# Epidemiological trends of Alpha1antitrypsin deficiency (AATD) in the UK: prevalence and incidence from 1990 to 2015

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### Administrative details

**Study description** 

EU PAS number		
EUPAS21791		
Study ID		
28295		
DARWIN EU® study		
No		
Study countries		
United Kingdom		

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.

### **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
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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

#### Study start date

Actual: 27/09/2017

#### Data analysis start date

Actual: 04/10/2017

#### Date of interim report, if expected

Actual: 17/10/2017

#### 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

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

Not applicable

## Methodological aspects

Study type

Study type list

**Study topic:** 

Disease /health condition

#### Study type:

Non-interventional study

### Scope of the study:

Disease epidemiology

#### **Data collection methods:**

Secondary use of data

#### 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.

#### Age groups

Adults (18 to < 46 years)

Adults (46 to < 65 years)

Adults (65 to < 75 years)

#### Special population of interest

Other

#### Special population of interest, other

Chronic obstructive pulmonary disease (COPD) patients

#### **Estimated number of subjects**

600

## Study design details

#### **Outcomes**

Frequency of testing, prevalence and incidence of AATD

#### 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, Miravitlles M, Carter V, Small I, Price D, Mahad... Soriano JB. Challenges in interpreting trends in testing for  $\alpha$ 1-antitrypsin def...

### 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

### **Data sources (types)**

Electronic healthcare records (EHR)

### Use of a Common Data Model (CDM)

#### **CDM** mapping

## Data quality specifications

### **Check conformance**

Unknown

### **Check completeness**

Unknown

### **Check stability**

Unknown

### **Check logical consistency**

Unknown

### Data characterisation

#### **Data characterisation conducted**

Unknown