European network of population-based registries for the epidemiological surveillance of congenital anomalies

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Data source | Human | Congenital anomaly registry

Administrative details

Administrative details

Data source ID

15950

Data source acronym

EUROCAT

Data holder

European Commission, Joint Research Centre (JRC)

Data source type

Congenital anomaly registry

Main financial support

European public funding

Funding by own institution

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

Secondary care – specialist level (ambulatory)

Data source qualification

If the data source has successfully undergone a formal qualification process (e.g., from the EMA, ISO or other certifications), this should be described.

No

Data source website

https://eu-rd-platform.jrc.ec.europa.eu/eurocat_en

Contact details

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Main

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Data source regions and languages

Data source countries

Austria

Belgium

Bulgaria

Croatia

Czechia

Denmark

Finland

France

Germany

Ireland

Italy

Malta

Netherlands

Norway

Poland

Portugal

Spain

Sweden

Switzerland

Ukraine

United Kingdom

Data source languages

English

Data source regions

Agder

Ahvenanmaan maakunta

Allier

Andalucía

Antwerpen

Arezzo

Asturias, Principado de

Beja

Birkaland

Blekinge län [SE-10]

Bologna

Canarias

Cantabria

Cantal

Castilla y León

Castilla-La Mancha

Catalunya [Cataluña]

Ceuta

Cork

Côtes-d'Armor

Dalarnas län [SE-20]

Dolnośląskie

Drenthe

Egentliga Finland

Egentliga Tavastland

England

Etelä-Karjala

Etelä-Pohjanmaa

Etelä-Savo

Évora

Extremadura

Faro

Ferrara

Finistère

Firenze

Forlì-Cesena

Fryslân

Galicia [Galicia]

Gävleborgs län [SE-21]

Gotlands län [SE-09]

Groningen

Grosseto

Guadeloupe

Hainaut

Hallands län [SE-13]

Haute-Loire

Hauts-de-Seine

Ille-et-Vilaine

Illes Balears [Islas Baleares]

Innlandet

Istarska županija

Jämtlands län [SE-23]

Jan Mayen (Arctic Region)

Jihočeský kraj

Jihomoravský kraj

Jönköpings län [SE-06]

Kainuu

Kajanaland

Kalmar län [SE-08]

Kanta-Häme

Karlovarský kraj

Kerry

Keski-Pohjanmaa

Keski-Suomi

Khmelnytska oblast

Koprivničko-križevačka županija

Kraj Vysočina

Královéhradecký kraj

Kronobergs län [SE-07]

Kujawsko-pomorskie

Kymenlaakso

Kymmenedalen

La Rioja

Landskapet Åland

Lappi

Lappland

Liberecký kraj

Lisboa

Livorno

Lodi

Lubelskie

Lubuskie

Lucca

Madrid, Comunidad de

Martinique

Massa-Carrara

Mazowieckie

Małopolskie

Melilla

Mellersta Finland

Mellersta Österbotten

Milano

Modena

Moravskoslezský kraj

Morbihan

Murcia, Región de

Møre og Romsdal

Namur

Navarra, Comunidad Foral de

Nordland

Norra Karelen

Norra Österbotten

Norra Savolax

Norrbottens län [SE-25]

Nyland

Olomoucký kraj

Opolskie

Örebro län [SE-18]

Oslo

Österbotten

Östergötlands län [SE-05]

Päijänne-Tavastland

Päijät-Häme

País Vasco

Pardubický kraj

Paris

Parma

Piacenza

Pirkanmaa

Pisa

Pistoia

Pleven

Plzeňský kraj

Podkarpackie

Podlaskie

Pohjanmaa

Pohjois-Karjala

Pohjois-Pohjanmaa

Pohjois-Savo

Pomorskie

Portalegre

Prato

Primorsko-goranska županija

Puy-de-Dôme

Ravenna

Reggio Emilia

Rimini

Rivnenska oblast

Rogaland

Romssa ja Finnmárkku

Sachsen-Anhalt

Santarém

Satakunta

Scotland

Seine-Saint-Denis

Setúbal

Siena

Skåne län [SE-12]

Śląskie

Södermanlands län [SE-04]

Södra Karelen

Södra Österbotten

Södra Savolax

Steiermark

Stockholms län [SE-01]

Středočeský kraj

Svalbard (Arctic Region)

Świętokrzyskie

Syddanmark

Trento

Troms og Finnmark

Tromssan ja Finmarkun

Tröndelage

Trøndelag

Uppsala län [SE-03]

Ústecký kraj

Uusimaa

Val-de-Marne

Valenciana, Comunidad

Varaždinska županija

Värmlands län [SE-17]

Varsinais-Suomi

Västerbottens län [SE-24]

Västernorrlands län [SE-22]

Västmanlands län [SE-19]

Västra Götalands län [SE-14]

Vaud

Vestfold og Telemark

Vestland

Viken

Wales [Cymru GB-CYM]

Warmińsko-mazurskie

Wielkopolskie

Zachodniopomorskie

Zlínský kraj

Łódzkie

Data source establishment

Data source established

15/06/1979

Data source time span

First collection: 15/06/1980

The date when data started to be collected or extracted.

Publications

Data source publications

https://eu-rd-platform.jrc.ec.europa.eu/eurocat/Data-collection/guidelines-for-Data-registration_en

https://eu-rd-platform.jrc.ec.europa.eu/eurocat/publications_en

Studies

List of studies that have been conducted using the data source

Lamotrigine use in Pregnancy and Risk of Orofacial Clefts

Lamotrigine use in Pregnancy and Risk of Orofacial Clefts II

Survey on the collection of data on adverse events related to medicinal products through registries

Establish an EU catalogue of sources of real-world data, characterised by a common set of metadata and data quality measurements

Data elements collected

The data source contains the following information

Disease information

Does the data source collect information with a focus on a specific disease? This might be a patient registry or other similar initiatives.

No

Rare diseases

Are rare diseases captured? In the European Union a rare disease is one that affects no more than 5 people in 10,000.

Yes

Pregnancy and/or neonates

Does the data source collect information on pregnant women and/or neonatal subpopulation (under 28 days of age)?

Yes

Hospital admission and/or discharge

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Not Captured

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

Advanced therapy medicinal products (ATMP)

Is information on advanced therapy medicinal products included? A medicinal product for human use that is either a gene therapy medicinal product, a somatic cell therapy product or a tissue engineered products as defined in Regulation (EC) No 1394/2007 [Reg (EC) No 1394/2007 Art 1(1)].

No

Contraception

Is information on the use of any type of contraception (oral, injectable, devices etc.) available?

No

Indication for use

Does the data source capture information on the therapeutic indication for the use of medicinal products?

Not Captured

Medical devices

Is information on medicinal devices (e.g., pens, syringes, inhalers) available?

No

Administration of vaccines

No

Procedures

Does the data source capture information on procedures (e.g., diagnostic tests, therapeutic, surgical interventions)?

Captured

Procedures vocabulary

Other

Healthcare provider

Is information on the person providing healthcare (e.g., physician, pharmacist, specialist) available? The healthcare provider refers to individual health professionals or a health facility organisation licensed to provide health care diagnosis and treatment services including medication, surgery and medical devices.

No

Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

Karyotype is specified in free text

Biomarker data

Does the data source capture biomarker information? The term “biomarker” refers to a broad subcategory of medical signs (objective indications of medical state observed from outside the patient), which can be measured accurately and reproducibly. For example, haematological assays, infectious disease markers or metabolomic biomarkers.

Not Captured

Patient-reported outcomes

Is information on patient-reported outcomes (e.g., quality of life) available?

No

Patient-generated data

Is patient-generated information (e.g., from wearable devices) available?

No

Units of healthcare utilisation

Are units of healthcare utilisation (e.g., number of visits to GP per year, number of hospital days) available or can they be derived? Units of healthcare utilisation refer to the quantification of the use of services for the purpose of preventing or curing health problems.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

ICD-9

Medicinal product information

Captured

Medicinal product vocabulary

ATC

Not coded (Free text)

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Education level

Gender

Sex

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Estimated percentage of the population covered by the data source in the catchment area

Approx 25% of all annual live births in the EU

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are

registered only for private care)

EUROCAT registries aim to be population based, collect information on all cases of congenital anomalies in a defined geographical area , i.e. children born to mothers resident or delivering in the defined geographic area covered by a given registry. The main focus of this registry is newborns and while information on parents is collected (all ages) it is not the focus. Information is also captured on terminated pregnancies due to anomalies (prenatal-detection). Livebirths: 375000, stilbirths: 10000, Terminations of pregnancy due to fetal anomalies: 75000

Population

Population size

460000

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

https://eu-rd-platform.jrc.ec.europa.eu/eurocat/data-collection_en

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

No

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

No

Description of data collection

Local registries collect data on individual patients as described in the registry descriptions: https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-members/registries_en. Data is then transmitted the JRC-EUROCAT Central Registry twice a year.

Event triggering registration

Event triggering registration of a person in the data source

Other

Event triggering registration of a person in the data source, other

Upon diagnosis of congenital anomaly

Event triggering de-registration of a person in the data source

Other

Event triggering de-registration of a person in the data source, other

Cases are deleted from the Central Registry only if there is a revision of diagnosis

Event triggering creation of a record in the data source

Recording of a congenital anomaly as per the written guidelines issued by EUROCAT

Data source linkage

Linkage

Is the data source described created by the linkage of other data sources (prelinked data source) and/or can the data source be linked to other data source on an ad-hoc basis?

No

Data management specifications that apply for the data source

Data source refresh

February

October

Informed consent for use of data for research

Not Required

Possibility of data validation

Can validity of the data in the data source be verified (e.g., access to original medical charts)?

Yes

Data source preservation

Are records preserved in the data source indefinitely?

No

Data source preservation length (years)

75 years

Approval for publication

Is an approval needed for publishing the results of a study using the data source?

Yes

Data source last refresh

03/06/2022

Common Data Model (CDM) mapping

CDM mapping

Has the data source been converted (ETL-ed) to a common data model?

Yes

CDM Mappings

CDM name

EUROCAT

CDM website

https://eu-rd-platform.jrc.ec.europa.eu/eurocat/Data-collection/guidelines-for-...

Data source ETL CDM version

1.5

Data source ETL status

Completed