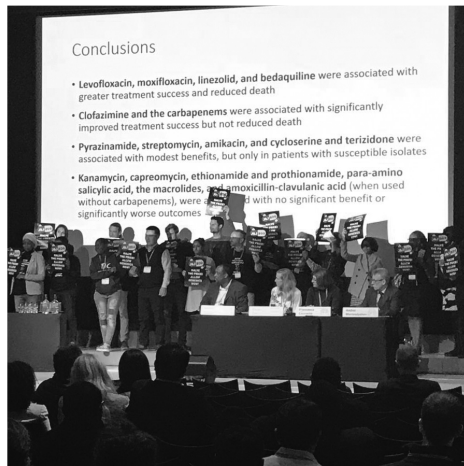


## 10-Year Anniversary Evaluation Report 2011-2021

March 2022  
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# Executive Summary

## BACKGROUND

In 2011, the Global Tuberculosis (TB) Community Advisory Board (TB CAB) was created to act in an advisory capacity to product developers and institutions conducting clinical trials of new TB drugs, regimens, diagnostics, and vaccines, and to provide input on study design, early access, regulatory approval, post marketing, and implementation strategies. To help mark and celebrate the 10-year anniversary of the TB CAB's founding, Treatment Action Group (TAG) undertook an independent evaluation of the evolution, reach, and impact of the TB CAB.

## PRIMARY OBJECTIVES

1. To reflect on how far the TB CAB and the field of TB community engagement have come in the past 10 years;
2. To measure and articulate the TB CAB's impact and influence; and
3. To document lessons learned and areas for further development that can help inform the TB CAB's approach to the next decade of community engagement in TB research.

## DATA SOURCES AND METHODS

This 10-year evaluation used a mixed-methods approach, with evaluation steps completed from June to October 2021. A document review was conducted and a natural language processing tool developed to quantify language in key documents, including terms of reference; work plans; correspondence with investigators, policymakers, and other global and national health actors and implementors; position statements; and public comments. The language processing tool was used to support evaluation findings through word frequency counts by year and document type.

For the qualitative analysis, 40 perspectives were sampled from two focus groups, three group interviews, and 25 key informant interviews with current and former TB CAB members and other stakeholders. This was followed by a quantitative survey to confirm findings from the interviews and develop evidence-based recommendations. An institutional review board (IRB) reviewed this evaluation project and declared it to be "Not Human Subjects Research." Four key findings are summarized below, with illustrative quotes and quantitative survey findings further detailed in the main body of the report.

## KEY FINDINGS

### KEY FINDING #1:

#### A SEASONED TECHNICAL PARTNER

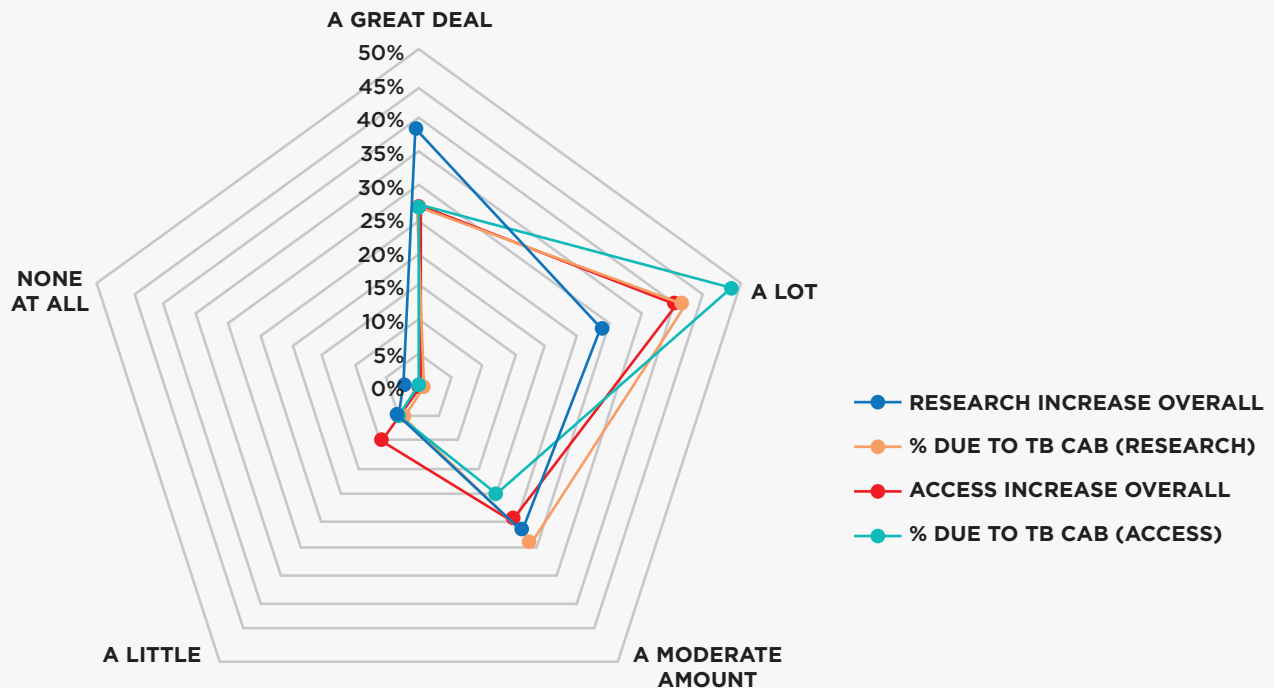
Over time, the TB CAB has successfully stepped into the role of a seasoned technical partner, with its members considered *scientific advocates* who provide community perspectives on TB research and development (R&D) at the global level. There was uniform appreciation and understanding of the TB CAB members' technical expertise as being central to successful engagement. There was also strong agreement across stakeholders on the specific purpose of the TB CAB, which is twofold: 1) to elevate and center consideration of community perspectives, needs, and priorities in TB R&D, and 2) to hold the powerful (research sponsors, funders, investigators, and implementers) accountable. Survey data confirmed the successes of the TB CAB in these areas, with 73% of respondents saying that the TB CAB has had "a lot" or "a great deal" of impact over time on elevating community voices in TB research, and 76% saying the same for elevating community voices in the translation of research to policy.

**KEY FINDING #2:  
AN AGENT OF CHANGE IN TB R&D**

Key informants were asked to assess how the TB CAB has influenced/changed TB R&D, and survey questions were constructed to assess how much of the overall changes in the TB field could be attributed to the TB CAB. Both data sources describe the TB CAB as **an agent of change in TB R&D** that has effected a “profound shift” in how community engagement is valued by decision makers in the TB R&D space. The survey sought to quantify these changes by asking how much community engagement changed in TB research overall in the TB CAB’s first decade, and how much of the increases could be attributed to the TB CAB. Sixty-seven percent of respondents said

that “a lot” or “a great deal” of the increases in community engagement in TB research were due to the TB CAB. The survey included a similar set of questions for community engagement in promoting access to TB prevention, diagnosis, and treatment innovations; 76% of respondents said that “a lot” or “a great deal” of the increases in community engagement in TB access issues could be attributed to the TB CAB (Figure 1). In terms of specific impact on clinical trial design, researchers in particular felt that the TB CAB played an instrumental role in pushing for the inclusion of vulnerable populations in clinical trials, especially children, which resulted in rapid uptake of recommendations for global pediatric treatment guidelines.

**FIGURE 1. INCREASES IN COMMUNITY ENGAGEMENT IN TB, 2011-21**





### **KEY FINDING #3: A RANGE OF PROVEN ADVOCACY METHODS AND TACTICS**

The TB CAB operates on the principle that activism plays a key role in accelerating public health innovation and improving the design, inclusiveness, and relevance of research studies. As described above, the TB CAB is recognized for its valuable and scientifically rigorous engagement, and most stakeholders expressed positive emotions, from satisfaction to great appreciation, for the TB CAB's work in study design and protocol review. Where feedback was less positive, and at times critical, was around the escalation techniques employed to hold research and product sponsors and policymakers accountable, particularly when community perspectives are either being ignored or undervalued. The CAB has historically followed an **escalation pathway** that allows the CAB to move from closed discussions to open letters and sometimes demonstrations to highlight community perspectives and priorities and to effect change. This defined pathway, which has been effective in historical and current activist movements, underwrites the TB CAB's ability to mobilize allies and apply public pressure after other avenues of influence are exhausted.

### **KEY FINDING #4: AN EQUAL SEAT AT EVERY TABLE**

All key informants were asked for their ideas on outcomes that might help the TB CAB to track impact, and for advice for the next decade. Just as there was a general and clear understanding of the TB CAB's purpose and impact on TB R&D, there is general, clear consensus that the TB CAB

should focus on increasing access points for the community to be part of the TB R&D process. Sharing resources for community advocate capacity building on TB R&D and facilitating connections among community advocates and key R&D decision makers were suggested as means to ensuring the incorporation of community voices at all stages of the R&D process. The survey confirmed the consensus that grassroots capacity building should be an important part of the next decade of the TB CAB's work: 73% of respondents said that the TB CAB should definitely invest time and effort in capacity building/training/networking with more national and subnational community and civil society groups. Other suggestions for increasing community access points in the TB R&D process include advocating for a "full vote" for community in the next large TB initiatives and for earlier engagement of communities in TB research agenda development and funding discussions.

## **CONCLUSIONS**

The findings of this evaluation reveal significant changes in how community voices have been elevated in TB R&D over time, with a great deal of change attributed to the TB CAB. Collectively, the key findings of this evaluation indicate a "transformative change" that has disrupted power dynamics on multiple levels in a way that has reshaped the overall environment of TB R&D. Through the TB CAB's work, TB survivors and advocates have more power in decisions about research and policies that guide national TB programs, which ultimately affect entire communities.

Collectively, the key findings of this evaluation indicate a "transformative change" that has disrupted power dynamics on multiple levels in a way that has reshaped the overall environment of TB R&D.

## RECOMMENDATIONS

- 1. Maintain Scientific Advocate and Technical Partner as Core Identity.** The TB CAB should work to maintain its core identity as a seasoned technical partner that raises community voices in TB R&D and holds the powerful to account. The diversity of advocacy tactics used by the TB CAB is tied to its ability to hold the powerful to account. To ensure that its core identity is maintained, the TB CAB should continuously invest in the development of its members' TB knowledge and technical expertise, as well as expand its connections to local community and civil society groups whose allyship is critical in holding key decision makers to account.
- 2. Increase Access Points for Community in TB R&D.** The TB CAB should consider mechanisms for making existing technical and networking resources available to other community groups and establish more formal mentorship and pathways through which information from global conversations can be more regularly transmitted to grassroots organizations, and vice versa.
- 3. Revisit CAB Strategies for TB Diagnostics and Prevention.** The first decade of the TB CAB's work focused on treatment research and access to new medicines and diagnostic technologies. Expanding this focus in the next decade to include TB vaccines and diagnostics research may require new skills and/or strategies.
- 4. Clarify Operations to Build Confidence.** Based on evaluation findings, the TB CAB has an opportunity to articulate its operating model more publicly in a way that facilitates interactions with new stakeholders and helps them better understand when to approach the TB CAB and what to expect from these interactions, which may help to build confidence and trust over time.

# Background

In 2011, Treatment Action Group (TAG), along with other stakeholders in tuberculosis (TB) product development and access, identified the need for the TB research community to benefit from strong, research-literate community activists. As a result, the Global TB Community Advisory Board (TB CAB) was created to act in an advisory capacity to product developers and institutions conducting clinical trials of new TB drugs, regimens, diagnostics, and vaccines, and to provide input on study design, early access, regulatory approval, post marketing, and implementation strategies. To help mark and celebrate the 10-year anniversary of the TB CAB's founding, TAG undertook an independent evaluation of the evolution, reach, and impact of the TB CAB.

## OBJECTIVES

- 1. To reflect on how far the TB CAB and the field of TB community engagement have come in the past 10 years;**
- 2. To measure and articulate the TB CAB's impact and influence; and**
- 3. To document lessons learned and areas for further development that can help inform the TB CAB's approach to the next 10 years of community engagement in research.**

## DATA SOURCES AND METHODS

This 10-year evaluation involved a mixed-methods approach, with evaluation steps from June to October 2021. The evaluator used a document review, qualitative interviews, and a quantitative survey to confirm findings and develop evidence-based recommendations. The Johns Hopkins School of Medicine IRB reviewed this evaluation project and declared it to be "Not Human Subjects Research."

## DOCUMENT REVIEW

The TB CAB's work over the past decade has involved a variety of strategies for engaging TB R&D funders, product developers, researchers, and policy

makers, utilizing public and private letters, open and closed meetings, protocol reviews, and other forms of correspondence (including scientific conference submissions, presentations, and publications, and public statements and testimony). Taken as a body of work, the documents represent a contextual canvas that is complementary to the other evaluation activities. To provide a mechanism for evaluating the document contents, the evaluation project intern developed a natural language processing (NLP) tool that extracted text from the documents and applied a series of natural language processing techniques to it.

Approximately 600 documents were included in the analysis. These were first categorized by document type (e.g., public statement, internal/operational, etc.), and then by primary focus area (e.g., drugs, regimens, diagnostics, prevention, etc.). The file's year was appended to each document. The NLP techniques removed punctuation, newline characters and stop words; normalized white space; and reduced all the words to their root form. This was done to make sure that the key ideas got through and were not obfuscated by language differences (e.g., "book" and "books" express the same idea, but computers are unable to recognize

this without the processing of natural language text). Subsequently, the processed text was organized by document type and year, and a cloud-based graphical interface was developed to provide easy access to the data and quick visualization creation. The NLP tool has been used in the analysis to review how quantification of key terms relates to key findings. The final cloud-deployed product is available online, with access to be provided per the TB CAB's discretion.

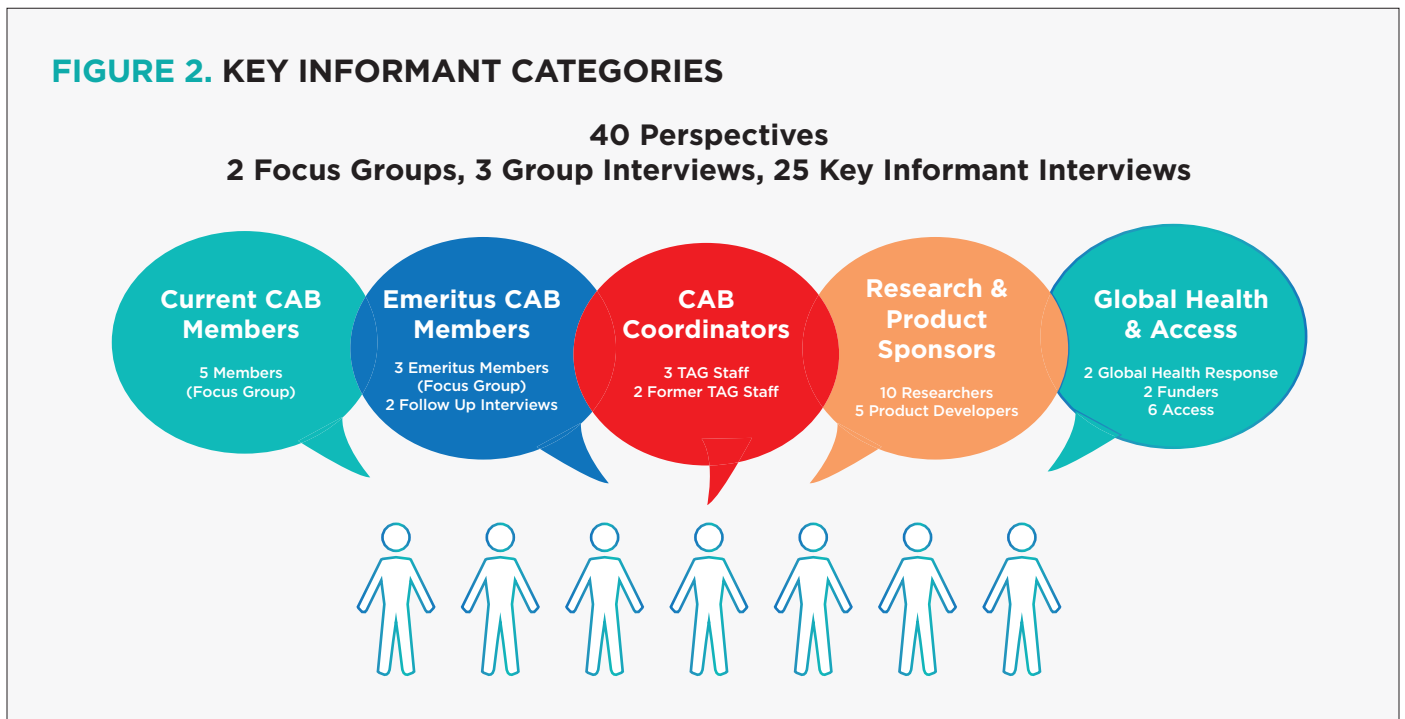
### QUALITATIVE INTERVIEWS

A case-study approach was selected to provide an in-depth exploration of the TB CAB in the context of its first decade of work. To develop a holistic view of the impact of the TB CAB across the domain of TB research and development, seven groupings of stakeholders were invited to participate in qualitative interviews (see Figure 2; a list of institutional representation is at the end of the report). Purposive sampling was used to recruit participants, with a contact list provided by TAG for information-rich cases who had interacted with or been part of the CAB from 2011 to 2021. Forty perspectives were sampled

from two focus groups, three group interviews, and 25 key informant interviews from July 2021 to September 2021. This large sample size was pursued to provide the best opportunity for data saturation given the range of stakeholder types and length of evaluation coverage.<sup>1</sup>

All interviews were moderated by the same person for standardization. The interviewer used defined research questions around the purpose and impact of the TB CAB, as well as exploratory questions around operations, indicators, and recommendations that were nondirective. Participants were also encouraged to add any other reflections on the TB CAB's first decade and next decade of growth. All interviews were recorded and de-identified during the transcription process.

Thematic content analysis was used to analyze the focus group discussions and key informant interviews using steps developed by Graneheim and Lundman.<sup>2</sup> Inductive analysis for initial coding, with triangulation of data by stakeholder type (perspective triangulation), and deductive coding to test and affirm the appropriateness





of the inductive content analysis was used. For the purposes of describing the impact of the TB CAB and future directions, four primary findings are presented with supporting evidence from the quantitative survey and document review.

## SURVEY

To further evaluate emerging themes from the qualitative interviews, a quantitative survey was developed and distributed to the key informants and more widely via TAG’s TB listservs and networks. A screening question at the beginning of the survey asked respondents if they had enough personal knowledge of the TB CAB to complete a series of questions. Survey questions included assessment of attribution for changes in community engagement in TB R&D, a brief analysis of TB CAB strengths and weaknesses, and questions about TB CAB processes and suggestions for the future.

The survey was distributed through an anonymous Qualtrics software link to listservs and to the key informants in September 2021, with all data analyzed in aggregate. A total of n=53 respondents initiated the survey (see Table 1 for additional survey respondent data); however, for the purposes of this report, key findings from the survey are presented as percentages in text alongside results of the qualitative interviews (see Appendices for the Interview Guide and Survey Questions).

**TABLE 1. QUANTITATIVE SURVEY RESPONDENT CHARACTERISTICS**

<b>Total number of responses</b>	<b>53</b>
<b>Total countries represented</b>	<b>21</b>
<b>Currently work in TB</b>	<b>52 (98%)</b>
<b>How much have you interacted with the TB CAB?*</b>	
• A great deal	19 (39%)
• A lot	10 (21%)
• A moderate amount	16 (33%)
• A little	2 (4%)
• Not at all	2 (4%)
<b>How many years have you interacted with the TB CAB?</b>	<b>6 years (average, range 0-11)</b>

\*Not all questions were required, so denominators changed based on attrition

## EVALUATION FINDINGS IN CONTEXT

As early as 2000, global health actors in the TB space had recognized the need to “summon some activism to more effectively achieve their mission.”<sup>3</sup> Still, stakeholders were slow to engage with community, even as global deaths due to TB were on the rise.<sup>4</sup> Early activists in the TB space described advocacy as “very lonely work” being done at the height of the collision of the co-epidemics of TB and HIV.<sup>4</sup> At the same time, large TB initiatives were recognizing the need to incorporate advocacy into their efforts to “bring about support and resources for this initiative, and to ensure its products reach all patients.”<sup>5</sup>

In 2009, TAG identified the need for the TB research community to benefit from strong, research-literate community advocates (because of the emergence of new candidate diagnostic tools and anti-TB drugs and regimens in clinical development). In HIV, structures such as the AIDS Treatment Activists Coalition (ATAC) and its Drug Development Committee (DDC) in the U.S., the European Community Advisory Board (ECAB), and the World Community Advisory Board (World CAB) of the International Treatment Preparedness Coalition (ITPC) had been developed to help ensure that research evaluating new tools and approaches would address community priorities. These global efforts in HIV built on the legacy of the U.S. National Institutes of Health (NIH) CAB program, which has incorporated people living with HIV and their advocates in every stage of HIV research continuously since 1990. At the time, parallel structures in TB did not exist. TAG started working with activists and subsequently conceptualized the Global TB CAB as a body that could act in an advisory capacity to institutions conducting clinical trials of new TB drugs, regimens, and vaccines, and provide input on study design, early access, regulatory approval, post marketing, and implementation strategies.

In 2011, when the TB CAB was first convened, involving community representatives in TB R&D was not common. While community engagement was “a well recognised component of tuberculosis prevention and care programmes . . . concerns have been expressed that community efforts are regarded and resourced as supplementary, instead of central, to the tuberculosis response.”<sup>6</sup> There was a call to develop a “credible evidence base” to document the value of community engagement in research so that it might become a part of standardized practice. The findings of this report contribute to that evidence base by quantifying and describing how the TB CAB has affected TB R&D over time.

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## TB CAB OPERATIONS

In addition to the above summary on context for interpreting key findings, readers may find publicly available information on the TB CAB’s operations and engagement processes online. The TB CAB has maintained a website for the past 10 years that describes in general terms information about the TB CAB’s purpose and the governance process. The site also hosts the TB CAB’s position statements and a link to its current Terms of Reference document, which fully describes the TB CAB’s mission, functions, and priority advocacy issues for the current work plan (at the time of this evaluation, covering years 2020–23).

The Terms of Reference document also describes member profiles and processes for recruitment of new members; this information has been provided with the aim of making the composition, aims, and independence of the TB CAB a transparent part of its public identity. In addition, there has been an intentional focus on having TB CAB members from high-TB-burden countries; TB CAB chairs over the past decade have included TB activists from Côte d’Ivoire, Peru, and South Africa. Technical leads included activists from South Africa and Kenya. A total of 37 people from 18 countries have served on the TB CAB over the past decade, with representation from all BRICS countries (Brazil, Russia, India, China, and South Africa). The TB CAB has monthly calls and before the COVID-19 pandemic met twice per year in person. During these calls and meetings, the agenda is typically focused on capacity building, specific protocol reviews, advancing initiatives or activities that are part of the TB CAB’s work plan, and discussions with research and product sponsors.

# Key Findings

Four key findings from the qualitative and quantitative assessments are summarized below, with illustrative quotes and survey findings detailed in each section.

## KEY FINDING #1: A SEASONED TECHNICAL PARTNER

### SCIENTIFIC ADVOCATES

Over time, the TB CAB has successfully stepped into the role of a seasoned technical partner that provides community perspective in TB R&D at the global level **as a scientific advocate**. The process for building technical expertise has involved intentional training over time, using targeted resources to develop a fundamental understanding of R&D processes, and exposure to R&D experts at the global level. There was uniform appreciation and understanding of the TB CAB members' technical skills as being central to successful engagement:

*It's just . . . amazing to see that as a scientific focus. We focus on one specific area, and we tend to forget about the other aspect of the patients. And then having a TB CAB looking at the protocol [from] the eyes of the patients and said, All right, this is something—it just made the protocol much more stronger. So it has been a valuable input. I really, I will tell it a different way: I'm not that not biased, but it has been very, very positive. **Research Funder** – 1013*

*I have been really, really, impressed by their singularly well focused and thoughtful input on protocols that we've shared with them, both on considerations for you know, changes, and also for practical thoughts on how we can actually operationalize those changes when they're really tricky. And I say singularly because honestly, it's better than the feedback*

*we get from the Scientific Advisory Committee for a particular set of projects, better than, you know, the DSMB [Data and Safety Monitoring Board]. **Researcher** – 1015*

All key informants were asked to define the purpose of the TB CAB to gauge whether there is a clear understanding of why the CAB exists, and whether the TB CAB's purpose has been met. There was strong agreement across stakeholders on the specific purpose of the TB CAB, which is twofold; 1) to elevate and ensure consideration of community perspectives, needs, and priorities in TB R&D, and 2) to hold the powerful accountable.

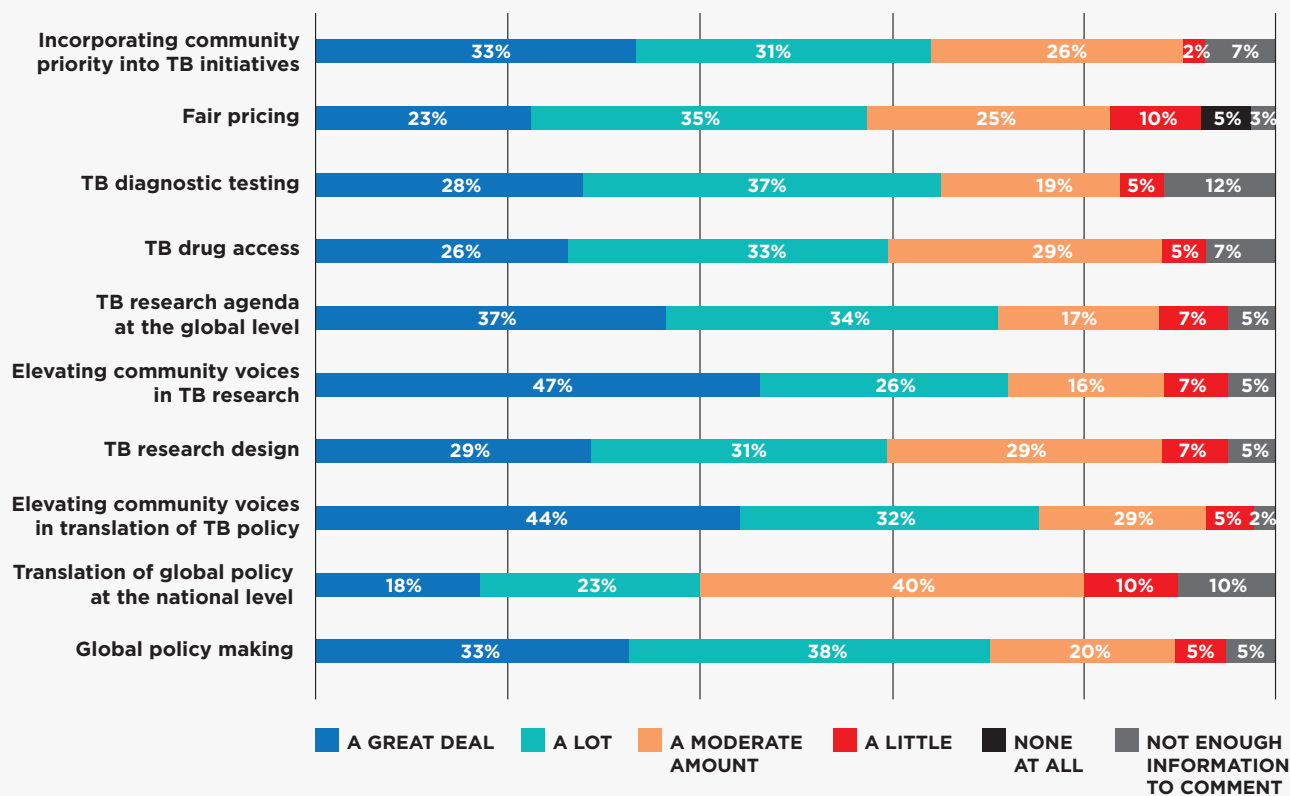
### COMMUNITY VOICES IN TB R&D

All of the key informants highlighted the primary role of bringing community voices into the TB R&D process. While this may be seen as a more normative role of a community advisory board, the specific success of the TB CAB has been to bring those voices to global-level conversations, where they had previously been absent.

*We cannot deny that the high level of global level work also contributes to what trickles down at the ground. And it is very important to have that aspect because then those voices go unheard. And even at the high level, the policies would not be cognizant of the needs of people in society [without the CAB]. **Access** – 1014*

*The purpose of the CAB has really been to bring together, to try to centralize, a lot of the community representation ... I think, ultimately, it's a global problem. And so you want to have*

**FIGURE 3. HOW MUCH IMPACT HAS THE TB CAB HAD OVER TIME?**



*this sort of global level strategy and probably cohesion of messaging. So the way I see it, is that it's to bring all of these groups together under one umbrella to, you know, share information, their best practices, and to align ... on some global messaging that is applicable across different regions. **Product Developer** - 1020*

Survey data confirmed these findings, with 76% of respondents saying that the TB CAB has had “a lot” or “a great deal” of impact over time on elevating community voices in translation of TB research into policy, and 73% saying the same for elevating community voices in TB research (Figure 3).

### HOLDING THE POWERFUL ACCOUNTABLE

Another clear purpose defined by key informants is the role of holding entities with power in the TB R&D space to account, or fulfilling a role of

ensuring accountability in technology development. This definition of purpose was common across all stakeholder types—even among partners who have been held accountable by the TB CAB.

*I just want to add that I really, really value having someone there, making sure that we are doing the right thing. Because we all have tendencies to go back to our default. And our default is to not be transparent. To do things the way we know how, even though that is not going to be valuable in the end. So I think having advocates call us on our shortcomings is important to make progress. They are mirrors, they show us where our face wasn't well-washed, so they can call us out on our BS [bullshit]. A lot of the things we did, and the announcement we made [about a product launch], we probably would not have had it not been for advocates. **Product Developer** - 1003*

*I think there are some stakeholders who wish they would go away. But I think those are the people who want to take shortcuts in the research, who don't want their feet held to the fire when it comes to things like including a control group, you know, or having fair pricing or being transparent ... I do think there are some people who think it would be easier if they were gone. But gosh, I shudder to think about the horrible ethical violations that would occur in the absence of the Global TB CAB, and you know, 20 years from now what people would be writing or saying. I think they keep us honest. **Researcher** – 1016*

Survey data confirmed these findings around purpose relating to accountability, with 59% of respondents saying that the TB CAB has had “a lot” or “a great deal” of impact over time on TB drug access, 65% saying the same for TB diagnostic access, and 58% saying the same for fair pricing (Figure 3).

After being asked to define the purpose, n=19 key informants who are not current/former TB CAB members or TAG staff were asked whether their purpose had been met in the first decade. Two felt that they did not have enough “line of sight” to provide their feedback on this question, n=16 (84%) said some variation of “Yes,” and n=1 said “Yes and No.”

## **NEED FOR ROLE CLARITY IN CAB INTERACTIONS**

Feedback from key informants highlighted the crucial role that TAG has played in the development and functioning of the TB CAB. TAG's role, when specifically discussed, was seen as an important part of establishing technical rigor and providing a platform for TB CAB members to raise community voices.

*I think the CAB has been very ably guided and assisted and managed by TAG. We think that TAG's, you know, ability to organize the CAB in a way that it ... acts very proficiently, was going to say professionally ... It's just extremely well-organized and focused, and you can just see the effects that TAG's expert management has had on the CAB's performance. So I think, because of TAG's input and always being there, they've been very, very successful and consistently so. **Researcher** – 1017*

*I see it [TAG's facilitation] as a little bit synonymous, like I sort of see the secretariat of TAG, almost, as part of the global TB CAB. You know, it's partly again, just the historical interactions with them ... I see them as just the way its function is facilitating the global TB CAB, ensuring full communication between the TB CAB and researchers and other stakeholders, as well as giving their input in areas maybe where they're stepping in that the global team might not have had the same expertise or strength. **Researcher** – 1012*

Several key informants felt there is room to make clarifications around which perspectives are being represented during interactions with stakeholders. While there was broad recognition that the scope of the TB CAB is separate from TAG, some expressed a wish for clearer delineation, or at least a clarification of who is bringing forward a request.

*But sometimes I'm a little fuzzy on when my interactions are with TAG and when they're with the TB community advisory board. **Researcher** – 1015*

In addition to feedback on TAG's specific role, there was general feedback that more clarity and transparency is needed around how TB CAB members represent themselves (e.g., as a TB CAB member or as the employee of an organization). Several key informants expressed a desire to understand which perspectives are being



represented, as an organizing principle and also during in-person or virtual interactions.

*Creating a very clear charter and a clear description of who they are and what they represent that is transparent, and transparency has to be a two-way street, so that people know why, because people in Pharma might be suspicious. You know, thinking, they just want to embarrass us, so people want to understand some of those issues. It's good at least for a company, and other companies, to understand who are we dealing with. Because there is a lot of suspicion and a lot of money riding on our business, and people can be very protective of their money. **Product Developer - 1003***

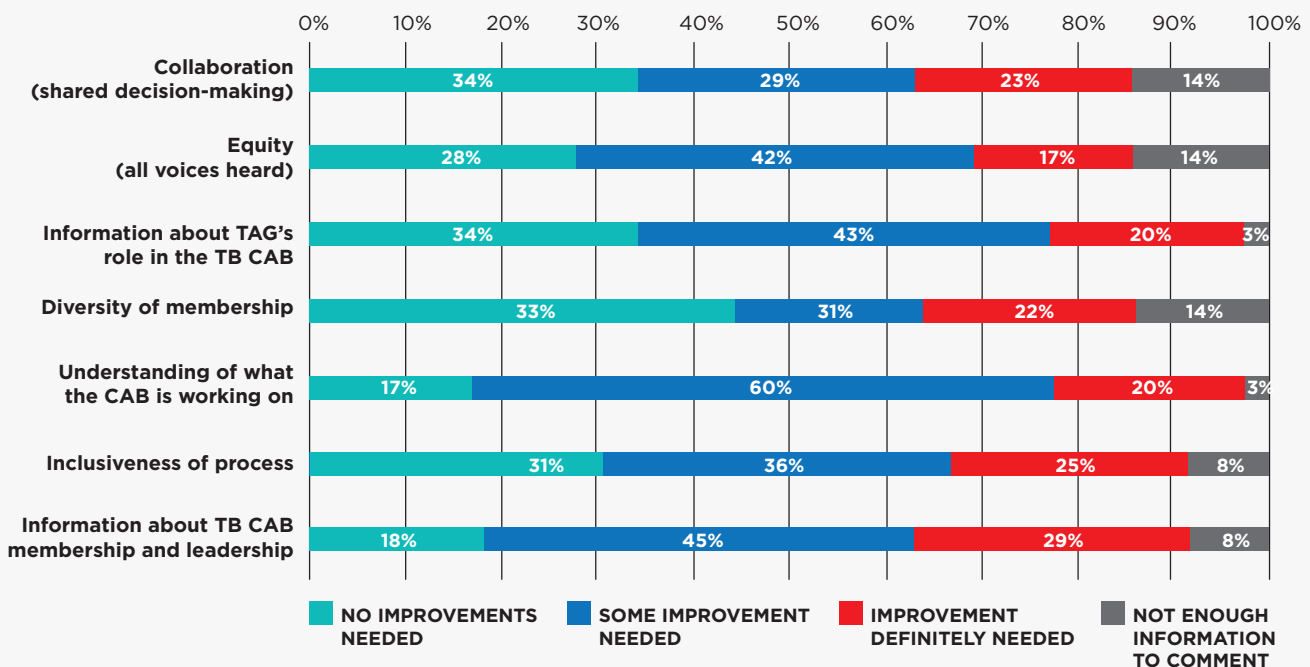
[Nota bene: see TB CAB Operations on page 8 for the TB CAB's online charter.]

*What is more important is to when we are approached, when you know, is to know whether, you know, this is coming from an individual, an institution, or a group of institutions like the TB CAB. That would be more helpful. I don't think I need to see the agenda, who is with leading with, you know, with chairing that year, I don't know if they rotate. I don't think that matters a lot. It is more is more like, who is bringing the information?*

**Global Health Response - 1008**

These findings were confirmed by survey feedback on the planning and process aspects of the TB CAB, with 45% of respondents indicating that some improvement is needed on information about TB CAB members and leadership, and 29% saying improvement is definitely needed. Similarly, 43% felt that some improvement is needed for information on TAG's role in the TB CAB, and 20% said improvement is definitely needed (Figure 4).

**FIGURE 4. FEEDBACK ON THE PLANNING AND PROCESS ASPECTS OF THE TB CAB**



## KEY FINDING #2: AN AGENT OF CHANGE IN TB R&D

Key informants were asked to provide their opinion on how the TB CAB has changed or influenced TB R&D, and survey questions were constructed to assess how much of the change described in interviews could be attributed to the TB CAB. Both data sources describe the TB CAB as affecting a “profound shift” in how community engagement is valued in TB R&D.

### CHALLENGING ASSUMPTIONS OF VALUE OF COMMUNITY ENGAGEMENT

Early efforts were focused on shifting how TB researchers and developers invited, listened to, considered, and responded to community feedback.

*I think, initially, what we were looking for was spaces being created for TB advocates. You know, whether that's speaking at events, being invited to meetings, and then getting leadership positions on those boards, all those bodies. **Former TAG Staff** - 1009*

*This is where I do think the lived reality of people, having experienced TB, sitting around the table does change the tenor of the conversation. Because then you can't just say, “Well, this is unimportant, because it happens to a minuscule population.” Because if that minuscule population is sitting around the table, then you suddenly recognize that this is a life, and part of our responsibility is also to make sure that that life does not go in vain. And so it does change the type of conversations that happened around, especially the working groups that I was part of. **Former TAG Staff** - 1028*

The survey sought to quantify these changes by asking how much community engagement changed in TB research overall in the TB CAB's first decade, and how much of the change could be attributed to the TB CAB (see Appendix 2, pages 39-40). Sixty-seven percent of respondents said that “a

lot” or “a great deal” of the increase in community engagement in TB research was due to the TB CAB. A similar set of questions was asked for community engagement in TB access; 76% of respondents said that “a lot” or “a great deal” of the increase in community engagement in TB access issues could be attributed to the TB CAB (see Figure 1 in the Executive Summary).

### NORMALIZING COMMUNITY ENGAGEMENT IN TB RESEARCH

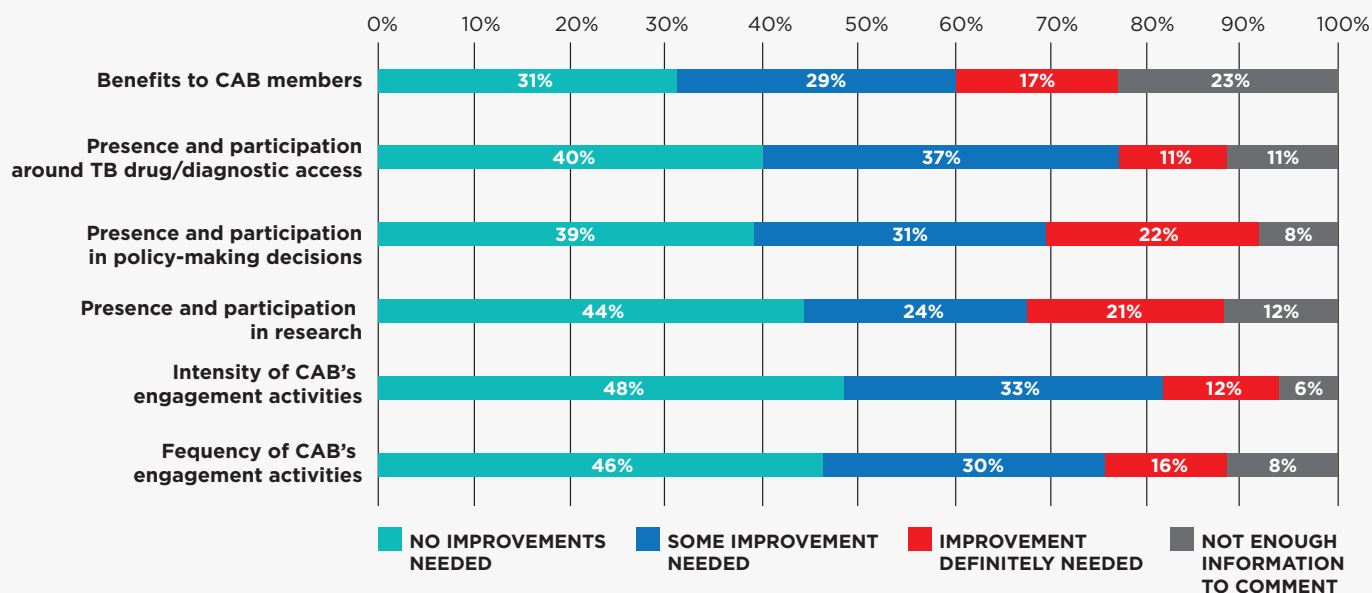
The focus on shifting the value of community engagement in the first decade of the TB CAB has resulted in a sort of “normalized” consultation process, a remarkable shift that has now provided “a seat at the table” for the TB CAB members. Normalizing community engagement in TB R&D was defined by each type of stakeholder, with CAB consultation being described as an “automatic consideration” and “for conversations about access and R&D, it would be weird if they weren't part of it.”

*There was a whole lot of work behind getting to the place where we could, where the CAB could review protocols. And I think that speaks to like kind of the relationship building. And so I think that's part of the process and kind of tactics that's like worth spelling out. Because even to get to the place where, you know, researchers trust the CAB with their review, you know, you have to have the CAB kind of like, do a lot of the forward-facing work that kind of makes a name for itself and makes them known as like a body to go to, monitoring what's going on in the research space to know when to reach out to like a trial if to say, you know, can you share your protocol with us if they're not doing that proactively? **TAG Staff** - 1023*

*I think sometimes people forget that was not necessarily the easiest process, right? It wasn't like everybody just said, “Oh, welcome, please come sit at the table with us.” Like, people fought hard for a seat at the table.*

**Researcher** - 1016

**FIGURE 5. FEEDBACK ON THE DELIVERY AND QUALITY ASPECTS OF THE TB CAB**

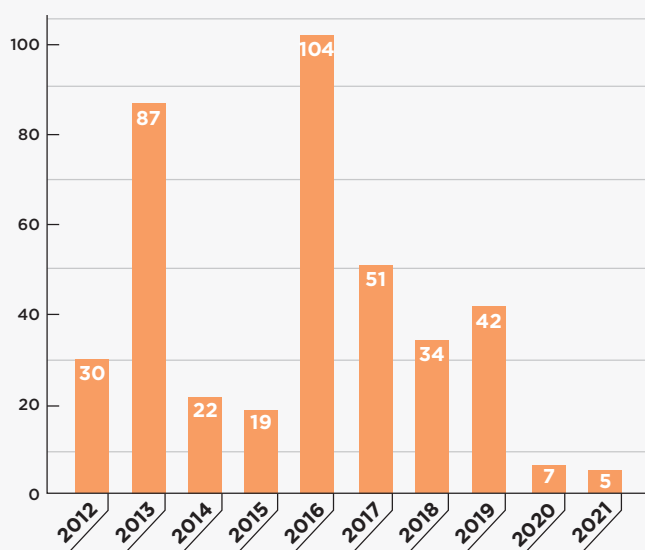


This adoption of CAB engagement as a new norm in TB R&D was reflected in survey data that asked about the delivery and quality aspects of the TB CAB; 46% of respondents said no changes are needed on the frequency of the CAB's engagement activities, with 30% saying some improvement is needed, and 16% saying improvement is definitely needed (Figure 5).

### CALLING FOR INCLUSION OF VULNERABLE POPULATIONS IN RESEARCH

In terms of impact, researchers in particular felt that the TB CAB played an instrumental role in including vulnerable populations in clinical trials, especially children and pregnant people. As with the “normalized” finding described above, this shift reflects sustained work over time; this is partly captured in the NLP language tool using a keyword search for “pediatric” (see Figure 6).

**FIGURE 6. RESULTS OF KEYWORD SEARCH FOR “PEDIATRICS” IN CAB DOCUMENTS**



*Honestly, I don't think things would have changed much on pediatrics had there not been a really strong push from the TB CAB. And particularly because WHO [the World*

Health Organization] was very aggressive with the recommendations for use of new drugs, like with bedaquiline and delamanid in pediatric patients, and that was definitely a direct result of TB CAB, right? Like, you can absolutely see that link. **Product Developer** – 1020

The TB CAB recommended including adolescents. And that was a change to the original design of the protocol that some of us on the protocol team embraced; others didn't. And we were able to convince the protocol team to embrace it. So that's an example where the TB CAB made a very specific and clear recommendation that changed the protocol. And I can tell you that the reason that I embraced it was because I thought it just made sense and would improve the study with essentially no downside and change. In doing that it accommodated a desire of the TB CAB and of the community and changed the minds of a number of investigators who were used to just excluding adolescents from studies because that's what they do. They didn't want them. That was a good example—very simple, not Earth-shattering, but you know, it was, it was important and turned out to be very, very effective of the, of the TB CAB. **Researcher** – 1017

Furthermore, considering the TB CAB's engagement at the global level, the survey assessed how its impact on the global TB research agenda had increased over time; 37% of respondents said “a great deal” and 34% said “a lot” (Figure 3).

### KEY FINDING #3: A RANGE OF PROVEN ADVOCACY METHODS AND TACTICS

The TB CAB operates on the principle that activism plays a key role in accelerating public health innovation using a variety of proven advocacy methods and tactics. As described above, the TB CAB is recognized for valuable and scientifically rigorous engagement, and most stakeholders

expressed positive emotions, from satisfaction to great appreciation, for its work in study design and review.

Where feedback was less positive, and at times critical, was around the escalation techniques employed to hold research and product sponsors and policy makers accountable, particularly when community perspectives are either being ignored or undervalued. The TB CAB has historically followed a strategic **escalation pathway** that allows it to move from closed discussions to open letters and even demonstrations to highlight community perspectives and priorities and to effect change. This defined pathway, which has been effective in historical and current activist movements, underwrites the TB CAB's ability to mobilize allies and apply public pressure after other avenues of influence have been exhausted. While a majority of engagements with the TB CAB do not result in escalation or direct action, the legitimacy of direct action as a tactic has deep roots in historical activism, particularly for HIV, a disease area and activist movement with great overlap with TB and from which TAG emerged and founding TB CAB members were recruited. Each step of the pathway is explored below.

### COLLABORATIVE ACTION TO ELEVATE COMMUNITY VOICES

Generally, the TB CAB works with stakeholders in TB R&D on common goals. Key informants were asked if particular strategies that the TB CAB has used (protocol reviews, closed meetings and letters, open letters, demonstrations) have been more successful than others. There was general consensus that progress involves steady, collaborative action that leads to change and that no single strategy works better than another.

*I think there isn't really one [strategy] because it's all, like, you have to chip away ... I think the fact that they do a whole range of activities and ways of addressing the same problem is what needs to be done. And access takes a long time,*

and I think often when you have an access when it's very hard to pin down that one thing that made it happen and I don't think there is that one thing that made it happen ... your big win which you make the headlines of, like, oh that drug's, you know, suddenly cheaper, or they've taken a price down—that has taken a group of people five to seven years of just nonstop emailing and meetings and public letters and closed letters, meetings with governments and policy makers.

**Access - 1001**

I think smart activism has probably been very successful over time. No one would have to unpick that. Sometimes what you need is a letter. Sometimes you need to embarrass someone on the stage at a TB conference. I'm sure there were missteps, but on the whole, I think strategic thinking on when to push which buttons was pretty good. **Emeritus CAB Member - FG1**

## HEALTHY TENSION

The next “escalation step” is reached when stakeholders in TB R&D are not able to reach consensus on TB CAB recommendations. An inability to reach consensus happens when there are differing motivations and incentives, organizational and funding-related restrictions, and potentially a perception that community input counts for less.

And so, you know, it's not like it's just everybody can come to the table and have an equal vote.

**Research Funder - 1022**

It is important to note that the TB CAB was founded with an understanding that not everyone will agree all of the time. Quotes below illustrate this from the point of view of a former TB CAB member and coordinator:

I think that tension is completely essential to having the industry and activists both play their roles effectively. And that shouldn't be so, you know, one should not preclude the ability to

engage in the other. Like, the activist scientist is the, is the model that we were actually trying to promote. And this actually has to be from both sides, not just from the activist side. Even the scientists need to take on some of the activist elements as well as the activists need to take on the scientist hats at some different points. In thinking about what is the most effective and what is the most, you know, ethical way for us to move certain things forward inside. **Former TAG Staff - 1028**

I think there was a what I think is a healthy tension between the kind of technical reviewing study protocols, that type of technical work and then pure activism like access to bedaquiline or holding a specific government accountable. So I think that tension was always there between, say, the technical and an activist stuff. And I think that's a healthy tension. I think it's good that it was ... activism and the research has to be in talking to each other at all times. So the CAB brings those things together and at times, you know, it's, it gets messy, but it's, it's good. Because, like, I said, were you able to bring your issues to the group? And together, we find a way to address it. **Emeritus CAB Member - FG1**

Most external partners also seemed to appreciate, or at least understand, this balance.

At times, we cannot be as bold as they will like us to be. Oh, I just need to acknowledge that. For example, we have just finished the work on target profiles. And they wanted a price that, you know, the rest of the committee didn't feel was possible at all. So, we have agreed that we like a range and, so, we have to listen to different voices.

**Global Health Response - 1008**

It was a little challenging at first. You know, we were explicitly called out by them, when they questioned an approach we were taking in the design of the trial. One of their public newsletters or something, it was very, it was a true callout,



which made us backtrack and reconsider what we were doing ... I don't come from an activist background. And ... part of me thinks, well, better to have discussion, then work our way through differences, rather than [have] a public airing. But maybe, you know, as I reflect, we were sort of going along with our heads down. This is what we were going to do, again, is early on with one particular approach. And maybe they felt that they were not going to get [that] changed from just suggesting to us, that's not the way forward. So maybe there are times when it is appropriate, when it's necessary. **Researcher** – 1012

## PUBLIC ACCOUNTABILITY

The widest gaps in perception and understanding emerged around this last step in the escalation pathway, whereby TB CAB members organize or participate in public demonstrations at major TB conferences. Both emeritus TB CAB members and current TB CAB members described participating collectively in demonstrations as a highlight of their experience.

I knew that I wasn't alone, I could fall back, I could count 100% on the support. So, it empowered me, gave me the courage to do a lot of firsts, the first ever protest for TB happened, because during the time that I was taking the big protest at the Union conference where bureaucrats were on stage as well. And they are literally telling [a] government to go home? Yes, you know, is it because they could speak as equals. You know, because we understood the science behind the access, the development, the institutes that needed to be advocated with. **Emeritus CAB Member** – FG1

On the opposite end of the spectrum, some external partners have felt surprised or alienated by this public strategy.

Yeah, let people know ahead of time. It has to be loud and noisy. I don't know, I'm feeling a little uncomfortable for them [the TB CAB

members] as well. And I've seen demonstrations in other diseases that were very, very tough. Right: so I could not say that that was a tough demonstration. But that was a demonstration. And given what we had done together until then, I think people didn't feel really great during that. **Product Developer** – 1005

The varying reactions may have to do with power: Demonstrations are a strategic, public, and tactile response to community voices going unheard, in a way that cannot be hidden or ignored. Taken in review, a conclusion can be drawn that while uncomfortable for some, public accountability has been a critical component of the escalation pathway (and historical activism in HIV). One key informant described how even at the receiving end, strategic demonstrations—or the understanding that they are part of the escalation pathway—can create change.

I saw a demonstration that was done at a symposium. And it really stuck out to me because it was so brilliant in terms of the branding and the messaging. Even people within the company had to smile and say it was brilliant ... [company executives] were really reluctant to, I think, engage with community and do the kinds of things that the CAB were pushing for. But it was really because of that CAB pushing that they made change. I saw it within the WHO, I saw [it] within our own organization. I think what happened was eventually, when, you know, some of their letters started to get up into the higher ends of the company and started to get the attention of, you know, the CEO and other [company executives] they were, they were going, "Wait a minute, what's going on here?" And that's when [things] started to change ... they started to fear that, you know, like that kind of a demonstration would happen [at their offices] or something like that. And so, you know, it really just, it didn't happen overnight, but it definitely, you know, created change over a period of time. **Product Developer** – 1020

## DIMINISHING VALUE THROUGH TONE POLICING

While nearly all people interviewed understood and could appreciate the Community Engagement model used by the TB CAB (having a clear purpose, demonstrating value, and utilizing an escalation pathway), one relationship in particular emerged as problematic (the specific partner name has been redacted, and is referred to as “the product developer” in the quotes below). This issue was described organically in a number of interviews, without prompting or probing for information; the product developer has been perceived as not valuing the TB CAB’s input and engaging in tone policing: focusing on the manner in which community priorities are delivered, rather than the content. These illustrative quotes from the product developer capture how the focus is on the expression of community priorities, rather than content.

*And so I think that the difficulty in this whole area is, how do you have a broader perspective, which implies different points of view? And how do you manage the give and take and the dialogue and the realization that not everybody is going to agree, OK? And just because you don’t agree does not mean you get to be disruptive and uncivil. **The Product Developer** - 1007*

*And sometimes I have the sense that, you know, there’s people that are not versed in [product] development, who think they know better. And I think that’s a little arrogant, frankly, because frankly, I would never presume to know how to do activism, advocacy, community work. I wouldn’t presume to be telling somebody in that endeavor how to do their job. **The Product Developer** - 1007*

The product developer is defining what they think is appropriate advocacy, based on a partial view of the Community Engagement model (being civil is “allowed”; being “disruptive” is not). And at the same time, the product developer feels TB CAB

members should not make presumptions about how product developers should do their jobs.

From the TB CAB’s point of view, the issue is not how the message is delivered in a single moment of disagreement, but rather that community priorities have not been taken into consideration during a much longer process of attempted engagement.

*But there’s only one major player that doesn’t really take us seriously enough, and I frankly don’t know how we can improve on that. Because there’s not enough respect, I guess, from [the product developer]. They do consultations, but they never, or I can’t remember when they ever took our recommendations into account. And one point we once burst out of a meeting because, you know, we were not taken seriously. But I don’t have a solution for that. **Current CAB Member** - FG2*

The CAB’s impression of community not being taken seriously, or respected, by this specific product developer was echoed by several other key informants, who described this partner as having used other stakeholders as a tool to help them execute decisions they had made ahead of time.

*Like, one of the things that I’ve noticed is [the product developer] I think is a relatively egregious industry partner. And what they’ve done is they’ve asked a number of people living with TB to be part of their advisory community. And then they don’t listen to a word they say, but they put their pictures on their website, right? So there’s a danger, right, with, with some of these industry partners sort of co-opting this idea of community, right? And they say, “Well, you know, these people may think our study wasn’t well done. But look at the pictures of all these TB survivors we have on our website.” And then when you talk to the TB survivors, they’re like, they never ask me anything. **Researcher** - 1016*

*The problem is that [the product developer] ... views its role as making decisions and executing them. And everybody else is a tool to help them execute the decisions they've already made. And that applies to academic partners, it applies to, you know, sites. And it certainly applies to the CAB and the community. You're all here to do our bidding so we can finish our study. And that's just been their method of operating since they were formed.* **Researcher** – 1017

This finding has been included as part of the escalation pathway description to highlight the need for public accountability as a mechanism of reclaiming power on behalf of the community when those voices go unheard or are disregarded. It is also to highlight the continued need to demand that community be valued in meaningful ways. Tone policing should be understood by all partners and identified as harmful when it “silences the narratives of oppressed populations.”<sup>7</sup>

## **KEY FINDING #4: AN EQUAL SEAT AT EVERY TABLE**

All key informants were asked for their ideas on outcomes that may help the TB CAB to track impact, and to provide advice for the next decade. Just as there was a general, clear understanding of the TB CAB's purpose and impact on TB R&D, there is general, clear consensus that the TB CAB should focus on increasing access points for community to be part of the TB R&D process, with the goal of ensuring that the community has an equal seat at every table where decisions about TB R&D are made.

### **GRASSROOTS CAPACITY BUILDING**

Sharing resources for community advocate capacity building on TB R&D and facilitating connections between community advocates and key R&D decision makers were suggested as means to ensuring the incorporation of community voices at all stages of the R&D process. TB CAB members and TAG staff identified a sort of passing of the torch to local advocates who can be developed

through the TB CAB's existing resources and support structures as a goal and nascent practice.

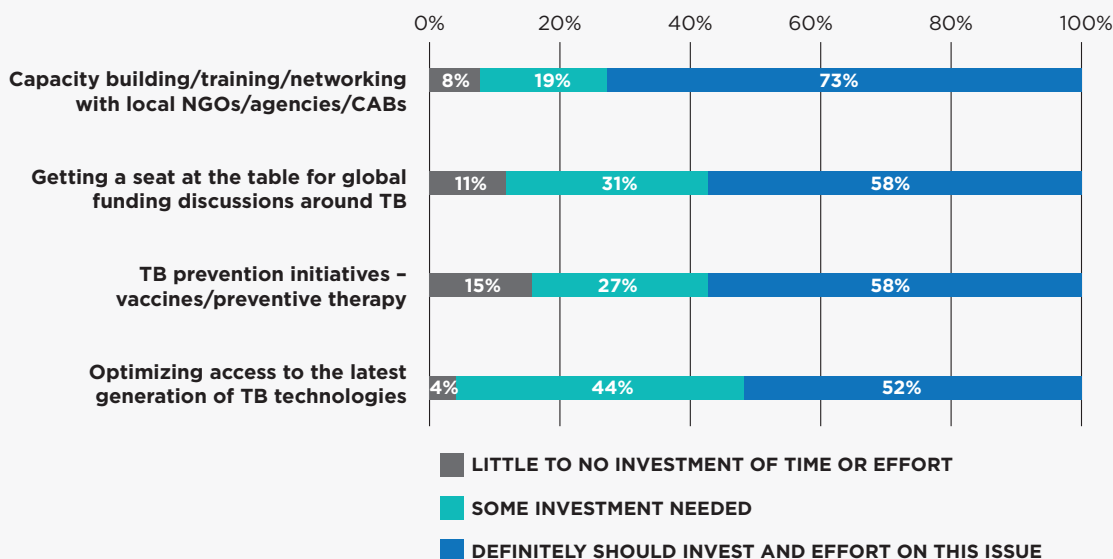
*And obviously, I think that there's a responsibility for the TB CAB members to also do treatment literacy and diagnostic literacy at the community levels because they have been exposed to a—we were exposed to platforms and contacts within this, you know, this niche field that other community members may not have the opportunity to have.* **Emeritus CAB Member** – 1024

*So sometimes connecting directly with each and every state or with each and every potential or rather, the present key stakeholders and advocates at their own respective states kind of becomes a challenge for me. And my opinion is that I do not know everything about the global scenario as well as even my country, or particularly even in my region as well. So my hands and mouths and legs are supposed to be my other colleagues [in country], who will also be here to guide me so that I can meaningfully try to bring all those to the table of the tiebreaker, then that will give much more meaningful shape. And, further, a meaningful and effective result.* **Current CAB Member** – FG2

Each of the stakeholder types interviewed expressed the desire for this type of feeder or mentoring system to increase community access points in TB R&D.

*So you know, the whole area around providing support for other CABs, for other groups to set up their own CABs. Because obviously, the global CAB rightly focuses on the high-impact projects. But if they can share the resources, and I think they're very keen to do, in ways that they can share a roster of members who have been trained, maybe accreditation for community members, some way of accrediting, their training and their experience.* **Researcher** – 1026

**FIGURE 7. HOW THE TB CAB SHOULD INVEST ITS TIME**



*So my prayer's always been that if TAG, getting their expertise in research can translate that expertise to other CAB members, that would be, that would be great ... I think that there is a need to expand the expertise or the type of people that are involved, not only because the community is not only laypeople, because people, the community will have lawyers, community will have shopkeepers, the committee would have different types of people. I think that we should start to think about expanding the cadre of people that can be part of the, of the project. And then we can also have that better perspective and building capacity and understanding research will be something that's going to be important. So I'm talking about research, but I think that could be the same for programming. **Research Funder** - 1013*

The survey confirmed the consensus that grassroots capacity building should be an important part of the next decade of the TB CAB's work: 73% of respondents said that the TB CAB should definitely invest time and effort in capacity building/training/networking with more national and subnational community and civil society groups (Figure 7).

### UPSTREAM ACCESS TO FUNDERS

The CAB's ability to engage at the global level around research and development was clearly described as being successful. A suggested approach to further expanding the TB CAB's impact on the overall research agenda was to engage donors and other funders of TB research earlier, especially before calls for research proposals are publicized. A few key informants suggested that TB funders may not understand the value of the TB CAB.

*I really, really think I do see a value of the TB CAB. And I think it's a value that needs to be, to be maintained and to be recognized better. I think that they probably need to, you probably are going to be talking to other donors, to get an understanding of why the other donors are not really supporting TB CAB right now and then what are the other thing that needs to be done so that they can, they can be on board with supporting take up? **Research Funder** - 1013*

*But again, I do think that with many of the funders and many of the global entities, I think they underestimate the capability of the TB*

CAB and the purpose and scope of their work. And so I don't know how much they value, say, the scientific reflections from the TB CAB? My suspicion is that they don't value them as much as, say, academics or WHO, or WHO ethics review committee, but I don't know that for sure. **Researcher** – 1015

As with the process of obtaining a seat at the global level for policy discussions and review and translation of evidence, the TB CAB may need to utilize similar processes to get a seat at research funding decision-making tables. Several key informants noted that this is a small group of funders who are likely to have their own agendas.

*Internally, you don't have that kind of leverage, and TB [as a field, compared to other disease areas] potentially has massive leverage, because the funding is essentially coming from foundations of government, et cetera, or agencies, and so you can really influence that from the beginning and create something that's a lot more open, transparent, collaborative, and also actually access-friendly from the beginning. I think I would put a lot of a lot of effort into that because if, over time, the companies get developed and then it's already been proven in the hands of wherever and maybe a small company, a large company, whoever—getting them to do what you want them to do at that stage is more difficult.*

**Access Partner** – 1002.

*Because funders are fairly opaque on how they do things. It would be great for, for example, the Gates Foundation, which is one of the biggest funders of TB research, to, to have more inputs [from the TB CAB]. You know, but I don't know how that can happen. I know the Gates Foundation, they have their own agenda, and they do their thing. You know, that's the nature of philanthropic funding, they get to do what they want. But, you know, if there was a way that the CAB*

*could influence ... that they can be at the table as part of their sort of research, set research agenda setting with the foundation, that'd be great. **Researcher** – 1026*

Fifty-eight percent of respondents said that the TB CAB should definitely invest time and effort in getting a seat at the table for global funding discussions around TB research, with 31% saying some investment is needed (Figure 7). Earlier engagement in discussions about the research agenda, before calls for proposals are finalized, may be another mechanism for the TB CAB to ensure that community perspectives, priorities, and needs are reflected in the TB R&D agenda and the research proposals and product development efforts that get taken forward.

*I think the TB CAB and TAG will have the biggest impact if they engage long before protocols are written and engage on program discussions. And I think that's what we, we've started in our interactions to talk about the entire program and shape it together. Because, yeah, protocol amendment is fine. But it needs, it needs to start before a phase III protocol is written. It's shaping the considerations that go into protocol design, rather than making a tweak to the protocol once it's been developed. I think for the future to have even bigger impact, it means being part of product development from an early stage and in shaping product development. **Researcher** – 1011*

Fifty-eight percent of respondents said that the CAB should definitely invest time and effort into TB prevention research initiatives, with 27% saying some investment is needed (Figure 7). Other suggestions for increasing community access points and influence in the TB R&D process include advocating for a “full vote” for community in the next large TB initiatives and for earlier engagement of communities in TB research agenda development and funding discussions.



## REPRESENTATION

Several key informants had suggestions on membership to increase representation, and therefore access to the TB CAB's activities and influence, on a much broader scale. Suggestions for additional member profiles included community health care workers/nurses, lawyers, shopkeepers, younger people, and broader country representation.

*I would hope to see a more diverse group of members ... other communities that can be very powerful. And acting on the ground, not just, I would say, demonstrating not just the communities that need the service, but the communities that can help make sure that these services are given ... because maybe that's another community of nurses, right? Especially in places like South Africa where they're such a core component [of the health care system]. And maybe you need to make it a bit bigger because nurses/health care providers, whatever we call it. Because it's sometimes not even nurses. That's right. But these people are very important. Very.*  
**Product Developer - 1005**

In addition to the composition of the TB CAB, several people mentioned a perception of a northern bias.

*I think there's a clear leadership role being played by TAG, is kind of the secretariat behind the CAB. I guess that also means that there's a very strong voice from some of the people associated with TAG and some of the, you know, other high-income country society groups, and I think it probably could benefit from having stronger voices from the developing countries involved in playing a more kind of leadership role in, in the, in the process.*  
**Access Partner - 1002**

*Ideally, you'd want TAG leadership to be from, to represent high-burden countries, right. So you're still, it still feels like you have a northern hemisphere organization working with affected communities. Ideally, you'd want people from affected communities to lead the entire effort, right.*  
**Researcher - 1011**

In the survey, participants could indicate weaknesses, and one replied, "Western dominance," while another indicated "bias to the leading agenda."

## AN ADDITIONAL FINDING

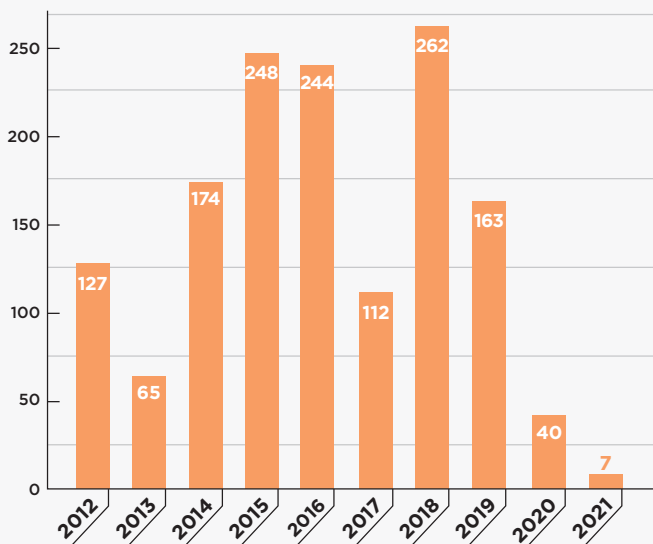
The TB CAB's work on bedaquiline was not prominently featured in the key informant interviews or survey results, though some did reference the TB CAB's work to advance all-oral regimens (for example, n=2 survey respondents cited "access to bedaquiline" and "involvement in the introduction of all oral regimens for DR [drug-resistant] TB" in response to a request to describe the CAB's greatest accomplishment in its first decade, and one key informant described the TB CAB as being a forceful advocacy partner around pricing for bedaquiline, delamanid, and pretomanid [Researcher, 1016]).

The emeritus and current TB CAB members reviewed the key findings of this report, as well as the recommendations below. They noted that their work around bedaquiline had not been fully captured, despite the strong feeling of this being an area of noteworthy impact to be included in an evaluation of their first decade. As such, a summary of the TB CAB's work on bedaquiline has been included here to highlight major points of engagement.

Following the processes described in Key Finding #3 above (A Range of Proven Advocacy Methods and Tactics), the TB CAB used a number of advocacy tactics over their first decade to advance the science around bedaquiline, as well as eventual policy change and patient access. The TB CAB engaged early in the development of bedaquiline directly with the product sponsor through in-person meetings starting in 2012, protocol reviews, and both private and public letters focused on research priorities and making the drug affordable. During product developer meetings, in addition to scientific engagement, there was a clear focus on anticipating and addressing regulatory issues while awaiting evidence of bedaquiline's safety and efficacy. The TB CAB was also deeply involved in advocating for and scientific review of studies evaluating how to optimize the use of bedaquiline to shorten or improve TB treatment. The TB CAB focused early on compassionate use of the drug ahead of regulatory approval and World Health Organization (WHO) recommendation and played a significant role in highlighting public investments in the development and introduction of bedaquiline. Working with the WHO and national-level policy makers (for example, the Ministry of Health in South Africa), TB CAB members invested significant time in accelerating policy change through advocacy. As the evidence base in favor of an all-oral, bedaquiline-based regimen became clear, the TB CAB zeroed in on holding the powerful to account in ensuring access, through advocacy and letters to the WHO and national programs and regulatory agencies. The TB CAB's access work continued in partnership with Médecins Sans Frontières via the \$1 a day campaign<sup>8</sup> and contributions to the development of *An Activist's Guide to Bedaquiline* and *An Activist's Guide to Treatment for Drug-Resistant TB*.

To confirm the TB CAB members' sense that bedaquiline-related advocacy was a core component of the TB CAB's work plan and success in its first 10 years, evaluators conducted an exercise to transpose the natural language processing tool/key documents review findings specific to bedaquiline over the timeline of significant bedaquiline-related events (see Figure 8).

**FIGURE 8. RESULTS OF KEYWORD SEARCH FOR "BEDAQUILINE" IN CAB DOCUMENTS**



**2012:** FDA accelerated approval granted

**2013:** Conditional WHO recommendation, bedaquiline categorized as group D medicine; J&J commercializes bedaquiline using tiered pricing (\$30,000; \$3,000; \$900)

**2015:** J&J/USAID bedaquiline donation program launched

**2016:** Phase 3 study initiated (STREAM II); pediatric studies initiated

**2018:** South Africa adopts bedaquiline as standard treatment for drug-resistant TB and negotiates price reduction (\$400); WHO categorizes bedaquiline as group A medicine, recommending 18-20-month all-oral, bedaquiline-based regimens

**2019:** WHO recommends 9-12-month all-oral, bedaquiline-based regimen

**2020:** J&J further reduces price (\$340) for 135 countries; FDA approves pediatric formulation

# Conclusions

The results of this evaluation reflect significant changes in how community voices have been elevated in TB R&D over time, with a great deal of change being attributed to the TB CAB. Collectively, the key findings of this evaluation indicate a **“transformative change”** that has disrupted power dynamics on multiple levels and has resulted in a change to the overall environment of TB R&D.

As described by Pruitt et al., **transformative change** challenges values and assumptions of a system.<sup>9</sup> The TB CAB challenged the assumption that community input counts for less by developing advocates that understand TB R&D through rigorous training and exposure to decision-making inflection points. As a result, community consultation has gone from being thought of as a tool to execute decisions that are already made, to including community voices to shape decisions at the very start of new technology development. Through the TB CAB’s work, TB survivors and advocates have more

power in decisions about research and policies that guide national response programs, which ultimately affect entire communities.

Strong examples of this are the development of all-oral regimens (see “An Additional Finding”), the push to have adolescents included in research, and for the acceleration of pediatric investigations so that new treatment guidelines would benefit people of all ages. Using the NLP tool, the following chart (adapted from Nelson et al.) has been populated to describe how the transformative work of the TB CAB can be captured (see Table 2):

**TABLE 2. TRANSFORMATIONAL CHANGE INDICATORS AND OUTCOMES FOR RESEARCH & ACCESS**

Level of Analysis	Indicator of Transformative Change	Strategy Used to Create Change	Outcomes of Transformative Change
Product Development	CAB request to product developer to describe commitment to pediatric studies	Open letter to product developer (2012); pediatric study protocol review (2015); WHO guideline development group participation	Commitment from Janssen to conduct pediatric studies “with the right partners” (2012); Pediatric investigations initiated (2016); FDA approved pediatric formulation (2020); WHO recommended bedaquiline for use in children of all ages (2021)
New Product Research	CAB feedback on study design to include pediatric population	Protocol reviews of primary studies (2012-19)	Inclusion of adolescents and children in study populations (e.g., endTB, endTB-Q, BEAT Tuberculosis)
Global Guidelines	Invited representation on guidelines committees	Letter to WHO to recommend bedaquiline for all patients with drug-resistant TB (2018)	WHO Consolidated Guidelines for treating drug-resistant TB (2019, 2020)
Country-Level Implementation	CAB partnering with civil society organizations for Ministry of Health inquiry on bedaquiline	Closed letter to Ministry of Health; joint letter with civil society partners (2018)	<i>Statement on South Africa’s adoption of bedaquiline for drug-resistant TB (2018)</i>

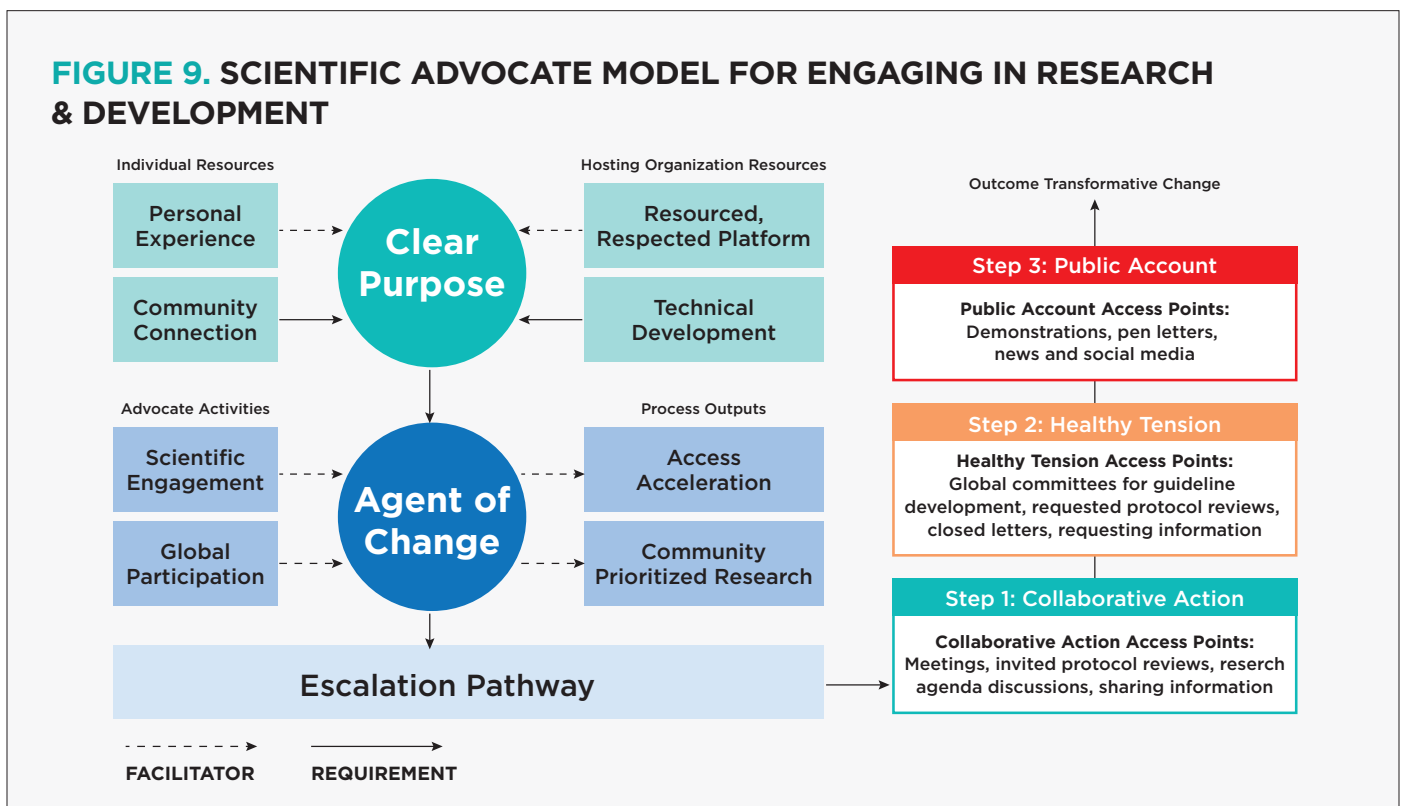
While this evaluation did not capture the impact of all the strategies used by the TB CAB, transformative change indicators can be described for current and future TB CAB efforts to further the evidence base regarding the value and impact of community engagement in R&D and how it can accelerate access to science and its benefits. It is also important to reiterate the finding about collaborative action as a body of work. To provide a replicable framework for scientific advocates, a logic model has been developed based on the findings of this 10-year evaluation.

## SCIENTIFIC ADVOCATE MODEL FOR ENGAGING IN RESEARCH & DEVELOPMENT

The results of this evaluation have implications for prioritizing community voices in research and development processes. The evolution of the TB CAB, and the key findings of this evaluation, have been developed into a Scientific Advocate Model for Engaging in Research & Development (Figure 9). The model includes inputs needed

from CAB members and the hosting organization (“Clear Purpose”) that have been critical to the TB CAB’s success. It also includes the strategies that the CAB has used to achieve its purpose, with scientific engagement and the global platform having been central to the ability to act as an agent of change. The process outputs—accelerating access to technologies and conducting research that incorporates community priorities—feed into a clear escalation pathway that has consistently yielded outcomes (for example, shifting researchers’ approach to including pregnant people and adolescents and children in their studies, and expediting the shift of global guidelines to all-oral, bedaquiline-based regimens for drug-resistant TB).

Ideally this model can be used by community groups seeking to change power dynamics in research and development. The escalation pathway, to be understood as a standardized mechanism for ensuring the meaningful incorporation of community input, provides a proven methodology that can be used to correct power imbalances necessary to effect change.



# Recommendations

The recommendations below are based on the evidence synthesis around impact and requests for opinions about the TB CAB's next decade. The strength of evidence has been categorized by type of evidence and rating (strong or very strong), with additional action points described under each recommendation. Evidence was categorized as "very strong" if the evaluation assessments showed highly consistent qualitative consensus and significant quantitative findings and "strong" if there was mostly consistent qualitative consensus and at least a majority (>50%) of quantitative findings (see Table 3).

## RECOMMENDATION #1: MAINTAIN SCIENTIFIC ADVOCATE AS CORE IDENTITY

The TB CAB should work to maintain its core identity as a seasoned technical partner that raises community voices in TB R&D. The diversity of advocacy tactics used by the TB CAB is tied to its ability to hold the powerful to account. To ensure that its core identity is maintained, the TB CAB should continuously invest in the development of its members' TB knowledge and technical expertise and expand their connections to local community and civil society groups whose allyship is critical in holding key decision makers to account.

### ADDITIONAL RECOMMENDATIONS FOR MAINTAINING A SCIENTIFIC ADVOCATE IDENTITY:

1. Consider specialized training, which has been reported by emeritus TB CAB members to be "life-changing" (e.g., McGill Summer Institute). The CAB can also consider a peer-to-peer training process with stakeholders in the TB R&D space to help them develop a better understanding of community engagement expertise. There are models for this that the

TB CAB may be able to utilize (with additional operational support/funding), including the Global Advocacy for HIV Prevention (AVAC) Engage platform.

2. Collect ongoing, qualitative information from members and other stakeholders to track the TB CAB's impact, using the "transformative change" structure to document indicators and outcomes. To increase evidence of TB CAB impacts at national, subnational, and grassroots levels, ask TB CAB members to report how they have used TB CAB training and resources for advocacy work on a monthly or quarterly basis.
3. Describe the escalation pathway as a key component of the TB CAB's operational workflow. Doing so may help to better prepare partners to understand why a tactic is used when engaging with the TB CAB.
4. Clarify the role of emeritus TB CAB members to expand opportunities for their continued engagement with the TB CAB, and to support TB CAB connection to advocacy priorities and work at regional, national, and grassroots levels.



## RECOMMENDATION #2: INCREASE ACCESS POINTS FOR COMMUNITY IN TB R&D

The TB CAB should consider mechanisms for making existing technical and networking resources available to other community groups and should establish more formal mentorship and pathways through which information from global conversations can be more regularly transmitted to grassroots organizations, and vice versa.

### ADDITIONAL RECOMMENDATIONS FOR INCREASING ACCESS POINTS FOR COMMUNITY:

1. Consider funding discussions and strategies that allow operations to shift toward a reflective global agenda (monthly updates from members, a process whereby external community stakeholders can submit issues for consideration to the TB CAB).
2. Create a description of resources needed to develop a scientific advocate incubator program (e.g., “TB CAB University”); determine how much time and what type of funding mechanisms would be needed to translate some of the suggestions from key informants (e.g., to make TB CAB training/capacity building resources and opportunities more widely available, to establish a certification for CABs or community members related to TB R&D that have been mentored by an in-country/regional TB CAB member).

## RECOMMENDATION #3: REVISIT CAB STRATEGIES FOR TB DIAGNOSTICS AND PREVENTION

The first decade of the TB CAB’s work focused on treatment research and access to new medicines and diagnostic technologies. Expanding this focus in the next decade to include more attention toward TB vaccines and diagnostics research may require new skills and/or strategies. In addition,

TB vaccine development may greatly benefit from the TB CAB’s engagement, particularly as COVID-19 provides lessons on how lack of community engagement and vaccine hesitancy affect uptake.

Importantly, there are two major emerging global-level TB initiatives (UNITE4TB to accelerate TB treatment development through phase II trials and the PAN-TB collaboration to develop novel regimens to treat all forms of TB) that will play a large role in TB treatment R&D over the next decade. The TB CAB needs to advocate for community representatives to have a “full vote” in all discussions where decisions are made that will ultimately affect communities.

And finally, to a large extent, the impact of COVID-19 on TB studies, and service delivery, will continue to evolve. The CAB may be in prime position to describe the impact of COVID-19 on community efforts in these areas.

### ADDITIONAL RECOMMENDATIONS FOR STRATEGIES FOR TB DIAGNOSTICS AND PREVENTION:

1. Evaluate lessons learned on new drug access based on experiences with the R&D and introduction of bedaquiline, delamanid, and pretomanid and make adjustments to the framework that can be used for engaging with emerging TB treatment development initiatives (UNITE4TB and the PAN-TB collaboration) and for TB diagnostics and prevention R&D engagement.
2. Ensure and support meaningful community engagement in the next decade’s TB research consortia and new TB R&D initiatives.
3. Consider how the CAB can use its network to report out on COVID-19’s impact on all parts of the TB R&D process, to highlight how the pandemic may be affecting current TB research and shaping future research questions.

## **RECOMMENDATION #4: CLARIFY OPERATIONS TO BUILD CONFIDENCE**

This evaluation found that there is an opportunity for the TB CAB to more publicly articulate its operating model in a way that facilitates interactions with new stakeholders and helps them better understand when to approach the TB CAB and what to expect from these interactions, which helps to build confidence and trust. The CAB can address this information gap by better articulating its mission, purpose, and operations in a way that facilitates interactions with stakeholders. Posting this information online, alongside the current terms of reference and list of current members, will address some of the uncertainty expressed by key informants. The TB CAB can also train members to clearly state whom they are representing (e.g., TB CAB versus an employer or other organization) when engaging with stakeholders.

### **ADDITIONAL RECOMMENDATIONS FOR CLARIFYING OPERATIONS:**

1. Revise TB CAB website to clearly detail leadership, membership, process for setting advocacy priorities, and the strategic escalation pathway. It may also help stakeholders to understand the scope or burden of the TB CAB's work by describing capacity as it relates to how many requests the CAB receives for review.
2. Expand documentation of successes in transformative change and include that information on website.
3. Set up strong online presence (and to address digital divide, consider social media strategy) to facilitate interactions outside of known networks. One option would be to develop an online form that community groups or allies can use to raise issues for the TB CAB's attention.

**TABLE 3. QUALIFICATIONS FOR EVIDENCE-BASED RECOMMENDATIONS**

Recommendations	Type of Evidence	Evaluation Evidence	Evidence Rating
<b>Scientific Advocate Identity</b>	Qualitative	Consistent description of and appreciation for CAB’s technical role, across 10 years of experience and multiple stakeholder profiles	<b>Very Strong</b>
	Quantitative	67% attribution for “a lot” or “a great deal” of the increases in community engagement in TB research overall; 76% said that “a lot” or “a great deal” of increases in TB access-related issues could be attributed to CAB overall (Figure 1)	
<b>Increasing Access Points for Community</b>	Qualitative	Description of need to increase access points for community consistent across key informant categories; highly consistent description of grassroots capacity building as an area of need	<b>Very Strong</b>
	Quantitative	73% of respondents said that the CAB should definitely invest time and effort in capacity building/training/networking with local agencies, with 19% saying some investment is needed	
<b>Revisit CAB Strategies for TB Diagnostics and Prevention</b>	Qualitative	Mostly consistent feedback on the need to increase activity around TB diagnostics and vaccines; some feedback that doing so will require current strategies to be adapted to these specific fields (additional training, more focus on regulatory issues, etc.)	<b>Strong</b>
	Quantitative	58% of respondents said that the CAB should definitely invest time and effort into TB prevention initiatives, with 27% saying some investment is needed	
<b>Clarify Operations to Build Confidence</b>	Qualitative	Somewhat consistent feedback regarding the need for transparency around leadership, and separation of TAG from the TB CAB	<b>Strong</b>
	Quantitative	45% indicated that some improvement is needed on information about TB CAB members and leadership, and 29% said improvement is definitely needed; 43% felt that some improvement is needed for information on TAG’s role in the TB CAB, and 20% said improvement is definitely needed	
<b>Description of Evidence Ratings</b>		Highly consistent qualitative consensus; significant quantitative findings	<b>Very Strong</b>
		Mostly consistent qualitative consensus; at least majority (>50%) quantitative findings	<b>Strong</b>

## LIMITATIONS

There are a number of limitations to this evaluation. The most important limitation is in regard to the purposive sampling approach. While it is likely that we have reached saturation with known TB CAB contacts, it is highly unlikely that we have produced an evaluation that reflects an understanding of the TB CAB's impact outside of its network. Because the survey was anonymous, qualitative findings cannot be directly linked to the quantitative; the survey was set up that way to encourage more open responses.

In addition, not all key informants who were invited to participate elected to: Three rounds of email invitations were sent to each person on the list. Out of all the categories, there is the lowest response rate from Global Health Response partners, and their perspectives are limited to n=2 interviews (out of n=5 invited).

## ACKNOWLEDGMENTS

The evaluator gratefully acknowledges the time, feedback, and expertise shared by the current and former TB CAB members, TAG, and the key informants. The brilliant Rushank Goyal is the project intern who developed the NLP tool for the document review, which is available online, upon request.

## ABBREVIATIONS

<b>ATAC</b>	AIDS Treatment Activists Coalition
<b>AVAC</b>	Global Advocacy for HIV Prevention
<b>CAB</b>	Community Advisory Board
<b>DDC</b>	Drug Development Committee
<b>ECAB</b>	European Community Advisory Board
<b>IRB</b>	Institutional Review Board
<b>ITPC</b>	International Treatment Preparedness Coalition
<b>NIH</b>	National Institutes of Health
<b>NLP</b>	Natural Language Processing
<b>R&amp;D</b>	Research & Development
<b>TAG</b>	Treatment Action Group
<b>TB</b>	Tuberculosis

## KEY INFORMANT INSTITUTIONAL AFFILIATIONS

### Research Implementers and Funders

Harvard University; The Union; Wits Health Consortium; University of California, San Francisco; Pan-African Consortium for the Evaluation of Antituberculosis Antibiotics (PanACEA); Bill & Melinda Gates Medical Research Institute; the U.S. Agency for International Development (USAID); AIDS Clinical Trials Group (ACTG); TB Trials Consortium (TBTC); Bill & Melinda Gates Foundation

### Access

Medicines Patent Pool, Lawyers Collective, the Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN), Harvard University

### Global Health Response

WHO, NTP South Africa

### Product Sponsors

Janssen, Otsuka, TB Alliance, Mylan, Cepheid

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# Appendix 1: Sample Interview Guide

## Understanding the evolution, reach, and impact of the Tuberculosis (TB) Community Advisory Board (CAB)

### PRODUCT SPONSORS

#### INTRODUCTIONS:

1. Thank participants for their willingness to participate in the group interview/focus group
2. Introduce facilitators, reporters and explain their role
3. Describe the detail of Focus Group Discussion (FGD)/interview using the following information:

The primary objective of this interview/focus group is to ask for your reflection on development of the TB CAB and its impact over the past decade. We will use your expert feedback to document lessons learned and identify focal areas for the next 10 years of community engagement in TB research.

We will start by asking about your experience with the TB CAB, and how you feel about its work over the past decade. We are also going to ask your opinions about TB CAB goals and future development.

The information you provide will become part of a larger assessment as we develop a description of the impact of the TB CAB and identify some considerations for future development. The results of this discussion will be included in a manuscript describing the 10-year evaluation.

**Focus Group:** During a focus group discussion, you are welcome to talk freely and spontaneously about everything you know and feel related to our discussion. The focus group session will last approximately 90 minutes. As everyone's ideas are highly valid, you are kindly asked to actively participate, listen to each other, and respect each other's opinion. Please refrain from criticizing others' opinions during the FGD and even outside

**Interview:** During this interview, you are welcome to talk freely and spontaneously about everything you know and feel related to our discussion. Our interview will be approximately 30-60 minutes.

The information collected will be de-identified; we will use an identifier to label the transcription we make of this conversation. This means that your identity as a participant and the information that you will provide will not be revealed to people other than the facilitators. We are not taking your name and address during the discussion. All audio recordings will be erased upon completing the evaluation.

We do not anticipate that participation in this evaluation will pose physical or psychological risks beyond what you encounter in everyday life. However, participation is voluntary, and if you are uncomfortable answering a particular question, you are free to refuse to answer the question, and you are free to stop the interview at any time. If you have any concerns, you may ask the facilitators at any time during this discussion.

TOPIC/FOCUS	PRODUCT SPONSOR CORE QUESTIONS
<p><b>High Level View of Purpose</b></p>	<p>To start our discussion, we'd like for you/everyone here to reflect on the TB CAB's purpose. Traditionally CABs are developed between research centers and an advisory board that act as a link between investigators and community members. In the past, CABs have acted as advisors and liaisons.</p> <p><i>In your own words, can you describe the purpose of the TB CAB?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Better-quality research? Increased funding? Priorities aligned to patient groups? Representativeness? Changing perceived value of community engagement by academics/policy? Increased translation/dissemination/uptake?</li> </ul> <p><i>Has the TB CAB met that purpose?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> How has the purpose of the CAB changed over time?</li> <li>• <b>Follow Up:</b> Why do you think some of those changes have occurred?</li> </ul>
<p><b>Value and Impact</b></p>	<p><i>Please describe your interactions with the TB CAB to date.</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> What have been some highlights? Why?</li> </ul> <p><i>Public and internal documents clearly show that engaging in product development has been met with varying degrees of success. What trends have you observed in your work with the TB CAB?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> In which direction are those trends heading?</li> </ul> <p><i>Which strategies of the TB CAB's research engagement with product development, such as protocol reviews, public letters, engagements in the research process, have been most effective?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> What skills and trainings are still lacking?</li> <li>• <b>Follow Up:</b> What skills do you think might be important to facilitate growth and sustainability?</li> </ul> <p><i>Which strategies of the TB CAB's product development engagement waxed and waned over time?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Why do you think momentum has shifted to/away from some of these tactics?</li> </ul> <p><i>How would you describe the value of your interactions with the TB CAB?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Has that value shifted for you over time?</li> </ul> <p><i>How would you describe the largest "bang for buck" in your interactions with the TB CAB?</i></p>
<p><b>Outcomes</b></p>	<p><i>What outcomes of the TB CAB's work are the best indicators of success?</i></p> <ul style="list-style-type: none"> <li>• <b>Follow Up:</b> What will be most important for the next decade?</li> </ul> <p><i>Are there outcomes that may be important to identify now in order to work toward sustainable funding and facilitation?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Are any new outcome measures needed for tracking national/grassroots level work?</li> </ul> <p><i>Can you think of some larger/long-term impacts that might be measurable/that you have observed?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Transparency in research, public trust, etc.</li> </ul>

TOPIC/FOCUS	PRODUCT SPONSOR CORE QUESTIONS
<b>TB CAB Leadership</b>	<p><i>How would you describe TB CAB leadership, and TB CAB facilitation?</i></p> <ul style="list-style-type: none"> <li>• <b>Follow Up:</b> Did you ever observe or experience any power differentials between your interactions with TB CAB members vs. TAG staff?</li> <li>• <b>Follow Up:</b> Was anything done to address those power differentials?</li> </ul> <p><i>In your opinion, are there any operational limitations for current CAB members? Funding and capacity building at the national level are not a funded part of the scope of work.</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> Do you think funding/operational challenges have limited impact?</li> </ul> <p><i>What, if anything, would you change about your experience with the TB CAB?</i></p>
<b>Unique to TB</b>	<p><i>If you had a background in HIV work, or in another disease area, what makes the TB CAB unique?</i></p> <ul style="list-style-type: none"> <li>• <b>Probe:</b> How have the learnings from HIV CABs run in parallel or not?</li> </ul>
<b>Reach</b>	<p><i>If the first decade of the CAB's work had the most impact on study design and equity (early access, pricing)—what should the focus of the next decade be?</i></p> <ul style="list-style-type: none"> <li>• <b>Follow Up:</b> Who are the most important stakeholders for the CABs to engage with, and why?</li> </ul> <p><i>COVID has hugely disrupted everything and may have set back years of on-the-ground progress for TB detection, treatment, and management. In this era, how would you set a goal for the CAB's reach?</i></p> <ul style="list-style-type: none"> <li>• <b>Follow Up:</b> What objectives would you set in an incubator-like environment to test the next version of the TB CAB in this post-pandemic world?</li> </ul> <p><i>Connection to local communities—this is challenging for a global CAB. What is needed to “funnel up” and connect CAB members to be a truly representative global body?</i></p>
<b>Future</b>	<p><i>What other needs do you see for the future around ownership and growth?</i></p> <p><i>What would you hope to see for the TB CAB in 20 years?</i></p>
<b>Final Question</b>	<p><i>Anything else I didn't cover?</i></p>

Thank you for your valuable time and information, and work on behalf of the millions of people fighting TB this very day.

# Appendix 2: Quantitative Survey

## 10-Year TB CAB Evaluation

The Global TB Community Advisory Board (TB CAB) is dedicated to increasing community involvement in tuberculosis (TB) research and to mobilizing political will regarding key TB product development issues. The TB CAB is comprised of TB research-literate activists from Mexico, Peru, the United States, Ukraine, Moldova, Russia, Côte d'Ivoire, Kenya, South Africa, Zimbabwe, India, and Indonesia who are extensively involved in HIV and TB community networks.

The broad goals of the TB CAB are to interact strategically with developers of TB drugs, diagnostics, and vaccines at key moments in the development process; influence research and roll-out decisions from a community perspective; and bring special attention to neglected populations.

To help us reflect on the first ten years of the TB CAB, we are so grateful that you have opened this survey. Please take the next ten minutes to honestly reflect on your experience engaging with the TB CAB directly and/or observing the work of the TB CAB from a distance and provide your recommendations on where the next decade should take us.

Your survey response is anonymous and will not be connected to your identity. All responses will be analyzed in aggregate. Your completion of this survey will serve as consent to take part in our evaluation of the TB CAB. Thank you in advance for your time.

---

**Are you familiar enough with the Global TB CAB to answer a series of questions on their impact to date, and ideas for the future going forward?**

- Yes
- No

*Skip To: End of Survey if "Are you familiar enough with the Global TB CAB to answer a series of questions on their impact to..." = No*

---

**What is your gender?**

- Male
- Female
- Other

---

x→

**In which country do you currently reside?**

▼ Afghanistan ... Zimbabwe

---

**What is the highest degree or level of school you have completed?**

- Less than a high school diploma
  - High school degree or equivalent (e.g. GED)
  - Some college, no degree
  - Associate degree (e.g. AA, AS)
  - Bachelor's degree (e.g. BA, BS)
  - Master's degree (e.g. MA, MS, MEd)
  - Doctorate or professional degree (e.g. MD, DDS, PhD)
- 

**Are you...**

- A current TB CAB member
  - A former TB CAB member
  - A TB survivor/family member of a TB survivor
  - Member of civil society or community-based organization
  - A policymaker, implementing partner, or part of a technical body or organization
  - A researcher
  - A research funder or other donor
  - A product developer
  - An industry partner
  - Other (please describe) \_\_\_\_\_
- 

**What is your current employment status?**

- Employed full time (40 or more hours per week)
  - Employed part time (up to 39 hours per week)
- 

***Display This Question:***

***If "Do you currently work in a field related to tuberculosis (TB)?"  
= Employed full time (40 or more hours per week***

**How many years have you worked in TB?**

---

---



---

**How much have you interacted with the TB CAB?**

- A great deal
  - A lot
  - A moderate amount
  - A little
  - Not at all
- 



**How many years have you interacted with the TB CAB?**

How many years have you interacted with the TB CAB?

---

---

What year was your first interaction with the TB CAB?

---

---

What year was your most recent interaction with the TB CAB?

---

Over the past ten years, how much impact has the TB CAB had on the following target areas?

	A great deal	A lot	A moderate amount	A little	None at all	Not Enough Information to Comment
Global policy making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Translation of global policy at the national level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevating community voices in translation of TB policy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB research design	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevating community voices in TB research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB research agenda at the global level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB drug access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB diagnostic access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fair pricing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incorporating community priorities into TB initiatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Over time, how has TB CAB engagement in the following areas changed? The TB CAB's engagement in \_\_\_\_\_ has become....

	Much better	Somewhat better	About the same	Somewhat worse	Much worse
Global policy making	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Translation of global policy at the national level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevating community voices in translation of TB policy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB research agenda at the global level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB research design	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevating community voices in TB research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB drug access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB diagnostic access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fair pricing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Incorporating community priorities in to TB initiatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

**In thinking about community engagement in TB research, overall from 2011 - 2021, to what extent has it increased over time?**

- A great deal
  - A lot
  - A moderate amount
  - A little
  - None at all
- 

**In thinking about community engagement in TB research, overall from 2011-2021, to what extent can any increase be attributed to the TB CAB?**

- A great deal
  - A lot
  - A moderate amount
  - A little
  - None at all
- 

**In thinking about community engagement on access issues for TB (translation of research to policy, access to new technology) overall from 2011-2021, to what extent has it increased over time?**

- A great deal
  - A lot
  - A moderate amount
  - A little
  - None at all
- 

**In thinking about community engagement on access issues for TB (translation of research to policy, access to new technology) overall from 2011-2021, to what extent can any increase be attributed to the TB CAB?**

- A great deal
  - A lot
  - A moderate amount
  - A little
  - None at all
-

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How has the TB CAB contributed to overall community engagement in TB research and/or programs?

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How has the TB CAB influenced your personal or organization's perceptions of the value of engaging community in TB research and/or programs?

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Rate the following **PLANNING** and **PROCESS** aspects of the TB CAB:

	No improvements needed	Some improvements needed	Improvement definitely needed	Not enough information to say
Information about TB CAB membership and leadership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inclusiveness of process	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding of what the CAB is working on	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diversity of membership	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Information about TAG's role in the TB CAB	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Equity (all voices heard)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collaboration (shared decision-making)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Please describe what improvements you recommend, if you indicated improvements are needed:

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Rate the following DELIVERY and QUALITY aspects of the TB CAB:

	No improvements needed	Some improvements needed	Improvement definitely needed	Not enough information to say
Frequency of CAB's engagement activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Intensity of CAB's engagement activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Presence and participation in research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Presence and participation in policy making decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Presence and participation around TB drug/ diagnostic access	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Equity (all voices heard)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Benefits to CAB Members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Please describe what improvements you recommend, if you indicated improvements are needed:

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What are some of the benefits of being involved in/with the TB CAB?

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Considering the first ten years of the TB CAB, and looking to the next decade, what are the TB CABs:

Strengths \_\_\_\_\_

Weaknesses \_\_\_\_\_

Opportunities \_\_\_\_\_

Threats \_\_\_\_\_

How would you advise the TB CAB for growing/maintaining/changing the balance of activist energy and strategies with their skills in scientific engagement?

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How would you recommend that the CAB invest their time and effort in some the following areas over the course of the next decade?

	Little to no investment of time or effort	Some investment needed	Definitely should invest time and effort on this issue	Not enough information to say
Optimizing access to the latest generation of TB technologies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the impact of COVID on TB care/services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understanding the impact of COVID on TB research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helping to shape the research agenda for TB implementation projects	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TB Prevention initiatives - Vaccines/Preventive Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Contributing to access frameworks for product development sponsors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting a seat at the table for global funding discussions around TB research	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Capacity building/training/networking with local NGOs/agencies/CABs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Navigating political environments and networks to increase access to TB technologies	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Addressing and reframing how TB civil society engages with historical frameworks (e.g. shifting the balances of power from North to South)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

In closing, please share what you think the biggest accomplishment of the TB CAB's first decade is:

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