Danish Health Data Registries

First published: 01/02/2024

Last updated: 27/01/2025

Data source | Human | Cancer registry | Death registry | Hospital inpatient records | Hospital outpatient visit records | Other | Pharmacy dispensing records | Population registry | Vaccination registry

Administrative details

Administrative details

PURI

https://redirect.ema.europa.eu/resource/1111217

Data source ID

1111217

Data source acronym

DK-DHR

Data holder

Danish Health Data Authority

Data source type

Cancer registry

Death registry

Hospital inpatient records

Hospital outpatient visit records

Other

Pharmacy dispensing records

Population registry

Vaccination registry

Data source type, other

Registry of Laboratory Results

Main financial support

Funding by own institution

Other

Care setting

Hospital inpatient care

Hospital outpatient care

Other

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

We on-boarded Darwin EU May 2024 and are updating DK-DHR annually.

At the time of on-boarding and at each update extensive quality control is run on the DK-DHR OMOP CDM database.

Data source website

National health registers - The Danish Health Data Authority

Contact details

Claus Møldrup

Main

clml@dkma.dk

Claus Møldrup

Alternate

elvb@dkma.dk

Data source regions and languages

Data source countries

Denmark

Data source languages

Danish

Data source establishment

Data source established

01/01/1943

Data source time span

First collection: 01/01/1943

The date when data started to be collected or extracted.

Publications

Data source publications

The Danish National Patient Registry: a review of content, data quality, and research potential

The Danish Cancer Registry

The Danish vaccination register

The Danish National Prescription Registry

Existing Data Sources in Clinical Epidemiology: Laboratory Information System Databases in Denmark

The Danish Civil Registration System

Studies

List of studies that have been conducted using the data source

SAFETY-VAC: Network of Data Sources for Vaccine Safety Evaluation

SAFETY-VAC: Background incidence estimation of flares of pre-existing chronic diseases using pan-European electronic healthcare data sources. (SAFETY VAC)

SAFETY-VAC: Phenotype proposal and rates of immunocompromised populations in real-world data sources.

DARWIN EU® – Paracetamol prescribing and paracetamol overdose in Europe: a descriptive analysis of trends and patient characteristics

DARWIN EU® - Antipsychotic prescribing in the general population in Europe: a descriptive analysis of trends and patient characteristics

DARWIN EU® - Antipsychotic prescribing in people with dementia in Europe: a descriptive analysis of trends and patient characteristics

A Post-Authorisation Safety Study (PASS) of ABRYSVO (Respiratory Syncytial Virus Stabilised Prefusion Subunit Vaccine) in Pregnant Women and their Offspring in a Real World Setting in Europe and UK

DARWIN EU® - Suicidality incidence rates in adult male patients and in patients treated with finasteride and dutasteride

DARWIN EU® - Characterisation of exposure to acitretin and purpura and related conditions

DARWIN EU® - Prevalence of hypertrophic cardiomyopathy (HCM) and obstructive hypertrophic cardiomyopathy (oHCM) in six European countries

DARWIN EU® - Prescription trends of ketamine and esketamine

DARWIN EU® – Incidence rates of venous thromboembolic events in patients with selected cancers

DARWIN EU® - Association of venous thromboembolism with non-steroidal anti-inflammatory drug use in women 15-49 years using hormonal contraceptives

DARWIN EU® Drug Utilisation Study of prescription opioids

Brand-specific influenza vaccine effectiveness in the Nordic countries

Data elements collected

The data source contains the following

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.

Yes

Rare diseases

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

Yes

Pregnancy and/or neonates

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

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

Yes

Cause of death

Captured

Cause of death vocabulary

ICD-10

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

RxNorm

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

RxNorm

Advanced therapy medicinal products (ATMP)

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

No

Contraception

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

Yes

Indication for use

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

Captured

Indication vocabulary

ICD-10

Medical devices

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

Yes

Administration of vaccines

Yes

Procedures

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

Captured

Procedures vocabulary

SNOMED

Healthcare provider

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

No

Clinical measurements

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

No

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

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Package size

Route of administration

Strength

Medicinal product vocabulary

RxNorm

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Marital 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)

Adult and elderly population (≥18 years)

Adults (18 to < 65 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)

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

100%

Description of the population covered by the data source in the catchment area whose data are not collected (e.g., people who are registered only for private care)

The data is representative of the entire Danish population. Healthcare is free in Denmark so we do not expect any bias in data collection based on socio-economic status.

Family linkage

Family linkage available in the data source permanently or can be created on an ad hoc basis

Permanently

Family linkage available between the following persons

Father-child

Household

Mother-child

Population

Population size

8500891

Active population size

5962689

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	1155838
Preterm newborn infants (0 – 27 days)	3860
Term newborn infants (0 – 27 days)	55005
Infants and toddlers (28 days – 23 months)	123081
Children (2 to < 12 years)	619485
Adolescents (12 to < 18 years)	413272

Age group	Population size
Adults (18 to < 46 years)	2082668
Adults (46 to < 65 years)	1480819
Elderly (≥ 65 years)	1213329
Adults (65 to < 75 years)	624146
Adults (75 to < 85 years)	454419
Adults (85 years and over)	134764

Median observation time

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

37.20

Data flows and management

Access and validation

Governance details

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

https://english.sundhedsdatastyrelsen.dk/

Biospecimen access

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

No

Access to subject details

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

No

Event triggering registration

Event triggering registration of a person in the data source

Birth

Disease diagnosis

Immigration

Other

Residency obtained

Start of treatment

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

Hospital inpatient / outpatient admission; vaccination; laboratory test result

---

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

Death

Emigration

Data source linkage

Linkage

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

No

Data management specifications that apply for the data source

Data source refresh

Monthly

Informed consent for use of data for research

Not Required

Possibility of data validation

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

Yes

Data source preservation

Are records preserved in the data source indefinitely?

Yes

Approval for publication

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

No

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

12,00 months

Data source ETL status

Completed

CDM name

OMOP

CDM website

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

Data source ETL frequency

12,00 months

Data source ETL status

Completed