European Multicentre Bronchiectasis Audit and Research Collaboration

First published: 01/02/2024

Last updated: 17/10/2024

Data source Human Disease registry

Administrative details

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Data source ID

18465

Data source acronym

EMBARC

Data holder

University of Dundee

Data source type

Disease registry

Main financial support

European public funding

Funding from industry or contract research

Care setting

Secondary care – specialist level (ambulatory)

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://hicservices.dundee.ac.uk/bronchiectasiseu/embarcregistry

Contact details

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(Main)

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Data source regions and languages

Data source countries

Austria

Belgium

Bulgaria

Croatia

Czechia

France

Germany

Greece

Ireland

Italy

Lithuania

Malta

Netherlands

Portugal

Spain

Switzerland

United Kingdom

Data source languages

English

Data source establishment

Data source established

02/03/2015

Data source time span

First collection: 02/03/2015

The date when data started to be collected or extracted.

Publications

Data source publications

Criteria and definitions for the radiological and clinical diagnosis of bronchiectasis in adults for use in clinical trials: international consensus recommendations. Aliberti S, Goeminne PC, O'Donnell AE, Aksamit TR, Al-Jahdali H, Barker AF, Blasi F, Boersma WG, Crichton ML, De Soyza A, Dimakou KE,

Elborn SJ, Feldman C, Tiddens H, Haworth CS, Hill AT, Loebinger MR, Martinez-Garcia MA, Meerburg JJ, Menendez R, Morgan LC, Murris MS, Polverino E, Ringshausen FC, Shteinberg M, Sverzellati N, Tino G, Torres A, Vandendriessche T, Vendrell M, Welte T, Wilson R, Wong CA, Chalmers JD

Bronchiectasis in Europe: data on disease characteristics from the European Bronchiectasis registry (EMBARC). James D Chalmers, Eva Polverino, Megan L Crichton, Felix C Ringshausen, Anthony De Soyza, Montserrat Vendrell, Pierre Regis-Burgel, Charles Haworth, Michael R Loebinger, Katerina Dimakou, Marlene Murris, Robert Wilson, Adam T Hill, Rosario Menendez, Antoni Torres, Tobias Welte, Francesco Blasi, Josje Altenburg, Michal Shteinberg, Wim Boersma, J. Stuart Elborn, Pieter C Goeminne, Stefano Aliberti, On behalf of the EMBARC registry investigators.

Characterization of Eosinophilic Bronchiectasis: A European Multicohort Study. Shoemark A, Shteinberg M, De Soyza A, Haworth CS, Richardson H, Gao Y, Perea L, Dicker AJ, Goeminne PC, Cant E, Polverino E, Altenburg J, Keir HR, Loebinger MR, Blasi F, Welte T, Sibila O, Aliberti S, Chalmers JD.

Endotyping Chronic Obstructive Pulmonary Disease, Bronchiectasis, and the "Chronic Obstructive Pulmonary Disease-Bronchiectasis Association. Huang JT, Cant E, Keir HR, Barton AK, Kuzmanova E, Shuttleworth M, Pollock J, Finch S, Polverino E, Bottier M, Dicker AJ, Shoemark A, Chalmers JD

Comparison of different sets of immunological tests to identify treatable immunodeficiencies in adult bronchiectasis patients. Aliberti S, Amati F, Gramegna A, Vigone B, Oriano M, Sotgiu G, Mantero M, Simonetta E, Saderi L, Stainer A, Tammaro S, Marchisio P, Polverino E, Chalmers JD, Blasi F.

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 (other)

Bronchiectasis

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

Captured

Cause of death vocabulary

Not coded (Free text)

Prescriptions of medicines

Captured

Prescriptions vocabulary

other

Prescriptions vocabulary, other

Predefined drop down options are available for selection

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

Not coded (Free text)

Medical devices

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

Yes

Administration of vaccines

No

Procedures

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

Captured

Procedures vocabulary

Not coded (Free text)

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?

Captured

Genetic data vocabulary

Other

Genetic data vocabulary, other

Not coded (free text)

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 (free text)

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

Not Captured

Medicinal product information

Captured

Medicinal product information collected

Active ingredient(s)

Route of administration

Medicinal product vocabulary

Not coded (Free text)

Quality of life measurements

Captured

Quality of life measurements vocabulary

QOLS

Lifestyle factors

Captured

Lifestyle factors

Tobacco use

Sociodemographic information

Captured

Sociodemographic information collected

Age

Gender

Ethnicity

Country of origin

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

Hard to estimate accurately. There are an estimated 200,000 people with bronchiectasis in the UK and registry includes approximately 8000 patients (<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 prospectively enrolled into the registry.

Population

Population size

16963

Active population size

15000

Population by age group

Age group	Population size
Adults (18 to < 46 years)	2019
Adults (46 to < 65 years)	5001
Elderly (≥ 65 years)	9943
Adults (65 to < 75 years)	5891
Adults (75 to < 85 years)	3540
Adults (85 years and over)	512

Median observation time

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

2.00

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

2.00

Data flows and management

Access and validation

Biospecimen access

Are biospecimens available in the data source (e.g., tissue samples)?

Yes

Biospecimen access conditions

Available to partners and project participants. External parties may apply to access the biospecimens or join the consortium.

Access to subject details

Can individual patients/practitioners/practices included in the data source be contacted?

Yes

Description of data collection

Medical notes, questionnaires and study forms

Event triggering registration

Event triggering registration of a person in the data source

Disease diagnosis

Start of treatment

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

Death

Practice deregistration

Loss to follow up

Event triggering creation of a record in the data source

Specialist encounter

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

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)

10 years

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

Common Data Model (CDM) mapping

CDM mapping

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

No