Deutsches Hämophilieregister

First published: 01/02/2024

Last updated: 17/10/2024

Data source | Human | Disease registry | Other

Administrative details

Administrative details

Data source ID

24838

Data source acronym

DHR

Data holder

Paul-Ehrlich-Institut

Data source type

Disease registry

Other

Data source type, other

exposure registry

Main financial support

Funding by own institution

Care setting

Secondary care – specialist level (ambulatory)

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

Primary care – GP, community pharmacist level

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://www.dhr.pei.de

Contact details

Christine Keipert dhr@pei.de

Main

dhr@pei.de

Data source regions and languages

Data source countries

Germany

Data source languages

German

Data source establishment

Data source established

01/01/2008

Data source time span

First collection: 01/01/2008

The date when data started to be collected or extracted.

Publications

Data source publications

B. Haschberger, J. Hesse, M. Heiden, R. Seitz, W. Schramm: Aufbau des Deutschen Hämophilieregisters [The German haemophilia register]. Haemostaseologie 2008 28(S 01) S12-S16

B. Haschberger, J. Hesse, M. Heiden, R. Seitz, W. Schramm: [DHR--ready for take-off] Das Deutsche Hämophilieregister am Start. Haemostaseologie 2009 29(S01) S19-S21

B. Haschberger, J. Hesse, M. Heiden, R. Seitz, W. Schramm: [Documentation of haemophilia treatment supported by the German Hemophilia Registry]. Haemostaseologie 2010 30(S 01): S62-S64

Neue Daten aus dem Deutschen Hämophilieregister

H. Duda, J. Hesse, B. Haschberger, A. Hilger, C. Keipert: The German Hemophilia Registry: Growing with Its Tasks. J. Clin. Med. 2020 9(11): 3408

Studies

List of studies that have been conducted using 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 (other)

The DHR collects specific disease information on haemophilia A (HA), haemophilia B (HB), von Willebrand disease (vWD) and other factor deficiency diseases (deficiency of FI, FII, FV, FVII, FX, FXI, FXIII)

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

Not coded (Free text)

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

No

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?

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?

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.

No

Unique identifier for persons

Are patients uniquely identified in the data source?

No

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Not coded (Free text)

Medicinal product information

Captured

Medicinal product information collected

Brand name

Quality of life measurements

Not Captured

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

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 (≥ 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 percent

DHR collects data data of all patients and age groups with the aforementioned diseases. Providing specific age distribution would need further analysis and a data export request.

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)

Nation-wide

Population

Population size

17000

Active population size

17000

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?

Yes

Description of data collection

Data documentation is performed by data entry by hand via a web interface or electronically via a data interface

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

Emigration

Event triggering creation of a record in the data source

Data on registered patients is updated anually after diagnosis

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

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

There is a committee to evaluate requests for data access

Common Data Model (CDM) mapping

CDM mapping

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

No