Aims and Objectives of EUROCAT

The aim of EUROCAT is to carry out epidemiologic surveillance of congenital anomalies in Europe.

EUROCAT's objectives are:

- To provide essential epidemiologic information on congenital anomalies in Europe.
- To facilitate the early warning of teratogenic exposures.
- To evaluate the effectiveness of primary prevention.
- To assess the impact of developments in prenatal screening.
- To act as an information and resource centre regarding clusters or exposures or risk factors for concern.
- To provide a ready collaborative network and infrastructure for research related to the causes and prevention of congenital anomalies and the treatment and care of affected children.
- To act as a catalyst for the setting up of registries throughout Europe collecting comparable, standardised data.

Why European Collaboration?

- Pooling of data
- Comparison of data
- Sharing of expertise
- Joint approach to European public health questions

Why Register Congenital Anomalies?

There are three main reasons why congenital anomaly registers are established:

1. To facilitate the identification of teratogenic exposures. Ever since thalidomide and rubella (german measles) were discovered as powerful teratogens, registries have been set up to facilitate research and surveillance concerning environmental causes of congenital anomalies, and to give early warning of new teratogenic exposures. Registers are also used for genetic studies, and for research into the interaction of genetic and environmental factors in causing congenital anomalies.

2. For the planning and evaluation of preventive health services. This includes primary prevention strategies such as periconceptional folic acid supplementation to prevent neural tube defects and vaccination against rubella to prevent congenital rubella syndrome, secondary prevention by prenatal diagnosis to prepare for birth and treatment, and tertiary prevention through paediatric surgery, rehabilitative and other services. Population-based registries are a particularly powerful tool for the evaluation of health services, because they represent the experience of a whole community, not the outcomes of specialist units which may serve only a selected group of women or children or which may have atypical expertise or financial resources.

3. Many birth defect registries in Europe have been set up to provide a mechanism for the audit of prenatal screening practice. A registry can provide data on the proportion of cases of congenital anomaly diagnosed prenatally, the proportion of positive prenatal screening results which were confirmed as cases of congenital anomaly, and the proportion of prenatally diagnosed cases which led to termination of pregnancy, as well as related information about prenatal screening and diagnostic methods. A population-based approach is important, for the reasons given above.

How Can A Register Be Used?

Whether concerned with the identification of teratogenic exposures, or with planning and evaluation of health services, or both, registers can be used in two main ways:

1. As a basis for surveillance using routinely collected data. Every register routinely collects a core dataset of standard information on each malformed child and more limited information on non-malformed children in the population.
2. As a basis for special or ad-hoc studies, such as case-control studies, which require further data collection. A register of congenital anomaly cases with diagnostic information can greatly facilitate the conduct of ad-hoc studies that seek to address specific hypotheses concerning teratogenic exposures or effectiveness of health services.

In chapter 2 we define the EUROCAT core dataset to be collected by all registries, and an extended dataset with optional non-core data items. The decision as to which data should be included in the routine dataset of a registry, and which data should be collected only in ad-hoc studies is a difficult one. Collection of incomplete and inaccurate data is generally a waste of resources. Depending on local circumstances, it may be justifiable for the registry to concentrate on data about the baby and its diagnosis in routine data collection, leaving most risk factor data for collection in ad-hoc studies. Some ad-hoc data collection will always be necessary to address new or more elaborate hypotheses. However, registers that do not record the identity of children for confidentiality reasons can experience difficulties in supporting ad-hoc studies.

With the advent of electronic healthcare databases, the opportunity arises to link registers with other databases e.g. with prescription databases for pharmacovigilance purposes. Registers can also be linked to spatial environmental databases through the place of residence of the case.

Risk factor data must be present for both cases and controls (non-malformed children) in order to be interpretable in terms of the risk of all anomalies combined. While all registers collect basic information about the number of births in their population by type of birth and maternal age, only a few registers routinely collect the same set of risk factor information on control babies as on case babies. There are useful approaches to analyzing risk factor data among malformed cases only, using a case-malformed control approach where children with different malformations act as controls for each other. For example, specific associations between particular drugs and particular malformation types can be sought.