

## Our IBD Registry Patient Privacy Policy

### Background

The IBD Registry understands that your privacy is important to you and that you care about how your personal data is used and shared. We respect and value the privacy of everyone and will only collect and use personal data about you as patients in ways that are described here, and in a manner that is consistent with our obligations and your rights under the law.

The UK IBD Registry collects data about patients with Inflammatory Bowel Disease (IBD) from all over the UK and brings it all together for a unique view of IBD in the UK, which supports better understanding by people, hospitals and other health-related organisations of how IBD is treated and about medicines that are used.

The Registry supports research into the causes of IBD and IBD treatments, it helps hospitals to improve their IBD services and it aims to improve society's understanding of how people's lives are affected by IBD. This is an opportunity for all patients with an IBD to make a real and significant contribution to a leading project to help people living with IBD.

This page is about the personal information we collect about you if you are a patient living with IBD. We want you to understand why we hold and process this information and let you know what your choices are. Please read this privacy policy carefully and ensure that you understand it.

### 1. Information About Us

We are a not-for-profit organisation, wholly owned by three joint members – the Royal College of Physicians, The British Society of Gastroenterology and Crohn's and Colitis UK.

We act as the Data Controller for personal data that is collected about you from any hospital where you receive treatment for your IBD and protect that data in accordance with all relevant laws.

We are registered with the ICO (Information Commissioner's Office).

Our Data Protection Officer is Clare Sanderson, who can be contacted by email at [DPO@ibdregistry.org.uk](mailto:DPO@ibdregistry.org.uk) or by post at the address below.

### 2. What Does This Policy Cover?

This privacy policy applies to the information we hold about you and your IBD treatment. You can find out more about this from our **Information for Patients** leaflet, which is available on our website.

### 3. The Lawful Basis for Processing your Personal Data

The purpose of the IBD Registry is to improve care of patients and understanding of the treatments they receive, to enable research, and to increase knowledge about IBD in the UK.

To achieve this we need to process your personal data but first we need to ensure that what we are doing complies with Data Protection Laws.

The data we process about you is health data. That is a special category of data under the Data Protection Act (which incorporates the EU's General Data Protection Regulation (GDPR)). This means that we need a lawful basis under Article 6 of the GDPR to carry out the processing as well as meeting a condition under Article 9 of the GDPR.

We have identified the lawful basis for processing your data in the Registry as being:

*6.1 (f) processing is necessary for the purposes of the legitimate interests pursued by the controller or by a third party, except where such interests are overridden by the interests or fundamental rights and freedoms of the data subject which require protection of personal data, in particular where the data subject is a child.*

*9.2 (j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.*

The data that we process is also considered to be confidential data. That means that the hospital that treats you needs a lawful basis to breach your confidentiality by providing this data. This lawful basis is provided either by your consent to the processing or through a process called Section 251 support.

#### **What is Section 251 support?**

Section 251 is a short-hand term, and refers to section 251 of the National Health Service Act 2006 and its current Regulations, the Health Service (Control of Patient Information) Regulations 2002.

If the hospital hasn't been able to ask for your consent to share your personal data with the Registry, Section 251 support means that the hospital that is responsible for the information (the data controller) can, if they wish, disclose the information to the Registry without being in breach of the common law duty of confidentiality. The Registry must still comply with all other relevant legal obligations e.g. the Data Protection Act 2018

In order to be granted support the Registry had to submit an application to the Confidentiality Advisory Group which undertakes an independent review of the purposes we are using the data for and our governance arrangements. This application is approved.

You can find out more about the Confidentiality Advisory Group and Section 251 support [here](#).

#### 4. **Your Rights**

You have the following rights under the GDPR, which this privacy policy and our use of personal data have been designed to uphold:

- The right to be informed about our collection and use of personal data;
- The right of access to the personal data we hold about you;
- The right to rectification if any personal data we hold about you is inaccurate or incomplete;
- The right to be forgotten – i.e. the right to ask us to delete any personal data We hold about you
- The right to restrict (i.e. prevent) the processing of your personal data;
- The right to data portability (obtaining a copy of your personal data to re-use with another service or organisation when you have given your consent for your data to be collected);
- The right to object to us using your personal data for particular purposes; and
- Rights with respect to automated decision making and profiling.

If you have wish to find out more about your rights in relation to our use of your personal data, please contact us using the details provided in section 6 below and we will do our best to resolve the problem for you.

If we are unable to help or you are unhappy with our response, you also have the right to lodge a complaint with the UK's supervisory authority, the Information Commissioner's Office. You can find out more [here](#).

For further information about your rights, please contact the Information Commissioner's Office or your local Citizens Advice office.

#### 5. **What Data Do We Collect in the Registry and How Do We Use it?**

You can find out more about the data we collect, how it is used, kept secure and who we share it with from our **Information for Patients** leaflet (available on our website)

We only keep your personal data for as long as we need to in order to use it and/or for as long as we have your permission to keep it.

Your data will only be stored within the European Economic Area ("the EEA") (The EEA consists of all EU member states, plus Norway, Iceland, and Liechtenstein).

## 6. Contacting Us

If you have any questions about our Registry website or this privacy policy, please contact us:

- by email at [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)
- call us on 0203 393 3639
- by post at IBD Registry The Ebbisham Centre, 6-7 Derby Square, Epsom, Surrey KT19 8AG.

If your contact is a request for information about the data we hold about you (as under section 4, above). please state clearly that it is a subject access request.

## 7. Changes to Our Privacy Policy

We may change this privacy policy from time to time (for example, if the law changes). Any changes will be immediately posted on our Registry website and you will be deemed to have accepted the terms of the privacy policy on your first use of our Registry website following the alterations. We recommend that you check this page regularly to keep up-to-date.

---