

Patient Advisory Group (PAG)

Guidance for participation and FAQs for Group Members

Purpose of this document

This document describes the role of a PAG member. It is intended to be read as a complement to the IBD Registry PAG Terms of Reference. Its purpose is to:

- Provide a more detailed explanation of what's involved
- Set expectations
- Give practical guidance

Role description in more detail

Members of the PAG are invited to use their experiences of IBD and the experiences of others affected together with any other relevant expertise to:

- Provide their perspective to inform the ongoing development and activities of the IBD Registry
- Attend PAG meetings (virtually if needed) where possible and continue the discussion outside the meetings via digital means (predominantly email).
- Contribute ideas and discussion to smaller project groups.
- Raise questions and concerns about the IBD Registry and their public and patient interaction and engagement activities.
- Assist with the development of clear communications to help us explain the purpose and functions of the IBD Registry to a wider audience including the IBD community and general public.
- Advise on potential responses and actions arising from concerns or questions raised by other members of the public.

Estimated Time Commitment

We aim to make membership of the PAG as accessible as possible, taking into account people's work, family and other commitments we recognise that there may be times when you are incapacitated through illness and hope that the virtual nature of the PAG meetings may minimise the impact to you and allow you to take part from the comfort and safety of your home. The time commitment for PAG activities is

likely to vary across the project, with more time required at the beginning than when things become more established.

Meetings and working together

Meetings will typically be held virtually with at least two meetings each calendar year, with further meetings organised following discussion with PAG members. We will try to keep these meetings to a maximum of 2 hours, especially where they are held remotely.

Sometimes we expect to have to focus on a specific topic, for which we will invite members to an adhoc project group. These may involve a combination of meetings and document review and comment.

We hope to hold one meeting annually face to face, to review our work together and provide a more sociable environment to strengthen our team work together.

Reading and reviewing documents, contributing to (digital) discussions

Between meetings, relevant documents will be shared with PAG members (typically by email) for their comments and suggestions. We will aim to allow 3-4 days for members to read and comment on the documents so that they can fit more easily into your schedule. It is not expected that all members will comment on all documents, but we ask that members make a reasonable attempt to contribute to most discussions where possible.

Our support for you

We want to support you in this role so that you have a positive experience. As a PAG member, you have a right to expect that:

- Your contributions will be respected and valued, your views heard and acted upon where practicable.
- Reasonable notice is given with regard to meeting dates and any other activity, taking into account suitable dates, times and venues for meetings.
- Clear information will be given about what is required for activities; research and involvement objectives; procedures of sharing work and decision-making.
- Where required, information will be provided in an accessible form (e.g. easy read)
- We will provide a named person within the IBD Registry who will be your point of contact for queries, concerns, issues and assistance, and who can escalate matters on your behalf as required

Respect and confidentiality

- Some topics may require debate and not have a right/wrong answer. Please challenge positively whilst respecting other peoples' opinions. We hope that the group will always manage to reach an agreeable consensus.
- On social media (such as Twitter) please ensure that you separate out your private opinions and identify them as such; especially that your views do not represent the IBD Registry
- We wish to be fully transparent to the outside world, and for this we hope that members would be happy to be identified as members; however, we understand and respect if you ask to be anonymous
- Further to our transparency goals, minutes will be published; but individual contributions will not be identified
- Any other details that we hold about you (such as email addresses) will be kept confidential. We will ask for your permission to share contact information with other PAG members in order to be able to undertake our work. [NOTE – REF PRIVACY P
- We value highly your experiences as a person with IBD, and that in this, people may choose to reveal personal matters relating to their IBD care. The group are requested to keep these relevant to topic under discussion and also to respect confidentiality by keeping within the group

Recognising your commitment

Thank you for offering your time and expertise for this role. Your contributions are really appreciated. If it is acceptable to you, by way of thanks, we would like to publish and publicise your involvement in our PAG.

Your Registry Contact

If you have questions about either this document or the associated Terms of Reference, or if you have any further questions, please contact the IBD Registry at: admin@ibdregistry.org.uk

Thank you for considering this role and your engagement with the IBD Registry.