BTS ILD Registry Annual Report 2021: a summary of the UK Sarcoidosis Registry for the general public

Sarcoidosis is a disease where cells in the body clump together to make small lumps called 'granulomas'. Granulomas can form in any organ of the body; however, the lungs are the most commonly affected organ (in over 90% of patients). Sarcoidosis is usually diagnosed between the ages of 20 and 50 years but it can also occur in those over 60. It is estimated that around 4,500 cases of sarcoidosis are diagnosed in the UK each year.

Some patients have no symptoms at all, and only know that they have sarcoidosis because it has been found incidentally when having tests for other conditions. Others have significant symptoms such as breathlessness, cough, fatigue or joint pain. While some people with symptoms recover, others gradually worsen over time.

Why is a registry needed?

Patient registries are collections of healthcare data on people living with a particular disease or condition. They aim to improve outcomes by making it possible to track treatment and care, and to link this to clinical outcomes of people living with the disease.

Sarcoidosis is a complicated condition which is sometimes hard to diagnose and treat. To improve understanding of sarcoidosis, it is important that researchers, people treating patients and people making decisions about healthcare policies can properly understand the experiences of people living with sarcoidosis.

Who is on the Registry?

Any patient diagnosed with sarcoidosis from 2013 onwards can be added to the Registry so long as they give their consent. As of 30th June 2021, a total of 774 patients with sarcoidosis were included on the Registry, with data collected from 41 centres over the lifetime of the Registry.

The British Thoracic Society (BTS) set up the BTS Interstitial Lung Disease (ILD) Registry in 2013. It currently covers two diseases: IPF and sarcoidosis. Information is submitted by hospitals on behalf of the patients they treat. The aim is to include as many people as possible in the Registry. BTS encourages hospitals and patients to agree to their data being collected so that the information in the Registry is as rich as possible.

What information is collected for the Registry?

The BTS ILD Registry now includes nearly nine years of data, which makes it possible to analyse data trends and enables us to gain a greater understanding of the disease.

The Registry includes demographic data, including the patient's gender, age, and medical problems other than sarcoidosis. From the data we know that:

- 59% of patients are male, and this has remained consistent over the lifetime of the Registry.
- People with sarcoidosis have an average age of 51.5 years at diagnosis, and just over a quarter of patients (26%) present over the age of 60.
- Most patients (66%) with sarcoidosis have no other reported medical problems at their first hospital visit. In the remaining 34% of patients, the most reported problems were high blood pressure (20%) and diabetes (16%).

The Registry also includes clinical information such as the route of referral to the first hospital clinic visit and information on how patients were diagnosed with sarcoidosis. For example, from the data collected since 2013 we know that 47% of patients are referred to a specialist clinic from respiratory physicians in secondary care and that referrals from general practice have remained low (23%), highlighting that more needs to be done to increase awareness of sarcoid and the complexities in diagnosing the disease. We also know that 95% of patients had at least one biopsy conducted as part of their investigations and that endobronchial ultrasound (a small camera passed into the windpipe to biopsy an enlarged gland in the centre of the chest) was consistently the most common biopsy technique, involved in 55% of all cases where a biopsy was carried out.

The Registry also captures information on the most common blood test abnormalities and the patterns identified on high-resolution computed tomography (HRCT) imaging of the chest. For example, we know that the most common abnormality recorded in blood tests at presentation was lymphopenia (low levels of a white blood cell called a lymphocyte) and this was identified in 56% of patients. We also know that the most common abnormality on HRCT scanning of the

chest at presentation is lung nodules, found in 84% of cases. Most patients presenting with sarcoidosis initially either require no treatment (42%) or are managed with steroids (47%). These data help us to understand the full picture of how sarcoidosis is investigated and treated in the UK.

The Registry also collects information on the proportion of patients participating in clinical trials, and whether patients are being referred or signposted to other services such as patient support groups. For example, over the lifetime of the Registry the proportion of patients with sarcoidosis recruited to clinical trials has remained consistently low (2.7%). This highlights the need to improve access to clinical trials for patients with sarcoidosis. Moreover, early data indicate that few patients (31%) are provided with information about sarcoidosis patient support groups, highlighting that more work needs to be done to improve access to other services for patients with sarcoidosis in the UK.

Hospitals can monitor their performance using Registry data and access data on their own patients. A local 'dashboard' is generated by the Registry every six months, which allows hospital healthcare professionals to keep an eye on how their service is running. Information which identifies individual patients is only available to the submitting hospital (i.e. the team responsible for treating the patients).

BTS can analyse data for the whole country to help improve care and when designing or recruiting patients to research trials. However, information which identifies individual patients cannot be seen in this national data.

Recent developments and plans for the future of the UK Sarcoidosis Registry

It has been a challenging year for the medical community as the respiratory workforce, in particular, has continued to turn its attention to managing patients with COVID-19 throughout 2021. Perhaps unsurprisingly this is reflected in a fall in the number patients registered onto the UK Sarcoidosis Registry (38 patients registered from January 2020 to June 2021 compared to 48 patients registered in the first six months of 2019 alone). This may limit the interpretation of recent data, but we hope that with the continued effort from everyone involved, the UK Sarcoidosis Registry will continue to grow from strength to strength as we recover from the COVID-19 pandemic.

Our vision for the future of the UK Sarcoidosis Registry includes supporting clinical trial involvement. It is exciting that for the first time the BTS ILD Registry is being used to collect data for a large clinical trial of a different lung disease called idiopathic pulmonary fibrosis (IPF). We hope that the UK Sarcoidosis Registry will also be used to collect data for participants in clinical trials in the future.

The future of the Registry depends on patients consenting to their information being used to help researchers, contribute to future planning of healthcare services and aiming to drive up standards of care for all patients with sarcoidosis. We hope that BTS can continue to build on the success of the Registry for many years to come.

Information for the public

This document has been prepared by Mr Steve Jones and Dr Wendy Funston, on behalf of the BTS ILD Registry Steering Group, as a brief summary of the content and key points from the BTS ILD Registry Annual Report 2021. If you have any queries about the report and your personal medical circumstances please discuss these with your health care professional.

The charity SarcoidosisUK supports patients who have been diagnosed with sarcoidosis: https://www.sarcoidosisuk.org/

The full report is available on the BTS website at: https://www.brit-thoracic.org.uk/quality-improvement/lung-disease-registries/.

The content of this document may be used by health care professionals in discussions with patients and/ or carers, but the source of the material must be acknowledged.

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