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

Study ID

28295

DARWIN EU® study

No

Study countries

United Kingdom

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.

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

Sarah Lucas sarah@effectivenessevaluation.org

Study contact

sarah@effectivenessevaluation.org

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 α1-antitrypsin def...

Data management

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

No

Data quality specifications

Check conformance

Unknown

Check completeness

Unknown

Check stability

Unknown

Check logical consistency

Unknown

Data characterisation

Data characterisation conducted

Unknown