

Terveystietojärjestelmän hoitoilmoitusrekisteri (Finland Care Register for Health Care)

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Data source

Human

Emergency care discharge records

Hospital discharge records

Hospital inpatient records

Hospital outpatient visit records

Specialist ambulatory care records

Administrative details

Administrative details

PURI

<https://redirect.ema.europa.eu/resource/1111187>

Data source ID

1111187

Data source acronym

Terveys-Hilmo

Data holder

[Finnish Institute for Health and Welfare \(THL\)](#)

Data source type

Emergency care discharge records

Hospital discharge records

Hospital inpatient records

Hospital outpatient visit records

Specialist ambulatory care records

Main financial support

National, regional, or municipal public funding

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.

No

Data source website

<https://thl.fi/en/statistics-and-data/data-and-services/register-descriptions/care-register-for-health-care>

Contact details

Care Register for Health Care

Main

Data source regions and languages

Data source countries

Finland

Data source languages

Finnish

Data source establishment

Data source established

01/01/1994

Data source time span

First collection: 01/01/1994

The date when data started to be collected or extracted.

Publications

Data source publications

[Quality measures of the population-based Finnish Cancer Registry indicate sound Data quality for solid malignant tumours](#)

[Completeness of pediatric cancer registration in the Finnish Cancer Registry](#)

[How reliable are health registers? Registration of induced abortions and sterilizations in Finland](#)

[Quality of Finnish Hospital Discharge Register: A systematic review](#)

Coverage and accuracy of myeloproliferative and myelodysplastic neoplasms in the Finnish Cancer Registry

Toimenpiteiden alueellinen vaihtelu korva-, nenä- ja kurkkutautien erikoisalalla

Kohti luotettavaa hoitoonpääsyn seurantaa: hoitoilmoitusrekisterin ja syöpärekisterin diagnoositietojen vertailu

Studies

List of studies that have been conducted using the data source

A Retrospective Cohort Study for Estimating Incidence Rates of Infusion Site Events for ABBV-951 for the Treatment of Advanced Parkinson's Disease

DARWIN EU® - Chondrosarcoma: patient demographics, treatments, and survival in the period 2010-2023

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

DARWIN EU® - CGRP antagonists - Treatment patterns and users characteristics

ADEPT: feasibility of estimating the risk of adverse pregnancy, neonatal and child outcomes following either in utero ASM exposure through the mother, or peri-conceptional ASM exposure through the father

DARWIN EU® - DUS Characterising STOPP criteria medication use in people with recurrent falls

Effectiveness of Pfizer-BioNTech COVID-19 mRNA vaccine against severe illness in the elderly and immunocompromised patients in Finland (RWE_COVID19_2023)

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.

No

Rare diseases

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

Yes

Pregnancy and/or neonates

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

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

Not Captured

Dispensing of medicines

Not 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)].

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

Yes

Procedures

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

Captured

Procedures vocabulary

Other

Procedures vocabulary, other

National classification of procedures (current national classification loosely based on NOMESCO)

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

ICPC-2

Medicinal product information

Captured

Medicinal product information collected

Brand name

Medicinal product vocabulary

ATC

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Health area

Living in rural area

Sex

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 (\geq 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)

Data is not collected on private outpatient health services, including privately provided occupational health care (an extension of data collection is in progress to cover this patient population).

Population

Population size

6883497

Active population size

5500000

Population by age group

Age group	Population size
Neonate	64495
Infants and toddlers (28 days - 23 months)	164057
Children (2 to < 12 years)	626372
Adolescents (12 to < 18 years)	351207
Adults (18 to < 46 years)	2010394
Adults (46 to < 65 years)	1430472
Adults (65 to < 75 years)	861108
Adults (75 to < 85 years)	799519
Adults (85 years and over)	575873

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://thl.fi/fi/tilastot-ja-data/aineistot-ja-palvelut/tilastojen-laatu-ja-periaatteet/laatuselosteet/esh>

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 is encounter-based. Data on patient's outpatient visits and inpatient stays are recorded within health care provider's information systems and electronically transferred to Hilmo.

Event triggering registration

Event triggering registration of a person in the data source

Other

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

First outpatient visit to a public healthcare provider or inpatient stay

Event triggering creation of a record in the data source

Outpatient visit, admission and discharge from inpatient care (specialized care)

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, possible linkage

It is possible to link Terveys-Hilmo to Other Finnish registers through the personal identification number. Examples of Other Finnish national health care registers are:

- Register of Primary Health Care Visits (Contains information on primary care health care visits and diagnoses)
- Prescription Registers (Contains information on prescription medication dispensed from community pharmacies)
- The Medical Birth Register (The register has relevant information on pregnancies that has lasted at least 22 weeks or the infant's birth weight was at least 500 g in Finland at home or in a hospital. This register includes linkage between infant and mother)
- The Cause of Death Register (Contains information on date and cause of death)

Linked data sources

Pre linked

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

No

Data source, other

Prescription Registers (Contains information on prescription medication dispensed from community pharmacies)

Linkage strategy

Deterministic

Linkage variable

Personal identification number

Linkage completeness

100%

Pre linked

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

No

Data source, other

Register of Primary Health Care Visits (Contains information on primary care health care visits and diagnoses)

Linkage strategy

Deterministic

Linkage variable

Personal identification number

Linkage completeness

100%

Pre linked

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

No

Data source, other

The Cause of Death Register (Contains information on date and cause of death)

Linkage strategy

Deterministic

Linkage variable

Personal identification number

Linkage completeness

100%

Pre linked

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

No

Data source, other

The Medical Birth Register (The register has relevant information on pregnancies that has lasted at least 22 weeks or the infant's birth weight was at least 500 g in Finland at home or in a hospital. This register includes linkage between infant and mOther)

Linkage strategy

Deterministic

Linkage variable

Personal identification number

Linkage completeness

100%

Data management specifications that apply for the data source

Data source refresh

February

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?

Yes

Data source last refresh

28/02/2022

Common Data Model (CDM) mapping

CDM mapping

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

Yes

CDM Mappings

CDM name

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