

Summary

The purpose of the IBD Registry is to improve the health of people living with inflammatory bowel disease (IBD) in the UK by the collection and analysis of data to improve understanding of the care of people with IBD and their treatments, and to facilitate research.

We want to work in partnership with a Patient Advisory Group (PAG) with people who have IBD or are involved with the support or care of people with IBD to make sure that this data is used in ways that are aligned with the expectations of patients and the public.

This page is about the personal information we collect about you if you apply to be, or are a member of our Patient Advisory Group.

Who we are

The [IBD Registry](#) is a company limited by guarantee registered in England under company number 11197749, whose registered address is 3 St Andrews Place, Regent's Park, London NW1 4LB. Our VAT number is: 291683766 (this is our registered office; see below for our office address)

We are a not-for-profit organisation, wholly owned by three joint members – the [Royal College of Physicians \(RCP\)](#), the [British Society of Gastroenterology \(BSG\)](#) and [Crohn's & Colitis UK](#).

We act as the Data Controller for the personal data that you submit to us and protect that data in accordance with all relevant laws. We are registered with the ICO (Information Commissioner's Office). Our ICO Registration Number is: ZA334069

How to Contact Us

Our office address is: Suite 9, Epsom Workhub, Epsom Square, 6-7 Derby Square, EPSOM, Surrey KT19 8AG.

For enquiries related to this tool, please contact us on covid19@ibdregistry.org.uk

Our Data Protection Officer can be contacted by email at dpo@ibdregistry.org.uk or by post to The DPO at the office address given above.

The purposes of the processing and recipients of personal data

This privacy policy applies to the information we hold about you in relation to your application to and/or membership of our Patient Advisory Group (PAG)

It is designed to allow us to collect personal details from you as part of any application that you make to us to join our Patient Advisory Group. These details include:

- a. Your contact information, so that we can contact you regarding the PAG
- b. Your IBD diagnosis (if any), to allow us to assess that we have a balanced representation of the IBD community in the PAG
- c. Any further information that you choose to disclose to us as part of the application to become a member of the PAG.

We will not share this data with anyone without your prior written permission (for example, sharing contact details of PAG members with each other for the purposes of involvement the Group).

The lawful basis for the processing

The data we process about you is contact data plus information about your IBD diagnosis, which 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 storage of personal data

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).

The retention periods for the personal data

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

Your rights

You have the following rights under the GDPR, which this Privacy Notice 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;
- In certain circumstances, the right to object to us using your personal data for particular purposes;
- In certain circumstances, the right to ask us to delete any personal data we hold about you;
- In certain circumstances, the right to ask us to restrict the processing of the information we hold about you; and
- Rights with respect to automated decision making and profiling.

If you wish to find out more about your rights in relation to our use of your personal data, please contact us using the details provided at the top of this Privacy Notice 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.