

BTS Interstitial Lung Disease Registry

Fair processing information for patients

1. Who we are

We are the British Thoracic Society (BTS), a Charity which exists to improve standards of care for people who have respiratory diseases. This notice sets out how your data will be used by BTS. We are a controller over the data described in this notice, and if you have any queries regarding our use of your data, please contact us using the details at the bottom of this notice.

2. What information do we hold about you?

The BTS Interstitial Lung Disease Registry holds data on patients who are receiving treatment for Idiopathic Pulmonary Fibrosis (IPF) or sarcoidosis. In the ILD Registry we will hold your date of birth, NHS, CHI or H&C number, sex, home postcode, details of your condition taken from your medical records and details of how you have responded to that treatment. Your data will only be sent to us by your clinician if you have given explicit consent to take part in our ILD Registry.

You can withdraw your consent to participating in our BTS ILD Registry at any time, by either notifying your clinician or contacting us using the details provided at the end of this notice.

3. How is your Data collected?

Clinicians collect your data from electronic and paper hospital records. These are entered onto a secure online data collection tool controlled by BTS and provided by our trusted external data storage providers, who store the data within the European Economic Area. Access to the data entry tool is securely controlled.

4. Research

Where you have provided your consent to participate in the BTS ILD Registry we use your data for research purposes to help others with similar medical conditions to you. This means that our researchers, as well as organisations we work with who are carrying out similar research, can analyse high volumes of data to obtain an overall picture of how patients are treated and how they respond to different treatments. Where possible, we fully anonymise your data before it is used for research purposes, and you can object to us using your data for research purposes at any time by contacting us. We never use any data which could directly identify you for research purposes, and only the team treating you at your hospital will ever be able to see your identifiable data. We use your data in this way because it is necessary for reasons of public interest in the area of health research by allowing us to ensure high standards of quality and safety of health care.

5. How long will we use your data for?

Patient identifiable data items (NHS, CHI or H&C numbers, date of birth and date of death (if relevant)) will be retained by us indefinitely. Retention of this information over a long period of time is important to ensure that research is robust and effective and to enable researchers to analyse changes in patient demographics, treatment or outcomes over time.

6. Your rights in connection with your Data

Under certain circumstances, by law you have the right to:

- **Request access** to your data (commonly known as a "subject access request"). This enables you to receive a copy of the data we hold about you and to check that we are lawfully processing it.
- **Request correction** of the data that we hold about you. This enables you to have any incomplete or inaccurate information we hold about you corrected.
- **Request erasure** of your data. This enables you to ask us to delete or remove data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your data where you have exercised your right to object to processing (see below).
- **Object to processing** of your data where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your data for direct marketing purposes, research or statistical purposes.
- **Request the restriction** of processing of your data. This enables you to ask us to suspend the processing of data about you, for example if you want us to establish its accuracy or the reason for processing it.
- **Request the transfer** of your data to another party.

Privacy law is often complicated, and whether these rights are available to you sometimes depends on the types of data we are handling, as well as why we are handling it. If you would like to exercise any of these rights, please contact us using the details at the bottom of this notice. You always have the right to lodge a complaint with us or the Information Commissioner's Office, the supervisory authority for data protection issues in England and Wales.

7. Feedback

We have worked hard to produce a short notice that clearly explains how your data is used.

Your feedback and suggestions on this notice are very welcome. If you feel that we have overlooked an important perspective or used language which you think we could improve, please let us know by using the contact details below.

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