# Collaboration on Quality Improvement Initiative for Achieving Excellence in Standards of COPD Care

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**Last updated:** 17/10/2025

Data source

Human

Disease registry

**Primary care medical records** 

# Administrative details

## Administrative details

#### **Data source ID**

42513

#### Data source acronym

**CONQUEST - COPD** 

#### **Data holder**

Optimum Patient Care (OPC)

#### **Data source type**

Disease registry

Primary care medical records

#### Main financial support

Funding by own institution

Funding from industry or contract research

#### **Care setting**

Primary care - GP, community pharmacist level

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**

https://opcrd.co.uk/

# Contact details

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# Data source regions and languages

#### **Data source countries**

**United Kingdom** 

#### **Data source languages**

English

#### **Data source regions**

East Riding of Yorkshire

North Yorkshire

Staffordshire

Stoke-on-Trent

York

### Data source establishment

#### Data source established

15/06/2021

#### **Data source time span**

First collection: 01/10/2021

The date when data started to be collected or extracted.

# 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

#### **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

Not Captured

#### **Prescriptions of medicines**

Captured

### **Prescriptions vocabulary**

other

#### Prescriptions vocabulary, other

SNOMED, dm+d, READV2

#### **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?

Yes

#### **Administration of vaccines**

Yes

#### **Procedures**

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

Captured

#### **Procedures vocabulary**

Other

**SNOMED CT** 

#### Procedures vocabulary, other

READV2

#### **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.

Captured

#### Biomarker data vocabulary

Other

#### Biomarker vocabulary, other

SNOMED. READV2

#### **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.

No

#### **Unique identifier for persons**

Are patients uniquely identified in the data source?

Yes

#### **Diagnostic codes**

Captured

#### Diagnosis / medical event vocabulary

Other

**SNOMED CT** 

#### Diagnosis / medical event vocabulary, other

READV2, READV3

#### **Medicinal product information**

Captured

## **Medicinal product information collected**

Dose		
Package size		
Medicinal product vocabulary		
dm+d		
SNOMED		
Quality of life measurements		
Not Captured		
Lifestyle factors		
Captured		
Lifestyle factors		
Frequency of exercise		
Tobacco use		
Sociodemographic information		
Captured		
Sociodemographic information collected		
Age		
Ethnicity		
Gender		
Quantitative descriptors		

Population Qualitative Data

Brand name

#### **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

25%. Denominator = COPD patients registered at practices within the CONQUEST localities.

# 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 - Data is procured from different sites within various integrated healthcare systems in the region(s) or country, namely primary care sites or GP practices.

# **Population**

#### **Population size**

58088

#### **Active population size**

24360

# Population by age group

Age group	Population size	Active population size
Adults (18 to < 46 years)	481	180
Adults (46 to < 65 years)	12728	7542
Elderly (≥ 65 years)	44897	16638
Adults (65 to < 75 years)	14272	7053
Adults (75 to < 85 years)	18164	6810
Adults (85 years and over)	12443	2775

# Median observation time

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

26.00

Median time (years) between first and last available records for unique active individuals (alive and currently registered) capt 27.00

# 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://www.regresearchnetwork.org/adept-committee/

#### **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**

The data source is electronic medical record (EMR) data from participating GP practices. At the end of the outcome evaluation period, the study team will receive a single, fully anonymised dataset of EMR data from participating practices. Extracted EMR data will contain both structured or coded entries (Read, SNOMED and ICD10 codes), and unstructured information (e.g. clinical notes). EMR data will be supplemented with patient reported information/outcome data in a subgroup of patients. collected during the associated trial (PREVAIL).

# 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

Loss to follow up

#### 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?

Yes

#### Linkage description, possible linkage

CONQUEST collects patient electronic medical records (EMR), supplemented with patient reported information/outcome data in a subgroup of patients. This data collected in primary care can be linked to secondary care/hospital data for the relevant patients. GP Practices participating in CONQUEST have consented to linkage of primary care data from CONQUEST in OPCRD to HES data supplied by NHS Digital/England via OPCRD-NEXUS. OPCRD has NHS HRA Research Ethics Committee (REC) approval, and CAG Section 251 approval (CAG Ref: 21/CAG/0001) to undertake quarterly, deterministic, patient-level linkage of HES data which is held in a separate database named OPCRD-NEXUS. The linkage involves approved use of direct patient identifiers (i.e. NHS number, data of birth, sex) which are securely transferred from participating sites to NHS Digital, with options for patient to opt out. Access to anonymised primary care and HES linked research datasets will be provided to ADEPT- approved researchers for study analysis and research. Further information is available at https://www.opcrd.optimumpatientcare.org/opcrd-nexus

#### Linked data sources

#### **Pre linked**

Is the data source described created by the linkage of other data sources?

No

#### Data source, other

Hospital Episode Statistics (HES)

#### Linkage strategy

Deterministic

#### Linkage variable

The CONQUEST database could be linked to other data sources using individual patient NHS numbers. Specifically for England Hospital Episodes Statistics HES data linkage, the linkage variables are patient NHS numbers, date of births, sex and unique OPCRD study ID. OPC would perform the linkage of the required dataset and run or perform the analysis of the dataset on behalf of the applicant and supply the applicant with an anonymised (aggregated and small-number suppressed) output dataset for further analysis.

#### Linkage completeness

Estimated linkage completeness is 60-80%, though true percentage will be determined upon actual linkage.

Data management specifications that apply for the data source

#### **Data source refresh**

Monthly

#### 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 committee to evaluate requests for data access

#### **Data source last refresh**

05/08/2023

# Common Data Model (CDM) mapping

#### **CDM** mapping

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

No