JRC - eurocat Central Registry

european surveillance of congenital anomalies

EUROCAT Membership Criteria

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Joint Research Centre

This document defines the criteria for becoming a EUROCAT member and describes the types of EUROCAT membership.

There are four types of EUROCAT membership (described in detail below):

- full members
- associate members
- affiliate members
- world affiliates.

Registries of congenital anomalies that wish to become members of the EUROCAT Association have to complete the EUROCAT Membership Application form and submit it to the JRC-EUROCAT Central Registry at the following address: JRC-EUROCAT@ec.europa.eu. A standard format registry description must be supplied for the EUROCAT website.

The application will be assessed by the JRC-EUROCAT Management Committee (MC).

Following MC approval, the applicant registry will become an affiliate member. If the registry applied to become a full or associate member, the registry will remain an affiliate member until suitable data have been received and published on the EUROCAT website. In order to send the data to the JRC-EUROCAT Central Registry for evaluation the applicant Registry has to sign the *Declaration* document provided by the JRC that allows the JRC-EUROCAT Central Registry to manage this data.

Once the affiliate registry has sent data to the JRC-EUROCAT Central Registry (for a minimum of 3 consecutive years) and the data quality is judged to be good according to the EUROCAT Data Quality Indicators, the registry becomes a full or associate member (details below).

When the applicant Registry changes status from affiliate to full or associate member the legal representative of the registry has to sign the *Collaboration Agreement* with JRC that defines the Rules and Responsibilities of the JRC and the Registry related to data collection, data management and access rights.

Full or associate members can be elected to the Steering Committee of the EUROCAT Association.

FULL EUROCAT MEMBER REGISTRIES

- Registries from EU Member States or non-EU European states.
- Population-based congenital anomaly (CA) registries, registering the full range of CAs, with high ascertainment, with an overall prevalence of all anomalies of at least 2% and very good data quality as reviewed by the Registry Advisory Service (RAS). Data should comprise all neonatally and antenatally diagnosed cases and preferably all diagnoses made up to 1 year of age, including all affected livebirths, stillbirths and terminations of pregnancy with a CA (see EUROCAT Guide 1.4).
- The registry should cover a recommended population of at least 10,000 annual births and data will not be published on the website unless it refers to at least 25,000 births over one or more years.

- Registries have to transmit individual data to JRC-EUROCAT Central Registry using the EDMP software and coded according to EUROCAT standards (see EUROCAT Guide 1.4).
- Full EUROCAT Member Registries must transmit individual data yearly by the first or second data collection deadline. All core data must be transmitted; non-core variables are recommended but not obligatory. Data are published on the EUROCAT website in standard tables and are updated twice a year.
- Full registries have full access to the EUROCAT internal website, EUROCAT communications, annual Registry Leaders' Meetings and EDMP software.
- If on the annual 15th of February data transmission deadline a full member registry has not been able to send data to the JRC-EUROCAT Central Registry for three consecutive years, the registry status will be changed to affiliate member upon decision of the MC.
- If the prevalence of all anomalies falls below 2% for three consecutive years the MC will discuss with the registry the membership status. The EUROCAT Registry Advisory Service is available for counselling on how to improve the data quality.
- Standard format registry descriptions must be supplied for the EUROCAT website and updated as necessary.

ASSOCIATE EUROCAT MEMBER REGISTRIES

- Registries from EU Member States or non-EU European states.
- The coverage of the registry preferably must not overlap geographically with a full member registry.
- Population-based congenital anomaly (CA) registries, registering the full range of CAs, with high ascertainment, with an overall prevalence of all anomalies of at least 2% and very good data quality as reviewed by the Registry Advisory Service (RAS). Data should comprise all neonatally and antenatally diagnosed cases and preferably all diagnoses made up to 1 year of age, including all affected livebirths, stillbirths and terminations of pregnancy with a CA (see EUROCAT Guide 1.4).
- Registries have to transmit aggregate data to JRC-EUROCAT Central Registry using the EDMP software. A DQI report generated using EDMP should be sent with the data.
- Associate EUROCAT Member Registries must transmit aggregate data yearly by the first or second data collection deadline. Data are published on the EUROCAT website in standard tables and are updated twice a year.
- Associate registries have full access to the EUROCAT internal website, EUROCAT communications, annual Registry Leaders' Meetings and EDMP software.

- If on the annual 15th of February data transmission deadline an associate member registry has not been able to send data to the JRC-EUROCAT Central Registry for three consecutive years, the registry status will be changed to affiliate member upon decision of the MC.
- If the prevalence of all anomalies falls below 2% for three consecutive years the MC will discuss with the registry the membership status. The EUROCAT Registry Advisory Service is available for counselling on how to improve the data quality.
- Standard format registry descriptions must be supplied for the EUROCAT website and updated as necessary.

AFFILIATE EUROCAT MEMBER REGISTRIES

- Registries from EU Member States or non-EU European states.
- Registries with an active interest in CA surveillance that do not conform to requirements for full or associate members, including national CA notification systems limited to selected CAs or those only collecting live births.
- Registries that have expressed the intention to attain EUROCAT membership as full or associate but are still working toward the requirements, or who have submitted an application for full or associate EUROCAT membership without final approval, or without data having yet been published on the website. They will remain affiliate members until suitable data have been received and published on the website.
- Affiliate registries have full access to the EUROCAT internal website, EUROCAT communications and EDMP software. Affiliate registries are invited at their own expense to the annual Registry Leaders' Meetings. However, registries that have applied to become full or associate members are funded to come to EUROCAT Registry Leaders' Meetings according to the MC decision based on the evidence of progress toward full or associate EUROCAT membership.
- Standard format registry descriptions must be supplied for the EUROCAT website, or if registry is not yet established, a description of the current status of CA registration in the region must be supplied for the EUROCAT website and updated as necessary.
- Data from affiliate registries are not published on the EUROCAT website, but may be appended to the registry description.

WORLD AFFILIATES

- Non-European registries with an active interest in CA surveillance.
- World affiliate members must provide a registry description for the EUROCAT website and update it as necessary.
- World affiliates will receive EUROCAT Newsletters and have access to the EUROCAT Registry Advisory Service. They are invited to the annual RLM at their own expense.
- World affiliates have no access to the internal EUROCAT website and do not receive the EUROCAT communications.

- World affiliates do not transmit data to the JRC-EUROCAT Central Registry and their data are not published on the EUROCAT website.

PAST MEMBERS

- Registries who are closing their activities or making such fundamental organisational changes that a new membership application is required should notify the JRC-EUROCAT Central Registry.

  They have the following options:

  1. Leave their anonymous data in the JRC-EUROCAT Central Registry Database and on the EUROCAT website but end participation in special projects and publications.
  2. Ask for all their data to be deleted and held only as a JRC-EUROCAT archived file (so that EUROCAT can comply with the retention period defined for EUROCAT data used in studies and/or publications (see http://www.eurocat-network.eu/aboutus/requestingeurocatdata).

- Registries which fail to communicate with the JRC-EUROCAT Central Registry (via e-mail, phone, etc.) for more than one year can, on decision of the MC, be given past member status under option 1 above.
- Registry descriptions will only remain on the EUROCAT website for past members choosing option 1 above. No contact details will be published.