



ILD REGISTRY NEWSLETTER

Issue 1 - June 2016

Welcome to the first issue of the BTS ILD Registry Newsletter. The ILD Registry is a national longitudinal database for the collection of data relating to two disease areas: IPF and sarcoidosis. Launched in 2013, we currently have 40 hospitals taking part in this important programme, with a further 27 in the process of obtaining approval. There are now over 1,000 patient records held on the Registry (with over 860 IPF records and over 230 sarcoidosis records).

As well as giving updates on Registry developments and other information that you might find interesting, each issue will include a data spotlight focusing on a finding from the Registry so far. In this issue we will be highlighting lung function of IPF patients at first presentation.



“The BTS ILD Registry has been steadily gaining momentum since 2013 and data analysis is already showing meaningful results relevant to our day to day management of IPF and sarcoidosis. These data will help us prioritise key areas in the care pathways that need addressing to achieve best quality care for all our patients. With this in mind, one of the objectives of this BTS ILD Registry Newsletter is to showcase emerging themes of current best practice or indeed shortcomings so that these can be addressed with all stakeholders and solutions implemented.”

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

Current Topics and Developments

There have been a number of exciting developments in the Registry over the last few months.

January saw the launch of our **Data Upload Function**, where users can upload data from a template spreadsheet. This makes it much quicker to enter information into the Registry than before. Full instructions are available on the website, and our team are available to go through the process with anyone who would like assistance. Direct data input into the website is still available for all users.

Our **Registry paperwork has been updated**, with fresh instructions, FAQs and hints/tips. All of these documents are available through the BTS site at <https://www.brit-thoracic.org.uk/audit-and-quality-improvement/bts-lung-disease-registry-programme/>

Lung function at first presentation in IPF patients: can all patients be treated?

56% of patients with IPF have an FVC % predicted between 50 – 80% at first presentation to clinic; 40% of patients have an FVC% predicted greater than 80%; and 4% of patients have an FVC predicted of less than 50% (Table 1). Therefore, 44% of patients with IPF in England, Wales and Northern Ireland and 40% of patients in Scotland will not be eligible to receive treatment for their disease under current national criteria set by NICE and Scottish Medicines Consortium respectively. The information in Table 1 and Figure 1 is currently based on a sample size of 606 patients.

The ILD Registry will be presenting at the 2016 ERS Congress, which will be held in London on 3 – 7 September. Our Sarcoidosis Registry poster will be presented between 12:50 and 14:40 on the 4th in T-11, our IPF Registry poster will be presented between 10:45 and 12:45 on the 5th in ICC Capital Suite 10, and we will also be showcasing the BTS Registry in a spoken presentation at the 'New and Useful Insights from Registries across the World' from 13:00 to 14:30, again on the 5th. For further information on the ERS Congress visit <http://erscongress.org/>

We are very pleased to be **supported by the British Lung Foundation and SILA**, the sarcoidosis charity. Working alongside these charities will help us keep the interests of patients at the heart of what we do and will increase awareness of the work of the Registry.

FVC % predicted - groups	< 50	50 to 80	> 80
Percentage of patients in FVC group	4%	56%	40%
Mean TLCO (% predicted) per group	28.2 ±17.9	36.9 ±13.9	48.3 ±16
Percentage of patients with over 25% of lung volume consisting of emphysema on HRCT scan	0%	4%	7%

Table 1 – Lung function details for each of the three FVC groupings used by NICE

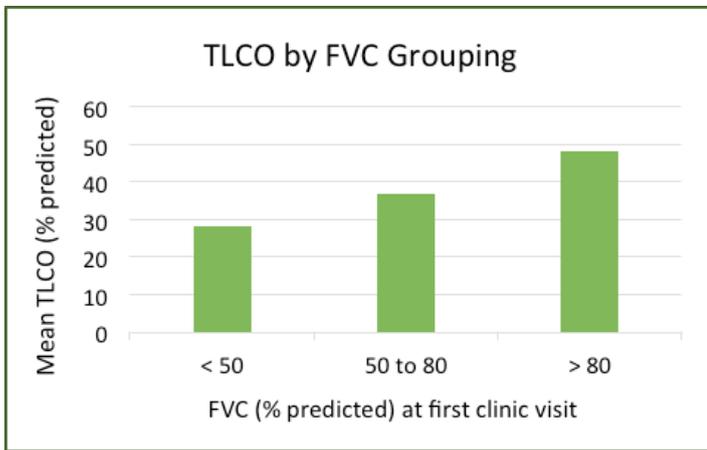


Figure 1 – Mean TLCO for patients in each of the three FVC groupings used by NICE

The Registry data indicates that patients with FVC greater than 80% predicted already have substantial decrease in their diffusion capacity (Figure 1) and that it is only a small percentage of patients (7%) who have HRCT scan evidence of 'over 25% of lung volume consisting of emphysema' (Table 1). Our challenge in everyday practice is that, whilst great strides have been made in the last two years to diagnose patients with IPF at an early stage in their disease process, we are unable to offer them treatment on the NHS unless they significantly deteriorate. There are no similar restrictions on treatment in Europe and US.

We welcome your views on this topic and encourage you to contact us using the details provided at the end of this newsletter.

You may also be interested in

The NHS England Specialised Services ILD Service Specification public consultation period closed in April and the finalised specification is expected to be released in due course. The draft specification is available at <https://www.engage.england.nhs.uk/consultation/clinical-commissioning-wave7>

The BTS Summer Meeting will include an ILD MDT Symposium on Friday 24th June from 8:30am to 10:00am. This year the Summer Meeting (#BTSsummer2016) is being held in York – for more information visit <https://www.brit-thoracic.org.uk/bts-learning-hub/bts-summer-and-winter-meetings/summer-meeting-2016/>

SILA have launched their first Scottish sarcoidosis support group, initially meeting in Glasgow. If you have a patient who may be interested why not let them know? Email info@silas.org.uk or visit <http://www.silas.org.uk/> for further information.

Contact Us

Would you like to get involved in the BTS ILD Registry? If you want your hospital to participate in the Registry please do get in touch. Our Registry team will give you all the information you need and can help you with the Caldicott approvals process.

We would really appreciate any feedback you have on our Lung Registry programme or newsletter. Many of the changes we make to the Registry are in direct response to feedback from those taking part.

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