



Patient & Public Involvement and Engagement (PPIE) Group

Terms of Reference

Version 4 - 18/12/2025

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 2023 after the creation of the Clinical Trials Unit to support the design and conduct of high-quality patient-centered trials and research at Ziauddin University.

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 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 and diagnostics
9. To raise public awareness of research rights, study methods and health issues

4. Governance, Structure & Roles

The PPIE group is part of the Critical Care Medicine Research Group at the Ziauddin University Group of Hospitals and is funded until April 2029 by the core grant of the International Severe Acute Respiratory and emerging Infection Consortium (ISARIC).

4.1. Senior Lead

The head of the Critical Care Medicine Research Group, Prof Dr Madiha Hashmi, is the senior lead of the PPIE Group. Prof Hashmi is responsible for the overall ethical, administrative, regulatory and legal aspects of the PPIE group, including managing the funding, contracts and approvals with ISARIC and Ziauddin University. 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 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 Log” & “Action Log” shared with the senior lead.

1. Engagement Coordinator: Responsible for recruitment of new members, correspondence 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.

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. Marketing Coordinator: Responsible for developing, implementing and monitoring the social media and marketing strategy of the PPIE initiative.

4.3. Patient & Public Members

The PPIE group consists of up to ten patients, their family members and members of the public.

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

5. Meetings of the Group

1. Meetings are held every 2 weeks or more frequently as deemed necessary by the 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. Meetings will not be recorded, however, 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 at least 75% of members are present.
10. Content discussed in meetings is confidential and should never be shared outside of the group.
11. Guest speakers can be invited to meetings as advisors or teachers as deemed necessary by the PPIE group.

6. Code of Conduct

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

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

7. Privacy & Personal Data

Personal data from each patient & public member is voluntarily entered together with a coordinator into a 'My Involvement Profile', which is reviewed by the member and stored on a password-protected shared drive. The data is confidential and only accessed by the coordinators to plan and improve the work done by the PPIE group. No other personal data is collected from members. Each member has the right to access, correct or erase their own data at any time. The data will be retained only for the duration of a member's involvement in the PPIE group and managed in accordance with the privacy policy of Ziauddin University.

8. 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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