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What is the IBD Registry?

The IBD Registry collects health data from NHS hospitals and analyses this information to help improve services for people with inflammatory bowel disease (IBD). It also supports new research into these conditions.

If you have IBD, which includes Crohn’s disease, ulcerative colitis and other forms of IBD, you can join the Registry to agree to your data being used to support this valuable resource.

What data do you collect?

We can collect information about your diagnosis and treatment from your hospital IBD team, and from you directly. For example, we might ask you to complete an online survey once or twice a year. To sign up to the Registry, you will need to provide some personal details including your name, NHS number and date of birth. This is so we can make sure you are eligible to join the Registry, and your hospital can identify you before sharing any data with us. We will ask what type of IBD you have, and how you would like to be contacted.

How do you use my data?

When you join the IBD Registry, you can tell us how you want us to use your data. Your information will join data from thousands of other people with IBD, which we can analyse to find out how treatment and care for people with IBD could be improved. You will also have the option to agree to your data being used for research, and to tell us if you want to be contacted about new studies that are relevant to you and you may want to take part in. This can make it easier for researchers to recruit the participants they need.

Is my data safe?

We meet strict NHS requirements for data security and ensure that any data about you is transferred to us safely. It is then held within secure electronic databases.

The data we hold is de-identified before any analysis or research can take place. This means we remove data which could identify you, such as your name or NHS number, and replace it with codes. This helps to protect your identity.

Qr code

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How do I sign up?

To find out more and join the IBD Registry online, visit   
**ibdregistry.org.uk/join** or scan the QR code using your   
smartphone.

Joining online helps us keep costs down, but if   
you cannot access the internet you can contact us to request

a paper form. Joining the IBD Registry is entirely voluntary,

and you can change your mind at any time.