



The CONTROL
(COgNitive Therapy for depRessiOn in tubercuLosis treatment)
to improve outcomes for depression and TB in Pakistan and
Afghanistan

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“PPIE Training Session with PPIE Advisory Group Members”

October 2nd, 2023

EXECUTIVE SUMMARY

The concept of the Patient Public Involvement and Engagement (PPIE) Advisory Group in CONTROL is innovative as it brings together individuals from diverse backgrounds who share a common link with TB and mental health disorders. The group will actively engage with the community and guide the research team at every stage of the study.

To develop the capacity of PPIE Advisory Group members, the second PPIE orientation and training session was held on October 2nd, 2023, at Khyber Medical University. The purpose of the session was to introduce the members to the CONTROL study work package 2 and for the research team to actively engage with them. Considering their primary remit to guide and advise the research team on all ongoing and upcoming project activities, the session was pivotal to ensure their active involvement in the study. This report will narrate the proceedings of the session.

INTRODUCTION

PPIE Advisory Group:

PPIE advisory group, comprises representatives from the service user population, relevant stakeholders, individuals actively engaged with the local and Afghan refugee communities, and individuals with expertise in the subject area being researched to provide input, feedback, and guidance to researchers in a particular field or domain.

The purpose of involving such a group in research project is to ensure that their perspectives, needs, and experiences are considered by the research team at every stage of the project to shape the direction of research projects, influence research methodologies, and enhance the relevance and impact of the research outcomes.

Activity Background:

The training session was held at Khyber Medical University following an initial phase of identifying its members and the first round of PPIE orientation by the Impact Accelerator Unit team at Keele University. The members brought along diverse experiences ranging from being TB patients themselves to others closely working with the community, including local Pakistanis and Afghan refugees.

The objective of the activity was not only to actively engage with the group members and to mutually benefit each other in terms of learning about their journeys and gaining insights into the community's perspective on TB and mental health challenges but also to involve them in designing effective community awareness strategies regarding TB and mental health outcomes and to minimize prevalent myths and misconceptions within the community.

Research User Group Members:

❖ Dr. Ghazala Yasmin

Dr. Ghazala Yasmin, a medical doctor by profession, personally experienced TB and faced TB-related stigma and mental health consequences.

❖ Ms. Ammara Iqbal

Ms. Ammara Iqbal is a speech therapist and psychologist by profession. She works closely with Afghan refugees especially female refugees regarding neglect, stigma, and gender-based violence.

❖ Mr. Naveed Faqeer

Mr. Naveed is an engineer by profession. He recovered twice from TB and experienced extreme difficulties at the workplace, in the community, and during his overseas stay.

❖ Mr. Asad

Mr. Asad, an Afghan national, works as a focal person with the Afghan refugees in different camps in Peshawar. Being a refugee himself, he is well aware of the mental health issues prevailing among Afghan refugees.

❖ Mr. Farman Ullah

Mr. Farman is an Afghan community social mobilizer and brings along the diverse experience of working with Afghan refugees all across the Khyber Pakhtunkhwa province.

Session Proceedings:

Facilitators:

Dr. Saima Aleem, CONTROL Communication Manager and CEI Lead, and Ms. Tauba Khan, Research Assistant in the CONTROL study facilitated the session.

About Meeting

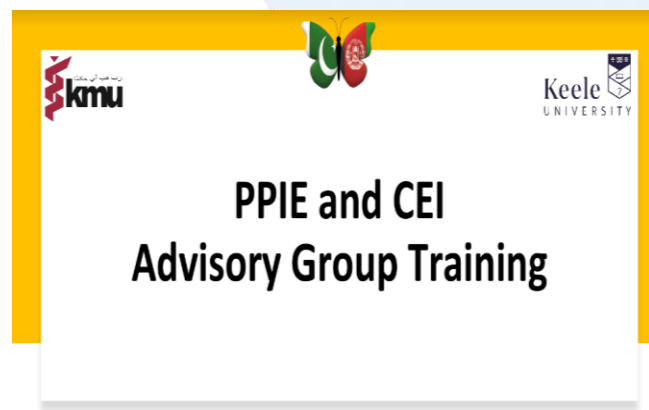
Dr. Saima Aleem welcomed the members, and after a round of introductions, she briefed them on the purpose, aim, and objectives of the activity, as well as how they can contribute and provide assistance to the project.

Training Content:

PPIE training content was designed and developed by Ms. Abbie Milner at Keele University UK.

The content of the training module was based on:

- ❖ What can you contribute?
- ❖ How will you be involved?
- ❖ What will you be expected to do?
- ❖ How will you benefit from being involved?



Overview of PPIE and CEI:

PPIE and CEI are active partnerships between patients, the community, the public, and researchers. Members become a part of the research team, working with researchers to design and run the study. Members offer their unique insights, advice, and experiences of health and care. This improves the quality, relevance, and effectiveness of research.

Importance of PPIE and CEI Activities:

After sharing the course content, a discussion was generated around the core concepts and to understand the perspective of advisory group members. The questions asked during the session and the responses from the participants are transcribed verbatim.



How can we contribute effectively to making change happen in our community regarding TB and mental health?

Dr. Ghazala: *“Through awareness sessions”*.

Ms. Ammara Iqbal: *“Awareness sessions are important, if you are aware then this will give you knowledge and if you have knowledge then you know what you need to do and the direction you need to go to make changes to actually happen and to improve”*.

Do you feel awareness sessions have more impact on the community?



Ms. Ammara Iqbal: *“Yes!, as I am working with Afghan refugees, they need psychosocial support and awareness. They go through war and terror; we do not know about their suffering as we haven’t gone through this suffering. They should know about the referral mechanism. They should be informed about the services offered by organizations in different provinces”.*

Dr. Ghazala: *“Female patients are not seeking treatment, the reason behind not seeking treatment is they are not given permission by the elders of the family i.e., mother-in-law, father-in-law, and husband of the female. Therefore, the family of the patient should be counseled about the problems and awareness should be given and this can be done through awareness”.*



Dr. Saima shared her observation when the team went to community engagement at Haripur, she added that *“we came to know that the elders of the family don’t give permission to the female patient, they are not empowered to*



take a step. In TB centers, the female patients do come on the first visit, but they do not come on their second or third visit. Male members of the family do not even bother to take her to the center and get her checked. Male members of the family visit

the center and take medicine for her”.

Do you feel that the absence of proper counseling for the patient and carer, in any way can hinder the TB treatment or lead to poor mental health outcomes?

Dr. Ghazala: *“Compliance with treatment can be the issue”.*

Ms. Ammara: *“Apart from compliance, and stigma associated with TB, TB patients have illness anxiety that if people understand about their TB, they have fears that they will be left isolated, and people will dislike them for their disease. If both patients and their family members are counseled right from the beginning, I feel they can have better treatment outcomes”.*

Mr. Asad: *“In refugee communities, there was much less awareness regarding where to get TB treatment from and once a patient gets diagnosed with TB, they used to hide it due to society's fear. If there is a proper counseling session, I believe we all can feel the difference.”*

Since Dr. Ghazala had TB experience, she added to the discussion:

Dr. Ghazala: *“Well, to be honest, when I was diagnosed with TB, there was a lack of social and emotional support from family and still it's an issue. Back in times when I was patient and was terribly neglected and stigmatized I used to pray for some miracle to happen to counsel my family that I am not someone to be ashamed of but rather taken care of. If at my time, there were such PPIE or CEI groups to extend support, I now feel my mental health could have been more stable”.*



Naveed Faqeer: *“I had a terrible time abroad, and I had to file a case against them as they were not allowing me to go back to my country, but the condition is the same abroad for TB patients they treat them differently. Today I am sitting here among all of you, and I feel so proud of my own journey but now getting to know about the PPIE and CEI and how being members, we can help someone makes me more motivated”.*

Mr. Farman: *“in Afghan camps, there is a dire need to spread awareness regarding TB and mental health. I never knew before coming here that a small group can make such a huge change in the community as we don’t understand the value, we all hold when we join together”.*

Since you all come from different walks of life, we really need your insights on what the community wants.

Dr. Ghazala: *“Community needs awareness and care. If we make them aware that their mental health is as important as their physical health, and the importance of mental health, having good mental health makes life easier. The community should know the common mental health problems along with their causes and they should seek a psychiatrist or psychologist instead of going to faith healers and wasting their time. Moreover, the community should be sensitized, and the concept of counseling should be highlighted and practiced”.*



Naveed Fageer: *“Flyers and leaflets will help spread awareness because this is exactly what anyone would want. We all somehow look for some authentic information”.*

Mr. Asad: *“Apart from flyers, I think during community engagement sessions, a psychologist or a psychiatrist should accompany the team and provide counseling to the patient on the spot”.*

Ammara Iqbal: *“In Afghan refugee camps the influential people are their elders, we should talk to them and provide mental health awareness as mental health issues prevail more in Afghan refugee communities and they have issues in reaching out, seeking treatment out of*

their community. Therefore, you people should mobilize, and sanitize them about your project. Currently, there are eight Afghan refugee camps in KPK i.e., Khurasan and Khazana in Peshawar, Jalala and baghicha in Mardan, Utmanzai and hajzai in Charsadda while Kheshgi and pashtoongari in Nowshera”.

In the next half of the session, the discussion was focused on the benefits the advisory group members can get from being a part of the CONTROL study and what strategies can be worked on to make the awareness more impactful.

Capacity development is the key benefit all the members can get as targeted PPIE and CEI training can help them understand their roles and responsibilities. All the advisory group members endorsed that this training and interaction with the CONTROL CEI team and working group members are already benefiting them to project their own voices and also to understand the voices of the community.

Way Forward:

It was decided that advisory group members would work closely with the CONTROL CEI team to develop content for flyers, posters, role-play scripts, and videos to which they have already started contributing.

Conclusion:

The advisory group members extended their special thanks to the CONTROL team at Keele for developing the specific training content. Dr. Saima Aleem concluded the session with a vote of thanks to all the participants on behalf of Prof. Saeed Farooq and Dr. Zohaib Khan.