INvestigating SIGnificant Health TrendS in progressive fibrosing Interstitial Lung Disease

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000161

Data source acronym

INSIGHTS-ILD

Data holder

GWT-TUD GmbH - Gesellschaft für Wissens- und Technologietransfer

Data source type

Disease registry

Main financial support

Funding from industry or contract research

Care setting

Hospital outpatient care

Secondary care – specialist level (ambulatory)

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

INSIGHTS-ILD

Contact details

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Data source regions and languages

Data source countries

Germany

Data source languages

German

Data source establishment

Data source established

01/12/2021

Data source time span

First collection: 09/12/2021

The date when data started to be collected or extracted.

Publications

Data source publications

Investigating significant health trends in progressive fibrosing interstitial lung disease (INSIGHTS-ILD): rationale, aims and design of a nationwide prospective registry

Real-life characteristics and management of patients with fibrosing interstitial lung disease: INSIGHTS-ILD registry

Studies

No information provided.

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

Interstitial lung disease

Idiopathic pulmonary fibrosis

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

Yes

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Captured

Cause of death vocabulary

MedDRA

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

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)?

Captured

Procedures vocabulary

ICD-10

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?

Yes

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.

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

ICD-10

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Brand name

Dose

Route of administration

Medicinal product vocabulary

ATC

Quality of life measurements

Captured

Quality of life measurements vocabulary

other

Quality of life measurements, other

R Scale

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Ethnicity

Gender

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)

Estimated percentage of the population covered by the data source in the catchment area

Sources provide different prevalence estimates (e.g. 80 patients per 100,000 or 0.21% of the population). The number of ILD patients in Germany therefore ranges from 64,000 to 168,000. INSIGHTS-ILD documents 900 of them.

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)

Patients not receiving specialist care are not documented. INSIGHTS-ILD investigators are pulmonologists, experts in the management of ILD patients. Patients without written informed consent and those not available for long-term follow-up are not eligible for documentation.

Population

Population size

1.300

Active population size

1.100

Median observation time

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

3,00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt

2,70

Data flows and management

Access and validation

Governance details

Documents or webpages that describe the overall governance of the data source and processes and procedures for data capture and management, data quality check and validation results (governing data access or utilisation for research purposes).

https://bmcpulmmed.biomedcentral.com/articles/10.1186/s12890-023-02333-7#Sec4

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 web-based registry collects long-term data on ILD management in routine (expert) clinical care, from consecutive patients newly initiated or receiving ILD therapy. It meets high quality standards through several measures (planned minimum centre contribution, automated plausibility checks of data at entry, statistical checks, queries, monitoring with source data verification in at least 20% of participating centres).

Event triggering registration

Event triggering registration of a person in the data source

Start of treatment

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

Death

Loss to follow up

Other

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

Withdrawal of patient consent

Event triggering creation of a record in the data source

Routine visit at the documenting center

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?

Yes

Linkage description, pre-linked

As of May 2024, there is no existing data source linkage.

Linkage description, possible linkage

The data source may potentially be linked to additional data sources, such as for with other registries or with post-authorisation safety studies; however, the specific methods for such linkage have yet to be defined.

Data management specifications that apply for the data source

Data source refresh

Every 6 months

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?

No

Data source preservation length (years)

10 years

Approval for publication

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

Yes

Informed consent, other

If pseudonymized data is used for purposes not originally covered in the patient information, ethics committees might require obtaining new informed consent from patients for these new purposes.

Data source last refresh

01/05/2024

Common Data Model (CDM) mapping

CDM mapping

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

No