



# British Isles Network of Congenital Anomaly Registers

## BINOCAR Standard Operating Procedure for Clinical input, Advisory groups and Steering groups

Instructions for the Registration and Surveillance of Congenital Anomalies in  
England and Wales

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## Introduction

The diagnosis and management of congenital anomalies are a complex area of medicine. Often the underlying reasons (aetiology) for a particular condition are not well understood. The care of babies (treatment, surgery, palliative care) and the wider needs of families are diverse and dependent on the nature and severity of the anomaly. In fetal medicine the care of the mother is important when she is faced with difficult decisions in the antenatal period.

The congenital anomaly register is at least one step removed from the front-line of patient care. But the value of a register is diminished if sight is lost of this wider picture of care. Clinical involvement is not only desirable but essential to fully utilise and feedback data to caring health professionals and planners of services.

All the BINO CAR registers recognise the value of clinical involvement for:

- Clinical audit
- Evaluation of screening programmes at local, regional and national level
- To aid staff in understanding and coding difficult cases correctly
- To feedback outcome data to improve and update the counselling provided to families
- To aid research and analysis of congenital anomalies

To this end mechanisms need to be put in place to ensure that a connection between the register and the wider medical community are established and maintained. How this takes effect may vary between regions, depending on existing networks, time and commitment. How such mechanisms develop will also vary over time.

## Clinical input

Clinical input is needed in a congenital anomaly register:

1. For register staff

Many register staff do not have a relevant scientific background or medical training. Congenital anomalies are often complex and confusing, and the terminology difficult to understand. Clinical input is essential if cases are to be correctly coded and categorised. Such input is invaluable for register staff to gain a greater understanding of anomalies, and to expand their knowledge and expertise. It can also be helpful for the clinician to understand the constraints of clinical coding and the difficulties that register staff face in the registration process.

2. For clinical audit

Advances in knowledge and improvement in care is often driven by the audit process. To have an agreed standard, measure compliance to it, and understand

the reasons causing deviation from the standard, are basic to the clinical audit process. Congenital anomalies are often rare, knowledge about best treatment, practice and care is not always available. Registers are able to contribute to the audit of screening programmes including antenatal detection by the timely provision of well ascertained, good quality, carefully coded data.

Provision of such data can help cement a stronger relationship between the register and the wider health service, which often rewards the register with better notifications of cases and improved ascertainment.

### 3. For better counselling of families

Data from congenital registers, showing successful surgical treatment and improved survival rates in children is very important to inform clinical staff. With this information they can present parents with an up-to-date profile of the condition, so that a truly informed choice is made when difficult decisions are necessary.

### 4. For evaluation of screening programmes

Congenital anomaly registers can be the missing link in screening programmes. Both antenatal and postnatal screening programmes are good at identifying the number of people screened and the number of screen positive and screen negative cases. What a screening programme often cannot do is identify the true screen positives from the false screen positives and the true screen negatives from the false screen negatives, or those that have missed screening completely. This is where a good register can play a helpful role, in feeding back data. This means that screening programmes can be audited and properly evaluated.

## **Advisory and steering groups**

Because congenital anomalies cover a wide field and often involve multi-disciplinary care, any formal or informal body constituted to provide guidance and advice, should be broad-based and aim to capture a range of speciality knowledge.

The level of formality chosen will reflect the broader managerial framework in which a register operates.

Suggested areas of expertise of value to a register includes:

- Medical / Clinical genetics
- Fetal medicine
- Paediatrics
- Ultrasound / radiology
- Paediatric cardiology
- Paediatric surgery

- Fetal / paediatric pathology

The tasks that an advisory / steering committee can help with include:

- Identifying areas of research
- Reviewing data for consistency and quality
- Discussing content of annual reports and meetings
- Encouraging engagement with and reporting of cases to the register

If a formal group is to be constituted, it is important that a firm idea of the time and commitment needed is clear to participants from the beginning. It is also recommended that terms of reference for the group are drawn up, so that it is clear what the aims of the group are.

## **Professional Networks**

An alternative way to maintain links between the regional register and the wider health service is for a designated member of staff to be appointed as a member of a clinical network. There may be number of such networks (Fetal medicine, paediatric cardiology, screening etc). The presence of a register staff member in such a group should be mutually beneficial. It provides a pathway where data addressing questions of real clinical concern can be directly fed back to medical staff. It also ensures that the needs of the register are not forgotten either.

## **Use of trainees**

Medical trainees need to provide evidence of research work and some understanding of epidemiology. Registers provides a treasure trove of data that can be used for research projects. Such links not only use the register data to advantage but foster long term relationships between the register and medical staff.

## **Meetings**

Many registers host annual meetings and other study days. This is a good way of establishing links with the wider medical community in which the register operates. Local experts can be invited as guest speakers to review a topic of interest. Work undertaken by trainees can be show- cased. Meetings provide an opportunity for the register to demonstrate its relevance to clinicians. It is important for registers not to be seen as something remote and of no clinical relevance. An annual meeting can breaks down barriers and if often the means of stimulating clinical staff to improve their reporting of cases to the register.