Appendix N: First Meeting Agenda

Date: 16th September 2023
Time: 10:00 a.m.
Location: Conference Room, Faculty of Law, Politics & Governance
7th Floor, Ziauddin University Building

Meeting Aim: To introduce the role of PPIE in clinical trials and to decide together how the group will work and what it aims to achieve

Overview

10:00 a.m. to 11:00 a.m.	Welcome & Introductions
11:00 a.m. to 11:15 a.m.	**Break**
11:15 a.m. to 12:30 p.m.	Clinical Trials & PPIE: Importance, impact and what do we want to do
12:30 p.m. to 12:45 p.m.	**Break**
12:45 p.m. to 2:00 p.m.	Terms of Reference: Decide the group's mission & code of conduct together
Lunch	

Welcome & Introduction

All attendees (coordinators and members) are asked to introduce themselves by giving their name, story of why they decided to join this PPIE group and any experiences relevant to engagement. The coordinators should point out any commonalities in motivations and interests to encourage relationship building and connection.

Clinical Trials & PPIE

Coordinators will provide a two-slide presentation to explain clinical trials and the research process. The first slide includes pictures of Drug A and Drug B, and the coordinator will explain that at their core, all trials are a systematic and robust way to determine which drug or treatment is safer and more effective. The second slide outlines a five-stage process diagram with the titles: i) what; ii) how; iii) do; iv) results and v) share. The coordinator will explain that research usually follows a five-stage process and that patients and members of the public can be involved in every stage.

- What: Deciding what disease, drug, treatment or population to study.
- How: Writing a protocol to describe how to study the disease, drug, treatment or population.
- Do: Conducting the study, including recruitment, treatment and follow-up.
- Results: Analysing data and coming up with the findings.
- Share: Informing doctors, patients, decision-makers and the public about the results.

The coordinators will facilitate a short discussion after introducing each step in the research process, asking members if and how they think patients, families and members of the public can be involved in that research step, what impact they think it can have and whether our group should contribute to that step of the research process. Coordinators will offer some examples of successful PPIE throughout the discussion to support the points raised by members. The discussion will form the basis of the list of activities to be included in the first draft of the Terms of Reference.

Terms of Reference

All members will be divided into pairs and given three blank A1 sheets and markers. All pairs will consider three topics, each with a set of guiding questions, to draft the Terms of Reference:

- Governance & Structure
    - Should the group have a leader?
    - What should be their responsibilities?
    - How should they be chosen?
    - If there is no leader, how would you like the group to operate?
- Meetings of the Group
    - How often should the group meet, how should the meeting times and agenda be decided?
    - What would the group like to talk about in these meetings?
    - How far in advance should the date and time of the next meeting be decided?
    - What should be the format of meetings (task-based, agenda-based, facilitated)?
    - Who should join the meetings?
    - How should decisions be made? i.e. unanimous, majority vote
    - Should meeting minutes be captured? Who should do this?
    - Should meetings be recorded?
- Roles & Responsibilities of the Members
    - What should be the group's rules and guiding values? (e.g. punctuality, respect, fairness)
    - Should there be a minimum required attendance? Should there be another option if a member cannot attend in-person (e.g. online attendance)?
    - Should everyone sign a Terms of Reference or code of conduct?

After all pairs have discussed and made notes on all three topics, the A1 sheets are collected. The sheets from each group for each topic are examined for similarities and differences, discussed and consensus agreement will be sought to all guiding questions as well as additional considerations. After the meeting, the coordinators will draft text for the Terms of Reference based on the decisions made by the group and share the first draft with members.

Conclusion

Coordinators close the meeting and explain the next steps in drafting the Terms of Reference and the next meeting.