Lifelines Data and Biobank

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Data source | Human | Biobank

Administrative details

Administrative details

Data source ID

1000000182

Data source acronym

Lifelines

Data holder

University of Groningen

Data source type

Biobank

Main financial support

Funding by own institution

National, regional, or municipal public funding

Care setting

Other

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

Website Lifelines

Contact details

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Main

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Data source regions and languages

Data source countries

Netherlands

Data source languages

Dutch

Data source regions

Drenthe

Fryslân

Groningen

Data source establishment

Data source established

01/12/2006

Data source time span

First collection: 01/12/2006

The date when data started to be collected or extracted.

Publications

Data source publications

Cohort Profile: LifeLines, a three-generation cohort study and biobank

Universal risk factors for multifactorial diseases: Lifelines: a three-generation population-based study

Cohort Profile Update: Lifelines, a three-generation cohort study and biobank

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.

Yes

Disease details (other)

For all diseases and variables, please take a look here:

https://wiki.lifelines.nl/doku.php?id=sections

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

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

ATC

not coded

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?

Yes

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?

Yes

Administration of vaccines

Yes

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.

No

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?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

University Medical Center of Groningen Genetics Lifelines Initiative (UGLI)

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.

Captured

Biomarker data vocabulary

BMO

FOBI

Other

Patient-reported outcomes

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

Yes

Patient-generated data

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

Yes

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

Not Captured

Medicinal product information

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

SF-36

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Diet

Frequency of exercise

Other

Tobacco use

Lifestyle factors included other

Exposure to noise/radiation, drug use, hobbies and activities, screen use, sleep

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Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Education level

Ethnicity

Gender

Health area

Living in rural area

Marital status

Other

Sex

Socioeconomic status

Type of residency

Sociodemographic information other

Employment, family composition, income, profession (job codes)

Quantitative descriptors

Population Qualitative Data

Population age groups

All

Paediatric Population (< 18 years)

Neonate

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

10% of the Northern population was included at baseline.

For more information about the general cohort and factsheet, see here: https://wiki.lifelines.nl/doku.php?id=cohort.

Family linkage

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

Ad hoc

Population

Population size

167729

Active population size

110000

Median observation time

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

18.00

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).

Lifelines website

Lifelines Wiki

Biospecimen access

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

Yes

Biospecimen access conditions

Whole blood, plasma, serum, urine, feces, DNA, buffy coats and hair.

Access to subject details

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

Yes

Description of data collection

Lifelines collects questionnaire data, measurements, and biological samples from the entire cohort in rounds or waves called general assessments. On top of the general assessments, additional assessments may be performed in selected groups of Lifelines participants (e.g. “subcohorts”) in order to collect additional questionnaire data, measurements and/or biomaterials. Additional assessments are performed at the initiative of (and in collaboration with) external research groups, and an embargo period for use of additional data by third parties may apply.

Event triggering registration

Event triggering registration of a person in the data source

Birth

Disease diagnosis

Start of treatment

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

Death

End of treatment

Loss to follow up

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

Gecco data, place of birth and some other CBS data (CBS data), air pollution, ELAPSE.

Linkage description, possible linkage

IKNL

IADB

CBS

Palga

Perined

Nivel

and other requests may be possible

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?

Yes

Approval for publication

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

Yes

Informed consent, other

Participants signed a broad consent for data usage for research purposes in the field of healthy ageing.

The general Lifelines protocol has been approved by the UMCG Medical ethical committee under number 2007/152.

Data source last refresh

06/06/2024

Common Data Model (CDM) mapping

CDM mapping

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

No