

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

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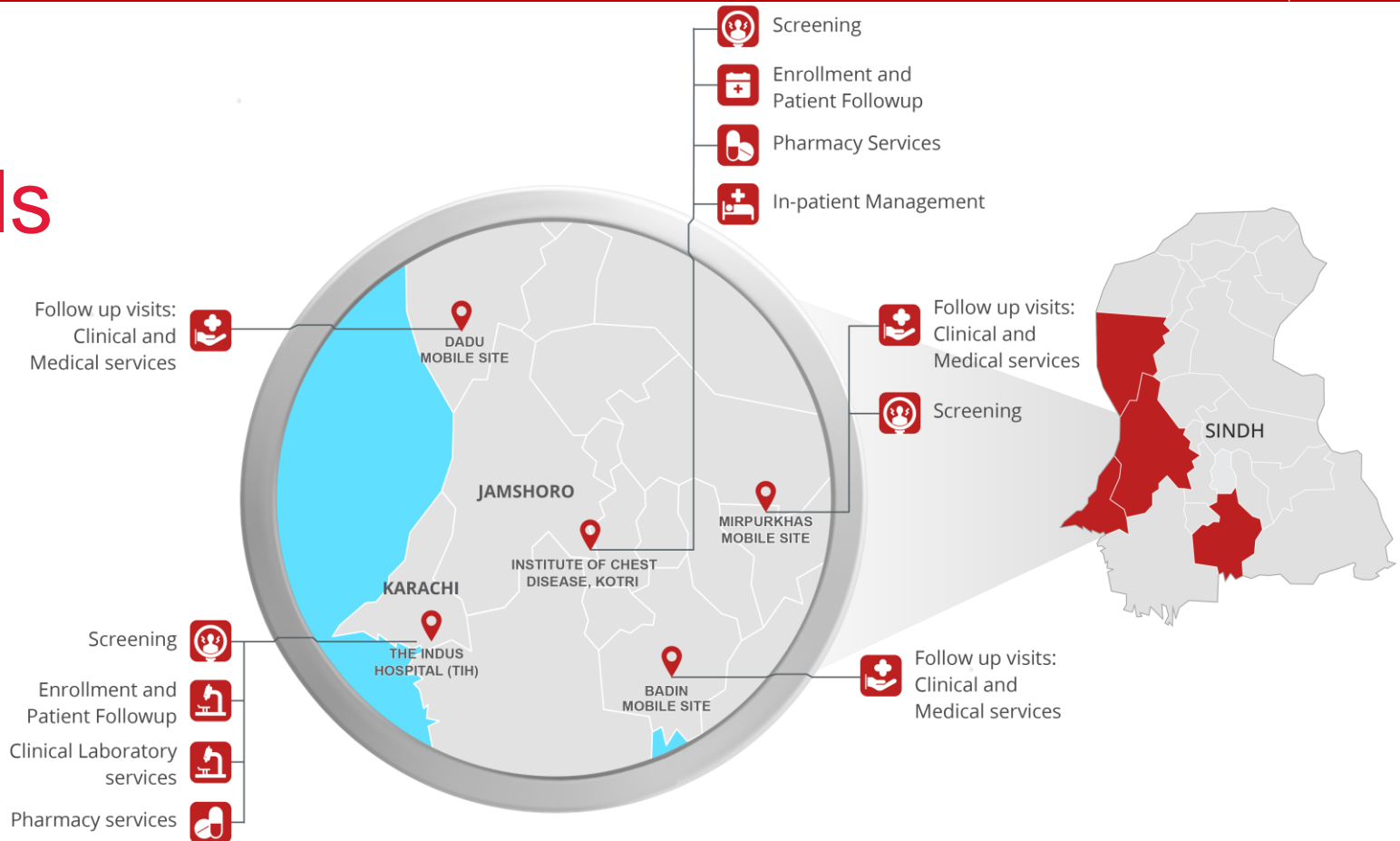


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endTB Clinical Trials

- **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*)

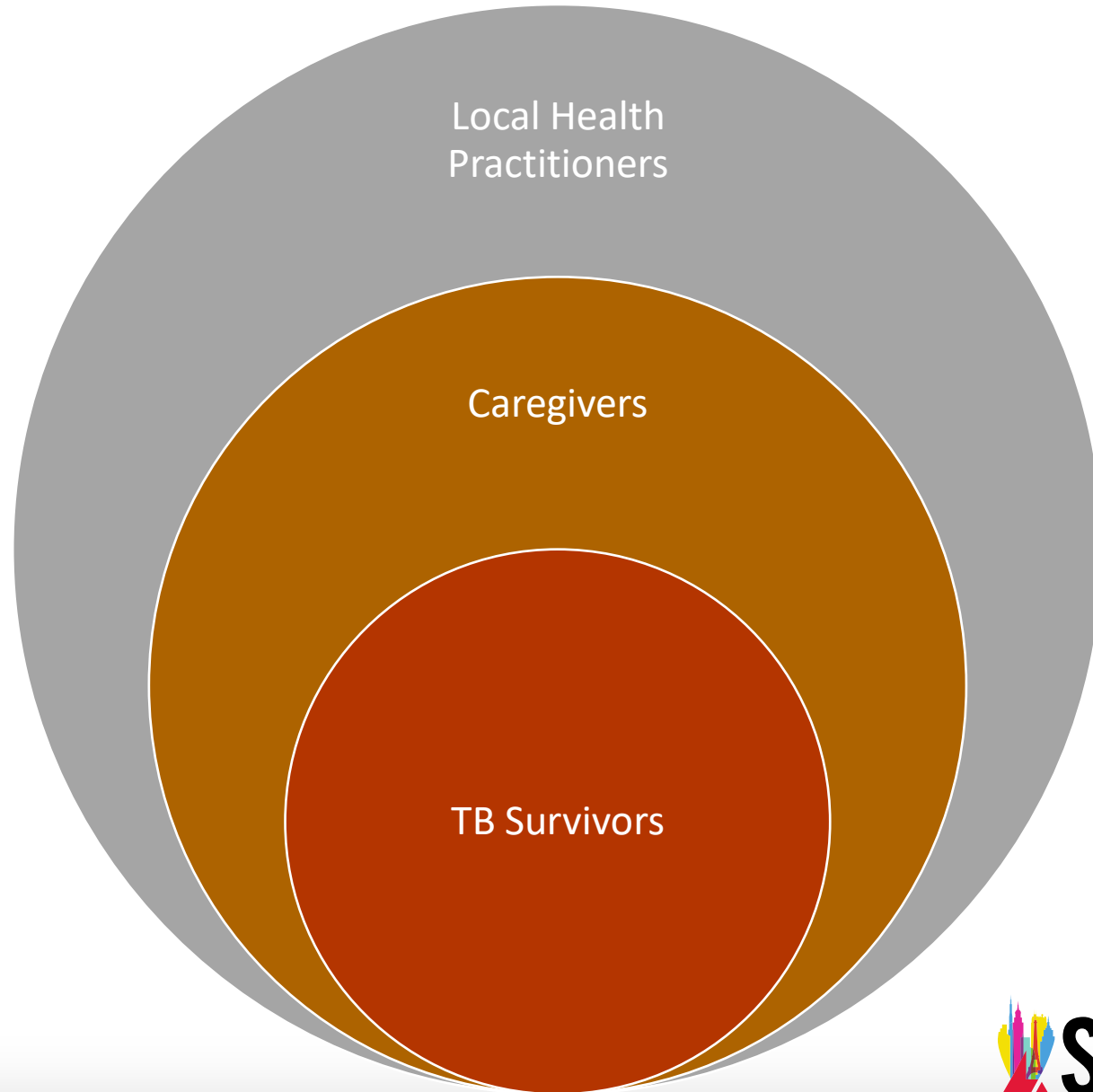


TB Survivor;
Woman; 29 years
old

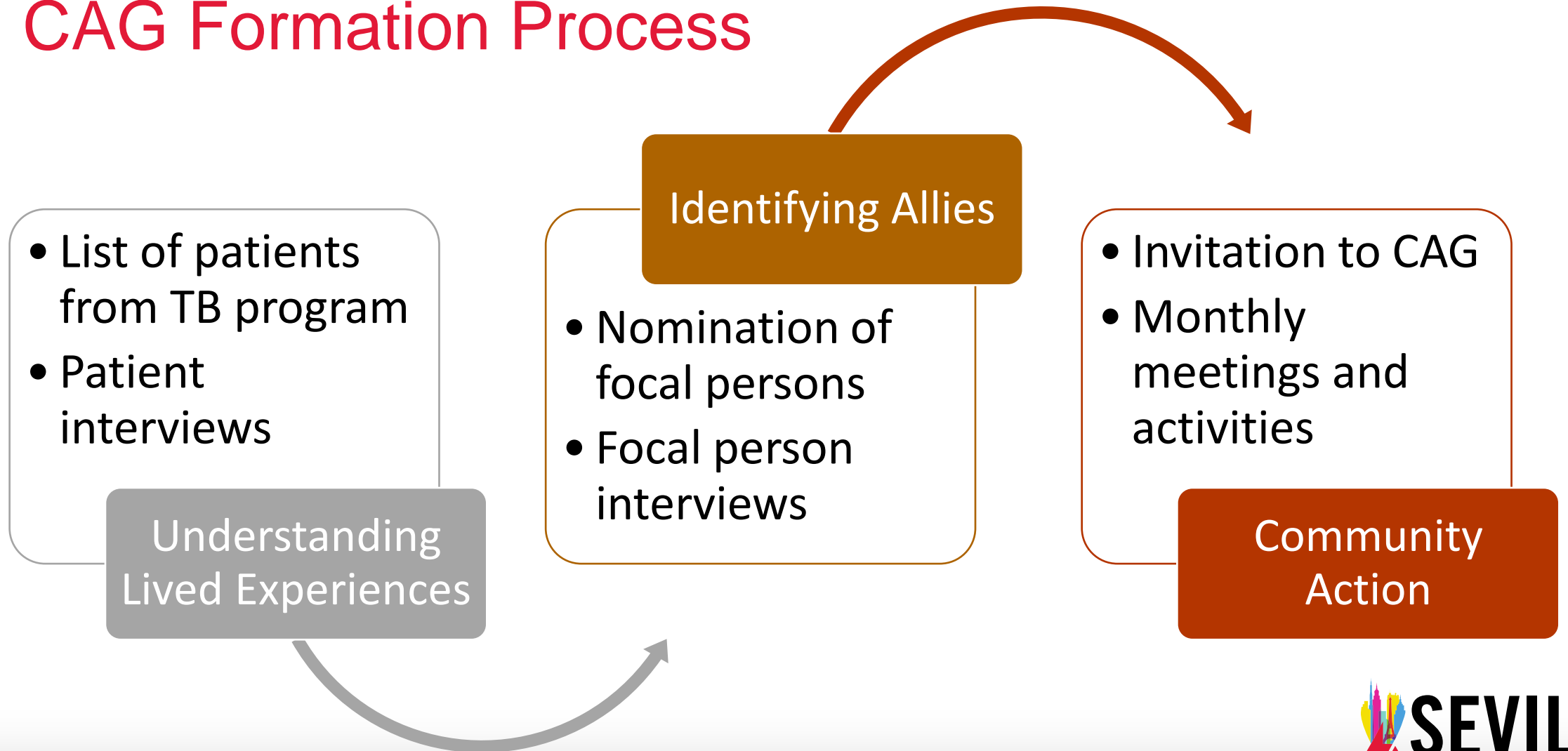
“Even while I had TB, I didn’t know what this illness was... What its symptoms are, how it spreads, or any prevention methods...”



Community Action Groups



CAG Formation Process

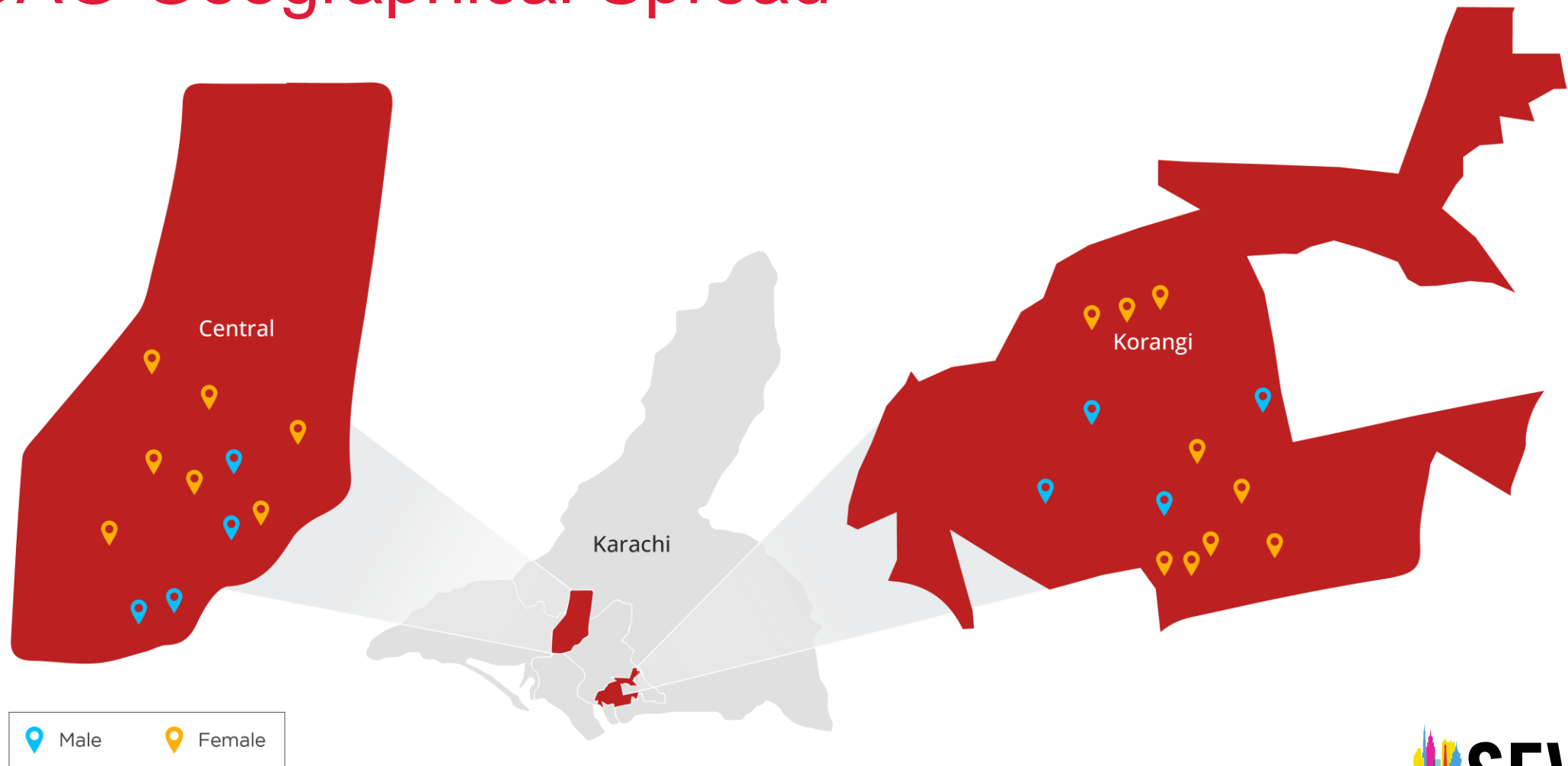


CAG Goals

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

Gender	Members (Total)	TB Survivors	Caregivers	Health Providers
Combined	24	6	16	2
Males	8	1	6	1
Female	16	5	10	1



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 policy change
- **Community engagement** must be integrated into program design and implementation to ensure putting **policy into practice**

Thank You

CAG Members:

Najab-ullah, Rehana, Hina, Ishtyaq, Saira, Waqar, Habib, Shameem, Sajida, Shama, Humaira, Safia, Tahira, Zunaira, Amna, Ghosia, Sakina, Rukhsar, Shadab, Imran, Shaista, Ishaq, Rabia, and Kiran.

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