In our case series the presence of pleural thickening on CT was a strong predictor of malignancy. However the majority of malignant cases had no evidence of pleural thickening.

#### Reference.

1. BTS pleural disease guideline - 2010.

#### Abstract P126 Table 1

Diagnosis	Numbers (%)
MALIGNANT	69 (62%)
Adenocarcinoma	21
Mesothelioma	19
Metastasis	13
Lymphoma	7
Squamous cell carcinoma	4
Sarcoma	2
Neuro endocrine tumours	3
BENIGN PLEURAL INFLAMMATION	40 (36%)
SARCOIDOSIS	1 (1%)
TUBERCULOSIS	1 (1%)

## Interstitial lung disease: epidemiology, care and survival

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PREVALENCE AND INCIDENCE OF IDIOPATHIC PULMONARY FIBROSIS IN UK HEALTHCARE DATABASES, GPRD AND THIN; THE NEED FOR AN IPF REGISTRY

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**Background** Idiopathic Pulmonary Fibrosis (IPF) is a fatal respiratory illness with limited treatment options.

We previously estimated the UK prevalence of IPF using The Health Improvement Network (THIN) data. We have now further investigated this using General Practise Research Database (GPRD) data.

**Aims** Calculate the prevalence and incidence of IPF diagnoses in the GPRD in 2010.

Calculate the prevalence of IPF diagnoses in the GPRD in 2007, to compare to the THIN 2007 findings.

Build a matrix of epidemiological data, to better target future public health resources.

**Methods** Descriptive cross-sectional study, using UK GPRD data to calculate the prevalence and incidence of IPF diagnoses in 2010. **Patients** with a Read/OXMIS code corresponding to IPF diagnosis were identified; H563.00 Idiopathic Fibrosing Alveolitis (IFA), H563z00 Idiopathic Fibrosing Alveolitis NOS (IFA NOS), H563.12 Cryptogenic Fibrosing Alveolitis (CFA), H563100 Diffuse Pulmonary Fibrosis (DPF). To investigate coding variability, IPF diagnoses were classified as broad (all codes), narrow (IFA/IFA NOS) and IFA+CFA

**Patients** with a first record of IPF during 2010 were classed as incident. Patients with a first record of IPF prior to or during 2010 were classed as prevalent.

**Results** In 2010 in the GPRD, IPF was most commonly diagnosed in males (56.5%) and ≥65 year olds (80.8%). Most IPF was coded as DPF (prevalence: 39.4 [37.6–41.3] per 100,000 persons; incidence: 9.6 [8.8–10.6] per 100,000 person-years).

For the broad definition, IPF prevalence was 50.7 (48.6-52.8) per 100,000 persons, with an incidence of 11.0 (10.1-12.0) per 100,000 person-years. For the narrow definition, IPF prevalence was 10.1 (9.2-11.1) per 100,000 persons, with an incidence of 1.5 (1.1-1.9) per 100,000 person-years. For the IFA+CFA definition, IPF prevalence was 13.3 (12.3-14.4) per 100,000 persons, with an incidence of 1.6 (1.3-2.0) per 100,000 person-years.

In 2007, compared to THIN, the GPRD IPF point prevalence was lower in both males and females, for all diagnosis definitions (Figure 1).

**Conclusions** IPF rates differ amongst UK healthcare databases; this may be due to GP coding variability, which is an inherent limitation of database studies. A prospective IPF registry is essential to characterise this orphan disease, to better target future public health resources.

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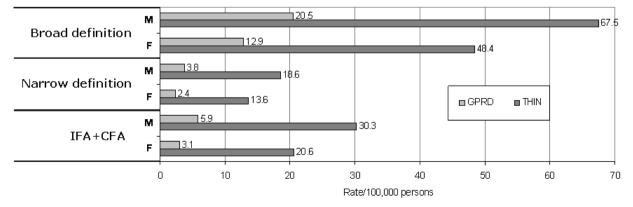
### PRACTISE PATTERNS IN IDIOPATHIC PULMONARY FIBROSIS: RESULTS OF A UK PHYSICIAN SURVEY

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**Introduction and objectives** Idiopathic pulmonary fibrosis (IPF) is a rare, progressive, fibrotic lung disorder that results in reduced lung capacity, disability and ultimately death. Its rarity, and the fact that many of its initial symptoms are common to other lung diseases, mean that it is often mis-diagnosed and patients can experience wide variations in standards of care. We conducted a survey of

Figure 1: Gender- and diagnosis-specific point prevalence of IPF in 2007, GPRD compared to THIN



Abstract P127 Figure 1

pulmonary physicians to better understand practise patterns and unmet needs in IPF.

**Methods** In December 2010 – January 2011, a structured, quantitative survey was conducted with lung specialists in IPF and non-IPF specialist centres principally in five EU countries (Germany, Italy, Spain, UK, France [5EU]). The survey was extended to a further five countries where fewer physicians were targeted. The survey covered clinical practise patterns over the preceding 12 months. Data from the UK are presented here.

**Results** The 5EU sample included 232 participating physicians. Of these, 26 were from the UK, with 15 from specialist IPF centres, and 11 from general lung clinics. Among the UK clinics, 46% of patients had stable IPF, versus 56% with progressive disease (51% versus 49% respectively for 5EU). Triple therapy (steroid + immunosuppressant + N-acetylcysteine [NAC]) was prescribed for 31% of UK patients versus 25% for 5EU. Nineteen percent of UK IPF patients went untreated, and a further 10% received palliative care. Steroid monotherapy was used in another 10% of UK patients, and 11% received steroid + immunosuppressant. NAC + steroids were used in only 5% of patients, and NAC alone in 6%.

**Conclusion** IPF is a serious condition, but no standard therapy exists, and many patients receive no treatment or palliative care only. Current therapies are ineffective and unproven. At the time of the survey triple therapy remained prevalent; however, concerns have now been raised regarding AEs and risks of death and hospitalisation. There is therefore an unmet need for effective and well-tolerated therapies to enable a greater range of patients to be treated with agents that have been proven to be safe and effective in clinical trials.

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# PATIENT AND PHYSICIAN DEMOGRAPHICS IN IDIOPATHIC PULMONARY FIBROSIS: RESULTS OF A UK PHYSICIAN SURVEY

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**Introduction and Objectives** Idiopathic pulmonary fibrosis (IPF) is a rare, progressive, fibrotic lung disorder of unknown origin, which leads to difficulty in breathing, functional disability and death. Due to symptomatic similarities with other lung conditions, IPF is difficult to diagnose, and patients experience varying standards of care. We undertook a survey of European pulmonologists to gain additional understanding of the characteristics of patients with IPF and the demographics of the physicians treating them.

**Methods** In December 2010–January 2011, a quantitative survey was conducted with lung specialists in IPF and non-IPF specialist centres in five principal EU countries (Germany, Italy, Spain, UK, France [5EU]). The survey was extended to a further five countries where fewer physicians were targeted. UK data are reported here.

Results The total number of patients seen by all the centres in the survey in the preceding 12 months was 7,302, 149 of which were from the UK. Among the UK patients, 87% were aged ≤85 years, which is similar to the value for 5EU (85%). Sixty percent of newly diagnosed UK patients were aged 65–80 years (5EU=56%), in contrast to 50% of the whole UK sample (5EU=57%). In 5EU, 70% of IPF patients were managed by 35% of pulmonologists, in contrast to the UK where 80% of patients were managed by 55% of pulmonologists. In the UK, 70% of pulmonologists were seeing fewer than 110 IPF patients annually, whereas in the 5EU, 70% of pulmonologists were seeing <30 IPF patients annually. Regional differences in the UK largely reflect population distribution with 14% of Scottish pulmonologists seeing ≥30 IPF patients, versus 33% for the north of England, 24% for the Midlands and Wales, and 29% for the south of England.

**Conclusion** In the UK, patient demographics for IPF were similar to the rest of Europe, but UK patients were being diagnosed at a younger age than previously compared to the rest of the EU. Importantly, the UK had a much wider spread of IPF patients among treating pulmonologists than the rest of Europe, which indicates a greater distribution of expertise in treating the disease.

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### LIVING WITH IDIOPATHIC PULMONARY FIBROSIS: RESULTS OF A EUROPEAN PATIENT SURVEY

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**Introduction and Objectives** Idiopathic pulmonary fibrosis (IPF) is a rare, fibrotic, progressive lung disease that results in shortness of breath and difficulty in breathing. IPF commonly presents with crackling sounds in the lungs discernable via stethoscopic auscultation. IPF is most prevalent in patients >50 years of age. Risk factors include smoking and environmental exposures (metal, wood dust and other airborne pollutants). Disease progression features clubbing of the fingers, increasing difficulty in breathing, requirement for supplemental oxygen and/or lung transplantation. IPF is ultimately fatal. We conducted a European survey of diagnosed IPF patients to identify unmet needs in the management of IPF and opportunities to improve care.

**Methods** Patients in Germany, France, Italy, Spain and the UK with a confirmed diagnosis of IPF underwent a structured interview at home. In some instances, involved carers were also interviewed. The interviews featured associative questions where images were selected to express feelings, and constructive questions where factual recall was tested. Patient emotions were mapped according to four principle stages of the patient journey: 1. Symptoms, 2. Initial diagnosis, 3. After diagnosis, and 4. Disease management.

**Results** Forty-five patients (median age 67 years) and 18 care givers were interviewed for the survey. In 58% of cases, diagnosis was protracted due to dismissal of symptoms and misdiagnosis. Patients could be categorised in one of four ways (combative, serene, dejected and stoic) based chiefly on their age and attitude to disease management. Patients expressed a range of emotions at the point of diagnosis, and diagnosis was recognised as a time at which the patient-doctor relationship could break down. Patients treated in specialist centres reported better satisfaction with care than those treated by generalists. The patients cited negative impacts of IPF on almost all aspects of their lives, which could lead to depression. Keeping fit was acknowledged as a means to control disease symptoms and maintain a positive outlook.

**Conclusion** IPF has an enormous impact on patient quality of life, and patients are affected differently by the disease and its diagnosis. Emotional support and participation in patient support groups should be considered a key component of IPF management.

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WHAT IS THE EVIDENCE FOR PHARMACOLOGICAL AND NON-PHARMACOLOGICAL INTERVENTIONS IN IMPROVING DYSPNOEA, OTHER SYMPTOMS AND QUALITY OF LIFE IN PROGRESSIVE IDIOPATHIC FIBROTIC INTERSTITIAL LUNG DISEASE?- A SYSTEMATIC REVIEW OF THE LITERATURE

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