



THE PRESIDENT
OF THE
GENERAL ASSEMBLY

22 June 2018

Excellency,

Further to my letters of 27 April and 30 May 2018, I have the honour to enclose herewith the summary of the interactive civil society hearing held on 4 June 2018 at the United Nations Headquarters in New York as part of the preparatory process of the high-level meeting on the fight against tuberculosis.

The summary has been prepared in accordance with paragraph 7 of resolution A/RES/72/268, which requests the President of the General Assembly to prepare a summary of the hearing prior to the high-level meeting.

Please accept, Excellency, the assurances of my highest consideration.

A handwritten signature in blue ink, appearing to read 'M. Lajčák', written over a light blue circular stamp.

Miroslav Lajčák

To all Permanent Representatives
and Permanent Observers to the United Nations
New York

Summary of the President of the General Assembly of the interactive civil society hearing as part of the preparatory process for the high-level meeting on the fight against tuberculosis

**4 June 2018
Conference Room 1**

United Nations Headquarters, New York

Overview

The President of the General Assembly convened an interactive civil society hearing on 4 June 2018 as part of the preparatory process for the high-level meeting on the fight against tuberculosis (TB) in accordance with resolution 72/268.

The hearing, organized with the support of the World Health Organization and the Stop TB Partnership, provided all relevant stakeholders with an opportunity to contribute to the ongoing preparatory process in a day of interactive panel discussions. The hearing was attended by Member States, as well as around 250 representatives of civil society, parliamentarians, non-governmental organizations, academia, medical associations and the private sector, as well as people affected by TB and broader communities.

The hearing focused on perspectives from civil society and other stakeholders, sharing experiences from the ground and making recommendations for a successful high-level meeting on 26 September 2018. Discussions were framed by four themes: reaching all people ill and affected by TB, financing, innovation, and partnerships to prioritize communities in an equitable, person-centred, rights-based response.

Opening Segment

The President of the General Assembly, H.E. Mr. Miroslav Lajčák, highlighted that world leaders have committed to end TB, but progress is not on track. Although curable, this disease continues to kill thousands each day, especially the vulnerable and marginalized, and presents new, evolving threats such as multidrug-resistant TB and co-infection with HIV and links to other diseases. Universal access to diagnosis, treatment and prevention, increased funding, more research and development, partnerships and accountability are all needed to achieve the goal of ending TB. Galvanizing political momentum will ensure a successful high-level meeting, as well as a political declaration that is more than words on paper.

Secretary-General António Guterres underscored the importance of addressing the social drivers of the disease, including poverty, inequality, migration, and of building multisectoral linkages. The high-level meetings on TB and noncommunicable diseases this year, related actions on strengthening health systems and response to antimicrobial resistance, as well as next year's meeting on universal health coverage can help bring further cohesion across the health landscape.

The World Health Organization Assistant Director-General for Communicable Diseases, Dr. Ren Minghui, expressed the institution's commitment to engagement with civil society and affected communities to end TB. He shared the message of Director-General Dr. Tedros Adhanom Ghebreyesus, emphasizing the opportunity for a concerted movement from the highest to grassroots levels. Civil society organizations have played a key role in building the political momentum. The recently-launched "Find.Treat.All.#EndTB"

Initiative of WHO, Stop TB Partnership, the Global Fund, countries, civil society and partners, demonstrates the commitment to leave no one behind.

The Executive Director of the Stop TB Partnership, Dr. Lucica Ditiu, called for the concrete engagement of Heads of State and Government towards ending TB. The interactive civil society hearing was an unprecedented platform to amplify the voices of the community, and Member States must do their part in hearing those voices. This year, some leaders have made bold pledges of commitment but more must come forward. The key to ending TB is to ensure that political leaders are on board, and to engage new stakeholders, and the high-level meeting is the perfect place to achieve this.

The United Nations Special Envoy on TB, Dr. Eric Goosby highlighted that activists and communities are extraordinary agents of change, especially in days of despair and hope. Now is the time to end TB, but this cannot be achieved without civil society. TB has consequences for entire communities, so those communities, especially survivors of the disease, should also be involved in decision making to end TB. All should build upon the critical actions regarding stigma, a patient-centred response, giving voice to the voiceless, and pushing for innovation and resources.

Ms. Ingrid Schoeman, a member of TB Proof, shared her story about surviving multidrug-resistant TB thanks to quality medical care and support from her family. But many do not have access to such benefits and their journeys are even harder. Anyone can be exposed to TB and the millions of people who fall ill each year must be reached with quality care. This will require improved diagnosis and prevention, a research-enabling environment to create better and new tools, and more investments. A follow-up high-level meeting in 2023 would be the best way to ensure that world leaders deliver on their commitments.

Interactive Panels

Panel 1 – Reaching the unreached: closing gaps in TB diagnosis, treatment, care and prevention: This panel addressed the need and means to reach the millions of people who are failing ill with TB disease annually, over 10 million, and the millions in need of treatment to prevent the development of the disease given infection with the bacteria that causes TB. Speakers highlighted that vulnerable and marginalized populations are often missing out on care and are stigmatized, including people co-infected with TB-HIV, miners, indigenous persons, prisoners, migrants, people who use drugs, children and all those people needing preventive treatment. Country-level targets can be set and each country can track their progress in reaching the missing people with TB.

The panel began with a personal story about being denied access to health services due to stigma, discrimination and marginalization. The speaker highlighted that people are often missed by disease registration processes; therefore, it is important to commit to find and treat them all. Children are particularly affected by TB and they need accessible and acceptable services, with integrated TB and maternal-child health services at primary care level; and to introduce specific global, regional and country indicators on childhood TB.

It was noted that miners are at high risk of TB and it is critical to improve registration and service provision close to mining communities, address social, stigma and other barriers to services, improve infection control measures; to scale-up screening programs and to strengthen cross-border cooperation; integrate TB services in primary health care.

Another speaker underlined that health systems and TB models of care need to be improved to address people's needs. TB programs need to be embedded in universal health coverage efforts. Multisectoral approaches need to be boosted. Schools, workplaces, communities and civil society need to be involved in finding people with TB and in TB care and support. Resources must be mobilized for people-centred approaches, and innovative funding needs to be introduced to reduce economic barriers.

Participants highlighted countries' experiences and good practices, the special challenges faced by civil society organizations and other stakeholders working in the field, and the need for stronger accountability at all levels. Special attention is needed on TB-affected people in challenging environments (e.g., in the case of disasters and conflicts), migrants, urban poor populations, protecting health workers, ensuring workplace infection control and addressing the shortage of health workers in TB. Also noted was the need for private sector providers to be enabled and incentivized to notify TB patients they diagnosis and treat. Lastly, speakers emphasized the support needed for civil society engagement, activism and advocacy to monitor progress and accountability.

Panel 2 – Investing to end the world's leading infectious killer: The panel focused on the need for increased investments to end TB. Speakers highlighted funding needs projected at US\$ 13 billion annually over 2018-2022 for TB implementation, and research needs at US\$ 2 billion annually.

It was noted that investments needed to end TB represent a mere fraction of expenditure in other fields such as the military. Panellists stressed that catastrophic costs impact people ill with TB today, especially those affected by MDR-TB – parents can be forced to choose between paying for one child's medicines or another's schooling. The high-level meeting offers an opportunity for countries to commit to prioritizing national resources towards efforts to end TB, with engagement by all levels of government across health, social and economic sectors.

To guarantee universal access to TB care, diagnostics and preventive measures, and to ensure that no one is left behind, participants called for the commitment of Member States and others gathered at the high-level meeting, to scale up both domestic and international funding for TB to meet the funding gap, including through full funding of the Global Fund to Fight AIDS, Tuberculosis and Malaria, which accounts for 80% of international funding for TB. Panellists proposed to earmark at least 3% of financing for community-led and based approaches and increased funding for TB R&D to ensure financing for all the improved and safer drugs, diagnostics and vaccines needed for TB care and prevention.

Panellists called on the international community to assist countries to strengthen capacity and collaboration on all levels. Better utilization of funds can be achieved through innovative, cost-effective interventions, such as community mobilization, the scale-up of trained community health workers, nutritional support for people affected by TB and their families. The need for specific commitments, targets and indicators was also noted to help policy makers take the right decisions and to allow for accountability.

Panel 3 – Innovation to End TB: new tools and approaches: The panel focused on the urgent need to accelerate research and development (R&D) for innovation to end TB. Speakers highlighted: (i) the need to catalyze research across the spectrum from basic science to product development to applied health

research; (ii) the need to increase financing for TB research, and (iii) the need to conduct research driven by the principles of people-centred care, equity, accessibility, and affordability.

The panellists noted significant gaps in TB R&D, particularly the need to accelerate the development of rapid and affordable point of care diagnostic tests; safer and more effective pre- and post-exposure vaccines; shorter, safer and more effective treatment regimens; and applied health research to support the optimal, timely, and equitable integration of these tools into health systems. Recognizing that many of the knowledge gaps in TB are related to lack of R&D investment, participants urged Member States to increase their investment in TB research with a global target of tripling current investments in TB R&D, and to develop and introduce innovative financing models and incentive strategies.

Participants underscored that research should be needs driven, evidence-based and a shared responsibility, guided by principles of affordability, effectiveness, efficiency, and equity, as well as the objective of delinkage. Speakers highlighted the importance of countries making full use of the policy space afforded to World Trade Organization member states in the agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) to fulfil their human rights obligations and to promote access to medicines for all. Speakers called for affordable MDR-TB regimens and pricing of component drugs. Participants stressed the need for the industry to widely register and fairly price products across countries, including in the form of tax breaks, regulatory incentives, funding and demand generation.

In addition, participants highlighted that slow adoption of life-saving technologies is dis-incentivizing investment in new research. They urged Member States to invest in applied health research, to facilitate scale up of existing tools and interventions, and to take steps in creating research-enabling environments in order to effectively streamline regulatory and ethics reviews of research studies, and promote collaboration across sectors, partners and with other Member States. Participants highlighted the BRICS TB research network and the AMR R&D Collaboration Hub as means to accelerate R&D efforts including in high TB burden countries.

Participants urged Member States to facilitate the meaningful participation of civil society and all relevant stakeholders from countries affected by TB in guiding research, from research priority setting, to supporting research implementation, and contributing to the dissemination of research findings and uptake of research into policy and practice.

Panel 4 – Partnerships for success – the role of communities in an equitable, person-centred rights-based response: The panellists emphasized the need for a political declaration that shifts the paradigm of the TB response to one that is guided by principles of equity, human rights, gender equality and is people centred.

Speakers voiced the importance of a human rights-based approach to TB. It was noted that attention should be given to efforts to facilitate an enabling environment for people affected by TB through: the promotion of the rights of all people affected by TB to life, health, liberty, non-discrimination, occupational safety, gender equality, privacy and confidentiality, informed consent, benefit from scientific progress, and access to justice and remedies. Speakers also highlighted the need to address stigma in all its forms, including institutional stigma, identified as a significant challenge for TB and for people affected by TB. Gender sensitive programming is important in finding the ‘missing millions’ affected by TB.

It was further noted that for the TB response to be equitable, people must have access to sustainable, affordable and high-quality prevention, diagnostics, medicines and other tools as well as social support including psycho-social support and peer-led counselling, nutritional supplements and financial support. Others noted the profound challenges that exist for many in accessing the medicines they need, including systems of trade and intellectual property rights that can impact access and the realization of a person's right to health.

Speakers highlighted the need to ensure that no person affected by TB nor their family nor their community be deprived social support services and incur catastrophic costs as a consequence of TB. In addition, participants expressed that TB affected communities and civil society have an invaluable role to play in ending TB. Community systems help to overcome barriers – whether they be cultural, legal, linguistic, technical, financial, or geographic – and can strengthen the health system as a whole.

Speakers underlined that communities must be empowered to participate in the TB response and broader health policy and program design, implementation, monitoring and evaluating processes. Engagement with affected communities and civil society must be meaningful, leveraging global, regional and national community and civil society networks and organizations. Responses should also recognise the special role religious, traditional and other community and development leaders and technical partners can play. Some speakers called for specific funding of affected community-led work, including service delivery, accountability and advocacy within national health budgets.

Speakers encouraged that accountability should be a critical component of the political declaration. The efforts to develop an accountability framework were acknowledged, with participants noting that such a framework provides a foundation from which independent, multi-sectoral mechanisms at global, regional and national levels can be advanced by stakeholders from across the global community. Ultimately, it was noted that the political declaration should secure commitment for a response guided by the principles of accountability, non-discrimination, empowerment, human rights, and sustainability.

Closing Segment

In the closing segment, the co-facilitators of the intergovernmental negotiations on the modalities and outcomes of the high-level meeting, H.E. Mr. Koro Bessho, Permanent Representative of Japan and H.E. Dr. Aubrey Webson, Permanent Representative of Antigua and Barbuda expressed their appreciation for the opportunity to listen to voices from all stakeholders. They thanked the representatives of civil society present for their role in keeping the world's attention on TB, and indicated their intention to guide Member States to an ambitious and actionable political declaration.

In his closing remarks, the President of the General Assembly reflected on personal stories shared by TB survivors. Such experiences reveal the human side of the struggle against TB and its devastating impact, which affects the vulnerable most. He emphasized the profound value of the ideas offered at the Hearing on funding, on care and support networks, advocacy, prevention and partnerships. The President thanked participants for sharing their perspectives, experiences and expertise in support of a successful high-level meeting.