COMMUNITY ENGAGEMENT:
COMMUNITY INVOLVEMENT IN THE TB DRUG DEVELOPMENT PROCESS

Having informed and engaged communities is one of the most critical components of conducting ethical clinical research. Through our Community Engagement (CE) program, TB Alliance works with people affected by tuberculosis to empower them with knowledge and skills to promote open communication and participation in the TB drug research being conducted in their communities.

Community Engagement builds and strengthens relationships between clinical trial researchers and local TB-affected communities, and helps ensure that community stakeholders, study participants, their families and others who may be affected by or at risk of TB infection have an opportunity to partner with the scientific community in the TB drug development process and in the implementation of research efforts.

Both researchers and community members participating in clinical trials benefit from open communication and mutual understanding of one another's goals and concerns. TB Alliance is committed to supporting the development of CE strategies at the research-site level, and to providing opportunities for community participation in clinical trials.

Community Engagement strategies can provide mechanisms for:
- educating communities about TB disease, treatment and the research process
- obtaining community input into clinical trial implementation
- understanding community perceptions and experiences, and identifying concerns so that they are addressed in the research process
- liaising with community leaders to facilitate smooth implementation of clinical programs
- dissemination of clinical trial and research results
- motivating communities to assist with advocating for policy and regimen change.
TB Alliance-Supported CE Programs

Community and Community Advisory Board (CAB) engagement in clinical research emerged as a gold standard of practice in HIV prevention trials over the last 20 years. The model of forming CABs to represent the community has become an important element of CE program strategies that help to ensure community concerns and feedback are shared with research teams.

TB Alliance supports the development and management of research site-level CE strategies through a Small Grants Program, which was established in January 2007. Funding, as well as guidance and technical assistance, is available to sites participating in TB Alliance late-stage clinical trials (such as REMox TB and NC-002). The organization supports the implementation of individualized community engagement strategies. CE activities at each site vary from the establishment of formal CABs, to organizing workshops and trainings on TB drug research, to large-scale public education and awareness campaigns.

Community Engagement: Building Capacity

CABs are comprised of community members involved in local leadership, social services, or healthcare delivery, and are provided the tools they need to be informed, active, and meaningful participants in the research and development of new tuberculosis treatments. A priority of the TB Alliance Community Engagement program is to provide research literacy training and facilitation skills to all CE program staff and CAB members participating in community education about TB disease and research. Through the research literacy training program, Community Engagement teams and communities are becoming more knowledgeable about TB drug research, and are better able to participate in discussions about clinical trials and the development of new TB regimens.

In addition to knowledge, training, and skills building, the TB Alliance is also committed to providing opportunities for cross-site engagement and learning through a series of Community Engagement Forums. Because CE strategies vary from site to site depending on the needs of the local community, it is beneficial for CE teams to be able to share strategies with each other, learn from common challenges, and develop solutions.

Each Community Engagement program is unique. Community members are encouraged to take the lead in determining the program’s structure and activity to ensure that each program is best suited for the site and the local community, with input from TB Alliance and other advisors with relevant experience and knowledge. TB Alliance also engages stakeholders in nations and regions involved in research and clinical trials to ensure the highest ethical standards are met and that our programs continually raise the bar for community involvement within the drug development process.

For more information on TB drug development and TB Alliance, please visit www.tballiance.org.

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