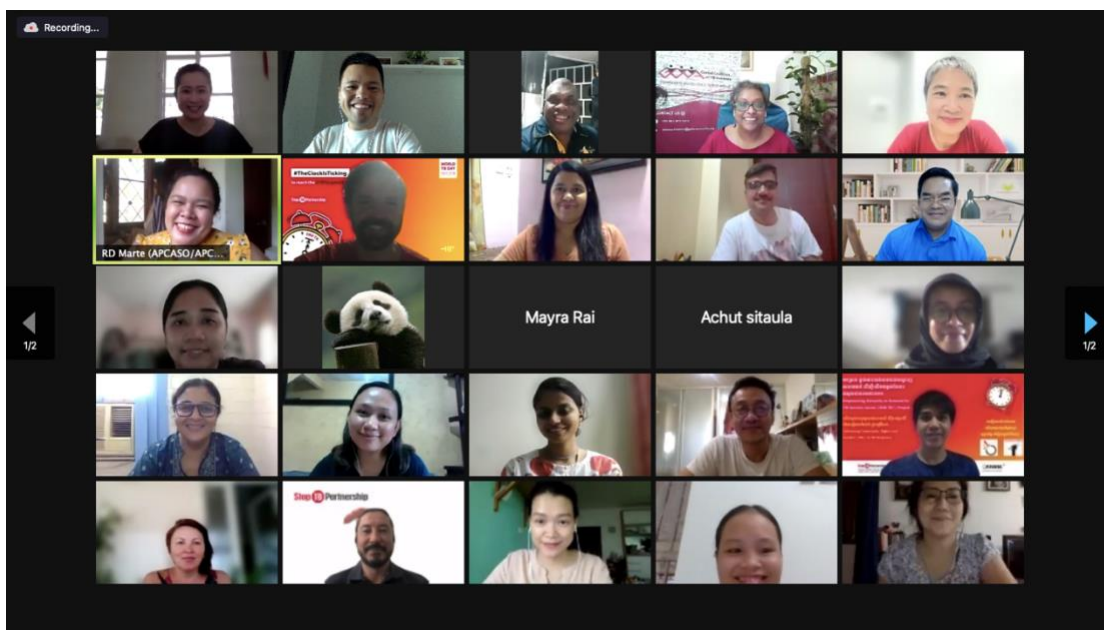




Asia-Pacific TB and Human Rights Advocacy Strategy Consultation 29 July 2021, Thursday, 14:00 – 16:00, via Zoom

Documentation Report



Background

With the adoption of the Political Declaration to Ending TB in 2018, the world has set key commitments and targets to intensify the global TB response and end it as a pandemic by 2030. While the Political Declaration has no specific strong targets were adopted around addressing stigma and discrimination and meaningful engagement of key populations to TB and TB survivors, organizations such as the Global Fund and Stop TB Partnership are beginning to develop targets to complement this. The TB accountability report *A Deadly Divide: TB Commitments vs. TB Realities*¹ further emphasizes that a rights based response to TB it a priority and requires action.

APCASO, in partnership with ACT! AP, as regional communities of advocates, is implementing a project titled “Scaling Up Human Rights Advocacy and Accountability among People With and Affected by Tuberculosis in Asia-Pacific”, with support from the Stop TB Partnership. This project aims to establish an Asia Pacific human rights advocacy agenda, which will provide a framework of advocacy priorities and strategies for APCASO and ACT! AP in engaging with regional and multilateral bodies, funders, stakeholders, and most importantly, national level government agencies and national TB programmes and advocate for a strengthened human rights-based response to TB in the region. Specifically, this project aims the following:

1. Support civil society, TB-affected communities, and TB survivors groups in the rollout of the TB and Human Rights Training Manual and in the implementation of their advocacy plans
2. Lead the development of a regional human rights advocacy agenda for the TB response
3. Advocate and influence inclusion of human rights agenda into the regional and national TB responses

To date, this project has trained 21 community facilitators and trainers from 9 countries to rollout its Right to Breathe training manual for people living with and affected by TB in late 2020. Corollary to this, APCASO supported 2 key population-led organizations and 1 civil society organization working on TB in Nepal, Papua New Guinea, and Vietnam to roll out national level TB and human rights trainings based on the Right to Breathe manual, and support succeeding activities that participants identified. This included sensitization and awareness building on the intersections of TB, human rights, and Community, Rights and Gender (CRG) concepts; meeting with national government representatives to promote the ongoing work on strengthening knowledge and capacity of communities on TB and human rights; and establishment of TB survivor groups.

Building on the progresses to advance rights-based approaches to TB in Asia-Pacific while at the same time learning from these experiences from the 3 countries and based on the outcomes of the regional Training of Trainers (TOT), APCASO in partnership with ACT! AP and Stop TB Partnership organized a regional community and civil society consultation that aims to develop a regional

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http://www.stoptb.org/assets/documents/communities/The%20Deadly%20Divide_TB%20Commitments%20vs%20TB%20Realities%20FINAL%20HLM%20Report.pdf

community-led advocacy strategy on TB and human rights. This includes identification of key priority objectives and interventions that will accelerate the achievement of a human rights-based TB response in the region, with clear strategies and activities. This TB and human rights advocacy strategy will frame the community priorities on TB and human rights for Asia-Pacific, and will be presented to NTPs, funders, and other stakeholders for further dialogue and identifying ways forward at the Regional Dialogue on TB and Human Rights, which will take place a month after this community consultation.

Proceedings of the Consultation

Introduction of the Activity

When all the attendees of this consultation activity have already logged into the Zoom meeting room and have settled down, the main facilitator, Ms. Jennifer Ho, APCASO's Deputy Director and the Manager for the Asia Pacific Community, Rights and Gender Communication and Coordination Platform, welcomed everyone and introduced herself. She reminded the group that this consultation activity would be recorded and the participants can approach the organizing team should they have any concerns regarding the recording. She also said that they will be sharing the recording as well as the presentations and materials after the session.

Following that, Ms. Ho gave everyone a brief background on this consultation activity. She mentioned that APCASO, in partnership with ACT! AP and with the support from Stop TB Partnership, has been implementing a project called "Scaling Up Human Rights Advocacy and Accountability among People With and Affected by Tuberculosis in Asia-Pacific". This project, she said, aims to establish an Asia Pacific Human Rights Advocacy Agenda which will provide a framework of advocacy priorities and strategies for APCASO and ACT! AP in engaging with regional and multilateral bodies, funders, stakeholders, and most importantly, national level government agencies and national TB programmes as well as advocate for a strengthened human rights-based response to TB in the region. Following this introduction, Ms. Ho then gave the floor to Ms. RD Marte, APCASO's Executive Director, followed by Mr. Choub Sok Chamreun, Co-Chair of ACT! AP, and Ms. Lucica Ditiu, Executive Director of Stop TB Partnership, to give the welcome remarks.

Welcome Remarks

To begin her short welcoming speech, Ms. RD Marte thanked the participants for coming to this consultation activity. She said that on behalf of APCASO, AP CRG Communication and Coordination Platform, as well as ACT! AP, they are all very pleased and happy to hold this activity in partnership with Stop TB Partnership.

Also in her remarks, Ms. Marte mentioned that it would be good to acknowledge that these virtual meetings, instead of the face to face activities they used to have, are being held for a reason and that their work does not stop even in the midst of a global pandemic. She added that the reality outside cannot really be escaped since friends, families, and even our colleagues themselves are afraid of dying

and are not being able to access vaccines in different degrees, in different countries, in different situations. She also said that the suffering of people everywhere is known to all of them and that a spirit of solidarity is continuously being felt. However, she said that despite all of these, they must continue with the work when it comes to advancing and moving the needle and pushing the envelope in terms of human rights in the context of TB. Ms. Marte also added that particularly for the Asia Pacific Region, there has already been some steady growth in the said aspect, especially in the last five (5) years since ACT! AP was formed. She said that before this, there wasn't really a regional network that was committed and resourced to come together to address the issues of human rights, communities and gender in the context of TB.

Furthermore, Ms. Marte also mentioned the changes that the Stop TB Partnership has brought into the movement in terms of putting a lot of attention to TB, CRG and to funding communities and community work. A lot of work has happened even at the country level, she said. She added that through various efforts, groups have been formed, activities have started, and activism has kicked off at many levels or for countries which it has already existed, activism has actually escalated. She said that the landscape is not so bad in terms of the strength that has been garnering. However, there are a lot of challenges to address still and one of which is the assertion that TB is not just a public health issue but a social justice and human rights issue as well. With that, responses must be put in place accordingly.

In addition, Ms. Marte also said that with all these milestones so far, this consultation is another milestone for Asia Pacific wherein a human rights advocacy agenda will be crafted collectively. This is a continuing process so the commitment of members is truly essential. Also, it is their hope that the advocacy agenda can also inspire movements and actions at the country and local levels in this area.

To close her speech, Ms. Marte acknowledged their country partners present in the day's activity. She ended her address by giving a warm welcome once again to everyone and stated her hope for a good and productive meeting.

The next one to give a welcoming message was Mr. Choub Sok Chamreun. In his speech, he first thanked the participants and guests for their presence in this activity. He also thanked APCASO and ACT! AP for organizing this consultation meeting and then expressed his hope that this particular session will allow them to strengthen their collective effort and action to push for a rights-based TB programming. He added that together, they will try their best to continue the work to ensure that the rights-based programming is at the center of the TB response in the region. He also mentioned that the rights-based approach to TB programming is a need and the partnership and collective action are very important especially among people living with and affected by TB.

To conclude his short message, Mr. Choub once again thanked everyone for participating in this workshop. He also expressed his hope that through this partnership and collaboration, more can be done and more support can be given on the ground in the countries, especially in the midst of the pandemic.

The last one to give her message was Ms. Lucica Ditiu. To open her speech, Ms. Ditiu thanked the participants present in this consultation meeting. She also thanked the team of APCASO for organizing this activity as well as ACT! AP through Mr. Chuob Sok Chamreun and Stop TB Partnership care of Mr. James Malar.

Ms. Ditiu said that it is indeed a difficult moment that everyone is going through currently due to the pandemic and a lot of adjustments had to be made. She added that human interactions and the direct face to face dialogues are much more productive than all of these virtual meetings which are very exhausting and dizzying. However, she said that she is still hopeful that this meeting would still be beneficial despite its virtual mode. She added that she has a lot of hope in this region because of the leadership of APCASO, of ACT! AP and of the groups represented in this consultation.

Moreover, Ms. Ditiu mentioned that the human rights approach in TB is now starting to get some ground, although there is still a long way to go and more work has yet to be done. She added that very often when human rights is talked about, it is in the context of CRG interventions. However, she said that the human rights approach is very relevant in all the areas. She then gave the UN HLM Targets as an example. She said that it is very important to have a human rights approach in research and development, in preventive therapy, in accountability, and so on. She emphasized that nothing can really happen without the human rights approach and without addressing the injustices happening in the TB response. With that, Ms. Ditiu reiterated that communities can no longer accept things and let things go. She said that they can no longer be polite in pushing for what is right. She then cited their experience in Romania in 2000 where they were not advised to look at children with TB. She said that with these varying recommendations, children in different parts of the world receive different health services and this right here is social injustice which still happens until today. This should be stopped, she said. Every single one should have access to the latest tools, guidelines and recommendations, and the programs should ensure and facilitate that. She also shed light on the current conversations regarding the vaccine for TB. She said that it would be such a shame if only a few rich countries would have access to the TB vaccine like what is being experienced now with the COVID-19 vaccine which is completely unacceptable. She then said that she is somewhat happy that this is happening because people are now a bit unleashed about these disparities. She added that she hopes these conversations help the TB response and the global plan that is looking to cover for the period 2023 – 2030 would be able to include a lot of work related to human rights and social justice. She ended by saying that they will definitely be reaching out to this group in the future to contribute and to ensure that those components are well crafted and included.

After the welcoming remarks were delivered, the facilitator thanked the speakers and proceeded to the next part of the session.

Agenda Overview

Before discussing the flow of activities for this consultation activity, Ms. Ho first relayed to the participants the goal and aims of this meeting. She mentioned that this consultation is building on the progress already made on advancing rights-based approach to TB in Asia Pacific while at the same time learning from the experiences from the three (3) countries that have been implementing the Human Rights: Right to Breathe Training Manual and also based on the outcomes of the regional Training of Trainers (TOT). This activity also aims to identify key priority objectives and interventions that will help

accelerate the achievement of the human rights-based TB Response in the region and hoping for clear strategies and activities. This TB and human rights advocacy strategy will frame the community priorities on TB and human rights for Asia-Pacific, and will be presented to NTPs, funders, and other stakeholders for further dialogue and identifying ways forward at the Regional Dialogue on TB and Human Rights, which will take place a month after this community consultation.

Following that, Ms. Ho presented to the group the Agenda of this activity. The Agenda can be seen below.

Time	Agenda	Person assigned
00:00-00:15 (15 minutes)	1. Welcome remarks and introduction to the consultation	RD Marte, Executive Director, APCASO Choub Sok Chamreun, Co-chair, ACT! AP Lucica Ditiu, Executive Director, Stop TB Partnership
00:16 – 00:20 (5 minutes)	2. Agenda overview	Jennifer Ho, APCASO
00:21 – 00:40 (20 minutes)	3. Results from the Deadly Divide Report & TB CRG Assessments	James Malar, Stop TB Partnership Anupama Srinivasan, REACH (India)
00:41 – 01:00 (20 minutes)	4.1 What’s available & what’s coming: Activating A Human Rights TB Response Declaration of Rights of People with TB, TB CRG SI grant, APCRG TA	Moderated by Jeff Acaba, APCASO Priyam Cherian, GCTA TBPeople Mangala Namasivayam, APCASO
01:01 – 01:20 (20 minutes)	4.2 Panel discussion: Lessons from Rollouts (Nepal, Papua New Guinea, Viet Nam)	Moderated by Jeff Acaba, APCASO Achut Sitaula, Trisuli Plus Lesley Bola, KP Advocacy Consortium Oanh Thi Khuat, SCDI
01:21 – 01:50 (30 minutes)	5. Breakout workshop: identifying strategies and approaches towards a rights-based TB response in Asia-Pacific	Guide questions: 1. How do we reach the goal of making TB response in the region human rights-based? 2. What are the steps needed to reach that goal? 3. What are some of the assumed challenges that you think will impede our progress in meeting our priority objective? 4. How do we address these challenges?
01:51 – 02:00 (10 minutes)	6. Forming the writing team 7. Closing and next steps	

Results from the Deadly Divide Report & TB CRG Assessments

Next to the discussion of the Agenda, Ms. Ho introduced the first presenter for the session, Mr. James Malar from the Stop TB Partnership to share with the group the results from the Deadly Divide Report as well as the TB CRG Assessments.

To begin his presentation, Mr. Malar first thanked the organizers of this activity. He said that this is a very important discussion and having such a diverse and broad group together for this consultation could really help the region come up with a productive outcome. His presentation, he mentioned, is a quick reminder of the Deadly Divide Calls to Action as well as to give the high level findings that came out of the TB Community, Rights and Gender Assessments. He also mentioned that there have been 20 of those who completed the said assessments and they have undertaken some high level analysis on those, noting the recurring themes and issues. He said that these might be something of use when developing the advocacy agenda for the region.

In the beginning of the presentation, Mr. Malar gave a quick reminder of the UN High Level Meeting with all the targets and commitments covering diagnosis, treatment, AMR, prevention, and funding, among other things. He also presented the clear commitments on communities, rights and gender, including the following:

- End TB Stigma and Discrimination
- Access to Medicines
- Overcoming Legal Barriers
- Gender equity
- Participation of TB key and vulnerable populations
- Psychosocial support
- An equitable and human-rights based approach

He noted that what he mentioned are specific commitments but people should also be looking more broadly at all of the targets and understand what a human rights agenda needs to adopt and what strategic positions needs to be taken.

He also shared to the group the six (6) areas for action of the Deadly Divide Report. These include the following:

- Area for action 1: Reaching all people through TB diagnosis, treatment, care and prevention
- Area for action 2: Making the TB response rights-based, equitable and stigma-free, with communities at the center
- Area for action 3: Accelerating the development of essential new tools to end TB
- Area for action 4: Investing the funds necessary to end TB
- Area for action 5: Committing to accountability, multi-sectorality and leadership on TB
- Area for action 6: Leveraging COVID-19 as a strategic opportunity to end TB

Furthermore, Mr. Malar also shared to the group that there are 21 TB CRG assessments already completed and there are 11 more coming from the Americas to give a more global angle. But in the Asia Pacific region, Bangladesh, India, Pakistan, Cambodia, Indonesia, Philippines and Vietnam have predominantly completed the process and have recommendations already endorsed at the country level. He said that these are good sources of evidence to lean on when developing the agenda. These assessments are led by TB-affected communities and civil society, in close partnership with National TB Programs. He noted that it is really good to see a rights-based approach in practice and see how it looks like to try to really advance these partnerships.

Another thing he mentioned is that once the assessments were completed, in several countries a National Costed TB CRG Action Plan has also been developed, and that includes a clear M&E and connections to the National Strategic Plan. These Plans, he added, have been completed in 5 countries. In addition, he also highlighted that community-led monitoring is an important tool to get real time data since it can include indicators directly linked to human rights and gender-related barriers to accessing services. He added that One Impact CLM for TB has already been piloted in 14 countries. Finally, Mr. Malar also mentioned that it is important to note that a series of investment packages have been developed based on the outcomes of these assessments which are practical and which the countries can use in strengthening human rights in TB responses.

With regard to the analysis of the broad range of CRG assessments that have been completed, 20 of them were part of this analysis and these seven (7) areas were used to analyze what came out. He said that he wanted to share these areas because these might be helpful in the development of the strategy. He also mentioned that they are now looking into publishing these along with the evidence very soon. These said seven (7) areas can be seen below:

- **Access, Affordability, Availability and Quality** - The AAAQ framework is very much at the heart of the right to health. It is globally accepted, academically endorsed and as part of this looks into access to information, economic impact, DOTS, stockouts, treatment duration, mental health support.
- **Stigma and Discrimination** – This would not surprise anybody but the thing is this is important because it was identified as such a prolific thing across countries. Lack of legal protection and experience of stigma and discrimination in health settings, families, communities and occupational settings, these are all human rights-related issues that are prevalent across the agenda.
- **Key Populations** – As part of the assessment, there is prioritization of key and vulnerable populations noting that in many national strategic plans, some of the most vulnerable and marginalized are not discussed. Or if they are, there is a lot nuance around the interventions to help them. These include prisoners, PLHIV, migrants/refugees/mobile populations, people who use drugs, health care workers, urban poor, and children. These are some of the key and vulnerable populations that came out across assessments. Again thinking about these in developing an agenda, how are these most vulnerable populations being catered to?

- **Freedoms:** Privacy, confidentiality and movement were the three things that came out strongly and most frequently. Privacy and confidentiality as barriers and movement as sort of an area where there is uncertainty particularly around MDR, treatment and when people can and cannot leave certain areas where treatment is mandatory and hospitalization or isolation responses are involved. The need to have clear guidelines that are based on human rights, are legally sound and have rights for review and appeal are areas there which are important.
- **Participation:** It is seen in these assessments that there is a critical need to unpack what participation means in a human rights-based perspective because it seems as though in majority of countries and contexts, this has been interpreted in very different ways so the idea of having to assess it is something very uncertain. Limited participation, capacity and investment beyond service delivery, participation extending to planning, prioritizing, implementing, reviewing and governance that includes advocacy for law and policy reform and investment required to do so. These are the few things that came up in participation.
- **Gender:** Prevalence among men may be higher but the barriers for women are significant.
- **Legal Remedies:** Across 20 countries lack of enforceable rights, limited access to legal aid and limited legal literacy were some of the key themes.

To close his presentation, Mr. Malar also shared more resources on TB and human rights including the Declaration of the rights of people affected by TB, Activating a Rights-Based TB Response, Right to Breathe, Guidance on Human Rights-Based TB Legislation, among others. He noted that all of these might have utility as they develop the agenda.

After his presentation, Mr. James Malar gave the floor to Ms. Anupama Srinivasan from REACH India.

Advancing CRG in India

Before she began her sharing, Ms. Anupama Srinivasan first thanked APCASO and Stop TB Partnership for this opportunity to speak about how they were able to take forward the CRG Agenda in India. She introduced REACH to the group as an organization based in India, working on TB for the last two (2) decades. She said that they began with private sector engagement but they eventually expanded their portfolio, working very closely with TB survivors, building their capacity, empowering them and engaging them meaningfully for a rights-based response.

After her brief introduction, Ms. Srinivasan talked about the CRG process in India. She said that they began in July 2017 when they participated in the CRG Training Workshop, with support from Stop TB Partnership. After that, they decided to constitute an Expert Advisory Group which had representation from the National TB Program, from the Ministry of Health and Family Welfare, from civil society and technical organizations, WHO, GCTA, and other community representatives who have expertise in other areas like gender, in the law and TB, keeping in mind that all of these were new

conversations that they were starting. The Expert Advisory Group met a couple of times and they went ahead with the assessments based on the tools shared by Stop TB, shared this with the groups for feedback, and finally the CRG Assessments were published in 2018.

Ms. Srinivasan also shared that their process was mostly collaborative in nature, particularly because they were getting into new areas and they were all learning new things. She added that they have also been clear from the very beginning that even for the TB program, there was a sort of venturing into new spaces, involving clients and making them part of the journey right from the beginning to have a sort of buy-in and participation and acknowledgement that these are important areas to be discussed.

In September 2018, Ms. Srinivasan shared that their three (3) CRG reports were published; the Legal Environment Assessment for TB In India, Data for Action for TB Key and Vulnerable Populations Rapid Assessment Report and Rapid Assessment of Gender and TB. What the CRG process was able to do was first, open up new areas for discussion among different actors in the TB response because no one was really talking about the TB agenda or TB and rights in quite the same way. She said that these have been missing elements in the TB response for a long time and it also sort of got everyone interested. No one had all the answers then but what they were able to do, she shared, was to get the program and communities thinking about these issues. She added that they were also able to broaden the understanding of key stakeholders on elements of rights-based, gender responsive approach to TB. Lastly, the process also revealed the eagerness within communities to strengthen their own knowledge base and understanding of relatively new aspects of TB response.

To give a quick example on what happened, Ms. Srinivasan said that before the assessment, there had been a National Consultative Meeting on TB and Gender in 2017 and she said that to be very honest, they were grappling then. After they had the chance to do the CRG assessments, they were able to figure it out a little bit and one of the recommendations of the assessments is the formation of the National Technical Expert Committee which happened immediately after the assessments were completed. In 2019, this committee which included gender experts, TB program representatives, TB champions and people from technical agencies and civil society met multiple times to develop what is now the National Framework for a Gender Responsive Approach to TB in India. This has been officially published and adopted by the National TB Program, Ms. Srinivasan shared.

Moreover, Ms. Srinivasan said that the real work that REACH is continuing to support is the operationalization of the said framework. What they've been able to do so far is to develop a Gender Sensitivity Training Curriculum for NTP staff which was piloted in September 2020 virtually. They were able to get useful feedback from the participants and for some of them, this has been the first time they thought of TB and gender and how to apply it practically in their work. They're now looking on how they can do training scale-up and how they can talk about TB and gender with the entire NTP staff.

Furthermore, Ms. Srinivasan also talked about the work they do with TB survivors. She said that this is integral in strengthening the rights-based approach. She shared that they work very closely with

TB survivors and basically tested and demonstrated a mechanism how to build their capacity, how to engage them to what they call the mentorship program, how to help them form networks and how to keep creating opportunities for people to recognize them at various forums, going beyond tokenism, and being part of the solution as well as talking about rights. She also shared that in the context of the conversation around rights, they developed a training curriculum that has been adopted by the National TB Program, from TB survivors to TB champions. It helps take TB survivors through that journey and equip them with some of the basic knowledge and skills that they would need. This curriculum was developed from inputs from several people.

Another thing she shared with the group was their learning that the empowerment of the TB champions themselves is truly essential. She said that TB champions can empower people in the community, get them to understand their rights, and get them to act on their responsibilities. This, she said, is something that the group can keep in mind as they move forward in the discussions around the rights-based agenda, identify what is the knowledge that people need to be equipped with that makes them feel more empowered.

Additionally, Ms. Srinivasan also talked about the rights-based training modules which were developed from the Legal Environment Assessment they have published. She said that they have developed this training module on TB and rights with inputs from TB champions and they are currently rolling this out, getting feedback on how it can be further strengthened. Lastly, she also shared that the stigma strategy around TB has been developed through a consultative process with several organizations. She said that operationalizing this strategy is going to be a part of how they can move forward in the discussion of a rights-based agenda in India. She ended her discussion by thanking the group once again for the opportunity to share.

Following Ms. Srinivasan presentation, Ms. Ho mentioned to the participants that they can type their questions to the speakers in the chat box, if they have any. The speakers can then respond to these questions in the chat box as well. In relation to this, Ms. RD Marte submitted a question for Mr. James Malar. She asked him if the first key issue identified in the TB CRG Assessments, AAAQ, doesn't collapse too many issues into one point, including issues regarding the impact of TB to the quality of lives of survivors. To respond to Ms. Marte's question, Mr. Malar said that just to clarity, they are just some of the issues, not all. However, those seven (7) areas are the focus they have used for analysis simply to find a way articulate the key areas. Yes, he said, AAAQ is very broad itself, and yes it has a lot in it. In many ways the other six (6) themes also fall into AAAQ as well. He added that the One Impact Framework is built around the AAAQ as well to provide insight in each area. He said that he would tend to agree that quality is particularly important and should be pulled out and would encourage the group to unpack each "A" and then the "Q" individually for the purposes of discussion. Ms. Marte acknowledged Mr. Malar's response and said that indeed, a lot of work still needs to be done.

Mr. L. Ramki Ramakrishnan also typed a comment in the chat box. He thanked Ms. Srinivasan for her presentation and said that the TB Champions Training Material has been really useful for them. He added that they are now using and adapting it for the TB champions from their identified survivors from

the transgender community. Ms. Srinivasan thanked Mr. Ramakrishnan for his comment and said that it was great to hear that the material is being useful for them.

What's Available and What's Coming: Activating a Human Rights TB Response, Declaration of Rights of People with TB, TB CRG SI grant, APCRG TA

For the next part of the program, Ms. Ho gave the floor to Mr. Jeffrey Acaba of APCASO who was the moderator of the succeeding panel discussions. Mr. Acaba began by saying that he hoped the participants were taking notes from the presentations so far because some of the elements discussed would be taken into the consultation later on. He mentioned that with the next succeeding sessions, there will be panels of presentations. He added that he did not want to bore the group with many presentations but they are encouraged to listen carefully and take notes, especially on the outcomes of the presentations. He said that these would be very relevant later on once they go into the consultation in developing the advocacy strategy for the region.

Furthermore, Mr. Acaba said that the first panel will focus on the global and regional initiatives in relation to TB and human rights. He said that Mr. Malar has already touched on some of these elements but the succeeding presentations would look into some of the organizations in terms of what they are currently doing and what future initiatives they will be initiating in relation to TB and human rights. He then turned the floor over to Ms. Priyam Cherian from GCTA for the first presentation.

GCTA

Before she began her presentation, Ms. Cherian thanked Mr. Acaba and APCASO for inviting GCTA to share their journey and engagements on what they have been doing on activating and taking forward the human rights-based response in TB. She then proceeded to mention that the GCTA had developed a brief on Activating a Human Rights-Based Tuberculosis Response which was launched in July 2020. This brief, she said, lays down the five (5) basic rights that are important while responding to TB and provides actionable guidelines to TB policy makers as well as program implementers. It is important that human rights-based response or promoting human rights and combating stigma and discrimination finds itself as one of the priority recommendations laid down by the UN Secretary General's 2020 Progress Report on the actions required to accelerate progress towards the Global TB Targets. She also mentioned that as a process of taking forward the work on utilizing the guidelines laid down on the brief, with support from the Stop TB Partnership, they have also been working with their partners in four (4) countries including Peru, Indonesia, India, and Cameroon. She added that they've been working with country partners and they have helped translate the brief into Bahasa, Spanish, French, Hindi and Marathi. The idea is to ensure that the local community will be able to access information about their rights and they are able to understand the information in a language more accessible to them. These translated briefs, she said, were used to train the local community on their

rights. She said that they have been using the brief to also engage the lawyers, to train them on what kind of rights come into play when talking about TB. She gladly reported that the response has been overwhelming. In one of the discussions, she shared, community members said that they realized that asking about what kind of treatment they are given is their entitlement. They can now ask what is happening to them and the next time they went to a TB center they were not scared to ask what medicines they have been provided. Similarly with the lawyers, some of them working on right to health mentioned that there were several communities coming to them but when it came to TB community, there was a certain hesitance or lack of literacy about their rights which reduced the number of people coming and asking for legal support. As part of the process, GCTA is trying to see how this engagement with lawyers can be developed into a legal support mechanism which can be in the form of acquainting the community with lawyers who can support them on TB responses, ensuring that the lawyers are aware of the issues surrounding TB and also looking at how there can be a periodic exchange between the legal community and the TB community in developing a better response to TB.

Moreover, Ms. Cherian also shared that they are trying to translate the brief she previously mentioned into more languages so more people can have more access to this very important information in languages that are more understandable to them. Taking forward the work, she said that they are also going to engage with community-based organizations in more countries including Pakistan and Guatemala. She added that they are also looking into translating the brief into other languages such as Tamil, Urdu, Pashto, and Russian. With this work, the idea is to work with more legal communities and the TB communities which will help develop partners in Asia and Latin America, where there can be legal support mechanism which can share its learning with each other. Through this, what is being implemented in Cameroon should also be the same rights that will exist to a TB survivor in India. They are hoping, she said, that these regional TB strategies would help develop a cross-country support and learning and also help develop model policies and action plans. She ended her presentation by thanking the group and passing the floor over to Mr. Acaba.

After Ms. Cherian's presentation, Mr. Acaba thanked her and informed her that a question was submitted in the chat box for her. In the chat box, Ms. Sharif Hossen Saimum asked this question: *"Do you have any findings/learning from using the actionable guidance to TB policymakers and program implementers? How effective were they? Any challenges? It would be really great to learn from your experience. Thank you."* To respond to the question, Ms. Cherian said that they are still implementing the program. She added that they will share the outcome of the project widely. She also mentioned that one of the challenges of the program is developing a legal mechanism where TB response has not been recognized as a human -rights based one. Ms. Saimum acknowledged Ms. Cherian's reply, thanked her and said that they are looking forward to seeing the program's outcomes.

The next presenter was supposedly from TB People but their representative was not around. With that, Mr. Acaba called on to the next presenter, Ms. Mangala Namasivayam from APCASO.

APCASO

To begin her presentation, Ms. Namasivayam first introduced herself to the group and thanked them for the opportunity to share the upcoming exciting work around TB that APCASO, as host of ACT! AP, and partners will be doing in the coming year. She proceeded to inform the group that earlier this year, ACT! AP was awarded with a grant under the CRG Strategic Initiative component. This said grant aims to do long term capacity strengthening of community networks and organizations of people affected by TB to support the community, rights and gender initiative. She added that this project started sometime in February 2021 and it will be ongoing until December 2023, hence it being long term. She said that the project is a regional project with the implementer being ACT! AP, with specific focus countries including Cambodia, Indonesia, Nepal, Pakistan and Vietnam. It has three (3) main objectives. These objectives are:

- **Objective 1:** Amplify the **participation and voice** of TB affected communities in policy and decision-making fora and in governance and stewardship of the TB response
- **Objective 2:** Strengthen the **influence** of TB affected communities on the design and implementation of national strategies and costed plans, so that they adequately reflect and respond to the realities and needs associated with HR, gender, community responses and community systems strengthening; and
- **Objective 3:** Empower TB affected communities to monitor national program coverage and quality, and commitments to end tuberculosis and to **utilize the information generated** for advocacy and programmatic action.

Discussing the objectives further, Ms. Namasivayam said that while the project is a regional one, it is also very much focused at the country level implementation. She said that the approach by ACT! AP as the regional implementer is to implement the project through three (3) tracks: one would be knowledge and information sharing; two is strengthening of the capacity of TB affected communities towards movement-building around TB; and three, the direct funding support that will be provided for country-level implementation. She mentioned that the key lesson incorporated in the project design based on the work they have done around TB is to ensure that this project is able to create a space and is able to provide catalytic resources for TB-affected communities to build on and strengthen ongoing efforts and initiatives to fulfill the agenda of a strengthened human-rights based response to TB in the Asia Pacific. This project, while being long term, would like to ensure that it is able to provide partners with a kinder space and a platform which they need to continue their efforts that are already being started and ongoing so they do not to lose the momentum.

Additionally, Ms. Namasivayam also said that one of the things that came out from the CRG SI assessments from the earlier years is the need to develop and implement work plans that have very specific country level impacts. She shared that together with their partners in these countries, they identified the intended outcome, taking into account the need, the context, and what is currently being done in the countries. Based on that, they have managed to come out with the following outcomes which the country level implementation will start in August 2021.

- People living with TB and TB-affected communities are able to effectively engage and advocate for the inclusion of CRG issues into the National TB Program and Country Coordinating Committee (CCC) in **CAMBODIA**.
- Highly marginalized TB affected communities in **VIETNAM** (women, ex-prisoners, ethnic minorities in Central Highlands) are capacitated to effectively advocate for the inclusion of CRG in the local and National TB Program.
- TB affected communities in **INDONESIA** are able to have their voices reflected in social protection mechanism for DRB-TB patients through the findings from a community-led action research and to have CRG perspectives included in the National TB Program through the community-led CRG Action Plan.
- TB-affected groups are strengthened and capacitated to participate in the promotion of CRG approaches in the district and National TB Program and to lobby for the inclusion of domestic resources for CRG related activities in the National TB Program of **NEPAL**.
- TB Community Support Groups are capacitated to advocate for CRG related issues including the inclusion of community developed TB Community Mobilization Strategy into the National TB Program of **PAKISTAN**.

To end, Ms. Namasivayam said these outcomes may all sound ambitious. However, the country partners have also identified very strategic activities and action plans and partners who will be working with them to achieve these. ACT! AP as the regional partner will also bring these learnings together, she added, as they move along with the project. Ms. Namasivayam then thanked the participants for listening and gave the floor back to Mr. Acaba.

Panel discussion: Lessons from Rollouts (Nepal, Papua New Guinea, Viet Nam)

Following the presentation of Ms. Namasivayam, Mr. Acaba proceeded to introduce the next set of presentations for the second panel discussion. He said that after listening to the global and the regional organizations regarding their current initiatives in making TB more human rights-based, the participants will now hear about the implementation and initiatives of the country partners in their work on TB and human rights. The countries working with the ACT! AP and APCASO Grant which shall be presenting in this session include the organizations like Trisuli Plus in Nepal, KP Advocacy Consortium in Papua New Guinea and SCDI in Vietnam. The support provided to them is specifically to assist in the roll out the Right to Breathe Training as well as to support some of their succeeding activities.

Trisuli Plus, Nepal

The first one to share their organization's initiatives at the country level was Mr. Achut Sitaula, Executive Director of Trisuli Plus from Nepal. To begin his presentation, Mr. Sitaula first expressed his gratitude to APCASO and ACT! AP for providing Trisuli Plus this opportunity. He said that APCASO has been playing a significant role in the advancement of Nepal's TB and PLHIV community through different support and technical assistance as well as financial support to enhance the community engagement in

their CCM. He shared that they began the Right to Breathe Project in November 2019 with the goal of building the capacity and mobilization of a resilient community of individuals affected by and working on the TB response. He added that this was with the intent to further create a people-centered atmosphere, community-led and rights-based approach.

Moreover, Mr. Sitaula mentioned that the project had three (3) main objectives:

- Identify and strengthen fundamental human rights amongst TB survivors, communities, and its leaders.
- Distribute training manuals to survivor groups; that has been carried out in other districts in Nepal already.
- Establish a group of individuals and organizations that will serve as the pioneering constituency of ACT Nepal.

To give further context, Mr. Sitaula mentioned that Trisuli Plus started in 2007 as a group of PLHIV in one of the remote districts in Nepal. Slowly, it evolved as the leading organization in that district and in the province. At present, Trisuli Plus is an active PLHIV and TB community organization and they have been acknowledged by the CCM and the National TB Program and other stakeholders as the leading TB organization in Nepal.

As for the outcomes of the project, they were able to come up with the following:

- TP was able to share the relevance of the project to several stakeholders working on TB in the country: DOTS focal persons from 10 Districts health offices, representatives from the National TB program, CCM and TB Global Fund Sub-recipients. This strengthened relationships between Trisuli Plus and these stakeholders, more specifically the DOTS focal persons who have allowed them to gain access to TB communities, survivors, and their families as well;
- 10 survivor groups were formed in 10 high TB burden districts;
- Translation of training manual in Nepali language and its roll out;
- Built knowledge on communities' rights through capacity building trainings;
- The access to TB services increased through the help of the grant. Accessibility was present in the form of TB survivor support groups creating an enabling atmosphere at the community level, in at least 10 service sites in 10 different districts;
- TP was able to influence proposal writing team as result TB community system strengthening, CRG and community mobilization component is included and coasted in TGF grant 2021-2024;
- Community-led monitoring, CRG and TB network strengthening activities in C19RM have been secured because of TP's advocacy through the project

Having said the outcomes enumerated in the list above, Mr. Sitaula expressed that they are proud of what they were able to achieve for the Right to Breathe Project so far. He also added that for the

upcoming Strategic Initiative Project, they are going to continue and build on these said achievements. They will also mobilize and advocate more in the local level and national level to keep on participating and to achieve meaningful engagement of the community in all decisions and planning levels. Mr. Sitaula closed his sharing by saying that they are always inspired by ACT! AP and APCASO and they hope for their continued support. He then gave the floor back to the facilitator, Mr. Acaba. Mr. Acaba then mentioned to the group that they should watch out for the blog that they co-wrote with Mr. Sitaula on the full details of the work they have done in Nepal.

Also to comment on Mr. Sitaula's presentation on Trisuli Plus's work in Nepal, the participants typed the following messages in the chat box. Ms. RD Marte said that they are all happy to hear the amazing new developments happening in Nepal through Trisuli Plus's initiatives. She then extended her congratulations to the said organization. Also, Mr. James Malar echoed what Ms. Marte said and congratulated Mr. Sitaula and his team for a job well done. Mr. Choub Sok Chamreun also congratulated Mr. Sitaula and said that it's great to learn that CRG initiatives were included and funded under C19RM in Nepal. Mr. Sitaula graciously received all of these messages and thanked them all, particularly the Stop TB Partnership, ACT! AP and APCASO for all their guidance and unconditional support.

Moving on to the next presentation, Mr. Acaba turned the floor over to Mr. Lesley Bola of the KP Advocacy Consortium from Papua New Guinea.

KP Advocacy Consortium, Papua New Guinea

To begin his presentation, Mr. Bola shared that the approach which they did in PNG is what they call a bottom-up approach, simulating a top-down response. Over the years, he said that their voices in the community have been lacking and one of the gap areas is the lack of empowerment of the community, especially the TB clients with their treatment supporters. He mentioned that the goal of the program was to strengthen TB advocacy and capacity-building in human rights, working with those infected and affected by TB. So far, he said that they have been working with three (3) target provinces – National Capital District, Eastern Highlands and Morobe provinces. He also shared that their primary target groups for the program were the following:

1. TB clients and their Treatment Support Volunteers (eg. LATA Group)
2. TB Clients and their families or other supporters

With regards to the interventions they have implemented, Mr. Bola enumerated the following:

1. TB & Human Rights Trainings – empowering TB clients and their Treatment Support Volunteers
2. Empowering TB clients to demand and access services freely with no stigma and discrimination

3. Collect basic information (CBM) from TB clients, checking on Accessibility, Acceptability, Affordability, Accountability and receiving Quality Health Services

Moreover, he also shared that they decided to do targeted messaging to target various people. This was done through collaborative planning of the TB clients themselves and other groups to discuss some of the issues. The developed messages were targeted to reach the following populations:

- a) TB clients – Many clients in PNG are demotivated and they lose hope (LTFU) so they are equipped to know their Basic Rights.
- b) Families and communities – Since there is high stigma and discrimination among families and within the communities, the messages target to reduce stigma and discrimination among the communities and families.
- c) Politicians – Since everyone has been focusing on COVID-19, they do not want to neglect and leave the TB clients behind so they're targeting the politicians to remind them that TB is still here and the clients should not be forgotten.

As for the outputs, Mr. Bola shared that they have developed targeted messages for various groups. Simple messages were given to clients to keep them motivated and to keep taking their medications. Through this, a lot of the clients have graduated with the treatment and they became role models for the others too. They were also able to develop simple TB CBM Tools. They have also collected data with the voices of the community and these are used to inform the policies and leaders.

And lastly, for the outcomes, Mr. Bola shared that the TB clients now know their rights and demand these to access services and commodities like TB drugs. Their CBM is also currently collecting data in the field in the three (3) provinces previously mentioned which will help the KP Advocacy Consortium and TB clients advocate for issues affecting them. He added that they should have all their data in by next month. In relation to this, he also shared that they now have a platform where the TB clients can voice any challenges using CBM Data to advocate through the KP Advocacy Consortium and TB Technical Working Groups. The Community Treatment Support workers also have been playing a critical role in ensuring that clients religiously take their meds. This supports a very weak health system and this is a gap area that they are still working on, he said. Additionally, the targeted messages they send out create a demand for clients to access TB services, motivated people to come back, and empowered TB clients and their families to know their basic rights in accessing services and commodities. Networks have also been strengthened and people now know and connect with each other for support. Lastly, Mr. Bola shared that currently, the biggest barriers which they aim to break down would be to address stigma and discrimination as well as the logistics to the hospitals and clinics. To end his presentation, Mr. Bola thanked everyone for the attention and support.

After Mr. Bola's presentation, several participants typed their messages in the chat box. Mr. Uzodinma Adirieje thanked him for the presentation and congratulated him for their work in Papua New Guinea. Mr. Harry Prabowo also commended Mr. Bola's presentation. Ms. Blessina Kumar expressed her gratitude to Mr. Achut Situala and Mr. Lesley Bola for their great presentations about their work. Ms. RD

Marte also congratulated Mr. Bola for his presentation and the movements their organization is making in their country. Mr. Bola courteously acknowledged the messages from everyone and said that there are indeed lots of similarities in the experiences of the communities in the region. He said that it is best to learn from each other through avenues like this activity.

Following the discussion led by Mr. Bola, Mr. Acaba then proceeded to introduce the next presenter, Ms. Oanh Thi Khuat from SCDI in Vietnam.

SCDI, Vietnam

To begin her presentation, Ms. Khuat shared that for the Right to Breathe Project, Vietnam came a bit later than many other countries. She added that they may be among those who have the least experience in TB compared to other organizations who have worked on TB for so long, like REACH in India, among others. For the Right to Breathe Project, she said that their overarching goal is to improve the capacity of people with and affected by TB on accessing TB services and human rights issues in Vietnam. She then mentioned that SCDI has managed to support the community to organize into what they now call VCTB or Vietnam Community for TB. However, it had only been in existence for the last couple of years and they were not getting a lot of support. Still, they try to fight and they have been struggling together, not giving up hope. Fortunately, the situation is getting better as time goes by. With the project, Ms. Khuat said that the community now has a better chance to be a significant part of the TB response in the country.

Ms. Khuat also shared the following objectives for this project:

- To strengthen the capacity of community leaders on TB advocacy
- To enhance access to TB services through amplifying the participation and voice of TB affected communities in policy and decision-making, as well as program implementation and service delivery.

She also shared the three (3) key activities which they have for this project. These were:

- Strengthening capacity of community leaders on TB knowledge and country policies as well as on Human Rights;
- Strengthening capacity of community on collecting information and evidence, and communicating to the larger community, service providers and program managers – using “Key Correspondent” model;
- Develop and sustain an online magazine on TB targeting community and service providers.

Ms. Khuan then noted that the contents of the magazine she mentioned in the activities as well as the advocacy work are all based on the CRG assessment since SCDI was the one who conducted the CRG assessment in Vietnam. She shared that they are still working on finalizing the report but they have already learned so much from the whole process. She said that it helped them to engage with different

stakeholders and through the assessment, the activities can be appropriately guided in terms of the content of the magazine, guidance for the key correspondent on the issues they should pay attention to as well as to strengthen the capacity of the community leaders to identify the key advocacy issues and messages.

Moreover, Ms. Khuat shared that so far, SCDI is a little bit slow in doing things because they are trying to learn as much as they can since they are also relatively new to this work. Aside from that, the COVID situation in the country is also a bit challenging. Nevertheless, she shared that they have already done the following activities despite the challenging situation:

- Translated the Right to Breathe Manual into Vietnamese to be used for training;
- Roll out of trainings: knowledge, policies, CRG aspects of TB, collecting evidence on rights violation, story writing and storytelling, etc.
- E-magazine “End TB” to be launched in August

Ms. Khuat ended her sharing by saying that information is power. She said that if the community does not have the right information, they are powerless in a way. She emphasized the importance of providing adequate information to the community. She said that the community must know relevant information like the policies of the government, the policies of the Global Fund, the entitlements and rights of the clients, and what the responsibilities of the agencies are. If they are rightfully informed, the communities then can start to demand for their rights and they will be empowered. She mentioned that this was what they have learned from the HIV response as well as from the CRG assessment which was useful in engaging the TB community. She added that information is what keeps the power balance between the service provider and the community and it facilitates a dialogue when people have the same information, when they read the same books, the same magazine, etc. This, she concluded, is what they are trying to accomplish in this project.

Before passing the floor over to the facilitator, Ms Khuat mentioned that their team members are also present in this activity so if the participants have any questions for them, they can type them in the chat box.

In the chat box, Ms. Blessina Kumar congratulated SCDI for the great progress they have initiated in Vietnam. She also said that indeed, information should be presented in a way easily understood by the community because in TB, the power dynamics is still very much skewed.

Breakout Group Discussion

When all of the presenters were done with their sharing, Mr. Acaba moved on to the ensuing session which was the breakout consultation sessions. Here, he informed the participants that they shall be divided into two (2) smaller groups. He mentioned that while one of the objectives of this activity is to develop a regional advocacy strategy, the ultimate goal of APCASO and ACT! AP is specifically to identify how to scale up human rights advocacy among people with and affected by TB in the region. He added that having heard from the organizations from the three (3) presenting countries and keeping in

mind the goal of scaling up human rights advocacy, their task now is to identify what would be the objectives of the region to further this goal. Also, the groups should also consider what critical steps are needed to be taken in order to achieve these objectives.

Mr. Acaba then proceeded to give the instructions for the smaller group consultation sessions. He informed them that the first group will be facilitated by Ms. Blessina Kumar while he, Mr. Acaba, will serve as the note taker. The second group on the other hand shall be facilitated by Mr. Choub Sok Chamreun with Ms. Mangala Namasivayam as the note taker. The groups shall utilize the template/matrix previously provided to them. They were given 20 minutes to do the discussion.

So as not to lose people for the group photo, the organizers decided to have the picture-taking before the participants went into the breakout rooms.

Results of the Consultation Workshop

In the interest of time, the groups no longer presented or reported back their outputs to the plenary. These outputs of the 2 groups are presented below:

Group 1

How do we reach the goal of making TB response in the region human rights-based? (Identify at most 3 objectives)	What are the steps needed to reach that goal?	What are some of the assumed challenges that you think will impede our progress in meeting our priority objective?	How do we address these challenges?
Obj. 1. Increase knowledge and awareness of affected communities both in TB infection and disease, entitlements, and rights	1A. Enhanced and effective communication among people affected by TB 1B. Gather voices of TB survivors 1C. 1D.	1. COVID-19 lockdown poses difficulty to gather voices and stories 2. Language and literacy can be an issue 3. Issues and conditions of people affected by TB are multi-layered (other co-morbidities, self-stigma, caste)	1. Civil society and communities to work together collaboratively (not tokenistic)
Obj. 2. Strengthen the capacity of the legal community and TB-affected communities about TB and human rights	2A. Develop strategic information about the rights of people affected by TB (use existing references) 2B. Inclusion of rights-based response to TB 2C. Community-based monitoring	2.	2.

	2D. Treatment literacy and understanding of communities on TB		
Obj. 3.	3A. 3B. 3C. 3D.	3.	3.

Group 2

How do we reach the goal of making TB response in the region human rights-based? (Identify at most 3 objectives)	What are the steps needed to reach that goal?	What are some of the assumed challenges that you think will impede our progress in meeting our priority objective?	How do we address these challenges?
Obj. 1. Building and strengthening human rights literacy and advocacy among TB affected communities	1A. 1B. 1C. 1D.	1.	1.
Obj. 2. Creating an enabling environment for a rights-based TB advocacy in the region through movement building and sensitization of key stakeholders.	2A. 2B. 2C. 2D.	2.	2.
Obj. 3. Investing in evidence building to ensure effective rights-based advocacy in the region.	3A. 3B. 3C. 3D.	3.	3.

Forming the Writing Team

After the allotted time for the group discussions has elapsed, Mr. Acaba proceeded to the next agenda which was the formation of the writing team. He asked the participants who among them would like to volunteer to be a part of the writing team whose tasks include the finalization of the advocacy strategy, building on the results of the breakout sessions. He assured them that he will be there to help out coordinate and consolidate everything but ultimately, the writing team would be the ones who

would review and finalize the advocacy strategy. He added that by the end of August or early September, a regional dialogue will be held where broader stakeholders including WHO Regional and Country Offices, national government representatives, among others, will be invited and where the advocacy strategy shall be presented. Also, during this said regional dialogue, other partners can express their commitment to the advocacy strategy that shall be presented. Again due to time constraints, Mr. Acaba asked those interested to join the writing team to type in the chat box their names and their email addresses. They can also reach out to him, Mr. Acaba said, through his email address (jeffacaba@apcaso.org).

In response to Mr. Acaba’s call for volunteers to join the writing team, the following individuals typed in their information in the chat box:

Name	Email Address
1. Ramki Ramakrishnan	LRamakrishnan@saathii.org
2. Dr. Uzodinma Adirieje	atm.afrihealth@gmail.com
3. Sudeshwar Singh	sudeshwar.tmv@gmail.com

Closing

To finally conclude the session, Mr. Acaba thanked everybody once again for the wonderful discussion and productive consultation. He said that with all the presentations and insights shared in this activity, this shall be one of the few consultations that he will definitely remember for a very long time. He then expressed his hope that Stop TB Partnership can also do a similar one for Asia, since they were able to do the same during the orientation. He said that hearing about the rest of the grants in terms of how they were able to wrap up their projects would be interesting and enlightening. Again, he thanked all the participants, presenters, and guests for joining this afternoon and he said that he’s looking forward to meeting with the writing team later on. With that, the activity ended a few minutes passed the second hour.