Gut Reaction Patient and Public Review Group

Role description and requirements for members

About Gut Reaction

Gut Reaction is a health data research initiative that brings together data from patients with Inflammatory Bowel Disease (IBD) who are enrolled in the NIHR BioResource, with data from other sources such as participating NHS Trusts, to make it accessible for research to improve outcomes for people with IBD. Find out more here. Applications to access Gut Reaction data will come in through the NIHR BioResource, and all applications are considered by the Patient and Public Review Group before progressing to either the NIHR Data Access Committee or Steering Group for final decisions - before any data is released for research.

About the Patient and Public Review Group

The Patient and Public Review Group (PPRG) assesses and provides recommendations on the scientific merit, health/social value, use of data and potential risks of data access applications for use of the NIHR BioResource data through Gut Reaction. The PPRG is made up of people affected by IBD, members of the public (lay members) and an NIHR BioResource representative. PPRG members are invited to use their particular perspectives and any other relevant expertise, to provide an insight into how data requests may be perceived by patients or the public, whether it seems an appropriate use of the Gut Reaction resource, whether it is in line with the Caldicott Principles, whether it is of value to the patient community, and are patients likely to see the benefit of that value.

How does the Patient and Public Review Group work?

When data access requests are received by Gut Reaction for NIHR BioResource data, a triage stage will take place to ensure applications are full and complete. Once this is established, the PPRG will review the application and provide recommendations to be considered at the next data access or steering committee meeting, where the final decision will be made. Non-commercial requests for data only will pass through the existing NIHR BioResource Data Access Committee. The PPRG chair and a second PPRG representative will also be full members of the committee and will present PPRG recommendations. The Steering Committee will review requests from industry partners, as well as requests for patient samples exclusively or in addition to data. A PPRG representative will also be a full representative of this committee to present the PPRGs recommendations.
What will be involved if I take part?

- The PPRG meetings will be held virtually every 2 weeks maximum, depending on the applications to be considered. A minimum of 6 patient/lay members should be present at each meeting.
- The Gut Reaction team and PPRG communicate via email as required between meetings.
- We will review the role with the PPRG informally after the first six months, with a full review of the process after 12 months. Thereafter, a review will be conducted every 2 years, to renew membership, gather feedback and update our working practices accordingly.

Who are we looking for?

- We are looking for 10 PPRG members in total, including 6 people affected by IBD e.g., a diagnosis of IBD, family, carer and 4 members of the public.
- The NIHR BioResource representative will be identified as appropriate.
- A good listener, able to work constructively with people with different experiences and views, being able to consider different perspectives.
- Confidence to ask clarification questions and to participate in group discussions.
- The ability to quickly read and digest large volumes of information.
- It would be desirable to have a demonstrable interest in research.

What can we offer you?

- An insight into new and exciting research into IBD.
- The knowledge that you are making a valuable contribution to research.
- Working as part of a team.
- A great addition to your CV – with the opportunity to develop new skills, which may be of interest for anyone who would like to work in the research sector.
- Full reimbursement of expenses and time in line with our Policy.
- Flexibility – we understand that you might not always be able to attend, and changes could be last minute.
- We want to support you in this role so that you have a positive experience. As a PPRG member, you have a right to expect that:
  - Your contributions will be respected and valued, your views heard and acted upon.
  - Reasonable notice is given for meeting dates.
  - Where required, information will be provided in an accessible form (e.g., easy read).
  - Appropriate training will be provided.

Diversity of Views and Inclusion of Under-heard Groups and Communities

We want to ensure that the views and opinions of as many people as possible are heard and considered. There are many factors that influence how people feel about the use of their health data for research, and we know that there are groups and communities who have more concerns and are less likely to participate in health data projects than others. We would be particularly interested in hearing from applicants from communities who have been historically excluded or underrepresented in research.

How can I join?

If you are interested in joining the PPRG, please complete this application form by 9am on 28th February.

If you have any questions, please feel free to contact gutreaction@crohnsandcolitis.org.uk

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