



## **The CONTROL**

**(COgNitive Therapy for depReSSIOn in tubercuLosis treatment) to improve outcomes  
for depression and TB in Pakistan and Afghanistan**

**Funded by: RIGHT3, NIHR**

**Reference: NIHR201773**

**Report Drafted by: Dr. Saima Aleem**

**Report Reviewed by: Dr. Zohaib Khan**



**Training Session on Public and Patient  
Involvement and Engagement (PPIE) for  
CONTROL Ph.D. Scholars**

**Thursday, 27<sup>th</sup> June 2024**



## **Executive Summary:**

The Public and Patient Involvement and Engagement (PPIE) training session was delivered virtually on 27<sup>th</sup> June 2024 to CONTROL Ph.D., students. It was designed to equip Ph.D. students with the necessary skills and knowledge to involve and engage the public and community in their research projects. This detailed report covers the various aspects of PPIE, including protocol development, stakeholder identification, session design, ethical considerations, reporting, and the impact of PPIE on research projects.

### **Workshop Participants:**

The workshop was facilitated and delivered by:

- ❖ Dr. Saima Aleem (CONTROL Communication Manager & Community Engagement Lead)

The lived experience regarding the community engagement field sessions, potential barriers, and facilitators was shared by:

- ❖ Mr. Ishfaq Azeemi (Manager, THE HOPE study)

The workshop was attended by all five CONTROL Ph.D. students:

- ❖ Huma Mughal
- ❖ Aliya Durani
- ❖ Safat Ullah
- ❖ M. Sohaib
- ❖ Abdul Latif

### **Proceedings:**

#### **Welcome, Introductions, and Housekeeping**

The session began with a welcome to all the participants, introductions, and housekeeping rules.

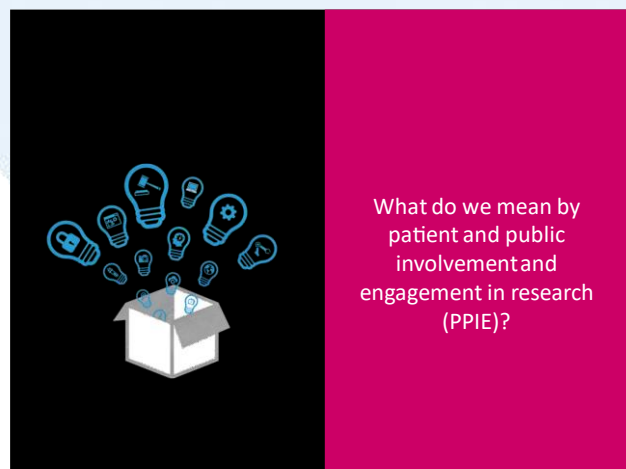
The session focused on:

- Concept of PPIE
- PPIE Protocol development
- Stakeholder identification and establishment of the advisory group for PPIE
- Sessions designed as per the research outcome
  - Ethical issues in the PPIE and how to address them

- Reporting of PPIE sessions
- The impact of PPIE on the research project

### **Introduction of Patient and Public Involvement and Engagement**

Patient and Public **Involvement** mean that activities and research are carried out ‘with’ or ‘by’ members of the public or patients, rather than ‘to’, ‘about’ or ‘for’ them. Patients and members of the public are actively involved in the development, conduct and management of research projects or activities. Patient and Public **Engagement** ensures that **information and outcomes** from research or activities are **disseminated** to patients and the public, so they can be informed of our work. It also allows us to gain insights and input from patients and the public.



### **Enhancing Research Relevance through PPIE**

Public and Patient Involvement and Engagement (PPIE) plays a crucial role in ensuring that research is closely aligned with the needs and concerns of the communities it aims to serve.

#### **1. Aligning Research with Community Needs**

By involving patients, caregivers, and members of the public in the research process, researchers can gain a deeper understanding of the real-world issues and priorities that matter most to these stakeholders. This ensures that research questions and objectives are directly relevant to the people who are most affected by the research outcomes.

- **Identifying Key Issues:** Stakeholders can highlight specific health issues, challenges, and gaps in current knowledge that they encounter in their daily lives. This input helps researchers focus on areas that will have the most significant impact.
- **Prioritizing Research Topics:** Engaging with the community allows researchers to prioritize topics that are of highest concern to patients and the public, ensuring that resources are allocated to the most pressing and relevant areas.

## 2. Co-designing Research Projects

Involving patients and public members from diverse backgrounds in the design phase of research projects helps ensure that the study methods and approaches are appropriate and acceptable to the target population. This collaborative approach can lead to more effective and efficient research designs.

- **Tailoring Research Methods:** PPIE members can provide insights into the most suitable methods for data collection and analysis, ensuring that the research design is sensitive to their experiences and preferences.
- **Enhancing Study Acceptability:** By involving them in the design process, researchers can address potential concerns and barriers to participation, making the study more acceptable and accessible to the target population.

## 3. Increasing Practical Applicability

PPIE ensures that the findings of research are not only academically rigorous but also practically applicable in real-world settings. This increases the likelihood that research outcomes will be used to inform policy and practice.

- **Real-world Relevance:** Patient and public involvement helps ensure that research outcomes are grounded in real-world experiences and contexts, making the findings more relevant and useful for policymakers, practitioners, and the community.
- **Translational Impact:** Engaging patients, the public, and community members throughout the research process helps bridge the gap between research and practice, facilitating the translation of research findings into actionable recommendations and interventions.

#### **4. Enhancing Dissemination and Implementation**

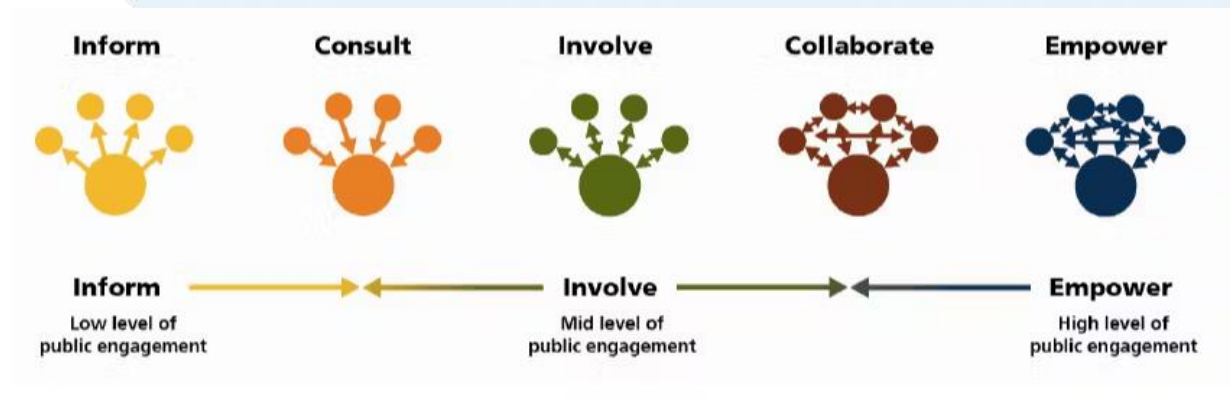
PPIE helps in the effective dissemination and implementation of research findings by involving stakeholders in the planning and execution of these activities. This ensures that the results reach and resonate with the intended audience.

- **Effective Communication:** PPIE members can help identify the most effective channels and formats for communicating research findings to different audiences, including patients, healthcare providers, and policymakers.
- **Facilitating Uptake:** Engaging them in the dissemination process increases the likelihood that research findings will be accepted and used by the community, leading to better health outcomes and more informed decision-making.

#### **Spectrum of PPIE Engagement and Involvement**

Public and Patient Involvement and Engagement (PPIE) exists on a spectrum, ranging from basic communication to full partnership. This spectrum illustrates the varying levels of

involvement and influence that patients, caregivers, and the public can have in the research process.



## 1. Informing

At the informing level, all the stakeholders are provided with information about the research. This is a one-way communication where researchers share details about the study, its progress, and its outcomes.

- **Purpose:** To keep stakeholders informed and aware of research activities and findings.
- **Methods:** Newsletters, websites, informational meetings, and press releases.
- **Outcome:** Stakeholders have a better understanding of the research, but they do not influence its design or implementation.

## 2. Consulting

Consultation involves seeking feedback from stakeholders on specific aspects of the research. This level includes obtaining their views, opinions, and suggestions, which researchers then consider in their decision-making processes.



- **Purpose:** To gather input and feedback to inform research decisions.
- **Methods:** Surveys, focus groups, public meetings, and consultations.
- **Outcome:** Stakeholders influence the research to some extent, but final decisions rest with the researchers.

### 3. Involving

Involvement means working more closely with stakeholders throughout the research process. At this level, stakeholders' input is actively sought and incorporated into various stages of the research, from planning to dissemination.

- **Purpose:** To ensure stakeholder input directly shapes the research.
- **Methods:** Workshops, advisory panels, and participatory research activities.
- **Outcome:** Stakeholders have a significant influence on research design, implementation, and dissemination.

### 4. Collaborating

Collaboration entails partnering with stakeholders on all aspects of the research process. At this level, patients, the public, community members, and researchers share decision-making power and responsibilities, working together as equals.

- **Purpose:** To achieve a true partnership where stakeholders and researchers co-produce the research.
- **Methods:** Joint research committees, co-design of studies, and collaborative analysis and interpretation of data.

- **Outcome:** Stakeholders and researchers share control over the research, leading to more relevant and impactful outcomes.

## 5. Empowering

Empowerment represents the highest level of PPIE, where stakeholders take the lead in initiating, designing, and conducting research. Researchers support and facilitate the stakeholders' efforts but do not control the process.

- **Purpose:** To enable stakeholders to lead research efforts, ensuring their needs and priorities drive the research agenda.
- **Methods:** Community-led research projects, stakeholder-driven funding applications, and peer research networks.
- **Outcome:** Stakeholders have full control and ownership of the research, leading to highly relevant and community-driven outcomes.

## Developing a PPIE Protocol for Research

Ph.D. Students were guided that creating a Public and Patient Involvement and Engagement (PPIE) protocol is crucial for integrating stakeholder input effectively throughout the research process. A well-developed PPIE protocol ensures that stakeholder involvement is structured, purposeful, and impactful.

### 1. Define Objectives and Scope

- **Establish Goals:**

Clearly outline the objectives of involving patients, caregivers, and the public in your research. This could include improving research relevance, enhancing participant recruitment, or refining study design.

- **Determine Scope:**

Define the extent and nature of stakeholder involvement, including which stages of the research they will participate in (e.g., design, implementation, dissemination).

## 2. Identify and Recruit Stakeholders

- **Identify Key Stakeholders:**

Determine who will be involved based on the research topic. This may include patients with specific conditions, caregivers, healthcare professionals, and community members.

- **Recruitment Strategies:**

Use a variety of methods to recruit stakeholders, such as community outreach, partnerships with patient organizations, and targeted invitations.

- **Diversity and Inclusivity:**

Ensure that the stakeholder group reflects diverse perspectives relevant to the research topic.

## 3. Establish an Advisory Group

- **Form Advisory Group:**

Create an advisory group composed of selected stakeholders who will provide ongoing guidance and feedback throughout the research process.

- **Define Roles and Responsibilities:**

Clearly outline the roles, responsibilities, and expectations of advisory group members.

- **Provide Training:**

Offer training and support to advisory group members to help them understand their role and contribute effectively.

#### **4. Develop an Engagement Plan**

- **Outline Engagement Activities:**

Plan the specific activities and interactions stakeholders will participate in, such as focus groups, workshops, or advisory meetings.

- **Create a Timeline:**

Develop a timeline for when and how stakeholder engagement will occur throughout the research project.

- **Determine Communication Methods:**

Decide on the methods and frequency of communication with stakeholders (e.g., meetings, emails, reports).

#### **5. Address Ethical Considerations**

- **Informed Consent:**

Ensure that all stakeholders understand the purpose of their involvement and provide informed consent.

- **Confidentiality and Privacy:**

Implement measures to protect the confidentiality and privacy of stakeholders' personal information.

- **Cultural Sensitivity:**

Be aware of and address cultural differences to ensure respectful and appropriate engagement.

## **6. Define Evaluation and Feedback Mechanisms**

- **Set Evaluation Criteria:**

Define how you will assess the effectiveness of stakeholder involvement and the impact on the research process.

- **Gather Feedback:**

Collect feedback from stakeholders on their involvement experience and the impact on the research.

- **Adjust Protocol:**

Use feedback to make necessary adjustments to the engagement process and improve future involvement.

## **7. Develop a Reporting Plan**

- **Document Involvement:**

Record the activities and contributions of stakeholders throughout the research process.

- **Share Outcomes:**

Provide regular updates to stakeholders on how their input has influenced the research and the outcomes achieved.

- **Create a Final Report:**

Prepare a comprehensive report summarizing the stakeholder involvement, its impact on the research, and any lessons learned.

## **8. Ensure Sustainability and Continuity**

- **Build Long-term Relationships:**

Foster ongoing relationships with stakeholders for potential future collaborations and continued engagement.

- **Provide Resources:**

Offer resources and support to stakeholders to maintain their involvement and address any issues that may arise.

### **Stakeholder Identification, Establishment and Retention of the Advisory Group for PPIE**

The next part of the session focused on guiding the Ph.D. students regarding identifying the stakeholders and establishing a PPIE advisory group for their ongoing research projects.

Identifying stakeholders and establishing an advisory group are critical steps in implementing effective Public and Patient Involvement and Engagement (PPIE) in research. Stakeholder identification begins with a thorough analysis of the research topic to pinpoint individuals and groups who are directly affected by or have a vested interest in the research outcomes. Key stakeholders typically include patients with relevant lived experiences, caregivers, healthcare professionals, community leaders, and representatives from patient advocacy organizations. Recruitment strategies should be inclusive and diverse, ensuring representation from various demographics, socioeconomic backgrounds, and cultural groups to capture a wide range of perspectives.

Once stakeholders are identified, the next step is to establish an advisory group. This group serves as a dedicated body to provide ongoing input, guidance, and feedback throughout the research process. Clearly defining the roles and responsibilities of advisory group members is essential, as is providing them with adequate training and support to facilitate their effective participation. Regular meetings should be scheduled to discuss progress, share updates, and address any concerns. Open and transparent communication is crucial for building trust and nurturing a collaborative environment. By identifying stakeholders and forming a well-structured advisory group, researchers can ensure meaningful and impactful engagement that enhances the relevance, quality, and application of their research.

Retaining PPIE advisory group members involves a multifaceted approach to ensure their sustained engagement and satisfaction. Ph.D students were guided to:

- ❖ Start by providing clear value and purpose, ensuring members understand how their contributions impact the research and regularly updating them on progress.
- ❖ Create a supportive environment where contributions are respected and recognized, and promote inclusivity to capture diverse perspectives.
- ❖ Offer training and resources to enhance members' skills and understanding of the research process.
- ❖ Maintain effective communication through regular meetings and open channels for feedback.
- ❖ Whenever required, provide both monetary and non-monetary compensation to acknowledge their time and effort, and facilitate meaningful participation by involving them in decision-making processes.

- ❖ Address practical barriers by offering flexible scheduling and logistical support, and build personal relationships to foster trust and community.
- ❖ Regularly evaluate the engagement process through feedback mechanisms, adapting strategies to meet members' needs.
- ❖ Finally, celebrate achievements and publicly recognize the contributions of the advisory group, reinforcing their importance to the research project's success.

### **Ethical Considerations for PPIE and Strategies to Address Issues**

#### **1. Informed Consent**

Informed consent is fundamental to ethical research practice, ensuring that participants are fully aware of their involvement and its implications. For PPIE, this involves communicating the nature of the research, the roles and responsibilities of stakeholders, and any potential risks or benefits of their participation.

- **Issues:**

- Stakeholders may not fully understand the complexity of the research or their role, leading to incomplete or uninformed consent.
- Changes in the research scope may require revisiting and updating consent.

- **Strategies:**

- **Provide Comprehensive Information:**
- Use plain language to explain the research goals, methods, and potential impacts.

Include visual aids or examples if needed.



➤ **Ongoing Consent:**

- Reassess consent periodically, particularly if there are significant changes to the research process or objectives.

## **2. Confidentiality and Privacy**

Protecting the confidentiality and privacy of stakeholders is crucial. This includes safeguarding personal information and ensuring that their input remains confidential.

- **Issues:**

- Risk of accidental disclosure of sensitive information.
- Breach of confidentiality could damage trust and harm stakeholders.

- **Strategies:**

- **Implement Data Protection Protocols:**

Use secure systems for storing and handling data. Anonymize or de-identify personal information when reporting results.

- **Confidentiality Agreements:**

Have all research team members and stakeholders sign agreements to formalize their commitment to maintaining confidentiality.

## **3. Power Dynamics**

Power dynamics refer to the influence and control exerted within the research process. In PPIE, it's important to manage these dynamics to ensure that all voices are equally valued and heard.

- **Issues:**

- Stakeholders may feel marginalized if their input is not given due consideration.
- Researchers may unintentionally dominate discussions, reducing the effectiveness of stakeholder contributions.

- **Strategies:**

- **Facilitate Equal Participation:**

Create a respectful environment where every stakeholder has an opportunity to contribute. Use trained facilitators to manage discussions and ensure balanced participation.

- **Empower Stakeholders:**

Provide training and resources to build stakeholders' confidence and capacity to engage effectively.

#### **4. Conflict of Interest**

Conflicts of interest occur when personal or financial interests may influence the impartiality of stakeholders or researchers. In PPIE, it's important to manage these conflicts to maintain the integrity of the research.

- **Issues:**

- Stakeholders or researchers with vested interests may bias the research process.
- Financial or personal incentives could influence stakeholders' contributions.

- **Strategies:**

➤ **Disclosure Policies:**

Require disclosure of any potential conflicts of interest from both researchers and stakeholders.

➤ **Neutral Facilitation:**

Use neutral parties to oversee stakeholder involvement and ensure that personal interests do not skew the research process.

## **5. Representation and Inclusivity**

Ensuring diverse and equitable representation of stakeholders is essential to achieving comprehensive and unbiased research outcomes. Inclusivity means engaging a broad spectrum of voices to reflect different perspectives.

- **Issues:**

- Certain groups may be underrepresented, leading to biased or incomplete findings.
- Accessibility barriers may prevent some stakeholders from participating.

- **Strategies:**

- **Actively Recruit Diverse Stakeholders:**

Implement strategies to reach and include diverse groups, ensuring representation across various demographics.

- **Use Inclusive Practices:**

Provide accommodations such as flexible scheduling, translation services, and accessible meeting formats to facilitate participation.

## 6. Compensation and Recognition

Fair compensation and recognition for stakeholders' time and contributions are important ethical considerations. It ensures that their involvement is valued and respects their effort and expertise.

- **Issues:**

- Inadequate compensation may lead to feelings of exploitation or undervaluation.
- Excessive compensation could influence stakeholders' responses or contributions.

- **Strategies:**

- **Establish Fair Compensation:**

Develop transparent and equitable compensation structures that reflect the time and effort of stakeholders without creating undue influence.

- **Acknowledge Contributions:**

Publicly recognize and appreciate the contributions of stakeholders in research outputs and communications.

### **Effective Reporting of PPIE Sessions**

Effective reporting of Public and Patient Involvement and Engagement (PPIE) sessions is essential for transparency, accountability, and demonstrating the impact of stakeholder contributions on the research process.

## 1. Document Session Details

- **Meeting Records:** Keep detailed minutes of PPIE sessions, including the date, time, location, and list of attendees. Record key discussions, decisions, and action items.
- **Agenda and Outcomes:** Include the agenda items and summarize the outcomes or conclusions reached during the session.

## 2. Summarize Stakeholder Contributions

- **Feedback and Input:** Document the feedback, suggestions, and concerns raised by stakeholders. Highlight any significant insights or ideas that emerged.
- **Action Taken:** Describe how stakeholder input was addressed or incorporated into the research. This shows how their contributions have influenced the research process.

## 3. Provide Context and Relevance

- **Contextual Information:** Explain the context in which the PPIE session occurred, including the research stage and relevant background information.
- **Impact on Research:** Discuss the relevance of stakeholder contributions to the research goals and how their input has shaped research decisions or outcomes.

## 4. Ensure Transparency and Accountability

- **Accessibility:** Make reports accessible to all stakeholders involved, ensuring they can review and verify the accuracy of the documented information.
- **Feedback Loop:** Establish a feedback mechanism where stakeholders can comment on the reports and provide additional input if needed.

## 5. Use Clear and Concise Language

- **Plain Language:** Write reports in clear, jargon-free language that is understandable to all stakeholders, including those without technical expertise.
- **Visual Aids:** Utilize charts, graphs, and other visual aids to present information in an easily digestible format.

## 6. Highlight Key Findings and Actions

- **Summary of Key Points:** Provide a concise summary of the main points discussed, including key findings and decisions made during the session.
- **Action Plans:** Outline any agreed-upon actions or next steps, including responsibilities and deadlines.

## 7. Integrate with Research Documentation

- **Research Reports:** Include relevant PPIE findings and outcomes in the main research reports or publications to demonstrate the integration of stakeholder input.
- **Updates and Revisions:** Regularly update research documentation with new PPIE insights and adjustments made based on stakeholder feedback.

## 8. Ensure Confidentiality and Sensitivity

- **Sensitive Information:** Researchers need to be mindful of confidentiality and privacy concerns when reporting sensitive information or personal feedback.
- **Anonymize Data:** Where necessary, anonymize or aggregate data to protect the identity of individual stakeholders.

## 9. Provide Regular Updates

- **Scheduled Reporting:** Implement a regular schedule for reporting PPIE session outcomes, such as monthly or quarterly updates.
- **Ongoing Communication:** Keep stakeholders informed about how their input is being utilized and any changes or developments in the research.

## 10. Document Lessons Learned

- **Evaluation:** Include a section on lessons learned from the PPIE sessions, noting what worked well and what could be improved.
- **Continuous Improvement:** Use these lessons to refine the PPIE process and improve future sessions.

### **Sharing of PPIE and Community Engagement Lived Experience by Mr. Ishfaq Azeemi:**

Mr. Azeemi is the manager, of THE HOPE study and also leading the community engagement in the said project. He shared his experiences working with spiritual healers and psychosis patients and their families as part of the Public and Patient Involvement and Engagement (PPIE) efforts and also conducting community engagement sessions for awareness. He recounted the journey of engaging these unique and often marginalized groups to ensure their perspectives and needs were integrated into the research process.

### **Sharing of Lived Experience**

Mr. Azeemi highlighted how his team had successfully facilitated the inclusion of spiritual healers and psychosis patients in the research process. He described organizing

workshops and focus groups that allowed these stakeholders to share their lived experiences openly. The aim was to understand the cultural and psychological dimensions that influenced their health and treatment preferences. Spiritual healers provided valuable insights into alternative approaches to mental health care, while psychosis patients and their families offered firsthand accounts of the challenges and needs they faced daily.

### **Barriers Faced**

1. **Cultural Sensitivities:** Mr. Azeemi mentioned that working with spiritual healers requires a deep respect for their traditional practices and beliefs. There were instances where research protocols clashed with cultural norms, leading to difficulties in aligning research objectives with community practices.
2. **Stigma and Misunderstanding:** Engaging psychosis patients and their families involved addressing significant stigma associated with mental health conditions. This stigma often led to reluctance or fear in participating, complicating efforts to recruit and engage these individuals meaningfully.
3. **Communication Challenges:** Effective communication was a significant barrier, particularly with spiritual healers who used different terminologies and frameworks compared to conventional mental health professionals. This disparity sometimes led to misunderstandings and hindered productive dialogue so establishing effective communication channels was of utmost importance.
4. **Privacy Concerns:** Ensuring the privacy and confidentiality of psychosis patients and their families was another challenge. They had to navigate sensitive information carefully to avoid potential breaches of trust or unintended disclosures.



### **Facilitating Factors:**

#### **1. Building Trust:**

Mr. Azeemi emphasized that establishing trust was crucial. By engaging in respectful, open dialogue and demonstrating a genuine commitment to understanding and incorporating their perspectives, they were able to build strong relationships with spiritual healers, psychosis patients, and community members.

#### **2. Flexible Engagement Approaches:**

Adapting engagement strategies to accommodate the unique needs of all stakeholders was vital. He mentioned that using flexible, tailored approaches helped overcome some of the barriers related to cultural and communication differences.

#### **3. Collaborative Workshops:**

Organizing collaborative workshops where both researchers and community members could exchange ideas and discuss research goals in a safe and supportive environment proved to be an effective way to address misunderstandings and foster mutual respect.

### **Feedback Session:**

In the last part of the training session, the Ph.D. students shared their feedback regarding the information and lived experiences shared. They discussed the identification of relevant stakeholders for their own PPIE sessions and took guidance from both facilitators to further refine their protocols and PPIE strategies.

### Way Forward:

- ✚ Dr. Saima Aleem requested the PhD scholars to prepare their PPIE plans and meet with her individually for further discussions and feedback.
- ✚ PhD scholar Abdul Latif will collaborate with Ishfaq Azeemi, a member of the HOPE project working with psychosis patients, in designing their PPIE plan.
- ✚ Mr. Azeemi also agreed to help Aliya during her first PPIE and community engagement session.