Procedure for obtaining EUROCAT Data
Version 27.03.2019

EUROCAT aims to encourage the use of its data for epidemiological surveillance and research whilst ensuring the protection of complete confidentiality of the data and ensuring that existing knowledge is fully brought to bear on the interpretation of its data.

Before submitting a request to obtain EUROCAT data, applicants are advised to fully consult:

- the Prevalence Data Tables where users can specify years, registries and congenital anomalies (CA) of interest (these tables indicate prevalence rates of CA and are updated twice a year and available at https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-data/prevalence

- the full publications list using EUROCAT data, available on the EUROCAT website at https://eu-rd-platform.jrc.ec.europa.eu/eurocat/publications,

- EUROCAT Guide 1.5 which provide full explanation of EUROCAT data are available at: https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection/guidelines-for-data-registration

- EUROCAT 'Members & Registry Descriptions', available at:

  https://eu-rd-platform.jrc.ec.europa.eu/eurocat/member-registries/eurocat-members

- the Data Quality Indicator Tables, available at: https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection/data-quality

EUROCAT data requests may concern:

a) aggregate numbers of cases where these are not available in EUROCAT publications or on the EUROCAT website,

b) a request for a data file of individual records.

Data requests (restricted to data not already available on the EUROCAT website) for research or policy purposes are welcome and JRC-EUROCAT Central Registry will process requests promptly, subject to resources.

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To obtain data from the JRC-EUROCAT Central Registry please follow the procedure outlined in Figure 1.

1. Read EUROCAT Authorship Guidelines and make sure you can comply fully

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2. Fill in the EUROCAT Data Request Form and send it to JRC-EUROCAT@ec.europa.eu, together with a CV of the Lead investigator and a detailed study protocol

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3. The EUROCAT data request will be considered by the JRC-EUROCAT Management Committee

3.a. The JRC-EUROCAT Management Committee will ask for revisions, if required

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4. The JRC-EUROCAT Management Committee will give approval

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5. Written permission will be requested by the JRC-EUROCAT Central Registry from registries included in the Data Request form

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6. Registries included in the Data Request form send back the Registry Participation Form to the JRC-EUROCAT Central Registry

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7. Data released electronically by the JRC-EUROCAT Central Registry to the Lead investigator
(*only from registries that sent written consent to participate in the study*)