





# 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** 

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# THE CONTROL'S VOICE

Value of Integrated Community Engagement





Community Engagement Initiative (CEI) Activity with Afghan Refugees 12th February, 2024





# **Executive Summary**

The CONTROL Community Engagement Initiative (CEI) organized the community engagement activity at the Paniaan Afghan Refugee village in Haripur on 12<sup>th</sup> Feb 2024, to engage with the Afghan refugees in their natural settings for the project overview and to discuss Tuberculosis and common mental disorders. Through interactive engagement sessions, the initiative promotes community involvement and empowers refugees to take charge of their health

We conducted two engagement sessions, one each for males and females. The sessions were conducted at the local Hujras following the socio-cultural norms of the camps. This report will narrate the CEI activities in both female and male Afghan community settings.





#### **About CONTROL's VoICE**

CONTROL's VoICE (Value of Integrated Community Engagement), is a series of interactive community engagement activities to establish strong linkages with community and patient groups in Khyber Pakhtunkhwa, Pakistan.

At the very outset of the CONTROL research program, CEI was envisioned to establish a mutual understanding between patients, communities, community gatekeepers and influencers, civil society representatives, and researchers regarding TB and mental health outcomes.

#### **VoICE Aim:**

CONTROL's VoICE is guided by the aim to improve mental health and TB outcomes among TB patients of both Pakistani and Afghan origin in KPK and to ensure CONTROL's decision-making at every step of the research process is driven by insights from the community.

#### **Community engagement spectrum**

To establish an effective community engagement foundation, the CEI team is following the community engagement spectrum.

Under the CEI, a series of interactive information sessions in both urban and



rural settings are arranged to cater to variety of communities affected by TB and mental health issues and explicitly recognizing the valuable expertise and insights that people with lived experience offer.





# **Female Afghan Community**

**Engagement Report** 





#### Introduction

#### **Activity background:**

The sixth community engagement activity under the CONTROL project was conducted with Afghan refugees on 12<sup>th</sup> February 2024 at Paniaan Refugee Village, Haripur. The activity aimed to engage with the Afghan community spread awareness about Tuberculosis (TB) and Mental Health multi-morbidity, and dispel myths and misconceptions predominant in the community regarding both health issues.

The activity also aimed to identify potential members of the CONTROL community advisory committee from Afghan refugees. The current advisory committee is guiding the research team during all phases of the CONTROL program and is bringing the community perspective in our planning and decision-making.

#### Paniaan camp CEI activity plan:

The community engagement activity at Paniaan refugee village was planned as a parallel activity in both male and female communities considering the socio-cultural norms of the area and ensuring active inclusion of both male and female residents.

Before the activity, the Afghan focal person/social mobilizer at the Paniaan camp was reached out for all the coordination, and invitations were sent out to all the male and female members of the camp through an Afghan social mobilizer, who was also tasked to make the necessary arrangement at the community hujra.





### **Female CEI meeting**

#### **Settings**

Paniaan Afghan camp's existence dates back to 1980 but was formally recognized in 2008 and is among the World's top ten refugee camps as per UNHCR. The camp houses over 60000 Afghan refugees.

#### **Participants:**

The activity was attended by 30 Afghan females aged 18-60 years, including female religious teachers and female community mobilizers.

# **Facilitator:**

Dr. Saima Aleem (Communication Manager and Community Engagement Lead, CONTROL),
Ms. Saara Khan (Communication Officer), Dr. Mahdia (Afghan National/ CONTROL Afghan

supervisor), and Ms. Tuba Khan
(Research Assistant) facilitated
the session with the female
Afghan community members.

### **Session proceedings:**

# **Opening of activity:**

The activity started with the

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introduction of the CONTROL project and team by Dr. Saima Aleem. This was followed by the sharing of the purpose and aims of the CEI activity.





#### All about tuberculosis

Dr. Saima Aleem highlighted the Tuberculosis signs and symptoms, diagnosis, and safety measures. This was followed by discussions with the participants and eliciting their views on tuberculosis and mental health in general. Dr. Aleem explained the facts and figures and talked about myths and misconceptions related to TB which prevails in the Afghan community to spread awareness regarding TB.

### Lived experiences of community:

The Afghan participants initially shared their experiences of living in a refugee village.

#### Verbatim as narrated by Afghan Participants:

#### **Participant 1:**

"The trauma of fleeing home still haunts me but life was tough back home. Being female, we had no rights. I wanted to study but we were not allowed to go to school. Our relatives were already settled in camps in Pakistan so my parents decided to marry me as it was the only way to escape the brutality. I came to this camp many many years ago and now I don't even remember the count of it. Now this is our only home. The people living here are now my family. Every human here has a story to tell. The kids born here now feel camp life is not easy but we tell them that the life we left behind was a nightmare".

# **Participant 2:**

"I moved here almost 15 years back and used to live in a tent. Some days we used to worry about food. Rain used to create more problems but slowly the tents were replaced by mud houses and this is how our life progressed here. Still, our girls don't go to school here. Our men feel that studying with boys will rot the fragile minds of our girls. I wanted my both





daughters to study so they could escape poverty and work but their father doesn't allow this.

Now most of the girls living in this refugee village only get religious education from a lady."

#### Do you face any problems while seeking health care?

#### Participant 3:

Almost all of us face a lot of problems while seeking treatment for any disease especially when our refugee cards are expired. We don't have Pakistani CNIC cards otherwise it would have been easy for us to go to any hospital to get treatment like regular Pakistani.

#### Did anyone from your family have TB or have seen any TB patients?

#### Participant 4 (social mobilizer):

"Yes, there are two families here who have TB patients but they are not here today. In one family, the husband has TB so his wife goes to houses nearby to wash utensils and to earn money for her family that's why she is not here today. In another family, their two kids have TB and so the mother looks after them and the father works at a shop here in the village".

#### What is the attitude of family members or community members towards them?

"We all are refugees here. We left our land but here we don't leave our countrymen. We are like a family on another land so we help each other. We send food to their houses. When the mother is down or depressed, we all get together to at least talk to each other. Initially, many people were scared to meet them but any of us can get any disease and die so now we don't leave anyone alone".

# **Mental Health & Depression:**

Ms. Saara Khan, a clinical psychologist focused on the importance of mental health, how we handle stress related to their situation, and make healthy choices. TB-related mental health





stressors and coping mechanisms were discussed in detail with participants. Special emphasis was laid on the mental health problems prevailing in the Afghan refugee community. Saara also conducted some relaxation exercises with the ladies, encouraged them all to share their experiences and suggested some coping strategies accordingly.

# Afghan refugees and stigma:

Refugees often experience a higher prevalence of mental health issues due to the complex and traumatic experiences they endure. They face multiple problems like gender-based violence, lack of education, and discrimination while seeking treatment being refugees.

This specific community engagement activity was also attended by Dr. Mahdia who joined the CONTROL study team as Afghan national supervisor. She introduced herself to the female participants and shared her journey and hardships regarding life back home and her educational journey to encourage all to focus on the education of girls.

In the next half of the discussion, the stigma associated with both TB and depression was explained to participants in the best possible way by taking daily life examples as a reference for better understanding.

# Lived experiences of the community regarding depression

Over this topic, the ladies openly shared their experiences and it was encouraging for the team to identify many risk factors contributing to their mental health.

#### Verbatim as narrated by participant

#### **Participant 5:**





"Me and my family have experienced traumatic events such as conflict, violence, persecution, torture, or displacement when we were in Afghanistan. We were lucky to escape. Still, our relatives living there keep telling us the hardships they all face and we can help them. We even can't help ourselves as daily we feel helpless over so many things.

I see dreams of being killed and then I see myself running everywhere for help. I have a very disturbed sleep. I want my family to have a good home, money, and good jobs but I can only dream about it all. When I think more about this, I don't feel like talking to anyone. I want to close myself in the room and cry for hours. But then I think maybe it's my test in this world from the creator".

#### Participant 6:

"I am a young 24-year-old lady with so many dreams. I want to be like all of you. I wanted to be a doctor or teacher but all I do is make up. My father didn't let us go to school or college as he felt our minds would get corrupted. I used to feel sad about it all so to escape my thoughts I started doing makeup. I mastered my skills and now all the girls and ladies come to me for makeup when we have a wedding in camp. My father doesn't like it but I feel good that at least I am helping my ladies in some way. I now have a mobile, so I am trying to learn new skills. When I was not doing makeup, I used to be lost in my thoughts, and many a time I either wanted to end my life or wanted to run away. Although I still imagine, how life feels like while living in big cities".

# Participant 7:

I have been living as a refugee in this country for over 20 years. I got married at a young age and I came here with my husband and kids. Now my sons are working in other cities but I feel if they had facilities here, schools and colleges here, or at least someone to tell us the importance of education, our life would have been easy or different. I always feel outsider here.





Although people visit our camps, some give us food, some give us clothes or money but no one gives education to our children and men, or a good future. I feel sad for all the kids here. How would you feel, if your kids are playing in mud or dirt the whole day, and don't have any future or status? Getting sick is like a curse as we don't get good treatment. We don't want to go back to our country at all but many of us are living illegally here. We always live in fear of being sent back to our country and it blows my brain. I feel a headache and my heart is always racing over these thoughts. I get sweats when I imagine this. Sometimes I feel as if I am mad".

#### **Participant 8:**

"I am always angry. I beat my kids a lot. They are so small but even their noise makes me angry. My husband is not doing any work and I face hunger. But I can't beat him so I take out my anger on my kids. Even today before coming here, I was beating them and then I cried a lot that why I beat such small kids. So I ran to my neighbor's house. I don't know if I am sick or what, but I want to feel good. All the time I am worried, I avoid people, I keep thinking the whole day why I can't have a good life. I know I need help but who will help me".

The neighbor of the participant 8 was also sitting next to her. She added:

"I always run to her house to save her kids as she beats them all the time and then she cries for hours for beating them. Sometimes, she comes to my house like today after beating kids. We all have issues, but we are humans and weak, so this is the only way to remove the frustrations. We keep telling her to calm down but tensions keep piling up one after the other. Here everything needs money even health and sickness require money, but when you don't have anything in hand, both health and illness bring tensions".

#### Relaxation technique and coping strategies:

The female participants requested the team to share some do-able advice that can make them relax, uplift their moods, and help them overcome anxiety and stress. Saara Khan conducted





breathing and relaxation exercises and all the ladies participated actively. Being a psychologist, Saara also guided them to easy activities that they could do in their leisure time even as a group.

#### **Recommendations:**

- ➤ Like our previous experiences of interacting with Afghan refugees at Khazana refugee camp in Peshawar, here too the female refugees stressed organizing regular sessions to improve their mental health and to spread awareness regarding TB and other health issues.
- They also suggested training one or two girls from their camp regarding coping strategies for basic mental health issues, so they can help their community.
- The female refugees also asked the team to develop and share some basic videos regarding mental health issues related to awareness as almost everyone in the camp has a phone and they all understand the videos easily.

# **Conclusion:**

The session was concluded with a vote of thanks to all the participants from Dr. Saima Aleem and Saara Khan.





# Lest We Forget



**Group picture of CEI Team CONTROL at Paniaan Refugee Village** 





# **Team members:**

- > Dr. Saima Aleem (Khyber Medical University)
- ➤ Ms. Saara Khan (Khyber Medical University)
- > Dr. Mahdia (Khyber Medical University)
- ➤ Ms. Tuba Khan (Khyber Medical University)





# **Male Afghan Community**

**Engagement Report** 





#### Introduction

#### **Settings**

Paniaan Afghan Refugee Village is a significantly populated area of Afghan refugees in the district Haripur, which is located in one of the two study districts for the CONTROL program of research.

#### **Participants:**

The workshop was attended by 30 refugee males aged 20-70 years, including male religious scholars, area counselors, refugee residents, TB patients, caregivers, and their family members. The participants belonged to different socio-economic groups and varied in terms of education. Among the participants, a few were shopkeepers, drivers, and community workers.

#### **Facilitator:**

CONTROL study PIs Prof. Saeed Farooq and Dr. Zohaib Khan joined the activity along with Dr. Zeeshan Kibria (Manager CONTROL), and CONTROL CEI team members Mr. Asad Ullah, Ihsan Ullah, and Mr. Ihtisham ul Haq.

# **Workshop proceedings:**

# **Opening of activity:**

The activity started with the recitation of the Holy Quran by a religious scholar, followed by the introduction of the CONTROL project by Dr. Zohaib Khan. This was followed up by sharing the purpose and aims of the CEI activity





#### All about tuberculosis

Dr. Zohaib then explained TB's signs and symptoms and details regarding how to treat it. He also mentioned his intent to set up a free clinic. This was followed by group discussions with the participants and eliciting their views on tuberculosis and mental health in general.

Prof. Saeed Farooq mentioned to the community members that "we all are interested to hear

your stories about tuberculosis if you could share experiences any involving their siblings, relatives, or friends who contracted TBthe and challenges they faced in seeking treatment.



Additionally, we'd like to know about the mental health issues they encountered".

#### Verbatim as narrated by male Afghan Participants

#### **Imam (Religious Scholar):**

"Allow me to begin. There's a story from the time when the Sahabas (Prophet Muhammad's companions) were with Prophet Muhammad SAW. One Sahaba noticed a camel in a group of animals that was unwell. Upon this, Muhammad SAW instructed to isolate the sick camel from the others to prevent the spread of infection. When asked who caused the camel's illness, the Sahaba responded, "Allah." Muhammad SAW emphasized the importance of caution, indicating that while Allah may cause illness, everyone must take precautions.

Similarly, when someone in a family gets TB, they often face mental health challenges due to the stigma associated with the disease. This stigma can exacerbate their health condition as





they dwell on their illness excessively. Additionally, there's a belief among elders that TB bacteria can persist in the environment for extended periods. Therefore, everyone must be aware of TB's signs and symptoms.

Muhammad SAW always prioritized his people's well-being; likewise, professionals like doctors and engineers should focus on the welfare of their communities. By spreading awareness, we can ensure that accurate information reaches every corner of society. Recently, I visited a patient who expressed fear of impending death. This highlights the mental health aspect of TB, underscoring the need for holistic care. A wise scholar once said, "Engaging in various activities can improve mental health." Hence, it's vital to address both physical and mental well-being to combat TB effectively".

Professor Saeed appreciated his point and mentioned that staying positive is a major contributor to improving mental health. If we control the negative thoughts and keep ourselves occupied



with some good engaging activities, we can improve both physical and mental health.

The religious scholar further added:

"Let me tell you a story from when I was

studying in a religious school. There was a shepherd who was feeling stressed and couldn't eat properly. He asked me to make a special necklace for him to help keep the stress and evil eye away. Normally, he'd take bread with him but hadn't been able to eat it for three months





because of his stress. So, I gave him a blank piece of paper to wear as a necklace, and suddenly, he could eat his bread again. It's like his mind changed for the better. We should all try to do things that make our brains work better. It's more like brain-shaping".

#### To this, Dr. Zohaib added:

"We're working on a project about spiritual blessings and healing. All we want is to help people in our community either by giving medical treatment or spiritual healing in its true spirit".

# Lived experiences of community:

#### **Community Member:**

"in our community language, we call TB "Nary-Ranz" or "cell-maraz" or Sal-maraz". My father had TB a long time ago and since we are refugees, initially it took us time to understand that he is having a serious issue because many times we take cough as being nothing serious. Wethan faced many difficulties in getting his treatment and it took a while for him to recover and during all this, his hearing was badly affected".







# **Mental Health & Depression:**

Prof. Saeed highlighted the importance of timely diagnosis and treatment of mental health issues and encouraged the participants to talk about it and seek advice or treatment rather than being shy and trying to hide the condition.

#### **Response of Community Regarding TB and Mental Health:**

Almost all the participants mentioned that life being a refugee is tough and lack of education, unemployment, and fear of being sent back to our country create an even more depressing environment for all of them. They mentioned that every other community member is taking antidepressants.

The team found the community's response encouraging, as they began to address misconceptions surrounding depression as the session moved on. It became evident that mental health is just as vital as physical health. People came to understand that mental well-being is important at every stage of life, from childhood to adulthood.

By discussing common mental health disorders and their symptoms, participants became aware that when mental health deteriorates, it can make individuals more susceptible to certain physical health issues but at the same time they have to develop their resilience to address these challenges.

#### **Conclusion:**

Community members actively joined the session and offered their wholehearted support to the research team and anyone facing TB or mental health issues. The male participants expressed thanks to the CONTROL PIs & CEI team for taking time out to visit them and listen to their narrative as they need utmost guidance to address their issues more effectively.





They also recommended organizing regular sessions to increase awareness about this disease. It was suggested that people should be trained on how to care for patients within families, and the community should offer support to all such patients and their caregivers.





# **Team members:**

#### **CONTROL PIs:**

- Prof. Saeed Farooq
- > Dr. Zohaib Khan

# **CONTROL Manager:**

> Dr. Zeeshan Kibria

# **CONTROL CEI Team (Male)**

- ➤ Mr. Asad Ullah (Khyber Medical University)
- ➤ Mr. Ihtisham ul Haq (Khyber Medical University)
- ➤ Ihsan Ullah (Khyber Medical University)





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

# **COMMUNITY ENGAGEMENT INITIATIVE**

Date: 12th February, 2024

Area: Paniaan Refugee Village, Haripur, KP.

Time slot	Topic/title	Resource person
11:00 am – 11:05 am	Recitation of the Holy Quran	Religious Scholars
11:05 am – 11:10 am	Welcome note and Introduction of	Dr. Zohaib Khan (male
	participants	side)
		Dr. Saima Aleem (Female
		side)
11:10 am – 11:20 am	Infectious disease burden in Pakistan	Dr. Zohaib Khan (Male
	(specifically TB) and in Khyber	side)
	Pakhtunkhwa.	
	Aim & objective of the Community	Dr. Saima Aleem (Female
	Interaction, the importance of	side)
	community engagement in improving	<b>\</b>
	healthcare delivery and access.	
11:20 am – 12:00 pm	Lived experiences of the	ne community
12:00 am - 12:20 pm	Overview of mental health disorders	Prof. Saeed Farooq (Male
	in chronic diseases and TB	side)
	Mental health disorders prevention	
	and treatment, the role of community	Ms. Saara Khan (Female
	in advancement of research and	side)
10.00	project-specific research activities.	101 001
12:20 pm – 12:30 pm	Speech by the community	Afghan Male Social
	representative (social mobilizer)	Mobilizer (Male)
		A.C.1
		Afghan Female social
10.20 10.40		mobilizer (Female)
12:30 pm - 12:40 pm	Speech by the religious representative	Imam Masjid (Male side)
	(Imam Masjid)	Religious Scholar (Female
10.40 10.45	X C C I	side)
12:40 pm - 12:45 pm	Vote of thanks	



