Enabling local response to build bridges for research with communities affected by Multidrug-resistant Tuberculosis in Pakistan

Mehek Ali
endTB Clinical Trials

- **Two Randomized, controlled, open-label, Phase III trials** evaluating the efficacy and safety of **shorter treatment regimens** containing newer and re-purposed drugs for MDR-TB

- **Countries**: Georgia, India, Kazakhstan, Lesotho, Pakistan, Peru, Vietnam, and South Africa

- **Study populations**: 1. **endTB**: Patients with rifampicin-resistant or MDR-TB that is **susceptible** to fluoroquinolones; 2. **endTB-Q**: Patients with rifampicin-resistant or MDR-TB that is **resistant** to fluoroquinolones

- **Enrollment Status in Pakistan**: 1. **endTB**: 102 enrolled *(recruitment completed)*; 2. **endTB-Q**: 101 enrolled *(recruitment ongoing)*
TB Survivor; Woman; 29 years old

“Even while I had TB, I didn’t know what this illness was… What its symptoms are, how it spreads, or any prevention methods…”
Community Action Groups

- Local Health Practitioners
- Caregivers
- TB Survivors
CAG Formation Process

- List of patients from TB program
- Patient interviews

Understanding Lived Experiences

Identifying Allies
- Nomination of focal persons
- Focal person interviews

Community Action
- Invitation to CAG
- Monthly meetings and activities
CAG Goals

1. Improve TB knowledge in local communities
2. Address stigma, garner support for TB patients and their families
3. Increase understanding of research amongst local populations, so that they may participate meaningfully
CAG Geographical Spread
## CAG Composition

<table>
<thead>
<tr>
<th>Gender</th>
<th>Members (Total)</th>
<th>TB Survivors</th>
<th>Caregivers</th>
<th>Health Providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combined</td>
<td>24</td>
<td>6</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Males</td>
<td>8</td>
<td>1</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>5</td>
<td>10</td>
<td>1</td>
</tr>
</tbody>
</table>
Goal 1: Improve Community Knowledge

- Trained on:
  - TB
  - Mental Health
  - COVID-19
  - Hepatitis C
  - Hypertension
  - Diabetes
  - Sexual and Reproductive Health

- Hosted 55 awareness sessions with 478 community members
- Linked to 12 local health providers

Goal 2: Address Stigma and Garner Support for People with TB

- Referred 44 people for TB Screening (6 [14%] diagnosed with DS-TB; 2 [4.5%] diagnosed with MDR-TB)
- Facilitated 14 X-Ray camps, resulting in over 1,000 people screened through community mobilization
- Distributed 154 ration bags to vulnerable community members
- Integrated with other public health programs, including COVID-19, mental health, and TB

Goal 3: Increase Understanding of Research in Community

- Consulted on:
  - endTB Clinical Trial(s)
  - Patient Orientation
  - Research protocols and consent forms
  - Rights of patients
  - Understanding new drug regimens and sub-studies

- Conducted exposure visit to study site
- Participated in self-assessment survey
- Participated in Focus Group Discussion for TB Active Case Finding study
TB Allies; Women; 28 and 48 years old

“Before being part of the CAG, I had no idea what a research trial is or what the importance of a consent form is!”

“Before [I joined the CAG] I used to feel really intimidated talking in front of people; my mind would go blank! But now I conduct community [awareness] sessions myself and answer people’s questions!”
Learnings

• To build a **sustainable decentralized model for TB care**, inclusion of **lived experiences and local voices** must be prioritized.

• A culmination of **patient-centered care** and **community-based support** will be drivers for **positive treatment outcomes** leading to政策 change.

• **Community engagement** must be integrated into program design and implementation to ensure putting **policy into practice**.
Thank You

CAG Members:

Authors: Mehek Ali¹, Meherunissa Hamid¹, Muhammad Shakeel¹, Komal Jaseem¹, Maryam Khan³, Muneeb Ahmed³, Momal Taimoor¹, Aqsa Jawed¹, Annum Aftab¹, Heba Mushtaque¹, Fariha Parvaiz¹, Kausar S. Khan¹, Aneeta Pasha¹, and Uzma Khan².

Institutional Affiliations: ¹IRD Pakistan; ²IRD Global; ³Indus Hospital & Health Network

Contact: mehek.ali@ird.global