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

**First published:** 01/02/2024

**Last updated:** 17/11/2026

Data source | Human | Disease registry | Other | Primary care medical records

## Administrative details

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**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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**Main**

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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.

# 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

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**Disease details**

Chronic obstructive pulmonary disease

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**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

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### Procedures vocabulary

CPT

Other

SNOMED CT

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### Procedures vocabulary, other

CPT4

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### 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

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### Clinical measurements

Is information on clinical measurements (e.g., BMI, blood pressure, height) available?

Yes

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### Genetic data

Are data related to genotyping, genome sequencing available?

Not Captured

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### 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 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)

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**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

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**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**

1.354

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**Active population size**

1.354

## 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

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**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

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

Death

Practice deregistration

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**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/