

# Cambridge Biomedical Research Centre

Cambridge University Hospitals' Patient and Public Involvement (PPI) Panel

## A guide for Focus Group, Steering Group and Advisory Panel members

**Welcome.** Thank you for your expression of interest in becoming a member of a focus or steering group. This guide has been written to provide information about joining a group.

### At a glance

A **Focus Group** is a group of people brought together to discuss a specific research issue or issues, to enhance understanding using open-ended questions. Often the group will consist of patient and public members brought together by a researcher, facilitated by a patient and public involvement coordinator.

A **Steering Group** is made up of experts and lay members who oversee a research study or project. The steering group will provide advice, usually to the Executive or Principal Investigator and trouble-shoot where necessary. The National Institute for Health Research (NIHR) state that it is good practice to include at least two

members of the public on a research study steering group.

An **Advisory Panel** is a mix of staff and patient/public (also called 'lay' members) that provide non-binding strategic advice to the management of an organisation. The Cambridge BioResource currently has an active Advisory Panel.

In summary, focus groups come together for a one-off meeting in order to address specific questions, while steering groups oversee a project; and advisory panels provide longer term consultation and advice.

**'We bring people together with researchers to develop health research. We do this by organising meetings, discussions and online reviews so that people can ask questions and provide input. We do this to improve research and make sure it is relevant to participants and benefits patients now and in the future.'**

*Joann Leeding, Communications and PPI Strategic Lead*

## Focus Groups

A focus group will usually be composed of people who don't know each other, but share a common interest or motivation to get involved. The focus group may be made up of patients or carers with knowledge of a particular health-related condition, sometimes called 'expert patients'; or it may be made up of members of the public brought together to give a more generalist view.

The focus group will be brought together to answer a researcher's specific questions. It is good practice for focus groups to have:

- A clear objective
- A predefined time scale
- Accurate recordings of the discussion, available to group members
- A safe environment in which to share thoughts, feelings and impressions, which is non-threatening
- A clearly defined end point
- Knowledge from the outset about what will be done with the information obtained

Focus groups may be thought of as interviews with small groups of people (usually between four and twelve). The

**“Do use any experience or knowledge from your life to add colour or illuminate the contribution you have to offer. If you have had any experience that might add to the reason why a project might not work, then say something”.**

*Jeremy, CUH PPI Panel member*

group will be encouraged to interact with each other and the group leader in addressing (focusing on) the issues of interest. They aim to explore specific issues, and have the advantage of making use of group dynamics to stimulate discussion, gain insight and generate ideas in order to pursue a topic in greater depth.

Focus group members may be asked to reconvene at specific points during a research study and can expect to receive dissemination of the results of the study in due course. However, some focus groups may only meet once. A professionally facilitated focus group should ensure that all views are listened to.

## Steering Groups

The role of a steering group is to provide input and direction, based on the members' direct experience of the topic under investigation. A steering group will not usually be a decision-making body but will provide advice to the Executive team or Director of a project. The steering group usually meets at key stages during the course of a study or project and influences decision making. It is best practice to have two patient/public members alongside

*Expressing your opinions and listening to those of others are vital skills for group members*





*Focus group in discussion with a researcher*

professional members. Training for new steering group members is available.

Steering groups will meet at regular intervals so members make a commitment to attend scheduled meetings whenever possible.

## Advisory Panels

Advisory Panels consist of senior staff and patient/public members and they work together to provide strategic advice.

Topics may be broad – for example, how to recruit and retain volunteers or participants, or how to raise the profile of an organisation and increase public awareness. A panel will typically meet two to four times a year.

You will see from this information that focus groups, steering groups and advisory

panels are all different in nature. Some people prefer to attend only one type of meeting, others will enjoy participating in a variety. The groups enable members of the public and patients to engage with researchers to discuss important and interesting health research. There are learning and personal development opportunities, too.

You can also expect to be supported by members of research and management staff. In addition, the Patient and Public Involvement Coordinators are there to provide support for you and answer any questions you may have.

**“I found the focus group with the PPI group incredibly useful, I gained very valuable insights and a deeper understanding of how my proposed research may be perceived, and excellent advice on how I could improve the methodology. I have made several amendments to my application based on the group discussions and am sure it is a stronger and better application as a result.”**

*Peter Hartley, Senior Physiotherapist*

CUH PPI panel members can expect the following support:

- A written description outlining the purpose of the group
- Practical support with clear information from the outset about issues such as how often the group will meet, where it will meet, when (or whether) to expect papers, and so on
- Support of the PPI coordinators to manage any frustrations with the

research process and outcomes, and to help in situations where other group members challenge the benefits of involvement

- Personal and professional development, providing constructive feedback on people's contribution to meetings
- The opportunity to raise items for the agenda and to receive written minutes of meetings
- To participate fully in the discussion

**“One of the best things for me about being a PPI panel member is meeting and working with other PPI panel members. The diversity, breadth and depth of experience, skills and knowledge members bring to the panel makes it a truly phenomenal one”.**

*Kathryn, CUH PPI Panel member*



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