British Thoracic Society

The British Thoracic Society Interstitial Lung Disease Registry Programme Annual Report 2014/15

"BTS continues to lead the way in harmonising the capture of valuable demographic and clinical information on IPF and Sarcoidosis patients onto a national database to enable better understanding and management of these life-threatening conditions. Preliminary analysis of the data obtained so far has highlighted some areas of best practice. However the data also pin-points key areas requiring much improvement and investment to enhance the quality of care for IPF and sarcoidosis patients across the country. These improvements in services are now much more critical than ever, given the recent treatment options for IPF that could slow disease progression. For sarcoidosis patients the challenge remains for managing a multi-system disease which can be severe and unresponsive to first-line corticosteroid therapy.'

Professor Monica Spiteri, Chair, BTS Lung Disease Registry Steering Committee

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Foreword

We are working in an NHS in which demand grows faster than funding, and if we are going to argue the corner for our patients with respiratory disease it is vital for us to have good data. We need information about the size of the problem, and we need to be able to show where current care is sub-optimal but could be improved with new resource, targeting this for maximal benefit to patients. The ILD Registry will serve this purpose and more.

As it builds it will provide a picture of the prevalence of IPF and sarcoidosis , their natural history and of outcomes on differing treatment. It will allow centres to compare themselves with others and help in the constant effort to improve their standards of patient care. It may come to have a role in benchmarking for specialised commissioning. Indeed, as this latest report shows, there is already data of interest. It is useful for example in IPF, to see how performance compares with that recommended in NICE's Quality Standards (see page 8).

In short, there are many good reasons for the BTS to support this Registry and help it grow. I am grateful to all those who have helped prepare this report, to all those who contribute data, and to the Registry Steering Committee, particularly Monica Spiteri who continues to chair this so ably.

Dr Bernard Higgins
Chair
BTS Executive Committee

Introduction

This is the second annual report from the BTS Idiopathic Pulmonary Fibrosis (IPF) and Sarcoidosis Registries, and the first to provide an overview of data collected since the Registry launched in 2013. The data analysis is preliminary and is based on the clinical metrics and experiences obtained from the Hospital Trusts across the UK who have actively engaged with the Registry. Nevertheless, there are meaningful messages emerging of good clinical practice as well as other crucial areas in the patients' care pathway that need urgent attention and improvement.

The BTS IPF and Sarcoidosis Registry continues to be a work in progress and like any other 'live e-platform' remains intuitive to its end-users and the changing clinical landscape. In the past year, supported by external short term funding, we have updated the platform to improve and streamline the datasets and to ease data upload. We have also been working with the British Lung Foundation (BLF) and other key stakeholders to ensure that the Registry becomes part of future interstitial lung disease (ILD) integrated care pathways and service commissioning. This BTS Registry Programme is absolutely essential in moving forward priorities in ILD care services and delivery to achieve the best quality standards for patients with IPF and sarcoidosis.

Professor Monica Spiteri
Chair
BTS Lung Disease Registry Steering Committee

BTS Lung Disease Registry Steering Committee Membership:

Professor Monica Spiteri, Chair
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Registry Ambitions

The BTS Lung Disease Registry for Idiopathic Pulmonary Fibrosis (IPF) and for Sarcoidosis launched in February 2013. In line with the overall objectives of the British Thoracic Society, this Registry has been designed to provide an on-going longitudinal national database that tracks demographic and clinical outcome data on patients with IPF and Sarcoidosis. By providing a secure, electronic, easily accessible system for prospective datasets in a large number of patients, it is anticipated that the public health and epidemiological status of these two conditions in the UK can be established.

IPF and sarcoidosis were selected as two of the most common Interstitial Lung Diseases (ILDs) with around 5000 new cases of IPF and 3000 new cases of sarcoidosis a year in the UK. Both diseases can pose significant challenges for clinicians, with diagnosis requiring expert integration of clinical, radiological and, when available, pathological data. Furthermore, management of these two conditions often requires multidisciplinary working with both specialist and community-based input throughout the patients' journey.

With patient consent, routine clinical data including demographic and socio-economic data for all adults newly diagnosed with IPF and sarcoidosis from 1 January 2013 onwards can be collected; all eligible centres (secondary care and ILD specialist respiratory clinics) across the UK are encouraged to participate. The Registry provides vital information on the natural disease behaviour, mode of patient referral to specialist, diagnostic trends and clinical outcomes of IPF and sarcoidosis. Data also includes treatments used and referral to other key services.

The over-arching ambition is for the Registry to serve as a valuable tool to aid clinical practice and improve standards of care for patients. Each participating Hospital Trust can produce customised reports on data entered on its IPF and sarcoidosis patients. Such data allows audit of current local practice, which can be benchmarked against nationally set quality standards of care or peer metrics. The information will hopefully also enable individual centres to develop ILD business cases for particular under-resourced or inaccessible services.

The power of such data cannot be underestimated. Looking at the NHS landscape and the way it is evolving, it is inevitable that future healthcare service commissioning and support in ILD will be driven by patient-related specific metrics and clinical outcomes. In 2013, NHS England, working through a series of Clinical Reference Groups (CRGs), produced more than 175 new service specifications. The service specification for ILD details the requirements expected from specialised service providers in terms of the quality of care and treatment to be offered to ILD patients (amongst others). These developments led to the set-up of 'specialist' ILD centres across the regions working in networks with nearby healthcare-providers. However, these designated centres have yet to receive formal commissioning approval. It is possible that as part of the evolving changes to service provision and access across the NHS, specialised commissioning of ILD services wholly or partly could be devolved to reorganised regional/ local commissioning networks. Thus the case for having a BTS Registry Programme for IPF and sarcoidosis against which local care provision could be benchmarked becomes even more critical.

In due course, it is anticipated that BTS Registry datasets could also facilitate clinical and applied research and be part of the National Institute of Health Research (NIHR) portfolio studies on IPF and sarcoidosis.

Registry Ethics Approval, Information Governance and Data Security

Ethical approval for the British Thoracic Society Interstitial Lung Disease Registry Project (12/EE/0381) was granted on 24 October 2012 by the NRES Committee East of England. Patient consent must be obtained before any patient information is entered on to the Registry. Information for patients and copies of consent forms are available on the Registry website: www.brit-thoracic.org.uk/audit-and-quality-improvement/bts-lung-disease-registry-programme/.

Participating centres are required to provide confirmation of approval to participate from the Caldicott Guardian before access is granted to allow Registry data entry.

All patient identifiable data (e.g. name, date of birth, postcode) is encrypted when saved to the Registry system, and will be visible only to the Registry users in the centre that has entered the patient details. No patient identifiable data is available to the BTS Registry Administrators. The British Thoracic Society Information Governance Policy and associated data security policy documents are available on the BTS website at:

https://www.brit-thoracic.org.uk/about-bts/governance/

The BTS Idiopathic Pulmonary Fibrosis (IPF) Registry

Background

Idiopathic pulmonary fibrosis (IPF) is a progressive lung disease of unknown cause characterised by variable degrees of inflammation and scarring. The aetiology of IPF is not known, although possible risk factors may include infectious agents, gastro-oesophageal reflux and genetic factors. The true incidence of IPF is unknown, but it is estimated that annually there are 5,000 new cases of IPF or an incidence rate of 7-9 per 100,000. Prevalence rate is estimated to be 15-25 per 100,000 but increases with age giving a current UK prevalence of approximately 15,000. Prevalence remains relatively low because unfortunately about 5,000 patients with IPF per annum die of their disease. (1)

The reported median survival in IPF is 3 years from diagnosis; it has a poorer prognosis than cancer of the colon, breast or ovary. Only 20% of patients survive to 5 years post-diagnosis. However these figures were obtained pre-introduction of new drugs for IPF and it remains to be determined how survival will be affected in future following the widespread use of such treatments.

Importantly, it is now evident that the incidence of IPF has rapidly risen with a 35% increase in diagnosed cases between 2000 and 2008, and is continuing to do so. The average age at diagnosis is 70yrs, but the rising incidence has been shown not to be a consequence of an ageing population.

The disease poses significant challenges for clinicians: diagnosis and management of IPF requires a multi-disciplinary approach and expert integration of clinical, radiological and, when available, pathological data. Diagnostic precision is critical to distinguish IPF from other interstitial lung diseases that may respond to immunosuppressant agents including corticosteroids. Corticosteroids are not recommended for treating IPF (2) but can be considered in the setting of acute exacerbations of IPF.

Over the past 2 years there have been a number of important developments. In July 2013 the first NICE-approved drug to treat IPF in the UK became available – Pirfenidone (Esbriet®) (3). However its use is currently limited to patients with a forced vital capacity (FVC) between 50 to 80% predicted only and if patients progress significantly whilst on drug it has to be stopped as defined by NICE criteria. In 2014, a second drug, Nintedanib (Ofev®) was licenced for use in IPF; this is currently available for use in England under the Patient in Need programme for IPF whilst undergoing formal NICE appraisal (4). In Scotland, following assessment under the orphan process, Nintedanib is accepted for restricted use within NHS Scotland in adults for the treatment of IPF where patients have a predicted FVC less than or equal to 80%. Both these drugs are "first-in-class" products and have been shown in clinical trials to significantly slow disease progression and have an impact on survival.

These advances in IPF treatment have been underpinned by a clear care pathway for the diagnosis and management of adults with suspected IPF from the National Institute for Health and Care Excellence (NICE) (2013) and more recently published NICE Quality Standards of Care for IPF patients (2015) (2, 5). These quality standards set the bar for the presence of a core multidisciplinary team around the patient and for cross-boundary working between specialist and community-based teams to provide seamless access to key services such as pulmonary rehabilitation and palliative care at appropriate disease stages for patients with IPF.

Despite these positive and very welcome advances in IPF management, many questions remain unanswered about this devastating disease. There is still much to learn about IPF and how its care is delivered across the NHS. Furthermore, the precise patient groups that would clearly benefit from the new IPF drugs remain to be defined. Data collected through the Registry will hopefully start to address these questions.

Criteria for inclusion in the IPF Registry

Participating centres are requested to enter data on patients who meet the following inclusion criteria:

- Patients with definite or strongly suspected idiopathic pulmonary fibrosis.
- Patients with a new diagnosis of IPF made at a clinic visit from 1 January 2013 onwards or
- Patients with a historical diagnosis of IPF seen for the first time in the clinic at the participating centre from 1 January 2013.

Patients with non-idiopathic disease (for example, those with a history of significant asbestos exposure, strong possibility of sub-clinical or evolving connective tissue disease or clear history of exposure to drugs known to cause interstitial lung disease) are not eligible for inclusion in the IPF Registry.

Data entry for individual patient records is organised into three sections:

- Patient information (age, gender, co-morbidities etc).
- Clinical features (clinical information including lung function data available at the time the patient is entered on to the Registry).
- Follow-up information (clinical information added at 6 months and then 12 month intervals following the entry onto the Registry).

Participating centres

The Registry is open to all secondary care institutions in England, Scotland, Wales and Northern Ireland.

At the end of July 2015, 30 Trusts/Health Boards had obtained approval to participate and a further 23 centres had the approval process underway. 24 centres have uploaded data to the Registry, and the full list of participating Trusts is given on page 15.

Information on participating centres

A brief survey of participating centres was undertaken in July 2015. Of the 20 centres that contributed to the survey:

- 70% (14/20) were university /teaching hospitals
- 30% (6/20) were district general hospitals.

ILD referrals: The average (mean) number of new ILD referrals per annum (based on estimates for the last available 12 month period) were:

- university/teaching hospital: 354 per annum (range from 100 to 564)
- district general hospital: 83 per annum (range from 20 to 200)

Clinics: 100% (14/14) of the University/teaching hospitals run a dedicated ILD clinic for ILD patients only. Of the district general hospitals, 50% run a dedicated ILD clinic and in the remaining 50% ILD patients are seen as part of general respiratory clinics.

IPF Registry Data

At 1 October 2015, 24 centres had contributed data to the IPF Registry:

Patient records - demographic information
660 patient records

Diagnosis
508 complete clinical records - diagnosis information

Follow-up
252 follow-up records

Gender	76% (504/660) Male 24% (156/660) Female
Age	34% (224/660), aged 61-70 56% (368/660), aged 71 and over Mean: 71 years SD: +/- 10
Smoking history	4% (29/660) patients current smokers 67% (443/660) ex-smokers 26% (172/660) never smoked 2% (16/660) not known
Clinical presentation	
Duration of chest symptoms prior to presentation at the clinic	47% (308/660) of patients recorded on the Registry had chest symptoms for more than 24 months before presentation at the clinic visit (see Figure 1).
Co-morbidities	Not unexpectedly a significant number of co- morbidities were reported in this patient group who are mainly over the age of 60 years old (see Figure 2). Approximately 972 co- morbidities were reported across 528 patients (117 reported no co-morbidities and 15 records were blank) on average giving 1.8 co morbidities per patient. The incidence of symptomatic GORD was 20%.
First degree relatives with IPF	Of the 508 records where family history was available, 6% (32/508) had a first degree relative with IPF.

Surgical biopsy	13% (66/508) of cases had a surgical biopsy. This is in keeping with other reports on UK cohorts of IPF patients.
Lung Function	54% (272/508) of patients had an FVC % predicted at presentation to the clinic of 50-80%. 40% (203/508) of patients had an FVC % predicted of over 80%. Only 5% (24/508) had an FVC % predicted of less than 50%. (9/508) of records were blank). This means that at least 45% of patients at presentation/data input point fell outside the current NICE- defined criteria for treatment with Pirfenidone.
Current treatment	51% (140/272) of eligible patients had received Pirfenidone and 4% (12/272) had received Nintedanib at time of data entry. It should be noted however that Nintedanib has only been available in the UK at some sites via a named patient access programme since October 2014 and data entry started in January 2013 at some sites. This anti-fibrotic drug use is thus only a snapshot of the current situation during a period of change. Nintedanib is currently undergoing formal assessment by NICE. Figure 3 displays data on current treatment for all patients and shows that patients were on a range of treatments that may not be the current standard of care for IPF. Again this simply reflects the time periods over which data was collected.
Lung transplantation	6% (32/508) of patients were referred for lung transplantation assessment. This reflects a small number within an aging patient group with co-morbidities that are potentially suitable for transplantation. International lung transplant data suggest that only approximately 3% of all IPF patients will ever receive a lung transplant. (6)
Follow up	Data from follow up records: 1% (3/ 252) of IPF patients at follow-up were reported to have been diagnosed with lung cancer since last review. The range of follow-up period was 6 months to 2.5 years.
Death since entry on to Registry:	Approximately 5% (35/660) patients were reported to have died since entry onto the Registry over a period of 2.5 years maximum. Of these, acute or chronic progression of IPF was the cause of death in 25 cases (71%). This dataset is incomplete at the moment and this mortality rate is much lower than the annual mortality expected in a generic IPF population.

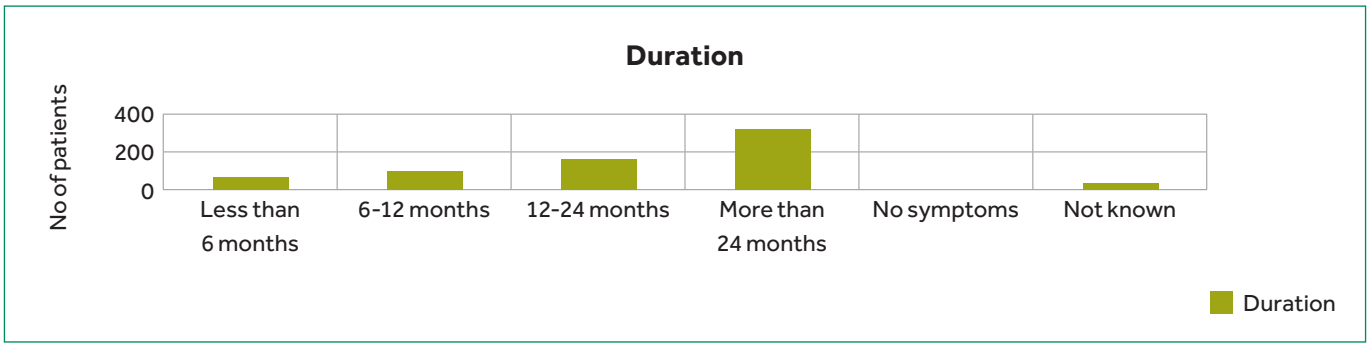

Figure 1: Duration of chest symptoms prior to first clinic visit

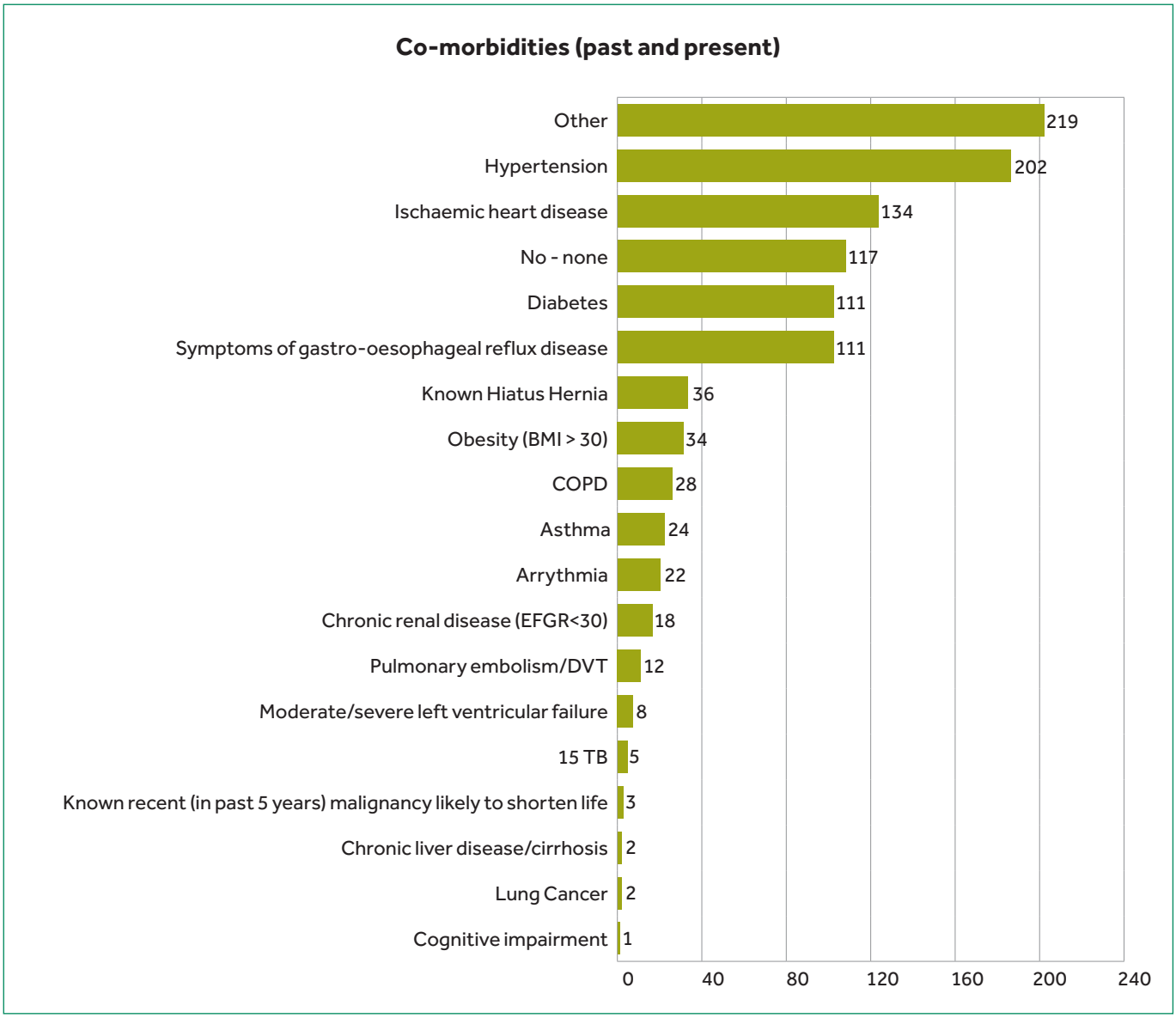

Figure 2: Co-morbidities reported

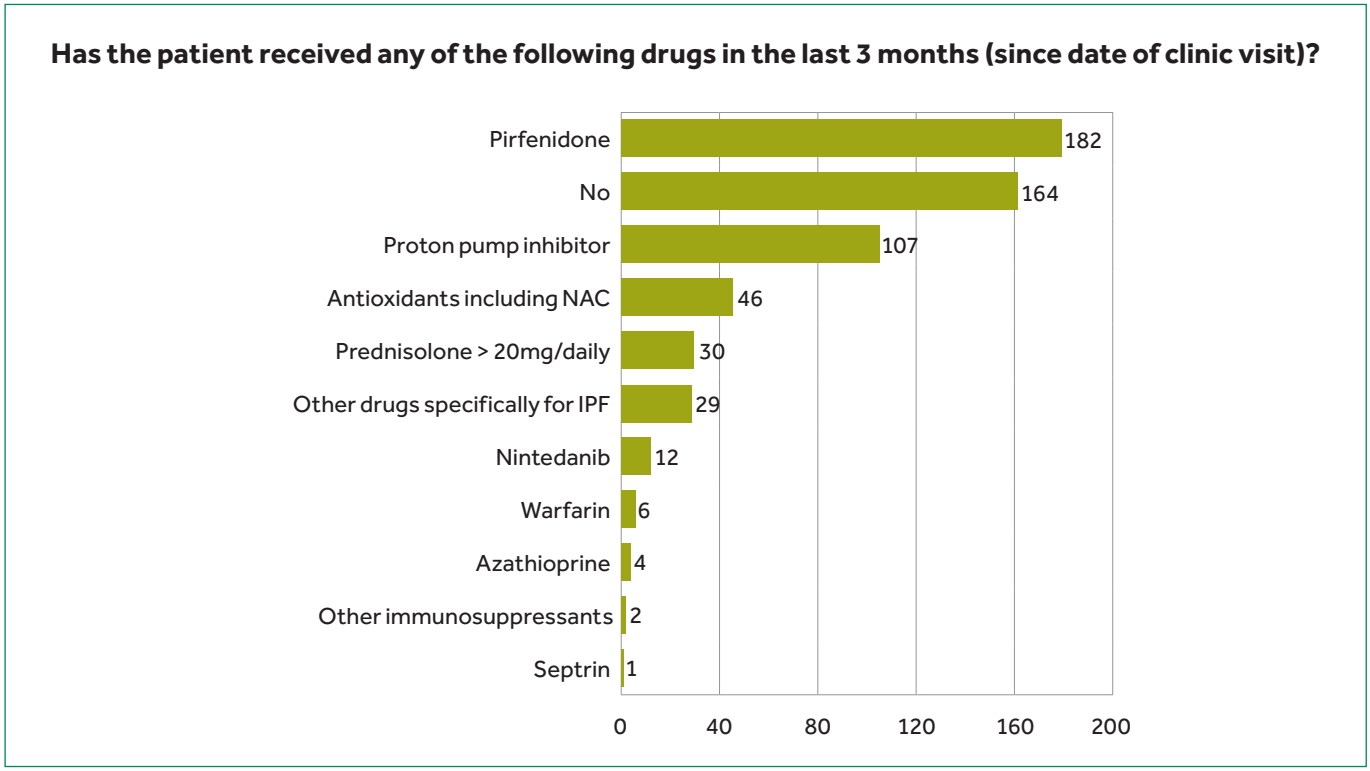

Figure 3: Current treatment (all patients)

How does the data collected by the IPF Registry relate to NICE Quality Standards for IPF?

In this section, data from the IPF Registry and an organisational survey of participating centres conducted in July 2015 is presented in relation to each NICE quality standard (5).

Quality Statement

Quality Statement 1 **People are diagnosed with idiopathic pulmonary fibrosis only with the consensus of a multidisciplinary team with expertise in interstitial lung disease.**	**Multidisciplinary Team Meetings** (MDT): Data from the organisational survey show that MDT meetings held specifically for ILD take place in 100% (14/14) of the university/teaching hospital centres, and in 50% (3/6) district general hospitals. The frequency of MDT meetings varies according to the number of referrals (once weekly to monthly). Of the patients entered onto the IPF registry, 6.3% (32/508) had not been discussed at an ILD MDT meeting. Of these just over two-thirds (69%; 22/32) were cases from district general hospitals. The composition of the MDT varies between university/teaching hospitals and district general hospitals. Thoracic radiologists and thoracic pathologists are members of the MDT in 70% of centres. Although 17 hospitals have an ILD MDT, the reported team members include only 15 radiologists and 16 respiratory nurses (11 ILD specialist nurses and 5 respiratory nurses) which is not in keeping with the NICE IPF Clinical Guideline (that is that all MDTs should have a thoracic radiologist and ILD nurse) (2).
Quality Statement 2: **People with idiopathic pulmonary fibrosis have an interstitial lung disease specialist nurse available to them.**	**The ILD team**: For the purpose of this report, an ILD specialist nurse is regarded as a specialist ILD nurse or a respiratory nurse specialist with an interest in ILD. The survey found that in 85% (17/ 20) centres, a specialist ILD nurse was a member of the ILD team. This is in line with the findings of recent reports from: ➢ British Lung Foundation: Lost in the System: IPF – the patient experience in England (7); (36% of patients had no access to an ILD nurse specialist) and Shining a light on IPF: the patient experience in Wales (8). ➢ Action for Pulmonary Fibrosis: Working together: delivering a better future for patients with IPF. (9). This reported that almost 1 in 3 patients did not have access to ILD nurse.
Quality statement 3: **People with idiopathic pulmonary fibrosis have an assessment for home and ambulatory oxygen therapy at each follow up appointment and before they leave hospital following an exacerbation of the disease.**	At presentation, Registry data shows that 23% (119/508) of patients are on oxygen (ambulatory, LTOT or short burst) and that oxygen assessment takes place in 72% (64/87) follow-up records. The BLF 'Lost in the system' report stated that only 39% of the patients surveyed had reported being reassessed for oxygen therapy (7). The Action for Pulmonary Fibrosis patient survey report notes that over 1 in 5 patients were not assessed at their follow- up appointments (9).

Quality Statement 4: **Pulmonary rehabilitation programmes provide services that are designed specifically for idiopathic pulmonary fibrosis**	Data from the organisational survey of participating centres shows that for 65% (13/20) of centres all providers of Pulmonary Rehabilitation (PR) services accept ILD patients onto their programmes. In 35% (7/20) of centres only some of the PR providers accepted ILD patients. The Registry has not collected data on whether the PR programmes provided are developed specifically for patients with IPF. In the Registry, referral for PR shows: 46% (235/508) of patients were referred for PR, 38% (193/508) of patients not referred for PR and a further 2% (11/508) patients declined (2%); this information was not known in 14% (70/508) of patients. The BLF 'Lost in the system' survey of IPF patients showed that 66% had been assessed for PR, but 28% rated the quality of their PR as average or worse (7). In the Action for Pulmonary Fibrosis report, less than 50%of IPF patients had been able to access pulmonary rehabilitation. Of those who took part in pulmonary rehabilitation programme only 4 in 10 had an IPF- tailored course (9).
Quality Statement 5: **People with idiopathic pulmonary fibrosis and their families and carers have access to services that meet their palliative care needs.**	All centres have access to palliative care services. However, with current data available on the Registry, we are unable to comment on how often these were actually used or if palliative drugs were part of the 360 degree assessment of IPF patients. Some centres will have much closer working with palliative care services than others with access to breathlessness management clinics for example. The current data shows that 3% (17/508) patients were referred for palliative care; 95% (485/508) patients were not referred.

The BTS Sarcoidosis Registry

Background

Despite recognition and description of the cutaneous lesions of sarcoidosis by Jonathan Hutchinson in London in 1869 and Norwegian dermatologist Caesar Boeck in 1899 (10), and, in the 21st century, an appreciation of possible genetic and environmental factors implicated in its causation, the pathogenesis and optimal management of this multisystem condition remain poorly understood.

Sarcoidosis affects the lungs in over 90% of patients and accounts for around one third of the interstitial lung disease seen in specialist respiratory clinics. Commoner in females, the incidence peaks between the ages of 20 and 50 years with a smaller peak after 60. The disease is more prevalent in Black and Afro-Caribbean populations, who also suffer more severe disease and a higher mortality. A significant proportion of patients with active disease are limited in their daytime activities by dyspnoea, fatigue or joint pains. The course of sarcoidosis varies considerably; there is a high rate of spontaneous remission but chronic disease may occur in up to 30%. To date it remains difficult to predict which patients will develop chronic, progressive severe disease and how best to manage them. Increased availability of cardiac MRI has prompted growing recognition of myocardial involvement, sometimes presenting with life-threatening ventricular tachycardias.

Treatment when indicated, usually for vital organ involvement, generally includes systemic corticosteroids with or without other immunosuppressive agents. Biologicals such as infliximab may be of value in some cases. Long term oxygen may be required. Lung transplantation is reserved for those with respiratory failure who fail to respond to maximal therapy, and is limited by organ availability. Other serious complications include pulmonary hypertension, mycetomata, and opportunistic infections resulting from immunosuppression.

It is hoped that the BTS Sarcoidosis Registry will enable a greater understanding of the characteristics of the sarcoidosis population across the country, and ultimately lead to both earlier recognition and improvements in diagnosis and management.

Criteria for inclusion in the Registry

Participating centres are requested to enter data on patients who meet the following inclusion criteria:

- Patients with a new diagnosis of Sarcoidosis made at a clinic visit from 1 January 2013 onwards, or
- Patients with a historical diagnosis of Sarcoidosis seen for the first time in the clinic at the participating centre from 1 January 2013.

Data entry for individual patient records is divided into three sections:

- Patient information (age, gender, co-morbidities etc).
- Clinical features on initial diagnosis and at current clinic visit (data available if diagnosis made more than 12 months before clinic attendance) or clinical information available at current clinic visit if diagnosis made less than 12 months prior to clinic attendance.
- Follow-up information (clinical information added at 12 month intervals following the entry onto the Registry).

Registry data

At 1 October 2015, 18 centres had contributed data to the Sarcoidosis Registry.

Patient records - demographic information
181 patient records

Diagnosis
142 complete clinical records - diagnosis information

Of these there are 57 records for Part B (data from initial diagnosis made more than 12 months prior).

Follow-up
38 follow-up records

Gender	38% (69/181) female; 62% (112/181) male.
	Of note, 62% (112/181) were male in contrast to the well-reported female preponderance.
Age	The age distribution is shown in Figure 4. Mean age at presentation was 49 years. A significant number of patients thus present to respiratory physicians over the age of 50, with some presenting over the age of 70. The diagnosis must therefore be kept in mind when assessing older patients.
Ethnicity	71% (129/181) were British and Caucasian, which is likely to represent the populations from which the Registry data were taken.

Referral	80% (145/181) of patients were referred from respiratory physicians in secondary care, which may reflect lack of familiarity in primary care and could contribute to delays in diagnosis.
Smoking history	Just 10% (14/142) of patients were smokers at presentation and 26% (37/142) were ex-smokers.
First degree relatives with sarcoidosis	Only 3% (5/181) reported having a first degree relative with sarcoidosis.
Co-morbidities	Over one third of patients (42%, 59/142) had no co-morbidity at the time of their current presentation. The commonest co-morbidities were asthma, hypertension, diabetes and obesity.
Symptoms at current presentation	Figure 5 shows that the commonest symptoms at current presentation were cough and breathlessness, with fatigue and eye symptoms also frequently reported. Improved treatment of fatigue in sarcoidosis, and early recognition of uveitis, will be essential to improving management.
Diagnosis made	In 61% (87/142) of patients, the diagnosis was confirmed on biopsy, and in 24% (34/142) the diagnosis was made on the basis of HRCT. In the remainder, the diagnosis was made on the basis of clinical features alone. The commonest feature on HRCT was the presence of widespread pulmonary nodules. Figure 6 shows that, unsurprisingly, EBUS-TBNA has overtaken mediastinoscopy and transbronchial biopsy as the most common biopsy sites for confirming pulmonary disease. It supports a requirement for EBUS-TBNA trained respiratory physicians to be available in all centres (11).
Sarcoidosis incidental	In nearly one third of patients (28%, 41/142), the diagnosis of sarcoidosis was made as a result of an incidental finding during the course of investigations for another condition.
Current treatment	In the majority of cases, patients were either not started on treatment, or managed with systemic corticosteroids. Alternative immunosuppressant agents included a wide range of options with no particular preponderance of any one agent.
Inclusion in clinical trial	While no patients were currently recruited into a clinical trial, 89% (127/142) would be considered for recruitment subject to inclusion criteria. The data collected from the BTS Sarcoidosis Registry should inform the design of future clinical trials. Questions which need addressing include when to start treatment, what dose to use, what tapering regime to use, when to add alternative immunosuppression and which agent to use first, how to long to continue treatment, and how to treat associated, often debilitating symptoms such as fatigue.

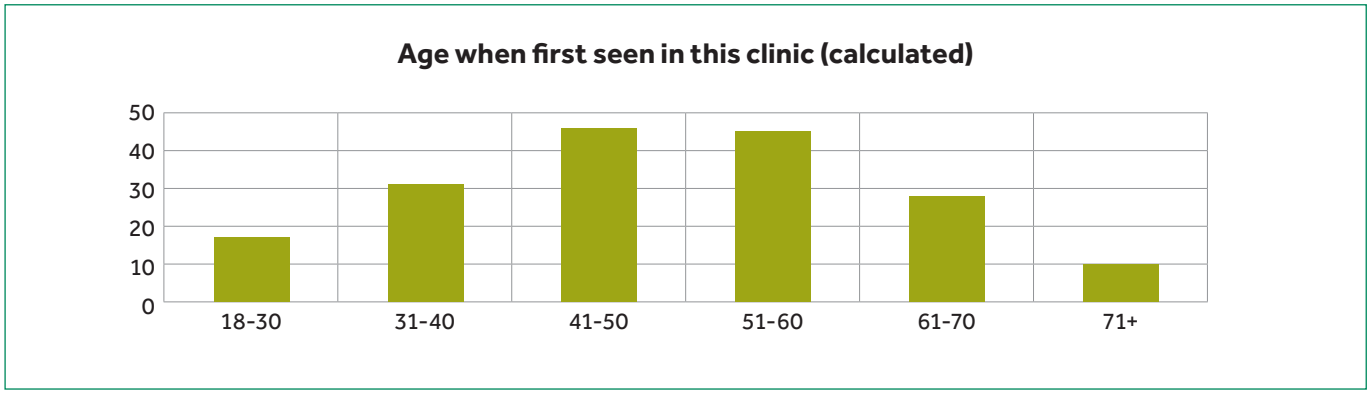

Figure 4: Age when first seen in clinic

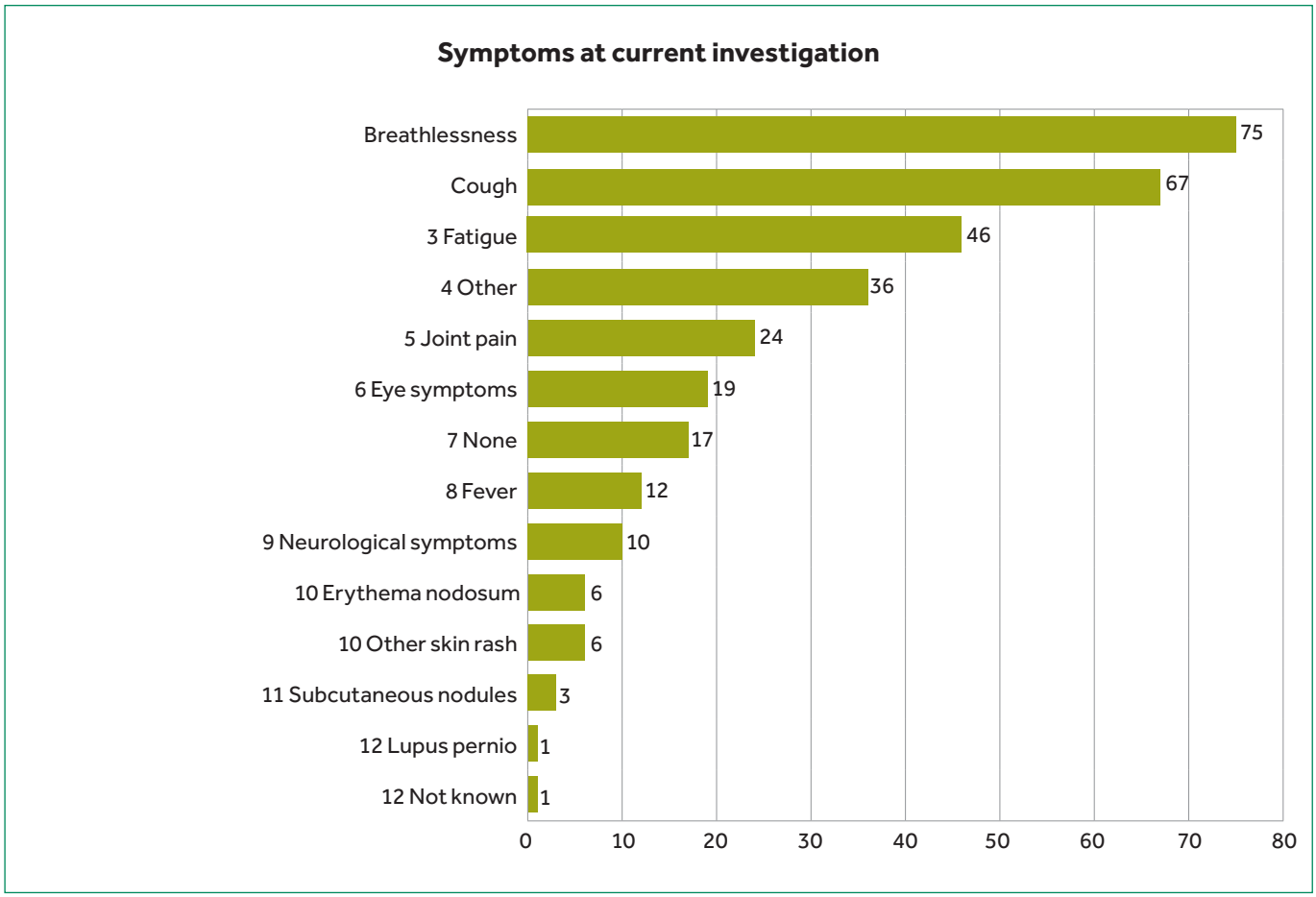

Figure 5: Symptoms at presentation

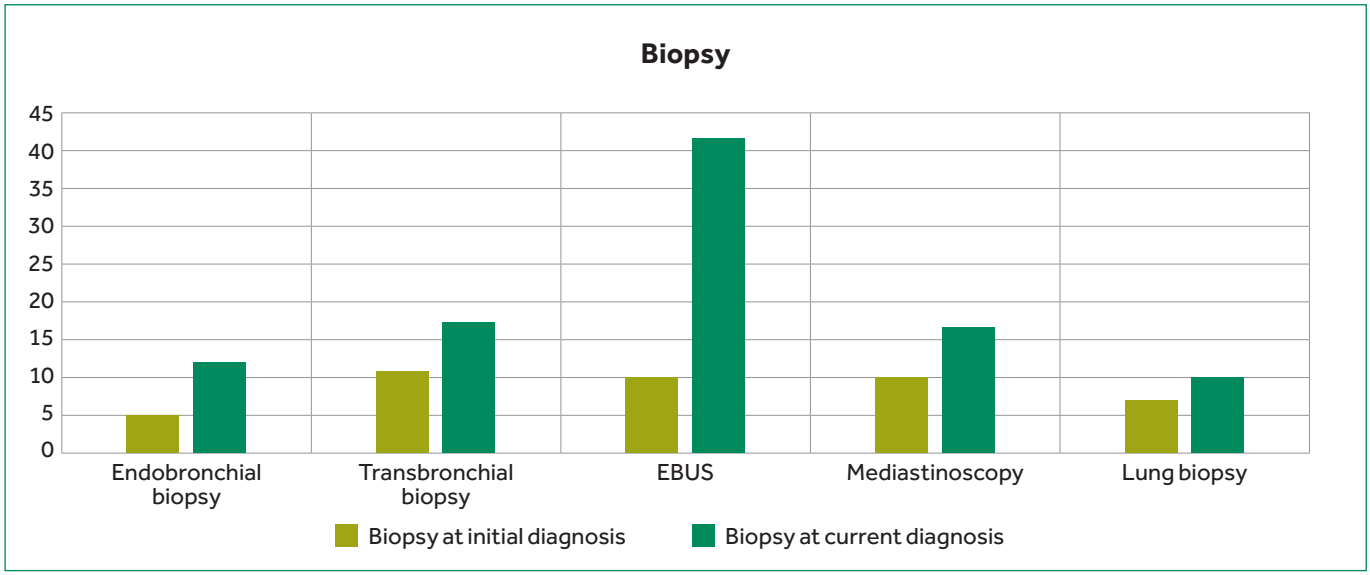

Figure 6: Biopsy

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The following organisations are currently participating in the BTS Lung Disease Registry – our thanks to all involved:

Aintree University Hospitals NHS Foundation Trust

Countess of Chester Hospital NHS Foundation Trust

Croydon Health Services NHS Trust

Gateshead Health NHS Foundation Trust

George Eliot Hospital NHS Trust

Gloucestershire Hospitals NHS Foundation Trust

Harrogate and District NHS Foundation Trust

Heart of England NHS Foundation Trust

Hinchingbrooke Health Care NHS Trust

Hull and East Yorkshire Hospitals NHS Trust

Imperial College Healthcare NHS Trust

King's Health Partners (Kings, Guys & St Thomas ILD service)

Newcastle upon Tyne Hospitals NHS Foundation Trust

Norfolk and Norwich University Hospital NHS Foundation Trust

North Bristol NHS Trust

Northern Devon Healthcare NHS Trust

Nottingham University Hospitals NHS Trust

Oxford University Hospitals NHS Trust

Papworth Hospital NHS Foundation Trust

Peterborough & Stamford Hospitals NHS Foundation Trust

Royal Devon & Exeter Foundation NHS Trust

Sheffield Teaching Hospitals NHS Foundation Trust

Taunton & Somerset NHS Foundation Trust

The Royal Wolverhampton NHS Trust

University Hospitals of North Midlands NHS Trust

University Hospital of South Manchester NHS Foundation Trust

University Hospital Southampton NHS Foundation Trust

University Hospitals of Morecambe Bay NHS Foundation Trust

Aberdeen Royal Infirmary, NHS Grampian

Betsi Cadwaladr University Local Health Board

If you would like to know more about the BTS Lung Disease Registry – see the details on our website at:

http://www.brit-thoracic.org.uk/audit-and-quality-improvement/bts-lung-disease-registry-programme/

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