

Our IBD Registry Privacy Policy

Background

The IBD Registry understands that your privacy is important to you and that you care about how your personal data is used and shared online. We respect and value the privacy of everyone who visits this website (www.ibdregistry.org.uk) (“our Registry website”) and will only collect and use personal data in ways that are described here, and in a manner that is consistent with our obligations and your rights under the law.

Please read this privacy policy carefully and ensure that you understand it. Your acceptance of our privacy policy is deemed to occur upon your first use of our Registry website. If you do not accept and agree with this privacy policy, you must stop using our Registry website immediately.

Definitions and Meanings

We have to define some key terms so that it is clear what we mean in key instances:

“Cookie”	means a small text file placed on your computer or device by our Registry website when you visit certain parts of our Registry website and/or when you use certain features of our Registry website. Details of the Cookies used by our Registry website are set out in section 13, below;
“Cookie Law”	means the relevant parts of the privacy and Electronic Communications (EC Directive) Regulations 2003;]
“personal data”	means any and all data that relates to an identifiable person who can be directly or indirectly identified from that data. In this case, it means personal data that you give to us via our Registry website. This definition shall, where applicable, incorporate the definitions provided in the Data Protection Act 1998 (from 25 May 2018, the EU Regulation 2016/679 – the General Data Protection Regulation (“GDPR”); and
“We/Us/Our”	means IBD Registry Ltd, 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

1. Information About Us

- 1.1 Our Registry website is owned by us and operated by Dovetail Strategies Limited, a limited company registered in England under company number 05743746, whose registered address is 414 Vox Studios, 1-45 Durham Street, London SE11 5 JH
- 1.2 Our VAT number is 291683766
- 1.3 We are a not-for-profit organisation, wholly owned by three joint members – the Royal College of Physicians, The British Society of Gastroenterology and

Crohn's and Colitis UK.

- 1.4 We act as the Data Controller for 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 Data Protection Officer is Clare Sanderson, who can be contacted by email at clare.sanderson@ig-l.co.uk or by post at the address on the website <http://www.igs-l.co.uk>

2. **What Does This Policy Cover?**

This privacy policy applies to your use of our Registry website and contact you make with us for information on this website and newsletter form this website. Our Registry website may contain links to other websites. Please note that we have no control over how your data is collected, stored, or used by other websites and we advise you to check the privacy policies of any such websites before providing any data to them.

3. **Your Rights**

- 3.1 You have the following rights under the GDPR, which this privacy policy and our use of personal data have been designed to uphold:
 - 3.1.1 The right to be informed about our collection and use of personal data;
 - 3.1.2 The right of access to the personal data we hold about you (see section 12);
 - 3.1.3 The right to rectification if any personal data we hold about you is inaccurate or incomplete (please contact us using the details in section 14);
 - 3.1.4 The right to be forgotten – i.e. the right to ask us to delete any personal data We hold about you (We only hold your personal data for a limited time, as explained in section 6 but if you would like us to delete it sooner, please contact us using the details in section 14);
 - 3.1.5 The right to restrict (i.e. prevent) the processing of your personal data;
 - 3.1.6 The right to data portability (obtaining a copy of your personal data to re-use with another service or organisation);
 - 3.1.7 The right to object to us using your personal data for particular purposes; and
 - 3.1.8 Rights with respect to automated decision making and profiling.
- 3.2 If you have any cause for complaint about our use of your personal data, please contact us using the details provided in section 14 and We will do our best to solve the problem for you. If we are unable to help, you also have the right to lodge a complaint with the UK's supervisory authority, the Information Commissioner's Office.
- 3.3 For further information about your rights, please contact the Information Commissioner's Office or your local Citizens Advice office

4. **What Data Do We Collect on our Registry website?**

Depending upon your use of our Registry website, we may collect some or all of the following personal data, primarily through our Mailing List opt-in page (please also see

section 13 on our use of Cookies and similar technologies and our [Cookie Policy](#).

- The information we collect for our mailing list are first name, last name and email address.
- If you use the email address provided by us on our website to contact us, we will store that information for the purpose of replying to you. (Your email address may include your name and your organisation, which is personal data).

5. How Do We Collect and Use Your Data?

We collect and use your personal Data for the following purposes and using the following services:

Mailing list management: we use the Mailchimp service to manage our mailing list, including new user 'opt-in' and 'unsubscribe' functions.

Website analytics: We use the Google Analytics services enable us to monitor and analyse web traffic and can be used to keep track of user behaviour.

Responding to your queries: if you contact us directly using the information on our website or in our newsletters and similar mailings, we will use the personal data (email address and your name) to respond to you.

All personal data is processed and stored securely, for no longer than is necessary in light of the reason(s) for which it was first collected. For more details on security see section 7, below.

- 5.1 You have the right to withdraw your consent to us using your personal data at any time, and to request that we delete it.
- 5.2 We do not keep your personal data for any longer than is necessary in light of the reason(s) for which it was first collected. We retain personal data that you provide to us for news and updates on an ongoing period, as long as the newsletters (or similar) are continuing. We retain personal data for replying to you for the reasonable duration of the conversation.

6. How and Where Do We Store Your Data?

- 6.1 We only keep your personal data for as long as we need to in order to use it as described above in section 6, and/or for as long as we have your permission to keep it.
- 6.2 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).

7. Do We Share Your Data?

- 7.1 We will not share any of your data with any third parties for any purposes, unless we have sought your express permission to do so.
- 7.2 In certain circumstances, we may be legally required to share certain data held by us, which may include your personal data, for example, where we are involved in legal proceedings, where we are complying with legal obligations, a court order, or a governmental authority.

- 7.3 We may compile statistics about the use of our Registry website including data on traffic, usage patterns, user numbers, sales, and other information. All such data will be anonymised and will not include any personally identifying data, or any anonymised data that can be combined with other data and used to identify you.
- 7.4 The third party data processors used by us are Mailchimp (mailing provider), WordPress (website content management) and Google Analytics (website usage) , both of which hold the data located inside the EEA.

8. **How Can You Control Your Data?**

- 8.1 When you submit personal data via Our Registry website, we give you options to restrict our use of your data. You can opt-out of receiving emails from us at any time by using the unsubscribe link provided in our emails, or by contacting us directly by email requesting to opt-out. These are in addition to your rights under the GDPR.

9. **Your Right to Withhold Information**

- 9.1 You may access all of our Registry website without providing any data at all.
- 9.2 You may restrict our use of Cookies. For more information, see section 13 and our [Cookie Policy](#).

10. **How Can You Access Your Data?**

You have the right to ask for a copy of any of your personal data held by us (where such data is held). Under the GDPR, no fee is payable and we will provide any and all information in response to your request free of charge. Please contact us for more details at our email address given at the top of this policy or using the contact details below in section 14.

11. **Our Use of Cookies**

- 11.1 Our Registry website may place and access certain first party Cookies on your computer or device. We use Cookies to facilitate and improve your experience of our Registry website and to provide and improve our services. We have carefully chosen these Cookies and have taken steps to ensure that your privacy and personal data is protected and respected at all times.
- 11.2 All Cookies used by and on our Registry website are used in accordance with current Cookie Law.
- 11.3 All our cookie related information is included in our [Cookie Policy](#).

12. **Contacting Us**

If you have any questions about our Registry website or this privacy policy, please contact us by email at support@indregistry.org.uk or call us on 0203 393 3639 or by post at 3 St Andrews Place, Regent's Park, London NW1 4LB. If your contact is a request for information about the data we hold about you (as under section 12, above).

please state clearly that it is a subject access request.

13. **Changes to Our Privacy Policy**

We may change this privacy policy from time to time (for example, if the law changes). Any changes will be immediately posted on our Registry website and you will be deemed to have accepted the terms of the privacy policy on your first use of our Registry website following the alterations. We recommend that you check this page regularly to keep up-to-date.
