**The British Thoracic Society (BTS) Lung Disease Registry Programme**

**BTS UK Interstitial Lung Disease Registry**

**Information for Patients**

*You are being invited to take part in a patient registry (the BTS UK Interstitial Lung Disease Registry). We are asking you to take part because you have a medical condition which is a type of interstitial lung disease. This is a group of conditions which affect the air sacs (alveoli) in your lungs, and the tissues and space around them.*

*Before you decide whether to take part, we want to make sure you understand what the Registry is and what it will involve. Please read this paper carefully. You can talk to others about it if you want to. You can also ask us if you would like more information or would like something explained.*

*Take time to decide whether or not you wish to take part in this project; it is entirely up to you.*

**What is the BTS UK Interstitial Lung Disease Registry?**

A patient registry is like a survey that collects health information about people with a specific medical condition. In our Registry this is people with interstitial lung disease. Specifically, people who either have scarring (fibrosis) in their lungs or have a condition called sarcoidosis.

These conditions are complex and not very common. Bringing together information on people across the UK means we can better understand these diseases, how patients are treated and what their outcomes are. Doctors can learn from this and provide better care for people with interstitial lung disease in the future

The information is held on a secure and confidential computer database. The Registry is paid for by the British Thoracic Society, and small grants are sometimes received to support this work.

**What information is kept in the Registry?**

What we collect is similar to the information that is recorded during a visit to your clinic. Things like:

* Height and weight
* Breathing tests (how well your lungs are working)
* Other test results (cultures, x-rays, blood test results and similar)
* What drugs and other treatments you receive
* Any other medical conditions you have.

The Registry also holds information which can be used to identify you (such as name and date of birth, etc.). These ‘identifiers’ are **only** collected to allow your care team (the staff treating you at hospital) to know which record is which. Information which could identify you is **never** shown to anyone outside your care team (even BTS staff do not know who you are) unless a numerical identifier is shared for the purpose of data linkage.

**How is the information collected and what is it used for?**

The information is taken from the notes your doctors and nurses make whenever you visit the hospital. The team caring for you enter the data into the Registry, and they can use it to see your results over time. They also use it to get a picture of how everyone in their clinic is being treated.

BTS is planning to maintain the Registry for the foreseeable future and will keep Registry data indefinitely. We regularly produce Registry reports which are available on the BTS website.

At BTS we analyse information from hospitals across the UK. Analysing Registry information helps to improve patient care by supporting us and the NHS in understanding:

* How many people are living with interstitial lung disease, and if this changes over time.
* How well people’s lungs work and how their disease is being treated.
* National trends (which might not be obvious in just one hospital)
* If there are any differences in how people are treated (e.g. by where in the country they live)
* Where more support is needed for services like your clinic.

**How does the Registry support research?**

1. Researchers can use anonymised Registry data

Researchers in other organisations may apply to BTS to access fully anonymous health information from the Registry. These organisations may be universities, NHS organisations (HSC in Northern Ireland) or companies involved in research in the UK or abroad. Registry information will only be used to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. It will only be used for the purpose of research; it cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

1. Helping identify people who could take part in studies/trials

Sometimes we will let the team at your hospital know about new research studies or trials. If the staff at your hospital think you might be suitable they could invite you to participate. You are free to say no to any invitations.

**Do I have to take part?**

No – it is completely your decision. People often find that taking part in research can help them understand more about their condition and feel that they are making a difference. The Registry aims to improve treatments and quality of life, now and for people in the future. If you choose to take part you will be given this sheet to keep and asked to sign a consent form. Your care will not be affected in any way if you do not take part.

**Can I change my mind later?**

Yes. If you agree to take part you can withdraw from the Registry at any time in the future without giving any reason. Your care will not be affected in any way.

* If you withdraw your consent before your information was used in any research project:

All data relating to your entry on the Registry will be completely removed. Your data would never be used in any research studies.

* If you withdraw your consent after your information was used in any research project

All data relating to your entry on the Registry will be completely removed. However, some fully anonymous data may still be archived as part of that research. This means that if researchers just looked at the date and results of your lung function tests then that is the only information that would be kept. Your data would never be used in any other research studies.

**Will my information be confidential?**

Yes - all the information in the Registry is held confidentially. The Registry is registered under the Data Protection Act (2018) and has Research Ethics Committee approval (renewed October 2022 22/EE/0235). It is managed in accordance with relevant laws and ethical guidelines.

To keep your information safe and secure:

* Information which can be used to identify you (such as name and date of birth, etc.) will only be visible to the team treating you at hospital.
* The team at BTS cannot identify you, we only see an anonymous patient identification number.
* When researchers use the Registry they are not even given your anonymous patient identifier. They only see a random one-time identifier which they cannot use to identify you in any database.

A very small number of experienced staff are responsible for protecting your identifiers. They encrypt them on the database, which means the information is converted into a highly complex code which nobody is able to read. Only the staff at your hospital have access to read it through their secure accounts. These staff maintain the system, in accordance with Data Protection legislation.

**Will my information be linked to information from any other datasets?**

We may also like to use your health information collected by other organisations. This means the Office for National Statistics, NHS Digital or similar. To obtain this information we will need to disclose information such as your date of birth and National Health Service number; these details will be treated in confidence and in accordance with the Data Protection Act (2018).

You may also separately consent to other projects. These could include another registry, a biobank, a clinical trial or similar. Researchers may request information from these datasets be ‘linked’. For example, linking your genetics to how well your lungs work. This means that researchers from the other project could see information such as your lung function results. We will only ever link these datasets if you have specifically given consent for both projects.

The use of any information from the Registry requires the approval of a formal BTS Committee*.*

**Your data rights**

The British Thoracic Society is the sponsor for this registry based in the United Kingdom. We will use information from your medical records to populate the Registry. We are the data controller for the Registry, which means we are responsible for looking after your information and using it properly.

You have the right to access, change or move your information. There are some small limitations to this because we need to manage your data in specific ways so the Registry to be reliable and accurate. To safeguard your rights we use the minimum personally identifiable information possible.

You can find out more by visiting the BTS website at [www.brit-thoracic.org.uk](http://www.brit-thoracic.org.uk). If you have any questions, if you want to make a complaint or if you want your information removed, please contact our Data Protection Officer at [registry@brit-thoracic.org.uk](mailto:registry@brit-thoracic.org.uk) or at the British Thoracic Society, 17 Doughty St, London WC1N 2PL.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

***Thank you for taking time to read this information sheet and for considering taking part in the BTS UK Interstitial Lung Disease Registry. If you have any questions or require any further information, please talk to a member of the care team at your hospital or contact the Registry Manager at the British Thoracic Society on 020 7831 8778.***