Hepatitis Delta International Network (HDIN) - Patient Registry

First published: 01/02/2024

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Data source

Human

Hospital inpatient records

Hospital outpatient visit records

Primary care medical records

Administrative details

Administrative details

Data source ID

20079

Data source acronym

HDIN - Hepatitis D

Data holder

Deutsche Leberstiftung (German Liver Foundation)

Data source type

Hospital inpatient records

Hospital outpatient visit records

Primary care medical records

Main financial support

Funds from patients organisations, charity and foundations

National, regional, or municipal public funding

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

http://hepatitis-delta.org/

Contact details

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Data source regions and languages

Data source countries

Austria

Azerbaijan

Belgium

Brazil

Georgia

Germany

Greece

Italy

Moldova, Republic of

Mongolia

Pakistan

Romania

Spain

Sweden

Türkiye

United States

Viet Nam

Data source languages

English

Data source establishment

Data source established

15/11/2013

Data source time span

First collection: 15/11/2013

The date when data started to be collected or extracted.

Publications

Data source publications

Wranke et al. (2017). Liver International. Clinical and virological heterogeneity of hepatitis delta in different regions world-wide: The Hepatitis Delta International Network (HDIN).

Studies

List of studies that have been conducted using the data source

Survey on the collection of data on adverse events related to medicinal products through registries

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)

HBV- and HDV Virology (qualitative + quantitative), Blood biochemistry, Hematology, Liver disease, Antiviral therapy

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

Other

Cause of death vocabulary, other

"Reason of death liver related/not liver related"

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Prescriptions vocabulary, other

Compound class listed

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?

Yes

Genetic data

Are data related to genotyping, genome sequencing available?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

IL28B: rs12979860: CC/CT/TT

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

Other

Biomarker vocabulary, other

Quality and quantity of virological measures (HBsAg, Anti-HDV, Anti-HAV IgG, Anti-HAV IgM, Anti-HCV, HCV-RNA, Anti-HBs, HBe, Anti-Habe, HBV-DANN, HDV-RNA#)

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?

Yes

Diagnostic codes

Captured

Diagnosis / medical event vocabulary

Other

Diagnosis / medical event vocabulary, other

virological measures, concomitant conditions (e.g. organ transplantation, concomitant infections etc.), liver related complications (e.g. cirrhosis, HCC, liver transplantation etc.)

Medicinal product information

Not Captured

Quality of life measurements

Not Captured

Lifestyle factors

Captured

Lifestyle factors

Alcohol use

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Gender

Other

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

Not available

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)

Not collected: patients with unknown infection, patients treated elsewhere

Population

Population size

2008

Population by age group

Age group	Population size
Paediatric Population (< 18 years)	14
Preterm newborn infants (0 – 27 days)	0
Term newborn infants (0 – 27 days)	0
Infants and toddlers (28 days – 23 months)	0
Children (2 to < 12 years)	9
Adolescents (12 to < 18 years)	5
Adults (18 to < 46 years)	955
Adults (46 to < 65 years)	766
Elderly (≥ 65 years)	263
Adults (65 to < 75 years)	192
Adults (75 to < 85 years)	62
Adults (85 years and over)	9

Median observation time

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

2.40

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

Patient data is gathered from the respective hospital/practice documentation (patient files) and entered into the registry

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Other

Practice registration

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

Informed consent by patient.

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

Death

Loss to follow up

Practice deregistration

Event triggering creation of a record in the data source

Investigator driven decision at routine patient visits

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

Data source refresh

Yearly

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 steering committee to evaluate requests for data access

Data source last refresh

31/05/2022

Common Data Model (CDM) mapping

CDM mapping

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

No