



Patient & Public Involvement and Engagement (PPIE) Group

Terms of Reference

Version 2 - 29/02/2024

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. With the creation of the new Clinical Trials Unit at Ziauddin University, the establishment of the PPIE group is essential to support the design and conduct of high-quality patient-centered trials and research.

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 Ziauddin University.

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 clinical trial protocols
3. To contribute to the ethical review of clinical trials
4. To support the development of study materials
5. To support the conduct and implementation of clinical trials
6. To participate in data analysis
7. To support the dissemination of results to the public
8. To advocate for post-trial access to approved and effective interventions

4. Governance & Structure

The PPIE group is part of the Clinical Trials Unit at the Ziauddin University Group of Hospitals and is funded until 30th June 2024 by a Public Engagement Bursary from the Mahidol Oxford Tropical Medicine Research Unit. The PPIE group consists of up to ten patients, their family members and members of the public as well as up to three researchers.

1. The group will have no designated leader and will function on the basis of equal participation.
2. Correspondence and logistical arrangements (i.e. create agenda, send reminders) will be facilitated by one of the research members, denoted as the 'PPIE coordinator.'
3. 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 PPIE 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
4. Guest speakers can be invited to meetings as advisors or trainers as deemed necessary by the PPIE group.

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 PPIE 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. Meetings will not be recorded, however, meeting minutes will be captured by a different group member volunteering each time.
7. Decisions will be made by a majority vote, as long as a minimum of 75% of members are in attendance.
8. Content discussed during meetings is confidential and should never be shared outside of the group.

6. Roles & Responsibilities of Members

Urdu will be the main language of communication during PPIE meetings to facilitate participation from all members. WhatsApp will be the main method of communication between members and the PPIE coordinator. 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. Research members are responsible for coordinating ongoing development opportunities for members.

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

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| 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. 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.