

## COMMUNITY CONNECT SESSIONS PROGRAMME

Tuesday, November 8, 2022

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Track: Track 1: Community rights, gender and stigma  
Type: Community connect  
Room: Community Connect Channel

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11:30 – 12:15 **CCP-UnionConf-2022-01520 INDIA REALITY CHECK: COMMUNITIES SPEAK THE TRUTH**

Chair: Blessina Kumar (India)

Tuberculosis in India is a major health problem. Globally, India has the largest burden of TB. In 2020, the Indian government made statements to eliminate tuberculosis from the country by 2025 through its National TB Elimination Program and since then bold claims have been made by the Government of India regarding their successful strides to eliminate TB. So much so that some states and union territories have been declared TB free. However, the ground realities are much different than what is being reported on paper.

We at the GCTA remain committed to empowering communities across the globe to sit on the same tables as all other stakeholders and make their voices heard. The lived experience of TB matters and it is crucial that communities are meaningfully engaged to ensure a people-centred rights-based approach to TB. To further this, the GCTA works with multiple Indian community-based organization sand TB champions, working directly on the field, with their communities, and time and again we have heard the communities disagree with the data and claims being presented by the government. Due to the highly medicalized approach to TB the voices of the affected community members are not taken into account while creating and implementing strategic interventions to end TB in the country. Additionally, stigma and discrimination towards TB patients continues to be a norm and health providers are not adequately capacitated to ensure competent care that upholds the human rights of the affected populations. However, it must be noted that the Government of India recently launched the Strategy to End Stigma and Discrimination Associated with TB. India is one of the first countries to develop a strategy to end stigma and discrimination associated with TB. This strategy was developed by affected communities and civil society members. However, the operationalization of this document is still under works.

If we are truly committed to end TB It is crucial that the affected community members are looked upon as equal stakeholders for creating and implementing strategies to end TB. The top-down approach needs to end. Community members are experts and their lived experiences can greatly strengthen strategic documents, help close implementation gaps, ensure more community buy-in and overall provide the best return on investment for every rupee invested in the TB response in India.

With this background, the GCTA proposes the community connect session – India Reality Check: Communities Speak the Truth. As a part of this session, we will invite affected community representatives from different underserved population groups to present reflections and field level realities and deliberate on how we can overcome the challenges together. The session will also include a list on concrete suggestions for the National TB Elimination Program, technical support partners and agencies, and other key stakeholders.

11:30 – 11:32 **Live Introduction**

11:32 – 11:39 **Ground Realities in Mumbai, Maharashtra: Fight against MDR TB**

Speaker: Ganesh Acharya (India)

11:39 – 11:46 **Trans community and the TB response in India**

Speaker: Sowmya Gupta (India)

11:46 – 11:53 **What will it take to be TB free? Reflections from the Drug User's Community**

Speaker: Prashant Sharma (India)

11:53 – 12:00

**What do the communities want? - TB Survivor experiences from India**

Speaker: Arti Singh (India)

12:00 – 12:15

**Panel with a Live Q&A**

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12:30 – 13:15

**CCP-UnionConf-2022-01565**

**SHAME DIES WHEN STORIES ARE TOLD IN SAFE SPACES:  
TB SURVIVOR STORIES**

Chair: Archana Oinam (India)

TB continues to be the leading infectious killer. Part of this is due to the lack of meaningful engagement with the community and community empowerment, followed by under-diagnosis, under-reporting and, inadequate access to health services due to stigma and other barriers. Taking from SDG, UHC and UNHLM agenda to eliminate TB, it is crucial to empower communities and ensure meaningful community engagement to end TB. However, to date, the response has been largely medical and those affected by TB and their families have had little or no part to play in the fight against TB. Their potential role as powerful advocates, with the ability to improve public understanding of the disease, support those affected, and to destigmatize the disease has remained largely untapped. Additionally, TB survivors are almost never given the space to share their stories, their lived experiences. At large, the TB response carpets these stories. This is unacceptable.

It is not uncommon for survivors to feel alone and isolated. For many, hearing and sharing stories can play a vital role in their recovery from trauma. No one person's story is alike. No one survivor's experience is the same. By telling these stories we can create safe spaces for people to deal with their loss and trauma and hopefully live better lives after recovering from TB.

We at the GCTA remain committed to empowering communities across the globe to sit on the same tables as all other stakeholders and make their voices heard. The lived experience of TB matters and it is crucial that communities are meaningfully engaged to ensure a people-centred rights-based approach to TB. To further this, the GCTA has hosted a string of trainings across the globe with affected community members.

Till recently, with every subsequent training we heard the communities list Stigma as one of the top barriers to accessing care and treatment. However, due to a highly medicalized response to TB, community voices were never heard and stigma has still not been acknowledged as a great barrier to accessing TB care and treatment. This needs to change. The Community Connect space at the Union Conference can be the ideal platform for this. We need to provide TB survivors to tell their stories over and over again till they reach the ears of all involved stakeholders and we buckle down to ensure stigma and discrimination free competent TB care for all at all levels. Shame dies when stories are told in safe spaces.

With this background, the GCTA proposes the community connect session – Shame Dies when Stories are Told in Safe Space: TB Survivor Stories. The session will have four speakers come in from different walks of life to present their journeys with TB.

12:30 – 12:32

**Live Introduction**

12:32 – 12:39

**My story as a trans woman affected by TB**

Speaker: Abhina Aher (India)

12:39 – 12:46

**Stigma in faith-based organizations**

Speaker: Maxwell Kapachawo (Zimbabwe)

12:46 – 12:53

**Women and TB – Survivor stories from Nepal**

Speaker: Binika Shrestha (Nepal)

12:53 – 13:00

**The Heavy Burden of TB Stigma: An Overview**

Speaker: Nadine France (Ireland)

13:00 – 13:15

**Panel with a Live Q&A**

Track: Track 1: Community rights, gender and stigma

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14:00 – 14:45

**CCP-UnionConf-2022-01637**

**The effective collaboration and resiliency of TB program, community and Civil Society Organizations to end TB under the challenging war condition in Ukraine**

Chair: Zahedul Islam (Kyiv, Ukraine)

The unprovoked Russia war against Ukraine has become a challenge for the whole world, but above all for Ukrainians. Every Ukrainian is affected to some extent by the problems associated with the war, but the most vulnerable categories have suffered the most. One such group are the people affected by TB. As a result of Russian shelling, hundreds of medical institutions that provided essential TB services have been destroyed and damaged, logistics chains (TB drugs, sputum, tuberculin and BCG vaccine etc.) were broken due to hostilities, and it is difficult or even impossible to provide the full range of TB services required to save every life, and tragically both people with TB and medical staff have died needlessly.

During the war, it became clear that the TB service need the support of diverse stakeholders to solve extremely complex issues and secure adequate care for every person with TB. The importance of partnership and cooperation has increased significantly. The possibility to provide people with TB with food and other essentials, deliver medicines, take them out of the occupied territories and territories where hostilities are taking place, and provide them with continued treatment and social support in unoccupied territories has appeared thanks to the partnership of medical institutions with each other, with NGOs, private sector and local administrations.

What we have learned is that in times of war, coordination of efforts across all TB stakeholders in Ukraine and outside is critical. As such the initiative of the Stop TB Partnership Ukraine and the Public Health Center (National TB Program) was appeared to create a platform for convening, collecting and finding ways to meet the needs of people affected by TB and this became possible with the support of the Alliance of Public Health within the project of the Stop TB Partnership, Challenge Facility for Civil Society; a mechanism for communities and civil society to engage and meet the needs of their communities.

The purpose of the Platform is to ensure a rapid and meaningful response to overcome the challenges and meet the fluctuating needs of people affected by TB caused by the war, by:

- collecting information on the changing need of people with TB needs in Ukraine,
- dissemination information among potential donor organizations operating in and supporting Ukraine;
- meeting identified needs and reflecting the dynamics of their satisfaction

Needs from all around the country are collected via Google Forms, are being verified by Public Health Center and Stop TB Partnership Ukraine and channeled to stakeholders for support. Concurrently the Platform partners are looking for options to meet needs which can't be meet by existing TB stakeholders or in country donors.

The Stop TB Partnership, along the support of Challenge Facility for Civil Society has joined this initiative by providing significant assistance to address urgent needs of people with TB in Ukraine. The platform is just getting started. The results of Platform, the main achievements, and lessons learned, roles of partner engagement, coordination and resource mobilization will be presented at the conference.

14:00 – 14:03

**Live Introduction**

14:03 – 14:12

**War in Ukraine and TB - community, CSOs and state collaboration for challenges overcoming**

Speaker: Olha Tsvilii (Ukraine)

14:12 – 14:21 **War in Ukraine and TB - community, CSOs and state collaboration for challenges overcoming**  
Speaker: Liliana Caraulan (Moldova)

14:21 – 14:30 **War in Ukraine and TB - community, CSOs and state collaboration for challenges overcoming**  
Speaker: Iana Terleieva (Ukraine)

14:30 – 14:45 **Panel with a Live Q&A**

Track: Track 1: Community rights, gender and stigma

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15:00 – 15:45 **CCP-UnionConf-2022-01546 People-Centered, Rights-Based TB Legislation in Eastern Europe and Central Asia**

Chair: Alesia Matusevych (Portugal)

This session will present the results of a new, groundbreaking legal study from the Global TB Caucus and the TB REP 2.0 project entitled "People-Centered, Rights-Based TB Legislation in Eastern Europe and Central Asia." The study comprehensively examines the region's laws on public health, health systems, labor, TB, and other infectious diseases. The review shines a light on the legal frameworks in place to respond to TB and other epidemics in the region. Key findings include that none of the laws in the study prohibit discrimination against people affected by TB or provide a role for civil society or community groups in the disease response, but all the TB and infectious disease laws allow for compulsory hospitalization or treatment. Using global norms and human rights standards, the study's analysis highlights a host of opportunities to modernize, strengthen, and expand protections for public health while laying the foundation for a rights-based, people-centered TB response. Recommendations include aligning national standards for TB care with global best practices, enshrining the rights to non-discrimination, privacy, and confidentiality for people affected by TB, designating TB as an occupational disease, and facilitating the meaningful participation of civil society and people affected by TB in the disease response. The study is part of a larger project that involved three regional workshops with Members of Parliament, civil society representatives, and people affected by TB.

15:00 – 15:03 **Live Introduction**

15:03 – 15:12 **People-Centered, Rights-Based TB Legislation in Eastern Europe and Central Asia: A Legal Study in 11 Countries**

Speaker: Brian Citro (United States)

15:12 – 15:21 **How the Community Developed a New Draft Law on TB in Ukraine**

Speaker: Olya Klymenko (Ukraine)

15:21 – 15:30 **The View from Parliament: People-Centered, Rights-Based TB Legislation in [Country TBA]**

Speaker: To be Confirmed.

15:30 – 15:45 **Panel with a Live Q&A**

Track: Track 1: Community rights, gender and stigma

Type: Community connect

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16:00 – 16:45 **CCP-UnionConf-2022-PD01 Rhetoric of Rights to Reality of Rights - A Human Rights-based Response to TB**

Chair: Daisy Lekharu (Geneva, Switzerland)

Chair: Blessina Kumar (India)

The intricate nexus between a lack of respect for the human rights of those infected with TB and the incidence and spread of TB must be recognised if we are committed to ending TB. When we

take any other approach than a human rights-based approach to dealing with TB, we inadvertently fuel spread of TB and TB stigma, and condemn those infected to poverty; because discrimination may hinder their access to health services and limit their opportunities for employment and income earning activities. This perpetuates a cycle of marginalization and pushes not just individuals but entire nations to economic degradation.

The global TB response has just awoken to the power of human rights. As we stand at the beginning of what seems like a new paradigm - with high-level political commitments, new technologies, and rush of new ideas - it's time to move past the 'Rhetoric of Rights' to the 'Reality of Rights'. We must harness the power of law and human rights to end stigma and discrimination and to empower and support people affected by TB around the world.

The Global Coalition of TB Advocates (GCTA) has been in the forefront of these efforts and discussions. Knowing our rights is the first crucial step but what next is something that is more important and needs serious consideration because knowing our rights and consequent cognizance of those rights being violated, without any knowledge or recourse to pathways for change, can be frustrating and disempowering. Hence, the need of the hour is to take stock of how far we have come in this journey while simultaneously course correcting and devising new pathways to build a stronger and decentralized understanding and uptake of a people centred human rights-based response to TB at all levels.

All stakeholders must work as one to ensure that the voices of the people affected by TB inform all decisions at all levels. With this background, the GCTA, as the track lead for the Community Rights, Gender and Stigma track organizing the panel discussion at the Community Connect – The Union World Conference on Lung Health 2022. The panel discussion will bring together representatives from the legal community, the TB affected community and policy makers in order collectively take stock of the progress that has been made so far and spark-off a cohesive dialogue on way forward.

16:00 – 16:06

#### **Introduction**

16:06 – 16:12

#### **Where we have been: A Historical Perspective on a Human Rights Based TB Response**

Speaker: Timothy Wafula (Kenya)

16:12 – 16:18

#### **Barriers to Accessing Care: Yesterday and Today**

Speaker: Meera Yadav (India)

16:18 – 16:24

#### **Role of Regional Platforms and coalitions in furthering a rights based response to TB**

Speaker: Jennifer Ho (Thailand)

16:24 – 16:30

#### **Stop TB Experiences and Tools Available for Communities**

Speaker: James Malar (Switzerland)

16:30 – 16:45

#### **Panel with a Live Q&A**

Track: Track 1: Community rights, gender and stigma

Type: Community connect

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17:00 – 17:45

**CCP-UnionConf-2022-01627**

### **Challenges and Triumphs of CRG approaches to TB in**

#### **Southern Africa**

Chair: James Malar (Switzerland)

This session brings together local NGOs from across Southern Africa to share their experiences with CRG approaches, the impact they've achieved and the challenges that remain in leveraging the knowledge and capacity of TB-affected communities and civil society.

Despite their pivotal role throughout the TB continuum of care, TB-affected communities and civil society actors often face significant barriers in effectively contributing to national TB response efforts. This session aims to provide key CRG insights from CSOs in Mozambique, Malawi and Angola on their work with National TB Programmes to find missing people with TB, ensure access to quality and people-centred care, and support people to successfully complete TB treatment.

The presenters in this panel represent members of the Federation Humana People to People, a

network of 29 national organisations working in 45 countries specialising in community-based and –led approaches to local development, including HIV and TB response. Federation members employ a rights-based, people-centred approach to TB response, including active case finding, comprehensive contact tracing, and home-based services including adherence support and early identification and of adverse drug events. The model works to strengthen linkages between TB affected communities and TB services to support retention in care, address internalised and experienced stigma, and address gender-related and socioeconomic barriers to care.

In the panel, presenters will share how their organisations are using CRG approaches to strengthen TB response and contribute to their country UNHLM targets and the Global Plan to End TB 2023-2030. ADPP Mozambique will share experiences in piloting and rolling out the One Impact digital tool for community-led monitoring and how the tool is contributing to health system strengthening and empowerment of people with TB. DAPP Malawi will lay out how its home-based and people-centred approach to supporting people on treatment is contributing to reductions in internalised stigma, as well as insights on working with health care workers to reduce experiences of stigma while seeking care. ADPP Angola will provide insights from its experiences supporting the NTP to develop the country’s first Community Strategy for TB. And HPP Congo will discuss how gender assessment and action plan have supported improved outcomes and services for men, women and children affected by TB.

Moderated by the Country and Community Support for Impact team at the Stop TB Partnership Secretariat, speakers will share experiences, achievements and recommendations going forward on addressing stigma, community-led monitoring, and development of National Community Strategies for TB. In particular, ADPP Mozambique, DAPP Malawi and ADPP Angola will share experiences and lessons learned from community-led monitoring, targeted efforts to reduce stigma, and supporting development of a National Community TB Strategy.

17:00 – 17:02

**Live Introduction by Chairs**

17:02 – 17:09

**Integrated pathways and interventions to reduce the effect of stigma among communities affected by TB in Malawi**

Speaker: Mtisunge Nkhono Phiri (Malawi)

17:09 – 17:16

**One impact and Community Led Monitoring: It starts with the people, not the disease**

Speaker: Pires Nota (Mozambique)

17:16 – 17:23

**Supporting National TB Programmes to develop Community Strategies for TB: why, how, and maintaining momentum**

Speaker: Evaristo Waya (Angola)

17:23 – 17:30

**Gender and age barriers to TB services in DR Congo: approaches and remaining gaps**

Speaker: Rachel Ngum (Congo (Democratic Republic))

17:30 – 17:45

**Panel with a Live Q&A**

Track: Track 2: COVID-19 – Lessons learnt to strengthen the TB response

Type: Community connect

Room: Community Connect Channel

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18:00 – 18:45

**CCP-UnionConf-2022-01632      Strengthening TB Services through COVID-19 Response: Lessons Learned from Nigerian Program**

Chair: McPaul Okoye (Nigeria)

Chair: Plang Jwanle (Nigeria)

**Background**

During the pandemic, access to health care services including tuberculosis (TB) care were adversely affected due to government restrictions on movement, shift to COVID-19 response over TB services, and overall impact on facility based health seeking behavior resulted in missed opportunities and undiagnosed TB cases.

To reverse the possible impact of COVID-19 pandemic on TBs case finding and treatment, APIN integrated COVID-19 into TB services, by operationalizing bi-directional screening and testing for patients who are presumptive for either TB or COVID-19 or both, leveraging existing TB Gene-

Xpert laboratory network for COVID-19 testing.

#### **Project Objective**

The project is focused on improving access to TB and COVID-19 services through integrated screening, testing and linkage to care service during the COVID-19 pandemic; and implement Infection Prevention and Control (IPC) measures in order to decrease the transmission of COVID-19 and TB among clients visiting the health facilities through differentiated service delivery(DSD) models.

#### **Project Description**

All patient seeking health services are triaged and screened for TB & COVID-19 at different service delivery points, using an adapted standard TB/COVID-19 screening checklist developed from the national COVID -19 and TB Algorithm. Presumptive patients are referred to the DOTs clinic where they produce sputum and then escorted to COVID-19 sample collection sites established within the facility. After the necessary documentations, samples are moved to GeneXpert laboratory for TB and COVID-19 test. TB positive patients are linked to treatment at the DOTs facility and placed on DSD model, which is a patient centered care.

A total of 78,186 patients were screened for both TB and COVID-19 from September 2021 to February 2022 in Benue and Plateau States, out of which 15,708 (20.1%) were presumptive for either TB and or COVID-19. Of the 15,708 presumptive cases, 11,950(76.1%) were tested for TB & COVID-19, out of which 1,052 (8.8%) tested positive for TB, 1,076 (9%) tested positive for COVID-19 while 109(0.9%)tested positive for both TB and COVID-1 and were linked to TB and COVID-19 care.

#### **Lessons Learnt**

Some of the COVID-19 lessons learnt to strengthen TB response by improving case finding and treatment are: The integrated delivery of COVID-19 and TB diagnosis coordinated through the DOTs clinic is feasible and efficient

The expansion of symptoms screening for TB and COVID-19 to Services Delivery Points (SDP) like OPD, ANC, wards and the DOTs clinics resulted in reduced missed opportunities and increased TB and COVID-19 case finding.

The “multi-pathogen testing” of TB and SAR-CoV-2 on GeneXpert equipment by trained laboratory scientists, created opportunities for increased access to TB and COVID-19 testing and the optimized utilization of GeneXpert facilities in Nigeria.

APIN leveraged COVID-19 funding to optimize Gene-Xpert utilization, increased TB case finding, and strengthened referral/ linkage system for TB and COVID-19 across implementing facilities in target states.

#### **Recommendations**

We recommend the integrated TB and COVID-19 services delivery for increased case finding through an expanded integrated screening and bi-directional testing for both diseases, and linkage to appropriate care, as well as implementation of standard IPC measures in health facilities.

18:00 – 18:06

#### **Live Introduction**

18:06 – 18:14

#### **Strengthening TB Services through COVID-19 Response: Lessons Learned from Nigerian Program**

Speaker: Ubong Okon (Nigeria)

18:14 – 18:22

#### **Strengthening TB Services through COVID-19 Response: Lessons Learned from Nigerian Program**

Speaker: Enenche Edigah (Nigeria)

18:22 – 18:30

#### **Strengthening TB Services through COVID-19 Response: Lessons Learned from Nigerian Program**

Speaker: Kaneng Pwol (Nigeria)

18:30 – 18:45

#### **Panel with a Live Q&A**

**Wednesday, November 9, 2022**

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Track: Track 4: Driving innovation and equitable access to new tools  
Type: Community connect  
Room: Community Connect Channel

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10:30 – 11:15 **CCP-UnionConf-2022-01598 Mapping Morbidities and Vulnerabilities for Social Inclusion: The Expanded Use of Non-Communicable Diseases (NCD) Risk Assessment Tools**

Chair: Dennis Batangan (Philippines)

Disease-specific risk assessment tools usually focus only on the individual risk factors associated with the disease. The risk factors however result from a confluence of social and economic variables predisposing certain population groups to certain disease patterns. The session aims to interrogate the expanded use of Non-Communicable Diseases (NCD) risk assessment tools in analysing morbidity patterns, associated vulnerabilities and how these tools can facilitate social inclusion of affected individuals. It aims to understand how disease-specific recording and reporting tools can serve to improve access and efficiency in the delivery of social services and health programs. The related issues that can be tackled in the session include gaps in the Communicable Diseases and NCD co-morbidities approach, low spending in social sectors and health programs, weak poverty targeting systems, and lack of policy and institutional coordination which then results in ineffective and low impact programs.

In particular the session would like to discuss the following learning questions ● How do development programs prioritize and address inequity issues? How can risk assessment tools help to identify what are the comparatively most optimal interventions and programs? ● What social vulnerability characteristics should determine the prioritization of benefits? What is the impact of individual characteristics and contextual factors (social vulnerabilities) on selected intervention programs? ● How do social vulnerability factors evolve for certain population subgroups? What vulnerability characteristics emerge from specific subgroups, e.g. older persons, persons with disabilities, women, and girls, etc, as they participate in development programs?

10:30 – 10:32

**Live Introduction**

10:32 – 10:46

**Prototyping the Non-Communicable Diseases Multi-Programme Local Mapping Tool (MuPLoMT) as a Vulnerability Assessment Tool in the Philippines**

Speaker: Dennis Batangan (Philippines)

10:46 – 11:00

**Evolving socially inclusive digital health ecosystems**

Speaker: Peter Drury (United Kingdom)

11:00 – 11:15

**Panel with a Live Q&A**

Track: Track 1: Community rights, gender and stigma  
Type: Community connect  
Room: Community Connect Channel

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11:30 – 12:15 **CCP-UnionConf-2022-01524 Tuberculosis Stigma Assessment in Indonesia**

Chair: Permata Imani Ima Silitonga (Indonesia)

**Background:**

People with Tuberculosis (TB) are mostly found in Southeast Asia, which is 44% of the total cases in the world. Globally, eight countries contribute to two-thirds of the total TB cases, and Indonesia is in second place after India. One of the serious problems that hinder the elimination of TB is the issue of stigma. Stigma in people with TB often leads to discrimination, which creates barriers to accessing services, delays in treatment, and discontinues treatment. Therefore, Indonesia TB Stigma Assessment is important to build knowledge and identify evidence regarding the issue of stigma and discrimination against people with TB in Indonesia. Furthermore, this assessment could be evidence for the government and policymakers to address TB Stigma in order to reduce peoples' vulnerability to TB infection, increase peoples' access to TB services and improve treatment outcomes.



**Objective:**

To assess to the extent to which and how TB stigma acts as a barrier to both accessing and providing services, and to support the development of recommendations to address TB stigma so that quality TB services are available, accessible and acceptable to all, with special considerations given to the needs of key, vulnerable and underserved populations in Indonesia.

**Methods:**

This was a mixed-method study using a triangulation convergent design based on The Stop TB Partnership Stigma Assessment Tool ([TB stigma assessment tool | Stop TB Partnership](#)). The study was conducted in 40 districts in 8 provinces (North Sumatra, South Sumatra, DKI Jakarta, West Java, Central Java, East Java, West Kalimantan, and South Sulawesi) in Indonesia. The semi-structured survey engaged 3200 respondents including people with or who had TB (PWTB) (n=1280), family who live with PWTB (n=640), community/neighbours around PWTB (n=640), and health care workers (n=640). Also, 12 key stakeholders participated in a focus group discussion in Jakarta, Indonesia.

**Result:**

PWTB experienced stigma. We found that community/neighbors (41%) and healthcare workers (35%) perceived stigma towards PWTB. As a result, PWTB reported stigma experienced in community/neighbors (13%) and healthcare worker (9%) settings inhibited them from seeking and accessing TB services. This study also revealed the condition of self-stigma felt by people with TB(3%), secondary stigma faced by their family members (33%), and structural stigma related to the harmful law (18%) and policy (31%) in Indonesia.

**Conclusion:**

This study proved that PWTB faced stigma-related issues is high. Consequently, this situation hinders effective TB prevention and care to end TB. It is urgent to incorporate stigma-reduction strategies in the national TB action plan. Moreover, the importance of the role of social support and healthcare worker communication in reducing TB-related stigma should also be emphasized.

11:30 – 11:33

**Live Introduction**

11:33 – 11:36

**Tuberculosis Stigma Assessment in Indonesia**

Speaker: Permata Imani Ima Silitonga (Indonesia)

11:36 – 11:39

**Tuberculosis Stigma Assessment**

Speaker: James Malar (Switzerland)

11:39 – 11:42

**Tuberculosis Stigma Assessment in Indonesia**

Speaker: Heny Prabaningrum Akhmad (Indonesia)

11:42 – 11:45

**Tuberculosis Stigma Assessment in Indonesia**

Speaker: Dwi Aris Subakti (Indonesia)

11:45 – 11:48

**Indonesia TB Stigma Assessment**

Speaker: Albert Wirya (Indonesia)

11:48 – 11:51

**Indonesia TB Stigma Assessment**

Speaker: Kristina Tobing (Indonesia)

11:51 – 11:54

**Indonesia TB Stigma Assessment**

Speaker: Endang Lukitosari (Indonesia)

11:54 – 11:57

**Indonesia TB Stigma Assessment**

Speaker: Paran Sarimita Winarni (Indonesia)

11:57 – 12:00

**Indonesia TB Stigma Assessment**

Speaker: Yuniar Ika Fajarini (Indonesia)

12:00 – 12:15

**Panel with a Live Q and A**

Track: Track 1: Community rights, gender and stigma

Type: Community connect

Room: Community Connect Channel

12:30 – 13:15 **CCP-UnionConf-2022-L00001 Meaningful Engagement of the Community in TB R&D through Community Advisory Groups - Best Practice Initiative from UNITE4TB**

Chair: Blessina Kumar (India)

Chair: Pippa Powell (United Kingdom)

"I started stigmatising myself because I was different from other people – because of the hearing loss due to TB medication. People constantly went on forgetting that I was deaf" – Phumeza Tisile, MDR/Pre-XDR TB Survivor, South Africa

Over the last three decades, the public health challenge of multidrug-resistant TB (MDR-TB) – the largest concern in the control of antimicrobial resistance (AMR) globally – has stimulated new research and development. However, most of the recent clinical trials are focussing on developing single drugs rather than looking at combinations of drugs. It is estimated that it will take 15-20 years using this approach to develop a new 3-4 drug combination regimen to treat all forms of TB.

New drugs and shorter regimens for the treatment of TB are urgently needed. These regimens need to be suited to the needs and lives of people living with TB, so that there is community uptake of any new regimens, and so we can reach the WHO targets of 95% death reduction and 90% incidence decline of TB.

Engaged and educated communities are an asset to researchers taking part in clinical trials. Clinical trial sites that are paired with well-established and supported community engagement (CE) programs are often able to more smoothly introduce and conduct trials, as well as see improved recruitment and retention of trial participants. Strong relationships with community stakeholders and groups of advisors, such as Community Advisory Groups (CAGs), are critical for managing many trial-related issues. CE programs can also activate local stakeholders as advocates for increased investment in R&D for new tools, more rapid approval and access to healthcare.

UNITE4TB (academia and industry united innovation and treatment for tuberculosis) is a public-private partnership with representation from academic institutions, small- and medium-sized enterprises (SMEs), public organisations, community groups and pharmaceutical companies. Over the next 7 years, the consortium will be active in approximately 40 trial sites on four continents (Europe, Asia, Africa, and South America), with the goal of delivering novel phase 2 clinical trials that will accelerate the development of new TB drugs and regimens. Achieving this goal will facilitate fulfilment of one of the main unmet needs in the TB field: better-tolerated drug regimens of shorter duration that can be deployed to tackle tuberculosis across various drug-resistance patterns and co-morbidities.

Within this project a CAG has been developed with representation from all regions. The CAG members bring years of CE experience and have already started providing advice and expertise to the consortium. One issue highlighted already has been the use of language used within the project; ensuring that the R&D community understand the importance of reaching out to communities in terms they understand is one of the first steps in UNITE4TB activities. This session will look into the challenges and opportunities of community involvement in TB R&D.

12:30 – 12:32 **Live Introduction**

12:32 – 12:37 **Introduction to Unite4TB and role of CAG**

Speaker: Clare Williams (United Kingdom)

12:37 – 12:42 **Ensuring that R and D is community centred: Addressing language and stigma**

Speaker: Paul Sommerfeld (United Kingdom)

12:42 – 12:47 **Best practices from HIV responses**

Speaker: Stephan Dressler (Germany)

12:47 – 12:52 **R&D and community engagement in EECA Region**

Speaker: Tolibjon Karimov (Tajikistan)

12:52 – 12:57 **Perspectives from Asia Pacific and South East Asia Regions**

Speaker: Blessina Kumar (India)

12:57 – 13:02 **Community Engagement for better TB treatment regimens**

Speaker: Agbassi Patrick (Cote D'Ivoire)

13:02 – 13:15

**Panel with a Live Q&A**

Track: Track 2: COVID-19 – Lessons learnt to strengthen the TB response

Type: Community connect

Room: Community Connect Channel

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14:00 – 14:45

**CCP-UnionConf-2022-PD02**

**Implementing TB Recovery Plans amidst the COVID-19 pandemic.**

Chair: Albertina Nyatsi (Eswatini)

COVID-19 pandemic exacerbated TB care cascade gaps faced by communities across the world, including increases in national loss to follow up rates, increased TB death rates, significant drops in TB testing, continued TB stigma and discrimination and inadequate provision of TB Preventive Therapy. In this session, panelists will discuss their experiences from the field strengthening the COVID-19 response to strengthen the TB response.

14:00 – 14:00

**Introduction**

14:00 – 14:00

**Integrated COVID-19 and TB screening**

Speaker: To be confirmed.

14:00 – 14:00

**Representing marginalised voices from communities affected by TB amidst COVID-19**

Speaker : To be confirmed.

14:00 – 14:00

**Community strengthening to ensured continued healthcare amidst pandemics**

Speaker: Kobto Ghislain Koura (Paris, France)

14:00 – 14:00

**Civil society advocacy for TB recovery plans amidst the COVID-19 pandemic**

Speaker: Ingrid Schoeman (Johannesburg, South Africa)

14:00 – 14:00

**Panel with Live Q&A**

Track: Community connect

Type: Community connect

Room: Community Connect Channel

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15:00 – 15:30

**CCP-UnionConf-2022-CT01**

**Community Connect - Creative Sessions**

In addition to content-driven sessions, we offer sessions where communities affected by lung disease (TB/COVID 19/Asthma and others) can creatively express themselves or share their personal experiences and journeys.

Track: Track 2: COVID-19 – Lessons learnt to strengthen the TB response

Type: Community connect

Room: Community Connect Channel

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16:00 – 16:45

**CCP-UnionConf-2022-01521**

**Challenges and lessons learned from the implementation of the tuberculosis program during the COVID-19 pandemic: Experience from Cambodia, Ecuador, India, and Ukraine**

Chair: Askar Yedilbayev (Denmark)

Chair: Zahedul Islam (Kyiv, Ukraine)

This interactive panel discussion will focus on the key lessons learned and practical reflections about experiences of implementing services during the COVID-19 response. Despite the fact that 2.5 years have passed since the start of the global COVID pandemic, countries still face organizational, institutional and logistical challenges in the fight against TB, and civil society is an important player in overcoming them.

The difficulties caused by the pandemic in the work of health systems negatively affect the TB diagnostics, treatment, prevention and monitoring.

The discussion will draw on practical experience of challenges that have arisen within NGO work in Cambodia, Ecuador, India, and Ukraine and how they responded to them.

During the session we will discuss in detail the following questions:

- What were the new approaches used NGO during the Covid19 pandemic?
- How to solve the problem with transportation during lockdown and travel restrictions
- Effective outreach and communication work for reaching the key population
- Algorithm for transportation sputum to specialized tuberculosis hospitals or private laboratory
- How to simplify access for the population, especially from the risk groups, to medical services for non-urgent diagnosis of pathology at all levels of medical care, which reduce the level of undetected cases of the disease;
- How to simplify the access of TB patients to specialized medical services for diagnosis and treatment, including access to the laboratory diagnosis of TB using the GeneXpert system;
- Organize testing for COVID-19 during hospitalization of TB patients;
- Delivery of anti-tuberculosis drugs for TB patients during outpatient treatment, especially to remote areas.

During the session will be made reference to program implementation, with particular attention paid to the role of cooperation between civil society and communities affected by TB. The participants would have the opportunity to discuss with the speakers the lessons learned in their countries and share their own experiences.

16:00 – 16:06

#### **Live Introduction**

16:06 – 16:12

#### **Lessons learnt in while working with private sector providers for Tuberculosis in India**

Speaker: Naveen Satle (India)

16:12 – 16:18

#### **Community response in pandemic times**

Speaker: Christian Acosta R. (Ecuador)

16:18 – 16:24

#### **The role of civil society in supporting the anti-tuberculosis efforts of the state in the context of COVID-19**

Speaker: Evgenia Geliukh (Kyiv, Ukraine)

16:24 – 16:30

#### **Challenges and lessons learned from the implementation of the tuberculosis program during the COVID- 19 pandemic: Experience from Cambodia's non-governmental organization**

Speaker: Sovannary Tuot (Phnom Penh, Cambodia)

16:30 – 16:45

#### **Panel with a Live Q&A**

Track: Track 4: Driving innovation and equitable access to new tools

Type: Community connect

Room: Community Connect Channel

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17:00 – 17:45

**CCP-UnionConf-2022-01533**

#### **Taking TB research literacy online**

Chair: Kate O'Brien (United States)

Chair: James Malar (Switzerland)

Affected communities and advocates provide an important perspective for TB research and should be engaged throughout the research and development process, from early stages of research through to implementation. The Stop TB Partnership Working Groups on New TB Vaccines, New TB Drugs, and New TB Diagnostics (together the New Tools Working Groups) and the Stop TB Partnership NGO and Affected Community Board Delegations have developed a self-guided online learning course on TB research. The course has been specifically designed with and for advocates and affected communities to provide a base of knowledge in TB research and to generate interest and engagement in TB research advocacy. This online course offers a new option to learn about and engage in TB research, as it allows learners to participate in the course whenever and wherever it is convenient for them. It covers key topics in TB research, including human rights, scientific concepts, and access to new tools, and learners will engage in activities and develop their own research advocacy plans as they progress through the course. In this

session you'll get to hear from the course development team on the TB research literacy curriculum and a demonstration video from the course will be played.

17:00 – 17:06	<b>Live Introduction</b>
17:06 – 17:12	<b>Why an online course on TB research literacy for advocates?</b> Speaker: Timur Abdullaev (Uzbekistan)
17:12 – 17:18	<b>Overview of the course - what learners can expect</b> Speaker: Jennifer Woolley (United States)
17:18 – 17:24	<b>Video demonstration of online curriculum</b> Speaker: Carolyn Barnwell (United States)
17:24 – 17:30	<b>How to give a LASER talk</b> Speaker: Rosemary Mburu (Kenya)
17:30 – 17:45	<b>Panel with a Live Q&amp;A</b>

## Thursday, November 10, 2022

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Track: Track 3: Political environments for community led advocacy and accountability  
Type: Community connect  
Room: Community Connect Channel

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10:30 – 11:15	<b>CCP-UnionConf-2022-01591</b>	<b>Progress on TB preventive treatment: a view from government and the grassroots</b> Chair: Blessina Kumar (India) Chair: Mike Frick (Brooklyn, United States)
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Though TB is preventable and curable, it is estimated that about a quarter of the world's population is infected with TB and about 5–10% of those infected develop active TB disease in their lifetime. Latent tuberculosis infection (LTBI) is defined as a state of persistent immune response to stimulation by *M. tuberculosis* antigens with no evidence of clinically manifest active TB. The risk for active TB disease after infection depends on several factors, the most important being the person's immunological status. The most effective intervention available to reduce the risk of latent TB infection progressing to active TB disease is TB preventive treatment (TPT). TPT is one of the best ways to keep individuals and families safe from TB and is also one of the key interventions recommended by WHO to achieve the End TB Strategy targets, as upheld by the UN High Level Meeting on TB in September 2018. The member states committed to rapid scale-up of access to testing for TB infection, treating at least 30 million people including 4 million children <5 years, 20 million other household contacts, 6 million PLHIV. The target for PLHIV has been met; however, progress toward the other two targets has been very slow. Only 29% of the 30 million people targeted (2018-2022) were provided TPT in 2018 - 2020. TPT given to people at the highest risk of progressing from TB infection to disease remains a critical activity to achieve the global targets. The identification and treatment of people with latent TB is an important part. Community members, National TB Program (NTP) and partners have been working to support scale-up globally. Various treatment regimens are in use. A few years ago TPT regimens were long and had side effects. Now, shorter regimens are available. While the policy reform and programmatic guidelines are in place, the rollout of the most effective shorter regimes has been slow. Community leaders globally have been advocating for an increased uptake of the shorter regime. With this background, the GCTA (Global Coalition of TB Advocates) and TAG (Treatment Action Group) propose this session to share the best practices, the challenges met and what further needs to be done to meet the global targets. This session will feature 5 presentations. The first four presentations will feature NTP managers and community/civil society. NTP Managers from Kenya and India will speak on 'TPT and National Strategic Plan – Reality check' and overview

government efforts to scale-up TPT, the results of implementation, future plans at the country level. These will be followed by interventions from Kenya and India which will highlight challenges at the ground level: what is working, and what isn't from a community perspective. The final talk by a TB survivor from Indonesia will discuss the way forward for government-community collaboration for preventing TB. This will be followed by an interactive discussion with participants.

10:30 – 10:35	<b>Live Introduction</b>
10:35 – 10:40	<b>TPT and National Strategic Plan – Reality check</b> Speaker: Rajendra Joshi (India)
10:40 – 10:45	<b>TPT implementation at the country level: Community perspective</b> Speaker: Eldred Tellis (India)
10:45 – 10:50	<b>TPT and National Strategic Plan – Reality check</b> Speaker: Jacqueline Kisa (Kenya)
10:50 – 10:55	<b>TPT implementation at the country level: Community perspective</b> Speaker: Stephen Anguva Shikoli (Kenya)
10:55 – 11:00	<b>Way forward: Government-community collaboration for preventing TB.</b> Speaker: Paran Sarimita Winarni (Indonesia)
11:00 – 11:15	<b>Panel with a Live Q&amp;A</b>

Track: Track 3: Political environments for community led advocacy and accountability  
Type: Community connect  
Room: Community Connect Channel

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11:30 – 12:15	<b>CCP-UnionConf-2022-01631</b>	<b>Working with elected representatives for TB elimination</b>
	Chair: Subrat Mohanty (India)	
	<p>REACH, through the USAID-supported Accountability Leadership by Local communities for Inclusive, Enabling Services (ALLIES) Project in four States of Chhattisgarh, Jharkhand, Odisha and Tamil Nadu is striving to end TB through community initiatives.</p> <p>As part of its initiatives, the project has identified Elected Representatives (ERs), including Members of Parliament (MPs), Members of Legislative Assemblies (MLAs) and Panchayati Raj Institution representatives (PRIs), as key stakeholders and influencers in the fight against TB. Promoting the meaningful participation of local decision makers has been a critical aspect of the ALLIES project's efforts to increase the availability of TB services and broaden the response to TB.</p> <p>Over the past year, a total of 573 ERs have been sensitized including PRI members and a few MLAs. Of those sensitized, 46 have been engaged. In Tamilnadu, PRI members have facilitated the participation of 44 TB Champions in 46 Panchayat Gram Sabha Meeting conducted on October 2, 2021, Gandhi Jayanti and pledged TB Free villages. Around 537 Panchayat representatives and an MLA and Minister were sensitized on their role in TB Free village and Anti-Stigma interventions across six districts of Tamilnadu.</p> <p>In Jharkhand, the Health Minister Mr. Banna Gupta encouraged 81 MLAs to engage in TB Elimination efforts. In Odisha an engagement is in progress with MLA Saraskana, Mayurbhanj for a TB Free Bijatala Block campaign. In Krishnagiri the local MLA Mr. Tamilselvan of Uthangarai Constituency extended support to 19 people with drug-resistant TB by providing nutritional supplements. In Durg, Chhattisgarh, after a sensitization meeting by members of TB Survivor led District Chapter network with the Durg Municipal Council Mayor he agreed for the sensitization for Councilors on November 16, 2021 where a total of 31 ward councilors participated.</p> <p>In Bokaro, Jharkhand following a PRI meeting the BDO took the decision that PRI members would support in dissemination of educational material related to TB at Panchayat Bhawans of the Block. The PRIs, National Tuberculosis Elimination Program (NTEP) Staff and TB Champions are also jointly working towards a TB-free block.</p> <p>Similarly, following meetings in Ranchi, Raipur, Mayurbhuj and Anugul districts PRI members have assured a variety of support to symptomatic and confirmed PWTBs and their family</p>	

members. PRI members are being encouraged to make TB an agenda item in Gram Sabha meetings, hold community awareness meetings about myths and misconception of TB along with provisions of the NTEP program.

This session is intended for TB advocates and community leaders, programme implementers and anyone looking to strengthen the community response to TB and hear directly from those at the forefront. Those who attend this session are expected to have a greater understanding of the role of ER for TB elimination.

11:30 – 11:37

**Introduction to how Elected Representatives can contribute towards a TB Mukht Bharat**

Speaker: Subrat Mohanty (India)

11:37 – 11:44

**Sensitization of Panchayati Raj Institution members the process**

Speaker: Subrakant Satpathy (India)

11:44 – 11:58

**Panchayati Raj Institution members engagement in the TB program at the field level**

Speaker: S Sunil Kumar (India)

Speaker: Kamin Patel (India)

11:58 – 12:13

**Panel with a Live Q&A**

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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12:30 – 13:15

**CCP-UnionConf-2022-01526**

**Advocacy to improve access to TB Preventive Therapy (TPT) in South Africa (SA)**

Chair: Ruvandhi Nathavitharana (United States)

Chair: Peter Ngo'la Owiti (Nairobi, Kenya)

Rationale: TB Preventive Therapy (TPT) is a life saving tool to prevent TB.

The political declaration on TB at the United Nations High Level Meeting on TB in 2018 and National Strategic Plans aim to increase coverage of TPT uptake among key risk groups, including people living with HIV (PLHIV), TB contacts and people who previously had TB. However, TPT targets are not being reached, with only 29% of household contacts under 5 years and 1.6% of households contacts over 5 years accessing TPT globally. In SA, only 51% of children below 5 years who were household contacts of people with TB were started on TPT in 2020.

Project Goal: TB Proof aimed to build advocacy capacity among key community and healthcare TPT implementation stakeholders who could raise awareness about TPT to increase TPT uptake and to advocate for evidence-based short-course TPT for PLHIV and contacts of people with confirmed pulmonary TB in SA.

Advocacy tactics: TB Proof worked closely with civil society organisations to sustain advocacy for the release of the updated TPT guidelines, through leveraging high level advocacy platforms:

- On 29 October 2021, TB Proof shared an advocacy letter with the Minister of Health that was supported by 29 organisations and 65 individuals. Advocacy priorities included to release the updated TPT guidelines, expand the use of short-course, rifampentine-based regimens such as 3HP, ensure inclusion of 3HP in the Essential Medicines List (EML) and to work with South African Health Products Regulatory Authority (SAHPRA) to approve new fixed-dose combination tablets of 3HP.
- TB Proof submitted a formal objection in response to the National EML Committee recommendation against the expansion of TPT to household contacts on 9 February 2022.
- On 10 March 2022, TB Proof co-presented [collective advocacy asks](#) on behalf of the South African National AIDS Council (SANAC) Civil Society Forum (CSF) at the SANAC CSF meeting with the Director General for Health and TB Director, calling on policy makers to release the updated TPT guidelines, increase eligibility criteria for TPT to include PLHIV, all household

contacts and other close contacts (including child contacts), expand the use of short-course, rifampentine-based regimens such as 3HP, and to ensure the inclusion of 3HP on the EML.

- On 18 March 2022, we engaged directly with the Deputy President, Minister of Health, Director General for Health, and TB Director and advocated for the [release of the TPT guidelines and expansion of TPT to contacts as well as the use of 3HP](#).
- We raised awareness about TPT using community pamphlets and pamphlets targeted at community health workers developed through an iterative process with input from TB survivors, health workers and TB advocates.

Learning points and next steps: TB Proof, in partnership with key TPT advocacy organisations, will sustain advocacy for the shared goal of release and implementation of updated TPT guidelines in SA. We will use this session to engage community and other stakeholders to share lessons learned and strategize regarding approaches to strengthen TPT advocacy and build collaborative partnerships.

12:30 – 12:34

**Live Introduction**

12:34 – 12:47

**Community-led awareness campaigns on TPT**

Speaker: Phumeza Tisile (Cape Town, South Africa)

12:47 – 13:00

**Advocacy tactics to increase access to TPT**

Speaker: Goodman Makanda (Western cape, South Africa)

13:00 – 13:15

**Panel with a Live Q&A**

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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14:00 – 14:45

**CCP-UnionConf-2022-01611**

**Mobilising the political power of clinicians and**

**researchers: The experience of UK Academics & Professionals to end TB**

Chair: Jessica Potter (United Kingdom)

Chair: Obiefuna Arinze Austin (Ghana)

In 2018 the World TB Day Theme was ‘Wanted: Leaders for a TB Free World’. The aim was to mobilise political power among politicians, affected communities, healthcare workers and researchers. UKAPT is a not-for-profit network of UK academics and professionals with a shared goal of ending TB. This session will create a platform to discuss attempts to mobilise the political power of academics and healthcare professionals in the world of TB advocacy.

Kerry Millington, co-chair of UKAPT will share our experience of forming an alliance whose aim is to contribute to the global work of ending TB by coordinating the academic and professional constituency to advocate for accountability, action, and progress towards the TB-related goals agreed in the Political Declaration at the UN High Level Meeting on TB in 2018.

With support of our secretariat Results UK, UKAPT was formed in December 2017 in preparation for the UN High Level Meeting on TB that took place in September 2018. We are a central point of contact for UK parliamentarians, government departments, civil society, affected community organisations and other bodies that wish to seek expert advice concerning the delivery of programmatic, implementation, and broader TB research and care activities, where this is not already met by existing expert advisory groups. Our objectives include lobbying the UK government to increase its investment in TB research and to produce evidence-based policies that strengthen global health systems and make a tangible contribution to the control and elimination of TB. We also try to galvanise political commitment to ending TB within our parliament and hold the UK government to account for delivering commitments made at the UN High Level Meeting in 2018 and subsequent relevant declarations and strategies.

We will begin the session by hearing from Nick Herbert, member of the House of Lords in the UK and chair of the Global TB Caucus – a network of parliamentarians committed to ending TB. Nick will talk about the power of engaging politicians. Virendra Sharma, sitting Labour Member of



Parliament from the UK and co-chair of the All-Party Parliamentary Group on Tuberculosis will discuss the political power of researchers and healthcare workers more specifically. The UKAPTB co-chair will then share our history, strategies, challenges and hopes.

Finally, we will consider whether this model can work globally. Obiefuna Arinze Austin, Executive Director of the Afro Global Alliance and former national Coordinator of the stop TB Partnership will share his perspective from his work in Ghana and Janika Hauser, a specialist in TB advocacy, will guide us through next steps: Ultimately, our hope is to support the replication of this model of advocacy– mobilising academic and professional communities in other countries to support political efforts to end TB.

14:00 – 14:05

**Live Introduction**

14:05 – 14:10

**The power of parliamentary engagement**

Speaker: Nick Herbert (United Kingdom)

14:10 – 14:15

**Why academics & professionals should engage parliamentarians to end TB**

Speaker: Virendra Sharma (United Kingdom)

14:15 – 14:20

**Harnessing the political power of academics & professionals to end TB - the UK experience**

Speaker: Kerry Millington (United Kingdom)

14:20 – 14:25

**Harnessing the political power of academics & professionals to end TB - Ghana's experience**

Speaker: Obiefuna Arinze Austin (Ghana)

14:25 – 14:30

**What now? Advice from an advocacy specialist**

Speaker: Janika Hauser (United Kingdom)

14:30 – 14:45

**Panel with a Live Q&A**

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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15:00 – 15:45

**CCP-UnionConf-2022-01590**

**The TB Vaccine Advocacy Roadmap: mobilizing a global advocacy response**

Chair: Mike Frick (Brooklyn, United States)

Chair: Rhea Lobo (Denmark)

We need new, effective, safe, and accessible TB vaccines to end the TB epidemic. To make this a reality, the TB vaccine pipeline urgently needs to be fully funded and resourced. While the need for new TB vaccines couldn't be clearer, progress in TB vaccine research and development (R&D) is hindered by chronic underfunding despite commitments made at the UN High Level Meeting on TB in 2018. In 2020, R&D for new TB vaccines received only US\$117 million, less than 10% of the \$1.4 billion per year now estimated to be needed to fully advance the pipeline.

The TB Vaccine Advocacy Roadmap (the ARM) is an international advocacy coalition that brings together multidisciplinary stakeholders from the global TB community, including civil society organizations, TB survivors, community groups, and research institutions. Formed in May 2021 in recognition of the promising science in the pipeline and prohibitive funding shortfalls, the coalition aims to raise awareness and mobilize the resources needed to advance the TB vaccine pipeline and TB R&D more broadly. Further, the ARM represents the first globally coordinated advocacy network to directly support TB vaccine R&D advocacy.

Led by an organizing group of representatives from five civil society and non-profit organizations and two community representatives, the ARM convenes monthly virtual meetings with the full network to share intel and plan activities. In the last 12 months, the coalition has launched a series of successful initiatives, including two global Open Letter campaigns (one to the [G20 ministers of health and finance in October 2021](#) and another to [EU leadership in February 2022](#)) and a social media advocacy fellowship for community advocates (see the [resulting campaign](#)).

While these initiatives largely focus on TB vaccine R&D, the prioritization of TB R&D in the global health, pandemic preparedness, and AMR agendas as well as the need for transformative funding mechanisms for TB R&D are central to these efforts. Building on this momentum, the

ARM is currently focused on cultivating political champions for TB vaccine R&D and engaging community advocates in skill-building opportunities.

The ARM represents an innovative network that is strategically placed to leverage the policy, advocacy, and scientific know-how of its expert stakeholders towards a common goal of a fully funded and resourced TB R&D pipeline. This interactive panel discussion will bring together ARM members to explore how engaging diverse stakeholders from across the global TB community can strengthen TB vaccine and TB R&D advocacy efforts. Speakers will discuss how we can effectively prioritize the voices of people affected by TB, how advocates and researchers can work in synergy, and how we can optimize community-led campaigns for new TB vaccines. Careful considerations will be paid to navigating advocacy

15:00 – 15:06

**Live Introduction**

15:06 – 15:12

**How can community advocates engaged in grassroots efforts engage in international advocacy initiatives?**

Speaker: Kate O'Brien (United States)

15:12 – 15:18

**How can community advocates engaged in grassroots efforts engage in international advocacy initiatives?**

Speaker: Deborah Ogwuche (Nigeria)

15:18 – 15:24

**How can researchers and advocates work together for greater impact in TB vaccine R&D advocacy?**

Speaker: Cheleka Mpande (South Africa)

15:24 – 15:30

**How can researchers and advocates work together for greater impact in TB vaccine R&D advocacy?**

Speaker: David Lewinsohn (Portland, United States)

15:30 – 15:45

**Panel with a Live Q&A**

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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16:00 – 16:45

**CCP-UnionConf-2022-01577 Country adaptation of the Standardized Package of Community-Based Support Services to improve TB outcomes**

Chair: Yuliia Kalancha (Ukraine)

Chair: Cristina Celan (Moldova)

Community-based support services, which include social and psychological support for people with TB, are an integral part of people-centred and rights-based TB care. Strengthening the role of local communities in the provision of support services is also envisaged by the concept of universal health coverage.

In addition, as part of the transition from donor- to domestic funding, it is important to have a sustainable mechanism for financing CSO activities through social order mechanisms. However, the lack of extensive experience and best practices in the EECA region in contracting CSOs and evaluating results prevents governments from developing effective collaboration with civil society and communities. At the same time, there is a clear need for patients for CSOs and communities to become part of the delivery of TB services, where it is possible, by building their capacity and developing a legal and regulatory framework for contracting.

In response to this challenge, a Standardized Package of Community-Based Support Services to improve TB outcomes was developed by WHO Europe, PAS Center and the TB Europe Coalition withing the TB-REP 2.0 project.

The document provides a detailed description of 12 support services as well as a methodology for calculating their cost, as a practical budgeting tool.

Since the adopted standards and operating procedures for CSOs in the provision of support services are the most important prerequisite for the implementation of social contracting, in 2021, an active advocacy was carried out for the adaptation of the Standardized Package at the country level in 9 countries of the EECA region. As a result, the document was adapted to the

context in all 9 countries and is already embodied at the national regulatory level in 4 of them. The exchange of experience at the regional level has greatly contributed to the progress made by the countries, since, having similar problems, the countries were able to learn from their counterparts in other countries how to overcome them.

In this session, we will once again consider the components of the Standardized Package and their use, as well as get acquainted with the experience of adapting the document from the side of state authorities in Moldova and from the standpoint of the advocacy experience of civil society in Azerbaijan.

The session will present key tools that have contributed to the rapid adoption of the Standardized Package at the national level by both the public sector and civil society, as well as discuss lessons learned and recommendations for adaptation to other countries.

16:00 – 16:03

**Live Introduction**

16:03 – 16:12

**Adaptation of the Standardized Package of Support Services is the most important prerequisite for the implementation of social order**

Speaker: Stela Bivol (Denmark)

16:12 – 16:21

**Adaptation of the Standardized Package of Support Services for Azerbaijan: Country Experiences from a Non-Governmental Organization Perspective**

Speaker: Parvana Valiyeva (Azerbaijan)

16:21 – 16:30

**Adaptation of the Standardized Package of Support Services for Moldova: Country Experience from a Public Sector Perspective**

Speaker: Valentina Vilc (Moldova)

16:30 – 16:45

**Panel with a Live Q&A**

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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17:00 – 17:45

**CCP-UnionConf-2022-PD03      Combining efforts and conducting joint advocacy activities between civil society and various government bodies: The executive (government), parliamentarians, and local authorities.**

Chair: Zahedul Islam (Kyiv, Ukraine)

This session would be on the topic of advocacy campaigns, and illustrate the examples in the different spheres:

- Budget advocacy
- Changes in the legislative framework
- Issues of access to treatment (including registration of new drugs).

17:00 – 17:05

**Introduction**

17:05 – 17:30

**Examples of successful advocacy campaigns and lessons learned**

Speaker: Zahedul Islam (Kyiv, Ukraine)

Speaker: Peter Ngo'la Owiti (Nairobi, Kenya)

Speaker: Blessina Kumar (India)

Speaker: Christian Acosta R. (Ecuador)

Speaker: Pasquine N Ogunsanya (Uganda)

17:30 – 17:45

**Panel with Live Q&A**

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**Friday, November 11, 2022**

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Track: Track 4: Driving innovation and equitable access to new tools  
Type: Community connect  
Room: Community Connect Channel

10:30 – 11:15 **CCP-UnionConf-2022-01535 Technology and Me ! – Experiences of TB Patients benefitted through technology innovations for TB diagnosed**

Chair: Ramesh Dasari (India)

Chair: Rajeshwari A (India)

In India which is contributing 27% of the world TB burden require innovations to increase TB diagnosis and treatment adherence. Many technology-based innovations for diagnosis and treatment are being piloted. The motive of these technology innovations is to reduce the diagnostic delays and provide proper TB care to people diagnosed with TB.

TB Alert India (TBAI) in one of the projects implemented in Telangana state used technology innovation for referral and testing of people with TB like symptoms (PTS). The project was supported by Stop TB Partnership as part of TB Reach Wave 6 Funding. Project was implemented from Oct 2018 to Dec 2020. Project was scaled up till Dec 2021. Objective of the project was to bring in active engagement of informal providers who are the first point of contact for medical care in rural and semi urban settings for early diagnosis of TB.

Two technology innovations were piloted in the project. First innovation was a mobile application to informal providers (unqualified health care providers) to refer PTS visiting their outpatient clinic. PTS were referred to National TB Program (NTP) clinics. Second technology was a portable handheld X-ray machine (Xair) of Fujifilm's enabled with Artificial Intelligence (AI) used for screening PTS for TB through chest X-ray. Both the technologies were used to enhance early identification of TB patients.

Both tools were very successful where 37775 (9245(phase-1)+28530(phase-2)) PTS were referred to NTP clinics through mobile application, out of them 36986(8939+28047) were tested for TB, and 6111 (1147+4964) were diagnosed with TB. Diagnosis and treatment initiation was facilitated within 3 days after visit to the informal provider. Around 3312 people were screened using the portable handheld X-ray machine in 52 camps. Around 482 were diagnosed with TB liaisons, and 85 were confirmed with TB Bacteriologically (after taking up all tested as per NTP algorithm).

This session will help to understand the perspectives TB patients who have benefitted from these two technology innovations. Informal providers who used the mobile application for referral, local NTP clinics staff who received information through the mobile application will share their experiences. One TB patient who was referred using the mobile application will share about their experiences of getting tested after referral by Informal Providers. Another TB patient referred using a referral slip will share journey of getting testing. These experiences highlight the convenience of using the mobile application in early TB identification.

This session will also highlight the experiences of TB patient who were diagnosed with TB using portable X-ray machine about their TB diagnosis journey. Another TB patient who was identified with the usual method of testing will share their experience. NTP medical officer who was part of the X-ray screening camps will share their experience with the X-ray machine.

10:30 – 10:30 **Experience Sharing of Referring people with TB like symptoms (PTS) using Mobile Application of RIPEND Project**

Speaker: Arun Kumar (India)

10:30 – 10:30 **My Experience with TB Testing**

Speaker: Berri Rajamouli (India)

10:30 – 10:30 **My Experience with TB Testing Process - Experience Sharing by TB patient who was referred with referral slip**

Speaker: Ch Laxmi (India)

10:30 – 10:30 **How Handheld X-Ray helped me in getting tested for TB ? - Experience Sharing by TB patient diagnosed with TB using handheld portable X-ray**

Speaker: Pellupu Mallesh (India)

10:30 – 10:30

**My Journey for getting Tested for TB - Experience Sharing by TB patient who was not a handheld X-ray machine beneficiary**

Speaker: Potta Kumar (India)

Track: Community connect

Type: Community connect

Room: Community Connect Channel

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11:30 – 12:00

**CCP-UnionConf-2022-CT02**

**Community Connect - Creative Sessions**

In addition to content-driven sessions, we offer sessions where communities affected by lung disease (TB/COVID 19/Asthma and others) can creatively express themselves or share their personal experiences and journeys.

Track: Track 3: Political environments for community led advocacy and accountability

Type: Community connect

Room: Community Connect Channel

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14:00 – 14:45

**CCP-UnionConf-2022-01636**

**Community Led TB Accountability: Priorities for the TB UN High Level Meeting in 2023**

Chair: Carol Nawina (Zambia)

Chair: Meirinda Sebayang (Indonesia)

In 2020, over 150 TB affected communities and civil society partners contributed to the first global community TB accountability report - A Deadly Divide: TB Commitments vs TB Realities.

<https://stoptb.org/assets/documents/communities/A%20Deadly%20Divide%20TB%20Commitments%20vs.%20TB%20RealitiesCall%20to%20Action.pdf>

The report was subsequently launched in 5 languages together with celebrities, journalists, MPs and TB actors. It looked a progress and priorities in relation to the UNHLM on TB Political Declaration targets and commitments. Based on the 5 key asks that the global TB community took to the UNHLM, and then adding a 6th looking at TB and COVID-19, the report was guided by 6 calls to action.

A second TB HLM will take place in 2023 and TB affected communities and civil society will develop an updated TB accountability report to help inform the next political declaration.

This session will be led by STP NGO and Community Delegations, will provide context on community led TB accountability efforts, give background and framing for the new Deadly Divide report and will provide participants with an interactive opportunity to share their priorities they hope to be highlighted in the report and subsequent advocacy priorities to be championed - all through a lens that promotes and protects human rights, gender, the end of stigma and discrimination, highlights the nuance of TB key and vulnerable populations and positions TB communities in the global health architecture.

14:00 – 14:03

**Live Introduction**

14:03 – 14:12

**Engagement Plan - Deadly Divide 2.0**

Speaker: Austin Obiefuna (Ghana)

14:12 – 14:21

**Community Participation and the UNHLM**

Speaker: James Malar (Switzerland)

14:21 – 14:30

**Drafting the Community Accountability Report**

Speaker: Amrita Daftary (York, Canada)

14:30 – 14:45

**Panel with a Live Q&A**

Track: Track 4: Driving innovation and equitable access to new tools

Type: Community connect

Room: Community Connect Channel

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15:00 – 15:45 **CCP-UnionConf-2022-01516** **Researchers sharing with communities (part 1): shorter regimens for drug-sensitive TB**

Chair: Lindsay McKenna (United States)

Chair: Rosa Herrera (Mexico)

For decades researchers have sought to shorten and improve treatment regimens for drug-sensitive TB. After 40 years of using a six-month regimen, the substitution of rifapentine for rifampicin and moxifloxacin for ethambutol has enabled treatment shortening down to four months (TBTC S31/ ACTG A5349). On the heels of this success, a series of phase III drug-sensitive TB treatment shortening trials, including to evaluate whether treatment for drug-sensitive TB can be shortened to just 2-months are poised to present results, including during the 53 Union World Conference on Lung Health. These trials include:

1. **RIFASHORT**, a phase III clinical trial evaluating four-month regimens containing high dose rifampicin for the treatment of drug-sensitive TB; NCT02581527.

2. **SimpliciTB**, a phase III clinical trial evaluating a four-month regimen containing bedaquiline, pretomanid, moxifloxacin, and pyrazinamide (BPamZ) for the treatment of drug-sensitive TB; NCT03338621.

3. **TRUNCATE-TB**, a phase III clinical trial evaluating two-month regimens containing rifapentine or high dose rifampicin given in combination with new and repurposed TB drugs for the treatment of drug-sensitive TB; NCT03474198.

This Community Connect session will provide a forum for researchers involved in these phase III studies to share results (RIFASHORT, TRUNCATE-TB) with or prepare members of TB-affected community and civil society groups for forthcoming results (SimpliciTB), and respond to questions. It will offer an opportunity to discuss next steps, both in terms of ensuring that communities are able to (1) access the benefits of scientific progress; and (2) shape the agenda for future research to further optimize TB treatment regimens.

15:00 – 15:05

**Live Introduction**

15:05 – 15:10

**RIFASHORT**

Speaker: Amina Jindani (United Kingdom)

15:10 – 15:15

**SimpliciTB**

Speaker: Morounfolu Olugbosi (South Africa)

15:15 – 15:20

**TRUNCATE-TB**

Speaker: Nicholas Paton (Singapore, Singapore)

15:20 – 15:35

**Panel with a Live Q&A**

15:35 – 15:40

**Community Respondent #1**

Speaker: Patrick Agbassi (Cote D'Ivoire)

15:40 – 15:45

**Community Respondent #2**

Speaker: Diptendu Bhattacharya (India)

Track: Track 4: Driving innovation and equitable access to new tools

Type: Community connect

Room: Community Connect Channel

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16:00 – 17:00 **CCP-UnionConf-2022-01551** **Researchers sharing with communities (part 2): shorter regimens for drug-resistant TB**

Chair: Lindsay McKenna (United States)

Chair: Wim Vandavelde (Cape Town, South Africa)

For decades researchers have sought to shorten and improve treatment regimens for drug-resistant TB. Recent advances have shortened treatment durations from 18-24 months to 6-9 months, and further optimized regimens by replacing injections with new all-oral treatments. Several phase III trials of shorter treatment regimens for drug-resistant TB have recently

reported, or are poised to report results, including during the 53rd Union World Conference on Lung Health. These trials include:

- **STREAM II**, a phase III clinical trial evaluating a 9-12-month, all-oral, bedaquiline-containing regimen; [NCT02409290](#).
- **TB-PRACTECAL**, a phase II/III clinical trial evaluating 6-month regimens containing bedaquiline and pretomanid for the treatment of multidrug-resistant TB; [NCT02589782](#).
- **BEAT-TB (India)**, a phase III clinical trial evaluating a 6-9-month regimen containing bedaquiline, delamanid, linezolid, and clofazimine for the treatment of drug-resistant TB; [CTRI/2019/01/017310](#).
- **BEAT Tuberculosis (South Africa)**, a phase III clinical trial evaluating a 6-month regimen containing bedaquiline, delamanid, linezolid, levofloxacin, and clofazimine for the treatment of drug-resistant TB; [NCT04062201](#).

This Community Connect session will provide a forum for researchers involved in these phase III studies to share their results with, and respond to questions from, members of TB-affected community and civil society groups. It will offer an opportunity to discuss next steps, both in terms of ensuring that communities are able to (1) access the benefits of scientific progress; and (2) shape the agenda for future research to further optimize TB treatment regimens.

16:00 – 16:03

**Live Introduction**

16:03 – 16:10

**TB-PRACTECAL**

Speaker: Catherine Berry (Newcastle, Australia)

16:10 – 16:17

**BEAT-TB**

Speaker: Padmapriyadarsini Chandrasekeran (India)

16:17 – 16:24

**STREAM II**

Speaker: Andrew Nunn (United Kingdom)

16:24 – 16:31

**BEAT Tuberculosis Trial, South Africa**

Speaker: Francesca Conradie (Johannesburg, South Africa)

16:31 – 16:46

**Panel with a Live Q&A**

16:46 – 16:53

**Community Respondent #1**

Speaker: Oxana Rucsineanu (Moldova)

16:53 – 17:00

**Community Respondent #2**

Speaker: Ani Herna Sari (Indonesia)

Track: Community connect

Type: Community connect

Room: Community Connect Channel

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17:15 – 17:45

**CCP-UnionConf-2022-CS Community Connect - Closing Session**

Chair: Ingrid Schoeman (Johannesburg, South Africa)

17:15 – 17:45

**Conclusion Remarks by UCAP chair, UCAP Track Leads and President of The Union**

Speaker: Zahedul Islam (Kyiv, Ukraine)

Speaker: Peter Ngo'la Owiti (Nairobi, Kenya)

Speaker: Wim Vandeveld (Cape Town, South Africa)

Speaker: Guy Marks (Sydney, Australia)