

PPI Code of Conduct for Researchers

This code of conduct outlines the principles and standards that researchers should adhere to when engaging in Patient and Public Involvement (PPI) activities with Bowel Research UK. By following these guidelines, researchers can adopt a collaborative and mutually beneficial relationship with the general public (referred to in this document as patient representatives), ultimately leading to more relevant and effective research.

Patient representatives include bowel cancer and bowel disease patients, carers, family members, and the general public with an interest in bowel conditions. PPI could include involving patient representatives in at least the following ways:

- in meetings such as focus groups, patient advisory groups, and trial steering groups
- by conducting surveys and questionnaires
- by working together to create documents such as leaflets and patient information sheets
- by having a patient or patients as an integral part of your trial team

This document assumes the above PPI activities are your current focus. However, you may consider alternative models, such as a more intensive collaboration with one or two patient representatives, to tailor PPI to the specific needs of your particular research project.

It is the responsibility of the researcher to ensure positive experiences for patient representatives in any PPI activity. As a researcher engaging in PPI with Bowel Research UK and the PaRT (People and Research Together) network, you should:

1. Be respectful and considerate
2. Maintain confidentiality
3. Be transparent
4. Collaborate
5. Be inclusive
6. Communicate clearly
7. Close the feedback loop
8. Offer compensation
9. Be open to patient feedback

The sections below explain each of these responsibilities in more depth.

1. Be respectful and considerate: Treat patient representatives with courtesy and respect.

- Create a mutually welcoming and respectful environment between patient representatives and researchers.
- Listen to patient representatives and give everyone an opportunity to have their say, allowing time in meetings for this to happen.
- Acknowledge and show appreciation for the work of patient representatives.
- Be respectful of people's time by ensuring meetings run to schedule.
- Provide timely responses to any questions raised.
- Value PPI as a helpful and necessary aspect of your research and not a tokenistic gesture.
- Remember that patients may be going through active disease management so consideration of their availability and energy levels at particular points will be appreciated.

2. Maintain confidentiality: Protect the privacy and confidentiality of patient representatives' information.

- Decide together with patient representatives on the meaning or extent of confidentiality, as there can be benefits from sharing contact details between other patient representatives and the research team.
- At the outset, stress that all information shared in the meeting must be regarded as confidential by everyone present to create a safe space for sharing health stories or other personal information.
- Comply with General Data Protection Regulation (GDPR) when handling data on patient representatives (see resource link on page six).
- Ask for permission to record virtual meetings. Delete video recordings of meetings when they are no longer needed and inform participants of this.
- Use BCC to copy patient representatives into emails so addresses are not being shared unnecessarily.

3. Be transparent: Be open and honest about the research as early in the process as possible.

- Clearly explain the nature of the research at the beginning and throughout the project, such as the research question, objectives, methodology, and risks and benefits to patients.
- Be upfront about and describe as specifically as possible the time commitment and specific activities patient representatives will be involved in.
- Be prepared to answer questions from patient representatives and be honest about what you know and don't know.
- When recruiting patient representatives, state whether payment is being offered or if it is an unpaid opportunity (see item 8: Offer compensation).
- Keep patient representatives informed about the progress of the research project, including any significant findings or changes to the project plan.
- Request confirmation that your explanations have been understood and if not, clarify any misunderstandings.

4. Collaborate: Adopt a collaborative relationship with patient representatives, valuing their insights and contributions.

- Involve patient representatives from the beginning of the project and throughout, rather than “bolting on” PPI at the end to confirm the work you have already completed.
- Provide regular updates in relation to insights and collaborations received.
- Acknowledge patient representatives as authors or contributors in papers and other research outputs, giving them the option to be named or remain anonymous.

5. Be inclusive: Ensure that PPI activities are inclusive and accessible to a diverse range of people.

- Consider how you can include people with a range of different ages, genders, ethnicities, education levels, religions, disabilities, lived health experiences, geography, and levels of PPI experience in your activities.

- Ask patient representatives if they have accessibility needs and fulfil these where possible. For example, accessibility needs at in-person meetings; large text for those with visual impairments; allowing people to leave their camera off if needed during online meetings; assisting people with using and modifying online features such as in Zoom meetings; and so on. Be aware that some of these needs may not become apparent until an event takes place, even when attendees have been asked.
- Allow people to communicate or contribute in a variety of ways. For example, some may find it difficult to speak up in a group and may appreciate being able to type into the chat function in an online meeting instead, or email their thoughts and ideas after the meeting.
- Consider holding meetings online rather than in-person for a larger geographical reach and to eliminate travel issues.
- If work is taking place online, consider how you might also involve those without internet access.

6. Communicate clearly: Maintain clear and effective communication with patient representatives throughout the entire research process.

- Consider that the language a researcher will use may be unfamiliar to patients and lay members of the public.
- Use plain language that is easy to understand and avoid jargon.
- If there is more than one researcher involved in a project or meeting, make sure that everyone knows who they are, what their function is and what role they will play.
- Consider any need for written or verbal interpretation or other accessibility needs.

7. Close the feedback loop: Communicate the impact and result of PPI contributions.

- Explain the impact of patient representatives' input on the research.
- If contributions are not usable, explain why.
- Explain how patient representatives' views will be represented in the dissemination of results and consider including them in this dissemination.

8. Offer compensation: Wherever possible, offer fair and appropriate compensation for patient representatives' time and involvement.

- Follow the [NIHR guidance](#) on paying patient representatives for their time.
- When possible, offer alternative payment if accepting money or gift cards/vouchers would cause difficulties for a public contributor (for example, by affecting benefits such as Universal Credit). Examples of other tokens of appreciation include giving a tour of the research lab, extending an invitation to a special event, or making a charitable donation on their behalf.
- For in-person meetings, provide travel expenses and hotel accommodation if needed.
- Organise payment quickly and make it easy for patient representatives to receive payment without the need to chase or follow it up.
- Keep patient representatives up to date with the progress of payment and expense claims.

9. Be open to feedback: Encourage feedback about the PPI experience from patient representatives.

- Explain how patient representatives can give feedback (positive or negative) on their experience of being involved in your project, including who they should contact and how.
- Emphasise to patient representatives that their feedback is actively encouraged and recorded.
- Listen to and respect feedback.
- Inform patient representatives about how you will act as a result of their feedback.
- Establish a process for patient representatives to report concerns or grievances.
- Provide regular updates on the actions resulting from the feedback provided.

Resources

- [NIHR guidelines for paying patient representatives](#)
- [How does GDPR influence my public involvement and engagement activities?](#)
- [Other NIHR resources for PPI](#)

Acknowledgements

This code of conduct has been prepared by Patient and Public Involvement (PPI) Manager Sam Alexandra Rose and the following members of the PaRT network:

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Frances Clegg

Jeff Andrews

Paul Terry

Pete Wheatstone

Reshma Punjabi

Sarah Laws

Sarah Parsons

Steve Clark

Tom Beard