

# Epidemiological trends of Alpha1-antitrypsin deficiency (AATD) in the UK: prevalence and incidence from 1990 to 2015

**First published:** 29/11/2017

**Last updated:** 08/08/2024

Study

Finalised

## Administrative details

### EU PAS number

EUPAS21791

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### Study ID

28295

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### DARWIN EU® study

No

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### Study countries

United Kingdom

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### Study description

This exploratory protocol aims to determine the epidemiological trends of Alpha1-antitrypsin deficiency (AATD) in the UK: frequency of testing, prevalence and incidence from 1990 to 2015. It will also aim to determine the demographic and clinical characteristics associated with AATD.

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## Study status

Finalised

## Research institutions and networks

### Networks

#### Respiratory Effectiveness Group (REG)

- Belgium
- Denmark
- France
- Germany
- Greece
- Hungary
- Italy
- Netherlands
- Spain
- Sweden
- United Kingdom

**First published:** 07/07/2021

**Last updated:** 04/06/2024

**Network**

**ENCePP partner**

## Contact details

### Study institution contact

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Study contact

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### Primary lead investigator

Joan Soriano

Primary lead investigator

## Study timelines

### Date when funding contract was signed

Actual: 27/09/2017

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### Study start date

Actual: 27/09/2017

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### Data analysis start date

Actual: 04/10/2017

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### Date of interim report, if expected

Actual: 17/10/2017

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### Date of final study report

Actual: 01/06/2018

## Sources of funding

- Other

## More details on funding

Respiratory Effectiveness Group

## Study protocol

[REG pilot AATD project.pdf](#) (754.04 KB)

## Regulatory

**Was the study required by a regulatory body?**

No

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**Is the study required by a Risk Management Plan (RMP)?**

Not applicable

## Methodological aspects

### Study type

### Study type list

**Study topic:**

Disease /health condition

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**Study type:**

Non-interventional study

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**Scope of the study:**

Disease epidemiology

**Data collection methods:**

Secondary use of data

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**Main study objective:**

Pilot study to determine the epidemiological pattern and characteristics of AATD in COPD patients in the UK population. Specifically-1) Prevalence and incidence of AATD, in all and by age and gender. 2) Determine the demographic and clinical characteristics associated with AATD.

## Study Design

**Non-interventional study design**

Cohort

## Study drug and medical condition

**Medical condition to be studied**

Alpha-1 anti-trypsin abnormal

## Population studied

**Short description of the study population**

Individuals who were diagnosed with Chronic obstructive pulmonary disease (COPD) before the age of 60 years, and have been tested for Alpha1-antitrypsin deficiency (AATD) (i.e. Read code for AATD) between 1990 and 2015.

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### **Age groups**

- Adults (18 to < 46 years)
  - Adults (46 to < 65 years)
  - Adults (65 to < 75 years)
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### **Special population of interest**

Other

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### **Special population of interest, other**

Chronic obstructive pulmonary disease (COPD) patients

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### **Estimated number of subjects**

600

## Study design details

### **Outcomes**

Frequency of testing, prevalence and incidence of AATD

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### **Data analysis plan**

This will be an exploratory and descriptive study. Summary statistics will be produced for prevalence and incidence of AATD, by all covariates. The number of patients/observations and percentage per category, mean plus standard deviation and median plus inter-quantile range will be given, as appropriate. Statistical tests (e.g. F-tests, t-tests, chi-squared tests) and models (e.g. linear models) will be used, as appropriate. Statistically significant results

will be defined as  $p < 0.05$ .

## Documents

### Study publications

[Soriano JB, Lucas SJ, Jones R, Miravittles M, Carter V, Small I, Price D, Mahad...](#)

[Soriano JB. Challenges in interpreting trends in testing for  \$\alpha\$ 1-antitrypsin def...](#)

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## Data management

### ENCePP Seal

The use of the ENCePP Seal has been discontinued since February 2025. The ENCePP Seal fields are retained in the display mode for transparency but are no longer maintained.

## Data sources

### Data source(s)

Optimum Patient Care Research Database

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### Data sources (types)

[Electronic healthcare records \(EHR\)](#)

## Use of a Common Data Model (CDM)

### CDM mapping

No

## Data quality specifications

### **Check conformance**

Unknown

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### **Check completeness**

Unknown

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### **Check stability**

Unknown

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### **Check logical consistency**

Unknown

## Data characterisation

### **Data characterisation conducted**

Unknown