

# DARWIN EU® Prevalence of rare blood cancers in Europe

**First published:** 31/01/2023

**Last updated:** 25/09/2024

Study

Finalised

## Administrative details

### EU PAS number

EUPAS50800

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### Study ID

50801

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### DARWIN EU® study

Yes

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### Study countries

-  Belgium
  -  Germany
  -  Netherlands
  -  Spain
  -  United Kingdom
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## Study description

In this study the prevalence of rare blood cancers (follicular lymphoma, diffuse large B-Cell lymphoma, multiple myeloma, chronic lymphocytic leukaemia, acute myeloid leukaemia, acute lymphocytic leukaemia) will be assessed.

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## Study status

Finalised

## 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**

**Educational Institution**

**ENCePP partner**

#### IQVIA NL, Real-World-Evidence

 Netherlands

**First published:** 25/11/2022

**Last updated:** 21/03/2025

**Institution**

**Other**

**ENCePP partner**

# Fundació Institut Universitari per a la Recerca a l'Atenció Primària de Salut Jordi Gol i Gurina, IDIAPJGol

 Spain

**First published:** 05/10/2012

**Last updated:** 23/05/2025

**Institution**

**Educational Institution**

**Laboratory/Research/Testing facility**


**Not-for-profit**

**ENCePP partner**


## University of Oxford


## Networks


### Data Analysis and Real World Interrogation Network (DARWIN EU®)

 Belgium


 Croatia


 Denmark









 Estonia

 Finland

 France

 Germany

 Greece

-  Hungary
-  Italy
-  Netherlands
-  Norway
-  Portugal
-  Spain
-  Sweden
-  United Kingdom

**First published:** 01/02/2024

**Last updated:** 30/04/2025

**Network**

## Contact details

### Study institution contact

Edward Burn [e.burn@darwin-eu.org](mailto:e.burn@darwin-eu.org)

**Study contact**

[e.burn@darwin-eu.org](mailto:e.burn@darwin-eu.org)

### Primary lead investigator

Edward Burn

**Primary lead investigator**

## Study timelines

### **Date when funding contract was signed**

Planned: 13/05/2022

Actual: 13/05/2022

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### **Study start date**

Planned: 01/11/2022

Actual: 01/11/2022

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### **Date of final study report**

Planned: 28/03/2023

Actual: 28/03/2023

## Sources of funding

- EMA

## Study protocol

[D2.2.3\\_DARWIN\\_EU\\_Study Protocol C1-001\\_v2.0\\_EU\\_PAS.pdf](#) (1.04 MB)

## Regulatory

### **Was the study required by a regulatory body?**

Yes

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

Not applicable

## Methodological aspects

### Study type

### Study type list

**Study topic:**

Disease /health condition

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**Study type:**

Non-interventional study

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**Scope of the study:**

Disease epidemiology

**Data collection methods:**

Secondary use of data

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**Main study objective:**

To estimate the prevalence of rare blood cancers (follicular lymphoma, diffuse Large B-Cell Lymphoma, Multiple Myeloma, Chronic Lymphocytic Leukaemia, Acute Myeloid Leukaemia, Acute Lymphocytic Leukaemia)

## Study Design

**Non-interventional study design**

Cohort

Other

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**Non-interventional study design, other**

Population-based

## Study drug and medical condition

**Medical condition to be studied**

Follicular lymphoma  
Diffuse large B-cell lymphoma  
Plasma cell myeloma  
Chronic lymphocytic leukaemia  
Acute myeloid leukaemia  
Acute lymphocytic leukaemia

## Population studied

### **Short description of the study population**

The study included all individuals reported in the five European databases, including IPCI, SIDIAP, CPRD, IQVIA LPD Belgium, and IQVIA DA Germany, to determine the prevalence of haematological cancers.

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### **Age groups**

- 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)
  - Adults (65 to < 75 years)
  - Adults (75 to < 85 years)
  - Adults (85 years and over)
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### **Special population of interest**

Other

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## Special population of interest, other

Patients with haematological cancers

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## Estimated number of subjects

10000000

## Study design details

### Outcomes

Follicular lymphoma, diffuse Large B-Cell Lymphoma, Multiple Myeloma, Chronic Lymphocytic Leukaemia, Acute Myeloid Leukaemia, Acute Lymphocytic.

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### Data analysis plan

5-year partial prevalence will be estimated for each outcome of interest.

## Documents

### Study results

[DARWIN\\_EU\\_Study\\_Report\\_C1-001\\_V3.2.pdf](#) (1.49 MB)

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## 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)**

Integrated Primary Care Information (IPCI)

The Information System for Research in Primary Care (SIDIAP)

Clinical Practice Research Datalink

IQVIA Longitudinal Patient Data - Belgium

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**Data sources (types)**

[Electronic healthcare records \(EHR\)](#)

## Use of a Common Data Model (CDM)

**CDM mapping**

Yes

**CDM Mappings****CDM name**

OMOP

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**CDM website**

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

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## Data quality specifications

**Check conformance**

Unknown

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**Check completeness**

Unknown

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**Check stability**

Unknown

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**Check logical consistency**

Unknown

## Data characterisation

**Data characterisation conducted**

No