



# IBD Registry –

## Information for Patients

The UK IBD Registry collects data from patients 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 in how IBD is treated and about medicines that are used. It 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 to make a real and significant contribution to a leading project to help people living with IBD.

### How does the Registry help patients?

The Registry uses the information about your IBD and its treatment to contribute to improving patient care and research. This can be in a number of ways:

- The IBD Registry team will analyse information about IBD and use this to inform hospitals, medical and other organisations on how they can improve patient care, including better treatments and improved knowledge about medicines.
- Researchers working within IBD may request to undertake anonymous studies with the Registry; for example, to compare different treatments and outcomes, or to monitor the safety and effectiveness of medicines.
- The information collected and published by the Registry and other researchers will all help in raising professional and public awareness by presenting a more accurate and complete picture of the number of people who have IBD and the impact on their lives.

### What is the IBD Registry ?

The IBD Registry aims to improve the lives, care and treatment for people in the UK with IBD (inflammatory bowel disease) by collecting, collating and analysing data from across the UK. Most of the data comes from hospitals across the UK who are taking part in the Registry. The IBD Registry is a company limited by guarantee, which means there are no shareholders. Six Board members from the three founding organisations govern the IBD Registry.

### What does it mean for me if my hospital is part of the IBD Registry?

Your hospital will send (share) some information about you, your IBD and your IBD care with a central Registry database. This will be done several times each year to keep the information up to date. The way the information is sent means that every patient's confidentiality is protected (you can read more about this below).

### What information about me is shared with the Registry?

The information that is shared with the Registry may include demographic data, IBD diagnosis, additional clinical information including disease classification, details of surgery, admissions, cancer diagnosis and class of drugs. A complete listing of the data we collect can be found on our website.

### Do I need to give consent for this information to be shared?

You will be asked to sign a consent form, to give permission for your IBD team to continue submitting your data to the IBD Registry and to confirm how you wish your information to be used.

If the data submitted to a registry includes patient identifiable data, as in the case of the IBD Registry, then the NHS legislation requires that written consent is obtained from each individual patient unless an exemption is granted by the Secretary of State. (This is called an s251 exemption). The IBD Registry

currently has an s251 exemption granted, but is working towards a full 'consent-based' system where patients decide to consent.

### What if I don't want my information to be shared with the Registry ("opt out")

If you do not want your information to be sent to the IBD Registry, you can 'opt out' on the consent form. The IBD Registry will be most effective if it has information from as many patients as possible, but if you do not want your information to be used, please tell a member of your hospital team. They will make sure your information is not sent to the IBD Registry. This will not affect your treatment in any way.

### How is the confidentiality of my personal information protected?

Information about you does not go directly to the Registry but is sent by your hospital to NHS Digital. NHS Digital modifies the information sent to the IBD Registry so it is not patient identifiable. (This process is called

pseudonymisation.) NHS Digital keeps a master file so that future information about you can be added to your registry record.

### **What identifiable personal information will be used?**

Your NHS number, date of birth and gender are included in the information that your hospital will send to NHS Digital. Your postcode is also sent. This information is pseudonymised before being sent to the IBD Registry. Your postcode is supplied to the Registry so that we can understand the care that people receive in different parts of the country.

### **Does the Registry share my information with anyone?**

The Registry is careful not to share your personal information, even in pseudonymised form. Any information that comes out of the Registry is in aggregated form (i.e. statistics and group results) that cannot be tied back to any single person.

The Registry has formal agreements with other companies to 'process' the data. 'Processing' means that those organisations do not control the data in any way, they are simply doing work involving the data instructed. These companies include the University of Liverpool, whose biostatistical analysis team perform much of the specialised analysis, and the hosting companies whose secure computer servers and equipment we license to hold the databases.

### **What does the Registry do with the information about me?**

The IBD Registry will analyse the information and publish reports about IBD in the UK. These will tell us how many patients there are in each area and how the illness affects them, as well as describing the healthcare services and treatments they receive. All public reports will be available at [www.ibdregistry.org.uk](http://www.ibdregistry.org.uk). Reports where the information has been fully anonymised may be made

available to hospitals, medical and academic organisations and to health-related companies, such as pharmaceutical companies. All applications for access to the anonymised data will have to be approved by the Registry Research Committee.

### **Does the Registry receive any money for my information?**

Running a national Registry does involve running costs, and an appropriate charge may be made for anonymised aggregated information services to help support the running costs of the Registry. The Registry does not share or receive any money for your individual information.

### **How long will the IBD Registry keep information about me?**

Crohn's Disease and Ulcerative Colitis are lifelong illnesses, so the Registry aims to keep information indefinitely. This will help us to understand the long-term pattern of disease and how different treatments work over time.

### **What happens if I change my mind and want to opt out later**

You can stop information about your IBD and your healthcare being held in the Registry at any time. Speak to your IBD doctor or nurse, or contact the Registry on [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)

### **Who is responsible for the information (data) about patients in the IBD Registry?**

IBD Registry Ltd is the Data Controller for the information once it has passed to the Registry and is responsible for ensuring that the IBD Registry complies with data protection and confidentiality laws.

### **How do I know that the Registry keeps my data secure?**

Before any hospital can submit data to the Registry, a formal authorisation is required from the local Caldicott Guardian, who is the

named 'guardian' of patient data at each hospital. Before NHS Digital will release any data, the IBD Registry has to formally demonstrate that it has satisfied the formal NHS requirements for data security. The IBD Registry holds and processes all its data within the UK.

### **How can I access the information that the Registry holds about me?**

You cannot be identified in the information that we hold in the IBD Registry database. You can be identified in the information that NHS Digital holds about you, on behalf of the Registry. While we do not have access to it we can help you obtain a copy.

### **How can I contact the Registry?**

You can find out more about us on our website at:

[www.ibdregistry.org.uk](http://www.ibdregistry.org.uk)

contact us by email:

[support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)

or by phone on: 020 3393 3969

If you are unhappy about any aspect of the Registry or how your information is being used, you should, in the first instance, talk to your IBD doctor or nurse to try and resolve the problem. If you want to make a formal complaint about any aspect of the IBD Registry, then you can do so by emailing [support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk).

**Thank you for your support!**

## **IBD Registry**

**020 3393 3969**

[support@ibdregistry.org.uk](mailto:support@ibdregistry.org.uk)

[www.Ibdregistry.org.uk](http://www.Ibdregistry.org.uk)

IBD Registry is a not for profit company limited by guarantee, with member organisations: British Society of Gastroenterology, Royal College of Physicians and Crohn's and Colitis UK. Company number 11197749

### **Changes to this patient information leaflet**

We may need to make changes to this leaflet from time to time, and we will publish the updated version on our website [www.ibdregistry.org.uk](http://www.ibdregistry.org.uk), with version date on it.