The CONTROL

(COgNitive Therapy for depRessiOn in tubercuLosis treatment)

to improve outcomes for depression and TB in Pakistan and

Afghanistan

"The CONTROL PPIE training sessions"

13th April 2023 & 24th May 2023

Khyber Medical University

EXECUTIVE SUMMARY

Patient and public involvement (PPIE) and engagement, an integral component of the CONTROL programme, envisions the fostering of a meaningful, collaborative, and equitable partnership between researchers, healthcare providers, policymakers, patients and public. Through the active involvement of patients and the public in decision-making, CONTROL's PPIE seeks to improve the relevance, quality, and impact of the research, and effectively inform TB and mental health services and policies.

The CONTROL team in collaboration with the Impact Accelerator Unit at Keele University arranged two comprehensive training sessions on April 13 and May 24, 2023 respectively. The aim of these activities was to familiarise the research team with the core concepts of PPIE, good research practices, barriers and facilitators to PPIE, setting up PPIE group, and evaluating and reporting PPIE. This report narrates the proceedings of both the sessions.

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INTRODUCTION

"Implementation needs everyone around the table - healthcare practitioners, patients, academics and managers."

Krysia Dziedzic, IAU Director, Keele University

The Patient and public involvement (PPIE) and engagement initiative of the CONTROL programme of research aims to deepen the involvement and engagement of patients, service users, and the general public, in the various aspects of research conducted under the umbrella of CONTROL. It emphasizes on the principles of co-production, capacity development, diversity and inclusivity, empowerment, transparency, advocacy, and sustainability to drive our research.

PPIE Training

The Impact Accelerator Unit (IAU) at Keele University in collaboration with the CONTROL's UK team developed a training module for the CONTROL research team at Khyber Medical University (KMU) Peshawar. Spread across two sessions, one month apart, the training covered the core concepts of PPIE and the importance of aligning research activities with the priorities and concerns of patients and the public.

Session 1

Participants & Facilitators

The first PPIE training session was held virtually via zoom on April 13, 2023. The session was attended by 25 team members of the CONTROL team and an additional eight team members from an MRC-UK funded research project, "The HOPE". To encourage interaction and discussions among the participants and avoid technology related glitches, the participants from Pakistan attended the meeting sitting together in the Senate Hall of Khyber Medical University.

The training session was facilitated by: Ms. Adele Higginbottom (PPIE Project Officer, Impact Accelerator Unit, Keele University, UK) and Ms. Alice Moult (Post-Doctoral Researcher, Knowledge Mobilization Research Fellow, Impact Accelerator Unit, Keele University, UK).

Proceedings

The CONTROL PPIE Training session covered the following topics:

- Overview of PPIE

- Good Practice

- What does PPIE mean to you?

- Why PPIE is important? (Group Activity)

- What are barriers to PPIE in research? (Group activity).

Overview of PPIE

PPIE is a mutually respectful and beneficial partnership with genuinely shared ownership in all aspects of the research. Patient and public involvement and engagement ensures that research aligns with the needs and priorities of those directly affected by the research outcomes.

The facilitators explained that involving patients and public members ensures accountability, quality and validity of research studies. Including diverse perspectives and experiences helps the research team gain a more comprehensive understanding of the research domain. This ensures that the studies capture the full range of patient experiences and preferences leading to more rigorous and reliable research outcomes.

PPIE & Research Cycle:

Dr. Alice Moult explained the Research cycle and its linkages with PPIE, highlighting that the research cycle and PPIE are interconnected and mutually beneficial. PPIE can be integrated at various stages of the research cycle. Patient and public involvement and engagement can help refine participant recruitment strategies, data collection methods, and ethical considerations, leading to more patient-centered and ethically sound protocols.

PPIE AT THE CORE

Source: PPIE Training for CONTROL study

Authors: Dr Alice Moult & Adele Higginbottom

Patients and the public can provide valuable input on participant recruitment strategies, materials, and processes. Their involvement can ensure that recruitment efforts are efficient, effective, considerate of participants' needs, and aligned with the target population's characteristics. They can also contribute to the development of participant-friendly informed consent documents. Their involvement can contribute to the development of plain language

summaries, lay-friendly reports, and dissemination strategies that are accessible and understandable to diverse audiences

Later, a video was shared regarding the PPIE and concept of their involvement in research.

Concept of Public in PPIE and Research User Group:

The facilitators explained the concept of public in PPIE. The public includes service users, families and carers, members of public and patient representatives, which also include charities or community groups.

Later, the journey of Research User Group (RUG) managed at IAU from 2006 till date was shared. Their role and partnership building in research projects was highlighted. UK standards for public involvement were also briefly explained.

Roles for public members in the Keele University research include:

- Co-applicants for grant applications

- Members of a research advisory group

- Members of a trial steering group

- Members of a research team monthly meetings

- School research committees

- PPIE community of practice groups

- Stakeholder meetings

- Reviewing NIHR annual reports

Group Activity

The second half of the session focused on a group activity. The group activities were moderated by Ms. Saima Sheikh (Project Manager, CONTROL) & Dr. Saima Aleem (Communication Manager & CEI Lead, CONTROL). Participants were divided into four groups and assigned the task of sharing their thoughts and engage in discussions within their teams on the following topics:

✦ "Why is PPIE important?"

✦ "What are the barriers to PPIE in research?"

The groups were then asked to share their thoughts and findings with all the participants. These thoughts are summarized below

Activity I:

Why is PPIE important?

Group 1:

- PPIE provides benefit to patients and public in order to have good healthcare services.
- Ensures improved relationships with communities and increased public trust.
- It results in more effective, and impactful research.

Group 2:

- Involving patients and members of the public in decision-making can increase trust, especially when they know their voices have been heard and where they have influenced decisions.

- It provides a safe environment.

- It ensures a sense of ownership in the public.

Group 3:

- PPIE ensures that the views, preferences, and priorities of patients and the public are considered, which leads to higher satisfaction with healthcare services.

- It is important in research to increase recruitment and retention of study participants, as it makes the research more relevant to patients and the public.

- It can increase the cost effectiveness of the research.

- It also helps in understanding the lived experiences of patients.

Group 4:

- PPIE ensures that the perspectives and experiences of people who are most impacted by healthcare services are considered when making decisions about healthcare service design or delivery.

- Healthcare providers can gain valuable insights into what works best for patients, which helps in improving service quality.

- It can help identify more cost-effective and efficient ways to deliver healthcare services, which saves resources.

Activity II: What are the barriers to PPIE in research?

Group 1:

- Some researchers may have negative attitudes toward PPIE or may be resistant to change.

- Language barriers i.e., there are different dialects and languages which can be a barrier in communication and understanding people's views.

- Cultural constraints in society

- Reluctance to share information.

Group 2:

- Stigma exists in the community, so patients/service users can be reluctant to participate.

- Existing structures within research organizations may not support PPIE.

- Other issues: trust issues, transportation and financial issues.

Group 3:

- Lack of awareness to deal with their issues.

- Privacy concerns and power imbalance.

- Gender-inequalities can become a hurdle for female involvement.

- Accessibility i.e., traveling issues.

- Patients and members of the public may lack the necessary support or incentives to participate in PPIE.

Group 4:

- The public and patients are often not aware of PPIE opportunities, so efforts are required to ensure that there is better engagement and more awareness-raising of the benefits of the involvement of patients and public and how to engage.

- Incorporating PPIE can increase the time and cost involved in research.

- Sometimes, initial attempts to involve patients and the public can be tokenistic i.e., not meaningfully involving them as collaborators.

- Lack of diversity is due to a tendency for researchers to work with the same patients and members of the public repeatedly.

Training Activity Feedback

The training was concluded on a very positive note as participants shared their feedback and highlighted that training session was well-conceptualized to make them understand the PPIE concept in a befitting manner.

After the session, the feedback forms shared by the Keele team were duly filled by all the participants and were submitted to Ms. Saima Sheikh via email.

PPIE workshop participants

Session 2

Training Proceedings

The second PPIE training session was held virtually via zoom on May 24th, 2023. The session was attended by team members from CONTROL and THE HOPE project.

The session was co-facilitated by Ms. Adele Higginbottom (PPIE Project Officer, Impact Accelerator Unit, Keele University, UK) and Dr. Alice Moult (Post-Doctoral Researcher, Knowledge Mobilization Research Fellow, Impact Accelerator Unit, Keele University, UK).

The topics covered in the second session included:

- ❖ How to set up a PPIE Group
- ❖ Reporting PPIE
- ❖ Supporting PPIE members

How to setup a PPIE group

Setting up a PPIE group for any research project is a robust yet iterative process involving several steps ranging from basic to advance.

Basic steps of setting up PPIE group:

- ✓ Identify the purpose

- ✓ Define the scope of PPIE

- ✓ Recruit diverse members

- ✓ Establish guidelines and terms of reference

- ✓ Provide orientation

- ✓ Facilitate effective communication

- ✓ Ensure meaningful engagement

- ✓ Allocate resources

- ✓ Recognize and acknowledge

Advanced steps for setting up PPIE group:

- ✓ Develop a strategic plan

- ✓ Engage stakeholders

- ✓ Implement training and capacity-building:

- ✓ Establish working groups and subgroups

- ✓ Develop processes for PPIE integration

- ✓ Foster collaboration and partnerships

- ✓ Evaluate and monitor impact

- ✓ Disseminate best practices and lessons learned

- ✓ Advocate for policy and system changes

By implementing these advanced steps, the project teams can establish a robust and impactful PPIE group that enhances research practices, improves patient outcomes, and contributes to positive changes in healthcare systems.

Public Member Speakers

The highlight of the second PPIE training session was two public member speakers, one each from UK and Pakistan, who shared their lived experiences and journey as PPIE members.

John Maddison: *A Member of Research User Group at Keele University*

John Maddison, a member of the Research User Group (RUG) at Keele University, brought along broad expertise in developing research questions with researchers, serving on Trial

Steering Committees, and advising about dissemination activities. He is also a member of the patient involvement group. He shared his valuable experience with the audience regarding PPIE

group setup. He emphasized that having the lived experience of certain health condition makes the person more motivated to be a part of PPIE, as their experiences can give valuable insights

to the research team. However, as easy as it seems to establish a research user group, it is even more challenging to retain the members. Fostering a supportive and inclusive environment within the PPIE group and ensuring that members feel valued, respected, and heard can encourage them to be more actively involved in research.

Considering the diverse needs and circumstances of PPIE group members, care should be taken to provide flexibility, accessibility, and alternate means of engagement, especially to those having any health issues, which can lead to more meaningful engagements.

Dr. Ghazala: *A Journey towards Health and Hope*

Dr. Ghazala, a TB, depression and stigma survivor is an embodiment of strength, resilience and perseverance. She has displayed unwavering determination and bravery throughout her TB and depression journey. In a society, where TB in female patients is considered a stigma, Dr. Ghazala shared her heart wrenching lived experiences. Despite belonging to a highly educated

family, her TB was considered a taboo and social stigma and she was even kept away from her children. Her experience was a beacon of hope and serves as a reminder of the power of determination, self-care, and seeking support. to the research teams both at Keele and KMU, her bravery in openly sharing her experiences not only contributed to raising awareness but also provided comfort and encouragement to participants who may be facing similar struggles at other fronts.

Dr. Ghazala added that spreading awareness regarding tuberculosis (TB) and reducing stigma surrounding the disease are crucial for early detection of disease, prevention and control. Stigma associated with TB can lead to delays in seeking diagnosis and treatment, social isolation, and negative psychosocial impacts. Spreading awareness about TB helps dispel myths and misconceptions, challenging the stigma and discrimination faced by TB patients and their families.

Evaluating PPIE

Evaluating PPIE in research helps assess the impact, effectiveness, and value of involving patients and the public in the research process and the key element is developing an effective framework.

- **Develop Evaluation Framework**:

  The facilitators highlighted the importance of developing an evaluation framework that outlines the evaluation methods, data collection tools, and indicators to assess PPIE.

  During the session, the Cube (Context, Understanding, Beliefs, and Empowerment) evaluation framework was discussed, which offers several benefits when used for evaluating PPIE in research. It considers multiple dimensions, including the context in which PPIE

takes place, the understanding and knowledge gained, the beliefs and attitudes of stakeholders, and the empowerment and capacity building achieved through involvement. This holistic evaluation helps capture the full range of impacts and outcomes of PPIE.
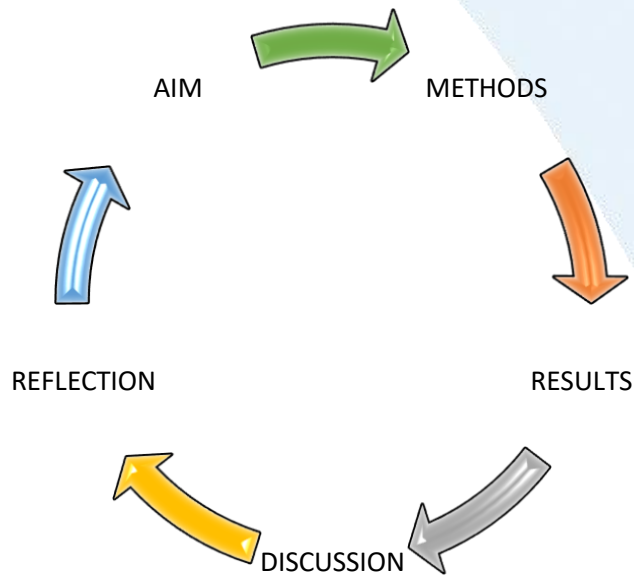
The CUBE framework recognizes the importance of empowerment and capacity building as key outcomes of PPIE. It assesses the extent to which PPIE activities have empowered stakeholders to participate meaningfully in research and decision-making processes, and encourages the qualitative research methods to assess the experience, perception and impact.

Reporting PPIE

The facilitators introduced the GRIPP2 reporting checklist to report the PPIE in research. It involves reporting around the following steps:

1. The aim of PPIE

2. Methods Used

3. Results of PPIE

4. Discussion and conclusion

5. Reflection or critical perspective

Group Activity

The second half of the session comprised a group activity. For this purpose, participants were divided into four groups and were given a task to take any examples of PPIE and fit into GRIPP-2 version. Group leads were tasked to present their group's findings to the participants.

All the groups presented the PPIE examples either from their current projects or from their previous experiences and followed the GRIPP2 reporting checklist to share details of their example.

This helped the participants in getting more clarity about how to use the check-list in future in their own respective projects.

Conclusion:

The session was concluded with the vote of thanks to the IAU facilitators and to Ms. Saima Sheikh for coordinating the both training sessions.

Session 2 Group Picture

The CONTROL PPIE training session 1

April 13th, 2023

Venue: Senate Hall, Administration Block, KMU

Time: 1- 3pm PKT (9 -11am UK time)

Time	Session	Resource Persons/ Facilitators
01:00-01:05	Introduction of IAU facilitators	Ms. Saima Sheikh
01:05-01:15	Aims and Objectives of the workshop	Ms. Saima Sheikh
01:15-01:25	Overview of PPIE	Alice Moult
01:25-01:40	Good Practice	Alice Moult
01:40-02:00	What does PPIE mean to you	Alice Moult
02:00-02:20	Importance of PPIE (Group activity)	Dr. Saima Aleem
02:20-02:40	Barriers to PPIE research (Group activity)	Dr. Saima Aleem
02:40-02:50	Feedback and discussion	Alice Moult and Adele Higginbottom
02:50-03:00	Question/Answers Session	Alice Moult and Adele Higginbottom
	Group Picture	

COGNITIVE THERAPY FOR DEPRESSION IN TUBERCULOSIS TREATMENT
(The CONTROL Project)

The CONTROL PPIE training session 2

May 24th, 2023

Venue: Senate Hall, Administration Block, KMU

Time: 2- 4pm PKT (10 -12am UK time)

Time	Session	Resource Persons/ Facilitators
02:00-02:05	Welcome note	All
02:05-02:15	Aims and Objectives of the workshop	IAU team
02:15-0:25	How to setup a PPIE group	Alice Moult Adele Higginbottom
02:25-03:10	Public Member Speaking	John Maddison Dr. Ghazala
03:10-03:30	Reporting PPIE & Supporting PPIE members	Alice Moult Adele Higginbottom
03:30-03:50	Group Activity	All participants
03:50-04:00	Question/Answers Session	Alice Moult
	Group Picture	