



**Results of a
global civil society
and TB affected
community led
survey**

The impact of COVID-19 on the TB epidemic: A community perspective



Acknowledgements

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Foreword



TIMUR ABDULLAEV
TB PEOPLE

“TB has always loved company: HIV, diabetes, poverty, stigma and discrimination, to name but a few. For TB, COVID-19-related lockdowns came in very handy, leaving people with no food, no work, no money, no healthcare. The various barriers we faced to access TB services were compounded. What a gift for TB – and what a disaster for people affected by TB. It is time to remind TB that its place is in history books, no matter who its friends are!”



ALLAN RAGI
EXECUTIVE DIRECTOR
KANCO

“COVID-19 is driving people affected by TB into a downward spiral of poverty, fear and anguish. The advent of COVID-19 is a wakeup call to the state of our health systems and the investments that we must make to not only end TB but to also realize universal health coverage. We therefore must re-think health in the context of the pandemic and beyond, by being deliberate on getting the right data to inform decisions and resource allocation while ensuring the best value for resources. Governments must be committed to deliver integrated and people centered health services, while citizens must arise and hold the governments accountable for the realization of national and global health commitments.”



BLESSI KUMAR
GLOBAL COALITION
OF TB ACTIVISTS

“This report is a rallying cry from communities affected by TB. We listen to the voices of people suffering, collected here by communities around the world. Our communities need support to be engaged and empowered in TB and COVID-19 response, and those caring and working need sufficient protective equipment. We hope that our voices as a community will be heard through this report and that the response will be shaped by this reality.”



AUSTIN OBIEFUNA
STOP TB DEVELOPING
NGO DELEGATION

“Communities have come together in this time of crisis. Collectively, we created a survey, reached out for responses, ensured wide representation, and coordinated our efforts to understand realities and inform decision makers. Together, we will advocate to realize the recommendations and action items as well. This is a real unique collaborative piece of work driven by communities. United is the only way we can respond to a global pandemic.”



JOANNE CARTER
RESULTS
INTERNATIONAL

“Coronavirus is exploiting the world’s inequities in health, making tuberculosis even deadlier in turn. Without massive new investment in TB and in primary health delivery overall, strong international partnerships, support for community-led services, and an approach grounded in equity, this pandemic’s consequences will continue to multiply.”



THE RT HON LORD HERBERT
CO-CHAIR OF THE
GLOBAL TB CAUCUS

“I welcome this report with its strong call from civil society for additional funding, increased resources and sustained political commitment to respond to both COVID-19 and TB pandemics in this time of crisis. As parliamentarians, we stand with you in advocating for stronger and better-coordinated health and social security systems.”



LUCICA DITIU
STOP TB
PARTNERSHIP

“The devastating impact of COVID-19 mitigation measures is projected to set TB programs back 5-8 years and needlessly add another 1.4 million TB deaths. TB programs, healthcare workers and TB-affected communities are innovating and overcoming challenges, while TB interventions and service providers are being reassigned, depleted and diverted. TB services are essential services and must be prioritized and supported!”



MADHUKAR PAI
MCGILL UNIVERSITY

“This report shows that the COVID-19 pandemic is absolutely devastating for our quest to end TB. If we were climbing a mountain before COVID-19, that mountain has now become Mount Everest. This means we need to work extra hard to mitigate the damage and stay focused on TB for the long haul. Collaboration and solidarity within the TB community are critical if we are to have any hope of getting back on track to reach the SDG goals.”

01 Executive summary

If we had used a quarter of the resources allocated to COVID... we would have eliminated TB a long time ago.

HEALTHCARE WORKER FROM MOROCCO

Tuberculosis (TB) is the world's leading infectious disease, killing around 1.5 million people each year. Despite global and national efforts to end TB and the availability of cost-effective medicines to treat and cure it, too many people continue to suffer from this old disease.

In response to early warnings that COVID-19 was having a devastating impact on people affected by TB and TB programs around the world, 10 global networks quickly came together to take action. They launched a civil society-led survey, aimed at enriching our understanding of experiences in various regions and key stakeholder groups, with the following objectives:

- To identify critical gaps and needs in TB services resulting from the pandemic and raise awareness among national governments, program implementers, policymakers, parliamentarians¹ and the wider global health community
- To raise the voices of TB-affected communities and civil society to ensure their ideas and concerns were incorporated into national, regional, and global responses
- To support greater alignment of TB and COVID-19 priorities and services at country level
- To work collaboratively to ensure coordinated advocacy efforts and concrete political actions to address identified gaps in funding, resources, and services
- To strengthen engagement of and relationships across TB-affected communities and civil-society networks engaged in the fight to end TB.

The findings of the survey offer a grassroots perspective on how COVID-19 is impacting five key stakeholder groups, namely, people with TB, frontline healthcare workers, program and policy officers, TB researchers, and TB advocates.² The report provides a summary of findings for each stakeholder group.



People with TB:

People with TB from Kenya (n= 159) and India (n= 58) reported significant challenges in accessing TB services during the pandemic and associated lockdowns. Difficulty finding transport to access TB care, changes in TB services, and fear of contracting COVID-19 during a healthcare visit were cited as key barriers. People with TB also reported experiencing increased stigma due to the similar symptoms of both respiratory diseases. While most people with TB were given additional medicines to continue treatment at home, they expressed a clear and urgent need for immediate non-medical support, including nutritional, economic and psychosocial support.



Frontline Healthcare Workers:

TB frontline healthcare workers (n=150) reported significant reductions in TB care due to the pandemic. The main reasons for interruptions related to the redeployment of essential resources and personnel to respond to the public health crisis at hand, and generally weak health systems struggling to cope with an influx in demand on services. Participants around the world reported a lack of personal protective equipment (PPE) and underscored how the unsafe and challenging working conditions were resulting in low morale and mental-health issues. There is an urgent need for increased support, including investment in PPE, personnel, supplies, and tools, as well as innovations in programming to offer quality digital and community-based care.



Policy and Program Officers:

Responses from policy and program officers (n = 115) revealed that TB services and program resources had declined significantly because of the pandemic. TB notifications have decreased drastically and personnel are being redeployed to respond to COVID-19. Participants from both the U.S. and Global Fund implementing countries reported decreases in the number of TB-afflicted people accessing care, as well as increases in



stockouts of or delays in TB medicines. Interruptions to TB programs included programmatic capacity, stigma and fear, human rights violations, and other psychosocial factors that impeded people with TB from accessing TB services. Programs are being adapted and need further financial support to increase and sustain the innovative mechanisms being deployed, such as telemedicine and family- or community-based care. The significant investments currently being made to respond to COVID-19 should be leveraged to strengthen the TB response.

TB advocates:

Individuals employed with civil-society or non-governmental organizations (NGOs) working to end TB, or who identified as a TB advocate or TB survivor from Global Fund implementing countries (n = 270), expressed deep concern for TB advocacy and people with TB as a result of the pandemic. Diverted political and media attention to COVID-19 was said to be seriously affecting advocacy work. Participants also raised alarm bells about people with TB not being able to access care and social support, and community support groups not being able to reach affected communities during lockdowns. Human rights issues, including stigma, economic inequalities, food insecurity, and fear were cited as key challenges in responding to COVID-19 and TB.³ To tackle the challenges at hand, advocates called for a strengthening of TB-affected communities' capacity and engagement in the fight to end both the epidemic and pandemic.

TB Researchers:

TB researchers around the world (n = 73) reported significant interruptions in TB research associated with a diversion of personnel, equipment, and funding of COVID-19 over TB. Survey participants repeatedly noted existing lab space and infrastructure being closed during lockdowns or repurposed for COVID-19. Similarly, respondents experienced reduced access to research participants due to immobility during lockdowns. There is unified demand from TB researchers for additional and continued resources for TB, and for research investments in COVID-19 to be leveraged for TB. TB research and infrastructure are currently being leveraged for COVID-19-related research.

This survey's findings complement reports on the devastating impact of COVID-19 on efforts to end TB published by the Global Coalition of TB Activists, Stop TB Partnership, the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund), the Global TB Caucus, the Americas TB Coalition, and Stop TB Partnership Indonesia. Assessments and modeling done by the Stop TB Partnership,⁴ Global Coalition of TB Activists,⁵ Imperial College London,⁶ and the World Health Organization (WHO)⁷ show that an additional 6.3 million people will develop TB by 2025 due to COVID-19-related disruptions of TB services, while an additional 1.4 million people will die. Similarly, a recent report by the Global Fund warned that progress made in the fight against HIV, TB, and malaria over the past two decades is at serious risk, estimating that deaths from the three diseases could double if health and social support systems are overwhelmed, prevention, diagnosis, treatment and care programs are disrupted, and resources are diverted.⁸ The COVID-19 pandemic is badly disrupting TB services everywhere and threatens to reverse hard-won gains in the fight to end the epidemic and achieve the *United Nations High Level Meeting (UN HLM) targets*, the *End TB Strategy*, the *Global Plan to End TB 2018–2022* and the *Sustainable Development Goals (SDGs)*.

The impacts of COVID-19 are not being felt equally across or within countries. Prior to the pandemic, every year, around 100 million people were pushed into poverty because of healthcare-associated costs, and half the world's population did not have access to the healthcare they needed.⁹ These already vulnerable populations are being disproportionately impacted by COVID-19 and are the same people hit hardest by TB:¹⁰ children,¹¹ people living with HIV/AIDS,¹² mobile populations¹³ (migrants and refugees),¹⁴ indigenous groups,¹⁵ miners,¹⁶ prisoners,¹⁷ and people who use drugs.¹⁸ We know that the challenges and barriers to accessing both COVID-19 and TB services disproportionately affect those who are most vulnerable and/or already marginalized. This impact is a particular concern from the perspective of human rights,¹⁹ stigma,²⁰ and gender.²¹

As civil-society groups and people affected by TB, we report on our findings with the intention of outlining concerns and needed actions with a people-centered lens and language that reduces stigma. Our findings present lived experiences, lessons learned, advocacy recommendations, and opportunities for mitigating the damage done by COVID-19 to get countries back on track to achieving elimination targets, as well as for building back better to end TB. The urgency and need is great, which is why we will continue to coordinate and ensure the findings of this initiative are used to mobilize and equip advocates to take action around the world. We urge the global community to activate a multidisciplinary, emergency, "all hands on deck" response to COVID-19 and TB.²²

**We know that united our calls
will not go unheard!**



02 Key findings and calls to action

TB and COVID are both diseases. Ignoring one to tackle the other is shocking. Basic guidelines should be followed, and patients inflicted with TB and COVID should be given justice.



01 Key Findings

COVID-19 has had an enormous impact on the number of people seeking and receiving healthcare for TB.

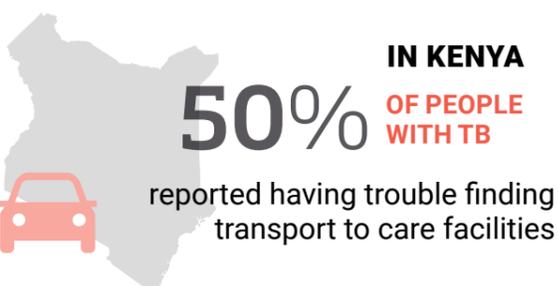
GLOBALLY

70%+ HEALTHCARE WORKERS

reported a decrease in the number of people coming to health facilities for TB testing.



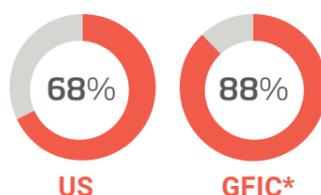
Healthcare workers also reported reductions in the number of people with TB coming to healthcare facilities for treatment:



*GFIC= Global Fund implementing countries

GLOBALLY

policy and program officers reported significant drops in TB notification

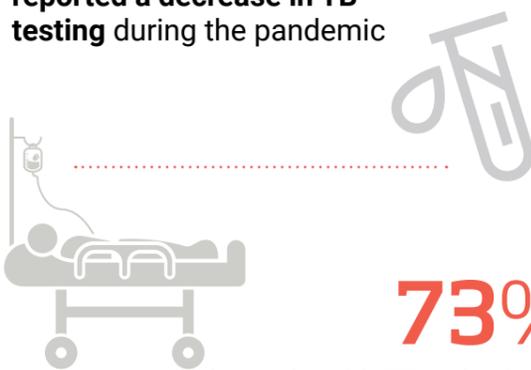


70% of officers from Global Fund implementing countries reported a **DECREASE** in the number of people with TB receiving treatment



75% OF ADVOCATES FROM GLOBAL FUND ELIGIBLE COUNTRIES

reported a decrease in TB testing during the pandemic



73% reported people with TB to be facing significant challenges accessing treatment and care

01 Calls to action

COVID-19 has had an enormous impact on the number of people seeking and receiving healthcare for TB.

Build back better: There is an urgent need for a recovery plan to get TB responses back on track to reach UN HLM TB targets and SDG commitments to end TB by 2030. COVID-19 has demonstrated the important role that affected communities play in responding to health crises, reporting barriers to access, supporting peers and filling gaps in services. The pandemic is an opportunity for national TB responses to become more people-centered and to involve communities.

We call on:



Governments to adapt national TB plans to COVID-19 and implement recovery plans with secured funding to get TB responses back on track to reach the UN HLM targets, the End TB Strategy, and the Global Plan to End TB (2018-2022); particularly by

- Ensuring representation of TB affected communities, civil society, health care workers on all health governance platforms involving the design, implementation, monitoring and evaluation of plans and interventions.
- Strengthening accountability and real time TB data collection and reporting in line with mechanisms developed in response to COVID19.



In-country partners including parliamentarians, civil societies, affected communities and technical partners to support the development and implementation of TB plans and interventions in all healthcare facilities (public and private sector) that ensure the uninterrupted continuation of TB services.



Civil-society organizations (CSOs) and the media to raise awareness, amplify voices of people affected by COVID-19 and TB, and advocate for additional investment and support.



Global technical partners and donors²³ to support governments with updated global coordination and financing mechanisms; particularly by

- Adapting the Global Plan to Stop TB (Stop TB Partnership) and The End TB Strategy (WHO) to address the COVID-19 pandemic and develop a clear accompanying financial investment case;
- Fully funding recovery mechanisms, such as the *Global Fund's COVID-19 Recovery Mechanism*, and ensuring TB is included in other global and regional COVID-19 political and financial frameworks, such as the United Nations General Assembly (UNGA), the World Health Assembly (WHA), the G7 and G20 groups, the European Union (EU), and the Brazil, Russia, India, China and South Africa (BRICS) group
- Significantly scaling up investments in the capacity and coordination of people affected by TB at national, regional, and global level through the *Challenge Facility for Civil Society*, the Global Fund Strategic Initiatives on *Finding Missing People Affected by TB* and *Communities, Rights & Gender (CRG)*, and USAID's *Local Organizational Network*.



Researchers to support governments with evidence-based research to quantify the proportion of people with TB and COVID-19 seeking and receiving healthcare, so as to inform policy and practice in affected communities.

02 Key Findings

COVID-19 is driving people with TB into poverty, and social isolation is increasing inequities and human rights-related barriers to TB services.

Qualitative and quantitative findings indicate that people with TB urgently need nutritional and socioeconomic support.

70%

OF KENYAN RESPONDENTS

reported not receiving enough support during the pandemic.

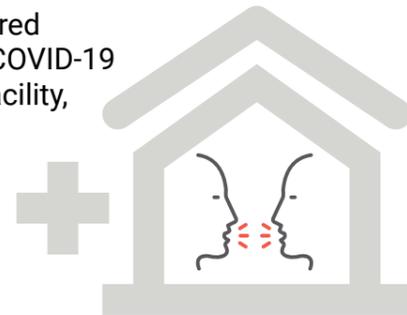


Advocates and healthcare workers called strongly for people with TB to be provided with nutritional support and transport costs to and from clinics.



50%+ OF PEOPLE WITH TB IN KENYA AND INDIA

said they feared contracting COVID-19 at a health facility,



50%+

OF PEOPLE WITH TB IN KENYA

said they felt shame because of the similar symptoms of TB and COVID-19

61% OF ADVOCATES FROM GLOBAL FUND ELIGIBLE COUNTRIES

reported an increase in misinformation and stigma in relation to people with TB, identifying stigma, human rights barriers, and fear as serious challenges to effective TB and COVID-19 responses.



02 Calls to action

COVID-19 is driving people with TB into poverty, and social isolation is increasing inequities and human rights-related barriers to TB services.

Provide social protection: COVID-19 has emphasized the critical importance of social protection systems. There is an urgent need to promote equity and access to financial support, transportation, healthcare and food for all people with TB, free from discrimination.

We call on:



Governments to strengthen social protection systems tailored to people with TB, affected communities and other vulnerable populations, respecting their privacy and confidentiality. Governments must act to protect livelihoods, income and workers' rights to health during and after COVID-19.



In-country partners including parliamentarians, CSOs and technical partners to support the development and implementation of social protection mechanisms and interventions for all populations affected by COVID-19 and TB.



CSOs and the media to highlight stories on the realities of people affected by COVID-19 and TB, and advocate for additional investment and support.



Global technical partners and donors to support governments with updated global social protection mechanisms.

- The Stop TB Partnership, through the *Challenge Facility for Civil Society*, to assess, identify and understand the legal, social and economic barriers experienced by people affected by TB and COVID-19, and to develop costed national CRG and stigma action plans, including the recommendations of *Activating A Human Rights-Based TB Response*.

- Donors to fully fund these interventions and action plans, and to develop relevant monitoring and evaluation plans for effective implementation.



Researchers to support governments with evidence-based research that explains the lived experience of persons with TB during the pandemic.

03 Key Findings

Health systems everywhere are weak and ill equipped to respond to simultaneous COVID-19 and TB epidemics.

GLOBALLY

There is not enough personal protective equipment (PPE) for people working in TB, resulting in unsafe and challenging working conditions



Healthcare workers reported lacking PPE to safely care for people with TB and COVID-19.



ACROSS BOTH PUBLIC AND PRIVATE SETTINGS,



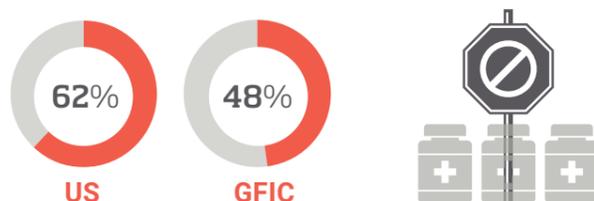
65%+ POLICY AND PROGRAM OFFICERS

reported healthcare facilities to be reducing TB services during the pandemic.



GLOBALLY
50%+
OF HEALTHCARE WORKERS

reported the healthcare facility they worked at to have decreased TB services.



Policy and program officers reported an **increase in stockouts and delays of TB medicines**

GLOBALLY

Healthcare workers reported issues of capacity related to their ability to provide TB care and diagnostics services



59% OF ADVOCATES FROM GLOBAL FUND ELIGIBLE COUNTRIES

reported resources for people with TB being diverted to respond to COVID-19



GLOBALLY
57%
OF TB RESEARCHERS
reported that they did not have the necessary resources to conduct important TB research during the pandemic

03 Calls to action

Health systems everywhere are weak and ill equipped to respond to simultaneous COVID-19 and TB epidemics.

Strengthen healthcare: Frontline healthcare workers and health volunteers have been the first line of defense against COVID-19 around the world. Yet, COVID-19 has weakened health systems everywhere, forcing healthcare workers to contend with unsafe working conditions. Healthcare systems need to address TB and COVID-19 in an integrated way. Fever and cough are symptoms of both TB and COVID-19, and simultaneous screening and diagnostic services are needed in both public and private health sectors.

We call on:



Governments to rebuild patient-centered healthcare systems where people with TB can seek care, and to ensure health facilities can provide quality TB care through providers within the universal healthcare (UHC) framework, across all government levels, mobilizing both the public and private health sectors, including community-based groups. They should:

- Protect the healthcare workforce with a safe working environment and enough PPE, as well as free mental-health support and resources.
- Ensure that all people with TB have access to medicines (at least 2–3 months' supply); switch to the shorter, all-oral drug regimens, as recommended by the WHO; and set up alternative medication delivery networks, such as courier services.
- Leverage testing platforms to increase COVID-19 testing capacity while ensuring that TB testing is not stopped; TB programs must continue running the Xpert mycobacterium tuberculosis/resistance to rifampicin (MTB/RIF) TB test, which is critical to early detection of drug-resistant TB in many settings.
- Invest in the overall capacity of health systems, with increased attention on community-led initiatives and community health workers, including TB survivors, to provide peer-to-peer patient support via digital and mobile platforms.



In-country partners including **parliamentarians, CSOs, and technical partners** to support the rebuilding of healthcare systems and interventions for all population groups, ensuring safe working environments and PPE for all healthcare workers, and increasing healthcare resources for screening, diagnostics and treatment.



CSOs to advocate for continued equal access to TB diagnostics, treatment and resources, including for manufacturers to continue producing essential TB products.



Global partners and donors to support governments in their commitments to healthcare workers, as well as those who provide related social support services, to work with urgency to ensure the supply of PPE through global mechanisms, and to build sustainable, resilient healthcare systems everywhere..

- The *Global TB Caucus* and other political networks to advocate for investment in health systems and UHC, and to press governments to commit to a holistic response to health, ensuring that we build back better than before the pandemic
- The Stop TB Partnership and donors to fully fund and support *TB REACH*, a mechanism supporting community-delivered, innovative initiatives.
- The Stop TB Partnership and donors to fully fund and support the *Global TB Drug facility* to ensure that TB drug stockouts are addressed.
- Technical partners, through the *TB PPM Learning Network*, to support the exchange of lessons learned and cross-learning of innovative adaptations in TB services and the engagement of the private sector.



Researchers to support governments with evidence-based research on healthcare capacity to care for TB patients during the pandemic.

04 Key Findings

People working in the TB field are seeing significant interruptions and diversions in their work and research towards COVID-19.

A majority of TB policy and program officers reported being reassigned to respond to COVID-19



GLOBALLY TB RESEARCHERS REPORTED:



[69% OF ADVOCATES FROM GLOBAL FUND ELIGIBLE COUNTRIES said their work with TB-afflicted people had decreased during the pandemic.]

GLOBALLY

50%+ OF HEALTHCARE WORKERS

reported reductions in TB services where they worked, particularly in private settings



Advocates from Global Fund implementing countries expressed frustration with political attention being diverted to COVID-19 and its dominance of the information and media space.



04 Calls to action

People working in the TB field are seeing significant interruptions and diversions of their work and research to COVID-19.

Build Capacity: Essential TB health services and research should never grind to a halt. The "covidization" of research and the overall health sector (communication, politics, implementation and research) has diverted attention away from TB activities. Interruptions need to be addressed, underscored by real-time data from those on the ground.

We call on:

- Governments** to invest in overall TB service capacity at all levels, by
 - Scaling up investment in community-led monitoring initiatives.
 - Setting regulatory frameworks for strong health systems with sufficient capacity at all levels, in both public and private settings.
- In-country partners** including parliamentarians, civil societies and technical partners to ensure TB capacity and interventions are continued for all populations groups.
- CSOs and the media** to actively highlight the disruptions to TB health services and research, emphasizing the needs of people with TB, and to press for political commitment and investment to end TB at the global, regional, country and local level.
- Global technical partners and donors** to support governments with continuous funding and support for full implementation of TB services in public and private sector, as well as research.
 - The Global TB Caucus and other political networks to advocate for investment in health and TB systems and the active inclusion of TB in global health policy frameworks, global health agreements and declarations on COVID-19 response and pandemic preparedness (such as, UNGA, the G7 and G20 groups, the EU, BRICS and the WHA).
 - Global partners and donors to fund and support accountability and real-time TB data collection and reporting, in line with mechanisms developed in response to COVID-19, including financial accountability frameworks.
 - Donors to ensure continuous funding for research in other health priorities, including TB and COVID-19, through academic, public and private research institutions.
- Researchers** to support governments with evidence-based research that evaluates the impact of COVID-19 on TB services.

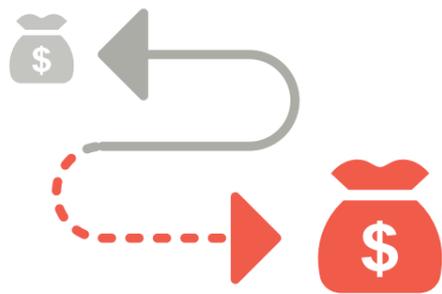
05 Key Findings

TB funding has decreased significantly since the beginning of the pandemic.

ADVOCATES

53% FROM GLOBAL FUND IMPLEMENTING COUNTRIES

said funding for TB was **diverted** to the COVID-19 response



51% said donor support for TB had decreased



GLOBALLY

34% OF TB RESEARCHERS

said their funding for TB had **decreased** since the beginning of the pandemic



All groups called strongly for additional funding and increased resources to respond effectively and safely to both COVID-19 and TB.



POLICY AND PROGRAM OFFICERS

65% FROM GLOBAL FUND IMPLEMENTING COUNTRIES

said funding for TB was being **diverted** for the COVID-19 response



05 Calls to action

TB funding has decreased significantly since the beginning of the pandemic.

Invest: COVID-19 has diverted funding away from TB. To meet the UN HLM TB targets and commitments, TB financing must reach US\$13 billion a year by 2022. The US\$3.3 billion funding gap posted in 2019 is being amplified by the additional funding required to address pandemic-related disruptions.

We call on:



Governments to leverage their domestic investments in COVID-19 to address TB targets, commitments and needs.



In-country partners including **parliamentarians**, **CSOs**, and **technical partners** to support national and global fundraising efforts.



CSOs and the **media** to actively highlight the disruptions in TB services and the needs of people with TB, and to press for political commitment and investment to end TB at global, regional, country and local level.



Global technical partners and **donors** to support program implementation and TB research with continuous funding and support.

- The **Global TB Caucus** and other **political networks** to advocate for investment in health and TB systems and to support governments in building back better TB services..
- **Donors** to fully fund recovery mechanisms such as the *Global Fund's COVID-19 Recovery Mechanism* and ensure TB is included in other global and regional COVID-19 political and financial frameworks (such as UNGA, the G7 and G20 groups, the EU and BRICS).
- **Donors** to recommit to closing the US\$1.2 billion funding gap for TB research and development (R&D). Product development partnerships, such as the *TB Alliance* and the Foundation for Innovative New Diagnostics (*FIND*), are well placed to absorb funds and deliver on TB R&D needs.



TB Researchers to monitor investments and needs across TB and COVID-19 to help build economic and investment cases.

06 Key Findings

ON A POSITIVE NOTE...

Many health facilities and programs have adapted the ways they deliver services and resources in response to COVID-19, which presents an opportunity for the future of TB care and prevention.

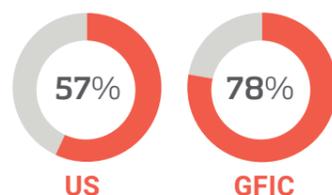
GLOBALLY

50%+ OF PEOPLE WITH TB IN KENYA AND INDIA



reported having received **additional medicine** to continue their treatment at home

Healthcare workers also reported sending people with TB home with treatment during the pandemic



GLOBALLY
60%
OF RESEARCHERS

said COVID-19 related research projects they were working on could be repurposed or leveraged for TB

Respondents reported the successful use of innovative solutions in telemedicine and digital health (video, phone, WhatsApp, apps, social media, etc.), as well as greater family and community support for people on TB treatment.



Policy and program officers lauded program innovations to boost virtual care and support, as well as TB community-led initiatives being adapted to incorporate TB- and COVID-19-related challenges, producing real-time information on accessibility, acceptability, availability and quality of services.



ALL GROUPS EMPHASIZED THAT PEOPLE-CENTERED ADAPTATIONS AND EMPOWERING MEASURES SHOULD BE SUSTAINED BEYOND THE COVID-19 PANDEMIC.

All groups identified an opportunity to strengthen the TB response during the pandemic: Investments in COVID-19, such as in contract-tracing or diagnostic capacity, can be leveraged for TB, while heightened interest in and awareness of infectious respiratory diseases and global health offer an entry point for increasing the political will to end TB.

06 Calls to action

Many health facilities and programs have adapted the ways they deliver services and resources in response to COVID-19, which presents an opportunity for the future of TB care and prevention.

Innovate and adapt: COVID-19 has made health a priority on the political agenda, and it must remain a priority beyond the pandemic. There are opportunities to draw on this momentum to strengthen the overall TB response by adapting strategies and taking advantage of innovative digital health platforms. A new paradigm is required to effectively meet current challenges and to champion the human rights, empowerment and engagement of people affected by TB.

We call on:



Governments to adapt TB plans and interventions in a people-centered framework and to actively collaborate with COVID-19 initiatives, ensuring the integration of TB services, such as

- COVID-19 systems being leveraged for TB response, including laboratory infrastructure, diagnostic capacity, testing facilities, contract-tracing mechanisms, infection-control procedures, prevention and awareness communication.
- Scaling up digital health and virtual care initiatives, tailored to the needs of people affected by TB.



In-country partners including parliamentarians, CSOs, and technical partners to support national and community-led initiatives in response to COVID-19 by ensuring that TB is integrated, and that digital health and virtual care initiatives are scaled up and tailored to the needs of people affected by TB.



CSOs to advocate for progress on TB care and prevention and to highlight impactful innovations. This includes pressing for political commitment and investments to end TB at global, regional, country and local level.



Global partners and donors, including the WHO, the Stop TB Partnership, the Global Fund, the Global TB Caucus, and technical partners, to speed up the adaptation of existing frameworks, policies, plans and related investments to enhance people-centered TB care and prevention.

- The **Global TB Caucus** and other political networks to advocate for investment in health and TB systems and to highlight positive adaptations to COVID-19 that can accelerate progress on ending TB and for the inclusion of TB within global health policy frameworks, global health agreements and declarations related to COVID-19 response and pandemic preparedness (such as UNGA, the G7 and G20 groups, the EU and BRICS).
- The **Stop TB Partnership** and donors to support innovative initiatives through global mechanisms, including the Global Fund, *TB REACH* and new funding streams.



TB Researchers to support governments with evidence-based and operational research on the development and evaluation of new tools and strategies to help diagnose, treat and prevent TB within the current pandemic. This includes evaluating how existing TB infrastructure and resources can be used for COVID-19, without compromising on TB services. Similarly, researcher should evaluate how COVID-19 infrastructure and resources can be used for TB, without compromising the COVID-19 response.

03 Methodology

COVID-19 funding should not take away from existing meagerly supported public health infrastructure and staffing, but rather add to the capacity. The co-existence of COVID-19 and TB [is] likely to persist for years/decades and a mistake would be to not build in additional capacity for COVID-19 that enhances TB/HIV prevention and control activities worldwide.

HEALTHCARE WORKER FROM THE US



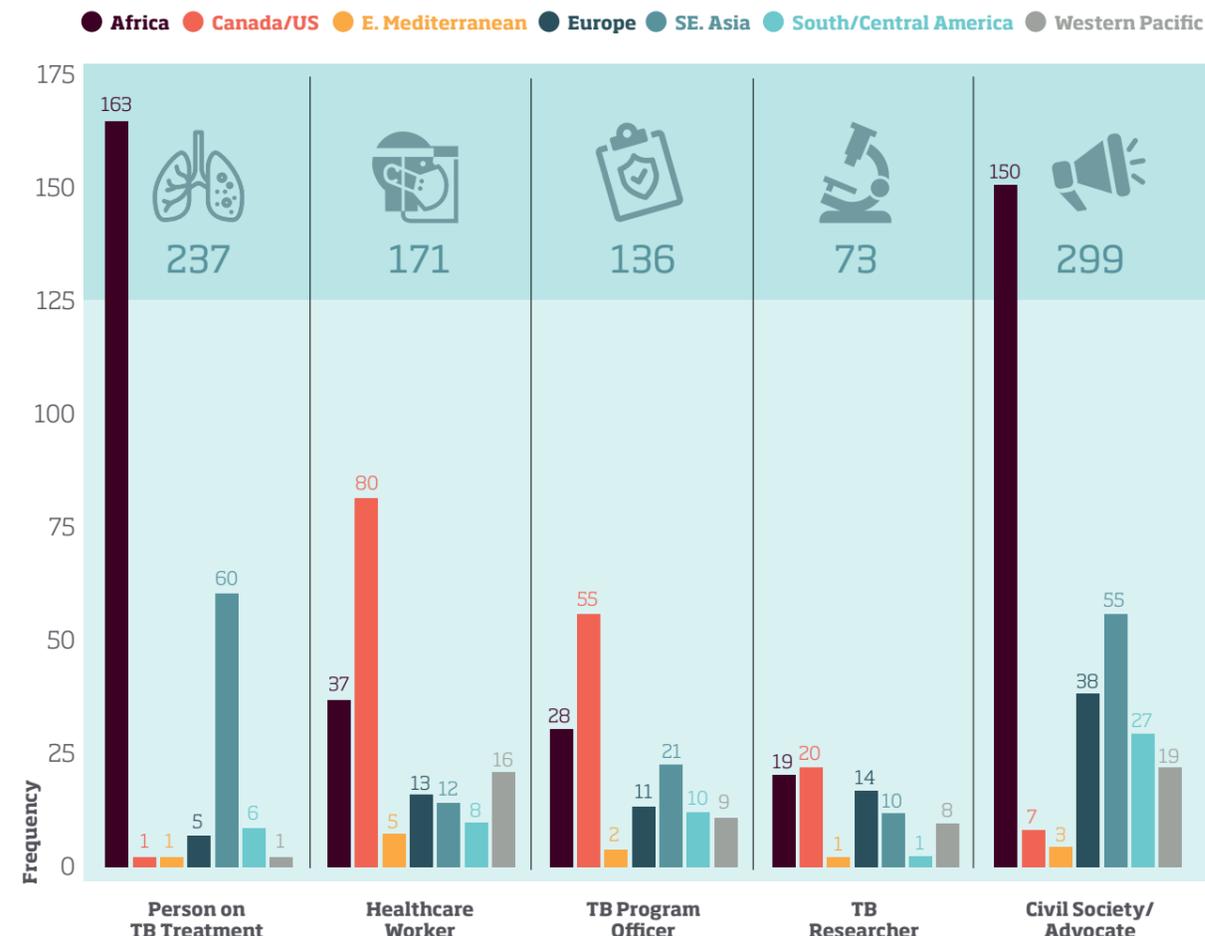
The survey was developed and piloted by a core working group of TB advocates and researchers. It first opened for participation in English on May 26, 2020. By the time data collection closed on July 2, 2020, thanks to the rallying efforts of the TB community, it was available in seven languages.²⁴ Each stakeholder group surveyed, including people with TB, frontline healthcare workers, TB program and policy officers, TB researchers, and TB advocates,²⁵ responded to a set of quantitative and qualitative questions designed specifically for them.²⁶ Quantitative questions were consistently presented across stakeholder groups as statements in a seven-point Likert scale, with responses ranging from “strongly disagree” to “strongly agree”. Statements were tailored to each audience. Open-ended questions were similar across all stakeholder groups and sought to understand key challenges and resource needs, potential solutions, and opportunities. Completing the survey took participants approximately 10 minutes.

Over 1,000 people from 89 countries participated. Calls for participation were advertised in partners’ newsletters, community email lists, and on social media.²⁷ In India, targeted community outreach to engage people with TB was conducted by three TB survivors. In Kenya, KANCO mobilized staff to engage their community networks and request participation in the survey across all stakeholder groups.

Survey data was collected online using SurveyMonkey, and data quality was assessed using Stata software v16.1 and Microsoft Excel 2007. Before data were analyzed, they were checked for duplicate, incomplete, and suspect entries. A number of healthcare workers in the U.S. indicated that they did not work in TB, so they were removed from the dataset. Among those with TB in Kenya, it became apparent that around 20 entries were from the same person, so all but one of these responses were removed from the dataset. Quantitative Likert scale analysis was undertaken using Stata, according to stakeholder group, while qualitative data were analyzed using Excel. Qualitative data, such as quotes from different participants under key emerging themes, were analyzed thematically by grouping.

This report presents the findings of the initiative by each stakeholder group surveyed. Across sections, data are presented slightly differently. For example, in the case of TB researchers, we present our global findings, whereas in the case of frontline healthcare workers, we compare data from countries eligible for support from the Global Fund with data from the U.S. Decisions on how to present findings were based on what was feasible with the data available, as well as what was most relevant for advocacy.

Graph 1 Overall Region



“We trained our health workers in participatory practices, so they work under community based organizations (CBOs). This has helped them create pressure groups to ask for food, detergents, sanitizers, masks and stay of rent payment. CBOs tackling psychosocial issues has helped us [to] focus on medical care.”

HEALTHCARE WORKER FROM KENYA

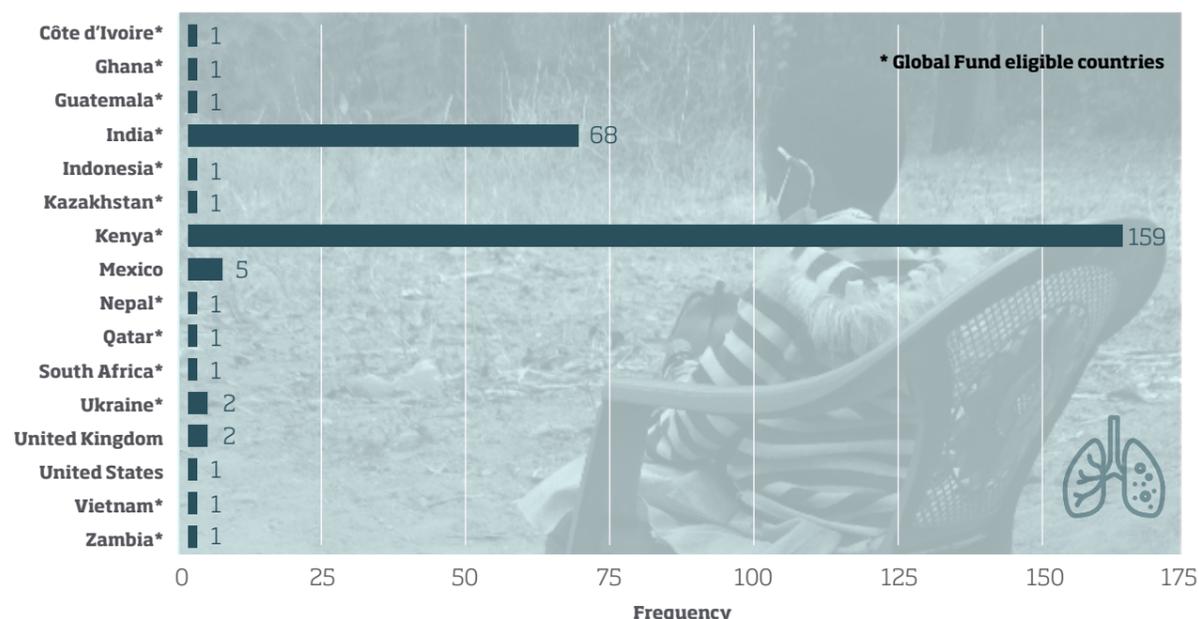


04 People with TB

[I am] sometimes rejected by family members because they think [I have the] same signs of covid. [I'm] even thinking of moving from the family.

PERSON WITH TB FROM KENYA

Graph 2 Person with TB



Responses were collected from 237 people with TB in 16 countries. In this section, we present and compare findings from Kenya and India.²⁸ After performing a quality check and screening for duplicates, 159 responses remained and were included in the Kenyan analysis,²⁹ while 58 were included in the analysis of India.

In Kenya, most participants reported being under partial lockdown (96%). Four (2.5%) reported being under complete lockdown, two (1%) said they were not under lockdown, and one (0.6%) did not know their lockdown status. Most of the people with TB surveyed in Kenya received TB care in public hospitals (56%), followed by public clinics (28%), and private hospitals (13%). Only five participants (3%) obtained TB care in private clinics, and only one (0.6%) sought care in an NGO/charity clinic.

In India, 34 (59%) participants reported being under partial lockdown, while 13 (22%) reported being under complete lockdown. Six (10%) said they were not under lockdown, and five (9%) did not know their lockdown status. Most people with TB surveyed in India sought care in public (31%) or private (29%) hospitals. Fewer participants visited clinics; 15 (26%) said they visited public clinics, and 10 (17%) reported visiting private clinics. Eight individuals (14%) sought care in NGO/charity clinics.

In both countries, using a seven-point Likert scale to “strongly disagree” or “strongly agree”, people with TB were asked 10 questions designed to understand their on-the-ground experiences

throughout the COVID-19 pandemic/lockdown. They also had an option to provide more information on resource needs in two open-ended questions.

The survey findings reveal significant variances in the experiences and perceptions of people with TB in India and Kenya. For example, in Kenya, most people with TB (70%) said they were not receiving enough non-medical support during the pandemic, while only 37% of respondents in India concurred. Likewise, 79% of people with TB in Kenya said they were given medicine to continue their treatment at home, while only 51% of Indian participants reported such an accommodation. Interestingly, people with TB in India were less likely to seek care during the pandemic than people with TB in Kenya (51% in India compared with 29% in Kenya) and were more concerned that they might get COVID-19 if they did visit a clinic (62% in India compared with 50% in Kenya). However, people with TB in Kenya reported feeling more stigmatized because of the similar symptoms of COVID-19 and TB than people in India (55% in Kenya compared with 28% in India).

It became clear from qualitative contributions on both country experiences that people with TB urgently need and want nutritional and economic support. Many participants, particularly in Kenya, said they were struggling to feed their families and to afford transport to access needed care. The struggles of people with TB to secure basic needs are being exacerbated by COVID-19 and the associated lockdowns, as people have not been able to work. For example, one participant from Kenya was a *boda boda* (bicycle taxi) driver, but because of lockdowns and the associated decrease in travel, his business and income had decreased significantly. Another Kenyan participant explained how his “wife [normally] washes clothes for other families, but now most mothers are at home so they do not need her services, because they can handle their own chores as they are also at home due to COVID-19.”

While participants from India did not share specific experiences of lost income, they did say they needed more financial support. One noted that “money from [the] fund is not sufficient for doctor’s appointments and mobile recharges”, while another said, “I don’t get any support. I am in need of money.” Although only a small handful of participants explicitly cited needing psychosocial support, comments on feeling stigmatized and having compromised mental health suggest that such support would also be valuable.

“I need transport and some food because I lost my job due to COVID-19, and I am now unable to get enough food for myself and my family.”

PERSON WITH TB FROM KENYA



CHART 1 Person currently on TB treatment: Kenya

159
RESPONSES

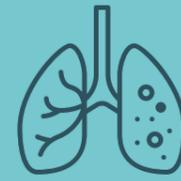


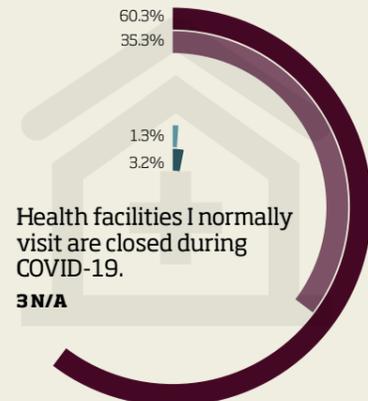
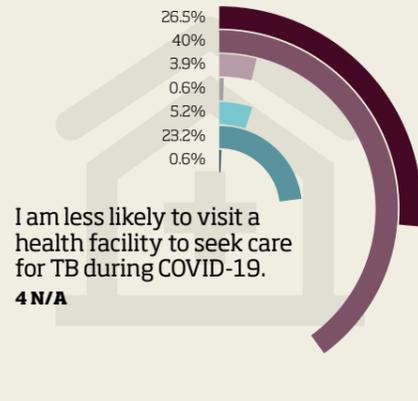
CHART 2 Person currently on TB treatment: India

58
RESPONSES

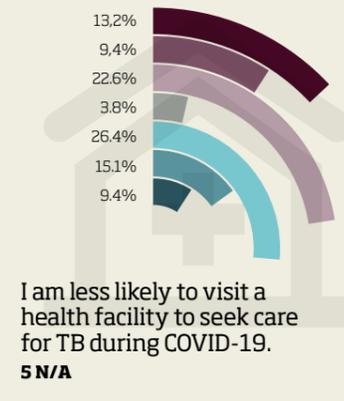
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● Strongly disagree ● Disagree ● Somewhat disagree ● Neither agree or disagree ● Somewhat agree ● Agree ● Strongly agree

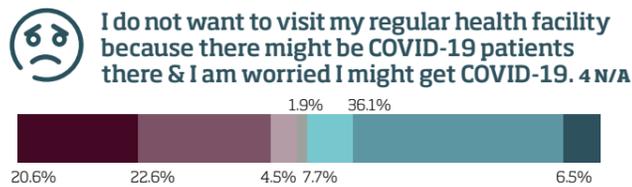
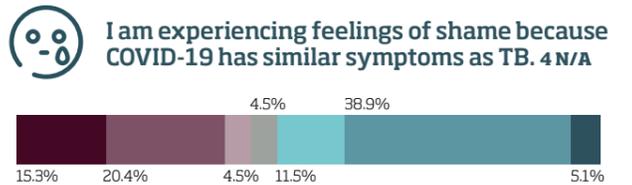
HEALTH FACILITIES



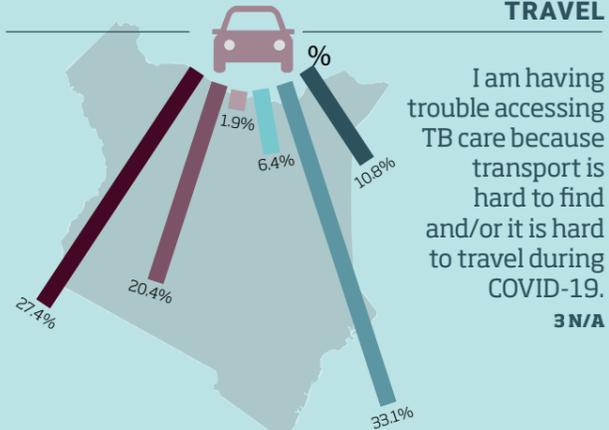
HEALTH FACILITIES



EMOTIONS

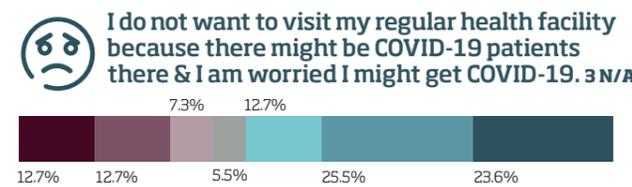
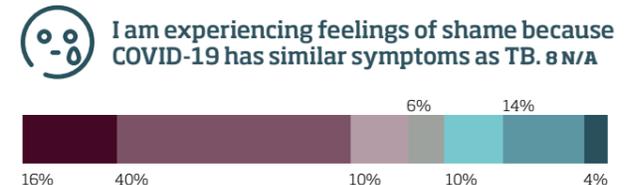


TRAVEL

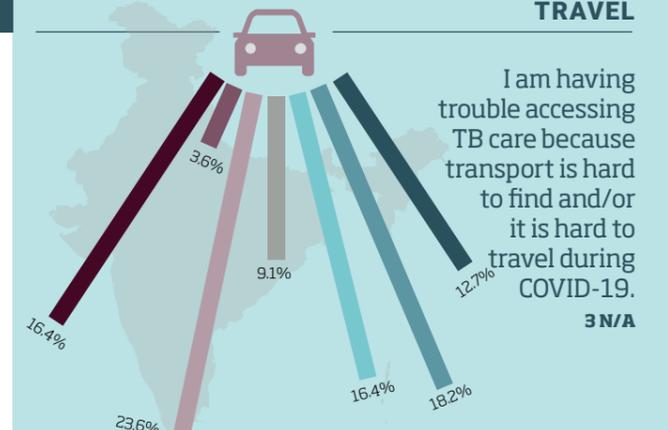


I am having trouble accessing TB care because transport is hard to find and/or it is hard to travel during COVID-19. 3 N/A

EMOTIONS

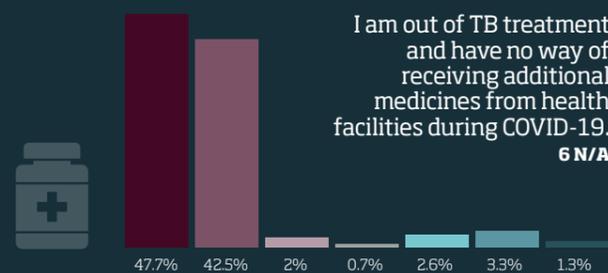
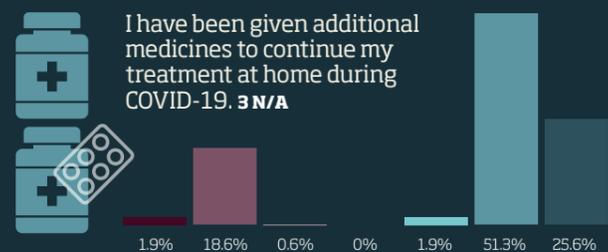


TRAVEL

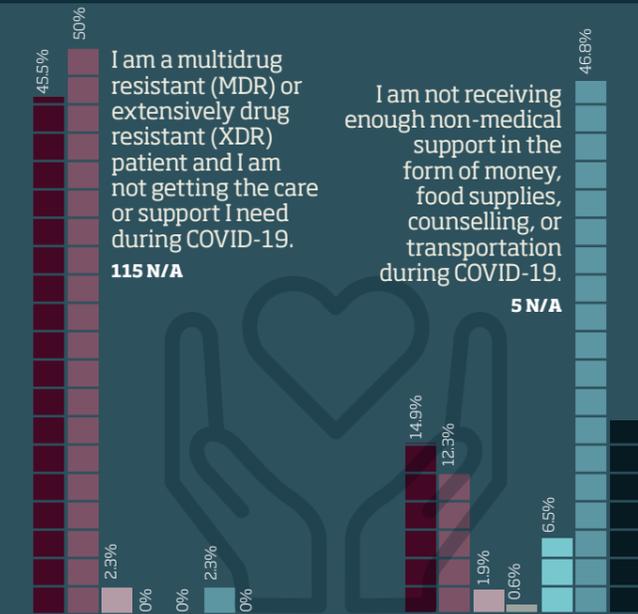


I am having trouble accessing TB care because transport is hard to find and/or it is hard to travel during COVID-19. 3 N/A

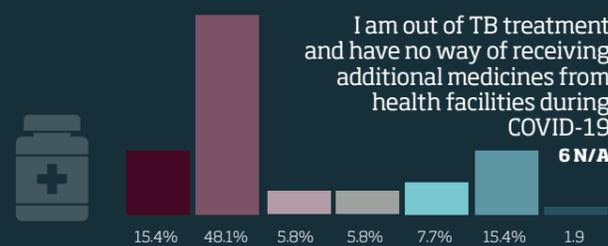
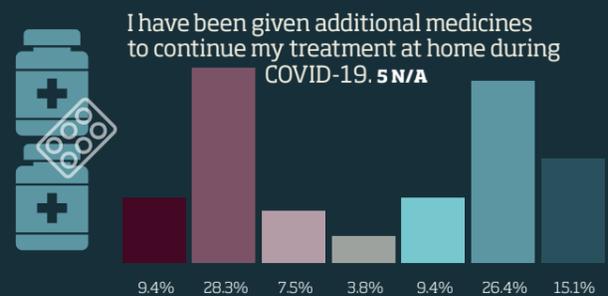
MEDICINE



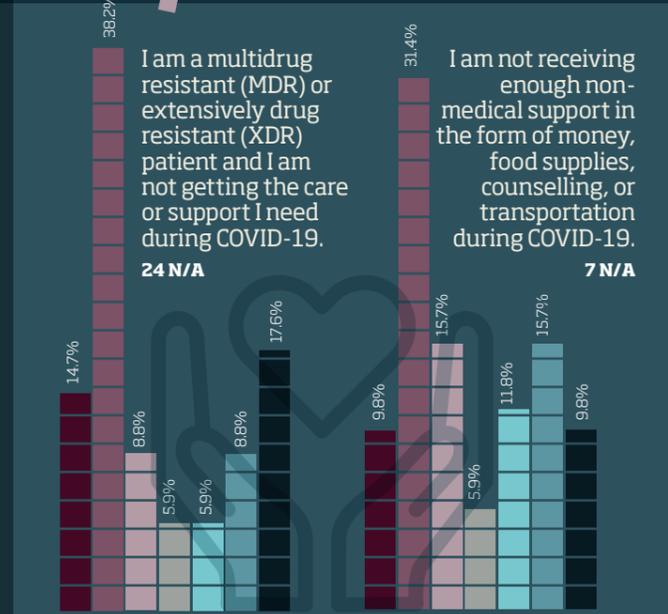
CARE/SUPPORT



MEDICINE



CARE/SUPPORT

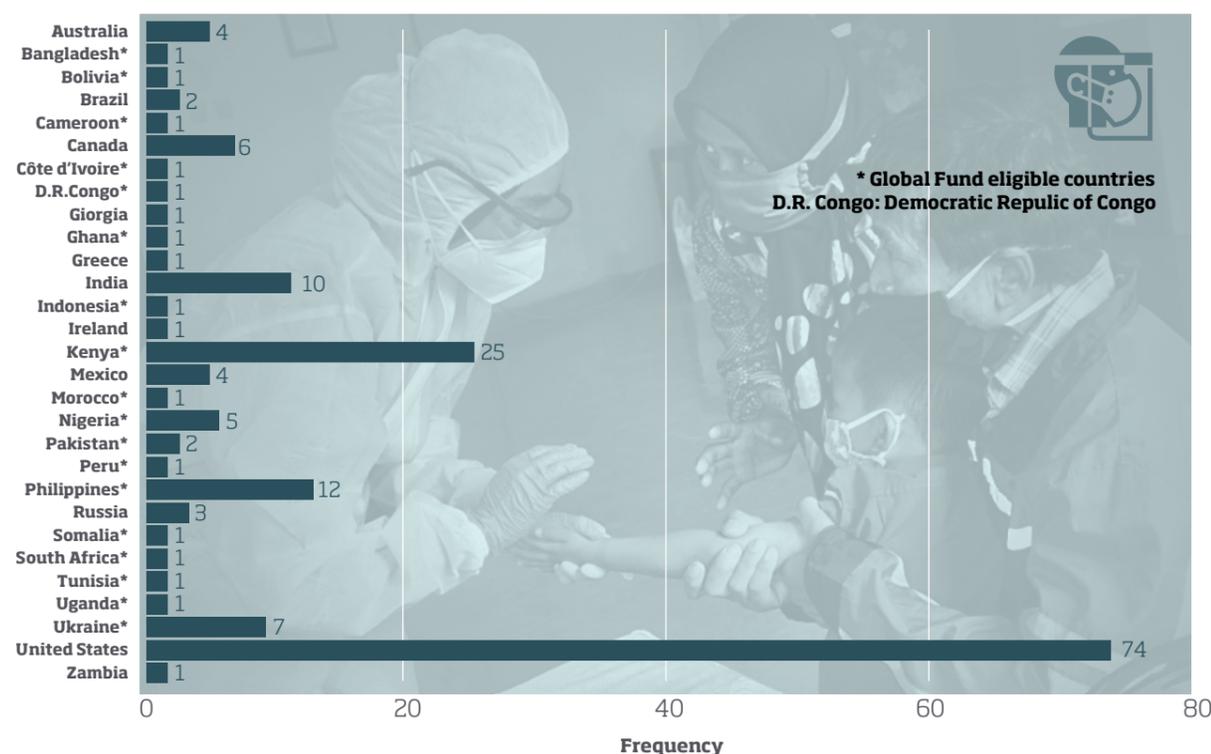




05 Frontline healthcare workers

The additional fear and stigma generated by COVID-19 is contributing to the hesitancy to present to care.

Graph 3 Frontline Healthcare Worker



Responses were collected from 173 TB frontline healthcare workers in 29 countries. Nearly half (44%) were based in Global Fund eligible countries. Most participants were from the U.S. (44%), followed by Kenya (14%), the Philippines (7%), and India (6%). In this section, we present and compare findings from the U.S. (n=74 responses) and countries eligible for Global Fund support (n=76 responses).³⁰

Within the U.S., most participants worked in public health clinics (46%), followed by public hospitals (24%), and private healthcare clinics (16%). Only two participants worked in private hospitals (3%), one worked in a NGO/charity clinic (1%), four worked in a combination of public/private hospitals and clinics (5%), and 11 (15%) worked in other healthcare settings.³¹ Most healthcare workers in the U.S. reported being under partial lockdown (84%), seven (9%) reported being under complete lockdown, and five (7%) said they were not under lockdown.

Most healthcare workers in Global Fund implementing countries worked in the public sector, with 24 (32%) working in public hospitals and 26 (34%) in public health clinics. In the private sector, 14 (18%) worked in private hospitals and 10 (13%) worked in private health clinics. Fifteen (20%) worked in NGO/charity clinics. Most healthcare workers in Global Fund eligible countries reported that they were under partial lockdown (82%), while seven (9%) reported being under complete lockdown.

Using a seven-point Likert scale to either “strongly disagree” or “strongly agree”, healthcare workers were asked 10 questions designed to understand their experience throughout the COVID-19 pandemic/lockdown. They also had an option to provide more information on resource needs, challenges, and opportunities in their responses to four open-ended questions.

The survey findings reveal that TB care has declined significantly because of the pandemic and that healthcare workers are working in challenging and unsafe environments.³² Issues of capacity and access to resources are acutely felt. For example, 69% of participants from Global Fund implementing countries and over a third of participants from the U.S. (36%) said they were lacking PPE. Respondents also reported TB beds and wards being repurposed for COVID-19 (50% of participants in Global Fund implementing countries and 39% in the U.S.), as well as TB medicine stockouts and delays in receiving shipments of medicines during the pandemic (48% of participants in the U.S. and 14% in Global Fund implementing countries). So that people with TB could continue their treatment, healthcare workers reported giving people with TB medicines to take home (57% of participants in the U.S. and 78% of participants in Global Fund implementing countries).

Qualitative contributions from healthcare workers in various countries suggest that key reasons for interruptions to TB care are the redeployment of essential resources and personnel to respond to the public health crisis at hand and generally weak health systems struggling to cope with an influx in demand on services. One healthcare worker in Somalia, for example, summarized their experience: “Since we work in limited or low resource settings, it’s very difficult to have the personal protective equipment [we need].” Another U.S. healthcare worker said, “I was redeployed and was required to cancel all of my Tuberculin skin test classes.”

In addition to healthcare systems struggling to meet the needs of people and programs, healthcare workers speculated that lockdown measures, stigma, and fear of COVID-19 were discouraging people with TB from attempting to access care and support. Fear of policing authorities was a unique factor in Global Fund implementing countries, with a healthcare worker from India saying people were “scared to come for follow-up due to risk of being punished by [the] authorities.”³³

Participants took the opportunity to express how working in challenging and unsafe work environments negatively impacted frontline staff morale and mental health. For example, a healthcare



© Nassuna Edwinah/ BRAC Uganda

"There is a fear but the job and [urgency] make us continue ahead, however our superiors do not ensure work safety and that is difficult"

HEALTHCARE WORKER FROM PERU

worker from Kenya explained how a "healthcare staff shortage" resulted in "poor working conditions", while one from Indonesia said that "with this lack of PPE ... [healthcare workers] are afraid to handle patient[s]... especially [those] that have cough symptoms." Likewise, a participant in the U.S. noted that "work is stressful, as we have [fewer] staff and more work", while another U.S.-based healthcare worker expressed frustration over "mostly encountering obstacles" in trying to do their job well. There were repeated complaints about not being able to reach people with TB because of lockdown measures.

To ensure continuity of TB care and to mitigate the impact of COVID-19, participants almost universally called for adequate PPE, increased capacity in terms of skill and number of healthcare personnel, and access to steady supplies of essential medicines, diagnostic tools, and labora-

tory space. Around the globe, healthcare workers also called for innovative solutions that would decrease the need for people with TB to travel to health clinics for in-person visits. Suggestions from participants repeatedly included telemedicine, "do-at-home" sampling kits and treatment regimens, virtual directly observed treatment (DOT), and renewed investment in community-based healthcare and service delivery. Unique to countries eligible for Global Fund support, healthcare workers frequently noted a need for people with TB to be provided with nutritional support and funds for transport to and from clinics. As most TB cases in the U.S. occur among non-US born people,³⁴ language barriers were highlighted as a challenge unique to the region. One participant cited "difficulty communicating with persons whose first language is not English."

Lastly, despite the many challenges, participants saw opportunities for improving TB care in the long term. Themes from qualitative responses included greater acceptance and willingness to use innovative digital care tools; increased public awareness, political prioritization and, thus, investments in strengthening health systems; increased standards of hygiene- and health-promoting behavioral change; and opportunities to leverage investments in community and primary healthcare infrastructure from the COVID-19 response for TB. For example, a healthcare worker from Kenya called particular attention to the opportunity for including TB in "contract tracing for COVID-19;" a colleague in India cited an opportunity for "improving PPE usage for the long term;" and a practitioner from the U.S. explained how COVID-19 had "made people more aware of hand and respiratory hygiene."



CHART 3 Healthcare workers: Global Fund eligible countries

76
RESPONSES



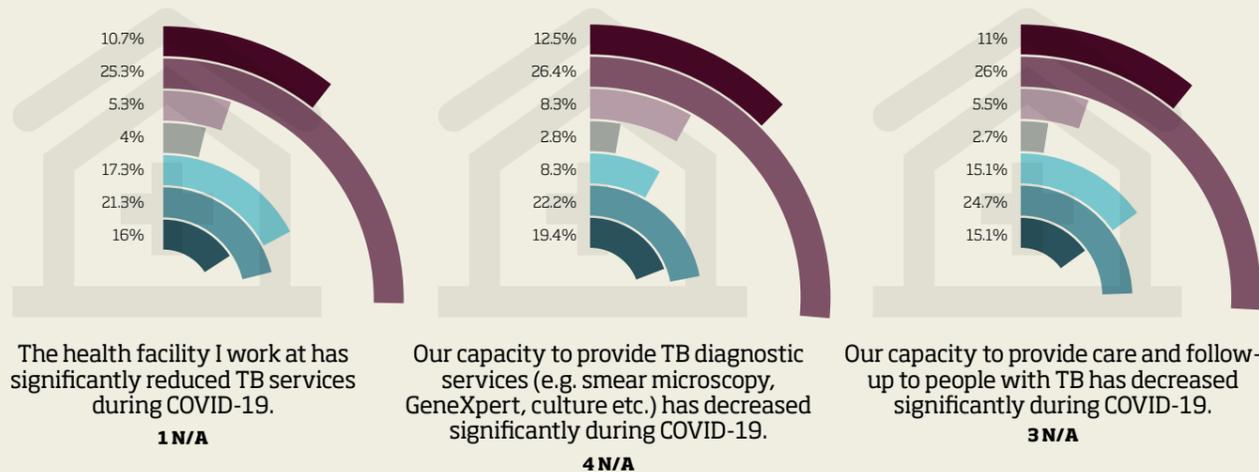
CHART 4 Healthcare workers: USA

74
RESPONSES

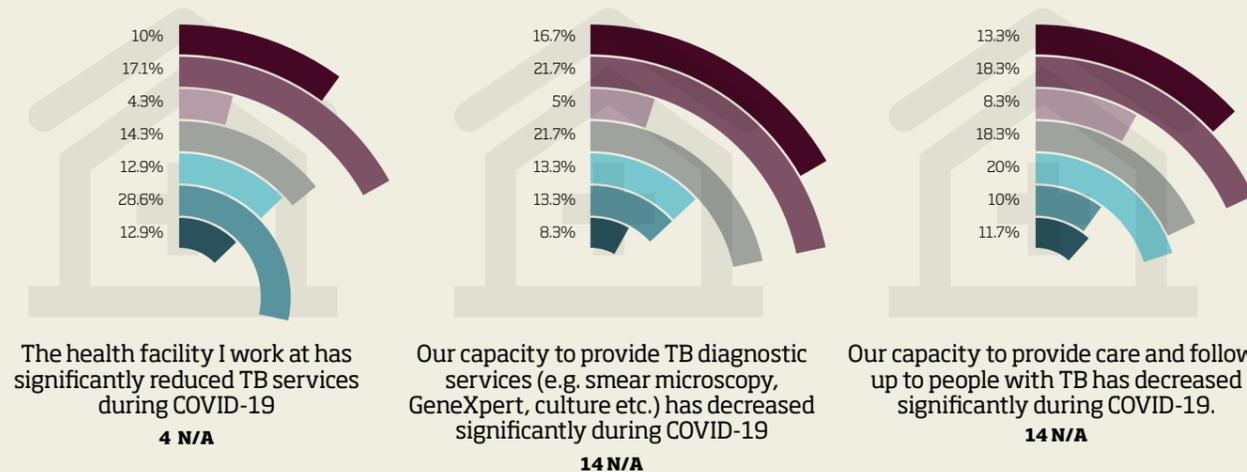
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HEALTH FACILITIES/CARE CAPACITY

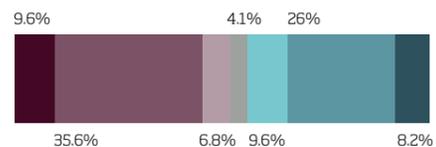


HEALTH FACILITIES/CARE CAPACITY



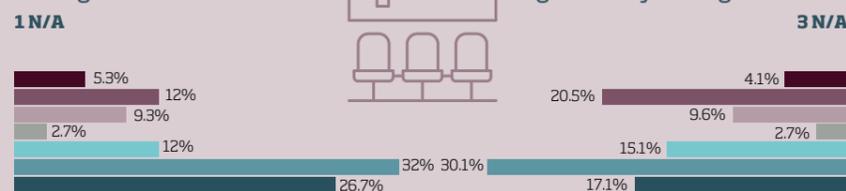
EMOTIONS

I or my colleagues keep getting reassigned from usual TB work to respond to COVID-19. 3 N/A



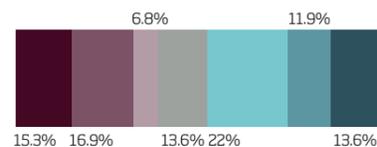
PATIENTS ATTENDANCE

The number of people coming to our health facility for TB testing has decreased significantly during COVID-19. 1 N/A



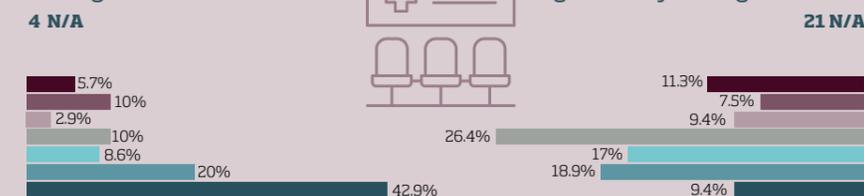
EMOTIONS

I or my colleagues keep getting reassigned from usual TB work to respond to COVID-19. 15 N/A



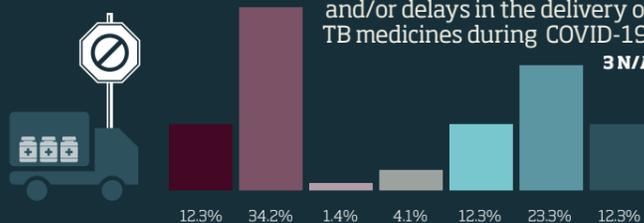
PATIENTS ATTENDANCE

The number of people coming to our health facility for TB testing has decreased significantly during COVID-19. 4 N/A

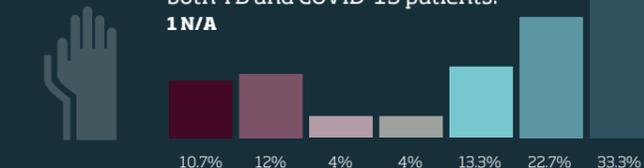


MEDICINE/PPE

Our health facility has seen a significant increase in stock-outs and/or delays in the delivery of TB medicines during COVID-19. 3 N/A

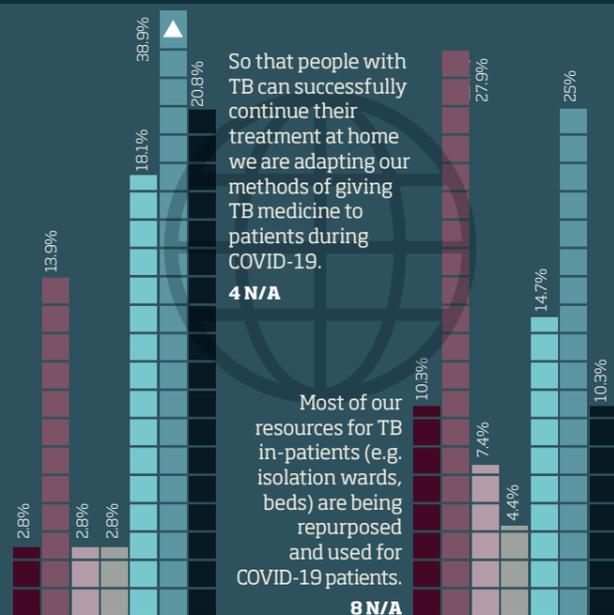


We are significantly lacking personal protective equipment (PPE) (e.g. masks) to safely care for both TB and COVID-19 patients. 1 N/A



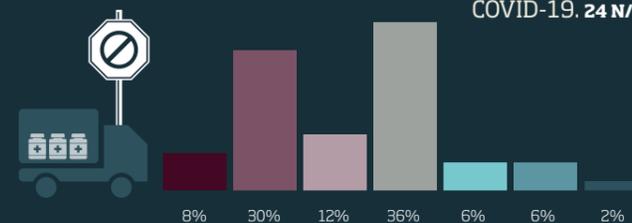
CARE/SUPPORT

So that people with TB can successfully continue their treatment at home we are adapting our methods of giving TB medicine to patients during COVID-19. 4 N/A

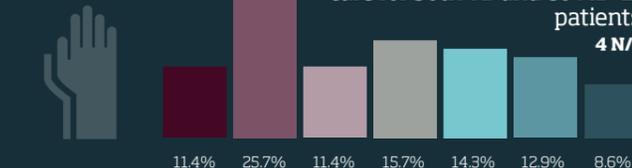


MEDICINE/PPE

Our health facility has seen a significant increase in stock-outs and/or delays in the delivery of TB medicines during COVID-19. 24 N/A

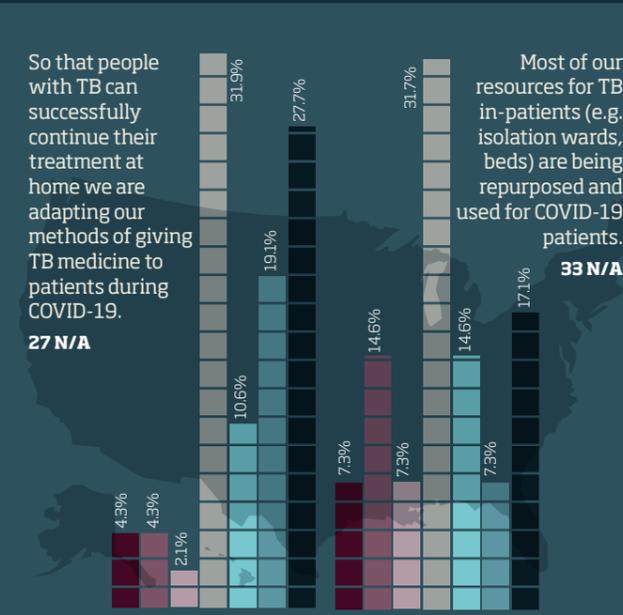


We are significantly lacking personal protective equipment (PPE) (e.g. masks) to safely care for both TB and COVID-19 patients. 4 N/A



CARE/SUPPORT

Most of our resources for TB in-patients (e.g. isolation wards, beds) are being repurposed and used for COVID-19 patients. 33 N/A



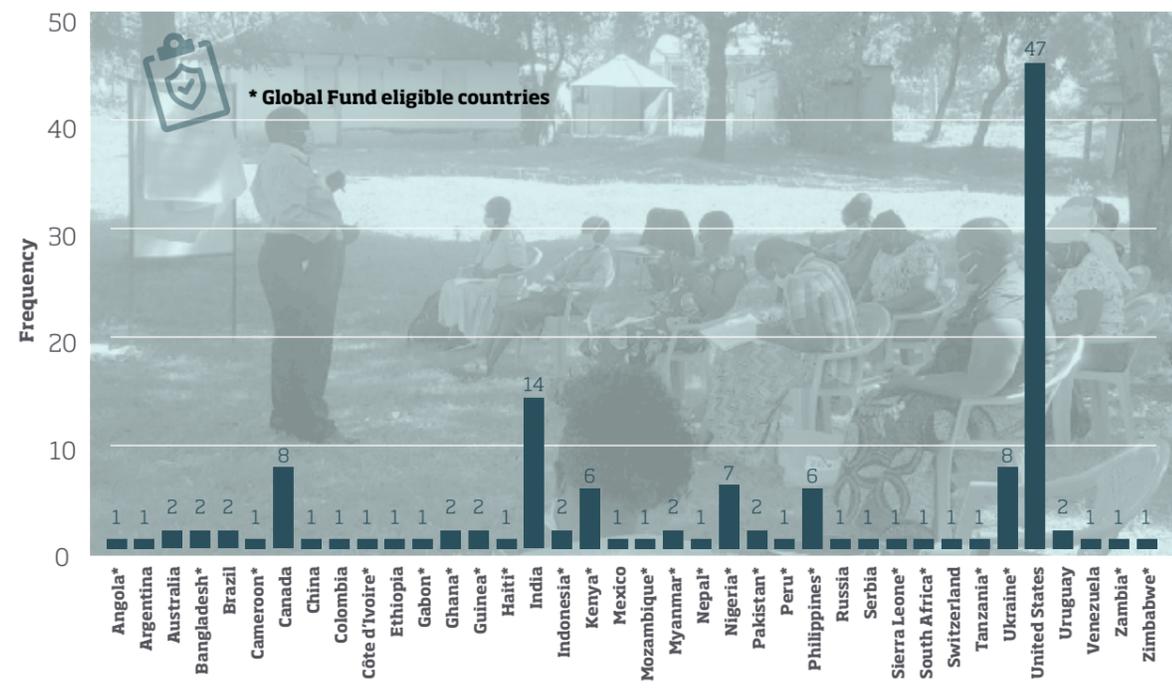
06 Policy & Program Officers

I haven't worked [on] TB since March 13 and have only had a couple days off during that time. [I'm] working on COVID-19 only.

POLICY OR PROGRAM OFFICER FROM THE US



Graph 4 TB Program or Policy Officer



Responses were collected from 137 TB program and policy officers in 37 countries, with almost half (49%) based in Global Fund eligible countries. The largest share of participants was from the U.S. (48%), followed by India (10%), Canada (8%) and Ukraine (8%). In this section, we compare the collated findings from Global Fund eligible countries (n = 67) with findings from the U.S. (n = 48).³⁵

U.S. TB program and policy officers were domestically based, working at state level (53%), county level (36%), or in a city (6%). Two (4%) reported working in other settings, including “the Northeast region” of the U.S. and an unspecified “large healthcare system [for] ambulatory infection prevention”. Most officers in the U.S. reported being under partial lockdown (87%). Two (4%) said they were under complete lockdown, while three (6%) said they were not under lockdown. One (2%) respondent said their lockdown status “varies”.

Among the TB program and policy officers in Global Fund eligible countries, the majority (38%) worked at the subnational level (district, region, state, etc.). Twenty (30%) worked in a city, while 18 (27%) worked at national level. Three respondents (5%) did not specify the level at which they

worked. Most officers reported being under partial lockdown (79%). Eleven (16%) said they were not under lockdown, while only one respondent from India (1%) reported being under complete lockdown. Two respondents (3%) cited other lockdown situations, with one from Bangladesh reporting “zone-wise lockdowns” and the other, from Nepal, not specifying the lockdown situation in their area.

Using a 7-point Likert scale to either “strongly disagree” or “strongly agree”, policy and program officers were asked eight questions designed to understand their experiences throughout the COVID-19 pandemic/lockdown. They also had an option to provide more information on resource needs, challenges, and opportunities in their responses to six open-ended questions.

Survey findings suggest that TB services and program resources have declined significantly as a result of the pandemic. Experiences across the U.S. and Global Fund implementing countries revealed both similarities and differences in the challenges being faced. In the U.S., a higher portion of participants reported staff being reassigned from usual TB work to respond to COVID-19 than in Global Fund implementing countries (87% in the US compared with 59% in Global Fund eligible countries). More U.S. respondents also reported stockouts or delays in the delivery of TB medicines (62% in the U.S. and 48% in Global Fund eligible countries). In Global Fund implementing countries, a higher portion of policy and program officers noted that the number of people receiving TB treatment had decreased significantly during the pandemic (70% in Global Fund countries and 36% in the U.S.). Similarly, just under one-third of respondents from the U.S. cited a diversion of TB funding, compared with more than two-thirds of respondents from Global Fund implementing countries (65% in Global Fund eligible countries and 21% in the U.S.).

Around the world, policy and program officers cited significant decreases in TB notifications (88% in Global Fund implementing countries versus 68% in the U.S.). Reports of healthcare facilities reducing TB services during the pandemic were broadly on a par (70% in the U.S. and 71% in Global

“We have integrated TB and COVID-19 screening processes to ensure that people with similar symptoms get investigated for both illnesses, so as not to miss a single case, since [the] primary focus for now has been shifted to [mainly] the pandemic.”

POLICY OR PROGRAM OFFICER FROM SIERRA LEON

“[We have worked to] re-arrange the delivery system and strengthen community involvement.”

POLICY OR PROGRAM OFFICER FROM INDONESIA

Fund implementing countries). Qualitative contributions show local variances. For example, participants from Myanmar and Nigeria, respectively, observed that there were a lot of “private TB clinic closure[s]” and that “private providers are not willing to screen patients.” Another participant from Nigeria noted that there was “low demand for TB services in the private sector because people have been impoverished by the extended lockdown.”³⁶

Qualitative contributions from policy and program officers in Global Fund eligible countries suggest that the main reasons for interruptions to TB programming are the redeployment of resources due to a general lack of programmatic capacity, as well as a shift in psychosocial behavior in response to the pandemic. Stigma and fear presented as particularly strong psychosocial drivers impeding people from accessing and receiving TB services. For example, one participant in the Philippines noted that the “stigma attached to COVID-19 ... hampers screening activities,” while a participant from Nigeria said there was a “decrease [in] patient turnout in hospitals and clinics due to fear of contracting COVID-19.” Concerns were repeatedly raised about the dual stigma of COVID-19 and TB causing “people with TB symptoms to hide it for the fear of Covid-19 stigma”, as one officer from Ghana put it. A participant from Kenya termed the phenomenon “the stigmatization of respiratory illnesses by healthcare providers” and explained how people were afraid to approach health services for fear of being quarantined if they showed respiratory illness-related symptoms.

To maintain a level of TB service provision during the pandemic, policy and program officers cited significant changes to the operation of TB programs. While participants cited an overall emphasis on the use of PPE and social-distancing protocols, they also noted solutions that reduced the need for people with TB to travel to health clinics for in-person visits. Globally, there was an effort to scale back overall in-person contact for drug delivery by providing a “larger drug dispense per visit” (according to an officer from Indonesia). This varied from program to program, from providing one month of take-home medicines to a three-month supply of at-home treatment. In the U.S., some programs even began to mail out medicines to avoid personal home delivery.

There were slight differences in priority when it came to adapting programs in different contexts. While there was, unsurprisingly, an across-the-board rise in the reported use of telemedicine and virtual platforms, U.S. participants placed stronger emphasis on such program innovations in their qualitative comments. Global Fund eligible countries, in contrast, emphasized program innovations that “strengthen[ed] family and community support systems” (according to an officer from Zimbabwe). Community interventions included training and mobilizing members of the community to deliver TB medicines, to check in on the mental health and wellbeing of people with TB, to report barriers to access through community-led monitoring, and to identify and triage TB notifications. Family members were likewise trained and asked to take on treatment follow-up responsibilities. One participant from Kenya summarized the strategy well, saying how they were filling gaps in services by using “community support in finding the missing cases, follow-up of patients, [and] home visits.”

To get TB programs back up and running, participants made a collective call for more resources for TB, as well as political and practical recognition of TB services as essential. In many instances, policy and program officers noted the opportunity to leverage current investments in COVID-19 to bolster TB infrastructure in future. Participants in Global Fund eligible countries were particularly interested in “funding for more diagnostics like the GeneXpert machines” (as one officer from Zambia noted), with one participant from Niger saying that “the use of GeneXpert instruments for Covid-19 diagnosis provides a great opportunity to strengthen the weak TB diagnostic network.” Policy and program officers frequently flagged similar opportunities for taking a more “general respiratory approach” (as an officer from Indonesia termed it), whereby case detection and contact tracing for TB could be strengthened alongside efforts being implemented for COVID-19.³⁷ In the U.S., participants primarily called for more staff, so that they could handle the growing COVID-19 burden without having to reassign personnel from essential TB and other health services.

“We are doing telemedicine primarily through phone calls. We need to find an appropriate platform so that videoconferencing can be done with patients that do not speak English as their primary language. We need to obtain all the proper equipment to conduct these activities.”

POLICY OR PROGRAM OFFICER FROM THE US



CHART 5
**TB Program/Policy Officer:
Global Fund eligible countries**

67
RESPONSES



CHART 6
**TB Program/Policy Officer:
USA**

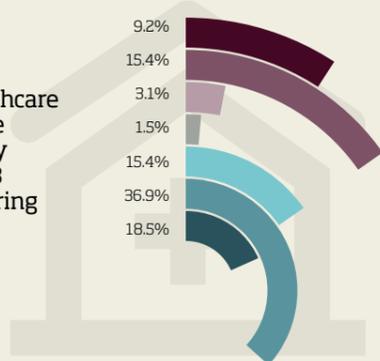
47
RESPONSES

● Strongly disagree ● Disagree ● Somewhat disagree ● Neither agree or disagree ● Somewhat agree ● Agree ● Strongly agree

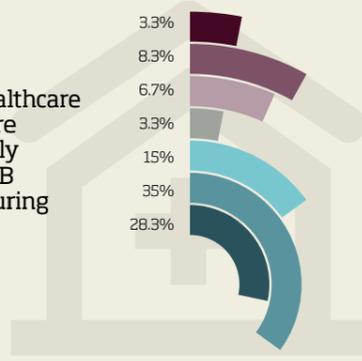
● Strongly disagree ● Disagree ● Somewhat disagree ● Neither agree or disagree ● Somewhat agree ● Agree ● Strongly agree

HEALTH FACILITIES

Public healthcare facilities are significantly reducing TB services during COVID-19.
2 N/A

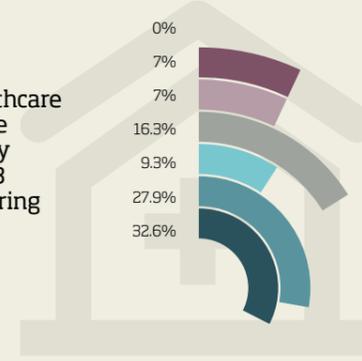


Private healthcare facilities are significantly reducing TB services during COVID-19.
7 N/A

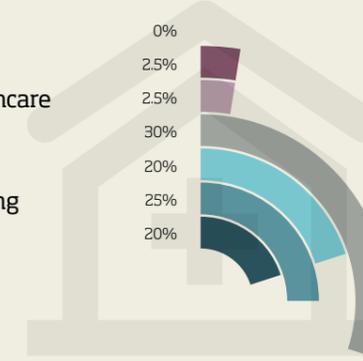


HEALTH FACILITIES

Public healthcare facilities are significantly reducing TB services during COVID-19.
4 N/A



Private healthcare facilities are significantly reducing TB services during COVID-19.
7 N/A



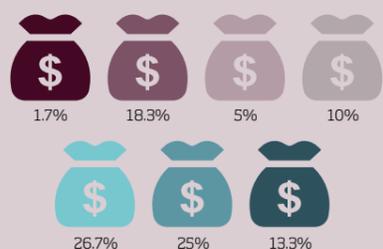
NOTIFICATIONS

There has been a significant decrease in TB notifications during COVID-19. **1 N/A**



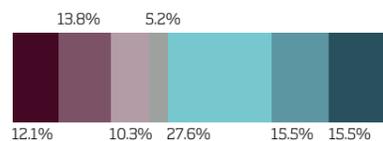
FUNDING

A significant amount of TB funding is being diverted for the COVID-19 response. **7 N/A**



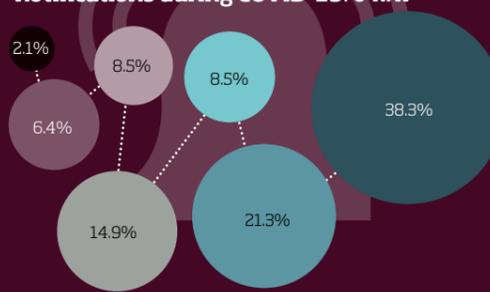
EMOTIONS

I or my colleagues keep getting reassigned from usual TB work to respond to COVID-19. **3 N/A**



NOTIFICATIONS

There has been a significant decrease in TB notifications during COVID-19. **0 N/A**



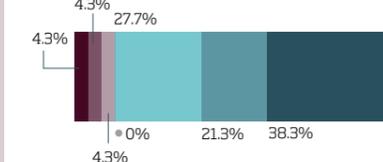
FUNDING

A significant amount of TB funding is being diverted for the COVID-19 response. **9 N/A**



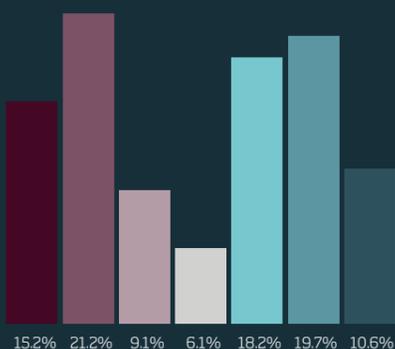
EMOTIONS

I or my colleagues keep getting reassigned from usual TB work to respond to COVID-19. **0 N/A**



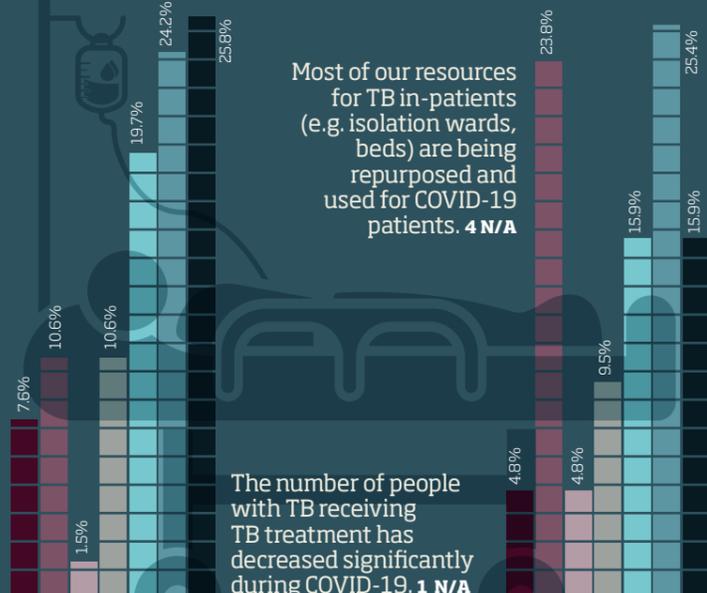
MEDICINE

We are seeing an increase in stock-outs and/or delays in the delivery of TB medicines during COVID-19. **1 N/A**



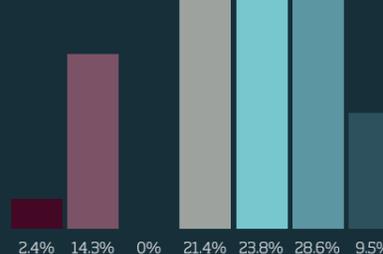
CARE/SUPPORT

Most of our resources for TB in-patients (e.g. isolation wards, beds) are being repurposed and used for COVID-19 patients. **4 N/A**



MEDICINE

We are seeing an increase in stock-outs and/or delays in the delivery of TB medicines during COVID-19. **5 N/A**



CARE/SUPPORT

The number of people with TB receiving TB treatment has decreased significantly during the COVID-19. **2 N/A**



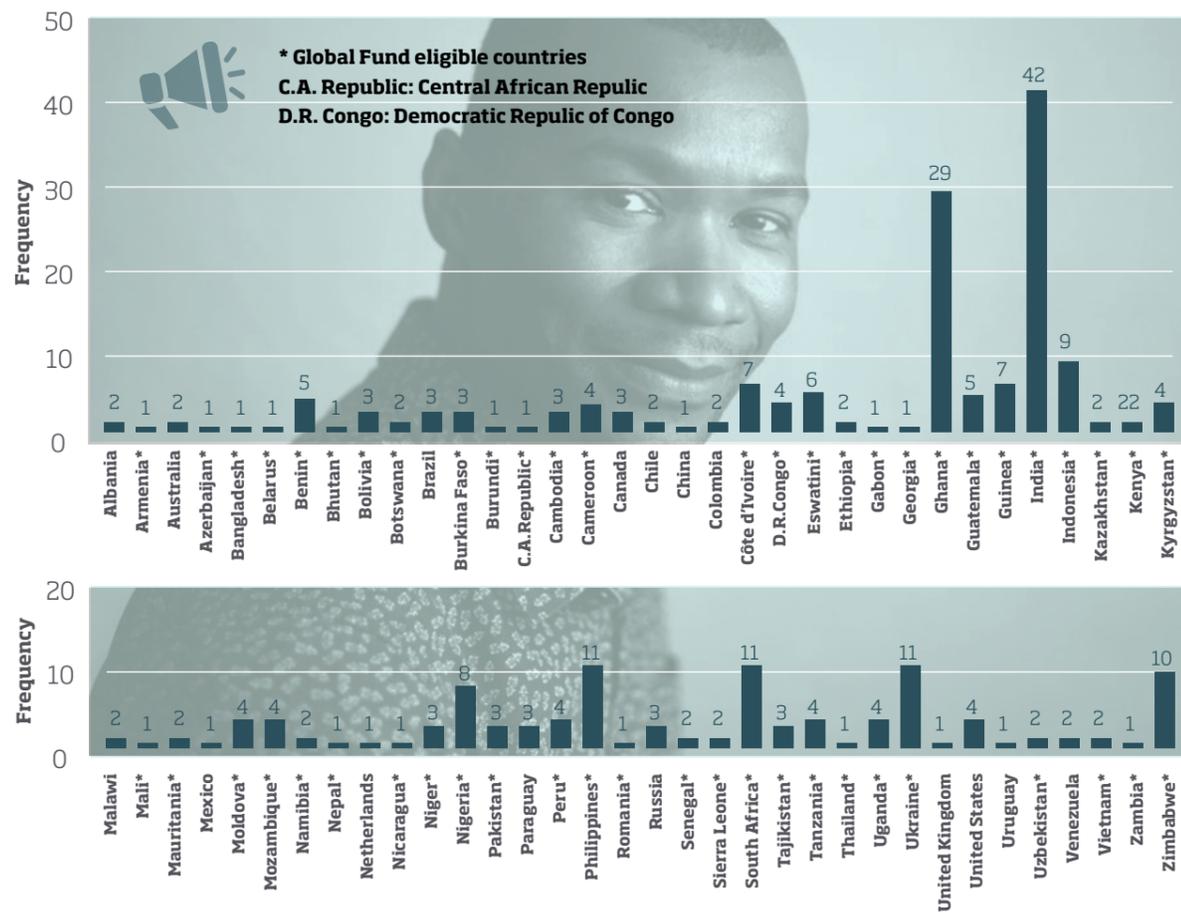
07 TB Advocates



We are advocating the need to start working at the community level.

ADVOCATE FROM ESWATINI

Graph 5 TB Advocate



Responses were collected from 299 individuals employed by CSOs or NGOs working to end TB, or individuals who identified as a TB advocate or survivor. 38 Participants were located in 68 countries, with the majority based in states eligible for Global Fund support (90%). In this section, we present only collated findings from Global Fund eligible countries (n=270).³⁹

Most respondents in Global Fund eligible countries were involved in TB activism (77%), followed by TB healthcare provision (53%), TB policy development (35%), TB program administration or management (27%), and research (26%). Other areas of engagement included case identification (20%), education (14%), community strengthening and engagement (12%), and human rights for people with TB (12%). Most respondents reported being under partial lockdown (68%); 20 respondents reported being under complete lockdown (7%) and 51 reported not being under lockdown

“From conversations with community health workers, there is a lot of stigma around COVID. ‘You can not cough in peace,’ one said, as any cough is mistaken as COVID, and when you become a suspected case, you are forcefully quarantined. There is a need for more education on human rights around COVID.”

ADVOCATE FROM KENYA

(19%). One respondent did not know their lockdown situation (0.4%). Fourteen respondents (5%) reported other lockdown situations, largely that their quarantine status was transitioning or had recently transitioned. Several respondents from Western Africa (Cameroon, Côte d'Ivoire, Guinea) indicated that confinement had been lifted, but that there were certain social rules in place that had to be respected. One respondent from Pakistan reported regional or “smart lockdowns” in areas of the country that had high prevalence of COVID-19, while another respondent from Nigeria said lockdown restrictions were eased on “Wednesdays, Fridays, and Sundays.”

Using a 7-point Likert scale to either strongly disagree or strongly agree, advocates were asked a set of 11 questions designed to understand their experience throughout the COVID-19 pandemic or lockdown. They also had an option to provide more information on resource needs, challenges, strategies, and opportunities in their responses to five open-ended questions.

Survey findings show TB advocates to be experiencing a high degree of pandemic-related anxiety; 83% felt that political leaders were focusing so heavily on COVID-19 that progress on TB would be significantly set back, while 79% said that it was very difficult to raise awareness about TB while the pandemic was dominating the headlines. More than half also reported funding being diverted away from TB to the COVID-19 response and a decrease in donor support to end TB. Advocates also raised concerns about people with TB not getting the care they needed; 75% reported a decline in TB testing during COVID-19, while more than half reported stockouts of TB medicines, or resources for people with TB being repurposed for COVID-19.

While advocates cited scores of challenges to ending TB as a result of COVID-19, three dominated the qualitative responses. First, participants said lockdowns were preventing both people with TB from accessing care and care/social support providers from accessing affected communities, including economic, nutritional and psychosocial support services. For example, a participant from Eswatini noted that “lockdowns/restrictions being in effect has limited awareness campaigns”, while a respondent from Uganda said it was “difficult to access TB patients due to the lock down; all of them are stuck in their villages with no transportation to the health facilities and drug refill.”



CHART 7

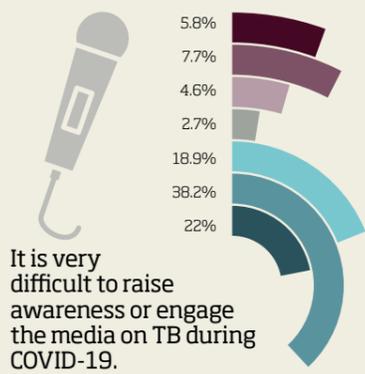
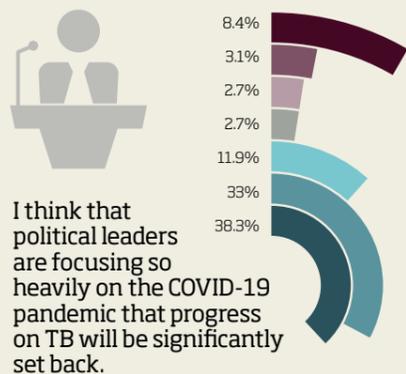
TB Advocates: Global Fund eligible countries

268

RESPONSES

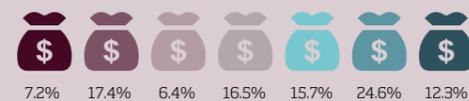
● Strongly disagree ● Disagree ● Somewhat disagree ● Neither agree or disagree ● Somewhat agree ● Agree ● Strongly agree

POLITICS/MEDIA

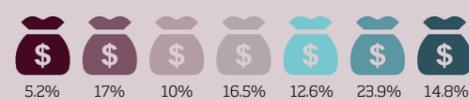


FUNDING

A significant amount of TB funding is being diverted for the COVID-19 response.
32 N/A

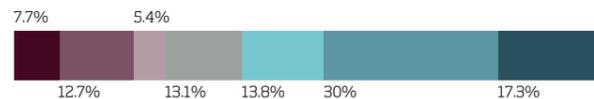


Donor support for TB has decreased significantly during the COVID-19 pandemic
38 N/A

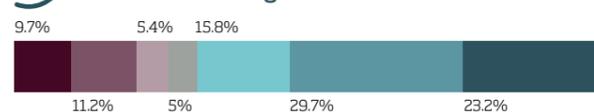


EMOTIONS

Misinformation and stigma against people with TB has significantly increased during COVID-19.
8 N/A

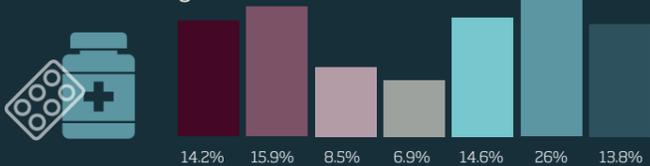


My work with people with TB has significantly decreased during COVID-19.
9 N/A

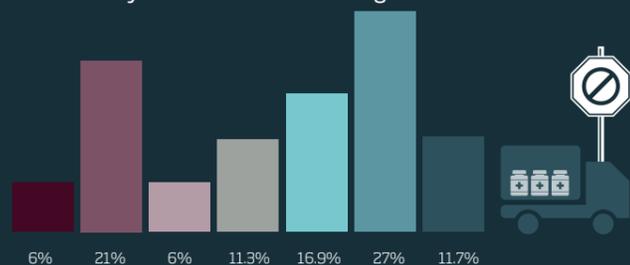


MEDICINE

People with TB are receiving additional medicines to continue their treatment at home during COVID-19.
22 N/A



We are seeing an increase in stock-outs and/or delays in the delivery of TB medicines during COVID-19.
20 N/A



CARE/SUPPORT



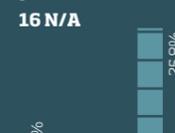
There has been a significant decrease in TB testing during COVID-19.
11 N/A



People with TB are having significant challenges accessing treatment and care during COVID-19.
5 N/A



Most resources for TB patients (e.g. isolation wards, beds, diagnostics) are being repurposed and used for COVID-19 patients.
16 N/A



Second, participants reported stigma, human rights barriers, and fear as serious hindrances to effective responses to both TB and COVID-19. A participant from Ghana summarized the situation very well, saying that “fear has gripped our TB patients as some of the symptoms look the same as the people with COVID-19 and, because of this, they don't seek medical attention like they used to.” Third, advocates expressed worry and frustration over COVID-19 “diverting attention” (as an advocate from Bhutan put it) and dominating the media and discourse. Decision makers and influencers are “tied up completely with COVID”, according to one advocate from Ethiopia, such that TB advocacy has become “a very difficult task” (according to a respondent from Zimbabwe) and “coordination and collaboration [among stakeholders] is lower” (as one advocate from Cambodia wrote).

Despite the challenges of attracting attention to health topics other than COVID-19, it became clear from participants' qualitative contributions that advocates felt reinvigorated to step up their efforts to end TB. Recognizing the devastating impact the pandemic was having on people affected by TB, respondents shared how they were leveraging every opportunity to “continue to talk about TB” (as an advocate from Nigeria said).

“Both COVID-19 and TB being respiratory system infections, [made] it easier to talk about both” when opportunities arise, according to an advocate from Kenya. Some respondents shared how they were able to highlight the interconnectedness of both diseases from the perspective of physiology, affected communities' lived experience, and public health response. To raise public awareness of TB during the pandemic, participants said they were working to maintain a “focus on community education and radio discussion to reach leaders” (said one advocate from Ghana), coordinating virtual meetings “between parliamentarians and civil society” through the TB Caucus (according to an advocate from Peru), issuing “press statements” and “providing evidence” (according to advocates from Sierra Leone and Ukraine). Efforts included the provision of real-time data on barriers to accessing services through community-led TB and COVID monitoring⁴⁰ to peers and decision makers, as well as using social-media platforms to share information and coordinate grassroots advocacy.

“Patients [are] denying cough symptoms because of fear.”

ADVOCATE FROM NIGERIA

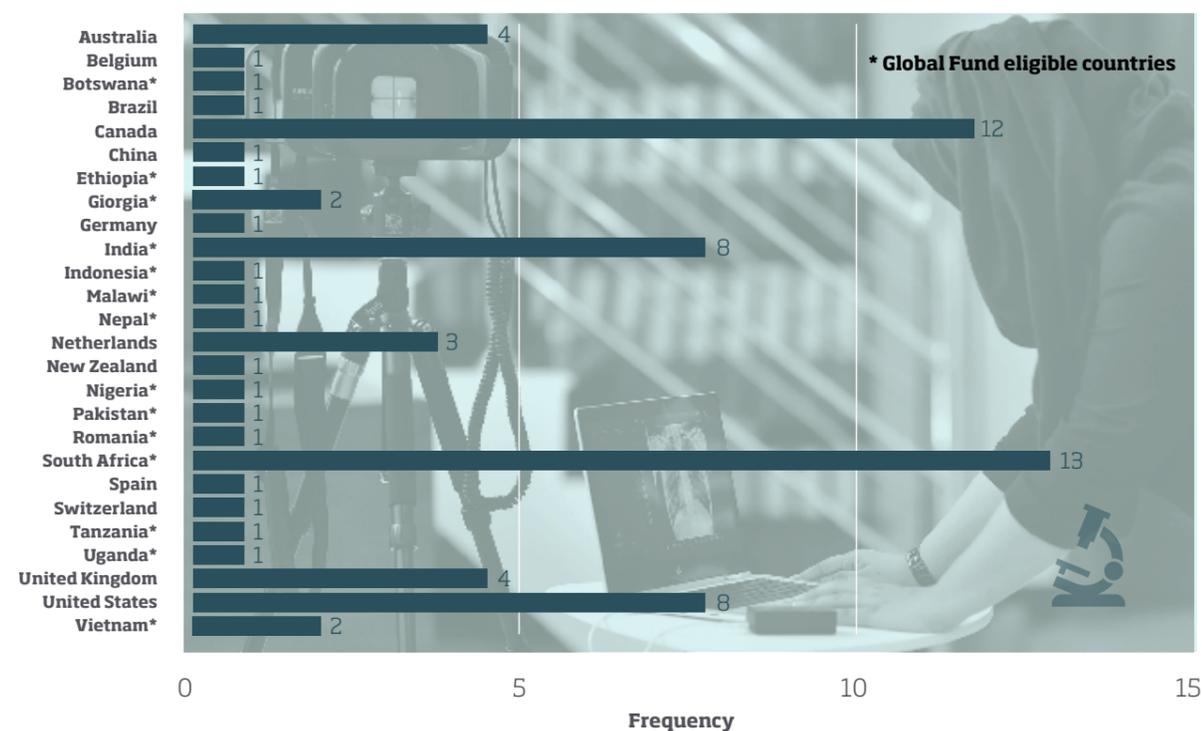
08 TB Researchers

Our team dropped our TB projects to work on covid and it has been hard to resuscitate the projects now that our covid projects have wrapped up. It was nice to contribute to covid while our TB projects were on hold, but it is clear that our TB projects have suffered.

RESEARCHER FROM CANADA



Graph 6 TB Researcher



Responses were collected from 73 TB researchers in 26 countries, with almost half (48%) of them based in Global Fund eligible countries. The geographic focus of participants' research varied, with most having project sites and/or labs in multiple countries. The most common research sites included South Africa (37%), India (23%), and Canada (11%). Participants were typically engaged in more than one type of research, with around half (49%) working on TB laboratory-based research, 40% in epidemiology, 33% in clinical trials, and 34% in operational research.

Most researchers reported being under partial lockdown (71%), while 15 (21%) reported not being under lockdown. Four researchers said they were under complete lockdown (5%) and one did not know their lockdown status (1%). One researcher from Malawi explained that their lockdown status was undefined, saying that a complete lockdown had been imposed, but that a civil-society injunction from Supreme Court had annulled it, so there was no clear current guidance or legislation on lockdown.

Using a seven-point Likert scale to either "strongly disagree" or "strongly agree", TB researchers were asked 10 questions designed to understand their on-the-ground experience throughout the COVID-19 pandemic and/or lockdown. They also had an option to provide more information on resource needs, challenges, and opportunities in four open-ended questions.

Survey findings show TB researchers to be experiencing significant stress and interruptions to their work because of the pandemic. Ninety percent of participants reported that work and travel schedules were interrupted, while 81% reported delays in research with human subjects. Seventy-nine percent of TB researchers also reported TB research involving laboratory procedures to be interrupted or delayed during COVID-19, while 73% said research personnel were being redirected to work on COVID-19-related projects. Survey participants even observed that the peer-review process for TB publications was significantly impacted. Interestingly, researchers reported that TB infrastructure and resources were being leveraged for COVID-19-related research and, likewise, suggested that COVID-19 projects could be repurposed and leveraged for TB-related research.

The qualitative responses suggested that the interruptions to TB research were partly down to COVID-19 becoming the political priority. A participant from the United Kingdom summed this up well, citing the "loss of opportunity to conduct TB studies due to prioritization of COVID-19 studies." A South African respondent bemoaned the fact that "far more attention is given to COVID-19 at the expense of TB." In response to the political focus being centered on COVID-19, TB researchers are having to "completely switch gears to COVID-19" to "sustain their labs", keep their positions and "get funding", said one TB researcher from Canada. Other factors causing researchers to "put TB work on hold", according to another Canadian TB researcher, related to a lack of capacity and resources, as well as the knock-on effects of the pandemic and associated lockdowns.

Research personnel, equipment, and funding have been diverted to the pandemic response, while strict infection prevention and control measures have made continuing research projects challenging. For example, TB researchers repeatedly cited lab space and infrastructure (such as biosafety level-3 laboratories) being repurposed for COVID-19 testing. Similarly, respondents were

"We need additional resources for PPE and other necessary equipment to assure work safety for TB researchers. We need to conduct both COVID-19 and TB research at the same time (for example, screening for both COVID-19 and TB). We need mHealth tools and infrastructure to support the use of mHealth to connect patients and healthcare workers and researchers."

RESEARCHER FROM VIETNAM

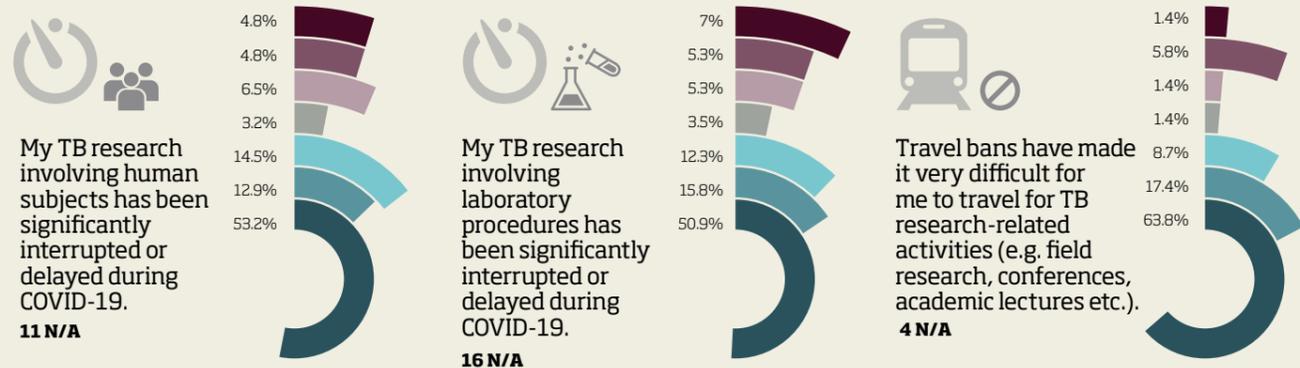


CHART 8 TB researchers: Global

73 RESPONSES

● Strongly disagree ● Disagree ● Somewhat disagree ● Neither agree or disagree ● Somewhat agree ● Agree ● Strongly agree

IMPACT ON TB RESEARCH



“TB research should not be a casualty of COVID-19.”

RESEARCHER FROM SOUTH AFRICA

less able to reach research participants due to lockdown restrictions on movement, as well as decreases in active study recruitment and community engagement with health services. Qualitative research, which relies on interviews with participants, has moved to virtual platforms, making it more difficult to recruit people with TB and to collect data.

To ensure the continuity of TB research and to mitigate the impact of COVID-19, participants took the opportunity to call for additional and continued funding for TB research. It also became clear from their qualitative contributions that to resume their research, significant investment would be needed to get TB services back up and running, to build out the capacity of labs and other health and research-system infrastructure, and to ensure adequate supplies of PPE, so that in-person interactions TB sufferers could take place. To successfully adapt and innovate within the context of the current pandemic, there was also a collective call from researchers for a step up in public awareness raising and education efforts, and for digital tools to be used to supplement traditional in-person interviews and engagements with research participants and teams.

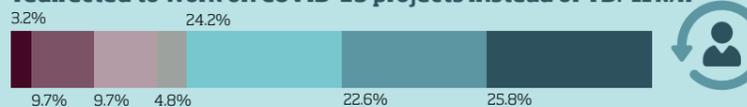
Lastly, despite the many challenges, participants saw opportunity for TB research. Themes from qualitative responses included greater acceptance and willingness to embrace innovative digital research tools, increased public awareness, political prioritization and funding for respiratory infectious disease research, and opportunities to leverage health- and research-system infrastructure investments in COVID-19 for TB research. Researchers further flagged investments in COVID-19 therapeutics, diagnostics, and vaccines as having the potential to benefit efforts to end TB. For example, a participant from Australia said that “drugs to treat COVID-19 lung inflammation may be useful for TB”, while a participant from Nepal noted that “GeneXpert infrastructure can be used for COVID-19 surveillance and [be] synergized with TB diagnosis networks.” A participant from South Africa, meanwhile, noted that the “accelerated development of SARS-CoV-2 vaccines is likely to have a positive impact on clinical trial site and laboratory capacity development.”

COVID-19 RESEARCH

I currently spend more time doing COVID-19 research than TB research. 3 N/A

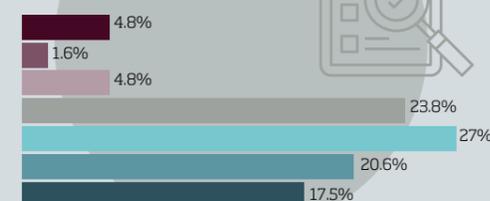


My employees (researcher assistants, field staff etc.) are being redirected to work on COVID-19 projects instead of TB. 11 N/A



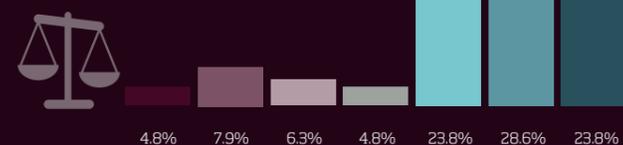
PEER-REVIEW PROCESS

The peer-review process for TB publications is being significantly impacted during COVID-19. 10 N/A

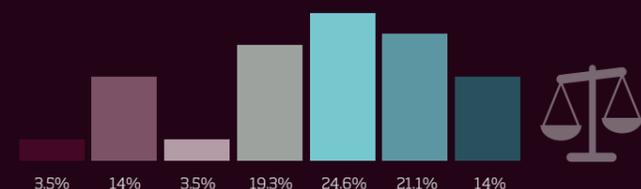


LEVERAGE

I am leveraging existing TB infrastructure and resources for COVID-19 related research. 10 N/A



The COVID-19 research and projects I am working on could be repurposed or leveraged for TB research and/or programs. 16 N/A



FUNDING/RESOURCES

My funding for existing/active TB projects has decreased significantly since the beginning of the COVID-19 pandemic. 14 N/A



Endnotes

- 1 We use the term “parliamentarians” throughout this report, but recognize that different countries have different governance systems, with different types of actors influencing policy and legislation.
- 2 Across all groups, more than 1,000 people completed the survey.
- 3 To learn more about vulnerable and underserved TB populations, see: Stop TB Partnership. 2017. “Data for Action for Tuberculosis Key, Vulnerable and Underserved Populations.” Geneva, Switzerland. <http://stoptb.org/assets/documents/communities/Data%20for%20Action%20for%20Tuberculosis%20Key,%20Vulnerable%20and%20Underserved%20Populations%20Sept%202017.pdf>.
- 4 Stop TB Partnership. 2020. “The potential impact of COVID-19 response on Tuberculosis in high-burden countries: a modelling analysis.” A collaboration with Imperial College London, Avenir Health, Johns Hopkins University and the United States Agency for International Development (USAID). Geneva, Switzerland. http://stoptb.org/assets/documents/news/Modeling%20Report_1%20May%202020_FINAL.pdf.
- 5 Stop TB Partnership and Global Coalition of TB Activists. 2020. “We did a rapid assessment: The TB response is heavily impacted by the COVID-19 Pandemic.” April 8, 2020. http://www.stoptb.org/news/stories/2020/ns20_014.html.
- 6 Cilloni, Lucia, Nimalan Arinaminpathy, Han Fu, Juan F. Vesga, David Dowdy, Carel Pretorius, Sevim Ahmedov et al. 2020. “The potential impact of the COVID-19 pandemic on tuberculosis: a modelling analysis.” MedRxiv, May 20, 2020. <https://www.medrxiv.org/content/10.1101/2020.05.16.20104075v1>.
- 7 Glaziou, Philippe. 2020. “Predicted impact of the COVID-19 pandemic on global tuberculosis deaths in 2020.” MedRxiv, May 4, 2020. <https://www.medrxiv.org/content/10.1101/2020.04.28.20079582v1>.
- 8 The Global Fund. 2020. “Mitigating the impact of COVID-19 on countries affected by HIV/AIDS, Tuberculosis and Malaria.” Geneva, Switzerland. https://www.theglobalfund.org/media/9819/covid19_mitigatingimpact_report_en.pdf.
- 9 World Health Organization. 2019. “Universal health coverage (UHC).” Last accessed September 1, 2020. [https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-\(uhc\)](https://www.who.int/news-room/fact-sheets/detail/universal-health-coverage-(uhc)).
- 10 For more, see: World Health Organization. n.d. “Tuberculosis (TB): Addressing the needs of vulnerable populations.” Last accessed September 1, 2020. <https://www.who.int/tb/areas-of-work/population-groups/en/>.
- 11 For more, see: World Health Organization. n.d. “Tuberculosis (TB): Child and Adolescent TB.” Last accessed September 2, 2020. <https://www.who.int/tb/areas-of-work/children/en/>.
- 12 For more, see: World Health Organization. n.d. “Tuberculosis (TB): TB and HIV, and other comorbidities.” Last accessed September 2, 2020. <https://www.who.int/tb/areas-of-work/tb-hiv/en/>.
- 13 For more, see: Stop TB Partnership. 2016. “Key Populations Brief: Mobile Populations.” Geneva, Switzerland. http://stoptb.org/assets/documents/resources/publications/acsm/KPBrief_MobilePopulations_ENG_WEB.pdf.
- 14 For more, see: World Health Organization. 2007. “Tuberculosis care and control in refugee and displaced populations: An interagency field manual.” Geneva, Switzerland. <https://www.who.int/tb/areas-of-work/population-groups/refugees/en/>.
- 15 For more, see: Stop TB Partnership. 2017. “Key Populations Brief: Indigenous Peoples.” Geneva, Switzerland. http://stoptb.org/assets/documents/resources/publications/acsm/6_27-UNOPS-KPB-Indigenous-Print.pdf.
- 16 For more, see: Stop TB Partnership. 2016. “Key Populations Brief: Miners.” Geneva, Switzerland. http://stoptb.org/assets/documents/resources/publications/acsm/KPBrief_Miners_ENG_WEB.pdf.
- 17 For more, see: Stop TB Partnership. 2015. “Key Populations Brief: Prisoners.” Geneva, Switzerland. http://stoptb.org/assets/documents/resources/publications/acsm/KPBrief_Prisoners_ENG_WEB.pdf.
- 18 For more, see: Stop TB Partnership. 2015. “Key Populations Brief: People Who Use Drugs.” Geneva, Switzerland. http://stoptb.org/assets/documents/resources/publications/acsm/KPBrief_PWUD_ENG_WEB.pdf.
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- 22 Clarke, David, Mark Hellowell, Barbara O’Hanlon and Cynthia Eldridge. 2020. “All hands on deck: mobilising the private sector for the COVID-19 response.” Blog. UHC2030, April 7, 2020. <https://www.uhc2030.org/blog-news-events/uhc2030-blog/all-hands-on-deck-mobilising-the-private-sector-for-the-covid-19-response-555347/>.
- 23 Global technical partners and donors include the usual suspects such as the WHO, the Stop TB Partnership, the Global Fund, government aid agencies and foundations, corporate partners, the Global TB Caucus, the World Bank, as well as other relevant bodies.
- 24 Russian, Spanish, Tamil, Hindi, Telugu, French, and English.
- 25 TB advocates” includes CSOs, NGOs, activists and TB survivors.
- 26 The survey included an “other” category, though the data were not included in this analysis.
- 27 Including Twitter, Facebook, and WhatsApp.
- 28 Due to the limited number of responses from other countries, we decided to present case studies of the two countries with adequate participant samples.
- 29 Approximately 20 of the Kenya responses from people with TB were repeat entries.
- 30 As responses from the U.S. dominated those of other countries not eligible for Global Fund resources, we decided to use it as the market comparison for Global Fund eligible responses.
- 31 Health departments (n=4), prison hospitals (n=2), assisted living (n=1), emergency medical services (EMS) (n=1), long-term care (n=1), public health laboratory (n=1), and a TB clinic (n=1).
- 32 The experience of healthcare staff working in unsafe environments is not new. Before COVID-19, the TB sector identified them as a key at-risk population. To learn more, see: Stop TB Partnership. 2017. “Key Populations Brief: Health Care Workers.” Geneva, Switzerland. http://www.stoptb.org/assets/documents/resources/publications/acsm/KPBrief_HealthCareWorker_ENG_WEB.pdf.
- 33 Reports of human rights violations during COVID-19 are well documented, including in Kenya. For more. See: Kenya Legal & Ethical Issues Network on HIV and AIDS (KELIN). 2020. “Kenya’s Growing Anti-Rights Public Health Agenda During COVID-19.” Blog, June 3, 2020. <https://www.kelinkenya.org/kenyas-growing-anti-rights-public-health-agenda-during-covid-19/>.
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- 35 As responses from the U.S. dominated those from other countries not eligible for Global Fund resources, we decided to use it as the market comparison for Global Fund eligible responses.
- 36 The webinar showcases how private practices have adapted their services to the COVID-19 pandemic and lockdown using telemedicine, tele-consultations and various home-based diagnostic options (x-ray), medicine delivery and treatment support. Learn more at: The TB PPM Learning Partnership. 2020. “Engaging private providers in TB Care: Strengthening people-centered primary care systems during COVID-19.” Webinar, June 22, 2020. <https://www.tbppm.org/news/293859>.
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- 38 From here on, referred to as “TB advocates.”
- 39 As most responses came from Global Fund eligible countries, hindering meaningful comparison between markets, we decided to focus solely on their experience. Elevating the voice of civil society in Global Fund implementing countries also made good sense from an advocacy perspective.
- 40 Stop TB Partnership. 2020. “Information Note: Digital Health Technologies, Virtual Care and Community Based Monitoring Solutions for TB Programs During the COVID-19 Pandemic and Beyond.” Geneva, Switzerland. http://www.stoptb.org/assets/documents/covid/Digital%20Technology%20Solutions%20for%20TB%20Programs%20during%20the%20time%20of%20COVID-19_v11.pdf.

Political will is central to the global TB response and needs to be consistently cultivated and built.

ADVOCATE FROM INDIA

