Advancing the Patient Experience in Chronic Obstructive Pulmonary Disease (COPD) Registry

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Data source **Human** **Disease registry** **Other**

Primary care medical records

Administrative details

Administrative details

PURI

https://redirect.ema.europa.eu/resource/34713

Data source ID

34713

Data source acronym

APEX COPD Registry

Data holder

Optimum Patient Care (OPC)

Data source type

Disease registry

Other

Primary care medical records

Data source type, other

Prospective studies database, Retrospective studies database

Main financial support

Funding by own institution

Care setting

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.apexcopd.org

Contact details

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Data source regions and languages

Data source countries

United States

Data source languages

English

Data source regions

Colorado

New York

North Carolina

Ohio

Texas

Data source establishment

Data source established

15/06/2019

Data source time span

First collection: 15/02/2020

The date when data started to be collected or extracted.

Last collection: 10/07/2020

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

Publications

Data source publications

COPD Population in US Primary Care: Data From the Optimum Patient Care DARTNet Research Database and the Advancing the Patient Experience in COPD

Registry

Development of the Advancing the Patient Experience in COPD Registry: A Modified Delphi Study

Variation in Demographic and Clinical Characteristics of Patients with COPD Receiving Care in US Primary Care: Data from the Advancing the Patient EXperience (APEX) in COPD Registry

Advancing the Patient EXperience (APEX) in COPD Registry: Study Design and Strengths

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

Chronic obstructive pulmonary disease

Disease details (other)

Free text CT scan and spirometry data for chronic obstructive pulmonary disease.

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

No

ICU admission

Is information on intensive care unit admission available?

No

Cause of death

Not Captured

Prescriptions of medicines

Captured

Prescriptions vocabulary

RxNorm

Dispensing of medicines

Captured

Dispensing vocabulary

RxNorm

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)].

Yes

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

CPT

SNOMED CT

Medical devices

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

No

Administration of vaccines

Yes

Procedures

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

Captured

Procedures vocabulary

CPT

Other

SNOMED CT

Procedures vocabulary, other

CPT4

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?

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?

Yes

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

ICD-10

ICD-9

Other

SNOMED CT

Diagnosis / medical event vocabulary, other

LOINC

Medicinal product information

Captured

Medicinal product information collected

Brand name

Package size

Medicinal product vocabulary

RxNorm

Quality of life measurements

Captured

Quality of life measurements vocabulary

Not coded (Free text)

Lifestyle factors

Captured

Lifestyle factors

Frequency of exercise

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Deprivation index

Ethnicity

Gender

Quantitative descriptors

Population Qualitative Data

Population age groups

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

0.33% Denominator: Estimated total prevalence of COPD in 5 catchment cities

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)

Regional sub-set - The data is procured primarily from primary care sites in a subset of North American states (Colorado, Texas, North Carolina, New York, Ohio, Tennessee and Virginia)

Population

Population size

1354

Active population size

1354

Population by age group

Age group	Population size	Active population size
Adults (18 to < 46 years)	15	15
Adults (46 to < 65 years)	423	423
Elderly (≥ 65 years)	916	916
Adults (65 to < 75 years)	509	509
Adults (75 to < 85 years)	305	305
Adults (85 years and over)	102	102

Median observation time

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

6.27

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

APEX COPD collects de-identified Electronic Medical Records (EMR) patient data from participating GP practices. EMR data is supplemented with patient reported information/outcome data.

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

Practice deregistration

Event triggering creation of a record in the data source

Patient visit

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)?

No

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

Data source last refresh

15/11/2020

Common Data Model (CDM) mapping

CDM mapping

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

Yes

CDM Mappings

CDM name

OMOP

CDM website

https://www.ohdsi.org/Data-standardization/

Data source ETL CDM version

6.0.0

Data source ETL frequency

12,00 months

Data source ETL status

Completed

Data source ETL specifications (link)

https://www.ohdsi.org/data-standardization/