

The national UK registry for people with IBD

Welcome to the registration and consent form for people with IBD who want to join the IBD Registry. Our role at the IBD Registry is to collect information about Inflammatory Bowel Disease (IBD) from across the UK.

We aim to improve the health of people living with inflammatory bowel disease in the UK. We collect and analyse data in order to improve understanding of the care of people with IBD and their treatments and to support research.

In joining us, you will be helping the collection of this essential data. Joining the IBD Registry is entirely voluntary.

We do our work by collecting information on your IBD from you directly, from your healthcare team, and from other healthcare datasets. We analyse this data on an ongoing basis to produce local and national pictures of IBD in the UK and of the care and treatments that patients receive.

There is a full description of what we do on our Patient Information Leaflet. You can download a copy from our website, which also has further information: ibdregistry.org.uk

All data that we collect will be processed in accordance with the General Data Protection Regulation (GDPR) and the Common Law Duty of Confidentiality (CLDC). The data is securely collected and then held within secure data centres in the UK which are compliant with industry and NHS data security standards.

For further information, including details of our lawful basis, the purposes for which personal confidential data will be processed, your rights and how to contact us, please see the full Privacy Notice (also on our website).

Stay informed about the IBD Registry and about IBD

If you want to be kept informed of our analysis, insights and research, please join our mailing list at ibdregistry.org.uk. You can also see our website for publications and results. We will only use the email address you have just supplied for Registry participation-related matters, not for general updates.

Crohn's & Colitis UK have further guidance on their website for people with all forms of IBD that you may find helpful.

Thank you again for joining our national Registry. We can only do our work because of the kind participation of people with IBD and their healthcare teams across the UK, and we are very grateful to all our contributors and supporters for this.

How to complete this form

To register you with the IBD Registry, we need to ask some questions about your IBD, about you and your hospital and GP, and about contacting you. As part of this process, we ask for some of your personal details including your NHS number, name and date of birth so that your hospital and the NHS can accurately identify you before sharing any data with us. The information you provide will be stored as part of your Registry record.

There is an online version of this application form available at ibdregistry.org.uk Please use the online form if you have access to the internet. Doing this will enable you to easily manage your details and consent options online in the future. If you do not have access to the internet then please return your completed and signed form by post to the IBD Registry:

IBD Registry Ltd
Suite 9, Epsom Workhub
Epsom Square
6-7 Derby Square
Epsom High Street
Surrey
KT19 8AG

The national UK registry for people with IBD

Welcome to the consent form for people with IBD who want to join the IBD Registry.

I have read and understood the Patient Information Leaflet (version 4.0, April 2021) (required)

Consent (to join the Registry)

Joining the IBD Registry

In joining the IBD Registry I understand the following:

- The IBD Registry will share my minimum personal details with the NHS, my hospital, GP, or other healthcare provider to confirm my identity and inform them I have joined the Registry. This will allow them to share relevant data from my health record so it can be added to the Registry
- The IBD Registry will use my minimum personal details to request relevant data from central NHS bodies (such as NHS Digital), registries and other national datasets, and will link this to my data within the Registry
- The IBD Registry will use my minimum personal details to allow relevant data previously supplied to the IBD Registry with my consent (such as the older Registry database or COVID-19 Risk Tool) to be added to the Registry.
- The IBD Registry can request and collect data about me from IBD relevant research studies or tissue banks that I have separately consented to (e.g. the UK Biobank, the NIHR BioResource), and will link this to my data in the Registry
- The IBD Registry can contact me to invite me to take part in optional surveys about me, my IBD and my health, and will add my responses to the Registry
- The IBD Registry can contact me with communications that are relevant to my involvement with the Registry or my IBD health
- The IBD Registry will analyse my data for the purposes of improving the understanding of IBD in the UK. We may also work with approved organisations to do this.
- The statistical results of the analysis will be published, with my identity protected and no connection to my name or other personal identifiers. These statistics may be for many different groups with an interest in IBD, including patients and the public, clinical teams, the NHS and public health bodies, companies developing healthcare products (e.g. drugs or medical devices), patient organisations and policymakers
- My participation is voluntary. I can withdraw or change my options at any time but processing or analysis that has already taken place using my data cannot be undone

I agree to join the IBD Registry (required)

Consent (research and contact options)

Research using my data (optional – you can choose whether or not you want to consent to this)

In joining the IBD Registry I have the option to allow my data collected by the Registry to be used for approved research purposes. In choosing this option, I understand that:

- Information gathered about me will be stored for use in research about IBD or in the interests of people who have IBD
- Information from my records held by the IBD Registry can be used in research run by the IBD Registry
- Information from my records held by the IBD Registry can be used in research studies run by approved organisations
- All research will have independent ethical approval where this is required
- Information from your records held by the IBD Registry may be linked to other relevant datasets where this forms a necessary part of a research study protocol approved by the IBD Registry
- Research data produced by studying my information may be included in publications and/or placed in electronic archives, without any connection to my name or other personal identifiers
- My participation in research is voluntary. I can withdraw or change my options at any time without giving any reason, but processing, analysis or research that has already taken place using my data cannot be undone

I agree that my data can be used in approved research for IBD (optional)

Contact for research (optional – you can choose whether or not you want to consent to this)

In joining the IBD Registry I have the option to be contacted to take part in future research. In choosing this option, I understand that:

- my contact information can be used by the IBD Registry to invite me to approved IBD-related research studies. Participation in any such future studies is entirely voluntary: you decide at the time.

I agree to be contacted for opportunities to be involved in future research (optional)

Signature (required):

Date (required):

Registration

What type of inflammatory bowel disease do you have? (required)

The IBD Registry is only open to people in the UK with inflammatory bowel disease.

(To join the UK IBD Registry you need a diagnosis of your IBD and what type it is. The diagnosis will have come from a doctor or a healthcare team, and it will be a form of inflammatory bowel disease such as: Crohn's disease, ulcerative colitis, microscopic colitis (lymphocytic colitis and collagenous colitis) or Eosinophilic colitis. Although IBS (irritable bowel syndrome) sounds similar to IBD, IBS is not a form of IBD. You can only join the IBD Registry if you have IBD.)

- | | |
|--|---|
| <input type="checkbox"/> Crohn's disease | <input type="checkbox"/> Phouchitis |
| <input type="checkbox"/> Ulcerative colitis | <input type="checkbox"/> Eosinophilic enterocolitis |
| <input type="checkbox"/> IBD unclassified | <input type="checkbox"/> Lymphocytic colitis |
| <input type="checkbox"/> Microscopic colitis | <input type="checkbox"/> Collagenous colitis |

What is your NHS Number (England & Wales), Health and Social Care number (Northern Ireland), CHI number (Scotland)? (required)

We will hold your NHS Number to uniquely identify you. Your hospital and the NHS also need this to identify you. It may be listed on appointment or clinic letters from your GP or hospital. If you have online access to your GP records, it may also be listed there. Your NHS Number is a 10 digit number that looks like 485 777 3456 (this is not the same number as your National Insurance Number). You can find out more about your NHS number, or use the online service to find your NHS number, at www.nhs.uk/using-the-nhs/about-the-nhs/what-is-an-nhs-number/

What country do you live in? (required)

To join the UK IBD Registry you have to live in either England, Wales, Scotland or Northern Ireland. Residents of the Isle of Man and the Channel Islands are not currently eligible to participate in the IBD Registry.

- | | |
|----------------------------------|---|
| <input type="checkbox"/> England | <input type="checkbox"/> Scotland |
| <input type="checkbox"/> Wales | <input type="checkbox"/> Northern Ireland |

What is your date of birth? (required)

We need your date of birth to confirm if this the right consent form for you based on your age. This information will also be used to validate your identity.

DD	MM	YYYY
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What is your home postcode? (required)

This is the postcode where you live, which is ideally the same as the postcode the NHS uses to send letters to you. Your hospital and the NHS use this to help identify you and it helps us to confirm your identity.

Contact details

What is your first name ? (required)

What is your preferred name (if different from your first name)? (optional)

We collect this information to ensure that we correctly address our communications to you.

What is your email address? (optional)

This will be our main form of contact with you including helping to confirm your identity.

_____ @ _____

If you have not provided your email address or mobile phone number, please provide the following contact details:

Your landline telephone number

How are you currently receiving care for your IBD? (required)

- | | |
|--|--|
| <input type="checkbox"/> At an NHS hospital | <input type="checkbox"/> Through my GP |
| <input type="checkbox"/> At a private hospital in the UK | <input type="checkbox"/> Self-care/ Other (e.g. dietician) |

What is your last name ? (required)

What was your sex at birth? (required)

Your hospital and the NHS use this to help identify you and it helps us to confirm your identity.

- Male
 Female

What is your mobile phone number? (optional)

This provides us with an additional form of contact to your email address. It will be our second choice means of contacting you.

If you have not provided your email address or mobile phone number, please provide the following contact details:

Your postal address

If you are receiving care at an NHS hospital, what is the most recent NHS hospital at which you have received care for your IBD? (required)

This will allow us to request your IBD related health records from your hospital
