



**Gut Reaction Patient Advisory Committee**

**Role Description for Committee Members**

**About Gut Reaction**

Gut Reaction is a health data research initiative that is bringing together data from patients with Inflammatory Bowel Disease (IBD) enrolled in the IBD BioResource, with data from other sources such as the IBD Registry and participating NHS Trusts, to make it accessible for research to improve outcomes for people with IBD. Find out more [here.](https://crohnsandcolitis.org.uk/research/projects/our-partnerships/gut-reaction)

**About the Patient Advisory Committee**

The Patient Advisory Committee (PAC) ensures that the project team of Gut Reaction understand what patients want from Gut Reaction and ensure that it is managed with patient needs and preferences in mind. The PAC is made up of people affected by IBD from each of the NHS trusts providing data for Gut Reaction. PAC members have a two-fold role; providing advice to the project team based on their own experiences, and helping to advise on issues arising from the broader patient and public involvement activities organised by Gut Reaction.

Committee members are invited to use their experiences of IBD and any other relevant expertise to:

* Provide a **personal** patient perspective into the design, set up and delivery of the Gut Reaction Data Hub project.

**AND**

* Provide a **lay** (non-health or research professional) perspective into the design, delivery, evaluation and implementation of Gut Reaction for people affected by IBD, including those from under-heard communities.

# What will be involved if I take part?

* The expected time commitment for this will not exceed 4 hours a month, however most months this will be much less.
* PAC meetings are currently held via video conference, but we are hoping to have at least one face to face meeting per year.
* The Gut Reaction team and PAC communicate via email as required between meetings. PAC will also have a private online platform to share and comment on useful materials.
* Meetings are held at least once every three months and arranged at least 1 month in advance, although we aim to provide meeting dates for the whole year in advance.
* We will review the role with the PAC each year, to gather your feedback and update our working practices accordingly.
* You can remain on the PAC for the whole project, but it is fine to leave if your circumstances or interest changes. If taking a break would be helpful, if you are unwell for example, we are happy to support you to do this and to resume activity when the time is right.
* Some of the specific tasks involved include:
* Helping to shape Gut Reaction’s Patient & Public Involvement/Engagement (PPIE) and Communications strategies and providing advice on how these are delivered.
  + Advising on approaches to disseminate the work of Gut Reaction Hub to the public.
  + Ensuring information communicated is clear and concise for a public audience.
  + Helping to devise an annual work plan that enables members of PAC to contribute their expertise effectively.
  + Representing Gut Reaction at meetings and panels at various health data events in the UK.
  + Helping to communicate the benefits of health data research to the public and, where reasonable, for members to act as advocates for Gut Reaction.
  + Advising on approaches to build public understanding and trust of using health data in research.
  + Discussing and evaluating applications from researchers looking to access data from Gut Reaction.
  + Helping to evaluate the impact of PAC.

**Who are we looking for?**

* Someone affected by IBD e.g., a diagnosis of IBD, family, carer.
* Good communication skills.
* A good listener, able to work constructively with people with different experiences and views.
* Confidence to voice opinions clearly and participate in group discussions.
* Willing and flexible individuals who commit to being actively involved in the project (we know that you may not always be able to attend meetings or might have to miss them last minutes, and that’s fine, we do our best to keep everyone involved and in the loop outside of the meetings).

**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 taken into account for Gut Reaction. There are many factors that influence how people feel about the use of their health data for research, and we know from others who have investigated social attitudes to data usage that there are groups and communities who have more concerns and are less likely to participate in health data projects than others. The Gut Reaction team wants to identify and work with such groups to ensure that their voices are included. Working with colleagues at HDRUK and others, this will involve identifying groups whose voices are under-represented in health data research, designing engagement activities suitable for their needs and using their feedback to guide the further development of Gut Reaction.

**What can we offer you?**

* An insight into, and an opportunity to shape new and exciting research into IBD.
* The knowledge that you are making a valuable contribution to research.
* Working as part of a team, with opportunity to meet other people affected by IBD with an interest in research.
* 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.

We want to support you in this role so that you have a positive experience that helps you develop and learn. As a PAC committee 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 for meeting dates and any other activity, considering 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) – please let us know if we can make our information more accessible to you.
  + Appropriate training will be provided where desired and practicable – please let us know what training support would be most useful.

**How can I join?**

If you are interested in joining PAC, please complete [this application form](https://forms.office.com/Pages/ResponsePage.aspx?id=dWI965P9GE6-OG37RsKC55ccUickWHlNphqB_XRrazFUQTZVU1dIRDVQOFpSQkZUOVZMRzhNNUs3My4u) by 20th June 2021. We will then review the completed forms and aim to arrange informal phone calls to discuss the role further with you, which will include the opportunity to meet and discuss the role with one of our current PAC members.

We are planning to develop a Gut Reaction Involvement Network, for people not on PAC who are interested in the project, willing to get involved and keen to stay up to date. You can indicate your interest in this network by emailing us or responding to the question at the end of the application form.

**If you still have any questions, please feel free to contact:**

Nikul Bakshi or Gemma Winsor at gutreaction@crohnsandcolitis.org.uk