Danish Health Care Registries

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Data source **Human** **Hospital discharge records** **Other** **Pharmacy dispensing records** **Population registry**

Administrative details

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Data source ID

1111216

Data source acronym

DHCR

Data holder

Danish Health Data Authority

Data source type

Hospital discharge records

Other

Pharmacy dispensing records

Population registry

Data source type, other

Central Person Register

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – GP, community pharmacist level

Data source qualification

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

No

Contact details

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Data source regions and languages

Data source countries

Denmark

Data source languages

Danish

Data source establishment

Data source time span

First collection: 01/01/1997

The date when data started to be collected or extracted.

Publications

Data source publications

The Danish Civil Registration System as a tool in epidemiology

Data Resource Profile: The Danish National Prescription Registry

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

Studies

List of studies that have been conducted using the data source

Silent Symptoms: The Comparative Risk of Developing Sexual Dysfunction after Treatment Initiation with Antidepressants

DARWIN EU® - Feasibility of studies on early (pre-symptomatic) stages of type 1 diabetes mellitus in the DARWIN EU® network

DARWIN EU® - Characterisation of aliskiren users

A Drug Utilisation Study of Qsiva for Weight Management: A Postmarketing Cohort Database Study in Denmark, Finland, Norway, and Sweden

Qsiva Use Among Pregnant Women and Prescribed Contraceptive Use Among Qsiva Users of Childbearing Potential: A Postmarketing Cohort Database Study in Denmark, Finland, Norway, and Sweden

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)?

Yes

Hospital admission and/or discharge

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

Dispensing of medicines

Captured

Dispensing vocabulary

ATC

Advanced therapy medicinal products (ATMP)

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

No

Contraception

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

No

Indication for use

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

Not Captured

Medical devices

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

No

Administration of vaccines

No

Procedures

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

Not Captured

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?

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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

ICD-10

Medicinal product information

Captured

Medicinal product information collected

Brand name

Dose

Formulation

Package size

Strength

Medicinal product vocabulary

ATC

Other

If 'other,' what vocabulary is used?

Nordic article number (VNR)

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

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)

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)

Anyone with a Danish recidency are automatically covered by data capture by the national registers that provide data for the data source described here

Family linkage

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

Ad hoc

Population

Population size

6800000

Active population size

5400000

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?

No

Description of data collection

Data collection for the national registers that provide data for the described data source, is the responsibility of the National Health Data Authority. Hospital data originate from electronic health records systems in all Danish hospitals. Filled prescriptions are reported from all danish pharmacies

Event triggering registration

Event triggering creation of a record in the data source

Any hospital encounter results in data being recorded in the national registers. Similarly, any filled prescription results in a record in the national prescription register

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

Linkage description, pre-linked

Linkage by unique person identifier

Linked data sources

Pre linked

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

No

Data source, other

As our OMOP ETL is gradually expanded, we expect to be able to include additional Danish health registers into the data source. This could e.g. be the national causes of death register

Linkage strategy

Deterministic

Linkage variable

cpr-number

Linkage completeness

Complete

Pre linked

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

Yes

Data source, other

The Central Person Register

Linkage strategy

Deterministic

Linkage variable

cpr-number

Linkage completeness

Complete

Pre linked

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

Yes

Data source, other

The National Patient Register

Linkage strategy

Deterministic

Linkage variable

cpr-number

Linkage completeness

Complete

Pre linked

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

Yes

Data source, other

The Register of Pharmaceutical Sales

Linkage strategy

Deterministic

Linkage variable

cpr-number

Linkage completeness

Complete

Data management specifications that apply for the data source

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)?

No

Data source preservation

Are records preserved in the data source indefinitely?

No

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

Sentinel

CDM website

https://www.sentinelinitiative.org/methods-Data-tools/sentinel-common-Data-model

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Data source ETL status

Completed

CDM name (other)

Other

Data source ETL status

Completed

CDM name

OMOP

CDM website

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

Data source ETL CDM version

5.4

Data source ETL status

In progress