DARWIN EU® – Prevalence of selected cancers

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Administrative details

U PAS number
UPAS100000715
Study ID
.000000715
DARWIN EU® study
'es
Study countries
Croatia
Denmark
Germany
Netherlands
Norway

Study description

Substantial uncertainty surrounds the prevalence of rare blood cancers.

Estimates generated from real-world data can be influenced by database type, setting, and quality.

This present study builds on a previous DARWIN EU® study (EUPAS50800), which estimated the prevalence of rare blood cancers using data from five sources in Europe, primarily reflecting primary care settings.

Across the databases included in the study, acute lymphocytic leukaemia and acute myeloid leukaemia were the least prevalent diseases, with the highest estimates for their 5-year partial point prevalence being 0.65 and 1.03 per 10,000, respectively.

The highest estimate of prevalence of diffuse large B-Cell lymphoma was 1.73 per 10,000, while the highest prevalence of follicular lymphoma was 2.83 per 10,000.

Lastly, the highest estimates for prevalence of chronic lymphocytic leukaemia and multiple myeloma were 4.13 and 4.27 per 10,000, respectively.

Importantly, the study assessed the impact of different design choices on the obtained results, including different windows for prevalence assessment (i.e., point vs. period prevalence) and outcome duration (i.e., complete vs. partial prevalence, using 2 and 5 years to define outcome duration).

Building on the methodological work of the previous study, the current study is now repeated to incorporate additional outcomes (i.e., pancreatic cancer and soft tissue sarcoma) and data sources, including registry data and claims data. Importantly, this study will incorporate two national cancer registries in Europe, which will require the use of external sources, such as national estimates, to derive denominators for prevalence estimation.

Study status

Ongoing

Research institutions and networks

Institutions

Department of Medical Informatics - Health Data
Science, Erasmus Medical Center (ErasmusMC)
Netherlands
First published: 03/11/2022
Last updated: 02/05/2024
Institution

Networks

Data Analysis and Real World Interrogation Network
(DARWIN EU®)
(DAITVIII LOW)
Belgium
Croatia
☐ Denmark
Estonia
Finland
France
Germany
☐ Greece
Hungary
Italy
☐ Netherlands
■ Norway

Portugal Portugal
Spain
Sweden
United Kingdom
First published: 01/02/2024
Last updated: 30/04/2025

Contact details

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Study contact

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Primary lead investigator

Berta Raventos

Primary lead investigator

Study timelines

Date when funding contract was signed

Planned: 09/04/2025

Actual: 09/04/2025

Study start date

Planned: 11/08/2025

Actual: 11/08/2025

Date of final study report

Planned: 30/01/2026

Sources of funding

EMA

Study protocol

DARWIN EU_Protocol_P4-C2-005_Prevalence of selected cancers_V3.0.pdf (952.47 KB)

Regulatory

Was the study required by a regulatory body?

Yes

Is the study required by a Risk Management Plan (RMP)?

Not applicable

Methodological aspects

Study type

Study type list

Study topic:Disease /health condition

Study topic, other:

Cancers

Study type:

Non-interventional study

Scope of the study:

Disease epidemiology

Data collection methods:

Secondary use of data

Study design:

A cohort study will be conducted using routinely collected health data from 5 databases from 5 countries across Europe. This will consist of a descriptive epidemiological study providing point prevalence estimates of selected cancers in each participating database.

Study Design

Non-interventional study design

Cohort

Population studied

Short description of the study population

All individuals in the database during the study period will be eligible for inclusion in the study. No prior history requirement will be applied in the primary analysis.

Age groups

ΑII

In utero

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)

Study design details

Setting

The primary aim of this study is to estimate the point prevalence of rare blood cancers, pancreatic cancer, and soft tissue sarcoma across selected databases in Europe.

The secondary aim of this study is to compare the prevalence of selected

cancers included in the primary aim of the study, using denominator data available within the data source versus denominator data obtained from external sources.

Data management

ENCePP Seal

The use of the ENCePP Seal has been discontinued since February 2025.

The ENCePP Seal fields are retained in the display mode for transparency but are no longer maintained.

Data sources

Data source(s)

Croatia National Public Health Information System (Nacionalni javnozdravstveni informacijski sustav)

Danish Health Data Registries

InGef Research Database

Netherlands Cancer Registry

The Cancer Registry of Norway

Data sources (types)

Cancer registry

Disease registry

Electronic healthcare records (EHR)

Use of a Common Data Model (CDM)

CDM mapping
Yes
CDM Mappings
CDM name
ОМОР
CDM website
https://www.ohdsi.org/Data-standardization/
CDM version
https://ohdsi.github.io/CommonDataModel/index.html
Data quality specifications
Check conformance
Unknown
Check completeness
Unknown
Check stability
Unknown
Check logical consistency
Unknown

Data characterisation

Data characterisation conducted

No