Actionable Real-world evidence network

First published: 01/02/2024

Last updated: 17/10/2024

Data source · Human · Administrative healthcare records (e.g., claims)

Disease registry · Pharmacy dispensing records

Administrative details

Administrative details

Data source ID

1111119

Data source acronym

ARWEN

Data holder

LOGEX Life Sciences

Data source type

Administrative healthcare records (e.g., claims)

Disease registry

Pharmacy dispensing records

Main financial support

Funding from industry or contract research

National, regional, or municipal public funding

Care setting

Hospital inpatient care

Hospital outpatient care

Secondary care – specialist level (ambulatory)

Data source qualification

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

Yes

Description of the qualification

ISO

Contact details

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Data source regions and languages

Data source countries

Netherlands

Spain

United Kingdom

Data source languages

Dutch

English

Spanish

Data source establishment

Data source established

15/06/2022

Data source time span

First collection: 01/01/2017

The date when data started to be collected or extracted.

Data elements collected

The data source contains the following information

Disease information

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

No

Rare diseases

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

No

Pregnancy and/or neonates

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

No

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

RxNorm

Dispensing of medicines

Captured

Advanced therapy medicinal products (ATMP)

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

Yes

Contraception

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

No

Indication for use

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

Captured

Indication vocabulary

ICD-10

SNOMED CT

Medical devices

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

Yes

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

ICD-10

SNOMED CT

Healthcare provider

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

Yes

Clinical measurements

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

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

Biomarker data

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

Not Captured

Patient-reported outcomes

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

No

Patient-generated data

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

No

Units of healthcare utilisation

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

Yes

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

SNOMED CT

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Package size

Strength

Medicinal product vocabulary

SNOMED

Z-index (G-standard)

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Living in rural area

Socioeconomic status

Quantitative descriptors

Population Qualitative Data

Population age groups

Paediatric Population (< 18 years)

Preterm newborn infants (0 – 27 days)

Term newborn infants (0 – 27 days)

Infants and toddlers (28 days – 23 months)

Children (2 to < 12 years)

Adolescents (12 to < 18 years)

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (≥ 65 years)

Adults (65 to < 75 years)

Adults (75 to < 85 years)

Adults (85 years and over)

Population

Population size

14000000

Active population size

4500000

Median observation time

Median time (years) between first and last available records for unique individuals captured in the data source

2.50

Data flows and management

Access and validation

Biospecimen access

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

No

Access to subject details

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

Yes

Description of data collection

Monthly batch uploads peformed by the hospitals themselves

Event triggering registration

Event triggering registration of a person in the data source

Insurance coverage start

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

Insurance coverage end

Event triggering creation of a record in the data source

Hospital encounter

Data source linkage

Linkage

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

Yes

Linked data sources

Pre linked

Is the data source described created by the linkage of other data sources?

No

Data source, other

Datasources which have unpseudonymized patient codes available (linkage to pathology, prescription, cancer registry, clinical registries such as the Dutch DICA registry and IKNL registry)

Linkage strategy

Deterministic

Linkage variable

Patient code or unique combination of characteristics

Linkage completeness

Highly dependent on disease and a data source

Pre linked

Is the data source described created by the linkage of other data sources?

Yes

Data source, other

DBC

Linkage strategy

Deterministic

Linkage variable

Patient code

Linkage completeness

Complete

Pre linked

Is the data source described created by the linkage of other data sources?

Yes

Data source, other

EVS

Linkage strategy

Deterministic

Linkage variable

Patient code

Linkage completeness

Complete

Data management specifications that apply for the data source

Data source refresh

Quarterly

Informed consent for use of data for research

Other

Possibility of data validation

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

Yes

Data source preservation

Are records preserved in the data source indefinitely?

No

Data source preservation length (years)

5 years

Approval for publication

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

Yes

Informed consent, other

Not required within specific purpose / waiver

Common Data Model (CDM) mapping

CDM mapping

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

Yes

CDM Mappings

CDM name

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

5.4

Data source ETL frequency

1,00 month

Data source ETL status

Planned