Comparative, Prospective Registry of Newly Initiated Therapies for Pulmonary Hypertension

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Data source | Human | Disease registry

Administrative details

Administrative details

Data source ID

1000000103

Data source acronym

COMPERA

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

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.compera.org/

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Data source regions and languages

Data source countries

Austria

Belgium

Germany

Hungary

Italy

Latvia

Lithuania

Netherlands

Poland

Switzerland

United Kingdom

Data source languages

English

Data source establishment

Data source established

01/07/2007

Data source time span

First collection: 01/07/2007

The date when data started to be collected or extracted.

Publications

Data source publications

Elderly patients diagnosed with idiopathic pulmonary arterial hypertension: Results from the COMPERA registry

Anticoagulation and survival in pulmonary arterial hypertension: results from the Comparative, Prospective Registry of Newly Initiated Therapies for Pulmonary Hypertension (COMPERA)

Incidence and prevalence of pulmonary arterial hypertension in Germany

Pre-Capillary, Combined, and Post-Capillary Pulmonary Hypertension: A Pathophysiological Continuum

Mortality in pulmonary arterial hypertension: prediction by the 2015 European pulmonary hypertension guidelines risk stratification model

Risk assessment in pulmonary arterial hypertension

The 6MWT as a prognostic tool in pulmonary arterial hypertension: results from the COMPERA registry

Idiopathic pulmonary arterial hypertension phenotypes determined by cluster analysis from the COMPERA registry

Risk stratification in pulmonary arterial hypertension using Bayesian analysis

Pulmonary Hypertension in Adults with Congenital Heart Disease: Real-World Data from the International COMPERA-CHD Registry

COMPERA 2.0: a refined four-stratum risk assessment model for pulmonary arterial hypertension

Pulmonary Hypertension in Patients With COPD: Results From the Comparative, Prospective Registry of Newly Initiated Therapies for Pulmonary Hypertension (COMPERA)

Risk stratification and response to therapy in patients with pulmonary arterial hypertension and comorbidities: A COMPERA analysis

Phenotyping of idiopathic pulmonary arterial hypertension: a registry analysis

Prognostic value of improvement endpoints in pulmonary arterial hypertension trials: A COMPERA analysis

Medical treatment of pulmonary hypertension in adults with congenital heart disease: updated and extended results from the International COMPERA-CHD

Registry

Performance of the ESC/ERS 4-strata risk stratification model for pulmonary arterial hypertension with missing variables

Treatment strategies and survival of patients with connective tissue disease and pulmonary arterial hypertension: a COMPERA analysis

Trends in COVID-19-associated mortality in patients with pulmonary hypertension: a COMPERA analysis

Mono and combination therapies in pulmonary arterial hypertension patients with comorbidities: A COMPERA analysis

Studies

List of studies that have been conducted using the data source

Post-authorisation safety study (PASS): observational cohort study of PAH patients newly treated with either UPTRAVI (selexipag) or any other PAH-specific therapy, in clinical practice (EXPOSURE)

Real-World Comparative Effectiveness Study of TYVASO (Inhaled Treprostinil) in the Treatment of PH-ILD

Effectiveness of inhaled treprostinil versus standard of care for the treatment of pulmonary hypertension associated with interstitial lung disease: A propensity score-weighted study of the INCREASE trial and registry data from Europe

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

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)?

Yes

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

ICD-10

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

Other

Indication vocabulary, other

WHO Group

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

Biomarker data vocabulary

Other

Biomarker vocabulary, other

Not Coded

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

MedDRA

Medicinal product information

Not Captured

Quality of life measurements

Captured

Quality of life measurements vocabulary

EQ5D

Lifestyle factors

Not Captured

Sociodemographic information

Captured

Sociodemographic information collected

Age

Country of origin

Ethnicity

Sex

Quantitative descriptors

Population Qualitative Data

Population age groups

All

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

10% is a conservative estimate. Pulmonary arterial hypertension (PAH), one specific type of PH, affects approximately 15 to 50 individuals per million, according to the European Lung Foundation. Given the population of the European Union is roughly 447 million, this would suggest an estimated 6,705 to 22,350 individuals could be affected by PAH across the EU. Of the 12,600 patients currently in the database, COMPERA documents 6,600 patients with PAH (Group 1), and 6,000 patients with non-PAH pulmonary hypertension (Groups 2-5).

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. COMPERA investigators are experts in the treatment of pulmonary hypertension, mostly pneumologists and cardiologists. Patients without written informed consent and those not available for long-term follow-up are also not documented.

Population

Population size

13500

Active population size

10000

Median observation time

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

4.00

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

3.80

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).

COMPERA Home Page

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 are entered into the central database by registered centres. In order to collect adequate data on PAH/PH treatment in routine clinical care, the COMPERA registry has been prospectively documenting consecutive patients with newly initiated treatment for PAH/PH since May 2007 (since 2014 mainly patients with newly diagnosed disease). The web-based registry meets high quality standards through several measures (planned minimum centre contribution of at least 10 patients per year, automated plausibility checks of data at entry, queries, monitoring with source data verification in >50% of participating centres).

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

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

Diagnosis of Pulmonary (Arterial) Hypertension

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

Linkage description, possible linkage

The data source may potentially be linked with additional data sources, such as for comparisons with other registries; however, the specific methods for such linkage are 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)

15 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

31/03/2024

Common Data Model (CDM) mapping

CDM mapping

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

No