5.1 Template for registry description

This template provides the basis of the Registry Description is regularly updated on the EUROCAT website under "Member Registries". The original Registry Description is based on the EUROCAT Membership Application Form, which is available on the website (https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-members/membership_en), but registries have the opportunity to give more details and updates.

The Registry Description should be updated every 3-5 years, or earlier if an important change in the registry occurs. It should help to interpret your data for all years transmitted to EUROCAT, not just the most recent years.

Registry Country and Region (if applicable)

Registry Name

History and Funding

1. Year started collecting data, first birth year collected, year joined EUROCAT, first birth year transmitted to EUROCAT
2. Who funds the registry – historical summary and current position
3. Describe the main aims of the registry
4. Institution that hosts the registry and collaboration with regional and national institutions (institutions to whom you regularly report your data)

Population Coverage

1. Population definition:
   - Population based I – All mothers resident in defined geographic area
   - Population based II – All mothers delivering within defined geographic area, irrespective of place of residence
   - Population based III – All mothers delivering in defined geographic area excluding non-residents of that area
   - Hospital based – All mothers delivering in selected hospitals
2. Geographic area covered by registry (give year to which this relates)
3. Has the registry area been the same since its inception? (Please give an historical summary). Has there been an expansion/reduction of the registry area? Have there been any important demographic changes?
4. Annual number of births covered (give year to which this figure relates)
5. Percentage of births in country which registry covers (give year to which this figure relates)

Sources of Ascertainment

1. Whether voluntary/compulsory
2. Number of sources of case ascertainment. Which sources of information e.g. hospital, paediatric records, cytogenetic laboratory, pathology laboratory, child health services, specialised departments for diagnosis and treatment, midwives
3. What type of records and process of consultation/notification. Do you go through all records to find cases or rely on notification of cases by clinicians?
4. Do birth certificates include notification of congenital anomaly? Do you get this information to use as a source? How? When?
5. Do death certificates allow for notification of congenital anomaly as cause of death? Do you get this information to use as a source? How? When?
6. Percentage of cases spontaneously reported by more than one source (give year to which this refers)
7. Please detail any feature of your registry which is unlike the typical EUROCAT registry requirements (e.g. do you exclude any anomalies? Do you use a system of coding specific to your own registry or different to EUROCAT specifications?). If so, please explain giving the years when this applies
8. Specific congenital anomalies not recorded by your registry

Maximum Age at Diagnosis

1. What is the maximum age at diagnosis of live births for inclusion on the registry

Termination of Pregnancy for Fetal Anomaly (TOPFA)

1. Is termination of pregnancy for fetal anomaly (TOPFA) following prenatal diagnosis legal – since what year?
2. If a congenital anomaly is diagnosed, what is the upper gestational age limit for termination? Does this differ for lethal anomalies?
3. What sources of information do you use to register TOPFAs? How complete is ascertainment of TOPFAs? What are the problems obtaining this information?
4. Prenatal diagnosis – describe the official policy in your region explicitly. What is offered (ultrasound/amniocentesis/chorionic villus sampling/ AFP/triple test, other. Why? When? How many? Is it free?)

Stillbirth Definition and Early Fetal Deaths

1. Official stillbirth definition in your country
2. Do you obtain stillbirth certificates for cases of congenital anomaly? How?
3. Do you register spontaneous abortions? How do you obtain this information? What records are available? Is there a lower gestational age limit or weight for cases for inclusion in your registry, or for cases to be recorded in the sources you consult
4. Autopsy rates for stillbirths Give autopsy rates for stillbirths percentage (number), TOPFA percentage (number), early neonatal deaths (0-7 days) percentage (number), and deaths with congenital anomaly percentage (number). Do you obtain all autopsy reports for cases of congenital anomaly? How?

Exposure Data Availability

Please detail the variables listed in Guide 1.5 (Chapter 2.2.1) which are recorded by your registry.

Denominators and Controls Information

1. Where do you get your birth statistics from?
2. Do you record the number of births by maternal age group
3. Do you record the number of births/month
4. Do you collect information on controls? If so, how do you select controls?

Ethics & Consent

1. Does the operation of your registry require the approval of an ethics committee or similar? Please give details
2. Does the operation of your registry require parental consent? If yes, please give details of procedure and percentage of cases where consent is withheld.

Address for Further Information

1. How is your registry staffed (expertise and time)?

Last updated 31.05.2022