



Patient and Public Advisory Group (PPAG)

List of Activities

Reviewing documents

Reviewing documents is one of the most common activities at the PPAG. We may contact you asking to review certain documents which are required for a grant application or website updates. Please find below the most common forms of documents we may need your help with. There may be some other documents (such as recruitment questionnaires) and we will always provide a clear explanation of what is required.

1. Lay Summaries

A plain English summary, sometimes called a lay summary, describes a research project in plain English and explains complex ideas and technical or scientific terms to people who do not have prior knowledge about the subject. A lay audience is diverse and can include members of the general public, patient groups, and researchers in different disciplines who could be potential research collaborators. A lay summary is intended to explain the research, what the researchers aim to achieve and how this may impact the rest of the research community and/or the quality of life of patient groups. Typical summaries might discuss the purpose of the research, its relevance to patient groups, the proposed methodology and/or the findings.

We may ask you to review the lay summary and ask you if it is readable, clear and understandable. You are welcome to provide any additional comments you think may be relevant as well as correct any mistakes.

2. Research Proposals

A research proposal is a concise and coherent summary of a research project. It usually includes the description of the research questions, design, methods, hypothesis, aims and objectives.

A researcher may ask for your feedback on some of these sections as well as your opinion on the study and its relevance to patients with certain lived conditions.

Attending focus groups

Focus group is a discussion with PPAG contributors chaired by a lead researcher. Focus groups can be either hybrid or online and we arrange them to suit your availability. You can expect a lively and engaging discussion where the researcher will set out the questions they would like to address and invite your comments on different issues relating to their project (e.g. their recruitment strategy, research design, ethical considerations, etc.).



Advisory Group

We may ask for your input on the best ways to approach PPI/E to achieve the greatest experience for the insight partners and the best impact for the outputs.

Being a co-applicant / a member of a steering committee

Ensuring that patients are partners throughout our projects is fundamental. Therefore, the Public Co-applicant and Steering Group roles are thoroughly embedded within the research collaborative. The main purpose of these roles is to provide a public and patient perspective on the research project.

A public co-applicant is involved in the development of a funding application and works as part of the research team to ensure the smooth delivery of the study if the application is successful.

A member of a steering committee provides strategic advice to the chief investigator and members of the research team and helps oversee the research project.

1. Responsibilities of Public Co-Applicant:

- Attend and contribute to meetings which will plan and review the work of this research project.
- Provide specific insights based on your own experience (or that of people you support) in relation to a specific illness or condition, or your experiences of health services. Your input should be aimed at helping the researchers to understand their work from the point of view of someone who experiences the topic of the research.
- Contribute ideas on the suitability of research for potential participants.
- Contribute to the design of questionnaires or other aspects of the research which will be received by patients and members of the public.
- You may be asked to help interpret the results that researchers are gathering.
- Take responsibility for the content of written reports and communications to which your contributions justify co-authorship.

2. Responsibilities of a Steering Committee member:

- Monitoring and supervision of all aspects of the study to ensure that the interim and overall objectives of the study are met.
- Meeting frequently, at least quarterly throughout the project, to discuss the research-related issues.
- Monitoring study progress against pre-agreed milestones (such as recruitment and follow-up rates), and adherence to agreed protocol.
- Advise on proposed changes to study plans in light of new evidence or unanticipated developments e.g major and minor ethics amendments.
- Provide advice to investigators and the study sponsor on the progression of the project through reports or minutes of meetings.



- Oversee and provide written evidence to support any requests for additional funding or time extensions.
- Oversee dissemination of research findings to research participants and the general public
- Oversee end-of-project report writing.

Researcher PPI training

Our centre aims to provide the best possible training opportunities to our PhD students. We may sometimes organise different events and workshops where we invite PPAG members to share their experiences with the new generation of scientists and discuss the best practices for involving PPI contributors in their research.