





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





"Panian Afghan Refugees Camp, Haripur, Community Engagement Activity"

3rd August 2024





EXECUTIVE SUMMARY

Afghan refugees are integral to the CONTROL study, with the CONTROL CEI team regularly engaging them in awareness initiatives. On August 3^{rd,} 2024, community engagement activities were conducted at the Panian Afghan refugee camp in Haripur, KP, with female and male Afghan refugees respectively. The primary objectives of this engagement were to interact with the community within their natural setting, provide an overview of the CONTROL study, and discuss tuberculosis and mental health outcomes. Additionally, the activity aimed to introduce the concept of co-creation and art-based community awareness genres and to get the community's perspective regarding the most suitable, sustainable, and culturally appropriate art genre for awareness regarding TB and Depression. This report will provide details of the community engagement activities held in both female and male hujras.





Activity Aims & Objectives:

On August 3rd, 2024, a community engagement activity was conducted at the Panian Afghan refugee camp in Haripur, KPK. This initiative aimed to actively engage with the community to raise awareness about the CONTROL study, tuberculosis, and mental health outcomes, while also introducing the concept of co-creation to the community members. Additionally, the activity sought to address prevailing myths within the community and highlight the significance of art as a powerful tool for awareness, particularly through community-driven creations for tuberculosis and mental health awareness.

Panian Camp CEI Activity Plan:

Before the scheduled activity, the CONTROL CEI team held a meeting with the Community Advisory Board members to gather their valuable recommendations. Following this, the research team visited the site, engaging with local hujra and elders to invite community leaders and members and finalize logistical arrangements. Additionally, a separate meeting was organized with a female religious scholar to ensure her participation and involvement in the activity.





Panian Afghan Refugee Camp

Panian Afghan Refugee Camp, located north of Haripur city near the village of Panian in Pakistan, is one of the largest camps established to shelter Afghan refugees fleeing conflict in their homeland. Nestled in a rural area surrounded by agricultural land, the camp has been a temporary home for thousands of Afghan families for decades. The residents of the camp primarily speak Pashto and Farsi, maintaining their cultural and linguistic heritage despite the challenges of displacement.









Female Hujra:

The designated female hujra for the activity was centrally located within the Panian refugee camp, making it easily accessible for both community members and the research team. The hujra was spacious and well-maintained, accommodating approximately 39 female participants.







Facilitator:

For female hujra:

From the CONTROL CEI team, the session was facilitated by:

- Saara Khan (CONTROL Communication Officer and MEAL Manager for CEI Guiding Principle Pilot Project)
- Dr. Kanwal Safeer (Co-Creation Coordinator, CONTROL CEI Guiding Principle Pilot Project)
- Rida Zarkaish (Co-Creation Coordinator, CONTROL CEI Guiding Principle Pilot Project)
- > Tuba Khan (Media Coordinator, CONTROL CEI Guiding Principle Pilot Project)
- Maria Marjan (Research Assistant & Volunteer, CONTROL CEI Guiding Principle
 Pilot Project)

Participants:

The workshop was attended by 39 female participants, together with an Islamic scholar (a teacher from the Madrassa) and local female residents.

Activity:

The activity commenced with the recitation of the Holy Quran by Tuba Khan. Rida Zarkaish welcomed all participants and described the purpose of the visit to the community members. She provided them with an information sheet and consent form for their participation in the CEI session.









Rida Zarkaish discussed tuberculosis, including its signs and symptoms, precautionary measures, and common myths. The facilitator then provided information on mental health and health issues, discussing the signs and symptoms of depression and anxiety. The female refugee shared their lived experiences.

Saara Khan talked about mental health and common mental health illnesses and shared strategies to overcome depression, anxiety, and stress, and how

to manage life stressors effectively. Participants shared their experiences with mental health issues, describing feelings of heaviness, anger, sadness, and the impact of grief on their daily lives. They were encouraged to seek both pharmacological and non-pharmacological treatments and to engage in activities that interest them to manage stress and depression. She conducted a deep breathing exercise with the participants to help them feel better and emphasized the importance of this practice.

The Lived Experience of Afghan refugees:

During the community engagement activity, the females were asked if they were familiar with TB, and the participants responded affirmatively. When inquired whether anyone in their households had experienced TB, several participants mentioned that they had not encountered





the disease personally but offered their perspectives on TB as both a physical illness and its connection to mental health.

Participant 1:

One participant shared her knowledge about TB. She said, "the chest infection, when you get a cough, along with sputum, a disease that spreads from one person to another by sitting with others."

The facilitator clarified that tuberculosis (TB) is not easily transmitted through casual contact, such as sitting near an infected person. Instead, TB spreads primarily when an infected individual coughs or sneezes without covering their mouth, especially if they have not yet received treatment. When this happens, TB germs are released into the air, increasing the risk of infection for those nearby.

Participants were also informed that TB can affect not only the lungs but other parts of the body as well. Common symptoms include a persistent cough lasting more than two weeks, body aches, night sweats, loss of appetite, fatigue, and weight loss. The facilitator stressed the importance of early diagnosis and adherence to treatment, noting that all hospitals provide free TB medication. Patients must complete their full course of treatment without interruption, as stopping treatment early can cause the disease to reoccur and become more difficult to treat.

Participant 2:

Another participant shared her experience suffering from mental health illness. She mentioned, "I am a patient with a mental illness, and most of the time, I manage to be fine and can tolerate things people say. But there are moments when I feel overwhelmed and wonder whether I should harm myself or others. I have young children, and when my mind isn't clear, I sometimes





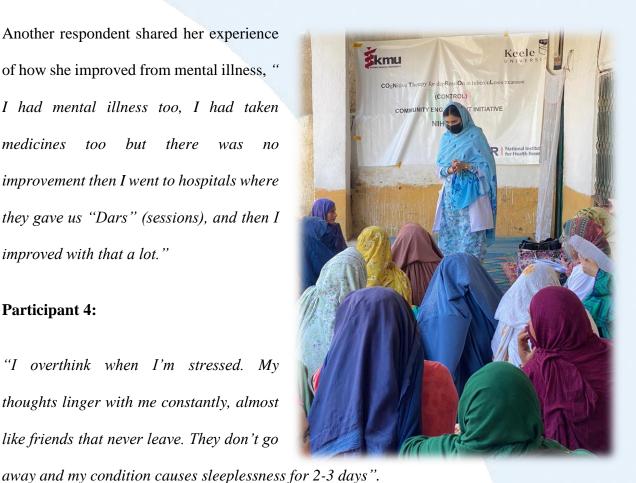
lash out and even hurt them. There was a time when I hit one of my kids so badly that, despite his sisters' efforts to protect him, I couldn't stop myself. Now, he doesn't listen to me and asks why I hurt him so much and pulls his hair. He's very small, but I know this behavior is because of my mental health. I take medication, but it doesn't seem to help"

Participant 3:

Another respondent shared her experience of how she improved from mental illness, " I had mental illness too, I had taken medicines too there was improvement then I went to hospitals where they gave us "Dars" (sessions), and then I improved with that a lot."

Participant 4:

"I overthink when I'm stressed. My thoughts linger with me constantly, almost like friends that never leave. They don't go



Participant 5:

The participant was emotional while telling her problem. She mentioned, "I'm not sure what to say. It feels like no one here really cares. I am constantly being mistreated, my husband frequently abuses me, and I face oppression from everyone. I don't want to endure this anymore. He never gives me any money. (patient cries)".





When Saara Khan asked what the participant does when racing thoughts overwhelm her, Participant 4 responded that "I haven't tried anything like medication or other methods. People often suggest that I should change my thoughts on my own. Sometimes, I sit with my kids, talk to them, and cook for them to shift my mindset".

The facilitator asked how she felt then? The participant answered "when I focus on my household chores, I start to feel better. I sometimes switch from one task to another, or I put on my burka and go out to socialize with friends or visit neighbors. All the people here are my friends; there are only about 7-8 of them. For instance, one is my sister, another is my niece and one more is a close friend. My niece is very dear to me and very close. Since we have no



one else to share our problems with, my niece helps by counselling me to stay calm and not worry".

Continuing this, the facilitator discussed the concept of catharsis, which involves expressing our emotions, especially those that disturb us. This can be done through music, poetry, or sharing our feelings with a trusted friend, and it is highly beneficial. As each of you has shared your challenges, it's important to remember that everyone faces different stressors. Even if we are

doctors, we still experience depression, anxiety, and stress. Keeping our issues to ourselves can lead to lingering stress and potentially develop into mental health issues. Therefore, it's crucial





to manage and reduce stress. We should address problems by talking to a trusted friend, staying engaged in household chores and hobbies, practicing deep breathing to reduce stress and anxiety, and maintaining good sleep hygiene. If the situation worsens, seeking psychological help is advisable.

Overview of Art-Based Activity:

The community members were informed about various art-based genres that can be used for community engagement and awareness. They learned about different mediums, including visual, performing, and digital arts.

Flyer:

A flyer that featured a cartoon character and written instructions was presented. To gauge the

effectiveness of the flyer, participants were asked whether they comprehended its message by reading the written instructions or if they understood it solely by observing the cartoon character. This inquiry aimed to assess how well the visual and textual elements of the flyer communicated its intended information. One participant responded that "they understood the message by looking at the cartoon, which depicted a frustrated character who was unable to manage household tasks". The facilitator



said that if similar cartoons and instructions were used for topics like TB and mental health, the message would be better understood. Most participants indicated visual elements like cartoon can make them understand the concept as most of them were illiterate. Few mentioned that their children can help read the message as well.





Flipbook:

A flipbook was shared featuring a cartoon on one side and information on the other. Those who cannot read can understand the content through the pictures. The calendar can be created in any language, including Urdu or Pashto, to make it easier for people to understand.

Song/Audio/Caller Tunes:



The facilitator introduced an additional method for conveying information about TB and mental health, which involves using songs, or audio tunes. They explained that it can be a powerful tool for illustrating and communicating key messages in an engaging and relatable way. Another method involves using ringtones as a tool for disseminating information. In this approach, when you dial a call, a pre-recorded message or information automatically starts playing. This technique

can be particularly effective because it ensures that the message reaches the recipient directly. The participants related the concept to the COVID-19 time when messages and awareness were spread via ringtones but they also mentioned that such caller messages are short time and they might lose impact.

Role-Play/Drama:

To gauge the participants' familiarity with this approach, the facilitator asked if they had ever watched any dramas. This was intended to understand whether the participants are accustomed





to or find value in drama as a medium for learning and engagement. Participants responded Yes; that they watched dramas. The facilitator explained that drama is not only a source of entertainment but can also be an effective medium for conveying important information. Additionally, during dramas, advertisements often play a significant role in delivering messages. For instance, during the COVID-19 and dengue pandemic, short videos were produced as part of these dramas to educate the public on how to protect themselves from the virus and the essential precautionary measures they should follow. These videos were designed to be both informative and engaging, making complex health information more accessible. Similarly, drama can be used to address other health issues, such as TB and mental health, by incorporating educational content into the storyline or through advertisements, thus helping to raise awareness and promote preventive measures in a format that is relatable and easily understood by the people.

Videos:

The females were shown an informative video regarding mental health to get clarity regarding the role of videos in community awareness. It was explained that there are various methods to disseminate information to people. However, visiting each household is challenging. If the information is not passed on to others, it is likely to be forgotten after a few days. Therefore, finding alternative ways to share information is crucial to reach as many people as possible.

Focused Group Discussion Proceedings:

Ms. Rida Zarkaish and Dr. Kanwal Safeer started the Focus Group Discussion (FGD) with the participants, recording their responses.

The participants were asked about their preferred methods of communication for receiving information. There were mixed views regarding the art mediums. Few participants expressed





a preference for direct, personal engagement, highlighting that the respectful presence of the team made the information-sharing process more effective. They mentioned that some of them rarely use mobile devices, but they do watch TV and dramas.



The moderator then asked questions about how participants would retain and continue to access the shared information in the team's absence. Most participants felt that watching dramas or advertisements is fleeting and reported that they don't remember them for long. One participant responded that "we prefer when people come and provide us with information directly, as it is the most effective way, they mentioned that while videos and other materials are initially watched, people often do not watch them again, and some may not watch them at all due to a lack of interest".

Kanwal introduced the idea of using flyers, which could be explained to the participants by their educated children. The majority agreed that this method is effective and could be easily





understood with assistance. inquired Rida about the preferred format for presenting information, whether through more written content or images which one participant to mentioned that "I feel flyers are the best method for awareness of TB and mental health, but makes it in Pashtu because we understand Pashtu word". Most written participants requested comprehensive awareness



materials in Pashto or Urdu, noting that their kids study and understand Pashto and Urdu. The majority agreed on the importance of using these for written materials. When asked about combining information on TB and mental health into a single resource, the participants preferred having all the information in one place, with flyers being the favored medium.

Regarding visual preferences for the flyers, the participants preferred realistic human images over cartoons for clearer message delivery. Due to cultural sensitivities, the use of animations was agreed upon. The majority also preferred content in Pashto for videos. They requested detailed written documents in Pashto, covering where to find treatment and other essential information about TB and mental health.





The facilitator then inquired about creating a video on TB and mental health, its duration, language, and content. The community members suggested creating a short video of 5 to 10 minutes in the Pashto language so they understand it better. They also suggested using characters whom they can relate to. Few suggested using animated characters as real characters might not be acceptable due to cultural issues.

The facilitator also asked how the community's voice could be ensured to be heard and acted upon throughout the project. Most participants shared that "Our camp is very large, and when we visit each other's homes, we are all like family. We support each other in times of trouble.



Whenever someone comes here and provides information about illnesses, we share it to ensure everyone's well-being. There have been other camps here before, but you are the first team to provide us with such thorough information about TB. We will definitely spread this information to others".

Concluding Remarks:

Ms. Saara concluded the session by expressing gratitude and offering a

vote of thanks to the Hujra owner for opening their doors to the team and community members.

CEI team appreciated the participants for their active involvement and valuable suggestions during the session. They were encouraged to be vocal in seeking information and to play active roles in their community.





LEST WE FORGET







Community Engagement Activity with Male Afghan Refugees at Panian Camp 3rd August 2024





Facilitator:

From the CONTROL team, the activity was facilitated by:

- Asad Ullah, (Project Manager for CEI Guiding Principle Pilot Project)
- ➤ Ihtesham ul Haq (Community Engagement Officer Local for CEI Guiding Principle Pilot Project)
- ➤ Ihsan Ullah (Project Community Engagement Officer Afghan for CEI Guiding Principle Pilot Project)

From the CONTROL study Community Advisory Group, the session was attended by:

> Farman Ullah

Workshop Proceedings:

Day & Venue

The community engagement activity was conducted on August 3rd, 2024, in Panian Camp, located on the rural outskirts of Haripur, Khyber Pakhtunkhwa (KP). This area is predominantly inhabited by Pashtuns, whose native language is Pashto. Panian Camp is recognized for housing Afghan refugees, primarily daily wage laborers, under the administration of the Commissionerate of Afghan Refugees (CAR).

Participants:

The workshop was attended by 30 - 35 males residing in the Panian camp, their religious scholars, hujra owner along with CEI advisory group members.





The activity was opened with the recitation of the Holy Quran by Ihsan Ullah. Later Asad Ullah introduced the CONTROL team and briefed the participants on the purpose of the activity, its aims and objectives, and how the community can help and contribute to the project.

All about Tuberculosis



Asad Ullah started the session and Ihtesham led the session by providing a comprehensive explanation of the signs and symptoms of

tuberculosis (TB), detailing that symptoms include a persistent cough lasting two weeks or longer, chest pain, and coughing up blood or sputum. Other symptoms of TB disease were also covered, such as weakness or fatigue, weight loss, lack of appetite, chills, fever, and night sweats. In addition to discussing the types of tuberculosis, they elaborated on various precautionary measures for patients, caregivers, and those interacting with TB patients.

They emphasized the importance of these precautionary measures to ensure the safety of both patients and caregivers. They also addressed prevalent myths within the community, highlighting the need for myth-busting to raise awareness and alter attitudes towards TB patients. This, in turn, can contribute to reducing poor mental health outcomes associated with TB lived experiences of the community.





TB Lived Experiences of Community and Mental Health:

The community members in the Afghan refugee camp demonstrated a significant awareness of mental health issues and their symptoms. Participants identified various signs of mental illness, including dizziness, loneliness, severe aggression, somatization (digestion problems), derealization (feeling of detachment from surroundings), depersonalization (disconnection from one's thoughts and feelings), and excessive talking. One participant shared their personal experience with sleep difficulties, mentioning the use of antipsychotic medication to manage their condition. This indicates that mental health challenges are present and recognized within the community, with some individuals actively seeking treatment.

Participant 1:

Verbatim as Narrated

The symptoms of mental illness included Dizziness, loneliness, severe aggression, somatization (digestion problems), derealization (feeling of detachment from surroundings), depersonalization (disconnection from one's thoughts and feelings), and excessive talking.

Participant 2:

Verbatim as Narrated

Yes, I am taking antipsychotic medicines at night, I cannot sleep, and sometimes I keep thinking



about why sleep will not come to me. Therefore, I take medication to help me sleep. If I do not take medication, I stay awake till the morning.

Islamic scholar

An Islamic perspective on illness and treatment was shared by religious scholar. They cited a Hadith from Sahih Muslim, which states, "For every disease there is a cure." This perspective emphasizes the belief that Allah has created remedies for all





illnesses, including mental health conditions. The scholar also mentioned the practice of "Dam-e-Shifa" (healing breath) as a form of spiritual healing referenced in the Quran. This integration of religious beliefs with health awareness demonstrates the potential for leveraging faith-based approaches in health communication within the community.

Participant 3

Verbatim as Narrated

"As Allah created illnesses, Allah also created cures for every illness. As in Hadith '[عَرَاءُ]' meaning 'For every disease there is a cure.' This hadith is reported in Sahih Muslim Book 26, Hadith Number 5466 narrated by Jabir bin Abdullah that the Prophet (PBUH) said, 'There is a remedy for every malady, and when the remedy is applied to the disease it is cured with the permission of Allah, the Exalted and Glorious.'"

Response of Community Regarding Art base CEI:



The CEI team presented the concept of co-creation and mentioned to the community members that only they can guide the team for what is needed to spread awareness as per their needs and they can guide the team on what art medium can be used for this purpose. The community





showed a mixed response to the art-based Community Engagement Initiative (CEI) materials presented. While some participants appreciated the visual aids such as calendars and posters, others pointed out potential challenges. A key observation was made regarding the literacy levels within the community, with one participant noting that many people might struggle to understand written information and instead rely on interpreting pictures according to their own understanding. This highlights the importance of using visual communication methods that are accessible to all community members, regardless of their educational background.

The participants emphasized the need for more awareness sessions in the community, suggesting that informed individuals could play a crucial role in spreading knowledge about TB and mental health among their families, friends, and neighbors.



Participant 4

Verbatim as Narrated

"It is crucial to note that while discussing very important topics, everyone has their own perspective. In my opinion, because most people in our community are uneducated, they struggle to understand what is written on calendars."

Participant 5

Verbatim as Narrated

"I believe we need more awareness sessions in our community. Every individual should understand TB and mental health. These informed individuals should spread

awareness in their homes and among friends, neighbors, and relatives."





Community Feedback of

Art Genres:

The community provided valuable feedback on various art genres presented for health communication.



Young participants showed a preference for video content with Pashto voiceovers, citing its effectiveness for both educated and uneducated community members, including women at home. Some participants favored illustrated booklets that combine cartoons with simple, accessible content in both Pashto and Urdu languages. This approach was seen as beneficial for those who might not be able to read one language but could understand the other.

Suggestions for improvement included adding more comprehensive content on the impact of illnesses, their causes, and available treatments. Participants also recommended using large-font posters and banners with clear cartoons, similar to those used during the COVID-19 pandemic, to convey messages about TB symptoms and mental health problems effectively.

Participant 6

Verbatim as Narrated

"Include the impact of illness that, for certain reasons or how these illnesses (tuberculosis and mental illnesses) are transformed. Because of these problems, our sleep is disturbed, so if all these problems are written in the booklet along with solutions and treatment, in every home there might be an educated person who gathers their own family and makes among them awareness."

Participant 7

Verbatim as Narrated





"No, the content in the Pashtu language you delivered is understandable, but the only problem is that some words in English need to be properly translated, like tuberculosis, session, gathering and mental health."

Participant 8

Verbatim as Narrated

"If posters, charts, and banners with large font sizes and clear cartoons are placed on camp walls, they will provide a clear message regarding tuberculosis symptoms and mental health problems. Like the banners of COVID-19, cartoons give us the message to keep our distance, wear masks properly, not shake hands, and patients with COVID-19 in different rooms."

Participant 9

Verbatim as Narrated

"A Booklet would be better because there is one person in every home educated, and it will reach every home."

Religious scholars concluded that "if one of our students had an illness, I would make all the students aware of tuberculosis symptoms and associated mental health problems. Additionally, during our religious teaching (Tabligh), we can also raise awareness about these issues in our



community."

The hujra owner mentioned that

"There is one thing that to our community, most doctors come to do

a session and then disappear but I appreciate that first time a team has come to sit and talk to us for our needs and how we can get more information about TB and mental health"





Concluding

Remarks:

The community
engagement
session revealed a
strong interest and
willingness among
participants to



engage with health awareness initiatives. They proposed practical solutions for disseminating information, such as leveraging educated family members to share knowledge from booklets within households. The community also suggested follow-up gatherings to assess the impact of the awareness materials after a period of time.

Religious leaders expressed their willingness to incorporate health awareness messages into their teachings and community outreach activities

The CEI team extended thanks to every member of the refugee camp for taking time out to attend the session and for their feedback.

Overall, the Community Engagement Initiative demonstrated the value of participatory approaches in developing culturally appropriate and effective health communication strategies for TB and mental health awareness in refugee camp settings.





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

Community Engagement Initiative CEI NIHR Pilot

Agenda: CONTROL Community Engagement initiative

Date: 3rd August 2024

Area: Panian Afghan Refugee Camp, Haripur

Male and female parallel in two different houses (Hujras)

Time slot	Topic / title	Resource person
10:30am-	Recitation of Holy Quran	Mr. Ihtesham (Male side)
10:35am		Ms. Tuba (Female side)
10:35am-	Welcome note and Introduction	Mr. Ihsan Ullah (Male side)
10:45am	of participants & informed	Ms. Rida Zarkaish (Female side)
	consent/Information sheet	
10:45am-	Infectious disease burden in	
11:00am	Pakistan (specifically TB) and in	
	Khyber Pakhtunkhwa.	
	Aim & objective of the	Mr. Ihsan Ullah (Male side)
	Community Interaction,	Ms. Rida Zarkaish (Female side)
	importance of community	
	engagement in improving	
	healthcare delivery and access.	
11:00am-	Overview of mental health	
11:15am	disorders in chronic diseases and	
	ТВ	Mr. Asad Ullah & Ihsan Ullah (Male
	Mental health disorders	side)
	prevention and treatment, role of	Ms. Saara Khan & Rida Zarkaish
	community in advancement of	(Female side)
	research and project specific	
11.15	research activities.	M. F. (ACI
11:15am-	Lived/shared experiences from	Mr. Farman (Afghan representative)
11:45am	CEI advisory group	Ms. Ammara Iqbal
11:45am-	Introduction to art-based CEI	
12:20pm	i.e.,	Mr. Ihsan Ullah & Mr. Ihtesham Ul Haq
	performance art, visual art and	Ms. Rida Kanwal & Ms. Kanwal Safeer
	digital art	





12:20pm-	Participant feedback on each	Mr. Ihsan ullah & Mr. Ihtesham Ul Haq
01:00pm	sample	Ms. Rida Zarkaish & Ms. Kanwal
		Safeer
01:00pm-	Speech by the community	Local counsellor (Male)
01:10pm	representative (counsellor)	Local counsellor (Female)
01:10pm-	Speech by the religious	Imam Masjid (Male side)
01:20pm	representative	Alma (Female side)
01:20pm-	Vote of thanks	Mr. Asad Ullah (Male side)
01:30pm		Ms. Saara Khan (Female side)