

2017-2019

ACT!

ACTIVISTS' COALITION ON TB
ASIA-PACIFIC

TB COMMUNITY SUPPORT MAPPING REPORT



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2017 - 2019



c/o APCASO
66/5 33 Tower Sukhumvit 33 Road, Klongton Nuea
Wattana, Bangkok 10110 Thailand
Email: apcasoteam@apcaso.org

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ABBREVIATIONS

ACT! AP	Activists Coalition of TB Activists – Asia Pacific
APCRG	Asia Pacific Community, Rights, and Gender Platform
ARV	Antiretrovirals
CCM	Country Coordinating Mechanism
CRG	Community, Rights, and Gender
CSS	Community Systems Strengthening
DNPET	District Network of People Living with and Experienced TB
GCTA	Global Coalition of TB Activists
HIV	Human Immunodeficiency Virus
JATA	Japan Anti-Tuberculosis Association
LaoPHA	Lao People living with HIV and AIDS
MSM	Men who have Sex with Men
NSP	National Strategic Plan
OSF	Open Society Foundation
PWID	People Who Inject Drugs
RHAC	Reproductive Health Association of Cambodia
RIT	Research Institute of Tuberculosis
SATA+	Supporting Alliance for Treatment Adherence for People Living with HIV
SCDI	Center for Supporting Community Development Initiatives
SI	Strategic Initiative
TA	Technical Assistance
TB	Tuberculosis
TBEC	TB Europe Coalition
VCTB	Viet Nam Community Network for TB Control
VNMSM-TG	Viet Nam Network of Men who have Sex with Men and Transgender People
VNTG	Viet Nam Network of Transgender People
WHO	World Health Organization
WPRO	Western Pacific Regional Office

EXECUTIVE SUMMARY

In Asia and the Pacific, the Activists Coalition on TB – Asia Pacific (ACT! AP) has been in the forefront in building the capacity of civil society organizations and TB-affected communities towards meaningful community engagement in the TB response, and in advocating governments towards a coordinated and well-funded TB response. Since its inception in 2016, the coalition and its members have worked with various civil society, TB-affected communities and TB survivors, and technical partners and national governments. However, there has not been an exercise that captured the breadth of reach of ACT! AP's work at the country level, primarily in terms of engaging and building the capacity of TB-affected and TB survivor groups.

Thus, this exercise aims to map out the reach and kinds of support that ACT! AP members have provided in the countries in Asia and the Pacific. Specifically, this survey aims to:

1. Map out TB survivor groups, TB support groups, NGOs, CBOs, civil society, key population, or TB-affected community organizations working on TB that ACT! AP and APCASO civil society partners have engaged or supported in terms of forming and/or strengthening the former's organization since 2017;
2. Identify the type of support that ACT! AP civil society partners have provided in relation to engaging with the national level or community level community partners; and
3. Identify potential support needs in enhancing or strengthening the current engagement with the local or national civil society partner.

Using a simplified Community Strengthening Systems Framework and employing a short online survey, this report hopes to build a case on the contribution of ACT! AP in the national and regional TB responses, particularly with regards to community mobilization and engagement. This will provide insight into the extent of the work that ACT! AP had conducted in reaching out to country and local level partners since its inception in 2016.

From the 16 respondents belonging to an ACT! AP member organization who responded to the survey, and by reviewing secondary sources, some key findings were observed:

- Some ACT! AP members started from the HIV advocacy and response and have utilized cross-learning strategies to address the TB response, especially among communities that are affected by comorbidities of TB and HIV. There were also ACT! AP members who started as a TB community-led organization.
- Almost all ACT! AP members have provided either mobilization (81.25%), partnership (81.25%), and/or technical support (81.25%) to community groups (either organized or in the process of) or partner civil society organizations. More than half (68%) of the organizations have provided funding support. ACT! AP's regional-level initiatives have also provided small funds to partner organizations to conduct trainings.
- Since 2017, 78 community-led organizations have been mobilized by ACT! AP members in various countries where ACT! AP is present. Eleven (11) CSOs were partnered in certain projects and interventions, and 12 technical partners and government agencies were collaborated (such as CCM and the national TB programme).

However, for these various efforts by civil society organizations and TB-affected communities to be sustained, significant amount of support and approaches are still needed. ACT! AP members who participated the survey recommended a number of ways that will sustain their work at the country and regional level:

1. Funders, donors, and national governments must provide specific organizational support, such as in capacity development, fundraising, and communication skills.
2. Community networks need to initiate and include areas of convergence with other health and social issues, such as migration, maternal and child health, and non-communicable diseases.
3. Support ACT! AP's need to expand its geographic coverage to cover countries that have not yet previously covered, and increase ACT! AP membership.
4. Civil society organizations must be encouraged to engage with and invite younger community members to sustain the TB movement.
5. Strengthen national Stop TB partnerships.
6. Leverage ACT! AP in sharing country learnings and expertise; sustain networking.

INTRODUCTION AND BACKGROUND

Civil society engagement remains a critical enabler towards an inclusive TB response that is responsive to the needs of the populations most affected by the pandemic. Learning from the HIV response, engaging civil society from service delivery, community-led research, community-based financing, and advocacy-related initiatives increase the likelihood of reaching global health targets.¹ While civil society and TB-affected community engagement has been highlighted in both the World Health Organization (WHO) End TB Strategy as one of its Pillars and as key priority action in the Stop TB Partnership's Global Plan to End TB, very little data and documentation has been made available about the contribution of civil society engagement in the TB response^{2,3}. This does not, of course, preclude initiatives to involve civil society and TB-affected communities. WHO's ENGAGE TB Approach, for instance, emphasizes the value of engagement between NGOs and CSOs, and national TB programmes to improve active case finding and referral to treatment of people diagnosed with TB.⁴ The Stop TB Partnership has also piloted a community-based monitoring application called OnelImpact that is aimed at enabling access to TB information using mobile devices, and also report problems that people with TB face during diagnosis, testing, and treatment.⁵

In Asia and the Pacific, the Activists Coalition on TB – Asia Pacific (ACT! AP) has been in the forefront in building the capacity of TB-affected communities and in advocating governments on the meaningful engagement of TB survivors and those most-affected by TB, working towards a coordinated and capacitated TB community and activist movement in the region. Its humble beginnings can be traced back in November 2016, at a time when regional civil society and TB-affected communities in TB has been patchy and less coordinated in the region. APCASO, through the Asia Pacific Community, Rights, and Gender (APCRG) Platform, ACT! AP emerged as an outcome of the meeting that aimed to increase advocacy towards putting more attention to TB and to jumpstart a regional civil society movement around TB in Asia and the Pacific.⁶ Despite a lack of funding, with the commitment and support from the Global Coalition of TB Activists (GCTA), Open Society Foundation (OSF), and the Global Fund CRG Strategic Initiative (SI), ACT! AP was able to organize its initial strategic meetings and has been established with an operational Steering Committee under

the custodian of APCASO as its Secretariat. Presently, ACT! AP has 31 members working in 15 countries in the region, working mainly among ACT! AP members, APCASO focal points, and the broader civil society and TB-affected communities in these countries. Membership has not delimited the work of ACT! AP, with two countries, China and Mongolia, wherein ACT! AP has worked previously.

BOX 1:

COUNTRIES WITH ACT! AP MEMBERS AND WHERE ACT! AP HAS WORKED

Australia	Lao PDR	Pakistan
Cambodia	Kiribati	Papua New Guinea
China	Malaysia	Philippines
India	Mongolia	Thailand
Indonesia	Myanmar	Viet Nam

These activities include provision of technical support to TB activists and TB-affected communities as they engage in The Global Fund and other programmatic and policymaking processes and collaborating with WHO or the National TB programmes in their programmatic work and strategic direction setting. ACT! AP members also work with and received funding with other stakeholders such as the Stop TB Partnership and its national counterparts through the National Stop TB Partnerships, The World Health Organization (WHO), and other partners in the region such as The Union and the Global TB Caucus.

Four years since ACT! AP's inception as a regional coalition, its contributions in the national and regional TB responses have not been fully documented due to funding limitations.

OBJECTIVES

This exercise aims to capture the extent of the breadth of reach of APCASO and ACT! AP's work at the country level, primarily in terms of engaging and building the capacity of TB-affected and TB survivor groups. Specifically, this survey aims to:

1. Map out TB survivor groups, TB support groups, NGOs, CBOs, civil society, key population, or TB-affected community organizations working on TB that ACT! AP

and APCASO civil society partners have engaged or supported in terms of forming and/or strengthening the former's organization since 2017;

2. Identify the type of support that APCASO and ACT! AP civil society partners have provided in relation to engaging with the national level or community level community partners; and
3. Identify potential support needs in enhancing or strengthening the current engagement with the local or national civil society partner.

BOX 2:

ACT! AP'S COMMITMENT TO ACTION

1. **WE WILL ACT** to give TB the political attention it deserves. ACT! AP enjoins international and regional development communities, governments, funders, researchers, and civil society movements to give TB the necessary attention matched with the resources needed to reach the global goal of ending TB by 2030.
2. **WE WILL ACT** to present an alternative model to the pervading biomedical approach to TB. ACT! AP advocates for a people-centered and meaningful community participation; respects, protects, and advances human rights; and gender equity and gender transformative policies as critical means to an effective TB response.
3. **WE WILL ACT** to overcome barriers to TB treatment and diagnostics access. ACT! AP works to overcome key challenges to universal and equitable access to TB drugs and diagnostics; the inefficiency of drug regulatory frameworks, including discrimination in the health care sector, and the slow movement and low investments in TB research and development.
4. **WE WILL ACT** towards securing adequate and strategic investments for TB, making sure that these investments go to the right interventions, including by communities. ACT! AP aims to secure core and programme funding for its organizational and programmatic priorities, as well as in coordinating and inspiring joint advocacies in the region.
5. **WE WILL ACT** to support a coordinated and capacitated TB community and activist movement. ACT! AP works with a number of key stakeholders in 12 countries in Asia and the Pacific, as well as among global stakeholders such as the World Health Organization (WHO), Stop TB Partnership, The Union, and the Global TB Caucus, among others.

This survey hopes to build a case on the contribution of ACT! AP and APCASO in the national TB response, and more broadly, in the regional TB response, particularly with regards to community mobilization and engagement. This will provide insight into the extent of work APCASO and ACT! AP had done since the latter's inception in 2016 through the APCRG Platform and provide a glimpse of the level of engagement a regional coalition has in working with national level and country level partners. As the current Global Fund CRG SI closes its support to current Regional Platforms, including the APCRG Platform, this 2019, it is important to layout and provide evidence on the outcomes of the level of support that the ACT! AP and its members have received from the APCRG Platform, and how these have either strengthened the TB activism movement, or ultimately have shifted the paradigm of the TB response in Asia-Pacific, based on the guiding Commitments to Action of the regional coalition.

Towards the end of this report, recommendations will be highlighted on the areas that ACT! AP and its increasing network can focus on and improve more, and the areas on how APCASO, as the ACT! AP coordinator, can sustain the support to the regional coalition as it continues to reshape the TB response in Asia Pacific.

FRAMEWORK

This report employed a simplified version of the Community Systems Strengthening Framework published by The Global Fund in 2014.⁷ Developed in light of the need for an increased understanding on how to strengthen community systems to respond more effectively to health issues particularly around TB, malaria, and HIV; Community Systems Strengthening (CSS) Framework has been developed to provide a systematic approach in identifying essential areas or components of community systems and design interventions targeting these components that can contribute towards improving health outcomes.

These core components are the following:

1. **Enabling environments and advocacy.** These includes community engagement and advocacy for improved policy, legal, and governance environments.

2. **Community networks and partnerships.** This includes advocacy, capacity-building, and financing in order to make sure that linkages and partnerships happen.
3. **Resources and capacity-building.** This includes allocating budget for human resources and in building the organizational, personal, and technical capacities of staff both for core and for the implementation of the activities.
4. **Service delivery.** This includes activities that would involve provision of direct medical and related services to clients, as well as providing information and education activities.
5. **Organizational and leadership strengthening.** This includes management, accountability, and leadership for organizations.
6. **Monitoring, evaluation, and planning.** This includes providing support and resources for organizations to develop and institutionalize M&E systems and be able to conduct planning activities.

It is assumed that when any or all of these components are supported and well-resourced, community engagement will improve and sustain; community-led organizations will thrive as active actors in the response. In turn, this will contribute into achieving the local or national health goals as communities are enabled to contribute towards improving health outcomes of those receiving the information, services, and commodities.

The Global Fund proposes that components must be translated into interventions that would “support the development and reinforcement of informed, capable, coordinated, and sustainable structures, mechanisms, processes, and actors through which community members, organizations, and groups interact, coordinate, and deliver their responses to the challenges and needs affecting their communities”.⁸ This entails providing sufficient funding towards strengthening these areas, identifying key areas of improvement and support, and facilitating a platform that can provide a space for communities to convene, discuss, and address the challenges that they face.

While it is expected that these interventions should be integrated into the national plans and budgets, either through specific diseases or health sector as a whole, this study looks at how civil society organizations support and help their peer organizations improve their activities as they contribute towards health and other related interventions. In particular, this report looked at four types of support that community organisations can provide:

1. **Mobilisation support.** This form of support includes giving advice in community organizing and mobilization, in the design of trainings and other capacity-building or strengthening activities, or in directly supporting mobilization activities with the community.
2. **Partnership or networking support.** Support around linking organisations to either another partner organization for synergy and increased collaboration, or to funders and other donors to augment their existing work falls under this type of support.
3. **Technical support.** This includes providing technical knowledge or sharing reference materials that can support activities such as community-led or community-based researches, service delivery, or any programmatic-related or policy development-related activities. Technical support can also be in the form of providing technical assistance (TA) either via The Global Fund TA program or other means.
4. **Funding support.** Support in the form of providing advice in the partner organisation’s resource mobilization activities, or even more direct support in providing seed funding, specific project activity funding, or support in drafting project proposals for organisational funds fall under this category.

These types of support are neither exhaustive nor linear in its provision. At the same time, forms of support can also overlap and be provided in conjunction with other types of support. For instance, an organization may only identify specific type of support initially but may require additional forms of support in order to meet a particular intended outcome or goal. This is specifically true in cases wherein the recipient organization is in its inception and require organizational foundations in order to solidify its growth.

This list of support also did not include “organizational support” as a form of support, mainly because several components of organizational support can be provided as part and parcel under each of the four. For instance, mobilisation support can, in turn, help the organization in building its network of community members, which consequently will contribute towards the organisation’s credibility as a representative of the community that it serves. It is then assumed that each of these four types of support contribute, directly or indirectly, towards the strengthening of not only the community system in general, but more specifically, to the organization requesting for that particular support.

METHODOLOGY

A short online survey tool was developed in November 2019 using Google Forms (Appendix 2). The tool detailed the objectives of the survey and asked respondents for information such as email address, name, organization, and country where the organization is based. Succeeding questions focused on the name and nature of the organization, as well as information about the respondent/responding organization has partnered or helped mobilise since January 2017.

The survey was shared through the ACT! AP members listserve twice: first in November 2019, and second in January 2020 as a follow-up. To ensure that ACT! AP members and partners respond to the survey, individual emails were sent as a third follow-up.

LIMITATIONS

This survey focuses mainly on the work of ACT! AP as a regional coalition, including its members and network partners, since 2017. While ACT! AP was established in November 2016, the decision to begin the coverage in 2017 provides initial footing of the regional coalition particularly its members at the country level. This is particularly relevant given that it was only in April 2017 when ACT! AP was formalized in Bangkok, Thailand, and wherein the Steering Committee was formed.

The survey was devised to also contain open-ended questions that provided respondents a space to share the breadth of their work as well as the nature of the organization that they are representing. The presentation of the findings is, thus, more contextual and narrative and less in the quantitative figures.

This report does not also intend to provide a scale of the work that civil society organisations provide to support other civil society organizations working on TB in general. This report may even be purported to understate the amount of response civil society organizations working on TB (mainly ACT! AP members) has done since 2017. Nonetheless, this report contributes towards the argument on the

need to support and sustain civil society organizations as important and critical partners in improving “the reach and sustainability of TB interventions”.⁹ While efforts and approaches such as WHO’s ENGAGE-TB has been established as early as 2012, documentation exercises on the contribution of civil society organizations and TB-affected communities have been limited and scarce, most of them focusing on specific engagements in funding mechanisms such as The Global Fund process, at least as far as the Asia Pacific region is concerned.^{10, 11, 12, 13} One of the difficulties in doing so was because of the limited indicators around community and civil society engagement in the context of TB. Under the WHO’s ENGAGE-TB Approach, only two indicators are being used to measure community and civil society’s engagement in the TB response: the first around “community-based TB activities”, and the second focusing on community health workers and community volunteers.¹⁴ The reportage is aggregated, however, which provides a rather skewed reporting on which countries truly partners and engages with civil society organizations.

Lastly, it is envisaged that this report will not only capture the experiences of civil society organizations working on TB, but also recommend ways to support and sustain civil society organizations’ response in addressing TB. By documenting the civil society’s experience in the TB response as well as the limitations of their work, this report can provide pathways in identifying key areas of civil society engagement that needs to be improved or scaled up.

FINDINGS

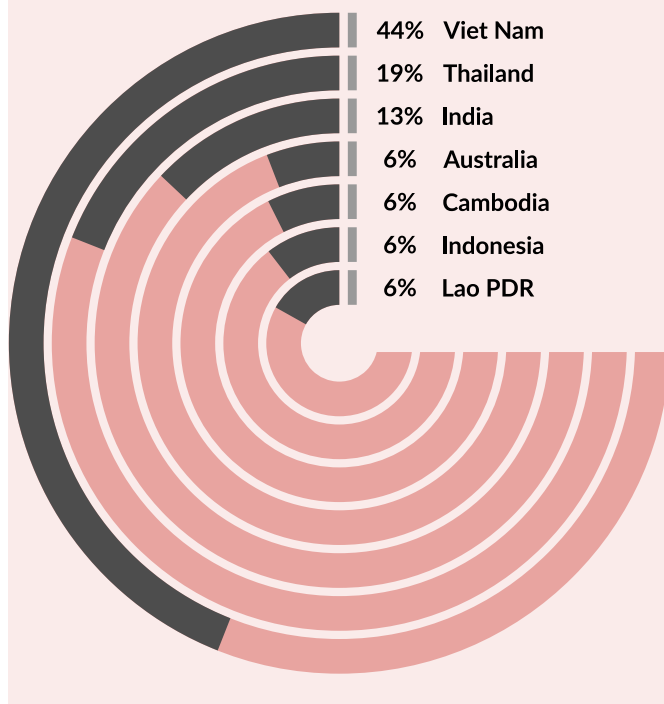
The survey gathered 16 responses from ACT! AP members based in seven countries – seven in Asia and one from the Pacific (Figure 1). Most of the responses came from Viet Nam, mainly due to the presence of and the reach of ACT! AP members in the country. These seven countries also cover 60% of ACT! AP’s member countries.

All 16 respondents belong to an organization and represent their organizations as members of ACT! AP. These 16 respondents represent 7 organizational members of ACT! AP, four (4) of which started as a civil society organization working on HIV or was initially a support group of people living with HIV and later expanded to include TB-related issues.

Organizational membership is optional to become a ACT! AP member, but belonging to an organization helps institutionalize ACT! AP's presence and work in partnership with the organizations on the ground.

FIGURE 1:

LIST OF COUNTRIES WHERE RESPONDENTS ARE BASED



Communities Stepping Up:

Learning from HIV and Addressing Comorbidities

The progression of civil society organizations to eventually work on TB-related issues, especially in relation to HIV, can be attributed to the comorbidities faced by people living with HIV, given that those with HIV are 20 times more susceptible to TB than those who are HIV-negative. TB also still remains the leading cause of death among people living with HIV.¹⁵ Some of these progressions to work in the field of TB also involved receiving funding (i.e. Global Fund) that provided organizations to expand their work to include TB-related interventions.

One good example of this expansion of work and inclusion of TB in existing HIV response of civil society organizations was the experience of the Center for Supporting Community Development Initiatives (SCDI). Established in 2010 in Viet

Nam, SCDI has been recognized in their work with the most marginalized populations, addressing intersectional challenges that people experience due to poverty, poor health access, among others. Since their inception, the organization has worked with people living with HIV, people who use drugs, and urban poor populations. Their work with key populations to HIV including people living with HIV allowed SCDI to include TB issues in their response, with their community partners raising concerns about the increasing TB incidence in their communities and how this complicates their work around HIV.¹⁶

Similar to SCDI, Yayasan Spiritia was among the organizations that started as a support group for key populations and people living with HIV. Their work around HIV later expanded the organization to become a national PLHIV organization working to support people living with HIV through an established PLHIV peer system. In 2016, Yayasan Spiritia was selected as a principal recipient for the TB/HIV component of The Global Fund grant in Indonesia, with an aim to reduce HIV and TB-related morbidity and mortality in 34 provinces in Indonesia, and to strengthen and improve the performance of health and community systems.¹⁷ This allowed Yayasan Spiritia to integrate TB in their existing HIV work. For the last two years, Yayasan Spiritia has been providing TB screening to more than hundred thousand men who have sex with men (MSM), transgender populations, and people who inject drugs (PWID) including their partners; referring them for testing and treatment and supporting their retention in TB care as well as in adherence. Yayasan Spiritia has also reached out to thousands of people living with HIV to screen and refer for TB-related services when needed, which has helped strengthen collaboration between TB and HIV programs in Indonesia. The organization has also contributed in the improvement of the reporting systems of both the national TB and national HIV programs, especially cases of people with TB diagnosed with HIV, or people living with HIV who are diagnosed with TB. This national grant also permitted Yayasan Spiritia to work in critical spaces where TB epidemic is relatively high, such as in the prisons. One of the outcomes of this Global Fund grant was to establish a national policy for HIV testing, treatment, and care provision among people in prisons, and proper screening and referral of those tested positive for TB.

There were also organizations that were established solely to address both TB and HIV from the onset. One response shared about the experience of the TB/HIV Research Foundation based in Chiang Rai, Thailand. The Foundation

was founded in the 1990s by a group of Doctor's degree students conducting a dissertation research project on the TB-HIV burden in Chiang Rai,¹⁸ wherein the HIV prevalence used to be around 16.5% and the TB mortality rose to 60% among people living with HIV. Eager to continue their work in Chiang Rai, they established the organization in 2002 and worked collaboratively with the Research Institute of Tuberculosis (RIT) and the Japan Anti-Tuberculosis Association (JATA).

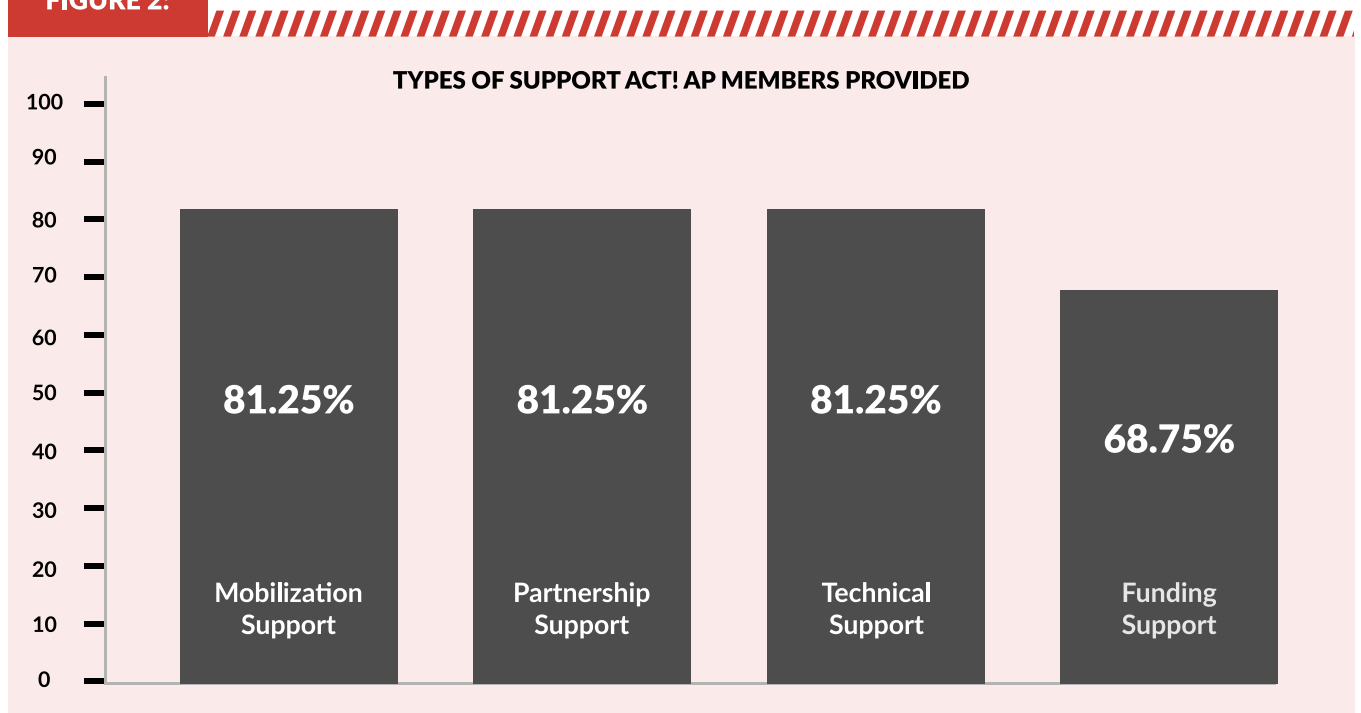
Presently, the TB/HIV Research Foundation focuses on three areas of work: (a) Research, which includes clinical studies, behavioral researches, and applied researches on community development; (b) Technical Collaboration, which includes organizing technical meetings with public and private healthcare facility providers, conducting trainings for community volunteers including prisoner volunteers, and collaborating with other policy bodies and institutions such as the Thai National TB/HIV Working Group, and the Alberta University School of Public Health based in Canada; and (c) Charity, wherein a Charity Fund was setup to support impoverished clients and those who are unable to pay for TB-related costs, such as transportation and nutrition expenses.

Types of Support Provided to CSOs and Partners

Survey results showed that almost all ACT! AP members have provided either mobilization, partnership, or technical support to community groups (either organized or in the process of) or partner civil society organizations (Figure 2). While it was not shown in the survey the cost in operationalizing each type of support that was provided to each partner, the three types of support mentioned above were made possible due to the existing funding grants that ACT! AP members receive, either directly through implementation of an existing grant, or as part of the organization's mandate to respond to the need of their community members or those that they serve.

For ACT! AP members, the need to mobilize people affected by TB and TB survivors remain a critical priority in achieving its Commitments to Action. Organized community groups of those most affected by, living with, and have survived TB is the lifeblood of ACT! AP. At the same time, to ensure the relevance of the ACT! AP and that its priorities are reflected from the needs of the grassroots, social mobilization remains critical to the success of this coalition.

FIGURE 2:



Mobilization and partnership come in tandem. With partnership support, ACT! AP members was able to solidify its space and position itself alongside other actors in the TB response. ACT! AP was able to identify not only its priority issues but also to understand the existing landscape to which organizations that ACT! AP has partnered with would be used in its advocacy.

Technical support has also been identified as a support that is being provided by ACT! AP members. Sources of these support come either from the ACT! AP Secretariat through the APCRГ Platform, or from the expertise of the civil society organizations based on its experience in the country and as a result of the consultations that they facilitate. These came either through the APCRГ Platform’s work as a communication and coordination facility of The Global Fund, as well as in linking ACT! AP members to updated tools and resources around TB prevention, treatment, and advocacy, especially during the height of the 2018 High-Level Meeting on TB.¹⁹

Eleven of the 16 respondents also identified providing funding or links towards potential funding pools or sources. These may come from the fact that some of these CSOs are existing Global Fund principal recipients or have received funding through other means. At the same time, ACT! AP’s regional level initiatives have provided small funds to partner organizations to conduct trainings.

Community Mobilization and Establishing Partnership: Critical Steps Towards Ending TB

Since 2017, ACT! AP members have either mobilized people with and affected by TB and TB survivors from the local and national level; or forged partnerships with bodies such as the Country Coordinating Mechanisms (CCMs), national Stop TB partnerships, and with other community networks of organizations working in other diseases (e.g. HIV key population networks) (see Figure 3). This was mainly to respond to the lack of organized groups that can engage in the national or local TB response. These forms of mobilization are significantly part of the scaling up that is needed to achieve the global targets for TB control.²⁰

Evidence has proven that community mobilization is key towards achieving substantial scale-up and improvement.²¹ Organized community organizations and groups of affected by and survived TB can provide support to people with

TB to refer to TB screening, enroll and complete their treatment, and advocate for a well-financed TB response and availability of lifesaving drugs in the local level. In mobilizing communities, it is important that community mobilization begins in places where people in the community converge and meet – either geographically (such as in neighborhood or in treatment centers) or where people hang out and come together (such as through support groups of people affected by TB). Spirita in Indonesia, for instance, has mobilized and linked around 70 community groups into their ongoing Global Fund TB/HIV programme, and has continued to provide funding support to these organizations.



SCDI’s work, especially with people living with HIV, and in organizing consultations with those affected with TB has allowed the organization to support the establishment of the Viet Nam Network for TB Control (VCTB), a community-led network of civil society, NGOs, and TB-affected communities and TB survivors in the country. Currently, VCTB has members from 21 countries in the country. When SCDI was granted as a sub-recipient of The Global Fund HIV grant in Viet Nam, SCDI started hosting a number of national networks of marginalized populations, such as the Viet Nam Network of Transgender People (VNTG), and the Viet Nam Network of Men who have Sex with Men and Transgender People (VNMSM-TG). One of the organizations that SCDI is currently hosting is the Viet Nam Community Network for TB Control (VCTB), which provides legal, administrative, and management support to the Network, as well as financial and technical support.

SCDI has also supported the coalition that supports treatment adherence for HIV, which also helped support TB treatment adherence among people living with HIV. Through the Supporting Alliance for Treatment Adherence for People Living with HIV (SATA+), members are given space to discuss their challenges in adhering to ARVs and to their TB treatment.

In Cambodia, ACT! AP member, KHANA, supported the establishment of a people living with and experienced TB in Siem Reap District. District Network of People Living with and Experienced TB (DNPET) is a network of TB peer support groups that has a mandate of bringing the voices of people living with and experienced TB in policy development forum, advocacy campaigns, and as part of Siem Reap's TB service delivery programming. These forms of support that HIV organizations such as SCDI in Viet Nam and KHANA in Cambodia shows the importance of learning from previous experiences in social mobilization coming from the field of HIV and apply them in mobilizing communities affected by TB. At the same time, engaging similar networks who were previously engaged in HIV ensures continuity and bridging of efforts particularly around addressing comorbidities (i.e. TB and HIV). For SATA+, these joint efforts to address adherence on both ARV and TB treatment enables discussions on the critical gaps that affect treatment adherence of people living with HIV who are diagnosed with TB or vice versa. Enabling such discussions can recommend specific interventions in aligning vertically designed country programmes and making them centered around people's needs and issues.

ACT! AP has also exercised global to local support in community mobilization. The Global Coalition of TB Activists (GCTA), for instance, supported the establishment of TB community-led organizations such as Touched TB India. This organization is a national coalition of people affected by TB in India and was established in 2017. The coalition's focus is in ensuring treatment literacy and awareness for people with TB; and advocacy to ensure that people affected by and with TB have access to comprehensive services, and their rights are respected, protected, and fulfilled. The support that GCTA provided to Touched by TB has helped the latter to work closely with the Ministry of Health and the National TB Programme of India and its partners and collaborative with their programmes towards the country's goal of ending TB as an epidemic by 2025.

Forging Multisectoral Partnerships With Other Actors in the TB Response

Forging partnerships is also equally important, especially in the era of Sustainable Development Goals and where multisectoral accountability is premium. These partnerships are necessary to develop and implement shared action plans to address TB. Thus, some of ACT! AP members have partnered with CCMs, HIV organizations, and other regional TB networks. GCTA's approach in social mobilization was not limited only to social mobilization at the grassroots level, but also in forging partnerships with regional networks such as with ACT! AP, as its founding member. GCTA has also reached out with regional advocacy networks in other regions, such as TB Europe Coalition (TBEC), whose main geographic coverage is Western and Eastern Europe and Central Asia. Through these partnerships, GCTA was able to ground its global advocacy agenda with regional experiences and priorities, support civil society organizations and activists in its advocacy role in the national level, and consult with peers and partners from the region as GCTA continues to advocate for an effective and responsive TB policy at the global level. This bidirectional relationship and approach is necessary to maintain alignment of priorities of civil society organizations across different levels and sectors of the TB responses.

Forging partnerships is also equally important, especially in the era of Sustainable Development Goals and where multisectoral accountability is premium.

More broadly, ACT! AP members engage in partnerships with non-community actors, such as TB programmers and ministries, that are critical to the success of achieving its national targets. In Thailand, ACT! AP member TB/HIV Research Foundation sits as a member of CCM Thailand in order to oversee TB grants in the country. As a member of the CCM, TB/HIV Research Foundation coordinates with the government, academic institutions, other civil society organizations, technical agencies, and people affected by TB groups and ensures that the priorities of civil society are reflected in upcoming Global Fund funding requests to address the TB epidemic in the country. In addition, TB/HIV

Research Foundation's role in the CCM acts as an additional layer of accountability to look at linkage and ensure consistency between Global Fund grants and other national health and development programs that may impact the TB response in the country.

Technical Support and Ensuring Financial Sustainability for Communities: The Experience of the Regional Initiative for Community Empowerment

Since December 2018, ACT! AP acted as Regional Secretariat of the "Regional Initiative for Community Empowerment" (or simply, the Regional Initiative), which ran until December 2019.²² Part of this commitment is for the Regional Secretariat to follow up with the participants on the action plan finalization, on the implementation plan, and the development and utilization of a score card by the end of the year.

This Regional Initiative shows a great example of how technical and financial support, when leveraged together, would ensure sustainability of intended initiatives that aim to improve community engagement at the country level.

The Regional Initiative aimed the following:

1. Build a strong coalition with civil society and affected communities is a major principle of the WHO End TB Strategy.
2. Engage and partners with affected communities and civil society is the key component of Pillar 2 and a key cross-cutting principle of the entire End TB Strategy and Regional Framework.
3. Reach the target of the UN HLM on TB in the region, civil society and affected community need to be empowered, capacitated, invested in and systematically engaged.

The seven countries that participated in the meeting were Cambodia, China, Lao PDR, Mongolia, Papua New Guinea, Philippines, and Viet Nam.

This Regional Initiative shows a great example of how technical and financial support, when leveraged together, would ensure sustainability of intended initiatives that aim to improve community engagement at the country level. Towards the end of 2019, six of the seven countries mentioned above have finalized their action plans with an aim to increase the engagement of TB survivors and civil society working on TB with their respective national TB programmes. The configurations of how community engagement varies from country-to-country. For instance, in Lao PDR and in Viet Nam, their definition of community engagement includes engaging with all populations and all stakeholders, including people in the military and the private sector. In Papua New Guinea and in the Philippines, the focus of engaging communities was among TB survivors and TB-affected communities, such as people living with HIV.

ACT! AP facilitated the finalization of these action plans remotely and through its ACT! AP partners in countries where ACT! AP members are present. At the same time, support was provided in the form of advising necessary advocacy steps to ensure that the national TB programme would be able to secure sustained support towards community engagement-related efforts. For instance, in Cambodia, through the successful lobbying and support of three CSOs, KHANA, the Cambodia Anti-TB Association, and the Reproductive Health Association of Cambodia (RHAC), their National Action Framework has adopted three strategic areas involving TB-affected communities and civil society in service delivery, advocacy activities and partnerships, and in demand generation. In Lao PDR, ACT! AP member, Lao People living with HIV and AIDS (LaoPHA) advocated to prioritize engaging communities and civil society in organizing orientation workshops for healthcare workers, police, and broader communities; as well as in reaching targeted populations that were not previously targeted, such as people in prison and migrant populations.

As a result, five out of seven action plans have been adopted into their national strategic plans (NSP). While some of these countries were not successful given the limitation of duration of the support from WHO WPRO, ACT! AP was able to secure spaces for TB-affected community members to engage in the NSP process. For instance, in Papua New Guinea, a TB survivor has been working as part of the country's writing team for their NSP and their Global Fund TB funding request.

CONCLUSION AND RECOMMENDATIONS

Since its inception, ACT! AP has envisioned an Asia Pacific wherein TB responses are centered around people’s needs: where issues are tackled, where rights are respected, and where TB response are sufficiently and strategically resourced - from service delivery, to research innovation, to community-led responses such as advocacy and social mobilization. By working with community-led organizations and civil society at the country level where ACT! AP is present, and capitalizing on the partnership at countries through global-national networking; as well as partnership with regional offices such as WHO WPRO, and global partnership such as the Stop TB Partnership and The Global Fund, ACT! AP was able to transform both the programmatic and policy aspect of the response. This was significantly true for the WHO-supported Regional Initiative for Community Empowerment. While only 5 of the 7 participating countries have a national ACT! AP member, the support and collaborative work that was provided by the ACT! AP Secretariat to country teams resulted in adopting the action plan into their national strategic plans, which will eventually be the basis for their Global Fund funding request for the 2020-2022 Funding Cycle. The presence of a regional secretariat to coordinate multi-country work of such kind, in partnership with a technical partner such as the WHO is an epitome of how multisectoral, multi-level partnership works in achieving the goals of the End TB Strategy.

Results of this report shows that ACT! AP members have provided some forms of support mainly to other civil society organizations in their locality. CSOs helped the establishment of community-led organizations and support groups that can augment not only the programmatic targets and the achievements of the country based on its national strategic plan on TB, but more importantly, in building the capacity of those most affected by TB, living with TB, and survived TB to participate meaningfully in the response. While a deeper analysis is further required in existing data from WHO, it shows that when community organizations participate in the TB response, it increases client referral by 27%, and support those undergoing treatment towards completion by 87%.²³

ACT! AP members, some of whom started from the HIV advocacy and response, have utilized cross-learning strategies to improve the TB response, especially among

communities that are affected by TB and HIV. While it is understandable that TB and HIV are different in terms of epidemiology, the focus towards the most affected populations and finding ways to address intersecting issues provides an opportunity to break vertical disease programming and eventually contribute to a broad concept of “people-centered” approach.

However, for these various efforts by civil society organizations and TB-affected communities to be sustained, significant amount of support and approaches are still needed. ACT! AP members who participated the survey recommended a number of ways that will sustain their work at the country and regional level:

1. **Funders, donors, and national governments must provide specific organizational support, such as in capacity development, fundraising, and communication skills.** Many funders, including funding mechanisms such as The Global Fund, are leaving implementing countries due to many reasons, mainly because of the country’s capacity to ideally domestically sustain initially supported efforts to combat the TB epidemic. However, spaces at the domestic level have not been very supportive of civil society engagement, both in policy development and TB programming. It is essential to recognize the role of TB-affected communities and civil society in several aspects of the TB response, and these will require efficient and inclusive funding.²⁴
2. **Community networks need to initiate and include areas of convergence with other health and social issues, such as migration, maternal and child health, and non-communicable diseases.** In continuously breaking the siloed approach of health programmes, including within the national TB programs, it is important to link TB programming to other national health (and non-health) programming. While this is crucial from the side of the government, community networks equally see the need to be supported in opening spaces for dialogue with other health and non-health social development agendas, as well as with other inter-related areas of work that impacts the lives of people with and affected by TB.
3. **Support ACT! AP’s need to expand its geographic coverage to cover countries that have not yet previously covered, increase ACT! AP membership.** ACT! AP, as a recognized regional coalition of people with affected by and living with TB, including TB survivors and civil society, needs to expand its

geographic coverage and programmatic coverage in order to scale up and step up its TB response. This is, of course, contingent to the funding and organizational support that ACT! AP receives.

4. **Civil society organizations must be encouraged to engage with and invite younger community members to sustain the TB movement.** Relating to the commitment of young people to be active in ending the TB epidemic, civil society organizations must equally recognize the role of young people in the area of advocacy, education, and research and innovation to address TB.²⁵ Thus, it is important that as civil society engage with TB-affected communities, that specific programming and support is provided to its younger peers in order to sustain the TB community movement.
5. **Strengthen national Stop TB partnerships.** Initiatives such as the Regional Initiative for Community Empowerment have been successful because of the existence of country teams composed of government agencies, TB-affected communities, and technical partners. At the same time, national Stop TB partnerships have been established to facilitate multisectoral collaboration at the country level. However, in some countries, national Stop TB Partnerships are either inactive or do not have active civil society participation. Stop TB Partnership, WHO, and The Global Fund must continue to support national-level partnerships so that these spaces for collaboration remain open.
6. **Leverage ACT! AP in sharing country learnings and expertise; sustain networking.** ACT! AP, as the first and only regional coalition of TB activists and civil society working with TB, have been working with a minimal funding support. Despite this, the work that the coalition has done at the regional and national level in Asia and the Pacific is proof of the critical presence and existence of such regional coalition in providing technical support, facilitating partnership, couring funding to civil society organizations working on TB, and in mobilizing people with and affected by TB. This report shows how ACT! AP Secretariat and members have worked with minimal support since 2017, and these good practices, such as this report, should be sustained and documented.

ENDNOTES

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5. <https://stoptbpartnershiponeimpact.org/>.
6. https://apcaso.org/apcrg/sdm_downloads/icaso-apcrg-documentation-report-lessons-from-crg-ta/.
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12. <https://apcaso.org/global-fund-new-funding-model-civil-society-and-community-experience-in-4-countries-of-asia/>.
13. <https://apcaso.org/apcrg/launch-of-the-global-fund-realities-on-the-ground-report/>.
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15. <https://www.unaids.org/en/resources/infographics/tuberculosis-and-hiv>.
16. <http://bell.org.vn/News-Events/VN-Civil-Partnership-Platform-on-AIDS-held-in-Da-Nang/5990.vgp>.
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APPENDIX 1: ACT! AP MEMBERS (as of MARCH 2020)

ORGANIZATIONS

ASIA PACIFIC

APCASO
 Asian Network of People who Used Drugs (ANPUD),
 Asia Pacific Network of People Living with HIV (APN+)
 Asia Pacific Transgender Network (APTN)
 Burnet Institute
 International Community of Women Living with HIV
 – Asia Pacific (ICW-AP)

GLOBAL

Global Coalition of TB Activists (GCTA)

AUSTRALIA

RESULTS

CAMBODIA

CPN Plus

KHANA

HEAD

INDONESIA

MAP Internasional
 Spiritia Foundation

LAO PDR

Lao People living with HIV/AIDS (Lao PHA)

PAKISTAN

APLHIV

PHILIPPINES

Samahan ng Lusog Baga

THAILAND

TB/HIV Research Foundation
 World Vision

VIET NAM

SCDI

INDIVIDUALS

Ketho Angami, India
 Lusiana Aprilawati, Indonesia
 Alfred Tonganibeia, Kiribati
 Norlela Binti Mokhtar, Indonesia
 Khin Swe Win, Myanmar
 Maura Mea Elaripe
 Surasit Bupachat, Thailand

STEERING COMMITTEE MEMBERS

Choub Sok Chamreun (KHANA), Co-chair
 Elvi Siahaan (MAP Internasional), Co-chair
 RD Marte, APCASO
 Blessina Kumar, GCTA
 Daniel Marguari, Spiritia
 Maura Mea Elaripe
 Jeffry Acaba, APCASO, Coordinator

APPENDIX 2: ONLINE SURVEY QUESTIONNAIRE

TB COMMUNITY STAKEHOLDER MAPPING SURVEY (2017 - PRESENT)

APCASO, as ACT! AP coordinator, is currently doing a survey to map out networks and organizations of civil society working on TB, TB-affected community stakeholders, TB survivor groups, and support groups for people with TB in Asia and the Pacific.

Specifically, this survey aims to:

1. Map out TB survivor groups, TB support groups, NGOs, CBOs, civil society, key populations, or TB-affected community organizations working on TB that you have partnered or supported in forming and/or strengthening since 2017;
2. Identify the type of support (technical, financial, other forms thereof) that you have received from APCASO and/or ACT! AP in relation to engaging with these identified partners; and
3. Identify potential support needs in enhancing or strengthening your current engagement with the identified partner/ stakeholder.

This survey hopes to build a case of the contribution of ACT! AP and APCASO in the TB response, particularly with regards to community mobilization and engagement.

INSTRUCTIONS

1. Use only one form per organization or group that you have engaged.
2. Should you have more than one organization that you have engaged since 2017, please use another form.
3. Feel free to send in as many forms as possible.
4. Fields with * are required.

1. EMAIL ADDRESS* _____

2. NAME* _____

3. ORGANIZATION* _____

4. COUNTRY* _____

5. CONTACT EMAIL* _____

6. NAME OF ORGANIZATION YOU HAD ENGAGED WITH OR HELPED MOBILIZE SINCE JANUARY 20

7. SHORT DESCRIPTION OF THE ORGANIZATION (Including when the organization was established)



ACT!

ACTIVISTS' COALITION ON TB
ASIA-PACIFIC

The Activists' Coalition on TB – Asia Pacific (ACT! AP) is Asia-Pacific's first and only regional coalition of TB activists. Emerged from a regional TB activists' meeting in 2016, ACT! AP is committed to give TB the political attention it deserves by presenting an alternative model of response that is person-centered, human rights-based, and reflective of the needs of people with and affected by TB. ACT! AP is currently being convened by APCASO.

