

PPIE Terms of Reference

Terms of reference were developed at the start of the project to guide the expectations of all parties with regard to PPIE. These were discussed and agreed at the first formal team meeting, and covered the following elements:

Purpose of PPIE

To play an important role in ensuring the relevance and quality of research for service users. This in turn benefits the public, researchers, practitioners and funders as well as health/social care service providers. By PPIE we mean research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them, as defined by NIHR INVOLVE.

For the purposes of this study, the term 'patient and public' refers to: patients; CH residents; potential patients/residents; informal carers and people who use health and social care services, as well as people from organisations that represent people who use services.

Aims of PPIE

- identify opportunities with and for PPIE members to influence the research methods, ethical protocols, conduct, analysis and dissemination of the research,
- have an active partnership between PPIE, the researchers working on the project, co-investigators and steering group members
- be commitment to documenting the process and impact of PPIE

Role and responsibilities

The Chief investigator will:

- maintain contact with the PPIE members throughout, providing opportunities to reflect on the process and engagement with the research
- work with PPIE members to identify any training required
- liaise with the other research team members, co-investigators, and steering group members to source suitable training
- ensure lengthy papers (more than 3 pages) are circulated at least a week ahead of meetings, wherever possible.

PPIE members will:

- make a reasonable contribution of time to attend meetings/enter into email/phone dialogue about the study
- make an effort to read through information sent in advance of meetings
- offer constructive feedback and take an active role within group discussions
- be reimbursed for their involvement, as outlined in their contract.

Co-investigators and Steering Group members will:

- actively invite PPIE members to share experiences and reflections
- take into account all representative views
- determine areas of particular priority for action.

Confidentiality

Members should be able to speak openly during investigator meetings. If a member wishes for information to be treated as confidential, then this should be stated during the meeting. All documents shared within the group, and any personal information or experiences shared by PPIE members, should be treated as confidential.