IDENTIFYING OPPORTUNITIES FOR EARLIER DIAGNOSIS OF IDIOPATHIC PULMONARY FIBROSIS IN ROUTINE CARE IN THE UK: A RETROSPECTIVE CLINICAL COHORT STUDY (OPPORTUNITIES FOR EARLIER IPF DIAGNOSIS)

First published: 14/01/2016

Last updated: 02/07/2024

Study Finalised

Administrative details

EU PAS number

EUPAS12086

Study ID

28880

DARWIN EU® study

No

Study countries

United Kingdom

Study description

In the UK, all patients who ultimately receive a diagnosis of IPF will have first presented in the primary care setting. Thus by carrying out a historical review of the primary care records for patient in the years preceding their IPF diagnosis, it should be possible to identify common patterns (trends) in healthcare resource utilization (HRU) and identify potential “red flags” to support decision support tools to aid earlier diagnosis.With a view to identifying potential opportunities for earlier referral to specialists and (ultimately) earlier diagnosis of IPF, this study aims to:(i) Evaluate patients’ patterns of HRU in the years preceding their IPF diagnosis.(ii) Characterise the clinical features of patients at the time of their IPF diagnosis.

Study status

Finalised

Research institutions and networks

Institutions

Observational & Pragmatic Research Institute Pte (OPRI)

United Kingdom

First published: 06/10/2015

Last updated: 20/08/2026

Institution | Educational Institution | Laboratory/Research/Testing facility | ENCePP partner

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

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Primary lead investigator

Study timelines

Date when funding contract was signed

Planned: 29/01/2016

Actual: 29/11/2016

Study start date

Planned: 05/02/2016

Actual: 10/12/2016

Date of final study report

Planned: 28/10/2016

Actual: 21/12/2016

Sources of funding

- Other

More details on funding

Respiratory Effectiveness Group

Study protocol

REG_IPF Earlier Diagnosis Protocol.pdf (449.92 KB)

Regulatory

Was the study required by a regulatory body?

Unknown

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:

With a view to identifying potential opportunities for earlier referral to specialists and (ultimately) earlier diagnosis of IPF, this study aims to:(i) Evaluate patients' patterns of HRU in the years preceding their IPF diagnosis.(ii) Characterise the clinical features of patients at the time of their IPF diagnosis.

Study Design

Non-interventional study design

Other

Non-interventional study design, other

Observational, historical database study

Study drug and medical condition

Medical condition to be studied

Idiopathic pulmonary fibrosis

Population studied

Short description of the study population

• Patients who have a diagnostic for Idiopathic pulmonary fibrosis (IPF) between 1990 and 2015

• Have a minimum of 2 years continuous clinical records in the years

immediately preceding their index diagnosis

• Aged 40 years or older at index date

Age groups

- Adults (18 to < 46 years)
- Adults (46 to < 65 years)
- Adults (65 to < 75 years)
- Adults (75 to < 85 years)
- Adults (85 years and over)

Special population of interest

Other

Special population of interest, other

Idiopathic pulmonary fibrosis (IPF) patients

Estimated number of subjects

2.000

Study design details

Outcomes

1. Consultations including lower respiratory (LR) consultations2. Hospitalisations (in-patient attendances): same day or following 7 days3. Out patient visits with a code for a LR complaint (same day or following 7 days)4. Accident & Emergency attendances coded for a LR complaint (same day or following 7 days)5. Chest X-ray

Data analysis plan

• The analysis will assess changes in HRU over the 25-year period (1990–2015), and in 5-year increments (0–5 years, 6–10 years, 11–15 years, 16–20 years and 21–25 years) • Summary statistics will be used to characterise patients at time of IPF diagnosis:o For variables measured on the interval or ratio scale, summary statistics produced will be:• Sample size (n)• Percentage non missing• Mean• Variance/standard deviation• Range (minimum- maximum)• Median• Inter-quantile range (25th and 75th percentile)o For categorical variable the summary statistics will include:• Sample size (n)• Range • Count and percentage by category (distribution)• Statistically significant results will be defined as $p<0.05$ and trends as $0.05 \leq p<0.10$. • Suitable tests (e.g. F tests, t tests, $\chi 2$ tests) and models (e.g. linear models) will be used, as appropriate, to explore the interaction between different clinical characteristics and features (e.g. year, age) of diagnosis.

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

No

Data quality specifications

Check conformance

Unknown

Check completeness

Unknown

Check stability

Unknown

Check logical consistency

Unknown

Data characterisation

Data characterisation conducted

Unknown