

TB Specific Impact Survey Initial Summary Report

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Introduction

As the world's leading killer among infectious diseases, tuberculosis (TB) continues to affect millions around the world, especially people living with HIV, in poverty or in densely-populated environments, and other vulnerable groups. In 2023, an estimated 10.8 million people fell sick with TB worldwide, and 1.25 million died - 15% of whom were children and young adolescents (WHO 2024 Global TB Report). Tuberculosis is a preventable, detectable, and treatable disease when health services are adequately funded and delivered.

In the first days of his presidency, the Trump Administration issued stop work orders and funding freezes for all foreign aid, disrupting global TB prevention and care. The order, which has since been turned into a termination of more than 90% of all US investments in global health, including TB programming, has impacted TB essential services, research, community-led interventions, and advocacy work (<u>Stop TB Rapid Assessment</u>).

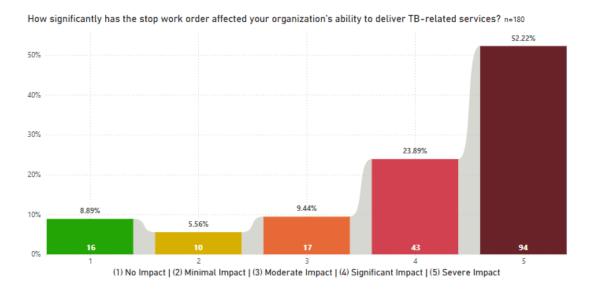
USAID is the largest bilateral donor in the fight to end TB, having invested more than USD \$4.7 billion to combat the airborne disease since 2000; investments that have saved more than 79 million lives. In 2024 alone, the US provided US\$406 million in funding to 24 USAID priority TB countries and 31 additional high-burden countries (Zumla, Sahu et al., Feb 2025). This funding withdrawal will undoubtedly have massive human and economic costs. Even with the full amount of Congressionally-appropriated funds, the current level of global investment was insufficient to stop an additional 43 million people falling ill with TB by 2030, leading to 6.6 million lives lost and a global economic cost of USD \$1 trillion (Stop TB Global Plan). Without US funding, these figures of preventable deaths and costs will significantly increase. Mathematical modeling from the TB Impact Counter estimates that an additional 3,146 lives have already

been lost to TB because of US inflicted disruptions of work, with a risk of losing more than 2 million lives over a 5-year period if funding amounts lost are never resumed.

The global TB community had already recognized the need to reduce donor dependency and has put focus on <u>domestic TB financing</u>, while calling for new leadership and financing solutions to "Commit, Invest, Deliver" to End TB before this changing financing landscape, including a US total withdrawal of funding and other donors like United Kingdom, Belgium, and the Netherlands cutting their foreign aid funding. However, the US stop work order came abruptly, preventing a measured and safe transition, without providing the time needed to develop the necessary domestic leadership and secure alternative long-term financing.

"Without alternative sources of bridging funds, these initiatives built up over the past three decades face imminent collapse." (Zumla, Sahu et al., Feb 2025)

To document the impacts of the stop-work order and funding freezes on TB programs and partners, and to mobilize action and resources, the <u>TB Community Coordination Hub</u> - a volunteer initiative launched in response to the crisis and comprising TB professionals, affected communities, activists and advocates from around the world - ran a TB-specific impact survey from February 11 - 24, 2025. This time-period reflects stop work orders and not final terminations of contracts, which began Feb 25. The survey, modelled on a <u>PEPFAR Impact Survey</u>, received 180 responses from over 30 countries¹. Respondents represented national NGOs (42%, n=76), local community organizations (18%, n=32), TB-affected community networks (11%, n=19), and international NGOs (9%, n=17). Most respondents (76%) reported the stop work order severely (52%, n=94) or significantly (24%, n=43) impacted their ability to deliver critical TB services, and 24% (n=43 out of 180) indicated that they had already closed down their office and projects.



¹ Azerbaijan, **Bangladesh**, Benin, Burkina Faso, **Cambodia**, Cameroon, Côte d'Ivoire, **Democratic Republic of Congo**, Eswatini, **Ethiopia**, Georgia, Ghana, Guinea, **India**, **Indonesia**, Iraq, **Kazakhstan**, **Kenya**, **Kyrgyz Republic**, **Malawi**, Moldova, **Mozambique**, **Myanmar (Burma)**, **Nigeria**, **Pakistan**, Peru, Poland, Romania, Sierra Leone, **South Africa**, Sudan, **Tajikistan**, **Tanzania**, **Uganda**, **Ukraine**, **Uzbekistan**, **Vietnam**, **Zambia**, and **Zimbabwe**. (USAID Priority TB Countries in **bold**)



As expected, respondents based in USAID Priority TB Countries reported a greater severity of impact from the stop work orders on their activities than those in non-USAID TB Priority Countries. Survey respondents in USAID TB Priority Countries, 63% (n=114) reported an average Impact score of 4.2; respondents working in non-USAID Priority Countries (22%, n=40) reported an average score of 3.5. Respondents who work in multiple countries, either identifying as global (9%, n=16) or regional implementers (6%, n=10), had the highest impact scores, averages of 4.5 and 4.2, respectively.

The Impact of Stop Work Orders on People Affected by TB and TB Services

"Several critical tasks such as facilitating effective communication, raising awareness, advocating for improved healthcare, and ensuring proper screening, case detection, treatment, and treatment support have come to an abrupt halt. This has created major gaps and undone years of effort to build momentum for increased TB case detection and treatment." Respondent from a National NGO, Nigeria.

Stops and disruptions have impacted a diversity of critical TB activities that directly strengthen health systems and save lives. These include, but are not limited to, the essential services required to identify persons at risk of TB (screening, transport and testing sputum specimens), enroll people affected by TB on the correct treatment regimen (including preventive treatment), support people to adhere to and complete their treatment (including mental health and nutrition), interventions that reach the 'hard to reach' and key and vulnerable populations, and demand creation for TB tools, awareness raising and stigma reduction programs. Local and national healthcare systems and TB programs are also impacted, including drug and test procurements, financial and human resources (frontline healthcare workers, clinicians, program staff, communities and community health volunteers), national and community-led monitoring systems, and the ultimate termination of the only mechanism (Challenge Facility for Civil Society) that has built and strengthened the TB community movement. In addition, TB activities including research and development (R&D), technical assistance and stakeholder engagement have been impacted.

It should be noted that in the "Limited Waiver to Pause of U.S. Foreign Assistance for Life-Saving HIV Service Provision" issued on February 1, 2025, the US State Department recognized "prevention and treatment of opportunistic infections *including TB*, *laboratory services*, *and procurement and supply chain for commodities/medicines*" (emphasis added) and the "Provision of *tuberculosis preventive therapy* (TPT) and *Tuberculosis Treatment*, as TB is the largest killer of people living with HIV" (emphasis added) as "life-saving humanitarian assistance." However, widespread confusion, barriers to securing waivers, delays in issuing approvals, and a lack of ability for award recipients to communicate with USAID staff meant that waivers made little impact on the ground.

All findings reflecting the impact of stop work orders on different TB services are presented by categories of type or work below. You can access and explore all data visualizations of findings on Power BI here.

Impact on "Essential" TB Services² to detect and treat persons with TB and prevent persons at highest risk of TB from developing the disease:

- 1. Of 164 respondents, 46% (n=76) have stopped and 37% (n=45) have reduced **TB screening** and outreach activities³
- 2. Of 139 respondents, 25% (n=48) have stopped and 23% (n=32) have reduced **sputum** collection and transportation
- 3. Of 143 respondents, 29% (n=41) have stopped and 24% (n=34) have reduced **initiating new** clients on treatment
- 4. Of 150 respondents, 27% (n=40) have stopped and 26% (n=39) have reduced **continuing** existing clients on treatment
- **5.** Of 146 respondents, 27% (n=39) have stopped and 25% (n=37) have reduced **TB preventive therapy** activities

Impact on Procurement of TB drugs, testing kits, and other products to support finding and treating TB:

- Of 143 respondents, 18% (n=26) have stopped and 14% (n=20) have reduced procurement of drugs
- Of 141 respondents, 16% (n=23) have stopped and 18% (n=26) have reduced procurement of diagnostics
- Of 141 respondents, 19% (n=27) have stopped and 18% (n=25) have reduced procurement of other essential commodities

Impact on Support for People with TB and Survivors provided by community health workers and volunteers:

- 6. Of 166 respondents, 37% (n=62) have stopped and 31% (n=52) have reduced **treatment** adherence support
- 7. Of 147 respondents, 30% (n=44) have stopped and 22% (n=32) have reduced **nutrition support** activities
- 8. Of 163 respondents, 37% (n=59) have stopped and 33% (n=53) have reduced **peer support** activities
- 9. Of 164 respondents, 42% (n=69) have stopped and 29% (n=47) have reduced **people living** with/or affected by TB led activities
- 10. Of 142 respondents, 33% (n=47) have stopped and 24% (n=34) have reduced **post TB support** activities

Impact on Community Supportive and Led activities to raise awareness, combat TB-related stigma, improve access and delivery of quality services, and address barriers to services for the most vulnerable and hardest to reach populations⁴:

² Note: these findings are from the time-period in anticipation of waivers and before the cancellation of USAID TB LON grants covering many of these essential services. With full award terminations the impacts are expected to be worse than what is reported here.

³ The survey has 180 respondents overall, allowing respondents to skip questions (if information not available, or answers not known). Specific questions therefore have a different denominator.

⁴Note: these findings are from the time-period in anticipation of waivers and before the cancellation of Stop TB Challenge Facility for Civil Society (CFCS), which supported 114 grantees across 38 countries to cover many of these community based and led services. With full award terminations the impacts are expected to be worse than what is reported here.

- 11. Of 158 responses, 51% (n=80) have stopped and 22% (n=35) have reduced **community led monitoring** activities
- 12. Of 170 respondents, 58% (n=81) have stopped and 33% (n=56) have reduced **advocacy** activities
- 13. Of 163 respondents, 52% (n=84) have stopped and 25% (n=41) have reduced **human rights**, **gender and key and vulnerable population** activities
- 14. Of 152 respondents, 39% (n=60) have stopped and 28% (n=42) have reduced activities to **create demand for tools**
- 15. Of n=171, 48% (n=80) have stopped and 28% (n=47) have reduced **stigma reduction** activities
- 16. Of 171 respondents, 54% (n=93) have stopped and 29% (n=49) have reduced **TB education** and community sensitization activities

Impact on additional TB program management & research activities to sustain progress achieved to date, improve future TB response, and create political will:

- 17. Of 153 respondents, 53% (n=81) have stopped and 24% (n=36) have reduced **technical assistance** activities
- 18. Of 135 respondents, 17% (n=23) have stopped and 12% (n=16) have reduced **clinical trial** related activities
- 19. Of 140 respondents, 34% (n=48) have stopped and 21% (n=29) have reduced all other **research** activities
- 20. Of 151 respondents, 44% (n=?) have stopped and 31% (n=?) have reduced **monitoring and** data collection activities
- 21. Of 165 respondents, 52% (n=86) have stopped and 35% (n=58) have reduced **stakeholder engagement**

Each of these activities has an immediate impact on the spread of TB and the gravity of the disease for individuals impacted. When there is an interruption of treatment more complicated and drug-resistant forms of TB develop. As one respondent explained, "due to the disruption of activities, the patients we are monitoring are being abandoned, the support we provide to [impoverished] patients is no longer there and we fear that they will be left to fend for themselves. They [are] also abandon[ed in] treatment which could promote resistant TB and an increase in tuberculosis cases". Respondent from a TB Affected Community Network, Cameroon.

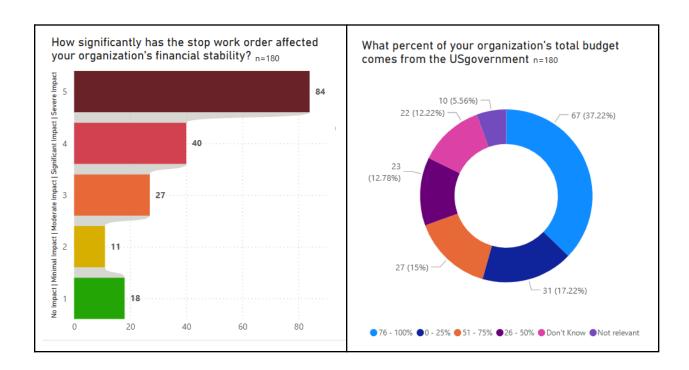
TB programs had just started to recover from the set-backs of the COVID-19 pandemic, which had reversed years of progress. The disruption of TB services in 2019 due to COVID-19 resulted in an 18% drop in TB notifications in 2020 and a surge in TB deaths in 2021 (from 1.4 million to 1.6 million), setting global mortality back to 2017 levels (WHO COVID 19 and TB, 2022). The abruptness of the funding cuts by the Trump Administration have similarly not allowed organizations to plan for continuation of their life-saving work, thereby risking again an increase in TB transmission and drug resistance globally due to delayed diagnosis and treatment. One respondent stated clearly that "these cuts were unexpected, giving us little to no time to strategize for survival. Many essential programs that support TB prevention, treatment, and care now face an uncertain future, putting countless lives at risk... Without proper planning, these funding gaps will disrupt progress made in combating TB, affecting patients, healthcare workers, and advocacy efforts worldwide." Respondent from a Local Community Organization, Ethiopia.

The US government's support for the global TB response not only affects high-TB burden countries, but also benefits Americans. TB anywhere is TB everywhere. Investments in TB abroad helps to lower global

transmission rates and prevent a global pandemic. Additionally, US-funded clinical trials have led to improved TB regimens now in common use in the United States, including preventive therapies for infants (TBTC Study 35) and a shortened treatment regimen for active TB disease. "The funds that USAID [spends] in aid, not only helps the people across the world in need, it also helps the US by generating [evidence] that [helps] the US formulate effective disease control policies. Such sudden withdrawal risks reversing the progress made in TB control over the past decades and even [the] US will not be immune to the resulting epidemic." Respondent from Bangladesh.

The Impact of Stop Work Orders on Organizational Resiliency and Operations

Even though the stop-work orders had only been in effect for a month at the end of data collection for this survey, 78% (n=140 out of 180) of respondents reported staff layoffs and furloughs. Community-based staff, those on the frontlines for finding and treating people with TB, were the most impacted (46%, n=65), versus HQ staff (32%, n=45) and clinical staff (21%, n=30). Nearly 70% of respondents (n=124 out of 180) also indicated severe or significant impact on their organizations finances. Since the start and completion of this survey, more than 90% of all US funding global health, development, and humanitarian awards have been terminated - including for TB. As already reported by the Stop TB Partnership, this means that significantly more staff layoffs and furloughs are anticipated (Devex, March 4, 2025).



Respondents expressed deep concern for the livelihoods of people committed to the fight to end TB, and those affected by this deadly disease: "The freeze has cost more than just money, it has disrupted lives, halted progress, and weakened the foundation of health program support in the community. The real impact is felt in the personal stories of those who dedicated their time to making a difference and those who were relying on the program to stay healthy." Respondent from a Local Community Organization, Tanzania.

Survey respondents likewise spoke to the urgency of building and protecting human-resource capacity and technical skills, trust and credibility, relationships, stocks and commodities, and of course life-saving and quality of life enhancing services. "Restoring credibility is crucial. Some individuals supported by our organization have limited access to information, making it difficult for them to understand the true reasons behind this disruption. As a result, they may view our organization as untrustworthy, feeling that we extended our support and then suddenly withdrew it." Respondent from a Local Community Organization, Mozambique.

Ultimately, this survey makes clear that community-based organizations and community-led activities are most impacted by the stop work orders, likely because they are so small that they are unable to maintain large cash reserves that would sustain them through a funding halt. From this survey 37% (n=67 out of 180) of respondents reported that three-quarters or more of their organizational budget came from US government sources; another 15% (n=27) reported that half to three-quarters of their budget was US dependent.

While the amount of funding lost by individual community-based organizations was often modest, the impact has been substantial. These organizations are critical to the fight against TB; they find people with TB, support them through treatment, advocate to end the stigma that surrounds the illness, and work to secure the political will needed to meet their countries' political commitments to the Sustainable Development Goals and the Political Declaration of the UN High Level Meeting on TB.

Conclusion and Calls to Action

The findings of the survey show a severe impact on essential services for people affected by TB. Clear gaps are emerging in responding to TB, including life-saving services such as finding and screening people for TB, sputum collection and transportation, initiating and continuing people on treatment, and drug and diagnostic procurement. It is essential that gaps in funding and programming be rapidly filled, either by restoring US funding, other donors stepping in to top-up their contributions, national governments allocating domestic resources to the fight, or innovative financing solutions being discovered and leveraged. If funding resumes and TB services are reinstated within 1 year, an additional 39,010 lives will be lost to TB over the course of the year. If funding never resumes, another 2.2 million people will needlessly die of this curable disease over the course of 5-years (TB Impact Counter).

The typically underappreciated, yet critically important supporting services, including psychosocial, nutrition, and treatment adherence support, advocacy, demand generation for new tools, human rights, gender sensitivity, a focus on key and vulnerable populations, government accountability, and community-led monitoring and engagement in the TB response have been particularly hard hit. Not unsurprisingly, the community led and based organizations driving this work are at a particularly high risk of not surviving the blow of US funding withdrawals. You can take action right now to help #KeepTheLightsOn for affordable and high return on investment community based work by supporting the Stop TB Partnership campaign to sustain community-led efforts. You can also call on other donors to step in to keep a community-led response for TB alive. The Challenge Facility for Civil Society requires just USD \$1 million to support 10 countries to have community initiatives in place to find people with TB, educate communities about TB, bring people to testing and support them through treatment and more! Now more than ever we need TB affected communities to be engaged in holding their health authorities to account and pushing for people centered care.

Please remember that the data from this survey are only a fraction of the overall impact on lives of people affected by TB. While a better understanding of the full impact is becoming clearer, further data-collection and modelling is needed for appropriate planning and responses to this crisis in the fight to end TB. The urgency of addressing the potential catastrophe of letting people die and TB spread in the world is real and we should not wait to take action. The upcoming World TB Day (March 24) tagline of "Invest, Deliver, Action" is not just a slogan, it is a call to action for everyone concerned with ending TB. People's lives are at risk and TB programs need support!

This initial summary report was developed and published to share initial findings from the TB Community Coordination Hub impact survey. You can access and explore all data visualizations of findings on Power BI here. More comprehensive findings and data from the survey will be released in a forthcoming report, accompanied by additional relevant calls to action.

The <u>TB Community Coordination Hub</u>, together with the survey respondents, remains committed to supporting our partners and ensuring that individuals living with or at risk of TB are not left behind. We will not waver in the face of challenges, nor will we be deterred by adversity. Our resolve remains strong, our dedication unwavering, and together, we will continue to drive progress and shine bright even in these darkest times. We will persist - because #TogetherYesWeCanEndTB.

If you would like to share any information on the impact of the USAID funding terminations on TB programs in your community, country or region, please reach out to us at tbcommunitycoordinationhub@gmail.com or join us for advocacy on Bluesky. Your insights, experiences and case stories are critical in shaping collective action and driving urgent solutions.