

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

First published: 01/02/2024

Last updated: 17/10/2024

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

Brand name

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

Population age groups

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Elderly (\geq 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 (\geq 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) captured

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