



TB CAB 10th anniversary

Chapter 2

Bactrin Killingo:

I'm Bactrin Killingo, a founding member of the Global TB CAB. This is the second chapter of a three-part series reflecting on the first 10 years of the Global TB CAB. Together with Mark Harrington, co-founder and Executive Director of Treatment Action Group, we will explore the important role the TB CAB has played in shaping and moving science forward and pushing for the rights of communities affected by TB to health and the benefits of scientific progress. The myriad of voices contained in these podcasts are from key stakeholders interviewed as part of an evaluation of the TB CAB; they have been re-created and de-identified to preserve their anonymity.

Mark Harrington:

Our previous chapter ended in 2011, when the Global TB CAB was first convened. Back then, the involvement of community representatives in TB research advocacy was still uncommon. But TB activism isn't lonely work anymore. Over the past decade, 37 people from 18 different countries have served on the Global TB CAB, including representatives from Brazil, Russia, India, China, and South Africa – all of them middle income countries with large economies that together bear almost 50% of the world's TB burden. The TB CAB chairs and leadership over the past decade have included activists from South Africa, Kenya, Côte d'Ivoire, and Peru.

And that's just the Global TB CAB. National and local CABs are now engaged in TB research and advocacy activities and growing and vibrant networks of TB survivor, activist, community, and civil society groups across the globe engage

with TB research and development efforts and push their governments for access to new TB tools and innovations.

Bactrin Killingo:

And as the TB CAB 10-Year Anniversary Evaluation Report reveals, our first decade has been an eventful one. In this episode, we'll explore the four key findings of the report, which emerged through detailed interviews with former and current CAB members, and other stakeholders that have worked with the TB CAB at various points since its inception, and which were confirmed using a quantitative survey. The methodology is described in greater detail in the report itself, which is available on the TAG website.

So, the four key findings, which we will explore one by one are as follows: one, that the Global TB CAB is considered a *seasoned technical partner*, two, that can help affected communities occupy an *equal seat at every table*; and three, that by using *a range of proven advocacy methods and tactics*, four, the TB CAB has become *an agent of change in TB R&D*.

Let's explore these.

Bactrin Killingo:

The first finding of the report is the importance of the role the TB CAB plays as scientific advocates, capable of elevating community perspectives, needs, and priorities in TB R&D. Feedback from researchers, funders, product developers and others made it obvious that the TB CAB has successfully become a seasoned technical partner.

Mark Harrington:

One of our objectives with the TB CAB was to create a community based and science informed advisory mechanism that drew on people's strengths.

Some early members had extensive knowledge from their previous experience as HIV treatment activists. Others had lived experience undergoing (or caring for people that had undergone) TB diagnosis and treatment, and so could speak directly to the shortcomings of existing TB diagnostic tests and treatment regimens.

The TB CAB has always spent a lot of time building its members' TB knowledge and capacity, deepening the group's understanding of TB, its co-infections, such as HIV, the biology of TB in the body, and regulatory, normative, and research processes. And these efforts have paid off: 71% of survey respondents believe that the TB CAB has influenced the TB research agenda a lot, or a great deal. And 60% said the same about research design. Here's how one researcher discussed the topic:

Anonymous Key Informant Voice 1015:

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 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, the TB CAB's feedback is better than the feedback we get from the Scientific Advisory Committee for a particular set of projects, and better than, you know, the Data and Safety Monitoring Board.

Mark Harrington:

Interviewees noted how important it has been that the TB CAB combines scientific knowledge with community and patient perspectives. Here's a product developer and another researcher:

Anonymous Key Informant Voice 1004:

The Global TB CAB is unlike a lot of community advisory boards, which tend to be very kind of access oriented -- the TB CAB has always struck me as having a much stronger kind of clinical and scientific orientation to products, it has a much more rigorous scientific dialogue, which, frankly, I've always appreciated.

Anonymous Key Informant Voice 1013:

It's just amazing to see, as scientific folks, we tend to focus on one specific area, and, sometimes, forget about the patients. Having a TB CAB looking at the study protocol from the eyes of patients, and said, "all right, this is something to improve," it just made the protocol much stronger. So, it has been a very valuable input.

Mark Harrington:

That last part – evaluating science from the perspective of people affected by the disease – is central to our work. Community participation in research, and as more than study participants, is a human right and ensures that research has social value and is ethical.

Bactrin Killingo:

And that leads us to the report's second key finding: that the Global TB CAB is well positioned to help communities affected by TB occupy an equal seat at every table. One former TAG staffer described how the presence of community changes the dynamics of TB research and policy discussions and decision making:

Anonymous Key Informant Voice 1028:

This is where I do think the lived reality of people who have experienced TB does change the tenor of the conversation. Because you can't just say, "well this is unimportant because it happens to a miniscule population." Because if that miniscule 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 life does not go in vain. And so it does change the type of conversation that happens around TB, especially the working groups I was part of.

Bactrin Killingo:

The report found that a majority of the stakeholders interviewed and surveyed think the TB CAB should facilitate connections between community advocates and key R&D decision makers. Each of the stakeholder types interviewed expressed the desire for the TB CAB to formalize some type of mentoring system capable of increasing community access points in TB R&D. 73% of survey respondents felt that in the coming decade, the TB CAB should definitely invest time and effort into grassroots capacity building.

But these access points are rarely just handed to us – as one researcher put it:

Anonymous Key Informant Voice 1016:

I feel like sometimes people forget that it wasn't necessarily the easiest process, right? It wasn't like everybody said, 'Oh welcome, please come sit at the table with us'. Like, people fought really hard to have a seat at this table.

Mark Harrington:

Over the TB CAB's first decade there definitely was an evident change in people's perceptions and practices of community engagement in TB research among scientists, product developers, research funders, and other stakeholders. This shift catalyzed by the TB CAB has taken us from a situation where we had to work hard just to get a sit at the table to one where our presence has been normalized although it's not always met with the same level of respect as other stakeholders around the table.

Every stakeholder has their own interests and goals – so not everyone always agrees, and at times the community perspectives are given the least weight. Which brings us to report finding number 3, the importance of the range of proven advocacy tactics that the TB CAB has used to make change happen.

To reach and influence research funders, product developers, and policy makers, and to rebalance the weight assigned to these perspectives compared to those of the affected communities, the TB CAB employs a range of strategies. These include closed discussions and letters, protocol reviews, open letters, and when needed, direct action demonstrations and public campaigns. One Emeritus CAB member explains why it is important to use this kaleidoscope of actions.

Anonymous Key Informant Voice FG1:

I think smart activism has probably been very successful over time. No one would disagree with 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 overall, I think strategic thinking on when to push which buttons was pretty good.

Bactrin Killingo:

Part of the success of the TB CAB's escalation pathway is that, when necessary, it can be used to expose a specific issue when consensus can't be reached – thereby shifting the dynamics to forge a path forward.

One of the product developers interviewed described an instance where even just observing another stakeholder being publicly held to account by the TB CAB shifted perceptions and willingness to engage with community groups like the TB CAB across the field.

Anonymous Key Informant Voice 1020:

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 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 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.

Bactrin Killingo:

That tension as a driver of change is not always welcome. The report found that, while nearly all people interviewed understood and appreciated the TB CAB's work, their approach – especially the various steps along the escalation pathway, when things went from closed to open discussion and even public demonstrations -- has created some controversy.

The report describes one specific relationship that emerged as problematic, without prompting or probing key stakeholders interviewed for information; the product developer in question has been perceived as not valuing the TB CAB's input, and objecting to the manner in which community priorities are delivered. This illustrative quote from the product developer details their objections:

Anonymous Key Informant Voice 1007:

And so, I think that the difficulty in this whole area is, how do you have broadened perspective, which implies different points of view? And how do you manage the give and take and the dialogue and the realization that not everyone is going to agree, okay. And just because you don't agree does not mean you have to be

disruptive and uncivil.... And sometimes I have the sense that, you know, there's people that are not versed in product development, that 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.

Mark Harrington:

This split is inherent to our work – it always has been, and it always will be. For example, back in 2001, TAG joined a group of activists including South Africa's Treatment Action Campaign calling on pharmaceutical giant GlaxoSmithKline (now GSK, co-owner of ViiV Healthcare) to stop supporting the International Pharmaceutical Society's lawsuit against the South African government. The lawsuit was trying to prevent that sovereign nation from manufacturing its own generic drugs to combat HIV and other diseases. GSK was displeased by our vocal advocacy and for a number of years thereafter, they stopped funding grants to support TAG's work.

However, the activists won -- GSK and the other pharma companies dropped the lawsuit, helping to set the stage for the rollout of generic antiretroviral treatment in South Africa in 2002 and 2003.

Ultimately, these clashes reflect diverging interests and different theories of change. Those in power – the people who make drugs or diagnostic tools, or the people who decide who gets access to them – too often believe that they can make the right decisions on their own terms and deserve patience and deference along the way – however long it may take. But HIV and TB activists know all too well how complacent power can be – especially when it comes to a disease whose burden falls disproportionately on the poorest people on Earth. The TB CAB's job is to build outside pressure to change anger into action, and to serve the interests of people living with and at risk of TB. That responsibility compels us to build productive relationships with stakeholders, including product developers. But those relationships won't always be easy or comfortable.

Bactrin Killingo:

But in the end, that discomfort can be effective – as emphasized by the report’s final key finding: that the TB CAB has become an agent of change in TB research and development. As another product developer noted, transformative change is often because of – not despite – the tensions between them and the TB CAB.

Anonymous Key Informant Voice 3:

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. A lot of the things we did, and the announcement we made, we probably would not have, had it not been for advocates.

Bactrin Killingo:

And, respondents agreed, the TB CAB delivered real results. One product developer noted how CAB’s focus on pediatrics impacted the field:

Anonymous Key Informant Voice 1020:

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 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 result of TB CAB, right? Like, you can absolutely see that link.

Bactrin Killingo:

Another researcher agreed:

Anonymous Key Informant Voice 1017:

The TB CAB recommended including adolescents. And that was a change to the original 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 it just made sense and would improve the study with essentially no downside. In doing that it accommodated a desire of TB CAB and of the community and changed the minds of a number of investigators who were just used to 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 important and turned out to be very effective from the TB CAB.

Mark Harrington:

But the TB CAB's greatest impact has been the influence it has had in shaping the trajectory of a new drug called bedaquiline. Bedaquiline is the first new TB drug from a new class in over 40 years, and its development has ultimately transformed the way that drug-resistant tuberculosis is treated, saving the lives of thousands of people living with drug resistant TB. That's going to be the story of Episode 3, up next.

VOICE ACTOR:

This podcast is produced by Treatment Action Group (TAG), with the support of Laia Ruiz Mingote and Alex Orozco.

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