European Venous Registry

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Data source | Human | Disease registry

Administrative details

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PURI

https://redirect.ema.europa.eu/resource/1000000508

Data source ID

1000000508

Data source acronym

EVeR

Data holder

European Society for Vascular Surgery (ESVS)

Data source type

Disease registry

Main financial support

Funding from public-private partnership

Care setting

Hospital inpatient care

Hospital outpatient care

Primary care – specialist level (e.g. paediatricians)

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

EVeR registry

Contact details

Nhi Cao

Main

info@esvs.org

Nhi Cao

Alternate

nhi@esvs.org

Data source regions and languages

Data source countries

European Union

Norway

Portugal

Sweden

Switzerland

Türkiye

United Kingdom

Data source languages

English

Data source establishment

Data source established

23/07/2024

Data source time span

First collection: 01/01/2025

The date when data started to be collected or extracted.

Last collection: 31/12/2035

If data collection in the data source has ceased, the date new records last entered the data source.

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

Deep vein thrombosis

Disease details (other)

undefined

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)?

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

Captured

Prescriptions vocabulary

ATC

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?

Captured

Indication vocabulary

ICD-10

SNOMED CT

Medical devices

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

Yes

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

SNOMED CT

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?

Yes

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

SNOMED CT

Medicinal product information

Captured

Medicinal product information collected

Dosage regime

Dose

Medicinal product vocabulary

ATC

SNOMED

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

other

Quality of life measurements, other

VEINES

Lifestyle factors

Not Captured

Sociodemographic information

Not Captured

Quantitative descriptors

Population Qualitative Data

Population age groups

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)

Median observation time

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

10.00

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

The EVeR Registry (European Venous Registry) collects structured clinical data on patients with deep venous disease across multiple hospital-based vascular centers in Europe. The primary objective is to evaluate patient outcomes, track treatment efficacy, and facilitate research on venous interventions. Patients are

enrolled based on specific inclusion criteria and must provide explicit consent to have their data recorded in the registry. Enrollment occurs in specialized hospital settings, including vascular surgery, interventional radiology, and hematology units.

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

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

Death

End of treatment

Loss to follow up

Other

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

Patient opting out

Event triggering creation of a record in the data source

A new record is created in the EVeR Registry (European Venous Registry) when a qualifying patient event occurs within a participating hospital-based vascular center. The primary event that triggers data entry is a confirmed diagnosis or a new clinical intervention related to deep venous disease, along with the patient’s consent to be included in the registry.

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?

No

Data management specifications that apply for the data source

Informed consent for use of data for research

Required for all studies

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?

No

Data source preservation length (years)

20 years

Approval for publication

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

Yes

Common Data Model (CDM) mapping

CDM mapping

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

No