'clusters'
- Investigation of putative teratogens
- Research on the epidemiology and aetiology of particular inherited conditions or malformations
- Data to aid understanding of the natural history of genetic disorders and syndromes

## Who do we Collect Data from?

- Maternity units in the South West Region
- All associated diagnostic departments: paediatric, neonatal, clinical genetics, antenatal ultrasound, fetal medicine, pathology.
- Regional Cytogenetics
- NHS Trust IT departments
- Neighbouring regional registers
- National specific registers e.g. CRANE database of cleft lip/palate cases
- Local audit schemes
- Office for National Statistics

## What Data do we Collect?

- Type of anomaly: structural, metabolic, endocrine or genetic
- Date of birth and date of diagnosis to calculate incident rates for specific periods of time
- Risk Factors: such as maternal age at birth, family history, consanguinity, substance abuse
- Diagnosis: method of detection :antenatal USS, karyotype, serum screening, examination of newborn, heel prick test, X-ray, cardiac studies, postnatal ultrasound, post mortem
- Outcome: live births, stillbirths, spontaneous fetal loss and termination
- Location details including postcode to investigate clusters, hospital of pregnancy to feedback for audit purposes, mother's GP or Primary Care Trust (PCT) for patient population analysis.

## Issues of Confidentiality

The collection of data for the register is covered by the following guidelines and regulations:

- Data Protection Act 1998
- Health & Social Care Act 2001 Section 60
- Caldicott Guardian Principles 1997
- Freedom of Information Act 2000

SWCAR complies by:

- ensuring all staff are trained and bound by a confidentiality agreement covering storage and transfer of information.
- All computer systems have controlled access.
- Patients have access to information leaflet about SWCAR and are able to obtain copies of their data on request.
- Data collection is relevant, not excessive and is used for legitimate medical purposes in the public interest.

## Issues of Consent

Section 60 of the Health and Social Care Act 2001 provides a power to ensure that patient identifiable information needed to support essential NHS activity can be used without the consent of the patient. It is used to support medical purposes that are in the public interest where consent is not practicable and anonymised information will not suffice. The Patient Information Advisory Group (PIAG) has authorised use of patient data without consent for regional anomaly registers under Section 60 of the Health and Social Care Act 2001.

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Contact details:

Rosie Thompson, Project Manager  
r.l.thompson@bristol.ac.uk  
Telephone: 0117 928 5141

Aileen McLoughlin, Co-ordinator  
aileen.mcloughlin@ubht.nhs.uk  
Telephone: 0117 928 5147

Julie Chamberlain  
Information Administrator  
julie.chamberlain@ubht.nhs.uk  
Telephone: 0117 928 5142

South West Congenital Anomaly Register  
Institute of Child Life and Health  
Level D  
St Michael's Hospital  
Southwell Street  
Bristol BS2 8EG

Fax: 0117 928 5154  
Website: [www.swcar.org.uk](http://www.swcar.org.uk)

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