





RESEARCH ARTICLE

Integrating tuberculosis research with public health infrastructure: Lessons on community engagement from Orizaba, Mexico [version 1; peer review: 1 approved, 1 approved with reservations]

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Abstract

Background: The Orizaba Health Region, in Veracruz, Mexico, has hosted the research programme of the *Consortio Mexicano contra la Tuberculosis* since 1995.



Methods: The objective of this retrospective case study conducted in 2009 was to describe and explain the evolution and outcomes of the stakeholder and community engagement activities of the *Consortio*. Recorded interviews and focus groups were coded to identify major themes related to the success of stakeholder and community engagement activities.


Results: The *Consortio* successfully managed to embed its research program into the local public health infrastructure. This integration was possible because the core research team tailored its engagement strategy to the local context, while focusing on a large spectrum of stakeholders with various positions of authority and responsibility. The overall engagement strategy can be described as a three-pronged endeavor: building a “coalition” with local authorities, nurturing “camaraderie” with community health workers, and striving to be “present” in the lives of community members and participants.


Conclusions: The *Consortio*'s efforts teach valuable lessons on how to approach stakeholder and community engagement in tuberculosis (TB) research, particularly in developing countries. Furthermore, the health outcomes reveal stakeholder and community engagement as a potentially under-tapped tool to promote disease control.

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Any reports and responses or comments on the article can be found at the end of the article.

Keywords

Tuberculosis, community engagement, community health workers, public health, community participation, qualitative research, research ethics

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Introduction

In the mid-1990s, it became clear that new initiatives were needed to step up the fight against TB in Mexico. The country’s TB strategy, established in 1973¹, came under scrutiny from a 1997 World Health Organization (WHO) Global Tuberculosis Programme evaluation², which led to recommendations to improve the policies and management practices of the country’s National Tuberculosis Prevention and Control Program. At the time, public health authorities around the world were confronting serious threats in the fight against TB: lack of precise, affordable diagnostic tools; long and demanding treatment regimens; multi-drug resistance; and high rates of latent TB. Against this backdrop, a group of Mexican researchers set out in 1995 to create the *Consortio Mexicano contra la Tuberculosis* (Mexican Consortium Against Tuberculosis), a scientific partnership that aimed to tackle some of the country’s most pressing TB challenges.

The work of the *Consortio* spanned almost two decades and resulted in significant contributions. One of these was the prospective evaluation of the effectiveness of the WHO’s Directly Observed Therapy – Short course (DOTS) strategy, a project that began as a pilot program led by the Mexican health authorities in Orizaba, Veracruz³. The study provided the *Consortio* with an opportunity to assess the impact of the DOTS strategy on the transmission of tuberculosis in areas with moderate rates of drug-resistant strains³. The pilot program’s success contrasted spectacularly with the mixed results of the previous control program, reducing TB incidence by more than half³. These results prompted the *Consortio* to wonder what factors might have played a role in the high success of the DOTS strategy in Orizaba. Though stakeholder and community engagement (CE) had not been an explicit focus of the *Consortio*⁴, its investigators wondered whether the nature of their interaction with the community might have contributed to the success of the research intervention.

The CDC has defined community engagement as “the process of working collaboratively with and through groups of people

affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people through partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for changing policies, programs, and practices”⁵. CE has become acknowledged as a cornerstone of ethical global health research, and it is increasingly gathering the attention of the TB research community specifically. Concerns have been reported in the literature over the fact that relatively few research sites have expertise in the appropriate conduct of TB research⁶. For this reason, it is crucial that lessons be drawn from the few sites that have such expertise⁷. In 2009 members of the Ethical, Social and Cultural Program for the Bill & Melinda Gates Foundation’s Grand Challenges in Global Health Initiative^{8,9} (RFB and JVL), were invited by *Consortio* representatives to conduct a retrospective case study of the Orizaba DOTS trial to explore the contribution of stakeholder and community engagement to its outcomes. This paper presents the findings from this case study.

Methods

Study setting

The *Consortio* conducted its studies in the Orizaba Health Jurisdiction in the centre of the state of Veracruz (see [Table 1](#) and [Table 2](#)). The study area covered 618.11 km² with a population of just over 400,000 encompassing five urban centres (Ciudad Mendoza, Nogales, Río Blanco, Orizaba, and Ixtaczoquitlán) and their surrounding rural areas, totaling 12 municipalities¹⁰. At the time of fieldwork (2009), the urban region was better developed than the rural communities, where people were living more marginally. For example, several indicators, such as percentage of households without access to municipal water, percentage of households with earthen floors, or average years of formal schooling were better for urban than for rural areas (6% versus 18%, 8% versus 21%, and 9 years versus 7 years, respectively)¹¹.

The *Consortio* initiated a population-based molecular epidemiology study to determine the dynamics of tuberculosis

Table 1. Characteristics of the study region.

Jurisdictional name	Orizaba Health Jurisdiction
Urban centres	Ciudad Mendoza, Nogales, Río Blanco, Orizaba, and Ixtaczoquitlán
Size	618.11 km ²
Population	400,000 (approximately)

Table 2. Development indicators of the Orizaba Health Jurisdiction (2009).

Variable	Rural	Urban
Households without access to municipal water	18%	6%
Households with earthen floors	21%	8%
Average years of formal schooling	7 years	9 years

transmission in the Orizaba region. Among other reasons, the study area was selected by the *Consortio* because the National Tuberculosis Program had chosen Orizaba as a pilot area to test the feasibility of implementing the DOTS strategy. This provided a promising opportunity to study tuberculosis transmission in the context of an established tuberculosis control program.

Sample and recruitment

Based on their affiliations or interactions with the *Consortio*, 17 key informants were purposely sampled and interviewed in their homes, offices, rural clinics, or public health facilities. Informants were either previous research participants of one of the *Consortio*'s trials or directly affiliated with the *Consortio* (community health workers, physicians, health authorities, or staff members). Potential participants were identified by the host research team (LGG, LFR, SCQ) and contacted to determine their willingness to participate in the study prior to the site visits. To be eligible, potential participants had to have been directly exposed to the activities of the *Consortio*, either as a research participant or as a partner. There were no formal exclusion criteria.

Data collection

To explore the various features of the *Consortio*'s community engagement process, we used open-ended interviews, focus groups, and field observations. These were carried out between September 2009 and March 2010.

Interviews lasted between 30 to 90 minutes. All interviews, with the exception of one, were conducted in Spanish with an interpreter affiliated with the *Consortio*. In addition, RFB is a competent Spanish-speaker. The other interview was conducted in Náhuatl, with the help of two interpreters (Náhuatl-Spanish, Spanish-English). During the interviews, staff members affiliated with the *Consortio* were present and often facilitated the discussion. Interviews with trial team members, public health officials, etc., were carried out in the offices of the interviewees. Interviews with trial participants were conducted in the homes of the interviewees.

We also conducted two focus groups with community health workers and the main *Consortio* trial management team, and we accompanied community health workers for follow-up visits with trial participants. Each focus group took between 45 and 90 minutes. Over the course of these data collection activities we spent 6 full days visiting participants' homes, public health authorities, local hospitals and clinics. We also conducted intensive debriefings after each day of interviews, during which we posed supplementary questions and, as a group, began some preliminary conceptualizations of the interview findings and field observations. Interviews and focus groups were not repeated.

Analysis

Audio recordings and hand-written notes were made for each interview. The recordings were then transcribed verbatim and translated by a professional agency (GMR Transcription) and were verified by RFB. Initial coding of interview transcripts

was conducted by RFB using the qualitative data software ATLAS.ti version 5.2. Subsequent analysis, interpretation, and re-coding of the data were conducted by RFB and JVL in Toronto, Canada. Through analysis meetings and iterative drafting, key concepts and themes were identified in the data and a "best fit" interpretation was developed. Quotes from various informants have been chosen to best represent the themes explored. The number in brackets following each quote indicates the interview from which the data are drawn; CHW indicates a community health worker, CS indicates a *Consortio* staff, PHA indicates a public health agent (e.g., government epidemiologist, physician), PT indicates a participant in the *Consortio*'s research activities.

Ethics approval and consent to participate

Written and verbal informed consent was obtained from all participants. The study was approved by the Research Ethics Board of the University of Toronto. It was part of a larger research program that included a series of case studies with similar methods¹²⁻¹⁴.

Results

Initial barriers to community engagement

Fragmentation of the healthcare system. When the *Consortio* arrived in the Orizaba Health Region, the health sector lacked effective coordination and communication, with fragmented service provision. At the time, a tuberculosis patient might be served by any of four institutions, depending on their insurance status¹. This contributed to a poor reputation among patients. For the *Consortio* it quickly became clear that "*The first thing we would need to do is create a group and work together*" [I12, CS] because "*the people in the community commented and kept saying, 'How can we trust you if you don't come to an agreement?'*" [I12, CS]

Limited tradition of interaction with the health sector.

Several of our community informants reported that they had grown accustomed to being ignored by the public health system. In one of the more remote villages of the Health Region, a community health worker explained that prior to the arrival of the *Consortio*, her community was:

"...one of the communities that was never visited by a policy chief before. We know that we live at a distant place and sometimes officials don't pay attention to us, even though we are all at risk of getting sick." [I7, CHW]

At the time of our fieldwork, recent moves to decentralise the Mexican health sector¹⁵ appeared to be largely unsuccessful at overcoming these experiences of marginalization, and at encouraging communities to be more proactive in seeking care. Consequently, the initial presumption of the *Consortio* leadership that it would be possible for the initiative simply to use the existing community engagement infrastructure of the public health service to reach marginalized communities was quickly dispelled.

Indigenous communities' distrust of outsiders. Attitudes of distrust in remote communities were most pronounced among

indigenous communities. One investigator described how the *Consortio* first had to gain the trust of the residents of a small village by going from door to door to discuss respiratory diseases before the research itself could begin. For this to work well, *Consortio* workers had to enlist the help of a local resident to act as an intermediary:

“When we first got here, they didn’t open their doors for us. We had to get one of them to open the doors for us. We had to explain it to them first.” [I4, CS]

In the indigenous populations, language barriers were also an obstacle to community engagement. In particular, some feared that the need to rely on mediators might increase the risk of misunderstandings that could undermine the future success of the *Consortio*’s projects.

Fear of TB-related stigma. The *Consortio*’s researchers also had to navigate through the ambiguous relationship local communities had with tuberculosis itself. On the one hand, people generally lacked direct, or experiential, knowledge of the disease, which limited their capacity to recognise symptoms. These were frequently downplayed or dismissed:

“I had a cough for three years and thought it was normal because it was cold outside and I got wet working.” [I4, PT]

“Having a cough, it’s normal for them...there is a tolerance for cough.” [I4, CHW]

On the other hand, interviewees were well aware of the contagious nature of tuberculosis and of the stigma attached to it, which further complicated case finding:

“Sometimes the person will say in fear: ‘Why go to the Health Center if I know I have tuberculosis and will be shunned by the people? It is better for me to stay at my house and see what happens.’ There are people like that.” [I5, PT]

Fear of stigma also limited the opportunities for open discussions with patients about TB:

“He didn’t say he had tuberculosis, he said he had a cough. If he were to tell people that he had tuberculosis, they will think that he will infect them. People may not want to be near him or come to visit him. He is not embarrassed, he is just afraid that they won’t get near him for fear of being contagious.” [I4, CHW]

Towards a common purpose: Building a coalition to support tuberculosis research

After selecting the Orizaba Health Region as a research site in the mid-1990s, the *Consortio* team began to build a supportive coalition of leaders of local health agencies and organisations to explore how the *Consortio* could contribute to improvements in TB-related infrastructure and service-delivery, for example, by providing improved diagnostics and outreach

to marginalized populations. The *Consortio* then undertook a second phase of coalition building, reaching out to other sectors (including the educational, financial and agricultural sectors) to strengthen the overall buy-in of local communities.

Phase One: Enlisting the support of local health authorities.

Tuberculosis was a recognised problem in the Health Region, but local epidemiologists feared that they “did not know the percentage of patients afflicted with tuberculosis in the region” [I13, PHA] and that they did not have the infrastructure to collect and analyze the necessary data. The local standard of care was also seen as sub-optimal:

“The treatment was very painful for patients. It involved injections...and sometimes the patient left the treatment because of the difficulty of the treatment.” [I12, CS]

Poor accessibility and affordability of treatments also undermined control efforts:

“In the beginning, before the Consortio and the Social Security centre, if people got sick, they had to go to Mendoza. The medical assistance was expensive. The patient would have to pay for the treatment and the diagnosis. They would give the drug only for one month. The risk was that the patient could not pay every time for the visit and the treatment.” [I4, CHW]

The *Consortio* was interested in determining whether the DOTS approach recommended by the World Health Organization would be viable locally. This offered an important opportunity to address health authorities’ concerns about inadequate treatment. In addition, other influential scientists were concerned by the “high percentage of patients with drug resistance without any prospect for treatment” [I13, PHA]. For these scientists, there was a clear “problem with public health” [I13, PHA], and the research projects of the *Consortio* offered a potential solution. By making the case that “the reasons to conduct the investigations were practical, believable, and that there would be enough resources for the continuation of the program” [I11, CS], the investigators of the *Consortio* demonstrated their responsiveness to the agenda of local health authorities.

Second, the resources the *Consortio* would bring to the Health Region also proved to be a strong incentive for prospective collaborators. It was clear from the outset that *Consortio* trials would require technologies and infrastructure and laboratory capacity that were previously unavailable locally. For example, rapid diagnostic capacity for drug-resistant strains needed to be expanded. The *Consortio* investigators assured the health authorities that the new laboratory spaces necessary to complete the trials would be made available to the public health system following the research initiatives.

Third, the prestige of hosting a highly promising research consortium, funded in part by prominent international sponsors, also appeared to play a role in the health authorities’ decision to partner with the *Consortio*:

“It was an honor that the National Institute of Public Health [Instituto Nacional de Salud Pública] should have chosen us, taking into account that there are so many jurisdictions throughout Mexico.” [I12, PHA]

Phase two: Reaching out to other sectors. After securing the support of the major public health stakeholders of the Orizaba Health Region, the *Consortio* sought to collaborate with other partners, such as municipal governments, the Orizaba chamber of commerce and regional agricultural associations. The aim of this broader engagement was to promote strong public appreciation of the social and economic significance of TB and help ensure that the lengthy trials that the *Consortio* planned to conduct would have broad and deep support locally. Important support came from the education sector. Because the *Consortio* conducted studies involving schoolchildren, it was important to have the support of teachers and parent associations. Support was also obtained from the local medical, nursing, and pharmacy schools. The *Consortio* offered students opportunities to conduct small clinical studies, to gain experience with epidemiological studies, and to practice laboratory skills. Some of the students who were trained by the *Consortio* later joined as staff or interacted with the *Consortio* in some other capacity (e.g., after having joined the health system in the study area).

Phase three: Sustaining partnerships. Once the coalition of public health service partners was formed, the *Consortio* understood that it would need to work actively to sustain it. The *Consortio* delivered on its promise to improve the public health system’s ability to manage the regional tuberculosis epidemic. Laboratory testing times were reduced, in some cases from four weeks to two days. More sensitive diagnostic techniques were introduced, which allowed the detection of cases that would otherwise have gone undiagnosed. The *Consortio*’s research protocols also expanded the scope of existing treatment programs, since they included outreach to marginalized communities using community health workers. It was also instrumental in Orizaba’s inclusion in the WHO Green Light Committee Initiative/Mexican Tuberculosis Prevention and Control Program for provision of second line drugs, a move that resulted in important improvements in the treatment of drug resistant TB locally. These tangible benefits played a significant role in fostering trust and credibility in the *Consortio*, and in revealing the extent of the tuberculosis epidemic in the region.

Building from the ground up: Nurturing camaraderie with the community health sector

By securing the support of the relevant health authorities and making them champions of the project, the researchers leading the *Consortio* gained preliminary access to the social and physical infrastructure of the public health system necessary to conduct their studies. The mobilization of the community health sector made the large-scale research initiatives of the *Consortio* possible by effectively increasing its human resource pool. But while the *Consortio* initially harnessed the commitment and infrastructure of the community health sector by engaging the health authorities, the relationship between the *Consortio* and the de-centralized public health

sector was far from top-down. Instead, meaningful engagement of the community health sector was an integral component of the overall engagement strategy of the *Consortio* in the Orizaba Health Region.

In particular, the *Consortio* leadership quickly understood that community health workers (CHW) could serve as ideal intermediaries between the public and the *Consortio* research staff. Before the arrival of the *Consortio* to the study area, CHWs conducted home visits periodically for public health purposes, such as the identification of chronic coughers, vaccination, vector control, infant nutrition, and cholera surveillance. As part of the *Consortio* protocols, CHWs were asked to recruit and follow up participants. Each time a patient dropped out of treatment, the CHW who had initially invited that patient to participate in the study was sent to visit him/her at home to discuss the importance of continuing treatment. CHWs received training to enable them to identify cases of persistent cough in the community. In addition to this general outreach, they were also sent periodically to visit shelters, jails, orphanages, self-support groups for patients with diabetes, and alcohol drug dependencies. In those locations, they explained the purpose of the study and identified coughers.

The initial strategic partnership between the *Consortio* and the community health sector quickly evolved into true ‘camaraderie’, with close friendships, trusting relationships, and a strong sense of common purpose. One of the physicians working with the *Consortio* said:

“We are like brothers. Earlier, I went to say hello to [a prominent Consortio member] with a hug and kiss...They are very polite and helpful. We exchange pamphlets and if there is something we don’t know about we ask them to explain it. There are no arguments or misunderstandings.” [I9, PHA]

Warm and openly friendly relationships—what we have termed camaraderie—were evident in all the exchanges we witnessed between the representatives of the *Consortio* and the members of the community health sector. The *Consortio* staff nurtured this camaraderie by diligently living up to the promises they made to the community health workers:

“[The Consortio researchers] keep their word. They come when they say they will, they go visit a patient when they tell me they will. That’s why we try to work together with them as a team.” [I4, CHW]

In the context of the scarcity of health services and the marginalization described above, such reliability held particular importance to community health workers who saw it as a powerful gesture of respect and solidarity. This view was reciprocated by the *Consortio* workers, who were impressed by the CHWs’ commitment to the well-being of local residents:

“We want to help people who don’t have the economical support or don’t have the opportunity to come to our clinic.” [I9, CS]

“I wanted to help my community and I like doing it.” [I9, CS]

The camaraderie between the *Consortio* and the community health workers was facilitated by a common view of the social importance of their public health mission. The shared commitment to the health of marginalized populations was evident throughout our interviews and field observations, and the *Consortio* also provided other important opportunities for community health workers by providing specific educational sessions and by facilitating the CHWs' access to patients in the community.

Ultimately, then, the *Consortio* provided an opportunity and the necessary means to catalyze the efforts and motivations of the community health sector towards the common goal of addressing the local TB epidemic:

"At the end of it all the Consortio has helped us a lot. In our community, I am happy to work with them." [I7, CHW]

Humanising research: Being present in the lives of participants

Just as the *Consortio* presented new opportunities for CHWs, the increased presence of the CHWs and other *Consortio* members was generally seen by prospective research participants as an opportunity to have some of their own unmet health needs addressed:

"Ultimately I wanted my health, so that is what I based my decision on." [I8, PT]

"I have seen in the internet how much it costs for a treatment like this and it is very expensive." [I5, PT]

While a number of study participants reported that they felt an obligation to help others by participating in the creation of new knowledge, most seemed to be keen to participate in the *Consortio*'s studies primarily because the public health system had failed them. For example, after having to see three different doctors to get a correct TB diagnosis in the public health system, a patient enrolled in the *Consortio* study reflected on the invitation she had received to join one of the trials:

"I said they could do whatever they wanted because I felt ill and I really needed the treatment so I signed." [I1, PT]

During fieldwork, it became clear very quickly to us that patients in remote areas had not been accustomed to the kind of personal attention they had received from the CHWs and the other *Consortio* workers during their participation in the trials. Although their enrolment might have been motivated initially by improved access to healthcare, it appeared that participants had rapidly come to trust the *Consortio* and recognised that the *Consortio*'s approach was shaped by a deep commitment to respectful treatment of all participants.

Establishing a presence in the community. With the frequent visits of team members and the home visits of the community health workers, the *Consortio* established an unprecedented presence in the participating communities. The increased presence was particularly obvious in outlying rural communities,

where access was generally more challenging. For example, during the rainy season, roads became dangerous and transportation was scarce. Many times, community health workers and study personnel walked long hours to be able to visit a patient who had missed an appointment. Community members we met commented frequently on the humility of the *Consortio* team and their willingness to devote much of their time to them. A former tuberculosis patient who mentioned how difficult it had been to access regular healthcare described the experience:

"They [the Consortio] were willing to come to me...this place is still not very well attended by health personnel. So for them to come to tend to diseases way over here, it's very hard to do." [I5, PT]

The *Consortio* leadership also insisted on the establishment of physical contact with participants in an effort to counter stigma and normalize attitudes towards people with TB. This was made explicit in directives to the outreach team. During our visits to participants' homes with the research team and CHWs, we observed that handshakes and hands on shoulders were common practice. The significance of these gestures was not lost on participants. At one home, the mother of a girl who had completed the trial cried as she thanked the research team for not turning away from her daughter when she was sick. The *Consortio*'s presence and the willingness to engage physically with participants seemed particularly important in neglected communities.

"They have helped the patients feel important by going to visit them and making the patients realize that they are not grossed out by them." [I9, CS]

Presence as a form of responsiveness. Even though there was a general understanding that the *Consortio* was conducting important research, the participating communities viewed the sustained interactions and attention they received from the *Consortio* team primarily as signs of its responsiveness to the communities' needs. *"We gained trust, because they would always check us, our blood pressure and everything very well."* [I8, PT] This view was reinforced by the fact that the experience of dealing with the *Consortio* contrasted sharply with that of seeking care in the two public hospitals in the study area:

"[There], they only have interest in you when they are student nurses. I go there and tell them I'm in a hurry and they tell me they are busy. Meanwhile they are sitting there reading the paper and tell me to go sit down until they call on me." [I3, PT]

Such experiences were dehumanizing and traumatic for patients, and they reinforced their perception that they were being actively shunned by the public health system:

"I think they even ignore you...They do not listen to you. They do not explain things the way they should be explained." [I8, PT]

In contrast, *Consortio* representatives were viewed very differently:

“It was more of a friendship. He would say hello all the time to me and we would chat a little.” [I3, PT]

“They were really attentive with us and all I can do is thank them. I have nothing to say. They treated us well.” [I1, PT]

The *Consortio* was also present in local communities in more intangible ways. For instance, the *Consortio* initiative streamlined access to treatment by coordinating the provision of drugs with the public health system and by decentralising care through community health workers and outreach teams. This contributed to the widespread perception that many things seemed better after the arrival of the *Consortio*. Similarly, by discussing tuberculosis openly, the *Consortio* not only helped teach local communities that tuberculosis could be treated effectively, it also helped alleviate the fear of marginalisation:

“The sadness is not there anymore. Fear too. Before we’d ask people to give us some phlegm and they’d say that they didn’t have tuberculosis. It was a fear to say that. Now they happily give it to us.” [I9, CS]

Discussion

The research programme of the *Consortio Mexicano contra la Tuberculosis* offers an opportunity to draw lessons from an initiative that has had experience with the conduct of CE in TB research. The *Consortio* is particularly exemplary in this regard because it successfully integrated its biomedical research projects with the public health system of the Orizaba Health Region throughout its active period from 1995 to 2012. This integration was possible because the core research team tailored its engagement strategy to the local context, while focusing on a large spectrum of stakeholders with various positions of authority and responsibility. This engagement strategy was three-pronged: building a “coalition” with local authorities, nurturing “camaraderie” with community health workers, and being “present” in the lives of community members.

Our findings suggest that the CE approach of the *Consortio* satisfied almost all of the necessary elements of the CDC CE definition⁵. But initially the *Consortio* paid very little attention to stakeholder and community engagement; the leadership did not view it as an integral aspect of their work. The initial impetus for formalizing the CE approach was ethical, but it quickly became clear to the *Consortio*’s leadership that respectful and ethical treatment of all of their stakeholders was also a complex management challenge. Over the course of its evolution, the CE approach became more explicit and proactive and better integrated into the day to day management of the *Consortio*. From that point on, more specific efforts took place and clear expectations were communicated to the team regarding the respectful conduct of outreach. This organic development, although falling short of the more comprehensive recommendations made in the *Good Participatory Practice Guidelines for TB Drug Trials*¹⁶, successfully

led to the establishment of trusting and cordial relationships throughout the *Consortio*’s extensive network of partners and stakeholders.

By presenting itself as an enabling force to help meet local health priorities, the *Consortio* research team secured the support and collaboration of the local public health authorities. As a result, they were able to negotiate access to public health resources, such as collaboration with the community health sector. Given the limited resources of the *Consortio*, it is likely that the necessary recruitment, retention and treatment of research participants would not have been possible without the collaboration of these partners. This collaboration was in turn successfully sustained because the *Consortio* leadership actively promoted a warm and responsive attitude toward all its stakeholders and partners. This attitude emphasized trustworthiness, reliability, and respectful relationships, putting the trial participants’ interests at the centre of all their activities. Simultaneously, given the social and political isolation of several of the communities in which the *Consortio* was active, the human presence made possible by the *Consortio* was deeply meaningful for community members and undoubtedly contributed greatly to their interest in the conduct of the trials.

Overall, this case study provides a number of important insights that may have broader relevance for CE in subsequent TB trials, and possibly in other global health research settings. First, building and sustaining the *Consortio* coalition was facilitated by carefully aligning the research initiatives with local interests and needs. This was the case at a broad level when, for instance, the *Consortio* tested the WHO’s DOTS approach at a time when its applicability and relevance in Mexico were debated. The *Consortio* also sought to understand better the epidemic of multi-drug resistant TB when local authorities began to realize that they had a limited understanding of the situation in the region. But responsiveness was also the case at more local levels, where the *Consortio* leaders spent a great deal of time meeting with local partners, listening to their needs and concerns, and devoting time to exploring potentially constructive ways to leverage the *Consortio*’s value for the region. Although these synergies were largely coincidental, the *Consortio* leaders also had considerable work to do to forge a shared understanding of the potential value among the partners. Importantly, the *Consortio* leadership viewed the local public health authorities, scientific community, education system, and other local leaders and organizations, not simply as potential partners, but also as legitimate stakeholders in the *Consortio*’s research enterprise. This mindset led the *Consortio* to view the establishment and fostering of strong, respectful relationships with these groups as having both strategic *and* ethical significance.

Second, the *Consortio*’s success has been highly contingent on its ability to integrate elements of the existing community health infrastructure. But it was the conscious attempt to nurture camaraderie and respectful relationships with public health workforce, including community health workers, agency

and clinic administrators, physicians, and other volunteers in under-serviced and remote areas of the Health Region, that contributed most to the sustainability of the *Consortio*. The community health sector served, essentially, as the human face of the *Consortio*: it was the *Consortio*'s presence in communities. This was extremely important in the Orizaba region, where social marginalization and limited availability of, and access to, health services played a significant role in sustaining the TB epidemic.

The presence of the *Consortio* had an indisputably positive impact on research participants. Although our retrospective case study approach cannot provide the necessary evidence to draw causal relationships between the community engagement activities described above and the outstanding health outcomes observed during the various research initiatives, it is not unreasonable to postulate some effect of these social processes—particularly the success in bringing health services to hard-to-reach communities—on the reported epidemiological outcomes. For example, by humanising the research process and making research participants feel valued, the *Consortio* might have successfully nurtured participants' faith in self-investment—the belief that it is 'worth' taking active steps to care for oneself—in ways that may not have been familiar to them prior to their experiences with the *Consortio*. This would appear consistent with the impact healthcare personnel's attitudes have been documented to have in other regions¹⁷.

If the CE practices we studied really had a synergistic impact and improved the epidemiological impact of the *Consortio* trial, as the investigators have speculated, then effective CE may best be understood as an integral element of the public health intervention itself, rather than as a facilitator. As such, deep questions remain about the role of CE strategies, especially in the context of research with marginalized communities. Our findings support the potential for a positive contribution of CE to the epidemiological outcomes of a TB treatment trial. However, further research is needed on the range of possible ways an enhanced "human infrastructure" of respectful relationships¹⁷ can have an impact on the behavior of individual participants during a trial. Pursuing these lines of inquiry may demonstrate that CE represents a critically under-developed resource for disease control more generally.

Limitations

To understand the origins and design of the *Consortio*'s CE approach and to gain access to current and former participants in *Consortio* studies, this project was conducted in close collaboration with the *Consortio* team. The presence of individuals affiliated with the *Consortio* during the interviews and focus groups might have suppressed more critical feedback from some respondents and thereby introduced a source of bias. We aimed to address this by having the lead researchers (RFB and JVL) direct the interview and focus group questions, and thus control the agenda of the study. The host co-authors contributed a wide range of insights, elaborations, and contextual information throughout the research process—including during data collection. We also used a group analysis approach

that allowed us to critically examine our initial impressions and conceptualizations of data on a daily basis during our data collection trips, identify any potential biases or unwarranted inferences, and flag them for further clarification during subsequent interviews and analyses.

Our perception is also that, given the deep, trusting relationships that emerged over time between the individuals affiliated with the *Consortio* and our research participants, their presence during the interviews might in fact have positively helped suppress (at least in part) the role that ethnic, gender, and socio-economic differences between the lead researchers and many of the research participants might have otherwise played.

Given the nature of this qualitative case study, we are unable to make any causal claims about the relationship between the CE practices and the higher-than-expected epidemiological outcomes of the *Consortio*'s DOTS trial. Although our study was not designed to explore them specifically, we were able to observe some of the 'Indicators of Success in Community Action' that have been reported in the literature¹⁸. The emergence of a 'warm, friendly atmosphere' is one we reported above. We were also able to identify some of the gaps in the public health system that likely played some role in sustaining high rates of TB. By helping address these, the *Consortio* is likely to have had a long-lasting impact locally. The *Consortio*'s CE practices also contributed to the "human infrastructure" of the public health system beyond the trial itself. Although our study falls short of a causal explanation, we believe it provides useful insights about how greater attention to strong and respectful interpersonal relationships might facilitate improvements in public health outcomes more generally.

Ultimately, the standing uncertainties about the causal impact of the *Consortio*'s engagement activities on the effectiveness of TB control strategies simply add credibility to the call for improvements to the science of CE in global health research^{19–21}. Improving our understanding of the potential impact of CE is particularly crucial in the context of TB research. Indeed, even though attention must be paid to how policies and poverty directly affect the TB epidemic²², recent modeling efforts have made clear that renewed research will be an indispensable component of the future efforts to curtail the ravages caused by TB.

Conclusions

Despite the lack of an explicit stakeholder and community engagement strategy at the outset, the *Consortio Mexicano contra la Tuberculosis* successfully integrated its research agenda and operations with a complex public health system. This effective integration enabled, and likely enhanced the outcomes of, several key TB studies in the region and brought an unprecedented level of TB care to its research participants. These outcomes were achieved by building a coalition with local authorities, nurturing camaraderie with community health workers, and establishing a presence in the lives of community members.

Data availability

Underlying data

The authors are not able to make the supporting data public due the absence of consent on the part of participants. In some cases, excerpts relevant to this manuscript could be made available if they do not compromise the anonymity of research participants. Any party wishing to receive additional information should contact James Lavery (jlavery@emory.edu).

Author contributions

RB and JL designed the study, collected and analysed the data, and drafted the manuscript. LGG, LFR, SCQ, and MPM made substantial contributions to the study conception and design, and helped acquire and interpret the data. APL contributed to interpretation of data and revised the manuscript for important intellectual content. All authors revised the article critically for important intellectual content and approved the final manuscript.

Acknowledgements

The authors wish to thank the personnel of the Orizaba health jurisdiction and the patients who participated in the interviews. We also thank Douglas Young for providing the link between the members of the Consortium with the researchers from the Ethical, Social and Cultural Program for the Bill & Melinda Gates Foundation's Grand Challenges in Global Health Initiative. We are grateful to José Sifuentes-Osornio and Elizabeth Ferreira-Guerrero for their support and insights in the field. We acknowledge the support and assistance of other members of the *Consortio Mexicano contra la Tuberculosis*, particularly Guadalupe Canales, Eva Campos and Yolanda Jaramillo from the Orizaba Health Jurisdiction, Alejandro Escobar from the Health Services of the State of Veracruz and Eduardo Sada and Martha Torres from the National Institute of Respiratory diseases. The authors wish to acknowledge Peter Small's contribution in initiating the population-based cohort study (Transmission of Paucibacillary and Drug Resistant Tuberculosis. NIH/NIAID 5U01 AI 35969) that gave birth to the *Consortio*.

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 **Jantina de Vries** 

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This is an interesting contribution and highlights the importance of thinking about and reflecting on (the role of) community engagement in the context of health research. That said, however, there is some possibility for improvement, particularly in terms of the background information provided. I hope the following suggestions are helpful to the authors:

Introduction:

- The background section lacks a description of what the CE activities for the DOTS/Consortio work consisted of. I understand that the current paper is a retrospective analysis of the effect of those activities; the paper therefore requires a description of what those activities were, whether they were planned as such or arose organically etc.
- The background section also lacks a description of the Consorcio itself, including e.g. how staff were funded etc. This is important in light of your conclusion that the Consorcio actively nurtured 'camaraderie' between itself and the community health workers. But when people work together for 20 years in a similar space (health), then one would normally expect relationships to develop. To really accept that 'nurturing camaraderie' was a deliberate, designed component of the Consorcio CE strategy (as you argue in your Discussion), it is really important that you provide the reader with sufficient information to understand that the Consorcio really was different from healthcare providers in the area.

Methods:

- It is somewhat confusing that the 'methods' referred to in this paper are the retrospective study exploring the effect of the Consorcio's CE strategy. This is probably partly because a) the introduction of the paper does not end in a clearly stated research objective and b) because the description of 'study settings' as a pilot uses words that put me on the back foot a bit (e.g. 'this was identified as an area to test feasibility of implementing DOTS strategy; provided a promising opportunity to do X'). Perhaps the end of that section could

be rephrased to make it clearer that those activities were in the past, were completed and not relevant to the current study. W.r.t. 1; it may be worthwhile slightly rewording the objective of this paper, indicating that when two of the authors were invited to conduct a retrospective case study, they opted to conduct a prospective qualitative research study aiming to collect the views and experiences of X on Y, and that this paper reports on the results from that study.

- How were participants selected for this study? What were they (thought to be) representative of? Are the results just informative about the CE activities at Orizaba, or the CE activities for the wider DOTS/Consortio work? Presumably, when you say 'they needed to be exposed to the activities of the Consortio' you specifically intended for interviewees to have been involved with/exposed to the *engagement* activities of the Consortio? How is that expectation true for the categories of interviewees you selected? And were there other types of interviewees you could have selected but didn't?
- You say you used 'field observations' of the Consortio CE process, but in the introduction you indicated that the work reported in this paper involved a 'retrospective case study'. How, then, did you conduct field observations, and what were you observing?

Results:

- Under 'fragmentation' (1st section of the results), I think it is really important to provide some contextual information. In the introduction, you indicate that the Consortio worked for two decades, so when people recall that 'before the Consortio arrived', are they reflecting on what the healthcare system looked like two decades ago? Were your interviewees even old enough to remember that?
- When you say 'existing community engagement infrastructure of the public health service', do you actually mean that the phs had an existing 'community engagement' programme in line with the CDC definition provided?

Discussion:

- Taken at face value, it seems to me like the Discussion is not always entirely objective or neutral. Take for instance this section: "This collaboration was in turn successfully sustained because the Consortio leadership actively promoted a warm and responsive attitude toward all its stakeholders and partners. This attitude emphasized trustworthiness, reliability, and respectful relationships, putting the trial participants' interests at the centre of all their activities." This section is problematic not in the least because a) your interviews/FGDs/observations all seem to have been conducted under the gaze of Consortio researchers and leadership; b) Consortio leadership apparently are co-authors on the paper. Was the experience really that exemplar? And were those words coming from your interviewees? (About the 'warm and responsive attitude' and 'putting participants' interests at the centre of all of their activities'). Were there no divergent views? And if there were no divergent views, then what could explain that? (Perhaps your participant selection?). This would merit more critical discussion I think.
- Have you really got the data to suggest that the presence of the Consortio researchers was 'deeply meaningful' for the isolated communities? For this study, you only conducted 17 interviews and 2 FGDs. None of the FGDs and only some of the IDIs were with community

members/participants. On what basis do you then indicate that the Consorcio presence was 'deeply meaningful'? (Consider this point particularly in light of my previous point. Is this observation biased?)

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: bioethics, empirical ethics

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Reviewer Report 23 January 2020

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Nicola Ann Desmond 

Department of International Public Health, Liverpool School of Tropical Medicine, Liverpool, UK

This paper provides further evidence on the value of community engagement to the improvement of outcomes within medical research, drawing on a case study from the Orizaba Region in Mexico where a large research programme on TB control took place between 1995 and 2012. As such the paper is written based on data collected retrospectively, after several years of engagement between the research programme and the communities.

The paper is very well written and engagement approaches discussed are well considered as expected from the research team, who are experts in this area. On the whole I was very impressed with the paper although I have a few general issues to raise, issues that frustrated me a little whilst reading the paper, but not ones that necessarily detract from the central argument. These are as follows:

1. There is no background information on prevalence or incidence of TB in this region or in Mexico generally such that it is difficult to frame the responses to the TB Consorcio as either due to prioritisation of TB within the area (it is described at one point as an 'epidemic') or whether it is due to the quality of the engagement approach. The authors do state that there are varying perspectives amongst the community on their exposure to the disease and their inability to recognise symptoms, which suggests that the engagement approach through the introduction of the Consorcio which drove focused attention within the broader public health system on TB, was effective in raising awareness and thus engagement. However, without the background rates/description of context, it is hard to place this.
2. I was concerned that Consorcio members were present at all the interviews and FGDs conducted by the key authors in this assessment of CE strategies. This suggests a high level of bias and an unwillingness to trust outsiders to evaluate the engagement approach. There is no real explanation for why they were present although of course this was mentioned as a limitation to the study. Perhaps it might be useful to include a rationale as to why they were present to avoid misconstruing their presence.
3. The authors mention that the approach within this TB programme would be relevant to other TB research and state that it may also be relevant to other disease areas and health interventions. They also state that the results led the Consorcio to 'view the establishment ... of strong, respectful relationships ... as having both strategic and ethical significance'. I would be interested to know which rationale drove the engagement approach - were they driven by an ethical need to ensure strong relationships and co-production etc. or were they rather driven by the strategic need to engage stakeholders to promote the objectives of the programme? Whilst this may not make a difference instrumentally, it does help to understand the intrinsic objectives of the programme and how purposive the engagement was. Similarly how far was the engagement approach responsive and how far was it purposive?
4. Finally, whilst the authors refer in passing to sustainability, it would be of benefit to hear more about the impact of the programme on TB engagement at each level post-2012 i.e. some explanation of how lasting engagement might have been. As it stands, the paper highlights the very real benefits of engagement in the success of a research programme but does little to persuade the reader that this type of engagement is long-lasting and 'empowering' beyond the objectives of the more intensive engagement within the programme period.

I hope these responses make some sense to the authors. They are in no way a criticism of the paper but rather thoughts prompted by it. I really enjoyed reading this and highlight, as the authors do, the very real challenge of evaluating community engagement impact in both the short and long term but emphasising the need to continue to find ways of doing this appropriately, an area in which the authors are leading research.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Partly

If applicable, is the statistical analysis and its interpretation appropriate?

Not applicable

Are all the source data underlying the results available to ensure full reproducibility?

No

Are the conclusions drawn adequately supported by the results?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Medical anthropology, community engagement, bioethics, implementation science, mixed methods, qualitative research, behaviour change

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.
