TB Affected Community & Civil Society Priorities for new Global AIDS Strategy

There is a clear connection and relationship between tuberculosis and HIV/AIDS. However, many stakeholders lament that while this relationship is well recognized, integration of TB/HIV policies, programs, services, targets and M&E, is far less developed. As a new Global AIDS Strategy development process commences, it is critical that global health responses better address TB and HIV together. This paper shares some ideas from TB affected communities and TB civil society on how best to do that.

Background

In response to requests from the Stop TB Partnership Community and NGO Delegations, Stop TB Partnership, with support from UNAIDS, conducted two virtual consultations and facilitated an online survey, together reaching over 100 TB affected community and civil society actors from the Americas, Africa, Asia and Eastern Europe Central Asia. This survey and online consultation identified the priorities that the TB and TB/HIV community want to see strengthened and scaled up in the new Global AIDS Strategy. Significant constructive feedback was received, and a great deal of common ground emerged. These priorities will be articulated here for consideration by the UNAIDS PCB and other TB/HIV stakeholders.

By way of quick summary, there were five (5) clear priorities that TB affected community, TB and TB/HIV civil society identified as being critical for inclusion in the new Global AIDS Strategy:

1. 100% coverage of **TB preventative therapy (TPT) for all eligible PLHIV** to realize TB and HIV/AIDS UNHLM targets and commitments.
2. Regular, accessible **TB screening and testing for all PLHIV**;
3. Measuring and reducing **stigma and discrimination** as well as the identification and elimination of structural barriers to access TB/HIV prevention, diagnosis, treatment, care and support services.
4. Scale up access to TB/HIV **new tools**, including TB LAM, and looking to the future a TB vaccine, should be a priority, and a participatory TB/HIV research agenda should be developed to assist this.

And,

5. **Bold global and country level targets, financing, data and M&E plans for accountability** to give effect to 1-4 above, along with a representative from Stop TB Community Delegation included in the UNAIDS PCB to assist in the development of and monitoring of these indicators.

Feedback from Consultation

TB HLM Targets

- Respondents were asked if they believed, in their contexts, that they were on track to achieve the UNHLM TB targets of TB preventative therapy for 6 million people globally and UNHLM HIV/AIDS targets to reduce TB deaths among PLHIV.
- The responses were 43.33% yes, 20% no, and 30% unsure. A further 6.67% did not provide a direct response but commented that it may not be possible to achieve the targets since data collection strategies are not well designed, and that issues around data quality, misinformation, and diversion need attention.
- Asked if we need new targets and/or monitoring indicators, including community-led monitoring, regarding progress on the TB/HIV response, 89.29% agreed, and 10.71% did not.

Priority Areas for Action

Survey respondents were invited to indicate which of the following areas they consider to be priority areas for action:

Enabling environments: rights, stigma, gender, barriers to access, social protections re: TB/HIV	83.33%
TB screening and testing among PLHIV	73.33%
TB prevention (TPT) among PLHIV	70%
Enhanced TB/HIV partnerships and synergies	70%
Real time TB/HIV data	60%
Alignment of TB and HIV financing	60%
TB/HIV recovery plans and advocacy	56.67%
Monitoring of TB/HIV targets and commitments	50%
HIV budgeting for TB prevention among PLHIV at country level	46.67%

*during the consultations and online survey, additional issues were identified to be included. Research and development was a prominent addition to those themes and issues listed above.

Barriers to an Enabling Environment: Consideration of, and investment in nuanced legal, gender, stigma, discrimination (and other related social barriers), and economic barriers to accessing TB services, particularly among key populations and marginalized/criminalized groups. Barriers to access to TB can be different to HIV related-barriers and this requires greater levels of understanding and nuance. Also, risks to enabling environments and progressive legal, social, and economic structures, which we have seen wound back in recent times, needs significant re-commitment. In addition, in understanding these challenges, community-led monitoring initiatives that explore availability, accessibility, acceptability, and quality of TB/HIV services has great potential for scale up.

This was selected as a priority area by **83.33%** of respondents, with the following points of interest:

- Addressing poverty, including food security, mental psychosocial support, and social protection systems, was highlighted as it is a root cause and exacerbating factor. To effectively engage with treatment, affected communities need access to nutritional therapies, transport costs, social welfare, counselling and other social supports.
- More political will and financing are required to ensure access to the highest available standard of care based on the best available scientific evidence/progress.
- A human-rights-based approach can promote healthy practices and behavior, thereby contributing to promotion of prevention and treatment at community level.

- Stigma was highlighted as a primary barrier to access in TB/HIV, especially at the institutional level, with rising conservatism as a root cause in many cases. Stigma can be compounded by other indicators of vulnerability including legal status or gender dimension for example, in some contexts men are more reluctant to engage in health, while power dynamics and societal norms, impede the way women engage with TB/HIV services.
- There is a need to implement TB and TB/HIV Stigma Assessments in high burden contexts and to develop evidence-based plans to overcome identified issues. The Stigma Assessment Tool for TB can assist - http://www.stoptb.org/assets/documents/communities/STP%20TB%20Stigma%20Assessment%20Implementation%20Handbook.pdf
- Community engagement was identified as an essential way to ensure that the collective experience of TB/HIV affected communities is represented in strategies. The shift to online work and telemedicine was highlighted as an opportunity in this regard.
- Empowerment of affected communities was identified, as well as support for community caregivers. Committees and advisory boards – at all levels – should include representatives of TB/HIV affected communities. Peer support networks should be established in the community and investment provided so they can be coordinated and capacitated.
- Targets on TB/HIV affected community and civil society engagement could encourage governments to hold regular dialogue and include them in policy making.
- Accountability for governments and medical professionals are key. The Multisectoral Accountability Framework (MAF) for TB should be adopted and implemented by every country – and include relevant partnerships required to address the TB prevention among PLHIV targets.
- Indicators for TB and HIV plans should be reviewed to take COVID-19 into account. See more at https://drive.google.com/file/d/1rxREVzu_K-5EYNqLahMmTnKHJSaff0-Q/view

Screening and Testing: Screening and testing for TB among PLHIV and TB/HIV key populations at every possible opportunity, using the best tools available. For PLHIV, appropriate access and use of LAM, Xpert/Trunat, X-rays and DST for DR-TB. Also, looking forward, ensuring reference to new TB diagnostics that are in the pipeline but are likely available during the strategy period.

This was selected as a priority area by **73.33%** of respondents, with the following points of interest:

- Simultaneous and widespread testing for both TB and HIV should be the norm.
- More political will is required to speed up the rate of screening and testing.
- All testing must be done with informed consent.
- Confidentiality must be ensured, and HIV testing must be voluntary.
- Post-test support and services are essential.
- Access to health facilities is a major obstacle in the Global South.
- Effective and efficient TB screening and testing should be readily available and accessible in community settings.
- PLHIV should be screened for TB every six months.
- Governments should be encouraged to incorporate TB screening and testing into national COVID-19 testing efforts and HIV prevention programs, which is more efficient for domestic budgets.
- Several respondents referred to tools that should be made more available, such as all test types including Abon, LAM, and SD Bioline, as well as Genexpert machines.
- More sensitive and accurate diagnostic technologies should also be developed.
- More TB/HIV laboratory capacity is required in several contexts.

- There is a need for widespread capacity-building of healthcare workers on Voluntary Counselling and Testing (VTC) and Provider-Initiated HIV Testing and Counselling (PITC) for people with TB.
- There is confusion among health care providers on the protocols for re-administration of TPT after TB treatment and after a single course of TPT among adults and adolescents.
- More effective case management approaches are needed.
- The Patients Pathway Analysis (PPA) should be carried out to identify why missing cases remain high and identify barriers to accessing services.
- It was suggested that, in developing countries, the definition of elderly could be revised downward for the clinical management of TB/HIV.
- Looking forward, a TB vaccine must be appropriate for and accessible to PLHIV.

Prevention: Prevention of HIV should also include prevention of TB/HIV. Linkages to the UNHLM TB targets on TB preventative therapy among PLHIV is one important shared target (6 million PLHIV to receive TPT by 2022) – 100% coverage of all eligible PLHIV and reporting on commencement and completion of TPT. In addition, promotion of airborne infection protection/prevention measures (for TB and COVID) in health settings utilized by PLHIV.

This was selected as a priority area by **70%** of respondents, with the following points of interest:

- More engagement on prevention is needed, including increased community awareness. Case finding alone will not eradicate TB.
- Modelling that demonstrates the economic and social benefits of investing in prevention could assist with advocacy.
- TB advocacy should emphasize prevention and be adequately funded.
- TB prevention should be promoted not just for new PLHIV, but for those who have lived with HIV for several years.
- TB prevention should extend to KPs including those who are marginalized or criminalized.

Partnerships & Synergy: At the global level, a closer strategic relationship between Stop TB Partnership and UNAIDS in terms of strategy, implementation, monitoring and advocacy.

This was selected as a priority area by **70%** of respondents, with the following points of interest:

- There is strong support for aligned strategies and deeper collaboration across UNAIDS, Stop TB, and WHO, and for more innovative partnerships with health and development stakeholders in general and at all levels.
- Closer partnerships should also be extended to include participation of TB survivors from Stop TB Community Delegation on the UNAIDS PCB.
- Respondents called for UNAIDS to make its voice heard on TB and call for the integration of prevention, screening, diagnosis, and treatment of TB among PLHIV into the HIV prevention and treatment research agendas.
- TB/HIV priorities should be well represented in the new global HIV response, in terms of strategy, governance, implementation, and accountability.
- People with TB/HIV should be included in the development of new HIV therapies to better ensure that ART regimens can be safely administered alongside TB drugs. This effort could be modelled on the work done to align pediatric TB and HIV research.
- Joint capacity-building and community institutions strengthening for TB and HIV communities and civil society will encouraged more joined-up, impactful action.
- Local management councils should bring TB and HIV partners together with local leaders.

- One respondent suggested that UNAIDS was at risk of losing its focus on community-led interventions.
- Distrust between TB and HIV partners should be addressed.
- A global Information, Education & Communications strategy on TB/HIV should aim to emulate and build upon the sense of solidarity inspired by the COVID-19 pandemic, reaching beyond affected communities to mobilize additional support in less-affected communities and countries. Tackling misinformation should be a concern.
- This may require a review of the language used in communications campaigns. Messaging could be adapted to increase its relevance for unaffected communities, with a focus on issues such as negative economic impacts, fighting poverty, gender equality, efficiency and effectiveness in domestic spending, and prestige associated with scientific advancement.
- Decentralized access and innovative models of distribution of ART to PLHIV who are stable must be sustained to reduce demand in ART centers.

Data: Monitoring of TB mortality among PLHIV, linked to the UNHLM HIV indicator of reducing TB deaths among PLHIV; and, enhancing data collection pertaining to PLHIV who have active TB and identify as key populations; taking steps to realizing TB/HIV data in real time, as is already progressing in India.

This was selected as a priority area by **60%** of respondents, with the following points of interest:

- Several respondents proposed the establishment of a universal international data collection tool, developed with and accessible to key stakeholders and UN-approved, which can be used at the national level to capture both TB and HIV data, thereby feeding into the global data in a more consistent and standardized manner.
- Commitment toward real time data for TB/HIV – similar to what we are seeing for COVID.
- Enhancing commitment to data of TB and TB/HIV among TB key populations
- Collection and management of quality, real-time data should be encouraged, transparent, standardized, and be made readily available to the public and decision makers, to ensure interventions are based on up-to-date, accurate data.
- Data collection should capture evidence of best practice, and this should underpin any new targets. There is a scarcity of data on treatment outcomes; for TB this could be captured daily and reported weekly, monthly, and annually.
- It was suggested that individualized, anonymized data should be available to relevant stakeholders to allow for deeper analysis of the gaps in coverage and progress on reducing those.
- Lessons learned and new methodologies arising from COVID-19 should be applied.
- There was a call for timely and accurate data to capture the number of PLHIV who are tested, diagnosed, and placed on TB treatment, and vice versa. The process should be streamlined across TB and HIV partners and the responsibility for monitoring and follow-up clarified.
- Data should also capture the percentage of people with TB who are diagnosed at community level.
- Data quality should be regularly audited with the involvement of TB and HIV communities and civil society.
- There was also a call for more community involvement in monitoring, with accountability and direct feedback mechanisms. Community leaders should be trained in monitoring.
- The community could report on, *inter alia,* case referrals, quality of services, stock management, and experiences of stigma and discrimination in health care facilities.
- Lack of time was identified as a reason why data is not reported in real time.

- PEPFAR should pay more attention to mortality figures and report progress in the same way as is done for other epidemic control indicators.
- One respondent suggested that the NIKSHAY reporting tool (India) should be adapted to capture HIV data.

Funding: The current funding landscapes for TB, HIV and the development sector are uncertain. There will be a need to leverage opportunities to strengthen TB/HIV responses through COVID responses, while to strengthen and scale up investments from donors, including the Global Fund, in priority areas. National HIV responses must also ensure to budget for TB preventative therapy among PLHIV.

Alignment of TB and HIV financing was selected as a priority area by **60%** of respondents, and HIV budgeting for TB prevention among PLHIV at country level was selected by **46.67%** with the following points of interest:

- More investment is needed, including in domestic budgets; advocacy should call for this.
- TB is a serious concern for PLHIV and should be factored into decisions made on budget allocation. TB prevention and diagnosis should be included in activities on HIV prevention and diagnosis.
- TB communities and civil society should be involved in HIV budgeting discussions and vice versa.
- One respondent encouraged governments to have a unified budget stream for disease prevention, with testing available for all.
- Another respondent called for dedicated TB prevention funding.
- Budget allocation for TB/HIV co-infection was also proposed.
- National TB Programs (NTPs) are primarily responsible for developing budgets for their TB National Strategic Plans and grant applications to multilateral (e.g. The Global Fund) or bilateral donors (e.g. USAID) and partnerships with HIV programs is key on the issue of budgeting prevention among PLHIV.
- Donors should be encouraged to include joint TB/HIV programming as one of the criteria for HIV strategies.
- Donors should make grant proposals easier to prepare as complicated processes can be a barrier for community-based organizations.
- Integrated budgeting is essential even where programs require vertical elements.
- Performance-based financing tactics should be used routinely.
- The community focus needs to be reinforced with adequate funding, not merely to mobilize individuals for testing, tracing, and treatment, but also to ensure social, nutrition, livelihood, and psychological support.
- Empowering local civil society and affected community organizations through budgeting and building institutional capacity can help to address the hard-to-reach segments of communities in the Global South.

COVID, TB & HIV Advocacy and Recovery Plans: There is potential for joint TB/HIV high level advocacy in multilateral forums (UNHLMs, G20 etc), heads of state, mayors, and governors of cities to advance the prioritization of TB/HIV responses. In addition, the impact of COVID on TB/HIV programs has been significant (note the modelling), and there is a need to get TB/HIV responses back on track.

This was selected as a priority area by **56.67%** of respondents, with the following points of interest:

- The UNAIDS and Stop TB strategies should both address how TB and HIV care can be provided in the context of the pandemic.
- There is a concern that COVID-19 is being prioritized at the expense of TB and HIV, with financial stability highlighted as a concern.
- Global and national plans to address COVID-19 should also address TB and HIV, with appropriate prioritization according to the specific context.
- In high burden countries, TB and HIV mortality rates should be published alongside COVID-19 data.
- Improving access to services in the context of movement restrictions – both mandated measures and resulting from fear – was also a concern.
- It was also flagged that notifications have decreased in the context of COVID-19.
- The safety and efficacy of vaccines for COVID-19 for people with TB and HIV must be clearly established.
- On the positive side, respondents were inspired by the speed of the global response to COVID-19, and the increased risk acceptance.
- One respondent noted that UNAIDS had been visionary in calling for a patent-free, free, equitably accessible COVID-19 vaccine, and proposed that advocacy on TB and HIV vaccines should call for the same.

TB/HIV Research Agenda: Development of an inclusive joint TB and HIV research agenda that includes people affected by TB in clinical trials etc. of ART.

- There should be an increased focus on children and adolescents with TB/HIV.
- TB affected communities must be integrated into HIV research agenda
- PLHIV should be engaged as part of TB vaccine research agenda as well.

Indicators, Monitoring and Accountability: Throughout the consultations and survey there was a clear need for enhanced accountability of TB/HIV targets and commitments. Many TB and TB/HIV community respondents called for bold and ambitious targets and indicators at the global and country level, that are routinely monitored and reported against. Targets, indicators and M&E would cover prevention, screening, human rights/stigma/barriers to access, research, financing and data – and should be developed and implemented with the involvement of TB affected communities and TB/HIV civil society. For many respondents, this was the critical element in integrating and operationalizing commitments to TB/HIV in the new Global AIDS Strategy.