



## Appendix M: Terms of Reference Template

### 1. Background

Patient and public involvement and engagement (PPIE) is research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This approach involves an active and meaningful partnership between patients, the public, doctors and researchers to identify research priorities, design studies, carry out research and disseminate study findings. Involvement and engagement promotes research that is more relevant and useful to the public. The PPIE group was established in XXXX by the core team of [names of individuals] to [aim of the group].

### 2. Mission Statement & Philosophy

*To advocate for our community and ensure its voice is heard in healthcare practices. To advise on and support the undertaking of high-quality patient-centered research at [name of site].*

We are committed to ensuring meaningful dialogue between researchers and the community in order to facilitate transparency in research practice and to impact decision-making. Together we are determined to foster a research culture that values diverse opinions and caters to cultural sensitivities. Our work adheres to the National Institute for Health and Care Research Standards for Public Involvement.

### 3. Aims & Activities

The broad aims and activities of the PPIE group are:

1. To advise on research priorities
2. To advise on the design of research protocols
3. To contribute to the ethical review of research studies
4. To support the development of study materials
5. To support the conduct and implementation of research studies
6. To participate in data analysis
7. To support the dissemination of results to the public
8. To advocate for post-study access to approved and effective therapeutics as well as diagnostics

## 4. Governance, Structure & Roles

The PPIE group is part of the [name of department and site] and is funded by [name of funder].

### 4.1. Senior Lead

The head of the [department], [name], is the senior lead of the PPIE Group. [Name] is responsible for the overall ethical, administrative, regulatory and legal aspects of the PPIE group, including managing the funding, contracts and approvals on behalf of [name of organisation]. All public-facing materials, including social media posts, website content, newsletters, marketing products and academic outputs, require approval from the senior lead prior to publication. The senior lead will meet with the coordinators every 3 months to review the “Project Roadmap” and agree the objectives for the subsequent 3 months.

### 4.2. Coordinators

The PPIE group has up to three coordinators that attend PPIE group meetings as non-voting members. All coordinators are responsible for arranging development opportunities for patient & public members. Coordinators will meet on a weekly basis and maintain the “Meeting & Action Log” shared with the senior lead.

1. Engagement Coordinator: Responsible for recruitment of new members, correspondence, payments and logistical arrangements for all meetings and PPIE group activities. Acts as the key liaison for patient and public members.
2. Public Coordinator: Responsible for building strategic relationships with local leaders and institutions. Provides advice on outreach and marketing.
3. Scientific Coordinator: Responsible for leading project development and evaluation as well as assisting the senior lead in reporting to ethics, funding and regulatory bodies. Acts as the key liaison for international partners.

### 4.3. Patient & Public Members

The PPIE group consists of up to ten patients, their family members and members of the public. Members will be compensated for their time spent preparing and attending meetings and events, as well as their travel to in-person meetings and activities.

1. The group will have no designated leader and will function on the basis of equal participation.
2. Members are free to leave the group at any time and will be replaced by new members. New members will be recruited and vetted by the Engagement Coordinator based on the following criteria:
  - a. Must be able to contribute to the group critically
  - b. Must be willing to give time
  - c. Should ideally have experience in community engagement, research or social work
3. New members joining the group will undergo an onboarding process, involving training and a review of these Terms of Reference with the Engagement Coordinator.

## 5. Meetings of the Group

1. Meetings are to be held every 2 weeks or more frequently as deemed necessary by the PPIE group.
2. Meetings are to be alternated between in-person and online sessions. Members can opt for online participation during in-person meetings as well.
3. Members must inform the Engagement Coordinator if they are unable to attend a meeting.
4. Meeting dates will be scheduled at least 10 days in advance.
5. In-person meetings will be 2 hours long maximum. Online meetings will last 1 hour.
6. Any materials for review will be sent to members based on their language and format preferences as indicated in the 'My Involvement Profile' completed before they started their involvement in the group.
7. Urdu will be the main language of communication during PPIE meetings to facilitate participation from all members.
8. Meeting minutes will be captured by a different group member volunteering each time.
9. Decisions will be made by a majority vote, as long as a minimum of 75% of members are in attendance.
10. Content discussed during meetings is confidential and should never be shared outside of the group.
11. Guest speakers can be invited to meetings as advisors or trainers as deemed necessary by the PPIE group.
12. Refreshments will be organized by the Engagement Coordinator and provided to members during in-person meetings.

## 6. Code of Conduct

All members will adhere to the following values and principles during all interactions.

- |                    |                   |
|--------------------|-------------------|
| 1. Honesty         | 5. Tolerance      |
| 2. Trust           | 6. No judgment    |
| 3. Confidentiality | 7. Punctuality    |
| 4. Respect         | 8. Accountability |

## 7. Ratification & Review of this Terms of Reference

This 'Terms of Reference' document has been reviewed, ratified and signed by all members of the PPIE group as well as the senior lead and coordinators. The Terms of Reference will be reviewed annually, or more frequently as deemed necessary by the PPIE group. All new members of the PPIE group will be asked to review and sign the Terms of Reference upon joining the group.

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