

IMI2 821520 - ConcePTION

ConcePTION

WP1 – Moving beyond pregnancy registries to enhance our understanding of disease-related pregnancy outcomes, medication use and safety of use during pregnancy

D1.1 Spreadsheet containing all additional data sources for the ConcePTION Data Source Catalogue

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¹ See Appendix 1 for full list of contributors who provided information on data sources in their country for inclusion in ConcePTION FAIR Data Source Catalogue

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Document History

Version	Date	Description
V0.1	05 Mar 2020	First draft
V0.2	19 Mar 2020	Second draft including non-contributor comments from WP1 leads (Helen Dolk and Anja Gelhof)

V0.3	24 Mar 2020	Third draft for MB review
V1.0	30 Mar 2020	Final version

Abstract

The objective of this task is to identify population-based data sources that may be used for medication utilisation and medication safety studies in pregnancy. This inventory will then form the basic input to a publicly accessible and searchable ConcePTION Data Catalogue, to which details of each data source will be added, and from which data sources will be selected for five multi-country medication safety demonstration projects.

We have done this by updating and extending the existing EUROmediSAFE inventory. In year one, we have focused primarily on European sources, and will add available non-European data sources in future updates.

The EUROmediSAFE inventory of data sources for evaluating perinatal and long-term childhood risks, led by Prof J Morris of St George's University London, included names, contact information, reference documents and details about population-based health data collection systems (registries), electronic health records databases, electronic prescription or dispensing records, hospital records, biobanks and birth cohorts across 28 member states. Last updated in July 2018, it contains information on 511 different data sources, and 57 birth cohorts with >1000 births:
http://euromedicat.eu/content/EUROmediSAFE%20Inventory_Finalv2_2018_07_06.pdf.

We updated the EUROmediSAFE inventory by contacting each European country for updates or new data sources that could potentially be useful for studies on medication use and safety in pregnancy, using available networks (EUROmediCAT, EUROCAT, Euro-Peristat), literature review and website searches. In addition, the search was widened to all of Europe. In the period April to September 2019, we added or updated 307 database sources for inclusion in ConcePTION's FAIR data catalogue. Since October 2019, we added/updated information on a further 99 databases. These included 19 databases/ sources of breastfeeding data and 74 databases with neurodevelopmental outcome information. In total, we have added and/ or updated 406 database sources between April 2019 to February 2020 of which 239 were new data sources identified in 25 countries and 167 were updated data sources identified in 24 countries.

We also collaborated in developing the ConcePTION FAIR Data Catalogue by classifying data sources, identifying and categorising information items needed in data sources, specifying how researchers would query the catalogue, reviewing Catalogue specifications, and co-designing a questionnaire for data access providers to complete.

The deliverable (D1.1) is a spreadsheet containing all additional data sources for the ConcePTION FAIR Data Source Catalogue. We have transferred a series of Excel spreadsheets with new and updated information on European population-based data sources to WP7 on 3rd October 2019 and 10th March 2020 to the Catalogue developers. We will continue to provide annual updates on potentially linkable European data sources and identify non-European data sources for inclusion in the ConcePTION FAIR Data Source Catalogue until March 2024 when the project ends.

Introduction

Information to guide decision-making on the safe and effective use of medications during pregnancy is limited. As few as 5% of available medications have been adequately monitored, tested and labelled for use in pregnant and breastfeeding women. The ConcePTION project aims to address this gap by building a pan-European ecosystem for better monitoring and communication of medication safety in pregnancy.

In recent years, new opportunities for using electronic healthcare data, and for linking data sources, have become available but also present new challenges. Challenges include linkage between mother and baby, the need to cover terminations of pregnancy for congenital anomaly and spontaneous abortions as well as births, the potential for late diagnosed effects such as neurodevelopmental effects and childhood disease, and the dependency of the effects of exposure on the gestational age

at exposure (starting before the pregnancy has been recognised). Furthermore, to assess later neurodevelopmental effects, information on breastfeeding is also needed.

ConcePTION involves eight distinct strands of work (work-packages (WP)). The overall objective of WP1 is to generate timely evidence about pregnancy outcomes, including perinatal and long-term effects of medication use during pregnancy, using population-based data. The aim of WP1 is to move beyond medication exposure pregnancy registries by continuously identifying secondary data sources, optimising analytic methods and tools, and identifying the strengths and limitations of different approaches to generate actionable evidence on medication use and safety in pregnancy.

In order to achieve this objective, the first step (Task 1.1) is to identify potential population-based data sources that may be used for medication utilisation and safety studies in pregnancy. This inventory of data sources will form the basic input to a publicly accessible and searchable ConcePTION Data Catalogue, to be developed by WP7, to which details of each data source will be added (data dictionaries, data characterisation, data quality indicators, data access requirements). The completed Catalogue will be used by WP1 to select data sources for the WP1 Demonstration Projects. These Demonstration Projects will test the IT platform being developed by WP7 for data access negotiation, data harmonisation and data sharing.

We have constructed the inventory by updating and extending the existing EUROMediSAFE inventory. In year one, we have focused primarily on European sources, and will add available non-European data sources in future updates.

The EUROMediSAFE inventory of data sources for evaluating perinatal and long-term childhood risks, led by Prof J Morris of St George's University London, included names, contact information, reference documents and details about population-based health data collection systems (registries), electronic health records databases, electronic prescription or dispensing records, hospital records, biobanks and birth cohorts across 28 member states. Last updated in July 2018, it contains information on 511 different data sources, and 57 birth cohorts with >1000 births: http://euromedicat.eu/content/EUROMediSAFE%20Inventory_Finalv2_2018_07_06.pdf.

Methods

The link to the EUROMediSAFE inventory², version July 2018, was forwarded to WP7 on April 3rd 2019 for inclusion in the searchable catalogue database. For each country, the inventory included background information, an EXCEL file containing the information listed in Table 1 below, and embedded links to electronic files of codes, classifications, variables, application forms and relevant reports.

Table 1: Information included in country-specific EUROMediSAFE EXCEL files

<i>SHEETS (TABS)</i>	<i>CONTENT</i>
1. DATA	Main information on the data source, registers, links, data type, linkage, availability, permissions, costs
2. DESCRIPTION	Comprehensive information on coverage, size, completeness, variable lists, list of codes (coding dictionary), data entry professional and system
3. REFERENCE	User guides, application forms, publications using the data, collaboration and ownership information, links/URL, including register URL
4. NOTES	Further information as and when applicable per register
5. CONTACT	Name of contact, including telephone, email, address
6. BIRTH COHORTS	Name of cohort, main link and/or cohort URL, coverage, size, contact

The collection of updates was made according to the following steps:

² <http://www.EUROMediCAT.eu/euromedisafe>

- For each country, the information included in Table 1 was collated into a single EXCEL worksheet to make it easier for the country representatives to see what was missing and update accordingly. We limited the information sent to country representatives to the name of the database, the local/ native name of the database, the data source and the website link.
- The EUROmediSAFE table detailing Pan-European data sources was also searched. If a country contributed to a Pan-European data source it was also included in the EXCEL file sent to the country representatives.
- Country representatives were asked to add new data sources that could potentially be used in a medication utilisation, medication safety study or both, either directly or through linkage with other data sources. We defined useful data sources as containing individual level data on mothers and/or children relating to:
 - Pregnancy
 - Maternal medication exposure and indication
 - Outcome data (either pregnancy outcome or offspring outcome, at birth or later during childhood)
 - Information on confounders (maternal disease, smoking status, BMI, folic acid use etc).

Note that data sources were identified according to their potential only. In WP7, the relevant information will be collected to establish the feasibility of data use and quality of data.

- We sent this information to all ConcePTION WP1 Partners and Third Parties. We then contacted our colleagues in the EUROmediCAT and EUROCAT networks. For countries where we had no contacts, we asked our IMI ConcePTION partner Jennifer Zeitlin (19 – INSERM), leader of Euro-Peristat, to forward our email to the representatives of the 31 Euro-Peristat member countries on our behalf. See Appendix 1 for all contributors.
- We presented an update on the scope and progress of Task 1.1 at the Joint WP1, WP2 and WP7 workshop in Basel, June 3rd, 2019.
- On November 13th, 2019, we organised a workshop at the annual Euro-Peristat meeting in Dublin for approximately 50 Euro-Peristat members from across Europe involved in ConcePTION. The purpose of this workshop was to explain the ConcePTION project, to review the inventory and ask members to send information on local data sources that could be included in the inventory
- We conducted specific searches for breastfeeding and neurodevelopmental data sources. Breastfeeding sources were identified by contacting our ConcePTION partners specifically asking for details of any data source in their country with breastfeeding information. Our colleague Sue Jordan (21 – Swansea University) also conducted a short survey on available breastfeeding sources among ConcePTION WP1 and EUROmediCAT partners. These searches were also supplemented by literature searches. Additional data sources providing information on neurodevelopmental outcomes were also identified through literature searches, see Appendix 2.
- We forwarded all updates to WP7 at the beginning of October 2019 and March 2020. We will continue to provide annual updates on potentially linkable European data sources and identify non-European data sources for inclusion in the ConcePTION FAIR Data Source Catalogue in February of each year until the end of the project.
- The UK Medicines and Healthcare products Regulatory Agency (MHRA) have in addition agreed to provide an inventory of UK data sources, compiled with their MHRA/ Commission on Human Medicines (CHM) ad hoc Expert Group on Optimising Data on the Safety of Medicines Used in Pregnancy. This will be cross-checked with the current inventory for the February 2021 update.

To ensure that the FAIR Data Source Catalogue is fit-for-purpose to inform population studies of medication safety starting with the WP1 demonstration projects, WP1 worked closely with WP7 to construct and operationalize the FAIR catalogue by providing a classification of data sources (Appendix 3) and categorisation and list of information items (Appendix 4). In addition, we commented on the following documents produced by WP7:

- Proposal CDM ConcePTION for WP1.doc (Common Data Model proposal),
- ConcePTION data strategy WP1/7.doc,

- Task 7.6: ConcePTION Data Characterization outline.doc,
- FAIR Catalogue query elements as meta-data or characterisation.doc,
- WP1 Catalogue outline Draft.xls,
- WP1 Catalogue outline Draft Metadata Indicators Char.xls

We provided catalogue requirements (document FAIR catalogue query.doc) and had a number of teleconferences with BBMRI/ WP7 to discuss details and to clarify the inventory requirements of the FAIR data catalogue in relation to WP1. We provided feedback on the inventory section, agreed definitions and approved the first version of the prototype (EXCEL file).

Results

By the end of month 6 (September 2019), we received responses from 59 individuals across 25 European countries, see

Appendix 1. At the start of month 7 (October 3rd, 2019), we sent three EXCEL files to the WP7/ BBMRI team to inform the FAIR data catalogue. These files contained information on:

- 1) 195 new databases identified across 19 countries
- 2) updates on 112 databases across 16 countries that were already listed in the EUROMediSAFE inventory
- 3) 12 databases in 4 countries listed in the EUROMediSAFE inventory were deleted as they were not linkable to medication data, not a database, or not available for research etc.

From October 2019 to March 2020 (months 7-12), we added

- 44 new data sources in 6 countries
- 55 databases in 8 countries

Figure 1 shows new and updated data sources across Europe to be added to the ConcePTION Data Source Catalogue. New data sources are defined as those that were not included in the original EUROMediSAFE inventory. Appendix 5 lists the data sources in each country as of 28th February 2020. This includes those listed in the EUROMediCAT inventory which were unchanged, and all updates and new data sources identified. It does not include any data sources which were removed from the inventory.

In addition, we identified 19 databases/ sources of breastfeeding data across eight countries (see Appendix 6) with information on definition of breastfeeding, timing of breastfeeding assessment, and who recorded breastfeeding status (midwife etc). We also identified 74 databases across 15 countries (see Appendix 7) with information on neurodevelopmental outcomes including the aspect (type) of neurodevelopment recorded and how it is measured. Data sources with breastfeeding and neurodevelopmental outcomes are relevant to the demonstration projects in Task 1.5 and were sent to WP7 on 10th March 2020.

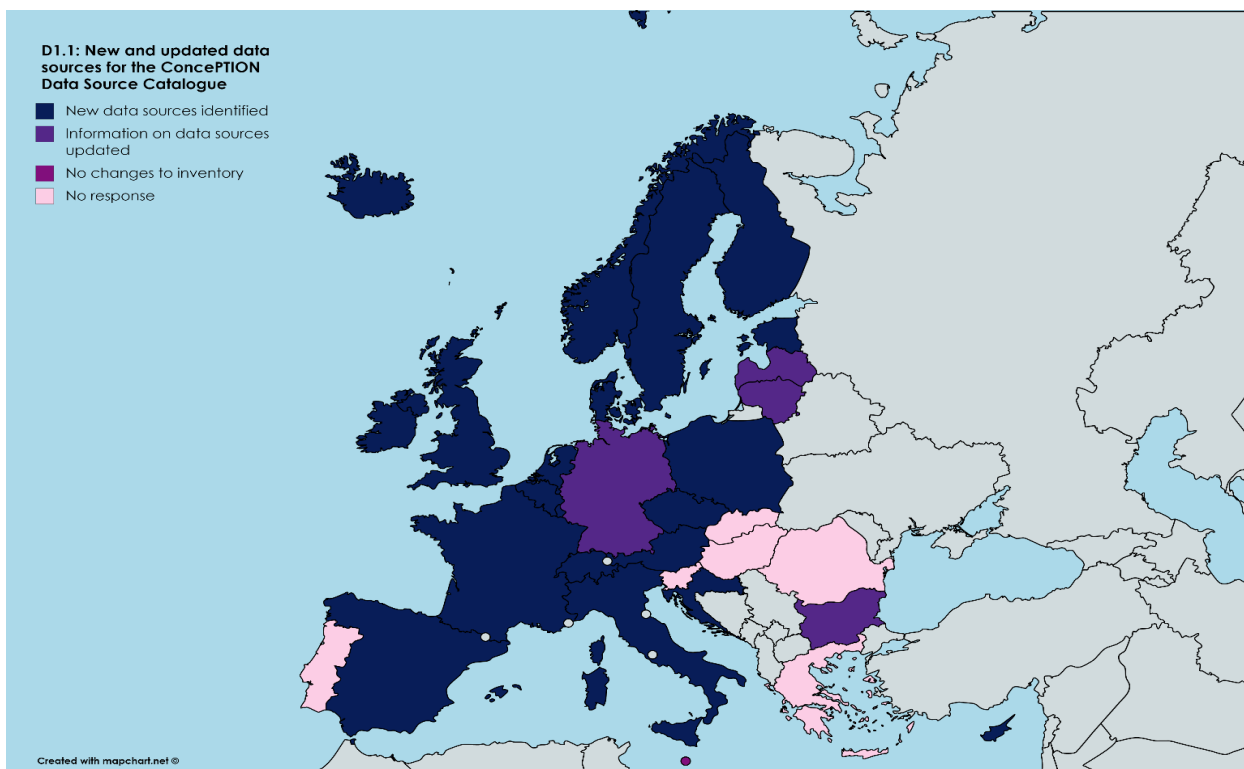


Figure 1: map of Europe showing new and updated data sources for the ConcePTION FAIR Data Sources Catalogue

Figure 2 shows the total number of data sources in 31 European countries including pan-European data sources. This includes the data sources that were documented in the EUROMediSAFE inventory, as well as the new and updated data sources that were identified in Task 1.1. The EUROMediSAFE inventory only included pan-European sources for three countries, as these countries are not EC member states (Iceland, Norway and Switzerland).

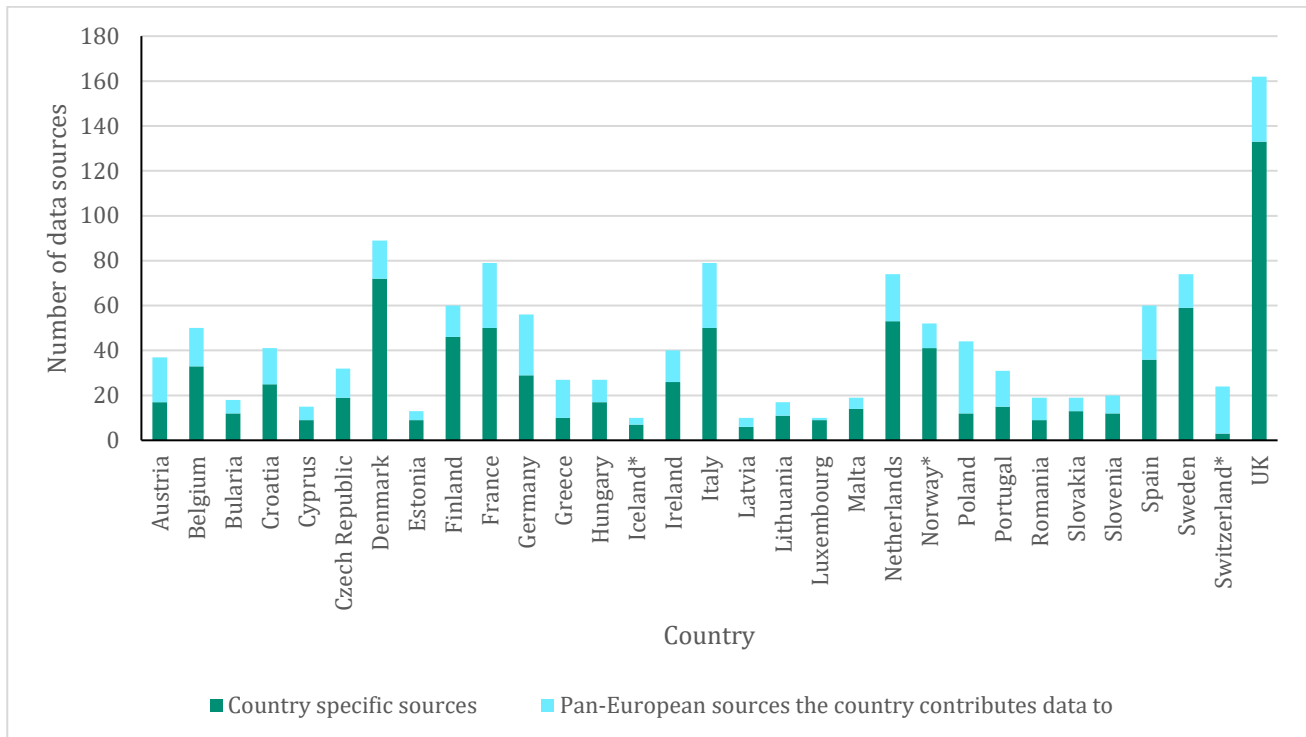


Figure 2: Total number of data sources in each European country

Discussion

Overall, we had a good response rate across Europe with only a few countries not responding to our requests for information. Some of the non-respondent, mainly Eastern European, countries may not have linkable data sources. The results suggest a large number of data sources that may have potential for medication safety studies in pregnancy. The next step is to test the feasibility of access and quality and suitability of these data in the ConcePTION project.

We will continue to collect information on European databases sources, and also non-European database sources, until the end of the project.

Conclusion

This deliverable has been successfully completed with the relevant information passed on to WP7. In total, we have added/ updated 406 database sources among health care, administrative and research databases that may potentially be used for medication safety/ utilisation studies. Of the 406, 239 were new data sources identified in 25 countries and 167 were updated data sources identified in 24 countries.

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Czech Republic	35
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France	53
Germany	60
Greece	66
Hungary	68
Iceland	71
Ireland	72
Italy	76
Latvia	83
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Netherlands	90
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Romania	106
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Slovenia	111
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Sweden	118
Switzerland	126
UK	128
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Appendix 1: Individuals who provided information on data sources in their country

EUROmediCAT members

1. Amanda Julie Neville (22 - Universita degli Studi di Ferrara)
2. Anke Rissmann (Malformation Monitoring Centre Saxony-Anhalt, EUROCAT, Germany)
3. Anna Jamry-Dziurla (Polish Registry of Congenital Malformations, EUROCAT, Poland)
4. Anna Latos-Bieleńska (Poznan University of Medical Science, EUROCAT, Poland)
5. Anna Pierini (10 – Agrenzia Regional di Sanita Tuscany)
6. Awi Wiesel (Universitätskinderklinik Mainz, EUROCAT, Germany)
7. Babak Khoshnood (19 – INSERM. EUROCAT, France)
8. Christine Damase-Michel (21 – Centre Hospitalier Universitaire de Toulouse)
9. Clara Caveró Carbonell (33 - Fundacion Para El Fomento De La Investigacion Santaria Y Biomedica De La Comunitat Valenciana)
10. Elly Del Hond (Provinciaal Instituut voor Hygiene, EUROCAT, Belgium)
11. Ester Garne (Paediatric Department Hospital Lillebaelt, EUROCAT, Denmark)
12. Hedvig Marie Egeland Nordeng (14 – Universitetet I Oslo)
13. Joan Morris (15 – St George’s Hospital Medical School, London)
14. Jorieke Kammen-Bergman (17 – Academisch Ziekenhuis Groningen)
15. Jose Ramón Aja (Basque Country Registry, EUROCAT, Spain)
16. Karin Källén (The National Board of Health and Welfare, Sweden, Euro-Peristat)
17. Ljubica Boban (Children's Hospital Zagreb, EUROCAT, Croatia)
18. Maarit Leinonen/ Mika Gissler (31 -Terveyden Ja Hyvinvoinnin Laitos – National Institute for Health and Welfare)
19. Marie-Claude Addor (CHUV Lausanne, EUROCAT, Switzerland)
20. Mary T. O’Mahony/ Niamh Bambury (Department of Public Health, HSE South (Cork & Kerry); EUROCAT, Ireland)
21. Miriam Gatt (Health Information and Research Department for Policy in Health, EUROCAT, Malta)
22. Sue Jordan/ Dan Thayer (23 - Swansea University)

Euro-Peristat members

23. Jennifer Zeitlin (19 - INSERM)
24. Alison Macfarlane (City University of London, Euro-Peristat)
25. Anastasia Nyman (The National Board of Health and Welfare, Sweden, Euro-Peristat)
26. Guy Weber (Ministry of Health, Luxembourg, Euro-Peristat)
27. Helga Sól Ólafsdóttir (Landspítali University Hospital, Iceland, Euro-Peristat)
28. Janis Misins (Centre for Disease Prevention and Control of Latvia, Euro-Peristat)
29. Jeannette Klimont (Statistics Austria, Euro-Peristat)
30. Jelena Isakova (Institute of Hygiene, Health Information Centre, Lithuania, Euro-Peristat)
31. Katarzyna Szamotulska (National Research Institute of Mother and Child, Poland, Euro-Peristat)
32. Laust Mortensen (Statistics Denmark, Euro-Peristat)
33. Luule Sakkeus (Tallinn University, Euro-Peristat)
34. Peter Achterberg (National Institute for Public Health and the Environment, Netherlands, Euro-Peristat)

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35. Rachel Wood (University of Edinburgh, Euro-Peristat)
36. Sheelagh Bonham (National Perinatal Reporting System, Dublin, Euro-Peristat)
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38. Urilija Rodin (Croatian National Institute of Public Health, Euro-Peristat)
39. Wei-Hong Zhang (ULB-ESP, Euro-Peristat)
40. Željka Draušnik (Croatian National Institute of Public Health, Euro-Peristat)
41. Additional Euro-Peristat contacts in Switzerland, Spain, Bulgaria, Czech Republic, Italy, France and Norway.

Other

42. Helle Kieler (11 - Karolinska Institutet)
43. Jonathan Richardson (12 -Newcastle upon Tyne Hospitals NHS Foundation Trust/27 - ENTIS)
44. Rebecca Bromley (28 - The University of Manchester)
45. Sandra Lopez (38 – Novartis Pharma AG)
46. Saskia Vorstenbosch (09 –Lareb)
47. Victoria Simms (02- Ulster University)
48. Tom MacDonald (University of Dundee)
49. Tania Schink (Leibniz Institute for Prevention Research and Epidemiology – BIPS)
50. Brian Cleary (The Rotunda Hospital, Dublin. School of Pharmacy, Royal College of Surgeons in Ireland)

Appendix 2: Literature search for data sources

Neurodevelopmental outcomes

Task 1.1 co-lead Florence Coste searched Embase on the 29th July 2019.

LIMITS: 10 years

EXCLUSION: conference abstracts

SEARCH QUERY,"(('pregnancy'/exp OR 'lactation'/exp) AND ('depression'/exp OR 'serotonin uptake inhibitor'/exp OR 'serotonin noradrenalin reuptake inhibitor') AND ('juvenile'/exp AND ('perinatal outcome'/exp OR 'low birth weight'/exp OR 'congenital malformation'/exp OR 'mental disease'/exp))) AND (2009:py OR 2010:py OR 2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py) AND ('case control study'/de OR 'cohort analysis'/de OR 'controlled study'/de OR 'cross-sectional study'/de OR 'drug surveillance program'/de OR 'evidence based practice'/de OR 'human'/de OR 'longitudinal study'/de OR 'meta analysis'/de OR 'observational study'/de OR 'population based case control study'/de OR 'prospective study'/de OR 'retrospective study'/de OR 'systematic review'/de) AND ('article'/it OR 'article in press'/it OR 'review'/it)"

Search results combined: n=2798

Articles screened on basis of title and abstract

EXCLUDED (n=3247) DUE TO:

- pre-clinical, genetic, epigenetic, case reports, case series
- outcome is child's depression; imaging, post-partum depression, pulmonary hypertension, PPHN
- exposure or intervention studied is smoking/ stress / violence/ trauma or acid folic/ lead/ DES/ opioid or other substances / psychological treatment, antipsychotics, antiepileptics
- study population focused on ethnicity, minorities, teenagers, or other socio-demographics
- study focused on sleep patterns, fetal alcohol syndrome, screening for mental disorder, social support, unplanned pregnancy
- RCT
- Conference abstract
- Article not in English

INCLUDED (n=450)

- 37 systematic literature reviews

Joanne Given reviewed each of the 450 articles identified by this search. The data sources, or combination of data sources, used in each of the articles exploring neurodevelopmental outcomes was then recorded in a spreadsheet so that this information could be added to the inventory.

Breastfeeding

PubMed and Google Scholar were searched for 'breastfeeding' AND ('data source' OR 'database'). The reference list of any relevant articles was also searched for additional publications which may have used data sources containing breastfeeding data.

Appendix 3: Types of data source

Healthcare databases – created for operational health care purposes and reimbursement of costs. Include:

- **Community/Outpatient/Inpatient Prescription databases** – for reimbursement of prescription costs for prescriptions dispensed. Inpatient prescriptions are usually in separate databases from community (pharmacy) prescriptions. Where outpatient prescriptions are documented varies by country.
- **Hospitalisation (Admission/Episode/Discharge) databases** - for inpatient/outpatient care. Include Maternity databases (for care given to pregnant women up to delivery) and specialist databases such as Neonatal Intensive Care, fetal medicine and paediatric surgery databases.
- **Primary care databases** – healthcare provided by General Practitioners (GPs). Includes prescriptions issued.
- **Administrative health insurance claims database** – for reimbursement of healthcare costs. May be specific to a single insurer or combined across insurance schemes. May include both primary and hospital care.
- **Child surveillance databases** – record growth and development as measured by community child health teams/public health nurses.
- **Medical Birth Registries (Nordic)** – Baby based records starting from 16 weeks gestation or later. **Establishes legal person, and also includes medical information about pregnancy and baby.**

Other administrative databases – other operational databases for the delivery of services, reimbursement of costs.

- **Educational databases** - created for operational education administration purposes for example school results, special educational needs and attendance.
- **Register of disability** - created for insurance purposes and service delivery.
- **Sociodemographic databases** – include the Census, population register, residents register, vital statistics (births and deaths) and area-based deprivation indicators.

Health surveillance and research databases – created for public health surveillance or research. May be derived from healthcare databases with extra validation or notification by clinicians or based on special recruitment and patient interview. Include:

- **Disease registries** - such as Congenital anomaly, Cancer, Cerebral Palsy or Diabetes registries.
- **Birth cohorts** - recruit pregnant women during pregnancy or at birth, irrespective of exposure, and follow-up prospectively.
- **Research Cohort by Data Linkage** – linkage of a number of healthcare or administrative data sources so that they can be used to conduct research into a specific area. An example would be EFEMERIS which can be used to monitor the prescription of reimbursed drugs to French pregnant women as well as to identify adverse pregnancy outcomes such as congenital malformations or effects on psychomotor development of the child.

Of relevance to WP2

Prospective Study Database – created for the purposes of a distinct research project such as a Randomised Controlled Trial. Often limited in size.

Pregnancy exposure registries – registries of pregnant women exposed to one or more medications.

Adverse drug reaction databases – databases notified of adverse health outcomes associated with medication exposure.

Appendix 4: Information items

Version 1.2 (06 August 2019)	Medication utilisation	Medication safety
Information item	<i>Select all that are required</i>	
<i>Pregnancy timing</i>		
Pregnancy timing - start and end date to determine pre-pregnancy, 1 st , 2 nd , 3 rd trimester and post-pregnancy: This may be derived from the date of the Last Menstrual Period, Estimated Date of Conception, Date of birth, gestational age and Expected Date of Delivery.	<input type="checkbox"/>	<input type="checkbox"/>
<i>Medication exposure</i>		
<i>Source of medication information</i>		
Primary care/General practitioner	<input type="checkbox"/>	<input type="checkbox"/>
Inpatient	<input type="checkbox"/>	<input type="checkbox"/>
Outpatient specialist	<input type="checkbox"/>	<input type="checkbox"/>
Private prescriptions – relating to private healthcare and not reimbursed by the health system	<input type="checkbox"/>	<input type="checkbox"/>
Maternal self-report – prescribed, dispensed or purchased from a pharmacy (over the counter included) or from the internet	<input type="checkbox"/>	<input type="checkbox"/>
<i>Details of medication</i>		
Name/ATC code of medication of interest	<input type="checkbox"/>	<input type="checkbox"/>
Date of issued/dispensed prescription, administration or consumption (to combine with pregnancy timing to calculate timing of medication exposure)	<input type="checkbox"/>	<input type="checkbox"/>
Strength – the amount of the active ingredient. Different strengths may be used for different indications	<input type="checkbox"/>	<input type="checkbox"/>
Dosage – amount taken at any one time for e.g. 2 tablets or 5mls	<input type="checkbox"/>	<input type="checkbox"/>
Frequency – how often the medication is to be taken	<input type="checkbox"/>	<input type="checkbox"/>
Route of administration/medication formulation (oral, injection, cream etc).	<input type="checkbox"/>	<input type="checkbox"/>
Quantity prescribed or dispensed (tablets, vials, packets) (to combine with dosage instructions to derive length of exposure)	<input type="checkbox"/>	<input type="checkbox"/>
Prescriber speciality	<input type="checkbox"/>	<input type="checkbox"/>
Co-medications – as co-exposures or as a surrogate for maternal disease	<input type="checkbox"/>	<input type="checkbox"/>
<i>Maternal disease/medication indication</i>		
<i>Diagnosis</i>		
Diagnosis in healthcare database for e.g. ICD10 or read code of diagnosis	<input type="checkbox"/>	<input type="checkbox"/>
Diagnosis in disease registry	<input type="checkbox"/>	<input type="checkbox"/>
Intervention in healthcare database as surrogate for disease - for example radiotherapy, mastectomy etc.	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare admission as surrogate for disease/disease severity – for example to a mental health unit in depression or to hospital/day hospital for intravenous steroids in multiple sclerosis	<input type="checkbox"/>	<input type="checkbox"/>
<i>Severity of disease</i>		
Health care visit pattern	<input type="checkbox"/>	<input type="checkbox"/>
Co-morbid diagnosis/diagnoses	<input type="checkbox"/>	<input type="checkbox"/>
<i>Outcomes</i>		
<i>Maternal pregnancy outcomes</i>		
Spontaneous abortions	<input type="checkbox"/>	<input type="checkbox"/>

Termination of pregnancy - elective	<input type="checkbox"/>	<input type="checkbox"/>
Termination of pregnancy - for fetal anomaly	<input type="checkbox"/>	<input type="checkbox"/>
Pregnancy related conditions -for e.g. preeclampsia, hypertension, HELLP syndrome	<input type="checkbox"/>	<input type="checkbox"/>
Mode of delivery	<input type="checkbox"/>	<input type="checkbox"/>
Maternal death	<input type="checkbox"/>	<input type="checkbox"/>
Maternal postpartum diagnoses - infections, stroke, psychosis	<input type="checkbox"/>	<input type="checkbox"/>
<i>Perinatal outcomes</i>		
Stillbirth	<input type="checkbox"/>	<input type="checkbox"/>
Neonatal death	<input type="checkbox"/>	<input type="checkbox"/>
Major congenital anomalies	<input type="checkbox"/>	<input type="checkbox"/>
Gestational age at delivery/preterm birth	<input type="checkbox"/>	<input type="checkbox"/>
Small for gestational age/Intrauterine growth restriction	<input type="checkbox"/>	<input type="checkbox"/>
Birth weight	<input type="checkbox"/>	<input type="checkbox"/>
Head circumference	<input type="checkbox"/>	<input type="checkbox"/>
Length at birth	<input type="checkbox"/>	<input type="checkbox"/>
Apgar score - including timing (5, 10 minutes)	<input type="checkbox"/>	<input type="checkbox"/>
Admission to Neonatal Intensive Care Unit	<input type="checkbox"/>	<input type="checkbox"/>
<i>Childhood outcomes</i>		
Death - infant or childhood	<input type="checkbox"/>	<input type="checkbox"/>
Health visitor/public health nurse records	<input type="checkbox"/>	<input type="checkbox"/>
Growth in childhood	<input type="checkbox"/>	<input type="checkbox"/>
Diagnosis in a specialist disease registry	<input type="checkbox"/>	<input type="checkbox"/>
Healthcare diagnosis records - Autism Spectrum Disorder, cerebral palsy, depression/anxiety, neonatal lupus, infections, asthma, eczema.	<input type="checkbox"/>	<input type="checkbox"/>
Referrals to specialists	<input type="checkbox"/>	<input type="checkbox"/>
Hospital admissions during childhood	<input type="checkbox"/>	<input type="checkbox"/>
Childhood prescriptions	<input type="checkbox"/>	<input type="checkbox"/>
Registered disability in child	<input type="checkbox"/>	<input type="checkbox"/>
Academic examination results and school performance	<input type="checkbox"/>	<input type="checkbox"/>
Special educational needs/educational support	<input type="checkbox"/>	<input type="checkbox"/>
Psychometric measurements	<input type="checkbox"/>	<input type="checkbox"/>
<i>Confounders/covariates</i>		
<i>During pregnancy</i>		
Folic acid - pre-conception, first trimester, none	<input type="checkbox"/>	<input type="checkbox"/>
Assisted conception	<input type="checkbox"/>	<input type="checkbox"/>
Maternal age at delivery	<input type="checkbox"/>	<input type="checkbox"/>
Maternal socioeconomic status - individual or area-based measure of SES or occupation, employment, income etc. as a surrogate	<input type="checkbox"/>	<input type="checkbox"/>
Smoking status - during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol consumption - pre-conception	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol consumption - during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Substance misuse - during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Body mass index - pre-pregnancy or during pregnancy	<input type="checkbox"/>	<input type="checkbox"/>
Parity (number of pregnancies reaching a viable gestational age)	<input type="checkbox"/>	<input type="checkbox"/>
Plurality (singleton or multiple pregnancy)	<input type="checkbox"/>	<input type="checkbox"/>
<i>During childhood</i>		
Maternal socioeconomic status - individual or area-based measure of SES	<input type="checkbox"/>	<input type="checkbox"/>

or occupation, employment, income etc. as a surrogate		
Highest maternal education	<input type="checkbox"/>	<input type="checkbox"/>
Smoking status - postnatally	<input type="checkbox"/>	<input type="checkbox"/>
Breast feeding	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 5: Data sources in each country

Data sources that:

- can potentially be used in a medication utilisation, medication safety study or both,
- either directly or through linkage with other data sources.
- containing individual level data on mothers and/or children relating to:
 - Pregnancy
 - Maternal medication exposure and indication
 - Outcome data (either pregnancy outcome or offspring outcome, at birth or later during childhood)
 - Information on confounders (maternal disease, smoking status, BMI, folic acid use etc).

Austria

Data source name	Native name	Data provider	Website
Databases; Surveys	Ministerium Frauen Gesundheit	Federal Ministry of Health	https://www.bmgf.gv.at/home
Health Behaviour in the School-aged Children Study (HBSC Study)	Health Behaviour in School-aged Children Study (HBSC-Studie)	Federal Ministry of Health	http://www.hbsc.org/
OKIDS - Research Network for Pediatric Medicines	Österreichischen Studiennetzwerk für Arzneimittel und Therapien "OKIDS"	Federal Ministry of Health	http://okids-net.at/
Quality data for hospitals	Qualitätsdaten der Krankenanstalten Österreichs	Federal Ministry of Health	https://kliniksuche.at/
Statistical databases; Surveys	Statistik Austria	Statistics Austria	http://www.statistik.at/web_de/statistiken/index.html
Austrian National Cancer Registry	Österreichische Krebsregister	Statistics Austria	http://www.statistik.at/web_en/statistics/PeopleSociety/health/cancer_incidence/index.html
Deaths	Gestorbene	Statistics Austria	http://www.statistik.at/web_en/statistics/PeopleSociety/population/deaths/index.html
Cause of Death Statistics	Todesursachenstatistik	Statistics Austria	http://www.statistik.at/web_en/statistics/PeopleSociety/health/causes_of_death/causes_of_death_at_a_glance/index.html
Births	Geborene	Statistics Austria	http://www.statistik.at/web_en/statistics/PeopleSociety/population/births/index.html
Medical and socio- medical characteristics of live birth	Statistik der medizinischen und sozialmedizinischen Merkmale von Geborenen	Statistics Austria	http://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/gesundheit/medizinische_und_sozialmedizinische_merkmale_von_geborenen/index.html
Deceased infants	Gestorbene Säuglinge	Statistics Austria	http://www.statistik.at/web_en/statistics/PeopleSociety/health/causes_of_death/index.html
Austrian Health Survey 2014 (ATHIS)	Österreichische Gesundheitsbefragung 2014 (ATHIS)	Statistics Austria	https://www.statistik.at/web_de/frageboegen/private_haushalte/gesundheitsbefragung/index.html
Styrian registry of		Office of the Regional	http://www.wissenschaft.steiermark.at/

congenital anomalies		Government of Styria	
Austrian Registry for Biologic Agents (BioReg-Austria)	BioREG	BIOREG	http://www.bioreg.at/
GAP-DRG (General Approach for Patient oriented Outpatient-based DRG)	GAP-DRG (Grundlagenarbeit für ambulante Patientenorientierte DRG)	Main Association of the Austrian Social Insurance Institutions	https://www.sozialversicherung.at/portal27/esvportal/content?contentid=10007.741910&viewmode=content&portal:componentId=gtn6c3f0dc3-cec0-4778-a11e-ca6fe547f549
EURAP Austria		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Hospital discharges	Spitalsentlassungsstatistik	Federal Ministry of Health	http://www.statistik.at/web_en/statistics/PeopleSociety/health/hospital_stays/index.html
Pan-European cohorts/databases/networks which contain data from Austria			Website
Biologika in der Kinderrheumatologie (BIKER)			http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)			http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)			http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)			http://www.encepp.eu/encepp/search.htm

European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European patient registry on TRAPS syndrome (EUROTRAPS - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Belgium

Data source name	Native name	Data provider	Website
Registers			
Minimum Hospital Data Set (MHD-MZG-RHM)		Federal Public Service (FPS) Health, Food Chain Safety and Environment	https://www.health.belgium.be/nl
Minimal Clinical Data (MCD-MKG-RCM)		Federal Public Service (FPS) Health, Food Chain Safety and Environment	https://www.health.belgium.be/nl
Minimal Psychiatric Data (MPD-MPG-RPM)		Federal Public Service (FPS) Health, Food Chain Safety and Environment	https://www.health.belgium.be/nl
Hospital Billing Data (HBD-SHA-AZV)		Federal Public Service (FPS) Health, Food Chain Safety and Environment	https://www.health.belgium.be/nl
Epidemiological surveillance databases		Scientific Institute of Public Health (WIV-ISP)	https://www.wiv-isp.be/en
Belgian Health Interview Survey (HIS)		Scientific Institute of Public Health (WIV-ISP)	https://hisia.wiv-isp.be/SitePages/Home.aspx
Initiative for Quality Promotion and Epidemiology in Diabetes Care (IQED-IKED-IPQED)		Scientific Institute of Public Health (WIV-ISP)	https://www.healthstat.be/ap18/register.xhtml?registerId=43
Belgian Cystic Fibrosis registry (BCFR)	Belgisch Mucoviscidose Register - Registre Belge de la Mucoviscidose - BMR-RBM	Scientific Institute of Public Health (WIV-ISP)	https://www.healthstat.be/ap18/register.xhtml?registerId=9
Surveillance of Infectious Diseases in Children by Paediatricians and GP (Pedisurv)		Scientific Institute of Public Health (WIV-ISP)	https://www.healthstat.be/ap18/register.xhtml?registerId=16
National Statistics		Zorg en Gezondheid	https://www.zorg-en-gezondheid.be/
Flemish Birth Registry	Databank Studiecentrum voor Perinatale Epidemiologie (SPE)	VZW Study Center for Perinatal Epidemiology	www.zorg-en-gezondheid.be/belangrijkste-trends-in-

		(SPE)	geboorte-en-bevalling
Farmanet OR Pharmanet		National Institute for Sickness and Disability Insurance (INAMI)	www.riziv.fgov.be
Permanent Sample	Echantillon Permanent – permanente steekproef	National Institute for Sickness and Disability Insurance (INAMI)	www.riziv.fgov.be
Belgian Cancer Registry		Belgian Cancer Registry	www.kankerregister.org
Intego	Intego OR Intego-project	KU Leuven	https://intego.be/en/Welcome
IMS LifeLink: Hospital Disease Database - Belgium		Real World Evidence Solutions IMS Health OR IQVIA	https://www.iqvia.com/
IMS LifeLink: Longitudinal Prescription Data (LRx) - Belgium		Real World Evidence Solutions IMS Health OR IQVIA	https://www.iqvia.com/
Belgium, Antwerp		Provincial Government and the University of Antwerp [EUROCAT]	http://www.eurocat-network.eu/
Belgium, Hainaut-Namur		Institute of Pathology and Genetics of Charleroi [EUROCAT]	http://www.eurocat-network.eu/
Belgian network of Sentinel General Practitioners (SGP)		Scientific Institute of Public Health (WIV-ISP)	https://emif-catalogue.eu/c/advance/fingerprint/7cac33675150772d2ac42874e5fa342a
National surveillance of Severe Acute Respiratory Infections (SARI)		Scientific Institute of Public Health (WIV-ISP)	https://emif-catalogue.eu/c/advance/fingerprint/26e339a92705ffeb24a7557a069d7aee
Paediatric Surveillance Network (Pedisurv)		Scientific Institute of Public Health (WIV-ISP)	https://emif-catalogue.eu/c/advance/fingerprint/0536400600976590d2e98dfefba8b530
EURAP Belgium		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Central registry of health		Intermutualistic Agency	https://ima-aim.be/Data-209

insurance companies		(IMA)	
Perinatal database in two Belgian regions : Wallonia and Brussels	Centre for Perinatal Epidemiology (CEpiP)	Centre d'épidémiologie périnatale (CEpiP)	CEpiP https://www.cepip.be/
Belgium Obstetric Surveillance System (B.OSS)		College of Mother and Newborn	https://www.b-oss.be/
eBirth Electronic Birth Registry	eBirth	DG Transformation digitale du SPF Stratégie et Appui/G Digitale Transformatie van de FOD Beleid en Ondersteuning	https://dtservices.bosa.be/nl/services/eBirth
Health Behaviour in School-aged Children (HBSC)	Service d'Information, Promotion, Education Santé, School of Public Health, ULB	Service d'Information, Promotion, Education Santé, School of Public Health, ULB	http://sipes.ulb.ac.be/
Le Datawarehouse marché du travail et protection sociale (DWH MT&PS)	Le Datawarehouse marché du travail et protection sociale (DWH MT&PS)		https://www.ksz-bcss.fgov.be/fr/dwh/dwh_page/content/websites/datawarehouse/about/mission.html
Vaccine coverage survey	L'Enquête de couverture vaccinale	School of Public Health	https://clinicaltrials.gov/ct2/show/NCT03673306?recrs=deh&cond=Pregnancy&sort=nwst&draw=13
A Multicenter Retrospective Study on the Prognostic Impact of Pregnancy in Women With History of BRCA Mutated Breast Cancer		Jules Bordet Institute	
Birth cohorts			
Flemish Environment & Health Survey I, II and III (FLEHS)	FLEHS I: 2001-2006; FLEHS II: 2007-2011; FLEHS III: 2012-2015	FLEHS consortium + Flemish Government	http://www.milieu-en-gezondheid.be/en/about-the-center-0
3xG study (Gezondheid, Gemeenten, Geboorten)		3xG consortium	http://www.studie3xg.be/
Pan-European cohorts/databases/networks which contain data from Belgium			
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm

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European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm

Bulgaria

Data source name	Native name	Data provider	Website
Registers			
Statistical Data		National Statistical Institute	http://www.nsi.bg/en
FERTILITY - Births, Live births, Birth rates, Mean age of the mother at birth and Total fertility rate	РАЖДАЕМОСТ - раждания, живородени деца, коефициент на раждаемост, средна възраст на майката при раждане и тотален коефициент на плодовитост	National Statistical Institute	http://www.nsi.bg/en/content/6610/fertility
Deaths by Causes and Mortality by Causes	Умирения по причини и смъртност по причини	National Statistical Institute	http://www.nsi.bg/en/content/5614/deaths-causes-and-mortality-causes
European Health Interview Survey (EHIS)	Европейско здравно интервю	National Statistical Institute	http://www.nsi.bg/en/content/5630/european-health-interview-survey
Mortality - dying, dead children up to 1 year of age, general and infant mortality rates and death rates	Смъртност - умирения, умрели деца на възраст до 1 година, коефициенти на обща и детска смъртност и таблици за смъртност	National Statistical Institute	http://www.nsi.bg/bg/content/3017/%D0%BC%D0%B5%D1%82%D0%B0%D0%B4%D0%B0%D0%BD%D0%BD%D0%B8/%D1%82%D0%B0%D0%B1%D0%BB%D0%B8%D1%86%D0%B8-%D0%B7%D0%B0-%D1%81%D0%BC%D1%8A%D1%80%D1%82%D0%BD%D0%BE%D1%81%D1%82
Marriages and Divorces	Брачност и бракоразводност	National Statistical Institute	http://www.nsi.bg/en/content/6651/marriages-and-divorces
POPULATION, DEMOGRAPHIC PROCESSES AND DEMOGRAPHIC PROJECTIONS - Population, Average annual population, Natural movement of the population, Population projections	НАСЕЛЕНИЕ, ДЕМОГРАФСКИ ПРОЦЕСИ И ДЕМОГРАФСКИ ПРОГНОЗИ - население, средногодишен брой на населението, естествено движение на населението, прогнози на населението	National Statistical Institute	http://www.nsi.bg/en/content/6703/population

Kindergartens (pre-primary education)	Детски градини (предучилищно образование)	National Statistical Institute	http://www.nsi.bg/bg/node/3414
Primary and secondary education (primary, lower and upper secondary)	Основно и средно образование (начално, прогимназиално и гимназиално)	National Statistical Institute	http://www.nsi.bg/bg/node/3432
Population Register - National Population Database (POPs - NDD "Population")	Регистъра на населението – Национална база данни „Население“ (PH – НБД „Население“)	General Directorate Civil Registration and Administrative Services	http://www.grao.bg/
National Cancer Register	Национален Раков Регистър	NCPHA	https://www.sbaloncology.bg/index.php/bg/%D1%81%D1%82%D1%80%D1%83%D0%BA%D1%82%D1%83%D1%80%D0%B0/%D0%BD%D0%B0%D1%86%D0%B8%D0%BE%D0%BD%D0%B0%D0%BB%D0%B5%D0%BD-%D1%80%D0%B0%D0%BA%D0%BE%D0%B2-%D1%80%D0%B5%D0%B3%D0%B8%D1%81%D1%82%D1%8A%D1%80.html
Personal Information System		Bulgarian National Health Insurance Fund	http://www.en.nhif.bg/
Pan-European cohorts/databases/networks which contain data from Bulgaria			Website
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
EudraVigilance			http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)			http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)			http://www.encepp.eu/encepp/search.htm

RD-Connect - Patient registries integrated platform (RD-Connect)

<http://www.encepp.eu/encepp/search.htm>

Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)

<http://www.encepp.eu/encepp/search.htm>

Croatia

Data source name	Native name	Data provider	Website
Registers			
National registers/ databases	Hrvatski Zavod za Javno Zdravstvo	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Birth Medical Database OR Croatian Births Registry and Perinatal Deaths Database	Baza Poroda u Stacionarnim Ustanovama	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Causes of Death Registry	Registar Uzroka Smrti	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatian Committed Suicides Registry	Registar Izvršenih Samoubojstava	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatian National Cancer Register	Registar za rak Republike Hrvatske	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatian Psychoses Register	Registar za Psihoze Hrvatske	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Vaccine Adverse Event Registry	Registar Nuspojava Cijepljenja	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Hospital Morbidity Database of Croatia	Godišnja Baza Hospitalizacija Hrvatske	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Registry of HIV/AIDS Patients	Registar za HIV/AIDS	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
National Register of Persons with Diabetes (CroDiab)	Nacionalni Registar Osoba sa šećernom Bolesti (CroDiab)	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatian Registry Persons with Disabilities		Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Register of Persons Treated for Abuse of Psychoactive Drugs	Registru Osoba Liječenih Zbog Zloupotrebe Psihoaktivnih Droga	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/

Croatian Infectious Diseases Registry		Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Hospital Discharge Database		Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatia, Zagreb		Ministry of Science, Education of the Republic of Croatia	https://mzo.hr/en
EURAP Croatia		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Register of Persons with Occupational Diseases and Workplace .	Registar profesionalnih bolesti	Croatian Institute for Health Protection and Safety at Work (CIHPSW)	http://hzzsr.hr/
Register of Health Care Workers	Registar zdravstvenih radnika	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Croatian registry of renal replacement therapy	Hrvatski registar zadomještanja bubrežne funkcije	Croatian Society of Nephrology, Dialysis and Transplantation of the Croatian Medical Association	www.hdndt.org/
Cardiovascular disease in Croatia	Hrvatski zavod za javno zdravstvo	Central Public Health Institute of Public Health in Croatia	https://www.hzjz.hr/
Register of congenital heart disease in Croatia	Registar prirođenih srčanih grješaka	Department of Pediatric Cardiology, Pediatric Clinic of KBC Rebro.	
Registry of drugs and e-registry of drugs	Hrvatska udruga poslodavaca u zdravstvu	Croatian Health Employers' Association	http://www.upuz.hr/ https://www.farmaceut.org/novosti/hrvatska/novo-registar-lijekova-i-e-registar-digitalna-integralna-baza-podataka-o-lijekovima-za-2017-godinu , http://www.hzzo-net.hr/trazilica_lijekovi.html
Vital statistics: births, deaths	Državni zavod za statistiku	Croatian Bureau of Statistics	https://www.dzs.hr/
Abortion database	Baza pobačaja	Croatian Institute of Public Health	https://www.hzjz.hr/
Primary health care database	Baza podataka iz Primarne zdravstvene zaštite	Croatian Institute of Public Health	https://www.hzjz.hr/

Pan-European cohorts/databases/networks which contain data from Croatia	Website
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm
Registry of newly diagnosed paediatric patients with Inflammatory Bowel Disease (PIBD)- EUROKIDS	https://www.eurokidsibd.com/about-us/
EUROCARE CF registry (cystic fibrosis)	http://www.registry.cz/index-en.php?pg=registries&prid=53
Primary Immune Deficiency registry- (PID)	https://www6.erasmusmc.nl/klinische_genetica/research/lijnen/pompe_center/
Pompe Registry (Comet study)	https://clinicaltrials.gov/ct2/show/NCT03292887#contacts
Hunter outcome study- (HOS)	https://clinicaltrials.gov/ct2/show/NCT03292887#contacts

Fabry Outcome Survey

<https://clinicaltrials.gov/ct2/show/NCT03289065>

Cyprus

Data source name	Native name	Data provider	Website
Registers			
Health Monitoring Unit	Μονάδα Παρακολούθησης Υγείας	Ministry of Health	https://www.moh.gov.cy/Moh/MOH.nsf/index_en/index_en?OpenDocument
Birth Registry	Μητρώο Γεννήσεων	Health Monitoring Unit	http://www.moh.gov.cy/moh/moh.nsf/page70_en/page70_en?OpenDocument
Causes of Death Registry or Death Registry (same registry)	Μητρώο Αιτιών Θανάτου or Μητρώο Θανάτων	Health Monitoring Unit	http://www.moh.gov.cy/moh/moh.nsf/page70_en/page70_en?OpenDocument
Cyprus Diabetes Register	Μητρώο Διαβήτη Κύπρου	Health Monitoring Unit	http://www.moh.gov.cy/moh/moh.nsf/page70_en/page70_en?OpenDocument
Injury Database - Minimum Data Set (IDB-MDS)	Ελάχιστη Βάση Δεδομένων Αρχείο Τραυματισμών	Health Monitoring Unit	http://www.moh.gov.cy/moh/moh.nsf/page70_en/page70_en?OpenDocument
Cyprus Cancer Registry	Μητρώο Καρκίνου Κύπρου	Health Monitoring Unit	http://www.moh.gov.cy/moh/moh.nsf/page70_en/page70_en?OpenDocument
Cyprus Statistical Service	Στατιστική Υπηρεσία Κύπρου	Cyprus Statistical Service	https://www.mof.gov.cy/mof/cystat/statistics.nsf/index_en/index_en?OpenDocument
European Health Survey	Ευρωπαϊκή Έρευνα Υγείας	Cyprus Statistical Service	https://www.mof.gov.cy/mof/cystat/statistics.nsf/index_en/index_en?OpenDocument
HEALTH AND HOSPITAL STATISTICS	Έρευνα Υγείας και Νοσοκομείων	Cyprus Statistical Service	https://www.mof.gov.cy/mof/cystat/statistics.nsf/index_en/index_en?OpenDocument
Pan-European cohorts/databases/networks which contain data from Cyprus			Website

European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Network of Cancer Registries (ENCR),	http://www.enccr.eu/index.php
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Czech Republic

Data source name	Native name	Data provider	Website
Registers			
National registers	Ústav zdravotnických informací a statistiky ČR (Úzis)	Institute of Health Information and Statistics of the Czech Republic	www.uzis.cz
National Oncology Registry (NOR)	Národní onkologický registr (NOR)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry-nzis/nor
National Registry of Hospitalized (NRHOSP)	Národní registr hospitalizovaných (NRHOSP)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry-nzis/nrhosp
The National Reproductive Health Registry (NRRD)	Národní registr reprodukčního zdraví (NRRZ)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry/narodni-zdravotni-registry/nr-reprodukčního-zdravi
National Registry of Assisted Reproduction (NRAR)	Národní registr asistované reprodukce (NRAR)	The National Reproductive Health Registry (NRRD)	http://www.uzis.cz/registry-nzis/nrar
National Registry of Newborns (NRNAR)	Národní registr novorozenců (NRNAR)	The National Reproductive Health Registry (NRRD)	http://www.uzis.cz/registry-nzis/nrnar
National Registry of Parents (NRROD)	Národní registr rodiček (NRROD)	The National Reproductive Health Registry (NRRD)	http://www.uzis.cz/registry-nzis/nrrod
National Registry of Congenital Defects (NRVV)	Národní registr vrozených vad (NRVV)	The National Reproductive Health Registry (NRRD)	http://www.uzis.cz/registry-nzis/nrvv
National Cardiac Surgery Registry (NKR)	Národní kardiologický registr (NKR)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry-nzis/nkchr
National Registry of Joint Replacements (NRKN)	Národní registr kloubních náhrad (NRKN)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry-nzis/nrkn
National Diabetology Registry (NDR)	Národní diabetologický registr (NDR)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry/narodni-zdravotni-registry/narodni-diabetologicky-registr
National Intensive Care Registry	Národní registr intenzivní péče	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry/narodni-zdravotni-registry/narodni-registr-intenzivni-

[pece](#)

Tuberculosis Registry (RTBC)	Registr tuberkulózy (RTBC)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry/organu-ochrany-verejneho-zdravi/registr-tuberkulozy
National Registry of Health services covered by public health insurance	Národní registr hrazených zdravotních služeb (NRHZS)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry/dalsi-registry/narodni-registr-hrazenych-zdravotnich-sluzeb
Database of Death certificates	Listu o prohlídce zemřelého (LPZ)	Institute of Health Information and Statistics of the Czech Republic	http://www.uzis.cz/registry-nzis/list-prohlidce-zemreleho
Birth information system	Informační systém Narození	Czech Statistical Office	https://www.czso.cz/csu/vykazy/obyv-2-12_psz_2017
Clinical registries (REGISTRY.CZ)	Clinical registries (REGISTRY.CZ)	Institute of Biostatistics and Analyzes of the Faculty of Medicine and Science of Masaryk University (IBA MU)	http://www.registry.cz/index-en.php
EURAP Czech Republic		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			Website
Czech Early Childhood Health			http://www.birthcohorts.net/
Pan-European cohorts/databases/networks which contain data from the Czech Republic			Website
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)			http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm

European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Denmark

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Danish National Patient Registry	Landspatientregisteret	Health Data Agency	https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-denationale-sundhedsregistre
The North Jutland Pharmacoepidemiological Prescription Database with linked registries			
Nordic Health Registers			
Registers			
Danish Transfusion Database (DTBD)	Dansk Transfusionsdatabase (DTBD)	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk
Access (Project specific) to Danish Medical Registries		Aarhus University	http://www.kea.au.dk/index.html
Aarhus University Hospital Database		Aarhus University	http://www.kea.au.dk/index.html
Clinical datasets	De kliniske kvalitetsdatabaser	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk
ADHD Database	ADHD Databasen	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/adhd-databasen/
Follow-up Program for Cerebral Palsy (CPOP)	CPOP - Opfølgingsprogram for Cerebral Parese	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/cpop---opfolgningsprogram-for-cerebral-parese-cpop/
Danish Children's Cancer Registry OR Danish Registry of Childhood Cancer (DBCR)	Dansk Børnecancer Register	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/boernecancer/
Danish Register of Child and	Dansk Register for Børne- og	Clinical Quality Development	http://www.rkkp.dk/om-rkkp/de-

Adolescent Diabetes (DanDiabKids)	Ungdomsdiabetes (DanDiabKids)	Program (RKKP)	kliniske-kvalitetsdatabaser/dansk-register-for-borne-og-ungdomsdiabetes-dandiabkids/
Danish Pharmaceutical Database (FOETO)		Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/dansk-fotalmedicinsk-database-foto/
Danish Register for Young People with Acquired Brain Injury	Dansk Register for Unge med Erhvervet hjerneskade	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/ikke-stottede-databaser/dansk-register-for-unge-med-erhvervet-hjerneskade/
Danish Fetal Medicine Database	Dansk Føtalmedicinsk Database	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/dansk-fotalmedicinsk-database-foto/
DK Health Data Agency Approved Clinical Quality Databases		Health Data Protection Agency (Sundhedsdata-Styrelsen)	http://sundhedsdatastyrelsen.dk/da/om-os
Danish Medical Birth Registry (NCBI) OR (MFR)	Fødselsregisteret (MFR)	Health Data Protection Agency (Sundhedsdata-Styrelsen)	https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-sundhedsregistre/graviditet-foedsler-og-boern/foedselsregisteret
Regsiters and services	Registre og services		https://sundhedsdatastyrelsen.dk/da/registre-og-services
The Cancer Registry (CAR)	Cancerregisteret	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
Cause of Death Register (DAR)	Dødsårsagsregisteret (DAR)	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx?rp:A_Register=20&rp:Visning=0&
The Children's Database (BDB)	Børnedatabasen	Health Data Agency	https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-

			sundhedsregistre/graviditet-foedsler-og-boern/boernedatabasen
Danish Vaccination Register (DDV)	Det Danske Vaccinationsregister (DDV)	Health Data Agency	http://sundhedsdatastyrelsen.dk/da/registre-og-services/om-vaccinationsregisteret
DRG Grouped National Patient Registry Data (DRG)	DRG-grupperet LPR	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
DUSAS (USS)	DUSAS	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
National Patient Register (LPR)	Landspatientregisteret	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
Register of Legally Induced Abortions (ABR)	Register over legalt provokerede aborter	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
Register of Medicinal Product Statistics (LSR)	Lægemiddelstatistikregisteret	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
Health insurance Register OR The National Health Insurance Service Register (SSR)	Sygesikringsregisteret (SSR)	Health Data Agency	http://www.esundhed.dk/dokumentation/Registre/Sider/Register.aspx
National databases; Biobanks; Research cohorts		Statens Serum Institut	http://www.ssi.dk/
Danish Biobank Register	Det Nationale Biobankregister	Statens Serum Institut	http://danishnationalbiobank.com/
Danish National Biobank	DANMARKS NATIONALE BIOBANK	Statens Serum Institut	https://www.nationalbiobank.dk/
Copenhagen Hospital Biobank	Biobankenheden	RIGSHOSPITALET	https://www.regionh.dk/blodbanke/afdelingen/enheder-paa-rigshospitalet/Sider/biobank.aspx
The Danish Cancer Society project Diet, Cancer and Health	Kost, kræft og helbred	Danish Cancer Society	https://www.cancer.dk/forskning/cancer-for-kræftforskning/kost-gener-miljoe/kost-kræft-helbred/
Patobank	Patobank		http://www.patobank.dk/
The Danish Pathology Register/National Register of Pathology (LRP)	Landsregisteret for Patologi (LRP)	National Board of Health	https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-

			sundhedsregistre/doesaarsager-og-biologisk-materiale/patologiregisteret
Danish Cancer Biobank (DCB)		Regionernes bio-og genombank (RBGB)	http://rbgb.dk/cancer/fagfolk/andelse-af-materialer/
Region Zealand biobank	Region Sjællands Biobank		https://www.regionsjaelland.dk/Sundhed/forskning/forfagfolk/region-sjaellands-biobank/Sider/default.aspx
The Danish Twin Registry		University of Southern Denmark	https://www.sdu.dk/en/om_sdu/institutter_centre/ist_sundhedstjenesteforsk/centre/dtr/researcher
OPEN Open Patient data Explorative Network		University of Southern Denmark	https://www.sdu.dk/da/Om_SDU/Institutter_centre/Klinisk_institut/Forskning/Forskningsenheder/open.aspx
MiBa, the Danish Microbiology Database	Den danske mikrobiologidatabase (MiBa)	Statens Serum Institut	http://miba.ssi.dk/
Danish Newborn Screening Biobank and Registry (DNSB) OR The Neonatal Screening Biobank (PKU biobank)	PDF-ikon Printikon Den Neonatale Screenings Biobank (PKU-biobanken)	Statens Serum Institut	http://www.ssi.dk/Diagnostik/Center%20for%20Neonatal%20Screening/Den%20Neonatale%20Screenings%20Biobank.aspx
Danish Civil and Health Registration System (CPR)	Det Centrale Personregister	Ministry for Economic Affairs and the Interior	https://cpr.dk/english/
Official statistics on persons, businesses and the economy		STATISTICS DENMARK	www.dst.dk/en
The Register of Medicinal Product; Fertility Database		StatBank Denmark	http://www.statbank.dk/statbank5a/default.asp?w=1920
Surveys		StatBank Denmark	http://www.statbank.dk/statbank5a/default.asp?w=1921
Odense Pharmacoepidemiological Database (OPED)		University of Southern Denmark	https://www.sdu.dk/en
Denmark, Odense		[EUROCAT]	http://www.eurocat-network.eu/

EURAP Denmark		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
The Danish National Prescription Registry	Lægemiddelstatistikregisteret	Health Data Protection Agency (Sundhedsdata-Styrelsen)	http://www.dsfe.dk/danish-registries/
Danish National Database of Reimbursed Prescriptions (DNDRP)	Dansk receptdatabase		
Electronic Patient Medication module (EPM)	Det Elektroniske Patient Medicineringsystem (EPM) [Hospitalslægemiddelregister for Region Hovedstaden]		
Danish Education Registers	Uddannelsesregistre		
Aarhus University Prescription Database (contains data from Aarhus, North Jutland, Ringkjøbing, and Viborg counties)	Aarhus Universitets Receptdatabase		http://kea.au.dk/
The Danish Psychiatric Central Research Register	Det Centrale psykiatriregister	Health Data Protection Agency	http://econ.au.dk/da/center-for-registerforskning/registre/det-psykiatriske-centralregister/
The Danish Adult Diabetes Registry (DADR)			https://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/voksendiabetes/
Danish Breast Cancer Cooperative Group (DBCG)			http://www.dbcg.dk/
The Danish Depression Database			https://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/dansk-depressionsdatabase/
The Danish Multiple Sclerosis Treatment Register (DMSTR)	Sclerosebehandlingsregistret	National Institute of Public Health/Copenhagen University Hospital	https://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/sclerose/
Danish National Quality Database for Births (DNQDB)/ Danish National Clinical Quality Database for Births (DKF)	Dansk Kvalitetsdatabase for Fødsler	The Danish Clinical Registries (RKKP)	https://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/foedsler/

Danish Fetal Medicine Database	Dansk Føtalmedicinsk Database	https://www.rkkp.dk/om-rkkp/dekliniske-kvalitetsdatabaser/dansk-fotalmedicinsk-database-foto/
Danish Quality Database for Newborns (DKN)	Dansk Kvalitetsdatabase for Nyfødte (DKN)	https://www.rkkp.dk/om-rkkp/dekliniske-kvalitetsdatabaser/dansk-kvalitetsdatabase-for-nyfodte/
RareDis - Rare Disease Database	RareDis - Database for sjældne sygdomme	https://www.rkkp.dk/om-rkkp/dekliniske-kvalitetsdatabaser/raredis-database-for-sjaldne-sygdomme/
Early Pregnancy and Abortion Quality Database	Tidlig Graviditet og Abort Kvalitetsdatabase	https://www.rkkp.dk/om-rkkp/dekliniske-kvalitetsdatabaser/tidlig-graviditet-og-abort-kvalitetsdatabase/
The Clinical Quality Databases	regionernes kliniske kvalitetsudviklingsprogram	https://www.rkkp.dk/om-rkkp/dekliniske-kvalitetsdatabaser/
Birth cohort		
Aarhus Birth Cohort (ABC)		http://www.birthcohorts.net/
Copenhagen Child Cohort 2000 (CCC2000)		http://www.birthcohorts.net/
Danish National Birth Cohort (DNBC (int'l), BSiG (danish))		http://www.birthcohorts.net/
Healthy Habits for two (HHf2)		http://www.birthcohorts.net/
Odense Child Cohort		http://www.birthcohorts.net/
Aarhus Birth Cohort Biobank (ABCB)		http://fetotox.au.dk/
Greenlandic Birth Cohort (ACCEPT)		http://fetotox.au.dk/
Danish National Birth Cohort (DNBC)	Statens Serum Institut	http://www.ssi.dk/English/RandD/Research%20areas/Epidemiology/DNBC.aspx
Copenhagen Prospective Studies on Asthma in Childhood		
Pan-European cohorts/databases/networks which contain data from Denmark		Website

Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
Association of the Nordic Cancer Registries (ANCR)	http://www.ancr.nu/
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Estonia

Data source name	Native name	Data provider	Website
Registers			
Medical registries and databases	Tervise arengu instituut	National institute for health development	http://www.tai.ee/en/
Estonian medical birth registry (embr) and estonian abortion registry (ear) - since 2019 estonian medical pregnancy information system.	Meditiiniline sünniregister ja raseduskatkestusandmekogu, 2019: eesti meditsiiniline raseduse infosüsteem	National institute for health development	http://www.tai.ee/en/r-and-d/registers/estonian-medical-birth-registry-and-estonian-abortion-registry
Estonian causes of death registry	Surma põhjuste register	National institute for health development	http://www.tai.ee/en/r-and-d/registers/estonian-causes-of-death-registry
Estonian cancer registry	Vähiregister	National institute for health development	http://www.tai.ee/en/r-and-d/registers/estonian-cancer-registry
Estonian tuberculosis registry	Tuberkuloosiregister	National institute for health development	http://www.tai.ee/en/r-and-d/registers/estonian-tuberculosis-registry
Estonian drug treatment database	Narkomaaniaravi andmekogu	National institute for health development	http://www.tai.ee/en/r-and-d/registers/estonian-drug-treatment-database
Population register	Rahvastikuregister	Republic of estonia - ministry of the interior	https://www.siseministeerium.ee/en/population-register
Digital receipt (digital prescription centre)	Digiretsept	Ministry of social affairs	https://www.haigekassa.ee/en/people/digital-prescription ; https://www.tehik.ee/tervis/infomaterjalid/
E-health (patient's portal)	Digilugu	Ministry of social affairs	https://www.sm.ee/en/patients-portal-and-health-information-system
Pan-European cohorts/databases/networks which contain data from Estonia			Website

European society for immunodeficiencies (esid)	Http://www.encepp.eu/encepp/search.htm
European registry for children on renal replacement therapy (espn/era-edta - children renal replacement therapy)	Http://www.encepp.eu/encepp/search.htm
Eudravigilance	Http://www.encepp.eu/encepp/search.htm
Galactosemia patient registry (galnet)	Http://www.encepp.eu/encepp/search.htm

Finland

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Finnish linked national health registers			
Nordic Health Registers			
Registers			
Aila Data Service	Palveluportaali Ailassa Tietoarkistoon	Finnish Social Science Data Archive	http://www.fsd.uta.fi/en/index.html
Register of Adverse Drug Reactions	Lääkkeiden haittavaikutusrekisteri	Finnish Medicines Agency Fimea	http://www.fimea.fi/web/en/pharmaceutical_safety_and_information/pharmaceutical_safety/reporting_adverse_reactions
Vaccine Adverse Effects Register		Finnish Medicines Agency Fimea	http://www.fimea.fi/web/en/pharmaceutical_safety_and_information/pharmaceutical_safety/reporting_adverse_reactions
Finnish Registry for Kidney Diseases	Munuaistautirekisteri	Renal and Hepatic Association (Munuais- ja maksaliito)	http://www.muma.fi/
Statistics Finland	Tilastokeskus	Official Statistics of Finland (OSF)	http://tilastokeskus.fi/index_en.html
Births	Syntyneet	Statistics Finland (part of OSF)	http://www.stat.fi/til/synt/index_en.html
Deaths	Kuolleet	Statistics Finland (part of OSF)	http://www.stat.fi/til/kuol/index_en.html
Causes of Death	Kuolemansyyt	Statistics Finland (part of OSF)	http://www.stat.fi/til/ksyyt/index_en.html
Upper Secondary General School Education	Lukiokoulutus	Statistics Finland (part of OSF)	http://www.stat.fi/til/lop/index_en.html
Discontinuation of Education	Koulutuksen keskeyttäminen	Statistics Finland (part of OSF)	http://www.stat.fi/til/kkesk/index_en.html

Families	Perheet	Statistics Finland (part of OSF)	http://www.stat.fi/til/perh/index_en.html
Statistical Databases & Registers	Tilastolliset tietokannat ja rekisterit	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en
Infectious Diseases Register	Tilastotietokanta	National Institute for Health and Welfare (THL)	https://www.thl.fi/ttr/gen/rpt/tilastot.html
Care Register for Health Care (Hospital Discharge Register)	Hoitoilmoitusrekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care
Medical Birth Register	Syntyneiden lasten rekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/newborns
Register of Induced Abortions	Raskaudenkeskeyttämisrekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/register-of-induced-abortions
Register of Congenital Malformations	Epämuodostumarekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/description-of-statistics/congenital-anomalies
Register of Child Welfare [Child Protection]	Lastensuojelurekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/child-welfare
Register of Social Assistance	Toimeentulotukirekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/social-assistance
Register of Sterilisations	Sterilomisrekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-

			statistics/register-descriptions/sterilisations
Finnish Cancer Registry	Syöpärekisteri	National Institute for Health and Welfare (THL)	http://www.cancer.fi/syoparekisteri/en/
Mass Screening Registry	Joukkotarkastusrekisteri	National Institute for Health and Welfare (THL)	https://cancerregistry.fi/screening/ https://www.thl.fi/fi/tilastot/tietoa-tilastoista/rekisteriselosteet/nakovammarekisteri
Visual Impairment Register	Näkövammarekisteri	National Institute for Health and Welfare (THL)	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care
Care Register for Health Care (HILMO)		National Institute for Health and Welfare (THL)	https://www.thl.fi/fi/web/thlfi-en/statistics/information-on-statistics/register-descriptions/register-of-primary-health-care-visits
Register of Primary Health Care visits (avoHILMO)	Perusterveydenhuollon hoitoilmoitusrekisteri	National Institute for Health and Welfare (THL)	https://thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/care-register-for-health-care
Care Register for Social Welfare (sosiaaliHILMO)		National Institute for Health and Welfare (THL)	https://www.thl.fi/fi/web/rokottaminen/kansallinen-rokotusohjelma/rokotusrekisteri
Immunisation Register	Rokotusrekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/research-and-expertwork/projects-and-programmes/drugs-and-pregnancy
Drugs and Pregnancy (Research Project) OR The Finnish Drugs and Pregnancy Database	Lääkehoito ja raskaus -hanke ja tietokanta.	National Institute for Health and Welfare (THL)	https://www.kanta.fi/en/professionals/data-requests-for-scientific-research
Prescription Centre and Prescription Archive (Kanta)		KELA The Social Insurance Institution of Finland	
School Health Promotion (SHP)	Kouluterveyskysely	National Institute for Health and Welfare (THL)	https://thl.fi/fi/web/thlfi-

study		Welfare (THL)	en/research-and-expertwork/population-studies/school-health-promotion-study
FinBioBank	Suomen Biobankit	Finnish Biobanks	https://finbb.fi/
The Finnish Hematology Registry and Clinical Biobank (FHRB)	Suomen hematologinen rekisteri ja kliininen biopankki	FHRB Biobank	http://www.fhrb.fi/front-page.html
THL Biobank		National Institute for Health and Welfare (THL)	https://thl.fi/en/web/thl-biobank
Register on Reimbursed Medication and Rights on Special Reimbursement	Resepti- ja lääkkeiden erityiskorvausoikeusrekisteri	KELA The Social Insurance Institution of Finland	https://www.kela.fi/web/en/medicine-expenses
Register on Sickness Allowance		KELA The Social Insurance Institution of Finland	https://www.kela.fi/web/en/sickness-allowance
Population Information System OR Population Register	Väestötietojärjestelmä	Population Register Centre	http://vrk.fi/en/frontpage
Register of work-related diseases	Työperäisten sairauksien rekisteri	The Finnish Institute of Occupational Health	https://www.ttl.fi/en/about-us/
EURAP Finland	EURAP Suomi	European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			
FinnBrain Birth Cohort Study (FinnBrain)			http://www.birthcohorts.net/
Kuopio Birth Cohort (KuBiCo)			http://www.birthcohorts.net/
PLASTICITY - life long follow-up of cognitive ability after birth risks (Plasticity)			http://www.birthcohorts.net/
Steps to the Healthy Development and Well-being of Children (STEPS Study)			http://www.birthcohorts.net/
Health and Early Microbiota (HELMi)			http://www.birthcohorts.net/
Northern Finland Cohorts		Infrastructure for Population Studies at the Medical Faculty,	https://www oulu.fi/nfbc/node/47960

Pan-European cohorts/databases/networks which contain data from Finland	Website
COST Action BM1105 Patient Registry - GnRH Network (COST-GnRH gonadotropin-releasing hormone deficiency)	http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm
Information Network on Rare Cancers (RARECARENet)	http://www.rarecarenet.eu/ http://www-dep.iarc.fr/NORDCAN/English/frame.asp
Cancer statistics for Nordic countries (NORDCAN)	https://nordscreen.org/
Nordic population-based screening programmes (NORDSCREEN)	http://gco.iarc.fr/databases.php
Global Cancer Observatory (GCO)	

France

Data source name	Native name	Data provider	Website
Register			
Demographic statistics; Databases	Institut national de la statistique et des études économiques (INSEE)	National Institute of Statistics and Economic Studies INSEE	https://www.insee.fr/en/accueil
Civil Register Databases	Etat Civil INSERM	National Institute of Statistics and Economic Studies INSEE INSERM	https://www.insee.fr/en/metadonnees/source/s1010 https://www.inserm.fr/
Database of medical death certificates	La base de données des certificats médicaux de décès	Center for Epidemiology on Medical Causes of Death (CépiDc)	http://www.cepidc.inserm.fr/ https://www.inserm.fr/professionnels-recherche/bases-donnees-pour-recherche-en-sante/bases-donnees-medicales-nationales-sniiram-et-egb
National medical databases (SNIIRAM and EGB)	Les bases de données médicales nationales (SNIIRAM et EGB)	INSERM	https://www.inserm.fr/professionnels-recherche/bases-donnees-pour-recherche-en-sante/bases-donnees-medicales-nationales-sniiram-et-egb
National system of health data (SNDS)		National Fund for Employee Workers' Health Insurance (CNAMTS)	http://www.snds.gouv.fr/SNDS/Accueil https://epidemiologie-france.aviesan.fr/
Databases; Registries; Cohorts	Portail Epidémiologie – France	Epidemiology-France portal	https://epidemiologie-france.aviesan.fr/
Surveys		Institute for Research and Documentation in Health Economics (IRDES) - Institut de Recherche et de Documentation en Economie de la Santé (IRDES)	http://www.irdes.fr/
Health and Social Protection Survey (ESPS)	Enquête Santé et Protection Sociale (ESPS)	Institute for Research and Documentation in Health Economics (IRDES) - Institut de Recherche et de Documentation en Economie de la Santé (IRDES)	http://www.irdes.fr/recherche/enquetes/esps-enquete-sur-la-sante-et-la-protection-sociale/actualites.html

Central Education Foundation - 2017	Base Centrale Sclolarité (BCS) - 2017	Institute for Research and Documentation in Health Economics (IRDES) - Institut de Recherche et de Documentation en Economie de la Santé (IRDES)	https://www.cmh.ens.fr/greco/enquetes/XML/lil.php?lil=lil-1199
SURVEY PHEDRE Compensation benefit of disability	ENQUÊTE PHEDRE Prestation de compensation du handicap	Institute for Research and Documentation in Health Economics (IRDES) - Institut de Recherche et de Documentation en Economie de la Santé (IRDES)	http://www.irdes.fr/recherche/enquetes/phedre-prestation-de-compensation-du-handicap/actualites.html
Health Barometer	Baromètre santé	National Institute for Prevention and Health Education (INPES)	http://inpes.santepubliquefrance.fr/default.asp
National System of Interregional Information of the Health Insurance (SNIIRAM)	Système National d'Information Inter-Régime de l'Assurance Maladie (SNIIR-AM)	Health Insurance	https://www.ameli.fr/l-assurance-maladie/statistiques-et-publications/sniiram/finalites-du-sniiram.php
Medicalization of information systems program in medicine, surgery, obstetrics and odontology (PMSI MCO)	Programme de médicalisation des systèmes d'information en médecine, chirurgie, obstétrique et odologie (PMSI MCO)	Technical Agency for Information on Hospitalization (ATIH)	https://www.atih.sante.fr/
EFEMERIS (Evaluation in Pregnant Women of Medicaments and their RISK)	EFEMERIS (Evaluation chez la Femme Enceinte des Medicaments et de leurs RISques)	Pharmacoepidemiology INSERM 1027	http://www.u1027.inserm.fr/
Child Disability Register in Haute-Garonne (RHE31)	Registre des Handicaps de l'Enfant de la Haute-Garonne	National Institute of Health Surveillance (InVS); National Institute of Health and Medical Research (INSERM)	https://rhe31.org/
Handicaps of the Child and Perinatal Registry Observatory Isere, Savoie and Haute-Savoie (RHEOP)	Registre de l'Enfants et Observatoire Perinatal	RHEOP	https://rheop.univ-grenoble-alpes.fr/
Sentinel Audipog Network	La base de données du Réseau	Audipog Sentinel Network	http://www.audipog.net/index.p

database (AUDIPOG)	Sentinelle Audipog		hp
IMS LifeLink EMR France (LifeLink EMR FR) (Formerly Disease Analyzer)		IMS Health [Currently IQVIA]	https://www.iqvia.com
IMS LifeLink Longitudinal Prescription Data - France OR Longitudinal Prescription Data(LRx) -France		IMS Health [Currently IQVIA]	https://www.iqvia.com
Cohort of the Terappel program (French Pharmacovigilance Centres participating to the Terappel program), a Teratology Information Service	Terappel	University Hospital Department of Pharmaceutical Toxicology Hospices Civils de Lyon (VIGItox)	http://vigitox.cap-lyon.fr
Cohort of the Centre de Référence sur les Agents Tératogènes (CRAT), a Teratology Information Service	Centre de Référence sur les Agents Tératogène (CRAT)	Reference Center for Teratogenic Agents (ARCT)	https://lecrat.fr
Stem Cell Transplant for primary ImmunoDeficiencies in Europe (SCETIDE) OR SCETIDE - Primary Immune deficiencies		Necker-Enfants Malades Hospital	https://scetide.org/scetide/
French pharmacovigilance database (BNPV)	Base Nationale de Pharmacovigilance (BNPV)	National Agency for the Safety of Medicines and Health Products (ANSM)	http://ansm.sante.fr/
Perinatal record (epidemiological surveillance component)	Dossier périnatalité (volet surveillance épidémiologique)	Public Health France (Santé Publique France)	http://santepubliquefrance.fr/ https://www.chu-besancon.fr/la-recherche/les-acteurs-de-la-recherche-au-chru/registre-des-tumeurs-du-doubs-et-du-territoire-de-belfort.html
Doubs Cancer Registry	Registre des Tumeurs du Doubs	CHRU of Besançon	http://www.santepaysdelaloire.com/registre-des-cancers/
Loire-Atlantique/Vendée Cancer Registry (EPIC-PL)	Loire-Atlantique/Vendée cancer registry (registre qualifié)	Association EPIC-PL	

Lille area Cancer Registry	Registre général des cancers de Lille et de sa région	Centre de référence régional en cancérologie	http://www.registrecancers59.fr/
Somme Cancer Registry	Le Registre du Cancer de la Somme	CHU Amiens Picardie	http://www.chu-amiens.fr/chercheurs/le-registre-du-cancer-de-la-somme/
France, Auvergne		[EUROCAT]	http://www.eurocat-network.eu/
France, Brittany		[EUROCAT]	http://www.eurocat-network.eu/
France, Ile de la Reunion		[EUROCAT]	http://www.eurocat-network.eu/
France, French West Indies		[EUROCAT]	http://www.eurocat-network.eu/
Rhône-Alpes Malformations Register (REMERA)	Le Registre des Malformations en Rhône-Alpes (REMERA)	InVS, Conseil Régional Rhône Alpes, Inserm, Afssaps	https://www.remera.fr/
Paris Register of Congenital Malformations (remaPAR)	Registre des Malformations congénitales de Paris (remaPAR)	EPOPé	http://www.epopé-inserm.fr/en/
EPIdemiology of Congenital heARt Diseases (EPICARD)	EPIdémiologie des enfants ou fœtus porteurs de CARDiopathies congénitales (EPICARD)	EPOPé	http://www.epopé-inserm.fr/en/
French National Uniform Hospital Discharge Data Set Database (UHDDS)		Department of Health and Human Services (HHS) - Department of Health, Education, and Welfare	http://www.scansante.fr/
CNAM Database	Caisse Primaire d' Assurance Maladie (CPAM)	National Health Insurance Fund (CPAM)	https://www.indiante.fr/
CDA Database		Antenatal Diagnostic Centre (Centre de diagnostic antenatal; CDA)	https://www.agence-biomedecine.fr/
PMI Database		Mother and Child Protection Centre (Protection Maternelle et Infantile; PMI)	https://drees.solidarites-sante.gouv.fr
EURAP France		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			

EDEN - Study on the pre and early postnatal determinants of child health and development	http://www.birthcohorts.net
Etude Longitudinale Francaise depuis l'Enfance (ELFE)	http://www.birthcohorts.net
Endocrine disruptors: Longitudinal study on pregnancy abnormalities, infertility, and childhood (PÉLAGIE)	http://www.birthcohorts.net
Pollution and Asthma Risk: an Infant Study (PARIS)	http://www.birthcohorts.net
Prescription Médicaments Mères Enfants (POMME)	
EFEMERIS (Evaluation in Pregnant Women of MEDicaments and their RISK)	http://www.efemeris.fr/
EPIPAGE 2 Cohort Study	https://epipage2.inserm.fr/index.php/en/
PregMed-France cohort/ French Pregnancy Cohort	
Teratology Information Services	
Paris Teratology Information Service (Centre de Référence sur les Agents Tératogènes) database	https://www.lecrat.fr/
Pan-European cohorts/databases/networks which contain data from France	
Website	
COST Action BM1105 Patient Registry - GnRH Network (COST-GnRH gonadotropin-releasing hormone deficiency)	http://www.encepp.eu/encepp/search.htm
European Management Platform for Childhood Interstitial Lung Diseases (ChILD-EU - Children Interstitial lung diseases)	http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm

European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/search.htm
European patient registry on TRAPS syndrome (EUROTRAPS - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EUROmedicAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
An EU Rare Diseases Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes (Euro WABB)	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
The European Clarkson's syndrome registry - EurêClark registry-Systemic Capillary Leak Syndrom	http://www.encepp.eu/encepp/search.htm

Gecem inventory (GECEM)	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/search.htm
MediGuard.org	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Germany

Data source name	Native name	Data provider	Website
Registers			
EURAP Germany - European Registry of Antiepileptic Drugs and Pregnancy	Das europäisches Register für Schwangerschaften unter Antiepileptika	German Society for Epileptology	http://www.eurap.de
Teratology Information Services Data - EMBRYOTOX	Embryotox, Pharmakovigilanz- und Beratungszentrum für Embryonaltoxikologie, Institut für Klinische Pharmakologie und Toxikologie, Charité-Universitätsmedizin Berlin, Germany	Institute for Clinical Teratology and Drug Risk Assessment in Pregnancy, Charité Universitätsmedizin Berlin (Embryotox)	https://www.embryotox.de
Teratology Information Services Data - REPROTOX	Beratungsstelle für Medikamente in Schwangerschaft und Stillzeit	Institute for Reproductive Toxikology, St. Elisabeth Hospital, Ravensburg	http://www.reprotox.de
Mainz Model	Geburtenregister Mainzer Modell, Abteilung für Pädiatrische Epidemiologie, Universitätsmedizin Mainz, Germany	Social Affairs and Health of Rhineland-Palatine	http://espnice-online.org/Online-Registry/Europe/Germany/MAINZ
Malformation Monitoring Centre Saxony-Anhalt, Germany	Fehlbildungsmonitoring Sachsen-Anhalt, Medizinische Fakultät Otto-von-Guericke Universität Magdeburg, Germany	Malformation Monitoring Centre, Medical Faculty Otto-von-Guericke University, Magdeburg, Germany	http://www.angeborene-fehlbildungen.com/
German Childhood Cancer Registry (GCCR)	Deutsches Kinderkrebsregister	Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI) at the University Medical Center of the Johannes Gutenberg University Mainz.	http://www.kinderkrebsregister.de/dkkcr-gb/about-us/overview.html?L=1
Claims data of statutory health insurance (AOK)	Wissenschaftliches Institut der AOK, AOK Bundesverband, Berlin, Germany	WIdO: Wissenschaftliches Institut der AOK (Scientific Institute of the health insurance AOK)	http://www.wido.de

Claims data of statutory health insurance (TK)	Versorgungsforschung der TK	WINEG: Wissenschaftliches Institut der TK für Nutzen und Effizienz im Gesundheitswesen (Scientific Institute of the health insurance TK for benefit and efficiency in health care)	http://www.wineg.de
German Pharmacoepidemiological Research Database (GePaRD)	Leibniz-Institut für Präventionsforschung und Epidemiologie, Bremen	Leibniz Institute for Prevention Research and Epidemiology (BIPS)	https://www.bips-institut.de/en/home.html
Claims data of statutory health insurance	Deutsche Pharmakoepidemiologische Forschungsdatenbank, Leibniz-Institut für Präventionsforschung und Epidemiologie, Bremen	[Funding project (Feb 2017 - Jan 2020): Investigation of Pharmaceutical Drug Safety During Pregnancy Based on Routine Data in Germany], Leibniz Institute for Prevention Research and Epidemiology (BIPS)	https://www.bips-institut.de/en/the-institute/departments/clinical-epidemiology.html
Aggregated health care data from the statutory health insurance funds	Informationssystem Versorgungsdaten, DIMDI, Germany	Information system for health care data (data transparency) (DaTraV), German Institute of Medical Documentation and Information (DIMDI)	http://www.dimdi.de/static/en/versorgungsdaten/index.htm
Health monitoring studies/surveys; Registers	Gesundheitsberichterstattung des Bundes (GBE)	Robert Koch Institute	https://www.rki.de/DE/Home/homepage_node.html
GEDA - German Health Update, questionnaire of the European Health Interview Survey (EHIS) is integrated in the survey	GEDA - Gesundheit in Deutschland Aktuell	Robert Koch Institute, nationwide health monitoring	https://www.rki.de/EN/Content/Health_Monitoring/HealthSurveys/Geda/Geda_node.html
KiGGS (German Health Interview and Examination Survey for Children and Adolescents)	KiGGS (Studie zur Gesundheit von Kindern und Jugendlichen in Deutschland)	Robert Koch Institute	https://www.kiggs-studie.de/deutsch/home.html
BELLA study (behaviour and wellbeing of children and adolescents in Germany)	BELLA-Studie als Modul von KiGGS	Robert Koch Institute - kiGGS	https://www.bella-study.org/die-studie/

National Diabetes Surveillance	Nationale Diabetes-Surveillance	Robert Koch Institute	https://www.rki.de/DE/Content/Gesundheitsmonitoring/Studien/Diabetes_Surveillance/diab_surv_inhalt.html
Clinical Cancer Registries	Zentrum für Krebsregisterdaten im Robert Koch-Institut in Berlin-Tempelhof	Robert Koch Institute - Center for Cancer Registry Data (ZfKD)	https://www.krebsdaten.de/Krebs/DE/Home/homepage_node.html
National Nutrition Survey II (NVSII)	Nationale Verzehrsstudie II, Max Rubner-Institut, Bundesforschungsinstitut für Ernährung und Lebensmittel	Max Rubner-Institut (MRI)	https://www.mri.bund.de/de/institute/ernaehrungsverhalten/forschungsprojekte/nvsii/
German National Nutrition Monitoring (NEMONIT)	Nationales Ernährungsmonitoring (NEMONIT), Längsschnittstudie NEMONIT,	Max Rubner-Institut (MRI)	https://www.mri.bund.de/de/institute/ernaehrungsverhalten/forschungsprojekte/nemonit/?sword_list%5B0%5D=nemonit
DAPI database	Deutsches Arzneiprüfungsinstitut e.V. (DAPI)	German Institute for Drug Use Evaluation (DAPI)	http://www.dapi.de/
ChildrenMS, Patient register for Germany	MS Patientenregister 2009-2012	Sylvia Lawry Centre- The Human Motion Institute, Nationwide recruitment of pediatric MS patients	http://www.thehumanmotioninstitute.org/node/27
Birth cohort			
Childhood Obesity - Early Programming by Infant Nutrition (CHOPIN)			http://www.birthcohorts.net
Dortmund Nutritional and Anthropometric Longitudinally Designed Study (DONALD)	DONALD Studie / Studie ist eine offene Kohortenstudie mit bislang über 1.500 Teilnehmern		http://www.birthcohorts.net
German Infant Study on the influence of Nutrition Intervention (GINIplus)	Helmholtz Zentrum München, Deutsches Forschungszentrum für Gesundheit und Umwelt (GmbH), GINI-Studie	Helmholtz Zentrum München	http://www.birthcohorts.net
LIFE Child	LIFE Forschungszentrum Leipzig	Leiter des Instituts für Medizinische Informatik, Statistik und	http://www.birthcohorts.net

Multizentrische Allergie Studie (MAS-90)	MAS-Studie (Multizentrische Allergie Studie)	Charité - Universitätsmedizin Berlin	http://www.birthcohorts.net
Influence of life-style factors on the development of the immune system and allergies in East and West Germany (LISA PLUS)	Prospective cohort study in 4 regions of Germany	Helmholtz Zentrum München, Deutsches Forschungszentrum für Gesundheit und Umwelt (GmbH)	http://www.birthcohorts.net
Healthcare databases - Adverse drug reaction databases			
Federal Institute for Drugs and Medical Devices	BfArM		
Teratology Information Services			
German Embryotox Pharmacovigilance Centre and database		Berlin Institute for Clinical Teratology and Drug Risk Assessment in Pregnancy	
Pan-European cohorts/databases/networks which contain data from Germany			Website
Biologika in der Kinderrheumatologie (BIKER)	BIKER Register/ Register der Gesellschaft für Kinder- und Jugendrheumatologie zur Biologikatherapie	Asklepios Klinik St. Augustin GmbH	http://www.encepp.eu/encepp/search.htm
European Management Platform for Childhood Interstitial Lung Diseases (CHILD-EU - Children Interstitial lung diseases)		Dr. von Hauner Children's Hospital, Division of Pediatric Pneumology, University Hospital Munich	http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central			http://www.encepp.eu/encepp/search.htm

Hypoventilation Syndromes)

European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Register for Multiple Sclerosis (EUREMS)	http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/search.htm

European patient registry on TRAPS syndrome (EUROTRAPS - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/search.htm
MediGuard.org	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Greece

Data source name	NATIVE NAME	Data provider	Website
Registers			
Statistics; Registries; Surveys	Ελληνική Στατιστική Αρχή	Hellenic Statistical Authority (ELSTAT)	http://www.statistics.gr/en/home
Health Survey	Έρευνα Υγείας	Hellenic Statistical Authority (ELSTAT)	http://www.statistics.gr/el/statistics/-/publication/SHE22/-
Hospital Discharged in-patients	Κλειστή Νοσοκομειακή Περίθαλψη (Εξερχόμενοι Ασθενείς)	Hellenic Statistical Authority (ELSTAT)	http://www.statistics.gr/en/statistics/-/publication/SHE12/-
Road Traffic Accidents Database	Οδικά Τροχαία Ατυχήματα	Hellenic Statistical Authority (ELSTAT)	http://www.statistics.gr/en/statistics/-/publication/SDT03/
Registry offices register (Lixiarxio) OR Special Registry	Ειδικό Ληξιαρχείο	Ministry of Interior	http://www.ypes.gr/el/
Hellenic Cancer Registry (HCR)	Εθνικό Αρχείο Νεοπλασιών (EAN)	Hellenic Centre for Disease Control and Prevention (HCDCP)	http://www.keelpno.gr/
Hellenic Renal Registry	Ελληνικό Νεφρολογικό Μητρώο	Hellenic Nephrology Society	http://www.ene.gr/
National Registry for Haemoglobinopathies in Greece (NRHG)		National Center for Thalassaemia and Haemoglobinopathies of Laikon General Hospital of Athens, Greece	https://www.enerca.org/members-centers/center/22/national-center-for-thalassaemia-and-haemoglobinopathies-of-laikon-general-hospital-of-athens-greece
Rhea Mother-Child Study in Crete (RHEA)		Dept of Social Medicine, Medical School, Heraklion, University of Crete	http://www.rhea.gr/
Birth cohort			
Mother Child Cohort in Crete (RHEA)			http://www.birthcohorts.net/
Pan-European cohorts/databases/networks which contain data from Greece			
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm

European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC) EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Hungary

Data source name	Native name	Data provider	Website
Registers			
Registers	Állami Népegészségügyi és Tisztiorvosi Szolgálatot (ÁNTSZ)	National Public Health and Medical Officer Service (ÁNTSZ)	https://www.antsz.hu
Registry of Rare Diseases OR Rare Disease Register (RB)	Ritka Betegségek Nyilvántartása (RB)	National Public Health and Medical Officer Service (ÁNTSZ)	https://www.antsz.hu/oszir/ritka_betegsegek
Hungarian Electronic Registry of Inborn Abnormalities (eVRONY)	Veleszületett Rendellenességek elektronikus Országos Nyilvántartási szakrendszere (eVRONY)	National Public Health and Medical Officer Service (ÁNTSZ)	https://www.antsz.hu/oszir/evrony
NEAK - National Health Insurance Fund Manager	Nemzeti Egészségbiztosítási Alapkezelő	National Health Insurance Fund of Hungary	http://www.neak.gov.hu
National Cancer Registry Database	Nemzeti Rákregiszter	National Institute Of Oncology	http://www.onkol.hu/en/node/171
Dissemination Databases	Központi Statisztikai Hivata	Hungarian Central Statistical Office (KSH)	http://www.ksh.hu
Deaths OR Deaths by Frequent Causes of Death	Halálozás	Hungarian Central Statistical Office (KSH)	http://www.ksh.hu/apps/meta.objektum?p_lang=HU&p_menu_id=120&p_ot_id=100&p_obj_id=WNH
Fetal Losses	Magzati veszteségek	Hungarian Central Statistical Office (KSH)	http://www.ksh.hu/apps/meta.objektum?p_lang=HU&p_menu_id=120&p_ot_id=100&p_obj_id=WNM
Live Birth	Élveszületés	Hungarian Central Statistical Office (KSH)	http://www.ksh.hu/apps/meta.objektum?p_lang=EN&p_menu_id=120

			&p_ot id=100&p_obj id=WNS
NETFIT		Hungarian Central Statistical Office (KSH)	http://www.mdsz.hu/netfit/
Hungarian Congenital Abnormality Registry (HCAR)		National Institute of Health Development (NEFI)	https://eurohealthnet.eu/
Hungarian Childhood Diabetes Register	Magyar Országos Gyermekdiabétesz Regiszter	[EMIF Catalogue - MOCHA]	https://emif-catalogue.eu/c/mocha1/fingerprint/880c9e4ff06cdafcf442bba93d0957e9/1/
Hungarian Pediatric IBD Registry (HUPIR)		Magyar Gyermek-gastroenterológiai Társaság Közhasznú Egyesület	https://emif-catalogue.eu/c/mocha1/fingerprint/880c9e4ff06cdafcf442bba93d0957e9/1/
Hungarian Pediatric Tumor Registry	Magyar Gyermek Tumor Regiszter	Semmelweis University	http://www.gyermekdaganat.hu/mgygyt/tumor-regiszter/
Neonatal Intensive Care (NIC) Database	Magyar Neonatalis Intenzív Centrum Regiszter	National Institute of Child Health (Budapest, Hungary)	http://www.ogyei.hu/en/index.php?page=main
EURAP Hungary		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Purpose built surveillance system			
Hungarian Case-control of Congenital Abnormalities Study			Ended 1996
Pan-European cohorts/databases/networks which contain data from Hungary			
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm

European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Iceland

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Icelandic Medical Birth Register			https://www.landlaeknir.is/english/
Nordic Health Registers			
Prescription drugs database			https://www.landlaeknir.is/english/
Registry of primary health care contacts			https://www.landlaeknir.is/english/
Hospital discharge registry			https://www.landlaeknir.is/english/
Cancer registry			https://www.krabb.is/english
Causes of death registry			https://www.landlaeknir.is/english/
Pan-European cohorts/databases/networks which contain data from Iceland			
Association of the Nordic Cancer Registries (ANCR)			http://www.ancr.nu/
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)			http://www.encepp.eu/encepp/search.htm
EudraVigilance			http://www.encepp.eu/encepp/search.htm

Ireland

Data source name	Native name	Data provider	Website
Registers			
Databases; Clinical audits		National Perinatal Epidemiology Centre (NPEC) - UCC Anu Research Centre, Cork University Maternity Hospital	http://www.ucc.ie/en/npec/npeconlinedatabase/
NPRS		National Perinatal Reporting System (NPRS)	http://www.hpo.ie/
Growing up in Ireland database		Department of Children and Youth Affairs (DCYA)	https://www.dcy.gov.ie/docs/EN/Research-and-Evaluation-Introduction/4711.htm
Register of pupils(Primary online database (POD))		Department of Education and Skills	https://www.education.ie/en/Publications/Statistics/Primary-Online-Database-POD-/
INFANT Biobank		The Irish Centre for Fetal and Neonatal Translational Research (INFANT)	http://www.infantcentre.ie/research; http://www.chiefscientificadvisor.ie/sfi-research-centres/infant/
PCRS-Primary care reimbursement scheme		Health Service Executive	https://www.hse.ie/eng/staff/pcrs/
Cork & Kerry Congenital Anomaly Register		Health Service Executive	https://www.hse.ie/eng/services/list/5/publichealth/publichealthdepts/howweimprovehealth/congenital-anomaly-registers.html
Dublin Congenital Anomaly Register		Health Service Executive	https://www.hse.ie/eng/services/list/5/publichealth/publichealth

		depts/howweimprovehealth/congenital-anomaly-registers.html
South East Ireland Congenital Anomaly Register	Health Service Executive	https://www.hse.ie/eng/services/list/5/publichealth/publichealthdepts/howweimprovehealth/congenital-anomaly-registers.html
Cancer registry	National Cancer Registry Ireland	https://ncri.ie/data/data-we-collect
Discharge data	Hospital Inpatient Enquiry system	http://www.hpo.ie/
National Physical and Sensory Disability Database (NPSDD); National Intellectual Disability Database (NIID)	National Ability Supports System (NASS)	https://www.hrb.ie/data-collections-evidence/disability-service-use-and-need/how-data-is-collected/
PCRS; NCRI	Linked HSE Primary care reimbursement scheme (PCRS) and National Cancer Registry (NCRI)databases	https://www.tcd.ie/medicine/pharmacology-therapeutic/research/pharmaepidemiology.php/
The Rare Kidney Disease Registry and Biobank	The Rare Kidney Disease Registry and Biobank	https://www.tcd.ie/medicine/thkc/research/rare.php
Palliative paediatric data	Palliative Care Research Network (PCRN)	https://aiihpc.org/our_work/research/pcrn/
	Paediatric Intensive Care Network (PICANET)	http://www.picanet.org.uk/
Cystic Fibrosis Registry	Cystic Fibrosis Registry of Ireland (CFRI)	http://www.cfri.ie
Statbank	Central Statistics Office (CSO)	www.cso.ie
UK and Ireland Epilepsy and Pregnancy Register	UK and Ireland Epilepsy and Pregnancy Register	http://www.epilepsyandpregnancy.co.uk/pages/contact.htm
Cerebral Palsy Register	Eastern Area Cerebral Palsy	https://www.crc.ie/

Register	
National Paediatric Mortality Register	National Paediatric Mortality Register(formerly national sudden infant death register) http://www.sidsireland.ie/
Irish Childhood Diabetes National Register (ICDNR)	Irish Childhood Diabetes National Register (ICDNR) National Children's Hospital Tallaght, Trinity College Dublin Not web enabled but information at; https://www.diabetes.ie/living-with-diabetes/child-diabetes/16867-2/
Healthy Ireland Survey	Health Service Executive (HSE), Health and Wellbeing http://www.hse.ie/eng/health/hl/hi/healthy-ireland-surveys/
Maternal and Newborn Clinical Management System	Cork University Maternity Hospital, University Hospital Kerry, the Rotunda Hospital and the National Maternity Hospital
Birth cohort	
Babies After SCOPE: Evaluating the Longitudinal Impact using Neurological and Nutritional Endpoints (BASELINE)	http://www.birthcohorts.net/
Lifeways Cross-Generation Cohort Study	http://www.birthcohorts.net/
Pan-European cohorts/databases/networks which contain data from Ireland	
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
UK & Ireland Duchenne and Becker muscular dystrophy patient registry (part of the TREAT-NMD network) (UK & Ireland Duchenne and Becker)	http://www.encepp.eu/encepp/search.htm
UK and Ireland Spinal Muscular Atrophy Patient Registry (part of the TREAT-NMD network) (UK SMA Patient Registry)	http://www.encepp.eu/encepp/search.htm

European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EUROmedicAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm

Italy

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Region Emilia-Romagna (RER) Database			
Tuscany			
Healthcare databases - Adverse drug reaction databases			
Italian National Pharmacovigilance Network			
Italian Pharmacovigilance Adverse Event (AE) Spontaneous Reporting System [Rete Nazionale Farmacovigilanza] (RNF)			
Registers			
ITACAN - The AIRTUM database (34 Cancer registries)	ITACAN - Associazione Italiana Registri Tumori (AIRTUM)	Institute for the Study and Oncological Prevention of Florence	http://www.registri-tumori.it/cms/
Data banks	Banche dati	Institute for National Statistics (ISTAT)	https://www.istat.it/it/dati-analisi-e-prodotti/banche-dati
Data tables	Tavole di dati	Institute for National Statistics (ISTAT)	http://dati.istat.it/
Italian National Registry of Rare Diseases	Registro Nazionale Malattie Rare	Istituto Superiore di Sanità	http://www.iss.it/cnmr/
EPN Registry - Paroxysmal Nocturnal Hemoglobinuria	Registro EPN - Emoglobinuria Parossistica Notturna	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=1&id=2325&tipo=14
Italian Cystic Fibrosis Registry (RIFC)	Registro Italiano Fibrosi Cistica (RIFC)	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=1&id=1120&tipo=14
Congenital Malformations Registers	Registri Malformazioni Congenite	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=2&id=993&tipo=53
Twins National Registers	Registro Nazionale Gemelli	Istituto Superiore di Sanità	http://old.iss.it/gemelli/

Italian National Registry of Assisted Reproductive Technology (ART)	Registro Nazionale Procreazione Medicalmente Assistita	Istituto Superiore di Sanità	http://old.iss.it/rpma/
Maternal mortality surveillance	Sorveglianza della mortalità materna	Istituto Superiore di Sanità	https://www.epicentro.iss.it/itoss/SorveglianzaMortalitaMaterno
Perinatal mortality surveillance	Sorveglianza della mortalità perinatale	Istituto Superiore di Sanità	https://www.epicentro.iss.it/itoss/SorveglianzaMortalitaPerinatale
Termination of pregnancy surveillance	Sistema di sorveglianza dell'interruzione volontaria di gravidanza	Istituto Superiore di Sanità	https://www.epicentro.iss.it/ivg/sorveglianza-ivg
LOMBARDY REGISTER	REGISTRO DELLE MALFORMAZIONI CONGENITE E DEGLI ESITI AVVERSI DELLA GRAVIDANZA IN LOMBARDIA	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=2&id=993&tipo=53
CAMPANIA REGISTER OF CONGENITAL DEFECTS (B.D.RE.CAM.)	REGISTRO CAMPANO DIFETTI CONGENITI (B.D.Re.Cam.)	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=2&id=993&tipo=53
SICILIAN CONGENITAL MALFORMATIONS INVESTIGATION (I.S.MA.C.)	REGISTRO REGIONALE DELLE MALFORMAZIONI CONGENITE DELLA SICILIA	Istituto Superiore di Sanità	http://www.iss.it/cnmr/index.php?lang=2&id=993&tipo=53
Italy, Tuscany OR TUSCANY REGISTRY OF CONGENITAL DEFECTS (R.T.D.C)	REGISTRO TOSCANO DIFETTI CONGENITI (R.T.D.C.)	National Research Council (CNR) Institute of Clinical Physiology (IFC)	http://www.rtdc.it
Italy, Emilia Romagna OR EMILIA ROMAGNA REGISTRY OF BIRTH DEFECTS (IMER)	INDAGINE MALFORMAZIONI CONGENITE EMILIA ROMAGNA (IMER)	Ferrara University Hospital	http://www.registroimer.it/
Themes: Woman and Child	Donna e Bambino	Ministry of Health	http://www.salute.gov.it/portale/home.html
Children's Health	Salute dei Bambini	Ministry of Health	http://www.salute.gov.it/portale/temi/p2_4.jsp?area=saluteBambino

Women's Health	Salute della Donna	Ministry of Health	http://www.salute.gov.it/portale/donna/menuContenutoDonna.jsp?lingua=italiano&area=Salute%20donna&menu=patologie
Certificate of Delivery Assistance (CEDAP) database	Certificato di assistenza al parto (CeDAP)	Ministry of Health	http://www.salute.gov.it/portale/temi/p2_6.jsp?lingua=italiano&id=3837&area=statisticheSSN&menu=vuoto
Hospital Discharge	Schede di dimissione ospedaliera	Ministry of Health	http://www.salute.gov.it/portale/temi/p2_4.jsp?lingua=italiano&tema=Assistenza,%20ospedale%20e%20territorio&area=ricoveriOspedalieri
Pediatric Allergy and Pneumology (PAP) Research Study Group		Respiratory Disease Research Center (RDRC) [PARENT Patient Registries of Europe]	http://parent-ror.eu/#/registries/140/details-basic?page=7
PEDIANET Database	PEDIANET	PEDIANET	http://pedianet.it/en
Regional Health Agency of Tuscany (ARS) OR Tuscany	Agenzia Regionale di Sanità della Toscana (ARS)	Osservatorio di Epidemiologia	https://www.ars.toscana.it/it/
Emilia Romagna Hospital Discharge		CeVEAS, Centre for the Evaluation of the Effectiveness of Health Care	http://www.regione.emilia-romagna.it/
Emilia Romagna NHS drug prescription in general practice		CeVEAS, Centre for the Evaluation of the Effectiveness of Health Care	http://assr.regione.emilia-romagna.it/en
Tuscany Hospital Discharges Database	SDO=Schede di dimissione ospedaliera	Tuscan Region	http://www.regione.toscana.it/-/01-scheda-di-dimissione-ospedaliera-sdo-
Tuscany Standard Prescriptions Database	SPF= prestazioni-farmaceutiche-in-regime-convenzionale	Tuscan Region	http://www.regione.toscana.it/-/05-prestazioni-farmaceutiche-in-regime-convenzionale-spf-
Tuscany Prescriptions Database of Medications Directly Dispensed by the Health System	FED=farmaci erogati direttamente	Tuscan Region	http://www.regione.toscana.it/-/20-farmaci-erogati-direttamente-dalle-strutture-fed-

Survey on maternity pathway in Tuscany	Indagine sul percorso nascita in Toscana	Laboratory Management and Healthcare of the Sant' Anna School of Advanced Studies in Pisa	https://indagini.santannapisa.it/percorsonascita/view/form_login.php
Caserta GP/claims database		University of Messina	http://www.unime.it/it/search/node/caserta%20dati
Healthcare Emergency Information System (HEIS)		Department of Epidemiology of the Regional Health Service - Lazio	http://www.deplazio.net/
Hospital Information System (HIS)		Department of Epidemiology of the Regional Health Service - Lazio	http://www.deplazio.net/
Mortality Information System (MIS)		Department of Epidemiology of the Regional Health Service - Lazio	http://www.deplazio.net/
Drug claims information system (PHARM)		Department of Epidemiology of the Regional Health Service - Lazio	http://www.deplazio.net/
Health Search/CSD Longitudinal Patient OR Health Search - IQVIA HEALTH LPD (Longitudinal Patient Database)		Italian Society of General Medicine (SIMG)	https://www.healthsearch.it/
EURAP Italy		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Congenital Anomalies Registry for the Metropolitan Area of Milan		Agency for Health Protection of Milan's Metropolitan Area	https://eu-rd-platform.jrc.ec.europa.eu/eurocat/eurocat-members/metropolitan
Register of Congenital anomalies of Veneto Region			http://www.icbdsr.org/programme-description/
Birth register of Veneto Region			https://www.cambridge.org/core/journals/public-health-nutrition/article/regular-monitoring-of-breastfeeding-rates-feasible-and-sustainable-the-emiliaromagna-experience/1F87D5B3F137761FC33
Emilia-Romagna paediatric immunisation database		Regional Health Authority of Emilia-Romagna	

Rare Diseases' Register of Veneto Region	
Birth cohort	Website
Multiple Births Cohort Study (MUBICOS)	http://www.birthcohorts.net/
Nascita e INFanzia: gli Effetti dell'Ambiente (NINFEA)	http://www.birthcohorts.net/
Piccolipiù	http://www.birthcohorts.net/
Pan-European cohorts/databases/networks which contain data from Italy	Website
COST Action BM1105 Patient Registry - GnRH Network (COST-GnRH gonadotropin-releasing hormone deficiency)	http://www.encepp.eu/encepp/search.htm
European Management Platform for Childhood Interstitial Lung Diseases (ChILD-EU - Children Interstitial lung diseases)	http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Register for Multiple Sclerosis (EUREMS)	http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm

European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/search.htm
European patient registry on TRAPS syndrome (EUROTRAPS - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
An EU Rare Diseases Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes (Euro WABB)	http://www.encepp.eu/encepp/search.htm
The European Clarkson's syndrome registry - EurêClark registry-Systemic Capillary Leak Syndrom	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm

RD-Connect - Patient registries integrated platform (RD-Connect)

<http://www.encepp.eu/encepp/search.htm>

Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)

<http://www.encepp.eu/encepp/search.htm>

European Rare Disease Infrastructure

<https://eu-rd-platform.jrc.ec.europa.eu/>

Latvia

Data source name	Native name	Data provider	Website
Registers			
Public Health Monitoring and Reporting System (SVMZS)	Sabiedrības Veselības Monitoringa un Ziņošanas Sistēmā (SVMZS)	Center for Disease Prevention and Control (SPC)	https://www.spkc.gov.lv/en/
Medical Birth Register	Jaundzimušo reģistrs	Center for Disease Prevention and Control (SPC)	https://www.spkc.gov.lv/lv/statistika-un-petijumi/datu-bazes
Register of Causes of Death	Latvijas Iedzīvotāju Nāves Cēloņu Datu Bāze	Center for Disease Prevention and Control (SPC)	https://www.spkc.gov.lv/lv/statistika-un-petijumi/datu-bazes
Register of Patients with Particular Diseases		National Health Service	
State Infectious Diseases and Monitoring System (VISUMS)	Valsts infekcijas slimību uzraudzības un monitoringa sistēma (VISUMS)	Center for Disease Prevention and Control (SPC)	https://www.spkc.gov.lv/lv/statistika-un-petijumi/datu-bazes
Management Information System (Health care payment settlement system)		National Health Service (NHS)	http://www.vmnvd.gov.lv/en
Pan-European cohorts/databases/networks which contain data from Latvia			Website
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)			http://www.encepp.eu/encepp/search.htm
EudraVigilance			http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)			http://www.encepp.eu/encepp/search.htm

Lithuania

Data source name	Native name	Data provider	Website
Registers			
Official Statistics Portal	Oficialiosios Statistikos Portalas	Statistics Lithuania	https://osp.stat.gov.lt/en_GB/pradins
Health Statistics Portal	Sveikatos statistikos portalas	Institute of Hygiene	http://stat.hi.lt/user-report-view.aspx?group_id=29
Causes of Death Register	Mirties atvejų ir jų priežasčių registras	Institute of Hygiene	http://www.hi.lt/en/mortality-in-lithuania.html
Information System Medical Data of Births	Gimimų medicininių duomenų informacinė sistema	Institute of Hygiene	http://hi.lt/lt/gimimu-medicininiai-duomenys.html
Compulsory Health Insurance Information System (SVEIDRA)	Privalomojo sveikatos draudimo informacinė sistema (SVEIDRA)	National Health Insurance Fund under the Ministry of Health	http://www.vlk.lt/sites/en
Register of Medicinal Products	Vaistinių preparatų registras	State Medicines Control Agency (SMCA)	https://vapris.vvkt.lt/vvkt-web/public/medications
Information System on Communicable Diseases	Užkrečiamųjų ligų ir jų sukėlėjų valstybės informacinė sistema	Center For Communicable Diseases And AIDS	http://www.ulac.lt/lt/ataskaitos
Tuberculosis Information System	Tuberkuliozės informacinė sistema	Vilnius University Hospital Santaros Klinikos	http://santa.lt/index.php?option=com_content&view=article&id=1114&Itemid=450
Lithuanian Cancer Registry	Lietuvos Vėžio Registras	National Cancer Institute	https://www.nvi.lt/cancer-registry/
EURAP Lithuania		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			
Kaunas cohort (KANC)			http://www.birthcohorts.net
Pan-European cohorts/databases/networks which contain data from Lithuania			Website
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm

European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm

Luxembourg

Data source name	Native name	Data provider	Website
Registers / surveys			
European Health Interview Survey (EHIS)	European Health Interview Survey (EHIS)	Ministry of Health / Directorate of Health	http://sante.public.lu/fr/statistiques/ehis/index.html
Causes of Death	Causes de Décès	Ministry of Health / Directorate of Health	http://sante.public.lu/fr/statistiques/statistiques-causes-deces/index.html
Database of the Accident Insurance Association	Banque de Données de l'Association d'Assurance Accident	Medical Control of Social Security (CMSS)	http://www.mss.public.lu/acteurs/cmss/index.html
Statistics Portal - Grand Duchy of Luxembourg	Le Portail des Statistiques du Grand Duché de Luxembourg	STATEC (National Institute of Statistics and Economic Studies of the Grand Duchy of Luxembourg) and collaboratives national data producers	https://statistiques.public.lu/en/index.html
National Cancer Registry (CNR)	Registre National du Cancer (RNC)	National Health Laboratory, national hospitals and oncology care centers, national screening programmes, etc.	https://www.rnc.lu/
National Register and Identification of Natural Persons (NPPN)	Registre National et Identification des Personnes Physiques (RNPP)	Government of the Grand Duchy of Luxembourg	http://www.guichet.public.lu/citoyens/fr/citoyennete/registre-national/index.html
Perinatal Health Register (SUSANA)	Registre de surveillance de la santé périnatale (SUSANA)	Ministry of Health / Luxembourg Institute of Health	http://www.susana.lu/web/Home/tabid/39/language/fr-FR/Default.aspx
Division Pharmacy and Drugs	Division de la Pharmacie et des Médicaments	Ministry of Health / Directorate of Health	http://sante.public.lu/fr/politique-sante/ministere-sante/direction-sante/div-pharmacie-medicaments/index.html

EURAP Luxembourg

European Registry of Antiepileptic
Drugs and Pregnancy (EURAP)

<http://www.eurapinternational.org/>

Pan-European cohorts/databases/networks which contain data from Luxembourg

Website

EudraVigilance

<http://www.encepp.eu/encepp/search.htm>

Malta

Data source name	Native name	Data provider	Website
Registers			
Directorate for Health Information & Research Registries		Ministry for Health	https://deputyprimeminister.gov.mt/en/Pages/health.aspx
National Obstetrics Information System (NOIS)		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/births.aspx
Malta Congenital Anomalies Register		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/birthdefects.aspx
Malta Cerebral Palsy Register		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/CerebralPalsyRegister.aspx
National Mortality Register		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/deaths.aspx
National Cancer Register		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/cancers.aspx
Injury Database (IDB)		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/injuries.aspx
National Hospitals Information System (NHIS)		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/hospitalstatistics.aspx
Malta Rare Diseases Register		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/Rare-diseases.aspx
National Organ Transplant Registry		Directorate for Health Information & Research	https://deputyprimeminister.gov.mt/en/dhir/Pages/Registries/transplan

		ts.aspx
National Communicable Disease Surveillance System	Directorate for Health Promotion and Disease Prevention – Infectious Disease Prevention and Control Unit.	http://deputyprimeminister.gov.mt/en/health-promotion/Pages/home.aspx
National Immunisation Electronic Database	Primary Child Health Unit within Primary Health Care	http://deputyprimeminister.gov.mt/en/phc/pchyhi/Pages/PCYHIU.aspx
National Oral Health Survey	Superintendence of Public Health	http://deputyprimeminister.gov.mt/en/sph/Pages/dphu.aspx
Pharmacy of Your Choice (POYC)	Pharmacy of Your Choice (POYC)	http://deputyprimeminister.gov.mt/en/poyc/Pages/Home.aspx
Pan-European cohorts/databases/networks which contain data from Malta		Website
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)		http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)		http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)		http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database		http://www.encepp.eu/encepp/search.htm
EudraVigilance		http://www.encepp.eu/encepp/search.htm

Netherlands

Data source name	Native name	Data provider	Website
Registers			
PHARMO Database Network	PHARMO	PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/
Eindhoven Cancer Registry (ECR)		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/cancer-registry/
General Practitioner (GP) Database		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/general-practitioner-database/
Out-patient Pharmacy Database		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/out-patient-pharmacy-database/
In-patient Pharmacy Database		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/in-patient-pharmacy-database/
Clinical Laboratory Database		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/clinical-laboratory-database/
Hospitalisation Database		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/hospitalisation-database/
Pathology Registry		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/pathology-registry/
Netherlands Perinatal Registry (Perined)	Perined	Perined	https://www.perined.nl/

Mortality Registry		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/mortality-registry/
PRO (Patient-Reported Outcomes)		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/pro/
PHARMO Database Network Tailored data collection		PHARMO Institute for Drug Outcomes Research	http://pharmo.nl/what-we-have/pharmo-database-network/tailored-data-collection/
Databases and Panels	NIVEL	NIVEL Netherlands Institute for Health Services Research	https://www.nivel.nl/en
Netherlands Information Network of General Practice (LINH) OR LINH Database		NIVEL Netherlands Institute for Health Services Research	https://www.nivel.nl/nl/NZR/zorgregistraties-eerstelijin
NIVEL Primary Care Database	NIVEL Zorgregistraties eerste lijn	NIVEL Netherlands Institute for Health Services Research	https://www.nivel.nl/en/dossier/nivel-primary-care-database
National Panel of the Chronically Ill and Disabled (NPCD)		NIVEL Netherlands Institute for Health Services Research	https://www.nivel.nl/en/national-panel-chronically-ill-and-disabled-npcd
Panel of People with Lung Disease		NIVEL Netherlands Institute for Health Services Research	https://www.nivel.nl/en/panel-people-lung-disease
pREGnant OR Dutch Pregnancy Drug Register	pREGnant	Lareb (Teratologie Informatie Service)	https://www.zonmw.nl/nl/over-zonmw/innovatie-in-de-zorg/programmas/project-detail/goed-gebruik-geneesmiddelen/the-pregnancy-drug-register-development-and-implementation/verslagen/
InterAction Database (IADB)	IADB	University of Groningen (RuG)	http://www.iadb.nl/
Nationwide Network and Registry of Histo- and Cytopathology in the Netherlands (PALGA)	Pathologisch-Anatomisch Landelijk Geautomatiseerd Archief (PALGA)	PALGA Foundation	http://www.palga.nl/en/about-stichting-palga/stichting-palga.html
Public Pathology Database OR	PALGA Openbare Databank	PALGA Foundation	http://www.palgaopenbaredataban

PALGA Public Database			k.nl/
Netherlands Cystic Fibrosis Registry	Nederlandse Cystic Fibrosis Registratie	Netherlands Cystic Fibrosis Foundation (Nederlandse Cystic Fibrosis Stichting)	https://www.ncfs.nl/onderzoek https://portal.juliuscentrum.nl/research/en-US/cohortsandprojects/cohortsprojects/agishealthdatabase.aspx
Achmea Health Database (AHD - Netherlands, previously AGIS Health Database)		UMC Utrecht, Julius Center	https://portal.juliuscentrum.nl/research/en-US/cohortsandprojects/cohortsprojects/agishealthdatabase.aspx
Integrated Primary Care Information Database (IPCI)		Erasmus Universitair Medisch Centrum Rotterdam (NL) - Erasmus MC	https://epi.grants.cancer.gov/pharm/pharmacoepi_db/ipci.html
CBS (Mortality Database)		Statistics Netherlands (Centraal Bureau voor de Statistiek (CBS)	https://www.cbs.nl/nl-NL
CBS (Health survey)		Statistics Netherlands (Centraal Bureau voor de Statistiek (CBS)	https://www.cbs.nl/nl-NL
Youth Monitor		Statistics Netherlands (Centraal Bureau voor de Statistiek (CBS)	https://jeugdmonitor.cbs.nl/
IMS LifeLink: Longitudinal Prescription Data - Netherlands		IMS Health - Real World Evidence Solutions	https://www.iqvia.com/
LifeLines cohort study and biobank		LifeLines	https://www.lifelines.nl/
Eurocat Northern Netherlands (NNL)		University Medical Centre of Groningen	https://www.umcg.nl/EN/corporate/paginas/default.aspx
KinCor database	KinCor database	Center Congenital Heart Disorders and Kinderthorax Center	https://kincor.nl/
The Mondriaan Project		TI Pharma	https://www.tipharma.com/home/
EURAP Netherlands		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/ https://www.dhd.nl/Paginas/home.aspx
Dutch Hospital Data			https://www.zorginstituutnederland.nl/
National Health Care Institute (ZiN)	Zorginstituut	National Health Care Institute (ZiN)	.nl/

Birth cohort

Rotterdam Periconception Cohort (Predict Study)		http://www.birthcohorts.net
Amsterdam Born Children and their Development (ABCD)		http://www.birthcohorts.net
Dutch Famine Birth Cohort Study (DFBCS)		http://www.birthcohorts.net
GECKO Drenthe cohort (GECKO Drenthe)		http://www.birthcohorts.net
Generation R		http://www.birthcohorts.net
Generation R Next		https://generationr.nl/next/
KOALA Birth Cohort Study (KOALA)		http://www.birthcohorts.net
LucKi		http://www.birthcohorts.net
PRegnancy and Infant DEvelopment Study (PRIDE Study)		http://www.birthcohorts.net
Wheezing Illnesses Study in LEidsche Rijn (WHISTLER)		http://www.birthcohorts.net
Peridos		https://www.peridos.nl/
EXPECT study	Obstetrician Consortium Limburg	https://www.zwangerinlimburg.nl/
Praeventis		https://bronnen.zorggegevens.nl/Bron?naam=Rijksvaccinatieprogramma
Aetiologic research into Genetic and Occupational/Environmental Risk Factors for anomalies in Children (AGORA)	UMC Radboud, Nijmegen	https://www.radboudumc.nl/patientenzorg/uw-afspraak/patient-in-een-umc/meedoen-aan-onderzoek/alles-over-meedoen-aan-wetenschappelijk-onderzoek/agora
Prevention and Incidence of Asthma and Mite Allergy Study (PIAMA)	University of Utrecht	https://piama.iras.uu.nl/
Tracking Adolescents' Individual Lives Survey (TRAILS) NEXT	University of Groningen (RuG)	https://www.trails.nl/

YOUth Cohort study	University of Utrecht	https://www.uu.nl/en/research/youth-cohort-study
Teratology Information Service		
Dutch Teratology Information Service	Netherlands Pharmacovigilance Centre Lareb	
Pan-European cohorts/databases/networks which contain data from the Netherlands		Website
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)		http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)		http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)		http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)		http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)		http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)		http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)		http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)		http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)		http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)		http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)		http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)		http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database		http://www.encepp.eu/encepp/search.htm

	rch.htm
EudraVigilance	http://www.encepp.eu/encepp/sear/rch.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/sear/rch.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/sear/rch.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/sear/rch.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/sear/rch.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/sear/rch.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/sear/rch.htm
X-linked adrenoleukodystrophy database (X-ALD - X-linked adrenoleukodystrophy)	http://www.encepp.eu/encepp/sear/rch.htm

Norway

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Norwegian Medical Birth Register (MBRN)			https://www.fhi.no/en/hn/health-registries/medical-birth-registry-of-norway/
Nordic Health Registers			
National Education Database NUDB.	Nasjonal utdanningsdatabase NUDB	Statistics Norway	https://www.ssb.no/utdanning/artikler-og-publikasjoner/nasjonal-utdanningsdatabase-nudb
Population data		Statistics Norway	https://www.ssb.no/en/omssb/tjenester-og-verktoy/data-til-forskning/befolkning
FD-Trygd database	FD-Trygd	Statistics Norway	https://www.ssb.no/en/omssb/tjenester-og-verktoy/data-til-forskning/fd-trygd
Population and housing census	utlan-av-data-fra-folke-og-boligtellingene	Statistics Norway	https://www.ssb.no/en/omssb/tjenester-og-verktoy/data-til-forskning/utlan-av-data-fra-folke-og-boligtellingene
Registers			
Norwegian Patient Register	Norsk pasientregister (NPR)	Norwegian Directorate of Health	https://www.helsedirektoratet.no/english
Municipal Patient and User Register	KOMMUNALT PASIENT- OG BRUKERREGISTER	Norwegian Directorate of Health	http://hrr.uit.no/hrr/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2FfStudy%2FKPR&context=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fcatalog%2FCatalog1
Cancer Registry	KREFTREGISTERET	Health South-East	https://www.kreftregisteret.no/Registre/Data/utlevering/
Abortion Register	ABORTREGISTERET	Norwegian Institute of Public Health (NIPH)	http://hrr.uit.no/hrr/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2FfStudy%2FABR&context=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fcatalog%2FCatalog1

			0%2Fobj%2Fcatalog%2Fcatalog1
Cause of Death Registry	DØDSÅRSAKSREGISTERET	Norwegian Institute of Public Health (NIPH)	http://hrr.uit.no/hrr/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fstudy%2FDAAR&context=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fcatalog%2Fcatalog1
Medical Birth Registry	MEDISINSK FØDSELSREGISTER	Norwegian Institute of Public Health (NIPH)	http://hrr.uit.no/hrr/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fstudy%2FMFR&context=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fcatalog%2Fcatalog1
Prescription Register/Norwegian Prescription Database (NorPD)	RESEPTREGISTERET	Norwegian Institute of Public Health (NIPH)	http://hrr.uit.no/hrr/velocity?v=2&mode=documentation&submode=ddi&study=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fstudy%2FRESEPTREGISTERET&context=http%3A%2F%2F129.242.10.77%3A80%2Fobj%2Fcatalog%2Fcatalog1
National Vaccination Register	NASJONALT VAKSINASJONSREGISTER SYSVAK	Norwegian Institute of Public Health (NIPH)	https://www.fhi.no/en/hn/health-registries/norwegian-immunisation-registry-sysvak/
Norwegian Tonsil register	Norsk Kvalitetsregister Øre-Nese-Hals – Tonsilleregisteret	Norwegian Health Network	https://www.kvalitetsregistre.no/registers/norsk-kvalitetsregister-ore-nese-hals-tonsilleregisteret
National Quality Register for Pain Management	Nasjonalt Kvalitetsregister for Smertebehandling	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/569/resultater
Norwegian newborn medical quality register	Norsk nyfødmedisinsk kvalitetsregister	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/norsk-nyfodtmedisinsk-kvalitetsregister
Norwegian quality register for lip-jaw cleft palate	Norsk kvalitetsregister for leppe-kjeve-ganespalte	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/571/resultater
National quality register for the treatment of harmful use or addiction to drugs (KVARUS)	Nasjonalt kvalitetsregister for behandling av skadelig bruk eller avhengighet av rusmidler (KVARUS)	Amund Aakerholt amund.aakerholt@sus.no	https://www.kvalitetsregistre.no/registers/1124/resultater
Norwegian Vasculitis Register & Biobank (NorVas)	Norsk vaskulittregister & biobank (NorVas)	University Hospital Nord-Norge HF	https://www.kvalitetsregistre.no/registers/776/resultater

National registry for organ-specific autoimmune diseases (ROAS)	Nasjonalt register for organspesifikke autoimmune sykdommer (ROAS)	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/563/resultater
Norwegian newborn medical quality register	Norsk nyfødtd medisinsk kvalitetsregister	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/553/resultater
National children's hip register	Nasjonalt barnehofteregister	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/539/resultater
Norwegian register for hereditary and innate neuromuscular diseases	Norsk register for arvelige og medfødte nevrologiske sykdommer	University Hospital Nord-Norge HF	https://www.kvalitetsregistre.no/registers/507/resultater
Norwegian MS register and biobank	Norsk MS-register og biobank	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/505/resultater
Cerebral palsy register in Norway	Cerebral pareseregisteret i Norge	Health South-East	https://www.kvalitetsregistre.no/registers/cerebral-pareseregisteret-i-norge
Norwegian diabetes register for adults	Norsk diabetesregister for voksne	Helse Bergen HF	https://www.kvalitetsregistre.no/registers/364/resultater
National medical quality register for child and youth diabetes	Nasjonalt medisinsk kvalitetsregister for barne- og ungdomsdiabetes	Oslo University Hospital HF (OUS)	https://oslo-universitetssykehus.no/avdelinger/barne-og-ungdomsklinikken/avdeling-for-barnemedisin/barnediabetesregisteret-bdr
National quality register for breast cancer	Nasjonalt kvalitetsregister for brystkreft	Manager Cancer Registry	https://www.kreftregisteret.no/registrene/kvalitetsregistrene/brystkreftregisteret/
National quality register for childhood cancer	Nasjonalt kvalitetsregister for barnekreft	Manager Cancer Registry	https://www.kreftregisteret.no/registrene/kvalitetsregistrene/barnekreftregisteret/
Norwegian stroke register	Norsk hjerneslagregister	St. Olavs Hospital	www.norsk-hjerneslagregister.no
Norwegian heart attack register	Norsk hjerteinfarktregister	Norwegian Institute of Public Health	https://stolav.no/norsk-hjerteinfarktregister
Norwegian heart surgery register	Norsk hjertekirurgiregister	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/478/resultater
Norwegian register for invasive cardiology (NORIC)	Norsk register for invasiv kardiologi (NORIC)	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/484/resultater
Norwegian vascular surgical register - NORWAY	Norsk karkirurgisk register - NORKAR	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/712/resultater
Norwegian heart surgery register	Norsk hjertekirurgiregister	Norwegian Institute of Public Health	https://www.kvalitetsregistre.no/registers/478/resultater

		Public Health	esultater
Communicable Disease Message System (MSIS)	Meldingssystem for smittsomme sykdommer (MSIS)	Folkehelseinstituttet	https://www.fhi.no/hn/helseregistre-og-registre/msis/
Cardiac and vascular register	Hjerte- og karregisteret	Folkehelseinstituttet	https://www.fhi.no/hn/helseregistre-og-registre/hjertekar/
National register of cardiovascular disorders (Cardiovascular, HKR)	Nasjonalt register over hjerte- og karlidelser (HKR)	Norwegian Institute of Public Health	https://www.fhi.no/hn/helseregistre-og-registre/hjertekar/
Birth cohorts			
Norwegian Mother and Child Cohort/MoBA Cohort and Biobank			https://www.fhi.no/en/studies/moba/
Norwegian Twin registry	Nasjonalt tvillingregister	Norwegian Institute of Public Health (NIPH)	https://www.fhi.no/en/more/health-studies/norwegian-twin-registry/
Pan-European cohorts/databases/networks which contain data from Norway			
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
Association of the Nordic Cancer Registries (ANCR)			http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)			http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)			http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database			http://www.encepp.eu/encepp/search.htm
EudraVigilance			http://www.encepp.eu/encepp/search.htm
European Porphyria Registry (EPR)			http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)			http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)			http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)			http://www.encepp.eu/encepp/search.htm

Poland

Data source name	Native name	Data provider	Website
Registers			
National Registry for Fetal Cardiac Anomalies	Ogólnopolski Rejestr Problemów Kardiologicznych u Plodów	Polish Society of Prenatal Cardiology	http://www.orpkp.pl/index.php?LANG=pl&level=1&struct=1&start_page=1
Polish National Cancer Registry	Krajowy Rejestr Nowotworów	Center of Oncology-Institute them. Maria Skłodowska-Curie	http://onkologia.org.pl/
Database of Late Effects Follow-Up after Childhood Cancer Treatment	Baza Danych Późnych Powikłań po Leczeniu Przeciwnowotworowym w Dzieciństwie	[CORDIS]	https://cordis.europa.eu/result/rcn/199817_en.html
Polish Registry of Congenital Malformations (PRCM)	Polski Rejestr Wrodzonych Wad Rozwojowych (PRWWR)	Department and Department of Medical Genetics, Medical University of Poznan	http://www.rejestrwad.pl
Central List of Insured Register	Centralny Wykaz Ubezpieczonych	National Health Fund	http://www.nfz.gov.pl/
Information Portal		Central Statistical Office of Poland	http://stat.gov.pl/
Where to give birth?	(Gdzie rodzić?)	Childbirth with Dignity Foundation	http://www.rodzicpoludzku.pl/Ogone/About-us.html
EURAP Poland		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/ https://krok.csioz.gov.pl/krok/?sessionid=537355A2FC8006735AFEE31C632E0E59?0
Krajowy Rejestr Operacji Kardiochirurgicznych			https://guzyslinianek.pcsc.pl/
Rejestr Nowotworów Niezłośliwych Dużych Gruczołów Ślinowych			https://guzyslinianek.pcsc.pl/
Birth cohort			
Polish Mother and Child Cohort Study			http://www.birthcohorts.net
Nutrition and physical activity during pregnancy			Dr hab. Katarzyna Szamotulska. zaklad.epidemiologii@imid.med.pl
Pan-European cohorts/databases/networks which contain data from Poland			Website

Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
An EU Rare Diseases Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes (Euro WABB)	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm

	earch.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/earch.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/earch.htm
European Reference Network on Rare Endocrine Conditions	https://endo-ern.eu/
European Reference Network on Rare and Complex Epilepsies	https://epi-care.eu/
European Rare Kidney Diseases Reference Network	https://www.erknet.org/index.php?id=home
European Reference Network on Rare Neurological Diseases	http://www.ern-rnd.eu/
European Reference Network on Rare Respiratory Diseases	https://ern-lung.eu/
European Reference Network on Rare and Undiagnosed Skin Disorders	https://ern-skin.eu/
European Reference Network on Rare Hematological Diseases	https://www.eurobloodnet.eu/
European Reference Network for Rare Neuromuscular Diseases	https://ern-euro-nmd.eu/poster/european-reference-network-for-rare-neuromuscular-diseases-euro-nmd/
European Reference Network on Rare Eye Diseases	https://www.ern-eye.eu/
European Reference Network on GENetic TUmour Risk Syndromes	https://www.genturis.eu/l=eng/ERN-GENTURIS-Home.html
European Reference Network for Rare Hereditary Metabolic Disorders	https://metab.ern-net.eu/
European Reference Network for Paediatric Cancer (haemato-oncology)	http://paedcan.ern-net.eu/
European Reference Network on Rare Hepatological Diseases	https://www.rare-liver.eu/
European Reference Network on Transplantation in Children (incl. HSCT, heart, kidney, liver, intestinal, lung and multiorgan)	https://www.transplantchild.eu/en/
European Reference Network on Rare and Complex Urogenital Diseases and Conditions	http://eurogen-ern.eu/

Portugal

Data source name	Native name	Data provider	Website
Registers			
PORDATA Database		Francisco Manuel dos Santos Foundation (Fundação Francisco Manuel dos Santos)	https://www.pordata.pt/
Primary Immunodeficiency Registers (PIDs) (REPORID)		Portuguese Society of Immunology (SOCIEDADE PORTUGUESA DE IMUNOLOGIA (SPI))	https://www.spimunologia.org
PNPSO-Estudos (a module of the Oral Health Information System)		Ministry of Health (Ministério da Saúde)	http://www.insa.min-saude.pt/
Portugal, South		National Institute of Health, Ministry of Health	http://www.insa.min-saude.pt/category/areas-de-atuacao/epidemiologia/
National Register of Congenital Anomalies (RENAC)	Registo Nacional de Anomalias Congénitas (RENAC)	National Institute of Health Doctor Ricardo Jorge (Ricardo Jorge Institute) (INSA)	http://www.insa.min-saude.pt/category/institucional/o-instituto/
National Survey of Health by Interview (INS)		National Institute of Health Doctor Ricardo Jorge (Ricardo Jorge Institute) (INSA)	http://www.insa.min-saude.pt/category/institucional/o-instituto/
Databases; Surveys		Statistics Portugal (Instituto Nacional de Estatística (INE))	https://www.ine.pt/xportal/xmain?xpgid=ine_main&xpid=INE&xlang=pt
Very Low Weight National Registry (RNMBP).	Registo Nacional dos RNMBP	Portuguese Society of Neonatology (SPN)	https://www.spneonatologia.pt/
MINISTRY OF EDUCATION - Direção-Geral da Educação (DGE) and Direção Geral das Estatísticas da Educação e Ciência	Direção Geral das Estatísticas da Educação e Ciência	Directorate-General for Health (Direcção-Geral da Saúde (DGS))	https://www.dgs.pt/

Service of Intervention in Addictive Behaviours and Dependencies (SICAD)	Serviço de Intervenção nos Comportamentos Aditivos e nas Dependências (SICAD)	General Directorate for Intervention on Addictive Behaviours and Dependencies (SICAD)	http://www.sicad.pt/EN/Paginas/default.aspx
Rheumatic diseases Portuguese Registry (Reuma.pt)	Registo Nacional de Doentes Reumáticos (Reuma.pt)	Portuguese Society of Rheumatology (SPR)	http://reuma.pt/pt_PT/Default.aspx
EURAP Portugal		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			
Generation XXI (G21)			http://www.birthcohorts.net/
Gestão Integrada Saúde e Ambiente (GISA)			http://www.birthcohorts.net/
Healthcare databases - Adverse drug reaction databases			
Portuguese pharmacovigilance system (PPS) database			
Pan-European cohorts/databases/networks which contain data from Portugal		Website	
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)			http://www.encepp.eu/encepp/search.htm

European Cystic Fibrosis Society Patient Registry (ECFSPR) <http://www.encepp.eu/encepp/search.htm>

European Database for Multiple Sclerosis (EDMUS) <http://www.encepp.eu/encepp/search.htm>

European Society for Immunodeficiencies (ESID) <http://www.encepp.eu/encepp/search.htm>

European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy) <http://www.encepp.eu/encepp/search.htm>

European Surveillance of Congenital Anomalies (EUROCAT) <http://www.encepp.eu/encepp/search.htm>

EudraVigilance <http://www.encepp.eu/encepp/search.htm>

Galactosemia Patient Registry (GalNet) <http://www.encepp.eu/encepp/search.htm>

PedNet Haemophilia Research Foundation (PedNet) <http://www.encepp.eu/encepp/search.htm>

Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases) <http://www.encepp.eu/encepp/search.htm>

RD-Connect - Patient registries integrated platform (RD-Connect) <http://www.encepp.eu/encepp/search.htm>

Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD) <http://www.encepp.eu/encepp/search.htm>

Romania

Data source name	Native name	Data provider	Website
Registers			
National Registers	Institutul National de Sanatate Publica	National Institute for Public Health	http://insp.gov.ro/
National Electronic Register of Vaccinations	REGISTRUL ELECTRONIC NAȚIONAL DE VACCINĂRI	National Institute for Public Health	https://www.renv.ro/renv/ https://emif-catalogue.eu/c/mocha1/fingerprint/38d7fc56b311507742a395f9c8ee2a3f/1
Maternal Mortality		National Institute for Public Health	http://cnsct.ro/index.php
National Electronic Register of Communicable Diseases	Registrul Electronic Național al Bolilor Transmisibile	National Center for Communicable Disease Control and Control	https://www.transplant.ro/(X(1)S(i4rl3xv2ku5mzo0qcdwh4hpd))/Registru.aspx
National Transplant NTA Registry	Registrul Național ANT	National Transplant Agency	http://ithub.gov.ro/2016/12/06/rensa-registrul-electronic-national-de-screening-auditiv/
RENSA - National Electronic Auditory Screening Register	RENSA - Registrul Electronic Național de Screening Auditiv	GovITHub	
Infant and child Mortality (child death under 1 year of age, and death for children 1 to 4 years of age)		National Center for Statistics and Informatics in Public Health (CNSISP)	http://cnsisp.insp.gov.ro/
ROM TEMPO – time series from Health - Chapters .:INFRASTRUCTURE OF HEALTH, MEDICAL STAFF, SANITARY ASSISTENCE (health services)		National Institute of Statistics	http://www.insse.ro/cms/en
Nutritional status and feeding practices for children under two years old		National Institute for Maternal and Child Health "Alessandrescu-Rusescu"	https://iomc.ro/index.php

Pan-European cohorts/databases/networks which contain data from Romania	Website
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Slovakia

Data source name	Native name	Data provider	Website
Registers			
National Health Registers	Národné Centrum Zdravotníckych Informácií	National Health Information Center (NCZI)	http://www.nczisk.sk/Pages/default.aspx
National Register of Electronic Medical Records	Národný Register Elektronických Zdravotných Knižiek	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-elektronickych-zdravotnych-kniziek.aspx
National Cancer Register	Národný Onkologický Register	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-onkologicky-register.aspx
National Diabetes Mellitus Registry	Národný Register Diabetes mellitus	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-s-diabetes-mellitus.aspx
National Registry of Congenital Errors	Národný register Vrodených Chýb	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-s-vrodenou-vyvojovou-chybou.aspx
National Registry of Circulatory Diseases	Národný Register Chorôb Obehovej Sústavy	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-so-srdcovocievny-m-ochorenim.aspx
National Registry of Neurological Diseases	Národný Register Neurologických Chorôb	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-

			pacientov-s-neurologickym-ochorenim.aspx
National Registry of Chronic Pulmonary Diseases	Národný Register Chronických Pľúcnych Chorôb	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-s-chronickym-ochorenim-pluc.aspx
National Register of Injuries Requiring the Provision of Institutional Health Care	Národný Register úrazov Vyžadujúcich Poskytnutie ústavnej Zdravotnej Starostlivosti	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-osob-s-urazom-vyzadujucim-poskytnutie-ustavnej-zdravotnej-starostlivosti.aspx
National Register of Inflammatory Rheumatic Diseases	Národný Register Zápalových Reumatických Chorôb	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-so-zapalovym-reumatickym-ochorenim.aspx
National Tuberculosis Registry	Národný Register Tuberkulózy	National Health Information Center (NCZI)	http://www.nczisk.sk/Registre/Narodne-zdravotne-registre/Pages/Narodny-register-pacientov-s-tuberkulozou.aspx
EURAP Slovakia		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Birth cohort			
Slovak PCB study			http://www.birthcohorts.net/
Pan-European cohorts/databases/networks which contain data from Slovakia			Website
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm

European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
An EU Rare Diseases Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes (Euro WABB)	http://www.encepp.eu/encepp/search.htm

Slovenia

Data source name	Native name	Data source	Website
Registers			
Databases	Nacionalni Inštitut za Javno Zdravje	National Institute of Public Health (NIJZ)	http://www.nijz.si/
Perinatal Information System (PIS RS)	Perinatalni Informacijski Sistem - PIS RS	National Institute of Public Health (NIJZ)	http://www.nijz.si/sl/podatki/perinatalni-informacijski-sistem
Fetal Death Information System (ISSFS)	Informacijski Sistem Spremljanja Fetalnih Smrti (ISSFS)	National Institute of Public Health (NIJZ)	http://www.nijz.si/podatki/fetalne-smrti
Report Death OR Causes of death data (CoD)	Zdravniško Poročilo o Umrli Oseb	National Institute of Public Health (NIJZ)	http://www.nijz.si/podatki/prijava-smrti
Monitoring of Hospital Treatments OR National Hospital Health Care Statistics Database	Spremljanje Bolnišničnih Obravnav - SBO	National Institute of Public Health (NIJZ)	http://www.nijz.si/sl/podatki/spremljanje-bolnisnicnih-obravnav http://www.nijz.si/sl/podatki/zunajbolnisnicna-zdravstvena-dejavnost-0
Out-Patient Healthcare Activity	Zunajbolnišnična Zdravstvena Dejavnost - ZUBSTAT -SZBO	National Institute of Public Health (NIJZ)	http://www.nijz.si/sl/podatki/zunajbolnisnicna-zdravstvena-dejavnost-0
Records of Consumption of Prescription Drugs	Evidenca Porabe Zdravil Izdanih na Recept	National Institute of Public Health (NIJZ)	http://www.nijz.si/podatki/evidenca-porabe-zdravil-izdanih-na-recept http://www.nijz.si/sl/podatki/anketa-o-zdravju-in-zdravstvenem-varstvu
European Health Interview Survey	Anketa o Zdravju in Zdravstvenem Varstvu	National Institute of Public Health (NIJZ)	http://www.nijz.si/sl/podatki/anketa-o-zdravju-in-zdravstvenem-varstvu
Cancer Registry of the Republic of Slovenia	Register Raka Republike Slovenije - RRRS	Institute of Oncology	https://www.onko-i.si/eng/crs/ https://www.onko-i.si/eng/sectors/epidemiology_and_cancer_registries/cancer_registries/hospitalbased_cancer_registry_of_the_institute_of_ljubljana/
Hospital-Based Cancer Registry	Register Bolnišnični Raka	Institute of Oncology	https://www.onko-i.si/eng/sectors/epidemiology_and_cancer_registries/cancer_registries/hospitalbased_cancer_registry_of_the_institute_of_ljubljana/

Statistics	Statistični urad Republike Slovenije (SURS)	Statistical Office of the Republic of Slovenia (SURS)	http://www.stat.si/StatWeb/en
EURAP Slovenia		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Pan-European cohorts/databases/networks which contain data from Slovenia			Website
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)			http://www.encepp.eu/encepp/search.htm
EudraVigilance			http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)			http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)			http://www.encepp.eu/encepp/search.htm

Spain

Data source name	Native name	Data provider	Website
Registers			
ECEMC - Spanish Collaborative Study of Congenital Malformations	ECEMC Estudio Colaborativo Español de Malformaciones Congénitas	Research Center on Congenital Anomalies (CIAC), of the Institute of Health Carlos III, of Spain	http://www.fundacion1000.es/ecemc
CAPV - Basque Country - Spain	Registro Anomalías Congénitas CAPV - Basque Country- Spain	Dirección y Subdirección de Salud Pública [EUROCAT]	http://www.eurocat-network.eu/
Comunitat Valenciana Registry of Congenital Anomalies - Valencia - Spain	Registro de Anomalías Congénitas de la Comunitat Valenciana	FOUNDATION FOR THE PROMOTION OF HEALTH AND BIOMEDICAL RESEARCH OF THE VALENCIAN REGION (FISABIO)/ Dir. Gral. Salud Pública Conselleria de Sanitat [EUROCAT]	http://www.eurocat-network.eu/
National Registries; Patient Registries	Spain RDR (Rare Diseases Registries)	Instituto de Salud Carlos III	https://spainrdr.isciii.es/en/Pages/default.aspx
National Registry of Rare Diseases (ReeR)	Registro Nacional de Enfermedades Raras	Ministry of Health	https://spainrdr.isciii.es/en/Pages/default.aspx
National Rare Disease Biobank	Biobanco Nacional de Enfermedades Raras	Instituto de salud Carlos III - Spanish Rare Diseases Registries Research Network (SpainRDR)	https://spainrdr.isciii.es/en/Pages/Biobank.aspx
Telephonic Information Service about Teratogens (SITTE)	Servicio de Información Telefónica sobre Teratógenos Español (SITTE)	Instituto de Salud Carlos III	http://www.fundacion1000.es/sitte
Paediatric and Developmental Medicine Programme	Centro de Investigacion Biomédicas en Red de Enfermedades Raras (CIBERER)	CIBERER Plattform	https://www.ciberer.es/en/platforms
National Databases; Statistics	Ministerio de Sanidad, Consumo y Bienestar Social	Ministry of Health, Consum and Welfare	http://www.msrebs.gob.es/en/estadEstudios/sanidadDatos/home.htm

BIFAP: Database for Pharmacoepidemiological Research in Primary Care	BIFAP: Base de Datos para la Investigacion Farmacoepidemiológica en Atención Primaria	DataBase for Primary Health Care. Ministry of Health, Consum and Welfare	http://www.bifap.org/
ADS Registry	Registro de ADS	[Registry of Registries (RoR)]	http://193.198.216.29/registries/?query=spain#!state/list_all
Asthma Data Bank	Banco de Datos de Asma	[Registry of Registries (RoR)]	http://193.198.216.29/registries/?query=spain#!state/list_all
REDECAN Joint Database	REDECAN - Red Española de Registros de Cáncer	REDECAN - Spanish cancer registries	http://redecan.org/en/index.cfm
Spanish Registry of Childhood Tumors (RETI-SEHOP)	Registro Español de Tumores Infantiles (RETI-SEHOP)	REDECAN - Spanish cancer registries	http://redecan.org/es/page.cfm?id=106&title=registro-nacional-de-tumores-infantiles
Pediatric Ambulatory and Home Health Nutrition (NEPAD)	Registro de Nutrición Enteral Pediátrica Ambulatoria y Domiciliaria (NEPAD)	Spanish Society of Gastroenterology, Hepatology and Pediatric Nutrition (SOCIEDAD ESPAÑOLA DE GASTROENTEROLOGÍA, HEPATOLOGÍA Y NUTRICIÓN PEDIÁTRICA)	https://www.seghnp.org/
Information System of Parc de Salut Mar (IMASIS)		Consorti Mar Parc de Salut de Barcelona	http://www.parcdesalutmar.cat/
Information System for Research in Primary Care (SIDIAP)	Sistema d'Informació pel Desenvolupament de la Investigació a l'Atenció Primària	IDIAP Jordi Gol	http://www.sidiap.org/
EpiChron Cohort	EpiChron	Aragon Health Sciences Institute (IACS)	http://www.iacs.es/
IMS LifeLink: Longitudinal Prescription Data (LRx) - Spain		IMS Health	https://www.iqvia.com/
Pharmacovigilance Program from Laboratory Signals at La Paz University Hospital (PPLS-LPUH)		Hospital La Paz, School of Medicine, UAM	https://www.uam.es/Medicina/Presentacion/1234890435483.htm?languaje=en
Real Life Data - Big-Pac		Real Life Data SLU	http://www.rlifedata.com/

Multiple Sclerosis registry of Catalonia (epidEMcat - Multiple sclerosis) OR Catalonia MS Registry		CEM-Cat	http://www.epidemcat.cat/ http://www.ine.es/ss/Satellite?c=Page&pagename=INE%2FINELayout&c id=1254735905566&L=1
INEbase	INEbase	National Statistics Institute (INE)	
Surveillance System of the Flu in Spain (SVGE)	Sistema de Vigilancia de la Gripe en España (SVGE)	Surveillance System of the Flu in Spain (SVGE)	http://vgripe.isciii.es/inicio.do
EURAP Spain		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
GAIA: Pharmaceutical Producer Manager	GAIA:Gestor de la Prestació Farmacèutica	Ministry of Health of the Generalitat Valenciana	http://www.san.gva.es/web/dgfps/gaia
The Cancer Information System of the Comunitat Valenciana	Sistema de Información de Cáncer de la Comunitat Valenciana	SIC. Conselleria de Sanitat. Generalitat Valenciana	http://www.sp.san.gva.es/epidemiologia/cancer
Rare Diseases Information System Comunitat Valenciana	Sistema de Información de Enfermedades Raras de la Comunitat Valenciana	SIER. Conselleria de Sanitat. Generalitat Valenciana	http://www.sp.san.gva.es/sscc/opciones2.jsp?CodPor=121&Opcion=SANMS59000&CodPunto=869&MenuSup=SANMS50000&Nivel=1
Perinatal mortality registry Comunitat Valenciana	Registro de Mortalidad Perinatal de la Comunitat Valenciana	Conselleria de Sanitat. Generalitat Valenciana	http://www.sp.san.gva.es/epidemiologia/perinatal
Spanish Renal Registry	Registro Español de Enfermos Renales	Organización Nacional de Trasplantes (ONT)	http://www.registrorenal.es/
Childhood Tumor Registry of the Comunitat Valenciana	Registro de Tumores Infantiles de la Comunitat Valenciana (RTICV)	Generalitat Valenciana Ir a Conselleria de Sanitat Universal I Salut Publica	https://www.sp.san.gva.es/sscc/opciones2.jsp?CodPor=121&Opcion=SANMS58100&CodPunto=990&MenuSup=SANMS58000&Nivel=2
Registry of Tumors of Castellón	Registro Tumores Castellón	Generalitat Valenciana Ir a Conselleria de Sanitat Universal I Salut Publica	https://www.sp.san.gva.es/sscc/opciones2.jsp?CodPor=121&Opcion=SANMS58200&CodPunto=991&MenuSup=SANMS58000&Nivel=2
Oncology Information System of the Comunitat Valenciana	Sistema de Información Oncológico	Generalitat Valenciana Ir a Conselleria de Sanitat Universal I Salut Publica	https://www.sp.san.gva.es/sscc/opciones2.jsp?CodPor=121&Opcion=SANMS58500&CodPunto=1541&Menu

Birth cohort			
INMA-Environment and Childhood Project (INMA Project)	INMA – Infancia y Medio Ambiente	INMA project	http://www.proyectoinma.org/en/
NELA - Nutrition in Early Life and Asthma (NELA)			http://www.birthcohorts.net/
Healthcare databases - Adverse drug reaction databases			
Spanish Pharmacovigilance System	Farmacovigilancia de Medicamentos de uso humano	Spanish Drugs and Health Products Agency (AEMPS)	https://www.aemps.gob.es/vigilancia/medicamentosUsoHumano/home.htm
Pan-European cohorts/databases/networks which contain data from Spain			Website
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)			http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)			http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)			http://www.encepp.eu/encepp/search.htm

	rch.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.euromedicat.eu/
EudraVigilance	http://www.encepp.eu/encepp/search.htm
The European Clarkson's syndrome registry - EurêClark registry-Systemic Capillary Leak Syndrom	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
European hereditary angioedema patient registry (HAE)	http://www.encepp.eu/encepp/search.htm
Hepatitis Delta International Network (HDIN) - Patient Registry	http://www.encepp.eu/encepp/search.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/search.htm
MediGuard.org	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Sweden

Data source name	Native name	Data provider	Website
Population-based record linkage surveillance systems			
Swedish Medical Birth Register			
Nordic Health Registers			
Registers			
LifeGene (Cohort)	LifeGene	LifeGene (Collaboration)	https://www.lifegene.se/
State Personal Address Book (SPAR)	Statens Personadressregister (SPAR)	The Swedish Tax Agency	https://www.statenspersonadressregister.se/
Statutory Health and Social Data Registers; Statistics	Socialstyrelsen	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/ http://www.socialstyrelsen.se/register/halsodataregister/lakemedelsregistret
Prescribed Drug Register	Läkemedelsregistret	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/cancerregistret
Cancer OR Swedish Cancer Register	Cancerregistret	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/insatserkommunalhalso-ochsjukvard
Efforts in Public Health	Insatser i kommunal hälso- och sjukvård	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/medicinskafofelseregistret
Medical Birth Registry	Medicinska födelserregistret	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/medicinskafofelseregistret/overvakningavfosterskador
Register of Birth Defects and Chromosomal Abnormalities OR Sweden Congenital Anomalies Registry	Registret över fosterskador och kromosomavvikelser	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/patientregistret
Patient Register OR Swedish National Inpatient Register (IPR) OR Hospital Discharge Register	Patientregistret	Welfare (Socialstyrelsen)	

IDB (Injury Data Base) Sweden	IDB Sverige	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/patientregistret/idbsverige
Dental Health Registry	Tandhälsoregistret	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/halsodataregister/tandhalsoregistret
Cause of Death Register	Dödsorsaksregistret	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/dodsorsaksregistret
National Quality Registers	Nationella kvalitetsregister	Welfare (Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister
Pregnancy Registry	Graviditetsregistret	National Quality Registers (part of Socialstyrelsen)	https://www.medscinet.com/GR/english.aspx
Swedish Neonatal Quality (SNQ)	Svenskt Neonatalt Kvalitetsregister (SNQ)	National Quality Registers (part of Socialstyrelsen)	http://kvalitetsregister.se/englishpages/findaregistry/registerarkivenglish/nationalqualityregistryforneonatalcaresnq.2191.html
Swedish Register for Inherited Metabolic Diseases	Svenska Registret för Medfödda Metabola Sjukdomar (RMMS)	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/svenskaregistretformedfoddamet
CPUP (CP-monitoring program in Sweden)	CPUP (CP-uppföljningsprogrammet i Sverige)	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/cpupcp-uppfoljningsprogrammeti
BORIS (BarnObesitasRegister in Sweden)	BORIS (BarnObesitasRegister i Sverige)	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/borisbarnobesitasregisterisver
Swedish barnreumaregistret (Child Rheumatoid Registry)	Svenska barnreumaregistret	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/svenskabarnreumaregistret

Swedish Children Kidney Registry	Svenska Barnnjurregistret	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/svenskabarnnjurregistret
Swedish Child Health Registry	Svenska barnhälsovårdsregistret	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/svenskabarnhalsovardsregistret
National quality of student health medical intervention	Nationellt kvalitetsregister för elevhälsans medicinska insats	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/nationelltkvalitetsregisterfor5
National quality for rehabilitation - HabQ	Nationellt kvalitetsregister för rehabilitering - HabQ	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/nationelltkvalitetsregisterfor2
Swedish Children Epilepsy Registry (BEPQ)	Svenska Barnpilepsiregistret (BEPQ)	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/svenskabarnpilepsiregisterbe
LKG register (quality monitoring of lip, jaw and palate)	LKG-registret (kvalitetsregister för uppföljning av läpp- käk- gomspalt)	National Quality Registers (part of Socialstyrelsen)	http://www.socialstyrelsen.se/register/register-service/nationellakvalitetsregister/lkg-registretkvalitetsregister
National Quality Registers	Nationella Kvalitetsregister	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/index.html
National Quality Registry for Childhood Cancer OR Swedish children's Cancer	Svenska Barncancerregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforchildhoodcancer.2235.html
National Quality Registry for Caries and Periodontitis OR Swedish Quality for caries and periodontitis	Svenskt Kvalitetsregister för Karies och Parodontit (SKaPa)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforcariesandperiodontitis.2149.html

National Quality Registry for Ear, Nose and Throat Care	Nationellt kvalitetsregister för öron-, näs- och halssjukvård	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforearnoseandthroatcare.2162.html
National Quality Registry for Child and Adolescent Habilitation OR National Quality for rehabilitation - HabQ	Nationellt kvalitetsregister för habilitering - HabQ	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforchildandadolescenthabilitation.2153.html
National Quality Registry for Child and Adolescent Psychiatry (Q-bup) OR National quality of Child and Adolescent Psychiatry, Q bup	Nationellt kvalitetsregister för barn- och ungdomspsykiatri, Q-bup	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforchildandadolescentpsychiatryqbup.2487.html
National Quality Registry for ADHD Treatment Follow-up (BUSA) OR BUSA National quality of treatment monitoring of significant ADHD	BUSA Nationellt kvalitetsregister för behandlingsuppföljning av säkerställd ADHD	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforadhd-treatment-follow-up-busa.2050.html
National Quality Registry for Child Preventative Health (BHVQ) OR Swedish Child Health Registry (as above)	Svenska barnhälsovårdsregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://bhvq.se/
National Quality Registry for Childhood Epilepsy (BEPQ) OR Swedish Children Epilepsy Registry (BEPQ) (as above)	Svenska Barnepilepsiregistret (BEPQ)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforchildhoodpilepsybepq.2236.html
National Quality Registry for Cleft Lip and Palate (CLP) OR LKG register (quality monitoring of lip, jaw and palate)	LKG-registret (kvalitetsregister för uppföljning av läpp- käk- gomspalt)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforcleftlipandpalateclp.2155.html

National Quality Registry for Congenital Heart Disease (SWEDCON) OR SWEDCON (National Directory of congenital heart disease)	SWEDCON (Nationellt register för medfödda hjärtsjukdomar)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforcongenitalheartdiseaseswedcon.2279.html
National Quality Registry for Cystic Fibrosis OR CF records, quality of cystic fibrosis	CF register, kvalitetsregister för cystisk fibros	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforcysticfibrosis.2158.html
National Quality Registry for Diabetes (NDR) with SWEDIABKIDS OR NDR (National Diabetes) with SWEDIABKIDS	NDR (Nationella Diabetes Registret) med SWEDIABKIDS	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryfordiabetesndrwithswediabkids.2161.html
National Quality Registry for Hepatitis (InfCare Hepatit) OR InfCare Hepatitis National Quality Registry for HIV (InfCare HIV)	Nationella kvalitetsregister	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforhepatitisinfcarehepatit.2239.html
National Quality Registry for HIV (InfCare HIV) OR InfCare HIV (quality register InfCareHIV)	InfCare HIV (Kvalitetsregistret InfCareHIV)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforhivinfcarehiv.2172.html
National Quality Registry for Intensive Care (SIR) OR SIR (Swedish Intensive Care Register)	SIR (Svenska Intensivvårdsregistret)	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforintensivecaresir.2175.html
National Quality Registry for Fractures OR Swedish Fracture Register	Svenska Frakturregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforfractures.2114.html
National Quality Registry for Haemophilia	Svenska Hemofiliregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforhaemophilia.2401.html

National Quality Registry for Leukaemia	Blodcancerregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://www.kvalitetsregister.se/englishpages/findaregistry/registerarkiv/english/nationalqualityregistryforleukaemia.2116.html
EURAP Sweden		European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
Population statistics		Statistics Sweden	https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-composition/population-statistics/
Demographic Analysis (DEMOG)		Statistics Sweden	https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-projections/demographic-analysis-demog/
Household and Housing Census		Statistics Sweden	https://www.scb.se/en/finding-statistics/statistics-by-subject-area/population/population-size-and-changes/household-and-housing-census/
BIRTH cohort			
All Babies in Southeast Sweden (ABIS)			http://www.birthcohorts.net/
Children (Barn), Allergy, Milieu, Stockholm, Epidemiological study (BAMSE)			http://www.birthcohorts.net/
Human Fertility at Risk from Biopersistent Organochlorines in the Environments			http://www.birthcohorts.net/
EXPRESS Extremely Preterm Infants in Sweden Study			http://express-study.se/english/
Uppstart (Uppsala Stockholm Assisted reproductive techniques)			https://ki.se/meb/uppstart

study

MAESTRO-study	https://ki.se/meb/maestro-maternal-asthma-events-stress-and-offspring
BASIC-study and BASIC_CHILD	https://www.basicstudie.se/
Uppsala family study	https://snd.gu.se/en/catalogue/study/EXT0175
U-birth	http://www.kbh.uu.se/forskning/obstetrisk-och-reproduktiv-halsoforskning/huvudforskningsomraden-och-projekt/#anchor-769822
Pan-European cohorts/databases/networks which contain data from Sweden	Website
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/search.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/search.htm
European Register for Multiple Sclerosis (EUREMS)	http://www.encepp.eu/encepp/search.htm
Association of the Nordic Cancer Registries (ANCR)	http://www.ancr.nu/
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/search.htm

European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/search.htm

Switzerland Error! Bookmark not defined.

Data source name	Native name	Data provider	Website
Healthcare databases - Adverse drug reaction databases			
Swiss national ADR database			https://www.swissmedic.ch/swissmedic/en/home/humanarzneimittel/market-surveillance/pharmacovigilance/vigilance-system.html
Teratology Information Services			
Swiss teratogen Information Service			http://www.swisstis.ch/
Birth cohort			
Helsana pregnancy cohort - PregMED (in development)			
Pan-European cohorts/databases/networks which contain data from Switzerland			Website
COST Action BM1105 Patient Registry - GnRH Network (COST-GnRH gonadotropin-releasing hormone deficiency)			http://www.encepp.eu/encepp/search.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)			http://www.encepp.eu/encepp/search.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)			http://www.encepp.eu/encepp/search.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)			http://www.encepp.eu/encepp/search.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)			http://www.encepp.eu/encepp/search.htm
European registry and network for intoxication type metabolic diseases (E-MID)			http://www.encepp.eu/encepp/search.htm
European Database for Multiple Sclerosis (EDMUS)			http://www.encepp.eu/encepp/search.htm
European Society for Immunodeficiencies (ESID)			http://www.encepp.eu/encepp/search.htm

European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/search.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/search.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/search.htm
EUROmediCAT central database	http://www.encepp.eu/encepp/search.htm
EudraVigilance	http://www.encepp.eu/encepp/search.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/search.htm
The European Clarkson's syndrome registry - EurêClark registry-Systemic Capillary Leak Syndrom	http://www.encepp.eu/encepp/search.htm
Galactosemia Patient Registry (GalNet)	http://www.encepp.eu/encepp/search.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/search.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/search.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/search.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/search.htm
European Health Interview Survey (EHIS)	http://ec.europa.eu

UK

Data source name	Native name	Data provider	Website
Registers			
British and Irish Network of Congenital Anomaly Research Database (BINOCARD)		British and Irish Network of Congenital Anomaly Researchers (BINOCAR)	www.binocar.org
Clinical Practice Research Datalink (CPRD) (previously General Practice Research Database (GPRD))		Clinical Practice Research Datalink (CPRD)	https://www.cprd.com
Children Looked After		Department for Education	https://webarchive.nationalarchives.gov.uk/20130903115319/http://education.gov.uk/researchandstatistics/stats/childrenlar
Children in need		Department for Education	https://data.gov.uk/dataset/aec05775-9db9-441a-88a7-8bac80578150/children-in-need
NHS Business Services Authority (NHSBSA) prescribing data		NHS Business Services Authority	https://www.nhsbsa.nhs.uk/
Prescription Cost Analysis (PCA)		NHS Digital	https://digital.nhs.uk/data-and-information/publications/statistical/prescription-cost-analysis
NHS Information Centre		NHS DIGITAL (previously HSCIC)	www.digital.nhs.uk
Hospital Episode Statistics (HES)		NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics
Data Access Request Service (DARS)		NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/services/data-access-request-service-dars#section-1

Community Services Data Set (CSDS)	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/children-and-young-people-s-health-services-data-set#how-can-i-make-an-enquiry-or-provide-feedback
Emergency Care Data Set	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/emergency-care-data-set-ecds
Maternity and Children's Data Set	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/maternity-and-children-s-data-set
Critical Care Minimum Data Set	NHS DIGITAL (previously HSCIC)	https://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/data_sets/critical_care_minimum_data_set_fr.asp?shownav=1
Maternity Services Data Set	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/maternity-services-data-set
Mental Health Services Data Set	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set
Neonatal Critical Care Minimum Data Set	NHS DIGITAL (previously HSCIC)	https://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/data_sets/neonatal_critical_care_minimum_data_set_fr.asp?shownav=1

Paediatric Critical Care Minimum Data Set	NHS DIGITAL (previously HSCIC)	https://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/data_sets/paediatric_critical_care_minimum_data_set_fr.asp?shownav=1
Statistics	NHS England	https://www.england.nhs.uk/
MBRRACE-UK data collection for stillbirths, perinatal and neonatal deaths	National Perinatal Epidemiology Unit (NPEU)	https://www.npeu.ox.ac.uk/
UK Obstetric Surveillance System (UKOSS)	National Perinatal Epidemiology Unit (NPEU)	https://www.npeu.ox.ac.uk/ukoss
National databases; Screening programmes; DATA.GOV.UK Beta	GOV.UK	https://data.gov.uk
National Pupil Database	Department for Education	https://www.gov.uk/government/collections/national-pupil-database
National Congenital Anomaly and Rare Disease Registration Service (NCARDS)	Public Health England (PHE)	https://www.gov.uk/guidance/the-national-congenital-anomaly-and-rare-disease-registration-service-ncards
PHE data and analysis tools	Public Health England (PHE)	https://www.gov.uk/guidance/phe-data-and-analysis-tools#about-this-resource
Child and Maternal Health Observatory (ChiMat)	Public Health England (PHE)	https://www.gov.uk/guidance/child-and-maternal-health-data-and-intelligence-a-guide-for-health-professionals
Dental Public Health Intelligence Programme	Public Health England (PHE)	http://www.nwph.net/dentalhealth
Q RESEARCH Database	Q RESEARCH	http://www.qresearch.org/
ResearchOne database	ResearchOne	http://www.researchone.org/
United Kingdom and Ireland Association of Cancer Registries	United Kingdom and Ireland Association of Cancer Registries	http://www.ukiacr.org/

National Registry of Childhood Tumours (NRCT)	Childhood Cancer Research Group	http://www.ccrq.ox.ac.uk/datasets/nrct.shtml
Cleft Registry and Audit NETwork (CRANE) Database	Cleft Registry and Audit NETwork (CRANE)	https://www.crane-database.org.uk/?!.id=etX
Secure Anonymised Information Linkage Databank (SAIL)	Swansea University Medical School	www.saildatabank.com
Congenital Anomaly Register and Information Service (CARIS)	Secure Anonymised Information Linkage Databank (SAIL)	https://saildatabank.com/saildata/sail-datasets/congenital-anomaly-register-and-information-service-caris/
The Health Improvement Network (THIN)	IMS Health Ltd	https://www.iqvia.com/
Juvenile Idiopathic Arthritis Register OR Etanercept registry	British Society for Rheumatology/ The University of Manchester	https://www.rheumatology.org.uk/practice-quality/registers/juvenile-idiopathic-arthritis
IMS - Hospital Treatment Insights - UK	IMS Health	https://www.iqvia.com/
Optimum Patient Care Research Database (OPCRD)	Optimum Patient Care	http://optimumpatientcare.org/
UK Renal Registry (UKRR)	Southmead Hospital	https://www.renalreg.org/
The electronic Data Research and Innovation Service (eDRIS)	ISD Scotland	http://www.isdscotland.org/Products-and-Services/EDRIS/
Prescribing Information System (PIS)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=9
Maternity hospital discharge records (including delivery records) SMR02	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=6
Carstairs and Morris Deprivation Index	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=100
Child Health Systems Programme - Pre-School (CHSP Pre-School)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=10
Child Health Systems Programme -	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/Natio

School (CHSP School)		nal-Datasets/data.asp?SubID=11
General Acute Inpatient and Day Case - Scottish Morbidity Record (SMR01)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=5
Mental Health Inpatient and Day Case - Scottish Morbidity Record (SMR04)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=7
MS Audit	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=112
Outpatient Appointments and Attendances - Scottish Morbidity Record (SMR00)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=4
Scottish Birth Record (SBR)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=2
Scottish Cancer Registry (SMR06)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=8
Scottish Health Survey (SHeS)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=78
NHS Central Register (NHSCR)	ISD Scotland/eDRIS	https://www.nrscotland.gov.uk/statistics-and-data/nhs-central-register
NRS Births, Stillbirths and Infant Deaths	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=65
National Records of Scotland (NRS) - Deaths Data	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=13
Scottish Stillbirth and Infant Death Survey (SSBID)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=82
Support Needs System (SNS)	ISD Scotland/eDRIS	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=86
Achievement of Curriculum for Excellence Levels	Scottish Exchange of Data (ScotXed)/Education Analytical Services (EAS) Division of the Scottish Government	https://www2.gov.scot/Topics/Statistics/ScotXed/SchoolEducation/CFELevels

School education	Scottish Exchange of Data (ScotXed)/Education Analytical Services (EAS) Division of the Scottish Government	https://www2.gov.scot/Topics/Statistics/Browse/School-Education
Scottish Health Informatics Programme (SHIP)	Farr Institute of Health Informatics Research	http://www.farrinstitute.org/
Lambeth DataNet	King's College London	https://www.kcl.ac.uk/index.aspx
Manchester Asthma and Allergy Study Database (MAAS)	University of Manchester	http://www.maas.org.uk
UK Case Record Interactive Search (UK-CRIS)	CHRIS Network	https://crisnetwork.co
Statistics; Datasets; Surveys	Office of National Statistics (ONS)	https://www.ons.gov.uk
Office of National Statistics (ONS) Death register	Office of National Statistics (ONS)	https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths
Office of National Statistics (ONS) Birth register	Office of National Statistics (ONS)	https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths
Children's well-being and social relationships, UK: 2018	Office of National Statistics (ONS)	https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuringnationalwellbeing/march2018
UK Children's Well-being Measures	Office of National Statistics (ONS)	https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/childrenswellbeingmeasures
NICOR-National Institute for Cardiovascular Outcomes Research	NICOR: NATIONAL INSTITUTE FOR CARDIOVASCULAR OUTCOMES RESEARCH NATIONAL CONGENITAL HEART DISEASE AUDIT WEBSITE	https://nicor4.nicor.org.uk/chd/an_paednsf/vwcontent/home
RCGP Database	Royal College of General Practitioners (RCGP) Research and	http://www.rcgp.org.uk/clinical-and-research/our-

	Surveillance Centre (RSC)	programmes/research-and-surveillance-centre.aspx
National Health Surveys; Longitudinal studies; Administrative data	UK Data Service	https://www.ukdataservice.ac.uk
Datasets	OpenDataNI	https://www.opendatani.gov.uk
Enhanced Prescribing Database (EPD)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/
Northern Ireland Maternity Information System (NIMATS)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2454.htm
Northern Ireland Cancer Registry	Queen's University Belfast	http://www.qub.ac.uk/research-centres/nicr/
UK and Ireland Epilepsy and Pregnancy Register	UK and Ireland Epilepsy and Pregnancy Register	http://www.epilepsyandpregnancy.co.uk/
Information Services Division (ISD)	NHS Wales Informatics Service	http://www.infoandstats.wales.nhs.uk/home.cfm?orgid=869
Patient Episode Database for Wales	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	http://www.infoandstats.wales.nhs.uk/page.cfm?orgid=869&pid=40977
Welsh Longitudinal GP Dataset	SAIL Databank	www.saildatabank.com
National Community Child Health Database	SAIL Databank	www.saildatabank.com / http://www.publichealthwalesobservatory.wales.nhs.uk/ncchd
Brecon Cohort (Welsh Register of children with type 1 diabetes)	SAIL Databank	www.saildatabank.com / http://www.publichealthwalesobservatory.wales.nhs.uk/wdshttp://www.publichealthwalesobservatory.wales.nhs.uk/ncchd
Welsh Demographic Service	SAIL Databank	https://nwis.nhs.wales (can't find the specific page)
Welsh Results Reporting Service	SAIL Databank	

Annual District Birth Extract (ADBE)	SAIL Databank (anonymised, linked) / also can apply directly to the Office for National Statistics (ONS)	www.saildatabank.com or https://www.ons.gov.uk/aboutus/watwedo/paidservices/virtualmicrodatalaboratoryvml
Outpatient Dataset (OPD)	SAIL Databank	https://saildatabank.com/saildata/sail-datasets/outpatient-dataset-opd/
Annual District Death Extract (ADDE)	SAIL Databank (anonymised, linked) / also can apply directly to the Office for National Statistics (ONS)	https://saildatabank.com/saildata/sail-datasets/annual-district-death-extract-adde/
Primary Care GP dataset	SAIL Databank	https://saildatabank.com/saildata/sail-datasets/primary-care-gp-dataset/
Education Attainment	SAIL Databank	https://saildatabank.com/saildata/sail-datasets/education-attainment/
Welsh Cancer Intelligence and Surveillance Unit (WCISU)	SAIL Databank	https://saildatabank.com/saildata/sail-datasets/welsh-cancer-intelligence-and-surveillance-unit-wcisu/
ONS births in Wales	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	www.saildatabank.com or https://www.ons.gov.uk/aboutus/watwedo/paidservices/virtualmicrodatalaboratoryvml
Hospital Information System (HIS) OR Hospital Statistics	Department of Health	https://www.health-ni.gov.uk/
Clinical Effectiveness Group East London Database	Centre for Primary Care and Public Health. Queen Mary University of London	https://www.qmul.ac.uk/blizard/research/centres/centre-for-primary-care-and-public-health/
Aberdeen Maternity and Neonatal Databank (AMND)	University of Aberdeen	https://www.abdn.ac.uk/iahs/research/obsgynaec/amnd/index.php
Scottish Health Informatics Centre (HIC) Services	University of Dundee	https://www.dundee.ac.uk/

Scottish Longitudinal Study	University of Edinburgh	https://sls.lscs.ac.uk/
EURAP UK - EURAP Scotland	European Registry of Antiepileptic Drugs and Pregnancy (EURAP)	http://www.eurapinternational.org/
The Cleft Collective	University of Bristol	http://www.bristol.ac.uk/dental/cleft-collective/professionals/access/
National Maternity and Perinatal Audit	Royal College of Obstetricians and Gynaecologists	https://maternityaudit.org.uk/pages/home
Northern Ireland Longitudinal Study	Queens University Belfast	https://www.qub.ac.uk/research-centres/NILSResearchSupportUnit/
NHS England Maternity Services Data Set (MSDS)	NHS Digital	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/maternity-services-data-set
The National Neonatal Research database (NNRD)	The Neonatal Data Analysis Unit, Imperial College London	https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data/
Human Fertilisation and Embryology Authority (HFEA) Register	HFEA	https://www.hfea.gov.uk/about-us/our-data/

Paediatric Critical Care Minimum dataset (PCCMDS)	Healthcare Quality Improvement Partnership	https://www.datadictionary.nhs.uk/data_dictionary/messages/supporting_data_sets/data_sets/paediatric_critical_care_minimum_data_set_fr.asp?shownav=1
UK Teratology Information Service	Public Health England (PHE)	http://www.uktis.org/
Admitted Patient Care Data Set (APCs)	NHS Wales Informatics Service	http://www.datadictionary.wales.nhs.uk/index.html#!WordDocuments/admittedpatientcaredatasetapcds.htm
Substance Misuse Data Set	NHS Wales Informatics Service	http://www.datadictionary.wales.nhs.uk/index.html#!WordDocuments/substancemisusedatasmids.htm
Radiotherapy Data Set	NHS Wales Informatics Service	http://www.datadictionary.wales.nhs.uk/index.html#!WordDocuments/radiotherapydatasetrtds.htm
Maternity Indicators Data Set	NHS Wales Informatics Service	http://www.datadictionary.wales.nhs.uk/index.html#!WordDocuments/maternityindicatorsdatasetmids.htm
National Data Set for Sexual Health in Wales	NHS Wales Informatics Service	http://www.datadictionary.wales.nhs.uk/index.html#!WordDocuments/nationaldatasetforsexualhealthinwales.htm
Child health surveillance data (CHSP)	SAIL Databank	http://www.datadictionary.wales.nhs.uk/#!WordDocuments/ncchdoperationalextract.htm
Prescribing Information System (PIS)	NHS Wales Shared Services	http://www.primarycareservices.wales.nhs.uk/general-practice-

National Community Child Health Database/Community Child Health 2000	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	www.saildatabank.com / http://www.publichealthwalesobservatory.wales.nhs.uk/ncchd
Emergency Department Data Set (EDDS)	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	https://saildatabank.com/saildata/sail-datasets/emergency-department/
Outpatient Referral	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	https://saildatabank.com/saildata/sail-datasets/outpatient-referral/
Critical Care Dataset	SAIL Databank (anonymised, linked) / also can apply directly to NHS Wales Informatics Service	https://saildatabank.com/saildata/sail-datasets/critical-care-dataset/
Patient Administration System (PAS)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2512.htm
Emergency Department Systems - NIRAES/eEmes (South Eastern and Southern Trusts)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2512.htm
Emergency Department Systems - Symphony (Belfast, Northern and Western Trusts)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2512.htm
GP Patient Registrations Index	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2512.htm
Consumer Data Research Centre Datasets	Consumer Data Research Centre	https://www.cdrc.ac.uk/data-services/cdrcdata/
Birth cohort		

Births and their outcomes by time, day and year: a retrospective birth cohort data linkage study	Professor Alison Macfarlane, A.J.Macfarlane@city.ac.uk, M104, Myddelton Street Building, City, University of London (permission given to J. Given [email dated 07/01/2020] to include contact details in inventory)	
Growing up in Scotland (GUS)	Growing up in Scotland (GUS)	https://growingupinscotland.org.uk/
Avon Longitudinal Study of Parents & Children/Children of the 90s (ALSPAC)	University of Bristol	http://www.bristol.ac.uk/alspac/researchers/our-data/
Born in Bradford (BIB)	Born in Bradford (BIB)	http://www.birthcohorts.net/
Gateshead Millennium Study (GMS)	Newcastle University	http://www.birthcohorts.net/
Leicester Respiratory Cohorts (LRC)	University of Leicester	http://www.birthcohorts.net/
Southampton Women's Survey (SWS)	Medical Research Council/University of Southampton	http://www.birthcohorts.net/
Study of eczema and asthma to observe the effects of nutrition (SEATON)	University of Aberdeen	http://www.birthcohorts.net/
Millennium Cohort Study	University College London	https://cls.ucl.ac.uk/cls-studies/millennium-cohort-study/
National study of HIV in Pregnancy and Childhood (NSHPC)	University College London	https://www.ucl.ac.uk/nshpc/about-nshpc
ROOTS Cohort	Department of Psychiatry, School of Clinical Medicine (University of Cambridge)	http://www.medschl.cam.ac.uk/
Pan-European cohorts/databases/networks which contain data from the United Kingdom		Website
COST Action BM1105 Patient Registry - GnRH Network (COST-GnRH gonadotropin-releasing hormone deficiency)		http://www.encepp.eu/encepp/research.htm

European Management Platform for Childhood Interstitial Lung Diseases (ChILD-EU - Children Interstitial lung diseases)	http://www.encepp.eu/encepp/earch.htm
Central data registry of the European Competence Network on Mastocytosis (ECMN-Mastocytosis)	http://www.encepp.eu/encepp/earch.htm
European prospective cohort on thrombophilia (EPCOT - Blood disorders)	http://www.encepp.eu/encepp/earch.htm
European central hypoventilation syndrome registry (EU-CHS - Central Hypoventilation Syndromes)	http://www.encepp.eu/encepp/earch.htm
European Haemophilia Safety Surveillance System (EUHASS - Blood disorders)	http://www.encepp.eu/encepp/earch.htm
UK & Ireland Duchenne and Becker muscular dystrophy patient registry (part of the TREAT-NMD network) (UK & Ireland Duchenne and Becker)	http://www.encepp.eu/encepp/earch.htm
UK and Ireland Spinal Muscular Atrophy Patient Registry (part of the TREAT-NMD network) (UK SMA Patient Registry)	http://www.encepp.eu/encepp/earch.htm
European Network and Registry for Homocystinurias and Methylation Defects (E-HOD)	http://www.encepp.eu/encepp/earch.htm
European registry and network for intoxication type metabolic diseases (E-MID)	http://www.encepp.eu/encepp/earch.htm
European Cystic Fibrosis Society Patient Registry (ECFSPR)	http://www.encepp.eu/encepp/earch.htm
European Database for Multiple Sclerosis (EDMUS)	http://www.encepp.eu/encepp/earch.htm
European Society for Immunodeficiencies (ESID)	http://www.encepp.eu/encepp/earch.htm
European Registry for Children on Renal Replacement Therapy (ESPN/ERA-EDTA - Children Renal Replacement Therapy)	http://www.encepp.eu/encepp/earch.htm
European Surveillance of Congenital Anomalies (EUROCAT)	http://www.encepp.eu/encepp/earch.htm
European registry for autoinflammatory diseases (EUROFEVER - Autoinflammatory diseases)	http://www.encepp.eu/encepp/earch.htm

	earch.htm
European Registry of Patients with McArdle Disease or other rare form of muscle Glycogenoses (EUROMAC)	http://www.encepp.eu/encepp/earch.htm
European patient registry on TRAPS syndrome (EUOTRAPS - Autoinflammatory diseases)	http://www.encepp.eu/encepp/earch.htm
EUROmedicAT central database	http://www.encepp.eu/encepp/earch.htm
EudraVigilance	http://www.encepp.eu/encepp/earch.htm
An EU Rare Diseases Registry for Wolfram syndrome, Alström syndrome, Bardet-Biedl syndrome and other rare diabetes syndromes (Euro WABB)	http://www.encepp.eu/encepp/earch.htm
European registry of alveolar echinococcosis (EURECHINOREG)	http://www.encepp.eu/encepp/earch.htm
International Niemann Pick Disease Registry (INPDR)	http://www.encepp.eu/encepp/earch.htm
MediGuard.org	http://www.encepp.eu/encepp/earch.htm
PedNet Haemophilia Research Foundation (PedNet)	http://www.encepp.eu/encepp/earch.htm
Rare Bleeding Disorders Network (RBD Network - Blood disorders and rare diseases)	http://www.encepp.eu/encepp/earch.htm
RD-Connect - Patient registries integrated platform (RD-Connect)	http://www.encepp.eu/encepp/earch.htm
Translational Research in Europe - Assessment and Treatment of Neuromuscular Diseases (TREAT-NMD)	http://www.encepp.eu/encepp/earch.htm
COLLECT Database	https://pregnancycolab.tghn.org/collect/
Global Pregnancy Collaboration (CoLab)	

Appendix 6: Data sources which contain breastfeeding data

Data source name	Native name	Data provider	Website
Finland			
Medical Birth Register	Syntyneiden lasten rekisteri	National Institute for Health and Welfare (THL)	https://www.thl.fi/en/web/thlfi-en/statistics/information-on-statistics/register-descriptions/newborns
France			
EFEMERIS (Evaluation in Pregnant Women of Medicaments and their RISK)	EFEMERIS (Evaluation chez la Femme Enceinte des Medicaments et de leurs RISques)	Pharmacoepidemiology INSERM 1027	http://www.u1027.inserm.fr/
Italy			
Survey on maternity pathway in Tuscany	Indagine sul percorso nascita in Toscana	Laboratory Management and Healthcare of the Sant' Anna School of Advanced Studies in Pisa	https://indagini.santannapisa.it/percorsonascita/view/form_login.php
Emilia-Romagna paediatric immunisation database		Regional Health Authority of Emilia-Romagna	https://www.cambridge.org/core/journals/public-health-nutrition/article/regular-monitoring-of-breastfeeding-rates-feasible-and-sustainable-the-emiliaromagna-experience/1F87D5B3F137761FC33A750A76BCC248
Netherlands			
pREGnant OR Dutch Pregnancy Drug Register	pREGnant	Lareb (Teratologie Informatie Service)	https://www.zonmw.nl/nl/over-zonmw/innovatie-in-de-zorg/programmas/project-detail/goed-gebruik-

Lifelines cohort study and biobank		Lifelines	geneesmiddelen/the-pregnancy-drug-register-development-and-implementation/verslagen/ https://www.lifelines.nl/
Norway			
Norwegian Mother and Child Cohort/MoBA Cohort and Biobank			https://www.fhi.no/en/studies/moba/
Spain			
Information System for Research in Primary Care (SIDIAP)	Sistema d'Informació pel Desenvolupament de la Investigació a l'Atenció Primària	The Catalan Health Institute (ICS)	http://www.sidiap.org/
INMA-Environment and Childhood Project (INMA Project)	INMA – Infancia y Medio Ambiente	INMA project	http://www.proyectoinma.org/cohort/sabadell/eu_resultats-sabadell.html?PAGE=1&thematic=73
Sweden			
Pregnancy Registry	Graviditetsregistret	National Quality Registers (part of Socialstyrelsen)	https://www.medscinet.com/GR/english.aspx
Swedish Neonatal Quality (SNQ)	Svenskt Neonatalt Kvalitetsregister (SNQ)	National Quality Registers (part of Socialstyrelsen)	http://kvalitetsregister.se/englishpages/findaregistry/registerarkivenglish/nationalqualityregistryforneonatalcaresnq.2191.html
National Quality Registry for Child Preventative Health (BHVQ) OR Swedish Child Health Registry	Svenska barnhälsovårdsregistret	National Quality Registers (NATIONELLA KVALITETSREGISTER)	http://bhvq.se/
United kingdom			
National Community Child Health Database	Secure Anonymised Information Linkage Databank (SAIL)	Swansea University Medical School	www.saildatabank.com / http://www.publichealthwalesobservatory.wales.nhs.uk/ncchd

Avon Longitudinal Study of Parents & Children/Children of the 90s (ALSPAC)	University of Bristol	http://www.birthcohorts.net/
Millennium Cohort Study		https://www.cls.ioe.ac.uk/page.aspx?sitesectionid=851
Community Services Data Set (CSDS)	NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/children-and-young-people-s-health-services-data-set#how-can-i-make-an-enquiry-or-provide-feedback-
The National Neonatal Research database (NNRD)	The Neonatal Data Analysis Unit, Imperial College London	https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data/
Northern Ireland Maternity Information System (NIMATS)	Business Services Organisation (BSO) Honest Broker Service	http://www.hscbusiness.hscni.net/services/2454.htm
Child Health Systems Programme Pre-School system (CHSP Pre-School)	ISD Scotland	https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=10

Appendix 7: Databases which contain neurodevelopmental outcomes

Data source name(s)	Native name	Data provider	Website
Bulgaria			
Registers			
Kindergartens (pre-primary education)	Детски градини (предучилищно образование)	National Statistical Institute	http://www.nsi.bg/bg/node/3414
Denmark			
Registers			
Aarhus Birth Cohort Denmark		Pedersen Aarhus University LHP@dadlnet.dk	http://fetotox.au.dk/the-fetotox-birth-cohorts/aarhus-birth-cohort-biobank-abcb/
Danish Medical Birth Registry/ Danish Fertility Database/	Nationale Sundheds Register	Statistics Denmark and the Danish Health Data Authority.	www.esundhed.dk/sundhedsregistre/MFR
National Patient Registry and Danish Registry of Causes of Death			-
ADHD Database	ADHD Databasen	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/adhd-databasen/sundhedsdatastyrelsen.dk/da
Danish Register for Young People with Acquired Brain Injury	Dansk Register for Unge med Erhvervet hjerneskade	Clinical Quality Development Program (RKKP)	http://www.rkkp.dk/om-rkkp/de-kliniske-kvalitetsdatabaser/ikke-stottede-databaser/dansk-register-for-unge-med-erhvervet-hjerneskade/
Danish Education Registers	Uddannelsesregistre	The Danish National Centre for Social Research vmj@sfi.dk	
Danish Psychiatric Central Register (DPCR)/The Danish Psychiatric Central Research Register	Det Psykiatriske Centralregister	The National Board of Health is authority of data. Centre for Psychiatric Research, Aarhus University Risskov Denmark	(http://psykiatriskforskning.dk/registre/1/

Danish National Patient Registry	Landspatientregisteret	Health Data Agency	https://sundhedsdatastyrelsen.dk/da/registre-og-services/om-de-nationale-sundhedsregistre
Birth cohort			
Denmark/ National Health Services in North Jutland Country			-
Healthy Habits for two (HHf2)		The Danish Epidemiology Science Centre: Jørn Olsen, PI	http://www.birthcohorts.net/
Copenhagen Child Cohort 2000 (CCC2000)		Civil Registration System, Danish National registries, public health nurses	http://www.birthcohorts.net/
Odense Child Cohort	OCC	Odense Childrens Hospital Steffen Husby steffen.husby@rsyd.dk	http://www.birthcohorts.net/
Finland			
Registers			
Finland National registries		National Registries	
Finish Register-Based Study (FinESSI)		Helsinki University Central Hospital	
Prediction and Prevention of Preeclampsia and Intrauterine Growth Restriction (PREDO)			
Upper Secondary General School Education	Lukiokoulutus	Statistics Finland (part of OSF)	http://www.stat.fi/til/lop/index_en.html
Discontinuation of Education	Koulutuksen keskeyttäminen	Statistics Finland (part of OSF)	http://www.stat.fi/til/kkesk/index_en.html
Finnish Hospital Discharge Register (FHDR)			-
Birth cohort			
FinnBrain Birth Cohort Study (FinnBrain)		hasse.karlsson@utu.fi	http://www.birthcohorts.net/ www.finnbrain.fi

PLASTICITY - life long follow-up of cognitive ability after birth risks (Plasticity)	Perinatal Adverse events and Special Trends In Cognitive Trajectory	Birth Cohort Helsinki	http://www.birthcohorts.net/
Northern Finland birth cohort of 1966		Department of Public Health Science Oulu Finland	
France			
Register			
Central Education Foundation - 2017	Base Centrale Scolarité (BCS) - 2017	Institute for Research and Documentation in Health Economics (IRDES) - Institut de Recherche et de Documentation en Economie de la Santé (IRDES)	https://www.cmh.ens.fr/greco/enquetes/XML/lil.php?lil=1199
Birth cohort			
EDEN - Study on the pre and early postnatal determinants of child health and development			http://www.birthcohorts.net
Endocrine disruptors: Longitudinal study on pregnancy abnormalities, infertility, and childhood (PÉLAGIE)			http://www.birthcohorts.net
EPIPAGE 2 Cohort Study			https://epipage2.inserm.fr/index.php/en/
EFEMERIS (Evaluation in Pregnant Women of Medicaments and their RISK)			http://www.u1027.inserm.fr/
Germany			
Registers			
German Pharmacoepidemiological Research Database (GePaRD)	Leibniz-Institut für Präventionsforschung und Epidemiologie, Bremen	Leibniz Institute for Prevention Research and Epidemiology (BIPS)	https://www.bips-institut.de/en/home.html
Birth cohort			
Influence of life-style factors on the development of the immune system	Influences of Lifestyle-Related Factors on the Immune System and the Development of	Contact person for the cohort: Dr. Joachim Heinrich (heinrich(at)helmholtz-	http://www.birthcohorts.net https://www.lisastudie.de/

and allergies in East and West Germany (LISA PLUS)	Allergies in Childhood plus Air Pollution and Genetics	muenchen.de), Helmholtz Zentrum München, Institute of Epidemiology I.	
Childhood Obesity - Early Programming by Infant Nutrition (CHOPIN)		LUDWIG-MAXIMILIANS UNIVERSITY OF MUNICH Lindwurmstrasse 4 80337 Muenchen	http://www.birthcohorts.net
LIFE Child		the Research Center for Civilization Diseases in Leipzig	http://www.birthcohorts.net
Greece			
Birth cohort			
Mother Child Cohort in Crete (RHEA)			http://www.birthcohorts.net/
Ireland			
Registers			
Primary Online Database (POD)		Department of Education and Skills (DES)	https://www.education.ie/en/Publications/Statistics/Primary-Online-Database-POD-/
National Physical and Sensory Disability Database (NPSDD)			
National Ability Supports System		Health Research Board (HRB)	http://www.hrb.ie/ https://www.hrb.ie/fileadmin/2. Plugin_related_files/Publications/2019_Publication_files/2019_HIE/NASS/NASS_data_collection_form.pdf
National Intellectual Disability Database (NIID)		Health Research Board (HRB)	http://www.hrb.ie/
Birth cohort			
Babies After SCOPE: Evaluating the Longitudinal Impact using Neurological and Nutritional Endpoints (BASELINE)		PI: Louise C Kenny, Irish Centre for Fetal and Neonatal Translational Research and Department of Obstetrics and	http://www.birthcohorts.net/

		Gynaecology, University College Cork, Ireland,	
Italy			
Birth cohort			
Multiple Births Cohort Study (MUBICOS)			http://www.birthcohorts.net/
Piccolipiù			http://www.birthcohorts.net/
Netherlands			
Birth cohort			
Amsterdam Born Children and their Development (ABCD)		Collaboration between the Public Health Service of Amsterdam and Academic Medical Center and VU University Medical Center	http://www.birthcohorts.net ; www.abcd-study.net
KOALA Birth Cohort Study (KOALA)	Child, Parent and Health Lifestyle and Genetic Constitution	Maastricht University	http://www.birthcohorts.net
PRegnancy and Infant DEvelopment Study (PRIDE Study)			http://www.birthcohorts.net ; www.pridestudy.nl
Generation R			http://www.birthcohorts.net
Generation R Next			https://generationr.nl/next/
GECKO Drenthe cohort (GECKO Drenthe)		University Medical Center Groningen	http://www.birthcohorts.net
Tracking Adolescents' Individual Lives Survey (TRAILS) NEXT		University of Groningen (RuG)	https://www.trails.nl/
YOUth Cohort study		University of Utrecht	https://www.uu.nl/en/research/youth-cohort-study
Observational study Amsterdam Hospital		Amsterdam Hospital	-
Dutch Smok Study (SSRI in pregnant Mothers, Outcome of the Kids)		Medical Centre Leeuwarden and Wilhelmina Hospital Assen	-

Norway			
Population-based record linkage surveillance system			
National Education Database NUDB.	Nasjonal utdanningsdatabase NUDB	Statistics Norway	https://www.ssb.no/utdanning/artikler-og-publikasjoner/nasjonal-utdanningsdatabase-nudb
Birth cohort			
Norwegian Mother and Child Cohort/MoBA Cohort and Biobank		Norwegian Institute of Public Health (NIPH) collaboration with hospitals in Norway	https://www.fhi.no/en/studies/moba/
Norwegian Twin registry	Nasjonalt tvillingregister	Norwegian Institute of Public Health (NIPH)	https://www.fhi.no/en/more/health-studies/norwegian-twin-registry/
Poland			
Birth cohort			
Polish Mother and Child Cohort Study		Prof. Wojciech Hanke Kinga Polanska PhD Nofer Institute of Occupational Medicine Department of Environmental Epidemiology Teresy 8 St. 91-348 Lodz, Poland	http://www.birthcohorts.net
Portugal			
Registers			
MINISTRY OF EDUCATION - Direção-Geral da Educação (DGE) and Direção Geral das Estatísticas da Educação e Ciência	Direção Geral das Estatísticas da Educação e Ciência	Directorate-General for Health (Direcção-Geral da Saúde (DGS))	https://www.dgs.pt/
Slovakia			
Birth cohort			
Slovak PCB study			http://www.birthcohorts.net/

Spain			
Birth cohort			
INMA-Environment and Childhood Project (INMA Project)	Infancia y Medio Ambiente	7 regiones of Spain population	http://www.birthcohorts.net/
NELA - Nutrition in Early Life and Asthma (NELA)			http://www.birthcohorts.net/
United Kingdom			
Registers			
National Pupil Database		Department for Education	https://www.gov.uk/government/collections/national-pupil-database
Education Attainment		SAIL Databank	https://saildatabank.com/saildata/sail-datasets/education-attainment/
National Community Child Health Database		SAIL Databank	www.saildatabank.com / http://www.publichealthwalesobservatory.wales.nhs.uk/ncchd
ResearchOne database		ResearchOne	http://www.researchone.org/
NHS Digital Child Health Initiative (https://digital.nhs.uk/services/digital-child-health) - this is being developed now (thus not currently useable) so not sure if you want to include			
Child Health Systems Programme - Pre-School (CHSP Pre-School)	ISD Scotland/eDRIS		https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=10
Child Health Systems Programme - School (CHSP School)	ISD Scotland/eDRIS		https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=11
Support Needs System (SNS)	ISD Scotland/eDRIS		https://www.ndc.scot.nhs.uk/National-Datasets/data.asp?SubID=86

Achievement of Curriculum for Excellence Levels	Scottish Exchange of Data (ScotXed)/Education Analytical Services (EAS) Division of the Scottish Government	https://www2.gov.scot/Topics/Statistics/ScotXed/SchoolEducation/CfELevels	
School education	Scottish Exchange of Data (ScotXed)/Education Analytical Services (EAS) Division of the Scottish Government	https://www2.gov.scot/Topics/Statistics/Browse/School-Education	
Community Services Data Set (CSDS)		NHS DIGITAL (previously HSCIC)	https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/children-and-young-people-s-health-services-data-set#how-can-i-make-an-enquiry-or-provide-feedback-
The National Neonatal Research database (NNRD)		The Neonatal Data Analysis Unit, Imperial College London	https://www.imperial.ac.uk/neonatal-data-analysis-unit/neonatal-data/
Birth cohort			
Avon Longitudinal Study of Parents & Children/Children of the 90s (ALSPAC)			http://www.birthcohorts.net/
Born in Bradford (BIB)			http://www.birthcohorts.net/
Southampton Women's Survey (SWS)			http://www.birthcohorts.net/
Millennium Cohort Study			https://www.cls.ioe.ac.uk/page.aspx?sitectionid=851
Growing up in Scotland (GUS)		Growing up in Scotland (GUS)	https://growingupinScotland.org.uk/