

Terms of Reference Template

The role of the group

Here, outline what the key role/s of the group would be. Suggestions could be:

- To identify a research aim/question based on experiences/perspectives of group members.
- Co-design the methods of a study
- Assist in the recruitment, data collection, data analysis, dissemination
- Advise on the development and coordination of patient, public involvement & engagement of a centre/organisation.
- Provide input on the design and conduct of individual research studies carried out by the centre/organisation.

Responsibilities

Here, outline what the key responsibilities of the group are. Suggests could be:

- Value and give voice to the views and perspectives of all members;
- To ensure meaningful patient and public involvement and engagement in all aspects of the organisation research;
- To provide input where appropriate on all aspects of individual studies that are developed and undertaken by the organisation;
- To contribute, where appropriate, to the development and drafting of academic publication/s and presentations.
- To review research documentation to improve clarity of content and ease of understanding;

Membership

Here, outline how many people are expected to form the group and the characteristics of group members (e.g., parent's/family members of a child with a life-limiting condition).

Make clear that members are free to take a break or leave the group at any time.

Ways of working

Here, outline key information pertaining to the workings of the group, including:

- How often the group will meet
- Set days/time for meeting?
- Mode of communication (online vs face to face meeting)
- Will meetings be recorded? If so, by whom
- Will an agenda be sent out in advance? Will members have the opportunity to comment on the agenda?
- Who will chair the meeting/s?
- How will group members be contacted about participation (email?)

Payment and expenses

Outline here the policy on payment and expenses.

The NIHR have produced a useful guide on the factors to consider when paying members (link below)

<https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>

Sharing of information and resources

Outline here information related to confidentiality and the handling of data including:

- How the personal details and information shared by group members (e.g., email addresses) will be stored by the organisation undertaking the research.
- Who will have access to this information.
- Protocol regarding confidentiality

Reporting Arrangements

Outline here how group activity will be recorded and reported (e.g., a PPIE log) and who will manage this (e.g., PPIE lead).

Any necessary funding reporting arrangements should also be outlined here.

Training

Are there opportunities available for PPIE members to take part in training?

Support

What support networks/pathways exist for group members?

Lifespan of the group

Here, outline the expected length of time members can expect to be part of the group. This is likely to be dictated by funding (in the case of a study).

This privacy notice explains how we use your personal information and your rights regarding that information.

Here outline:

- Where is the study based/or who is the organisation where the group will be based.
- Who is responsible for data processing and who is the data controller?
- What personal information of group members will be collected and why?
- How will the personal information of members be used?
- Privacy policy
- How long personal data will be stored for and why.
- Statement about third party requests (e.g., research funders and teams) for data and how this will be handled.

What to do if you are not happy with how your information is being used

Here outline the process members should follow if they are not happy about how their information is being used. E.g., contact details of the organisations data protection officer and details of the Information Commissioner's Office (ICO).