

# Inflammatory Bowel Disease (IBD) support group Information and privacy information

## The Royal Free Charity

The Royal Free Charity works in partnership with the Royal Free London NHS Foundation Trust because together we can do what the NHS can't achieve alone.

## The support hub

The Support hub was set up in 2018 by the Royal Free Charity to support patients with long term health conditions, offering information and advice to patients to help them better manage living with their condition (e.g. a welfare advice service, peer support groups).

## What is the IBD support group and what can I expect?

The IBD group is a peer-led group arranged by the Royal Free Charity (RFC) Support hub, co-facilitated with Royal Free London psychology team (trainee clinical psychologist), as well as peer-led by those attending the group.

It provides an opportunity to meet and share experiences with other people who have a form of IBD (e.g. Chron's disease or ulcerative colitis), sharing personal experiences, learning, and supporting each other.

Please note, the Support hub team and Psychologist are not medical experts, however the people in the group are fellow IBD patients with lived experience of IBD. We may occasionally have medical expertise or guest speakers join the group or do separate sessions.

## Privacy information

This leaflet lets you know about how we handle your personal information. The Data Subject rights under the UK GDPR applies, for full details please see our privacy policy at [royalfreecharity.org/about/privacy-policy/](https://royalfreecharity.org/about/privacy-policy/).

### Where is my information kept?

The support hub record and hold your information in a secure case management database.

We hold the information sent from you when you book into a group. This includes your name, mobile number, address and email address. The reason for collecting this information is so that we can get in touch about upcoming groups, service changes, or if there are any emergencies during a group.

For some support groups, we may ask and record some special category information (e.g. health information), if it is relevant to being involved in the group.

We ask for some 'equality monitoring information' such as gender and ethnicity, although it is completely optional as to whether you give this.

### Do you need my consent?

We are a support service, connecting patients with similar conditions to access social support via peer support groups. We cannot run these peer support groups or let you know about them without your information.

We will ask your consent to hold your information when you register for your first group.

### Who can see my personal information?

It can only be accessed and used by:

- The Royal Free Charity Support hub lead (co-chair of the group) and co-ordinator (who helps administer the group).

Those attending the group will have access to personal stories and experiences of others; this is a confidential group, so we ask attendees not to share stories outside of the group. It is a safe space for all that attend.

## Will my personal information always remain confidential?

We will not share your data with any third party unless we have your consent to do so.

We protect your confidentiality. However, we can share your personal information in the following circumstances:

- When there is a legal requirement – because of a law or a court order
- Where there is an overriding public interest (e.g. to prevent serious crime or serious harm to self or another person)
- To prevent a vulnerable adult from abuse (e.g. physical, sexual, psychological, financial).

## How long will you keep my personal information?

The RFC Support hub retains personal information for the advice industry standard of 6 years. If you would like us to remove your information before this, please let us know.

## How will you use my information?

We may contact you to remind you about upcoming support groups, via email or phone. If you would prefer us not to, please let us know by emailing: [elizabeth.fowler@royalfreecharity.org](mailto:elizabeth.fowler@royalfreecharity.org).

## What if I want more detail or give feedback?

If you ever have any feedback, issues, or questions, please get in touch with Liz Fowler, the support hub lead, at [elizabeth.fowler@royalfreecharity.org](mailto:elizabeth.fowler@royalfreecharity.org) or call Liz on: 07932 719176.

Full details of the Royal Free Charity privacy policy can be found here: <https://royalfreecharity.org/privacy-policy>.