

IBD Registry – Information for Patients



The IBD Registry is a national project to collect information about Inflammatory Bowel Disease (IBD) from across the UK for the first time.

Why we're supporting the IBD Registry – a message from Crohn's and Colitis UK and CICRA (Crohn's in Childhood)

The IBD Team at your hospital want to join in the UK IBD Registry.

This means sending information about patients and their treatment to a central database unless the patients state they do not wish their information to be shared.

We believe that the IBD Registry will benefit all IBD patients by:

- Helping hospitals to improve their IBD services.
- Supporting research into the causes of IBD and better IBD treatments.
- Improving society's understanding of

how people's lives are affected by IBD.

No one in the Registry team will be able to identify any individual patient and all the Registry publications will be completely anonymous. We are confident that the Registry team have taken all the right steps to make sure that your information will be handled safely and confidentially.

We encourage you to say yes to the questions on the consent form so we can help to improve care for all IBD patients. If you have any questions, please speak to your IBD doctor or

nurse, or call our helplines.

Thank you,

**David Barker, CEO
Crohn's and Colitis UK
Helpline: 0300 222 5700**



**Margaret Lee, Chair
Crohn's in Childhood (CICRA)
Helpline: 0208 949 6209**



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

Your hospital will send some information about you, your IBD and your IBD care to 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 fully protected and you can read more about this below.

If you do not want information about you submitted to the IBD Registry, section 8 tells you how to arrange this.

2 - How will the Registry help IBD patients?

Information about your IBD and its treatment can contribute to improving patient care and research in several ways:

- The IBD Registry team will analyse information about IBD and how it's treated across the UK and publish the results.

- Researchers from NHS or academic organisations, or from health-related companies may request anonymous information from the Registry to study IBD; for example to compare different treatments and outcomes or to monitor the safety and effectiveness of medicines.

- Researchers may ask the Registry to help find patients to take part in clinical studies. If a research project came up that might be relevant to you, your doctor would be contacted.

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: for example the frequency of surgery, hospital attendances and admissions.

3 - How is the confidentiality of my personal information protected?

Information does not go direct to the Registry, but is sent by your hospital to NHS Digital (formerly the Health and Social Care Information Centre). NHS Digital changes any identifiable personal information into a different format so that no one at the IBD Registry can identify any individual patient. (This process is called pseudonymisation.) NHS Digital keeps a master file so that future information can be added to the right patient's registry record and to be able to contact hospitals about

research studies.

4 - What is NHS Digital?

Previously known as the Health and Social Care Information Centre, NHS Digital is an organisation approved by the government for their standards of data security and confidentiality. It is authorised by the NHS to collect and process information about patients and the healthcare they receive. The information held by NHS Digital, including information from other NHS bodies, may be used to analyse the healthcare you receive, to help contact patients (e.g. about a research project) or to provide information to the IBD Registry about patients' health status.

5 - What identifiable personal information will be used?

Your NHS number, postcode, date of birth and gender are included in the information sent to NHS Digital. The NHS number means the IBD Registry can track the care a patient receives even if they attend different hospitals. The postcode means the IBD Registry can understand the care people receive in different parts of the country. This personal information is pseudonymised by NHS Digital before being passed to the IBD Registry.

6 - What happens to 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 published reports will be available at www.ibdregistry.org.uk. Some pseudonymised information may be shared with other UK NHS audits and research projects (e.g. the UK Bowel Cancer Audit). Reports with fully anonymised information may be made available to NHS and academic organisations and to health-related companies such as pharmaceutical

companies, for example to monitor the safety and effectiveness of medicines. All applications for access to the anonymised Registry information will have to be approved by the Registry Research Committee.

7 - How long will the IBD Registry keep my data and can I opt out later?

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. You can stop information about your IBD and your healthcare being held in the Registry at any time, by speaking to your IBD doctor or nurse, or by contacting the Registry Administrator at the address given below.

8 - If I do not want my information to be sent to the IBD Registry now, what should I do?

Talk to your IBD doctor or nurse about your concerns. 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 your doctor, nurse, or a member of the IBD clinic administration team. They will make sure your information is not sent to the IBD Registry. This will not affect your treatment in any way.

9 - Who is responsible for the information about patients in the IBD Registry?

The British Society of Gastroenterology is the Data Controller for the Registry information and is responsible for ensuring that the IBD Registry complies with the Data Protection Act 1998.

10 - How can I make a complaint?

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 writing direct to the Registry Administrator at the address given below.

11 - What will happen next?

Over the next year all patients will be asked to sign a consent form, to give permission for your IBD team to continue submitting your information to the IBD Registry and confirm how you wish your information to be used.

12 - Which organisations are involved in the IBD Registry?

The IBD Registry is run by the British Society of Gastroenterology and supported by:

- Crohn's and Colitis UK
- CICRA – Crohn's in Childhood
- Association of Coloproctology of Great Britain and Northern Ireland
- British Dietetic Association
- British Society of Gastroenterology
- British Society for Paediatric Gastroenterology, Hepatology and Nutrition
- Primary Care Society for Gastroenterology
- Royal College of Nursing - IBD Network
- Royal College of Physicians - IBD Programme

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The British Society of Gastroenterology is a charity registered in England: Charity number 1149074