2021

MEANINGFUL ENGAGEMENT OF THE COMMUNITIES OF PEOPLE AFFECTED BY TUBERCULOSIS IN THE DEVELOPMENT OF NATIONAL STRATEGIC PLANS ON TUBERCULOSIS

Research report

TBPEOPLE

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LIST OF ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
CCM	Country coordinating mechanism
CSO	Civil society organization
GFATM	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater involvement of people living with HIV/AIDS
HIV	Human immunodeficiency virus
LGBT	Lesbian, gay, bisexual, transgender
NGO	Non-governmental organization
NSP	National Strategic Plan
PLHIV	People living with HIV
RCM	Regional coordinating mechanism
TB	Tuberculosis
WHO	World Health Organization

GLOSSARY OF TERMS

Term	Definition
Civil society	The aggregate of non-governmental organizations and institutions that manifest interests and will of citizens. Civil society can be understood as the “third sector” of society, distinct from government and business.
Community	“Community” is a widely used term that has no single or fixed definition. Broadly speaking, communities are formed by people who are connected to each other in distinct and varied ways. “Affected community” a community that is affected by a disease, epidemic or pandemic. According to the Global Plan to End TB 2018-2022, “TB affected community” or “community of people affected by TB” refers to any person with TB or who has had TB, as well as their family members, social contacts and caregivers. In addition, “TB affected community” refers to TB key populations (see below). The Global Fund uses the term “communities” to describe people who are affected by HIV, TB and malaria. This includes “key and vulnerable populations”
Engagement and participation	These two terms are key for this study. They are partly synonymic, but they are different in that engagement is a process resulting in participation. Participation – and meaningful participation – means a full opportunity of community and NGO representatives to contribute to a certain process (e.g., NSP development)
Key population	Key populations are groups of people, who are socially vulnerable, lack adequate access to healthcare or are at-risk of getting TB infection and disease. Key populations are different in each country and include people at higher risk of TB disease due to the conditions they live and work in, people with limited access to quality health services and people who are at risk of TB due to biological or behavioral factors
LGBT	The term is used to emphasize diversity of sexuality and gender identity and is used to describe homosexual, bisexual and transgender persons

Membership-based organization	A non-governmental organization (see below), whether officially registered or not, where members elect their leaders, and which strives to operate based on the principles of democracy, in accordance with which elected officials are accountable to the members of the organization
Non-governmental organization	Non-governmental organization (or NGO) is a non-profit organization that operates independently of any government and is typically one whose purpose is to address a social or political issue
People affected by TB	In this report, *people affected by TB* means people, who have TB disease or had TB disease in the past, as well as their relatives, friends and other close ones
TBPEOPLE	The global network of people affected by TB

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1. INTRODUCTION

1.1. Background

During the 1994 Paris AIDS Summit 42 countries declared the 'Greater Involvement of People living with HIV/AIDS (GIPA)' a cornerstone of the HIV response. Since then, GIPA has catalysed a more nuanced understanding of how people openly living with HIV can and should influence the AIDS response. From facilitating the involvement of people living with HIV (PLHIV) in developing national strategic plans to influencing the global AIDS architecture of the Global Fund and shaping HIV service delivery and advocacy, GIPA has – in ways large and small – contributed to addressing stigma and discrimination.[1] In TB, the concept of meaningful involvement of the community started to emerge only with the establishment of the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) and the introduction of Country Coordinating Mechanisms (CCMs).

The concept of meaningful engagement of people affected by TB later evolved with the adoption of the Funding Model and introduction of the requirement to have country dialogue – a participatory process of development of country applications. Finally, in its Sustainability, Transition and Co-financing Policy, the GFATM speaks about an "inclusive multi-stakeholder process" of development of National Health and Disease-Specific Strategic Plans (NSPs).[2] While CCM and country dialogue may serve as a good proxy for assessment of community engagement in national TB-related decision-making, it is more comprehensively and accurately reflected in the way they are engaged in the development of NSPs. However, so far there have not been any systemic attempts to assess community engagement in this process.

To address this gap, TBPEOPLE, the global network of people affected by TB, with financial support of the GFATM conducted a study on engagement of the communities of people affected by TB in the processes of NSP development as an indicator of broader community engagement in national decision- and policy-making processes.

The study was designed to show how organizations and networks of people affected by TB, as well as organizations and networks of TB key populations, are engaged in NSP development in their countries.

All collected responses and comments were analyzed and presented in this document. They can be used for the development of specific recommendations on how to improve the current situation in community engagement in decision-making processes in countries.

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[1] The greater and more meaningful engagement of people living with HIV: Making the case for the HIV biomedical industry. Available at: https://www.iasociety.org/Web/WebContent/File/ILF__GIPA_survey__Report_2017.pdf
[2] The Global Fund Sustainability, Transition and Co-Financing Policy, GF/B35/04 – Revision 1. Available at: https://www.theglobalfund.org/media/4221/bm35_04-sustainabilitytransitionandcofinancing_policy_en.pdf.

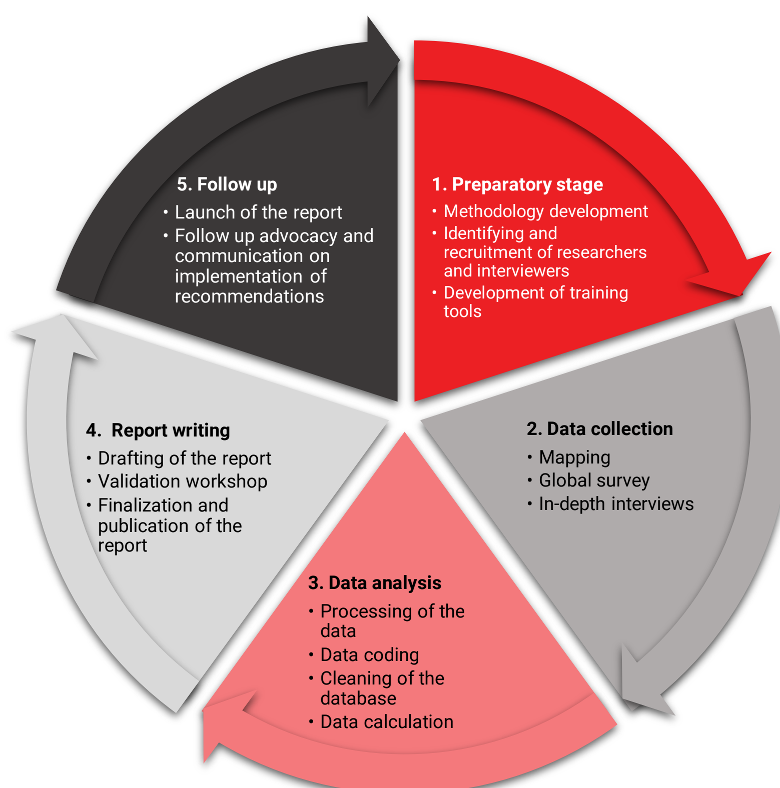
1.2. Methodology

The goal of this study was to identify the current state of and gaps in engagement of TB affected communities in TB-related decision-making and planning at the country level. To this end, the study had the following objectives:

1. To assess extent to which TB affected communities are engaged in process of development of NSPs;
2. To identify gaps, challenges and best practices in engagement of TB affected communities in the development of NSPs;
3. Based on the findings, to develop a set of global recommendations for the CRG and Global Fund, CCMs, technical partners, as well as other stakeholders engaged in TB response at the global, regional and national levels.

The study was held at the global level with a primary focus on high TB burden countries, which had or were developing TB-specific NSP or broader health NSP with a focus on TB. The study was carried out in several stages: preparation; data collection; data analysis; report writing. As a follow up, it is expected to conduct advocacy aimed at implementation of the study recommendations. Stages of the study are visualized on Figure 1 below.

Figure 1. Key stages of the study



At the first stage, it was decided to use combined data collection methodology, which envisaged collection of quantitative data using a standardized online questionnaire on the Surveymonkey platform[3]. The questionnaire included the following blocks: personal information

[3] https://www.surveymonkey.com/

of the respondent; profile of the respondent's organization; acting TB NSP in the respondent's country; new TB NSP.

At the second stage, mapping was done. The purpose of the exercise was to identify high-burden countries, which had or were developing NSPs specifically on TB or broader health. During the mapping, researchers created a database of community networks in TB high burden countries. Based on the outcomes of the mapping, the identified community organizations representing people affected by TB were invited to take part in the survey.

The survey was designed to collect information about representation of TB affected communities in the NSP development process. The link to the online survey and the questionnaire were disseminated among the community networks identified during the mapping.

The survey was aimed to: establish whether and to what extent representatives of the community organizations were satisfied with their participation in and contribution to the development of NSP; collect data on gaps and barriers to effective engagement; and obtain recommendations on overcoming existing barriers and problems.

To collect qualitative data, in-depth interviews with representatives of organizations representing TB affected communities were organized. The goal of the qualitative component of the study was to obtain additional information, which would supplement quantitative data from the survey.

The collected information was processed and analyzed, and results were presented in this report. Its findings can be used to inform global advocacy and other efforts aimed at removing gaps and barriers that prevent community organizations from participation in local and national TB responses.

1.3. Limitations

115 organizations, primarily from the African and European regions, took part in the study. In the future, if a follow up study is carried out to assess the changes in community engagement in TB responses, efforts should be made to ensure more geographically balanced coverage.

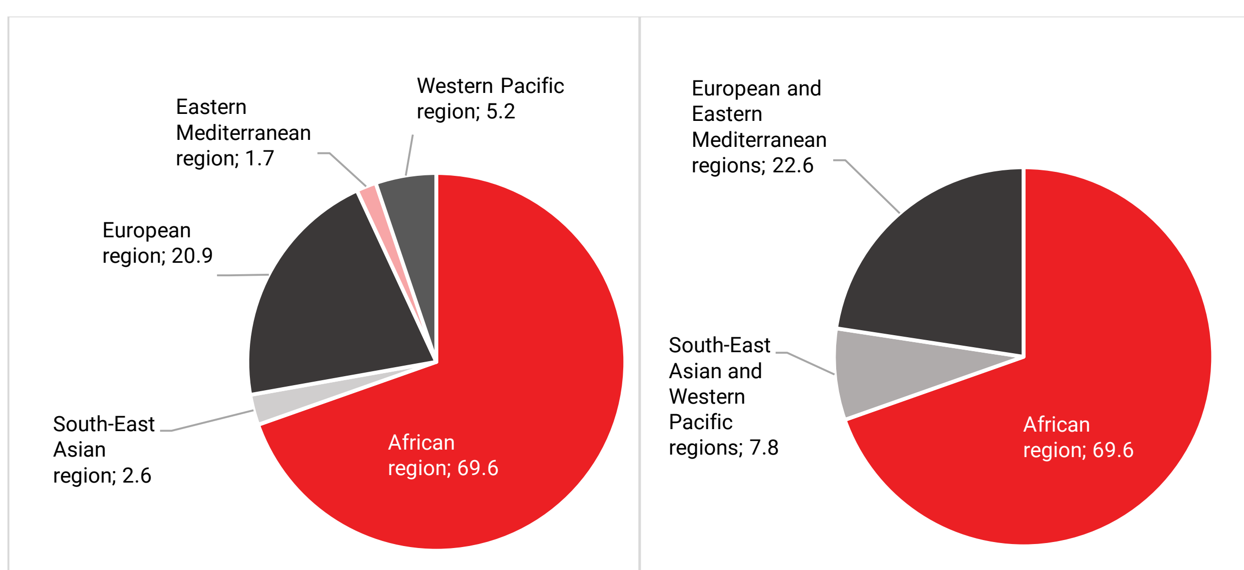
Besides, given the volume of the questionnaire (41 questions), when conducting similar or follow up studies it is important to envisage incentives for the respondents to complete the survey.

2. PROFILE OF PARTICIPATING ORGANIZATIONS

2.1. Regions represented and geographic coverage

The research used the WHO regional split, thus assigning all respondents to one of six regions: African region; region of the Americas; South-East Asian region; European region; Eastern Mediterranean region; and Western Pacific region. Organizations from five of these regions participated in the study, though their distribution by region was uneven. Overwhelming majority of respondents were organizations from the African (70%) and European (21%) regions. The coverage of organizations from South-East Asia and Eastern Mediterranean was very low (2-3%), and so was the share of respondents from the Western Pacific region. No eligible organization from the region of the Americas participated in the survey. Details of geographic coverage are presented on Figure 2 below.

Figure 2. Distribution of survey respondents by regions, %



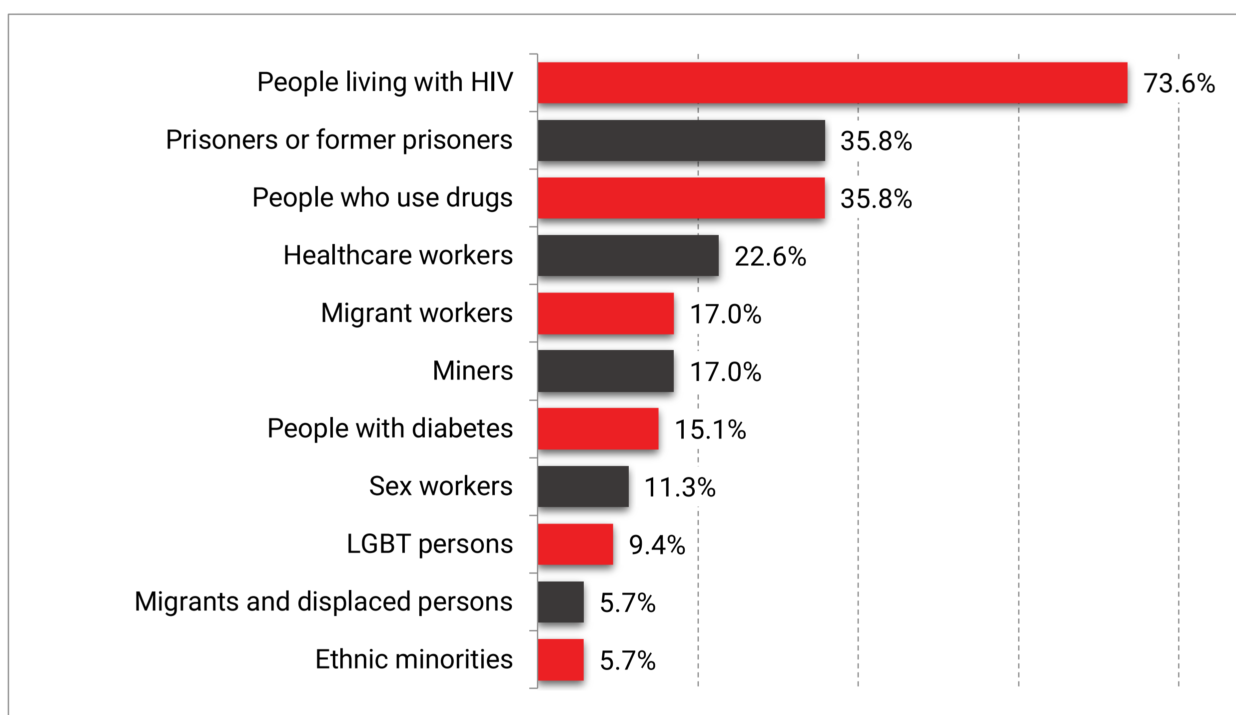
For the convenience of further analysis, regions were grouped into three macro-regions: i) African region (slightly under 70% of sample size), ii) South-East Asia and Pacific regions (8%), and ii) European and Eastern Mediterranean regions (about 23%). The split is presented in Figure 2 above.

In the African region, respondents are based in Anglophone and Francophone countries. In Anglophone Africa, NGOs from the following countries participated in the study: Botswana, Ethiopia, Ghana, Liberia, Malawi, Nigeria, Rwanda, South Africa, Sierra-Leone, South Sudan, Tanzania, Zambia, and Zimbabwe. From 17 Francophone countries, NGOs in Western, Central and Northern Africa are represented. These include respondents from Burkina-Faso (20%) in Western Africa, Cameroon (19%) in Central Africa, Maroc and Tunisia (2%) in Northern Africa. In Asia-Pacific region, respondents include community organizations from Cambodia, India, Indonesia, Lao, and Philippines. In European region, organizations from Azerbaijan, Belarus, Estonia, Kazakhstan, Kyrgyzstan, Moldova, Romania, Russia, Serbia, Tajikistan, Ukraine, and Uzbekistan participated in the study.

2.2. Populations represented and thematic scope

More than half of respondents were organizations representing people affected by TB (53.9%); the remaining 46.1% were organizations representing TB key affected populations. Of these latter, almost three-fourths (73%) represented people living with HIV. Next were people who use drugs and current and former prisoners (36% each), health workers (23%), migrant workers (17%) and miners (17%).

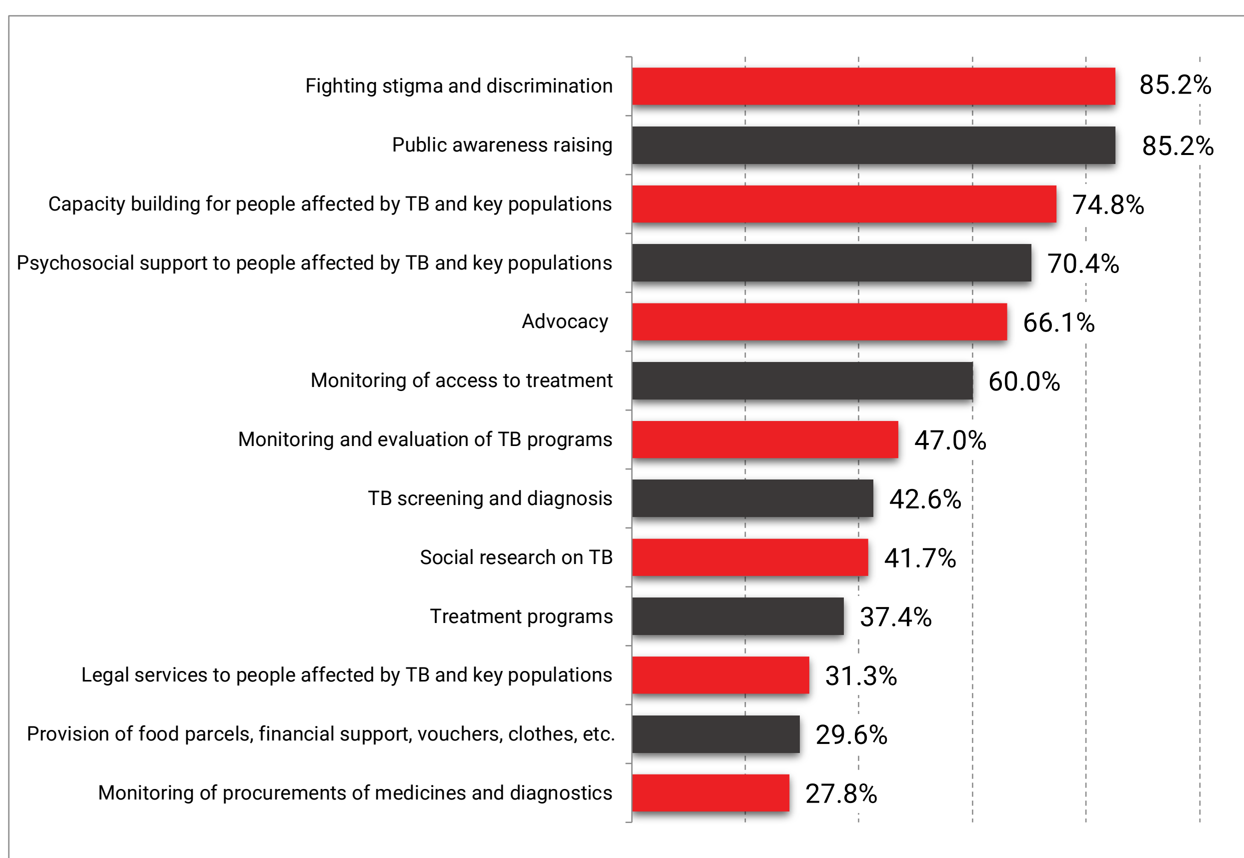
Figure 3. Distribution of responses to the question "Which key population does your organization represent?"



The sample size almost equally comprised of organizations for which TB is the main thematic area and those for which TB is one of priority areas. Organizations not working in TB did not participate in the survey. Organization's mandate is closely connected to the population the organization represents. Thematic scope of the organization is significantly connected with the population it represents: for 69% of organizations representing people affected by TB, tuberculosis is the main thematic area, while for 79% of organizations representing key affected populations TB is one of thematic priorities.

In context of key areas of their TB-related work, respondents most frequently mentioned fighting stigma and discrimination, as well as public awareness raising (both options were marked in 85% of responses). Other popular responses included capacity building for people affected by TB and key populations (75%), psychosocial support (70%), advocacy (66%) and monitoring of access to treatment (60%). Other options were marked by less than half of respondents, though, notably, none of the options was mentioned by less than 30% of respondents.

Figure 4. Distribution of responses to the question "In what areas related to TB does your organization work?"



The work of absolute majority of respondents representing people affected by TB includes raising public awareness (90%), fighting stigma and discrimination (86%) and capacity building of people affected by TB and key populations (79%). For organizations representing key affected populations, the most popular areas of work are fighting stigma and discrimination (85%), raising public awareness (79%), capacity building and psychosocial support for people affected by TB and key populations (70% each).

2.3. Membership in coordinating mechanisms

About two-thirds of respondents were members of either country (CCM) or regional (i.e., multi-country) coordinating mechanism (RCM), and around one-third of respondents were not CCM/RCM members.

Table 1. Distribution of responses to the question "Is your organization represented on country or regional coordinating mechanism on TB?"

	No.	%
Not a CCM/RCM member	39	33.9
Member of CCM/RCM	76	66.1
Total	115	100.0

An overwhelming majority of respondents represented on coordinating mechanisms (88%) were members of CCM, 21% were members of RCM.

Table 2. Distribution of responses to the question "Is your organization represented on country or regional coordinating mechanism on TB?"

	%
Yes, a member of country coordinating mechanism (CCM)	88.0%
Yes, a member of regional coordinating mechanism (RCM)	21.3%

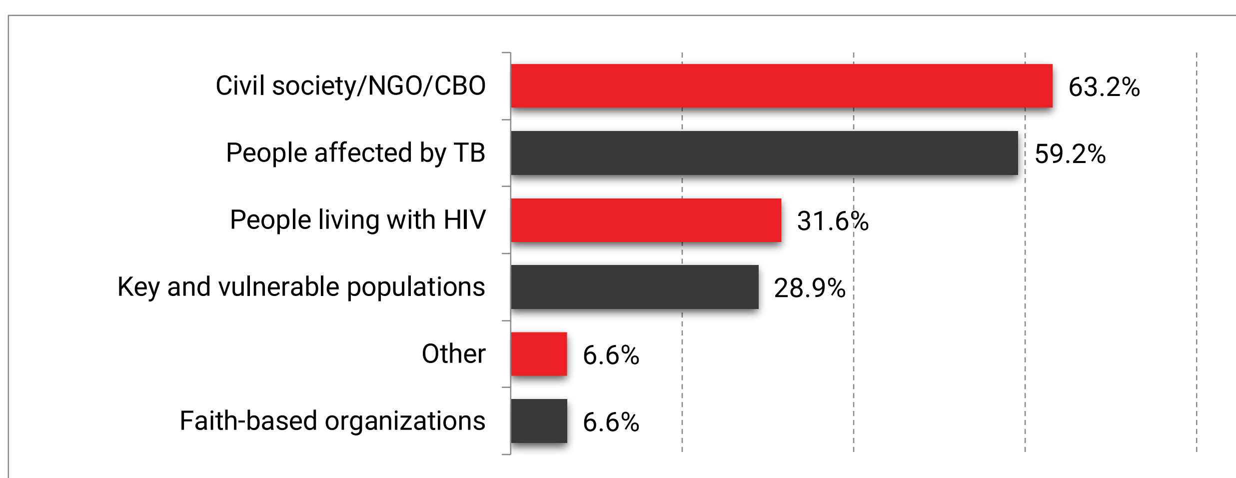
Organizations, for which TB was their main thematic area, were more represented on coordinating mechanisms (78%). Still, more than half of organizations, for which TB was one of thematic areas, had a seat in a CCM, and 21% were members of an RCM.

Table 3. Distribution of responses to the question "Is your organization represented on country or regional coordinating mechanism on TB?" relative to the thematic scope of the organization

	Does the mission/thematic scope of your organization include TB?		Total
	TB is the organization's main thematic area	TB is one of organization's thematic areas	
Not a CCM/RCM member	22.2%	44.3%	33.9%
CCM or RCM member	77.8%	55.7%	66.1%

Most frequent responses to the question on which constituency or constituencies the organization represents on CCMs or other coordinating mechanisms, were "Civil society/NGO/CBO" (63%) and "People affected by TB" (59%). Responses "People living with HIV" and "Key and vulnerable populations" were twice less frequent (31% and 29% respectively). "Faith-based organizations" and "Other" were least frequent responses (7% each).

Figure 5. Distribution of responses to the question "Which constituency or constituencies does your organization represent on the CCM or other coordinating mechanisms on TB?"



Generally, organizations of people affected by TB represent either their constituency (73%) or civil society/NGO/CBO constituency (64%) on CCMs or other TB coordinating mechanisms; while other constituencies were mentioned, too, they were rare (5-14%). There was significantly more diversity in constituencies represented on coordinating mechanisms by organizations of key populations. Civil society/NGO/CBO was the most frequent answer (63%), followed by people living with HIV (56%) and key and vulnerable populations (53%). 41% of such organizations also represent people affected by TB.

2.4. Participation in other national TB-related forums

Respondents were requested to indicate other national TB-related fora and processes in which they are engaged. Four answer options were offered: national coalition on TB, national Stop TB Partnership, civil society forum on TB, and country dialogue for the Global Fund proposal development. All four options were mentioned by a relatively similar number of respondents – from 45 to 57%. Significantly less frequently respondents chose the "Other" option (14%).

The most popular fora for both organizations of people affected by TB, and those of key populations was the country dialogue for Global Fund proposal development (59% and 55% respectively), civil society forum on TB (52% and 53%), and national Stop TB Partnership (45% and 43%). At the same time, a lot of organizations of people affected by TB (58%) indicated their participation in a national TB coalition; for respondents representing key populations, this answer was considerably less popular (34%).

Table 4. Distribution of responses to the question "Does your organization participate in other national TB related forums or processes?" relative to the population the organization represents

	Which group does your organization represent?	
	People affected by TB	TB key population
National coalition on TB	57.9%	34.1%
National Stop TB Partnership	45.6%	43.2%
Civil society forum on TB	52.6%	52.3%
Country dialogue for Global Fund proposal development	59.6%	54.5%
Other	12.3%	15.9%

Organizations, for which TB is the main thematic area, are more or less similarly involved in all fora and processes listed in the question (51-55%), although Country dialogue for Global Fund proposal development was mentioned slightly more frequently. The organizations, for which TB is one of thematic areas, more frequently mentioned the country dialogue (60%) and civil society forum on TB (54%), but their engagement in the national TB coalition or national Stop TB partnership is less frequent (40-44%).

Table 5. Distribution of responses to the question "Does your organization participate in other national TB related forums or processes?" relative to the thematic scope of the organization

	Does the mission/thematic scope of your organization include TB?	
	TB is the organization's main thematic area	TB is one of organization's thematic areas
National coalition on TB	51.0%	44.2%
National Stop TB Partnership	49.0%	40.4%
Civil society forum on TB	51.0%	53.8%
Country dialogue for Global Fund proposal development	55.1%	59.6%
Other	12.2%	15.4%

2.5. Geographic coverage

A majority of respondents are organizations working at the national level (covering the entire country) – 69% of respondents; 55% of respondents were involved at the local/grassroots level. Working at the level of a province (indicated by 39% of respondents) was relatively less frequent. Even less respondents work at the level of multiple countries, with 18% of respondents working regionally, and 4% internationally.

Table 6. Distribution of responses to the question "Geographic coverage: at what levels does your organization work?"

Answer options	%
International	4.3
Regional	18.3
National/country level	68.7
Provincial	39.1
Local/grassroots	54.8

As to the level where respondents work most, national/country level was indicated most frequently (52%), followed by local/grassroot level – i.e., below provincial level (32%). 11% of respondents work at the level of a province or a similar territorial unit, and only 4% of organizations worked at multi-country level, all of them covering countries of one geographic region.

Table 7. Distribution of responses to the question "Geographic coverage: at what level does your organization work most?"

	No.	%
Regional	5	4.3
National/country level	60	52.2
Provincial or local/grassroots	50	43.5
Total	115	100.0

For convenience, organizations' geographic coverage was grouped into three larger categories: i) multi-country, including regional and international levels; ii) national/country level, and iii) sub-national level, which included local/grassroots and provincial levels. This latter group represented 44% of the entire sample size.

All respondents working mostly at the multi-country level, are members of country coordinating mechanisms (CCMs), and none are part of regional coordinating mechanisms (RCMs). Membership in CCMs is also significantly more common for organizations working at the national and sub-national levels (77-93%) then membership on RCMs (18-29%).

Table 8. Distribution of responses to the question "Geographic coverage: at what level does your organization work most?" relative to CCM/RCM membership

	Is your organization represented on country or regional coordinating mechanism?	
	CCM member	RCM member
Multi-country (regional or international)	100.0%	0.0%
National	93.2%	18.2%
Sub-national (provincial or local/grassroots)	77.8%	29.6%

It should be noted that significant level of responses indicating engagement of sub-national organizations in RCMs could be attributed to respondents mistaking RCMs for provincial coordinating mechanisms, present in some countries, which are also sometimes referred to as "regional coordinating mechanisms". Therefore, to avoid confusion, when analyzing responses relative to representation on coordinating mechanisms, respondents are grouped into two distinct categories: those which are part of sub-national, country or multi-country coordinating mechanism, and those which are not.

Only 7% of organizations represented on coordinating mechanisms mostly work internationally; a majority (57%) are organizations working within the limits of one country. Most respondents not being members of coordinating mechanisms (57%) operate mostly at the local/grassroots level.

Table 9. Distribution of responses to the question "Geographic coverage: at what level does your organization work most?" relative to CCM/RCM membership

	Is your organization represented on country or regional coordinating mechanism?		Total
	Not a CCM/RCM member	CCM or RCM member	
Multi-country (regional or international)	0.0%	6.6%	4.3%
National	43.6%	56.6%	52.2%
Sub-national (provincial or local/grassroots)	56.4%	36.8%	43.5%

2.6. Membership profile

An overwhelming majority of respondents (82%) were membership-based organizations. Notably, membership-based organizations were more common among organizations representing key populations (91%) than among those representing people affected by TB (75%).

Table 10. Distribution of responses to the question “Is your organization membership based?” relative to the population represented by the organization

	Which group does your organization represent?		Total
	People affected by TB	Key population	
Membership based	75.0%	90.6%	82.3%
Non-membership based	25.0%	5.7%	15.9%
Other	0.0%	3.8%	1.8%

All non-membership-based organizations mostly work within a country. Organizations with a special governance system (i.e., neither membership-based nor non-membership-based) all mostly work at the country or multi-country levels.

Table 11. Distribution of responses to the question “Is your organization membership based?” relative to the organization’s geographic coverage

	Geographic coverage: at what level does your organization work most?			Total
	Multi-country	National	Sub-national	
Membership based	75.0%	78.0%	88.0%	82.3%
Non-membership based	0.0%	20.3%	12.0%	15.9%
Other	25.0%	1.7%	0.0%	1.8%

Approximately similar shares of respondents (42-44%) have individual membership (open to individuals only) and mixed membership (open to both individuals and organizations). Only a fraction of membership-based organizations (14%) had institutional membership.

Table 12. Distribution of responses to the question “What type of membership does your organization have?”

	No.	%
Individual membership: only individuals can be members of our organization	38	41.8
Institutional membership: only organizations/groups/networks can be members of our organization	13	14.3
Mixed membership: both individuals and organizations can be members of our organization	40	44.0
Total number of responses	91	100.0

The number of members in organizations, which took part in the survey, ranged from four to the maximum of 16,000. Median size of the participating organizations is fifty members. Every fourth organization (26%) had less than 20 members, and another quarter were 20 to 50 members large. Organizations with 50-100 members and 100-500 members represented 18% and 21% of the sample; only 9% of organizations had more than 500 members.

2.7. Registration status

Almost all participating NGOs (97%) are duly registered legal entities. However, 23 respondents did not answer the question on registration status. All respondents without an official status are organizations representing people affected by TB (which represents 6.5% of all such organizations in the sample). Thus, all non-registered organizations have TB as their main area of focus (7% of all such organizations in the sample).

Table 13. Distribution of responses to the question “Is your organization officially registered?” relative to the population the organization represents

	Which group does your organization represent?		Total
	People affected by TB	Key population	
Registered	93.5%	100.0%	96.7%
Not registered	6.5%	0.0%	3.3%

Importantly, all respondents with membership on coordinating mechanisms are officially registered.

Table 14. Distribution of responses to the question “Is your organization officially registered?” relative to the organization’s CCM/RCM membership

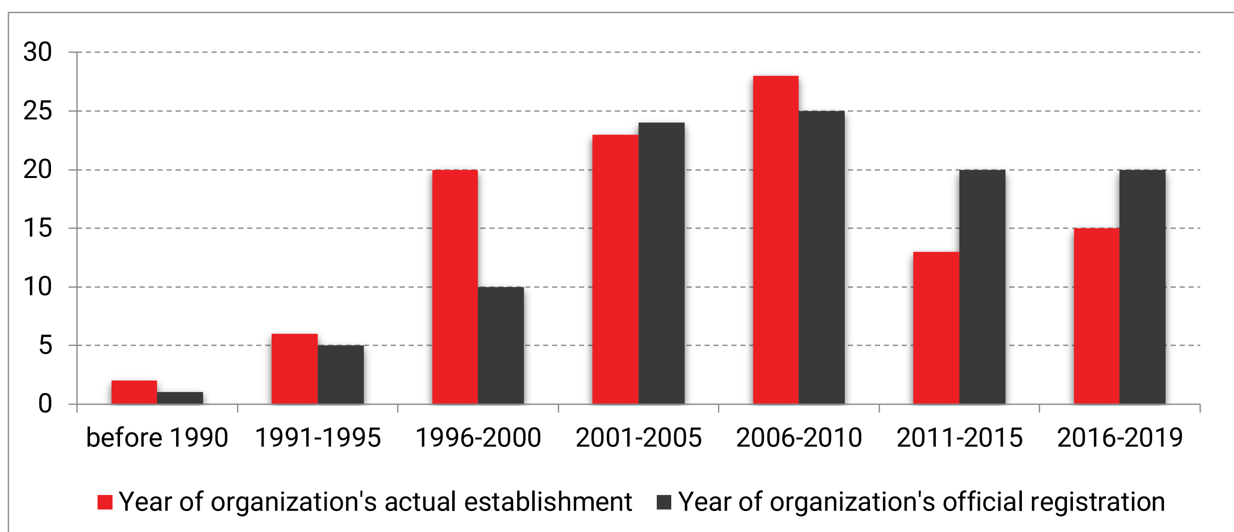
	Is your organization represented on country or regional coordinating mechanism on TB?		Total
	Not a CCM/RCM member	CCM or RCM member	
Registered	90.0%	100.0%	96.7%
Not registered	10.0%	0.0%	3.3%

2.8. Year of establishment

Globally, not-for-profit organizations representing various population groups are often first formed and operate as initiative groups. In practice, it means that such organizations have two dates of establishment: the date of the creation of an initiative group, and the date of the official registration and obtaining appropriate documents from registering authorities.

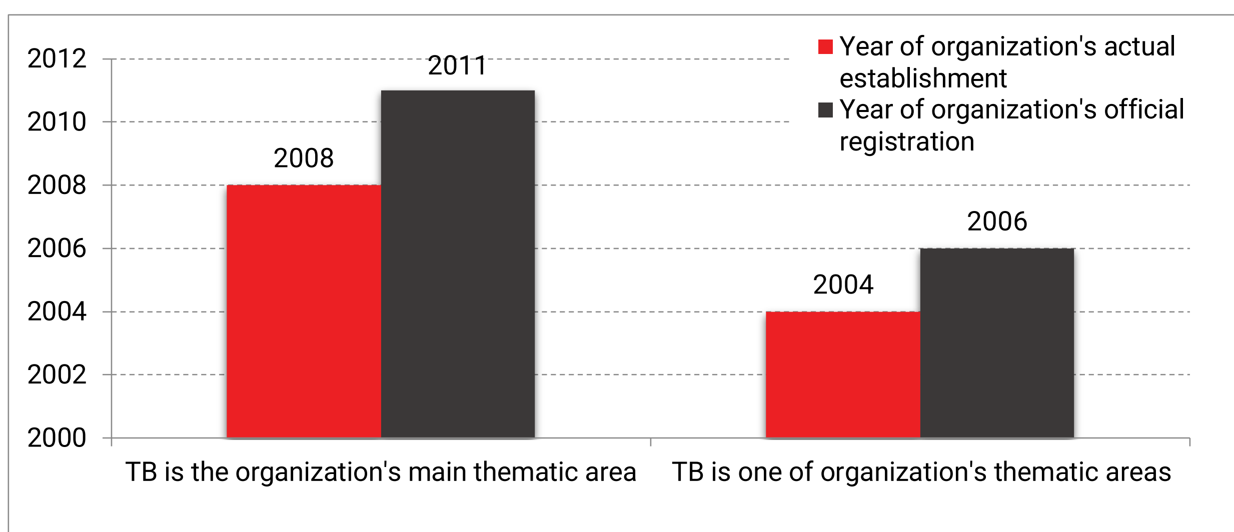
The earliest date of creation among the respondents was 1978; the earliest date of registration – 1980. The “youngest” organizations were created and registered in 2019. The average year of creation was 2006, and the average year of official registration was 2007-2008.

Figure 6. Comparative diagram showing the years of establishment and registration of organizations, which participated in the survey



Before 1996, creation and registration of TB-related community organizations was a rare phenomenon. In the second half of the 1990s, there was an increase in creation of such NGOs, which considerably outpaced their registration. In 2000-2010, the rate of creation and registration of new organizations both went up at relatively similar pace. From 2010 onward, there was a decline in establishment of new organizations, with the rate of creation of new initiative groups being lower than the rate of official registration of NGOs.

Figure 7. Comparative diagram showing the years of establishment and registration of organizations, which participated in the survey, relative to whether TB is the main or one of thematic areas; median values



On the average, organizations, for which TB is the main thematic area, were created and registered slightly later (the median being 2008 and 2010 respectively) than the organizations, for which TB is one of thematic areas (the median being 2004 and 2006 respectively).

Analysis of the two above trends reflects the global situation in community mobilization. 1990s saw a dramatic spread of the HIV epidemic in the world, which urged community responses in

the most severely affected regions. With the support from UN agencies and donors, and later the Global Fund, these initiatives were institutionalized in the 2000s. At the same time, in spite of a growing TB epidemic, including the spread of DR-TB, community response to TB remained limited due to scarce support and investments into community mobilization and strengthening. Funding for community-led responses to TB started to gradually increase after 2010, which contributed to the growing number of TB affected community groups and organizations emerging between 2010 and 2019. This highlights the importance of investments into TB community mobilization and strengthening efforts.

3. ENGAGEMENT IN THE DEVELOPMENT OF NATIONAL STRATEGIC PLANS ON TB

3.1. Availability of a current NSP on TB

Many countries – especially those with a high TB burden – adopt national strategic plans (NSPs) on TB. According to WHO, NSP for TB prevention, care and control is a fundamental component of National TB Programme vision and constitutes the backbone to efficiently implement TB policies in a country, over a period of time. The NSP is the most important strategic document guiding national health authorities in managing and implementing appropriate TB activities, while being part of a collective movement towards ending TB, and the overall global health-related SDGs.

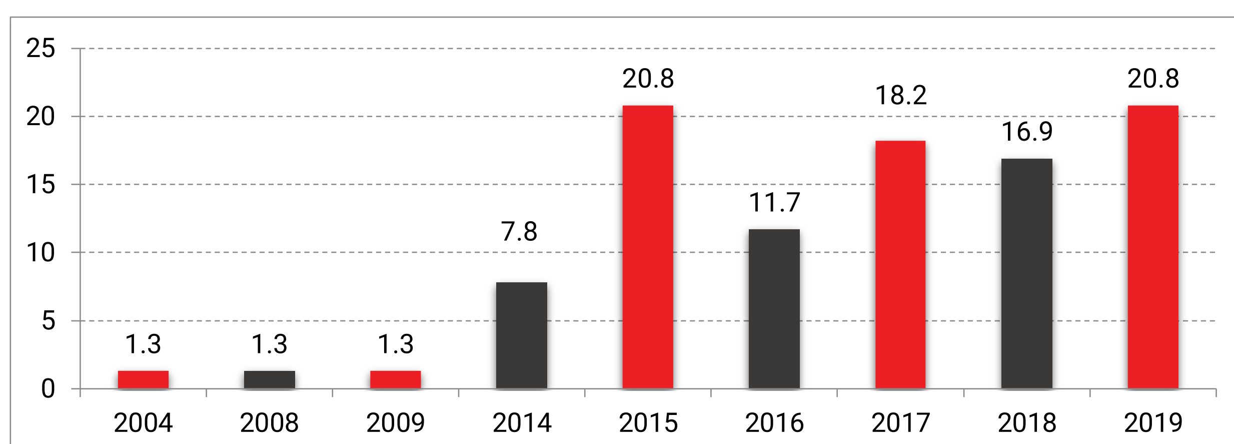
An overwhelming majority of respondents (77%) indicated that there is a current NSP on TB in their country; another 11% indicated that TB is covered by a broader NSP. Only 5% of respondents reported lack of NSP on TB in their country.

Table 15. Distribution of responses to the question “Is there an acting national strategic plan (NSP) on TB in your country, including if TB is part of a broader NSP (on several diseases, health, etc.)?”

	%
No, there is no acting NSP covering TB at all	4.7
Yes, there is an acting NSP specifically on TB	77.4
There is no NSP specifically on TB, but there is a broad acting NSP that includes TB	11.3
I don’t know	6.6
Total	100.0

Except for three instances, current NSPs covered period starting no later than 2014-2015. Notably, there was a similar number of responses indicating that the first year of the NSP was 2015, 2017, 2018 and 2019, ranging between 17% and 20%.

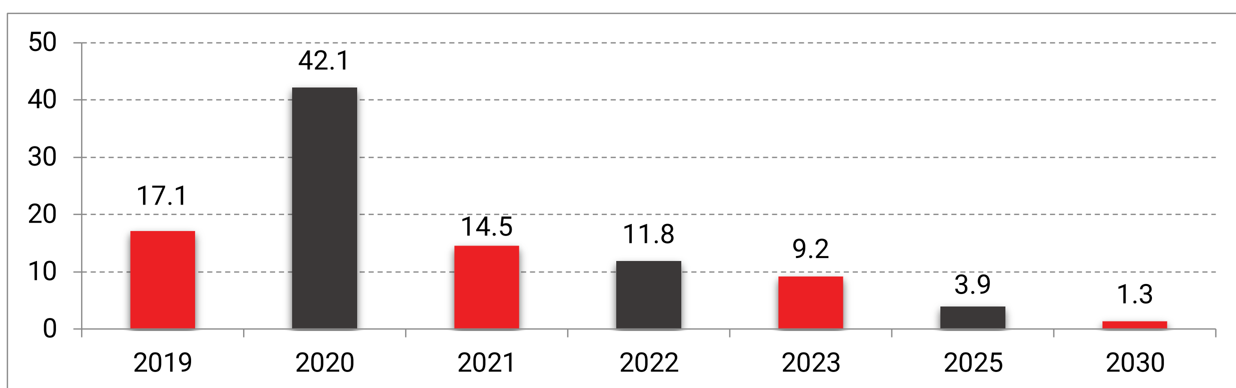
Figure 8. The first year of the acting NSP’s timeframe



Most often (in 42% of responses), respondents indicated that the existing NSP is coming to end in 2020; combined with the responses that the NSP was coming to end in 2019, the share of expiring NSPs was therefore more than half. Another 15% of respondents indicated 2021 as the

end year of the current NSP. Only a quarter of respondents reported that the current NSP is expiring at a later date before 2025, and in one instance the NSP was said to be covering the period till 2030.

Figure 9. The last year of the acting NSP's timeframe



3.2. Participation in the NSP development

> *"Unfortunately, there is unhealthy competition and lack of transparency, also on behalf of other [civil society] organizations. Right now, we are only contemplating getting engaged. A big problem in our country is that people, who are not part of the affected community, are controlling all NGO related matters. They hired a couple of community activists, they are feeding them and telling them when to yell and when to sit quiet. The 'nothing about us without us' slogan is not working. The real voice of the community remains in the background, unheard because of the noise made by these people".*
>
> *From an in-depth interview with a representative from Europe and Central Asia*

Nearly similar shares of respondents, who reported availability of an acting NSP in their country, said that their organizations had and had not participated in the development of the acting NSP (45% and 49% respectively). Another 7% of survey participants were not aware whether their organization was involved in the NSP development process.

Table 16. Distribution of responses to the question "Did your organization participate in the development of the acting NSP?"

	No.	%
Yes	45	49.5
No	40	44.0
I don't know	6	6.6
Total number of responses	91	100.0

As a rule, organizations representing people affected by TB participated in the development of the NSP (60%), while organizations representing key populations were more often not engaged in the NSP development process (56%).

Table 17. Distribution of responses to the question “Did your organization participate in the development of the acting NSP?” relative to the population the organization represents

	Which group does your organization represent?		Total
	People affected by TB	TB key population	
Yes	60.4%	37.2%	49.5%
No	33.3%	55.8%	44.0%
I don’t know	6.3%	7.0%	6.6%

Likewise, organizations, for which TB is the main thematic area, were more frequently involved in the NSP development (62%) than the organizations, for which TB is one of thematic areas (39%).

Table 18. Distribution of responses to the question “Did your organization participate in the development of the acting NSP?” relative to the thematic scope of the organization

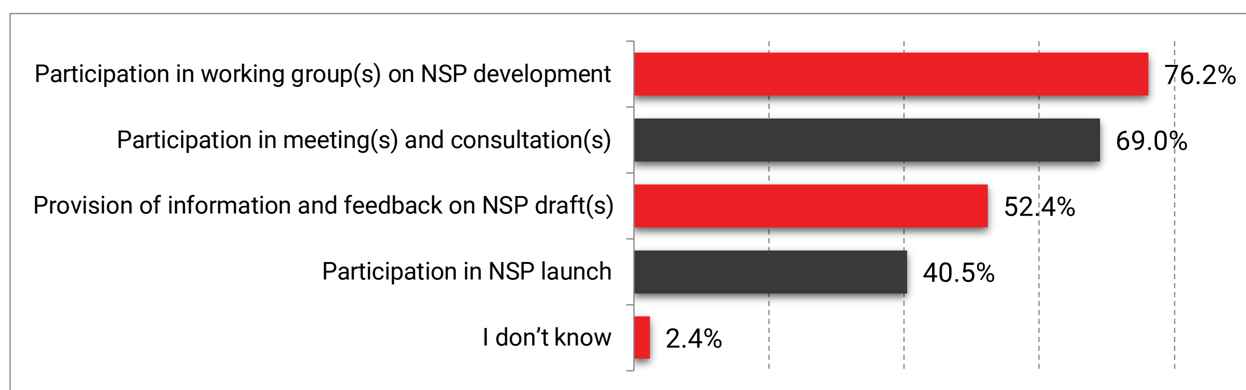
	Does the mission/thematic scope of your organization include TB?		Total
	TB is the organization’s main thematic area	TB is one of organization’s thematic areas	
Yes	61.9%	38.8%	49.5%
No	31.0%	55.1%	44.0%
I don’t know	7.1%	6.1%	6.6%

The most common types of engagement in the NSP development were the following:

- Participation in working groups (76%)
- Participation in meetings and consultations (69%)
- Provision of information and feedback on NSP draft (52%)
- Participation in NSP launch (41%)

There were very few instances when respondents, who confirmed participation in the NSP development, were not aware of what the contribution was.

Figure 10. Distribution of responses to the question “In which processes related to the development of the acting NSP did your organization participate?”



Both for organizations representing people affected by TB and for those representing key populations, two most common modalities of engagement were participation in working groups on NSP development and in meetings and consultations. However, respondents from among organizations of people affected by TB more frequently indicated participation in working groups (82%) than meetings and consultations (68%). For key population organizations, meetings and consultations were on the first place (71%), and working groups were on the second (64%). For both types of organizations, provision of information and feedback on NSP drafts was the third most common modality of participation (50%-54%), and participation in the NSP launch was reported least frequently (39%-43%).

Table 19. Distribution of responses to the question "In which processes related to the development of the acting NSP did your organization participate?" relative to the population the organization represents

	Which group does your organization represent?	
	People affected by TB	Key population
Participation in working group(s) on NSP development	82.1%	64.3%
Participation in meeting(s) and consultation(s)	67.9%	71.4%
Provision of information and feedback on NSP draft(s)	53.6%	50.0%
Participation in NSP launch	39.3%	42.9%
I don't know	0.0%	7.1%

The organizations, for which TB is the main thematic area, most often participated in working groups on NSP development (80%) and in meetings and consultations (60%). These two modes of engagement were also most common for the organizations, whose mission is not solely focused on TB, though meetings and consultations were mentioned more frequently (82%) than working groups (71%). For both categories of organizations, provision of information and feedback on NSP drafts was the third most common type of involvement (52%-53%), and participation in the NSP launch was mentioned least frequently (40%-41%).

Table 20. Distribution of responses to the question "In which processes related to the development of the acting NSP did your organization participate?" relative to the mission/thematic scope of the organization

	Does the mission/thematic scope of your organization include TB?	
	TB is the organization's main thematic area	TB is one of organization's thematic areas
Participation in working group(s) on NSP development	80.0%	70.6%
Participation in meeting(s) and consultation(s)	60.0%	82.4%
Provision of information and feedback on NSP draft(s)	52.0%	52.9%
Participation in NSP launch	40.0%	41.2%
I don't know	4.0%	0.0%

A similar distribution was found when comparing the responses based on the respondents being or not being represented on coordinating mechanisms on TB. So, participation in the working groups and attending meetings and consultations were two most commonly reported ways of engagement for both categories of respondents, with participation in working groups being on the first place for organizations-members of coordinating mechanisms (82%), while for non-members of CCM/RCM, it was participation in the meetings (69%). Less common for both types of organizations were provision of information and feedback on NSP drafts (52%-54%) and participation in the NSP launch (39%-41%).

Table 21. Distribution of responses to the question "In which processes related to the development of the acting NSP did your organization participate?" relative to representation on CCM/RCM

	Is your organization represented on country or regional coordinating mechanism on TB?	
	Not a CCM/RCM member	CCM/RCM member
Participation in working group(s) on NSP development	61.5%	82.8%
Participation in meeting(s) and consultation(s)	69.2%	69.0%
Provision of information and feedback on NSP draft(s)	53.8%	51.7%
Participation in NSP launch	38.5%	41.4%
I don't know	0.0%	3.4%

3.3. Factors supporting or preventing participation of the community in NSP development

Meaningful participation of community in processes of policy and program development requires certain conditions both regarding the capacity of the community itself, and in terms of technical opportunities. The survey had a number of questions to evaluate the extent to which these conditions were fulfilled in the process of NSP development.

So, respondents highlighted a huge gap in access to information and lack of capacity, which prevent communities from being meaningfully engaged in the development, implementation and monitoring of national strategies. Communities of people affected by TB cannot take meaningful and effective part because of inadequate knowledge and skills required for NSP development and lack of resources for participation in meetings and consultations. Communities of people affected by TB often lack technical expertise, which limits participation of communities in strategy development.

"In my opinion, there is insufficient civil society engagement in TB-related decision-making. State bodies responsible for the development and implementation of TB policy do not always involve civil society. It seems that civil society is only engaged when it is necessary to report to the main donor, the Global Fund. For instance, civil society representatives were involved in the development of strategies related to overcoming TB and HIV related legal barriers. They reported to the Global Fund that the documents were developed. But when the TB Service Reform Strategy had to be developed, civil society representatives were not engaged. Civil society representatives are also insufficiently involved in the processes of monitoring of TB response: monitoring visits are mainly carried out by medical professionals".

From an in-depth interview with a representative from Europe and Central Asia

Many participants of in-depth interviews indicated that while health ministries and other partners invited them to participate in discussions

around NSP development, community participation and engagement is often tokenistic in nature. Oftentimes, these meetings are attended by community activists, who do not have the expertise to adequately represent the community and are therefore unable to effectively contribute to these meetings. As they put it, "...in many instances, TB affected communities were ridiculous in some of these discussions". Interviewees shared that it would be beneficial if they were supported to have their own meetings with their representatives, which would allow them to agree on their vision and provide more substantial input into any decision- and policy-making processes.

> *"How can we participate, when we don't know what is going on with NSP development? You don't know what you don't know..."*
>
> *From an in-depth interview with a representative from Africa*

To present the opinion of the resondents on community engagement in NSP development, their responses were presented as a quantitative scale. The rating of statements was as follows: "not true" – 1 point, "more or less true" – 2 points, "very true" – 3 points. Answers "I don't know/Not applicable" were relatively rare (no more than 11 responses in the sample), so they were removed from the analysis. Based on this rating, average scoring for each statement was calculated.

Answers to this question can be divided into two groups: factors supporting and preventing community engagement in the NSP development process. As the neutral answer corresponds to 2, supporting factors need to score 2 or more to be considered adequate, and for the preventing factors the rating has to be under 2 to mean lack of seious issues.

Table 22. Assessment of statements regarding factors that support community participation in the development of the acting NSP

	Average score
The NSP development process allowed participation of all key populations	2.0
Selection of members of NSP development working group(s) was fair and transparent	2.2
There was an open call for stakeholders to apply for membership in the NSP development working group(s)	1.9
The beginning of the NSP development process was publicly announced	2.0
The government created a supporting environment for participation of civil society and affected communities in the NSP development process	2.2
Selection of main implementers and implementing partners for NSP activities was made in a transparent merit-based manner	2.0
International community supported the participation of civil society and affected communities in the NSP development process	2.2
We are involved in monitoring and evaluation of the acting NSP	2.2
Our organization/group is listed among NSP implementing partners	2.4
There was financial and/or technical assistance available for effective participation in the NSP development process	2.1
Most of our contribution/ comments/ recommendations were well reflected in the final version of the acting NSP	2.1
We had an opportunity to freely express our opinion	2.5
Our organization was invited to participate in the NSP development at early stages	2.3

Respondents gave a generally positive assessment to the organization of the acting NSP development process. On most of statements on factors that support community engagement, the average ranking was above 2. Respondents were particularly positive on the opportunity to openly share their opinion (average score 2.5), being listed as a partner in NSP development (2.4) and invitation to participate in NSP development at the earliest stages (2.3). Only two statements were rated 2 or lower: on an open call for application to join the working group and on the opportunity for all key populations to participate in NSP development. But even for these statements, the rating was 1.9-2.0, which is very close to the neutral "somewhat agree".

Table 23. Assessment of statements regarding factors that prevent community participation in the development of the acting NSP

	Average score
The timeframe for NSP development was extremely tight to ensure wide participation	2.3
The way NSP development process was organized resulted in conflicts between different stakeholders	1.7
The process of NSP development was poorly organized	1.7
Our organization did not have the human or financial resources to participate in the NSP development	1.8
Often there was negative or critical reaction to our comments and statements by public officials	2.0
Our organization was invited to the final workshop, when the document was already finalized	1.8
Some stakeholders could not participate in the development of NSP because they did not speak the language	1.6
Our participation in the NSP development was a pure formality; we were invited "to tick a box" and create an appearance of broad participation	1.8

"Speaking about community engagement, we have to admit some progress in this direction over last five years. Comparing the situation today and five years ago, it is obvious that TB became more of a priority for the community of people living with HIV, and that civil society focused on TB as the condition, not as a co-infection of HIV, is actively developing. Of course, this process is particularly evident in countries, where national TB programs are supported by the Global Fund and other international donors. Undoubtedly, Ukraine is a textbook example – it is a country where the community walked the path from understanding itself as an important player to almost full participation in key decision-making processes in the country. But also in countries, where international support is limited, for instance in Russian Federation, more and more NGOs and decision-makers, especially local ones, start understanding the importance of working with the community both for improving services and for better prioritization of work to be carried out. Nevertheless, to see how far we are from where we need to be and how much needs to be done, one can compare TB with HIV or hepatitis. It is clear that the community of people affected by TB requires technical and financial support so that the community in the region can achieve the same level of expertise and influence on decisions".

From an in-depth interview with a representative from Europe and Central Asia

Judging on the average score, respondents denied existence of serious issues in the engagement in NSP development.

This being said, they found that time allocated for NSP development was too little and insufficient to allow broad participation (average score 2.3). Also, the statement "Often there was negative or critical reaction to our comments and statements by public officials" received the "neutral" score of

2.0. However, these and other assessments should be dealt with caution as they represent an average score, while individual scores for most statements – both positive and negative – varied from "not true" to "very true".

Next, average indicators were compared between different categories of respondents.

For organizations representing key populations, language barrier was relatively more significant than for the organizations of people affected by TB (1.9 compared to 1.5), while an open call to join NSP development working group was reported by key population organizations more than by the organizations of people affected by TB (1.7 and 2.1 respectively). On the other statements, the disparity was less pronounced.

Table 24. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to the population represented by the organization

	Which group does your organization represent?	
	People affected by TB	Key population
Our organization was invited to participate in the NSP development at early stages	2.3	2.3
We had an opportunity to freely express our opinion	2.5	2.4
Most of our contribution/ comments/ recommendations were well reflected in the final version of the acting NSP	2.2	2.1
There was financial and/or technical assistance available for effective participation in the NSP development process	2.0	2.1
Our organization/group is listed among NSP implementing partners	2.4	2.5
We are involved in monitoring and evaluation of the acting NSP	2.2	2.1
International community supported the participation of civil society and affected communities in the NSP development process	2.2	2.2
Selection of main implementers and implementing partners for NSP activities was made in a transparent merit-based manner	2.0	2.0
The government created a supporting environment for participation of civil society and affected communities in the NSP development process	2.2	2.1
The beginning of the NSP development process was publicly announced	2.0	2.2
There was an open call for stakeholders to apply for membership in the NSP development working group(s)	1.7	2.1
Selection of members of NSP development working group(s) was fair and transparent	2.2	2.1
The NSP development process allowed participation of all key populations (e.g. people living with HIV, people who use drugs, migrants, prisoners, healthcare workers, miners, etc. as applicable for the country)	1.9	2.1
Our participation in the NSP development was a pure formality; we were invited "to tick a box" and create an appearance of broad participation	1.9	1.8

(Continued from previous page) Table 25. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to the population represented by the organization

	Which group does your organization represent?	
	People affected by TB	Key population
Some stakeholders could not participate in the development of NSP because they did not speak the language	1.5	1.9
Our organization was invited to the final workshop, when the document was already finalized	1.8	1.8
Often there was negative or critical reaction to our comments and statements by public officials	2.0	1.9
Our organization did not have the human or financial resources to participate in the NSP development	1.7	1.8
The process of NSP development was poorly organized	1.6	1.8
The way NSP development process was organized resulted in conflicts between different stakeholders	1.8	1.6
The timeframe for NSP development was extremely tight to ensure wide participation	2.4	2.3

There were certain discrepancies in evaluations of a number of statements between organizations represented and not represented on coordination mechanisms. So, CCM/RCM members were more likely to agree with statements on fairness and transparency of working groups, opportunity to freely express their opinion, being listed among NSP implementation partners, while those who were not CCM/RCM members more often indicated being involved in monitoring and evaluation of the acting NSP; they also more frequently reported that their comments and statements caused negative or critical reaction of public officials. On the other statements, the disparity was less significant.

Table 26. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to the membership on CCM/RCM

	Is your organization represented on country or regional coordinating mechanism on TB?	
	Not a CCM/RCM member	CCM or RCM member
Our organization was invited to participate in the NSP development at early stages	2.2	2.3
We had an opportunity to freely express our opinion	2.3	2.6
Most of our contribution/ comments/ recommendations were well reflected in the final version of the acting NSP	2.1	2.1
There was financial and/or technical assistance available for effective participation in the NSP development process	2.1	2.0

(Continued from previous page) Table 27. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to the membership on CCM/RCM

	Is your organization represented on country or regional coordinating mechanism on TB?	
	Not a CCM/RCM member	CCM or RCM member
Our organization/group is listed among NSP implementing partners	2.2	2.5
We are involved in monitoring and evaluation of the acting NSP	2.4	2.1
International community supported the participation of civil society and affected communities in the NSP development process	2.3	2.2
Selection of main implementers and implementing partners for NSP activities was made in a transparent merit-based manner	1.8	2.1
The government created a supporting environment for participation of civil society and affected communities in the NSP development process	2.3	2.1
The beginning of the NSP development process was publicly announced	2.0	2.0
There was an open call for stakeholders to apply for membership in the NSP development working group(s)	1.7	1.9
Selection of members of NSP development working group(s) was fair and transparent	1.8	2.3
The NSP development process allowed participation of all key populations (e.g. people living with HIV, people who use drugs, migrants, prisoners, healthcare workers, miners, etc. as applicable for the country)	2.1	1.9
Our participation in the NSP development was a pure formality; we were invited "to tick a box" and create an appearance of broad participation	1.7	1.9
Some stakeholders could not participate in the development of NSP because they did not speak the language	1.7	1.6
Our organization was invited to the final workshop, when the document was already finalized	1.8	1.8
Often there was negative or critical reaction to our comments and statements by public officials	2.2	1.9
Our organization did not have the human or financial resources to participate in the NSP development	1.6	1.8
The process of NSP development was poorly organized	1.8	1.6
The way NSP development process was organized resulted in conflicts between different stakeholders	1.7	1.7
The timeframe for NSP development was extremely tight to ensure wide participation	2.4	2.3

Only one organization working internationally answered the question on engagement in NSP development; therefore, the relationship between geographical coverage of organizations with its opinion on the NSP development process can only be described for the organizations working on the national and local levels. So, as compared to the organizations with national level of operation, the organizations working locally to a considerably larger extent were likely to report on open call for applications to join working groups and on public announcement of the beginning of the NSP development process. The difference in assessment of some other statements was less pronounced. So, the organizations working primarily at the national level were less likely to agree that the government created a supporting environment for participation of civil society and affected communities, and that the selection of members of NSP development working group was fair and transparent. On the other statements, average scores of these two categories of respondents were relatively similar.

Table 28. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to organization's geographic coverage

	National	Sub-national
Our organization was invited to participate in the NSP development at early stages	2.3	2.1
We had an opportunity to freely express our opinion	2.5	2.5
Most of our contribution/ comments/ recommendations were well reflected in the final version of the acting NSP	2.1	2.3
There was financial and/or technical assistance available for effective participation in the NSP development process	2.1	2.0
Our organization/group is listed among NSP implementing partners	2.4	2.5
We are involved in monitoring and evaluation of the acting NSP	2.2	2.2
International community supported the participation of civil society and affected communities in the NSP development process	2.3	2.1
Selection of main implementers and implementing partners for NSP activities was made in a transparent merit-based manner	2.0	2.2
The government created a supporting environment for participation of civil society and affected communities in the NSP development process	2.0	2.4
The beginning of the NSP development process was publicly announced	1.9	2.5
There was an open call for stakeholders to apply for membership in the NSP development working group(s)	1.6	2.4
Selection of members of NSP development working group(s) was fair and transparent	2.0	2.4
The NSP development process allowed participation of all key populations (e.g. people living with HIV, people who use drugs, migrants, prisoners, healthcare workers, miners, etc. as applicable for the country)	2.0	1.8
Our participation in the NSP development was a pure formality; we were invited "to tick a box" and create an appearance of broad participation	1.8	1.9
Some stakeholders could not participate in the development of NSP because they did not speak the language	1.6	1.7

(Continued from previous page) Table 29. Distribution of responses to the question "How true are these statements as applicable to the development and implementation of the acting NSP in your country?" relative to organization's geographic coverage		
Our organization was invited to the final workshop, when the document was already finalized	1.6	2.0
Often there was negative or critical reaction to our comments and statements by public officials	2.0	2.0
Our organization did not have the human or financial resources to participate in the NSP development	1.7	1.8
The process of NSP development was poorly organized	1.8	1.5
The way NSP development process was organized resulted in conflicts between different stakeholders	1.7	1.9
The timeframe for NSP development was extremely tight to ensure wide participation	2.3	2.4

4. PARTICIPATION IN THE DEVELOPMENT OF THE NEW NSP

4.1. Development of the new NSP

When asked about the status of the development of the new NSP, similar shares of respondents (18%-23%) answered that the process has not officially begun, that they heard the work has begun though no official announcement was made, that it is at early stages of development, or that they are not aware. Thus, more than 60% of respondents indicated that the work on the new NSP has not begun yet or is at early stages. Only 15% of respondents reported that the NSP is at the stage of the first draft (8%) or further (7%).

Table 30. Distribution of responses to the question "Is there an ongoing process of development of the new NSP?"

	No.	%
No, the process has not officially begun yet	22	22.7
It was not officially announced, but we heard that the work on the new NSP has begun	17	17.5
Yes, the development of the new NSP was officially announced and it is at early stages	21	21.6
Yes, there is an early draft of NSP	8	8.2
Yes, the draft of the new NSP has been finalized, but not yet approved	1	1.0
Yes, the new NSP has been approved and will become effective after the current NSP comes to end	6	6.2
I don't know	22	22.7
Total	97	100.0

4.2. Participation in the NSP development

Only 37 respondents answered the question on whether their organization was participating in the development of the new NSP. Of these, two-thirds confirmed their participation in the process, and 30% gave a negative response.

Table 31. Distribution of responses to the question "Is your organization participating (or has participated) in the development of the new NSP?"

	No.	%
Yes	25	67.6
No	11	29.7
I don't know	1	2.7
Total number of responses	37	100.0

Of these, an overwhelming majority of the respondents representing people affected by TB, participate in the development of the new NSP (84%). From among organizations representing key populations, 50% confirmed their participation.

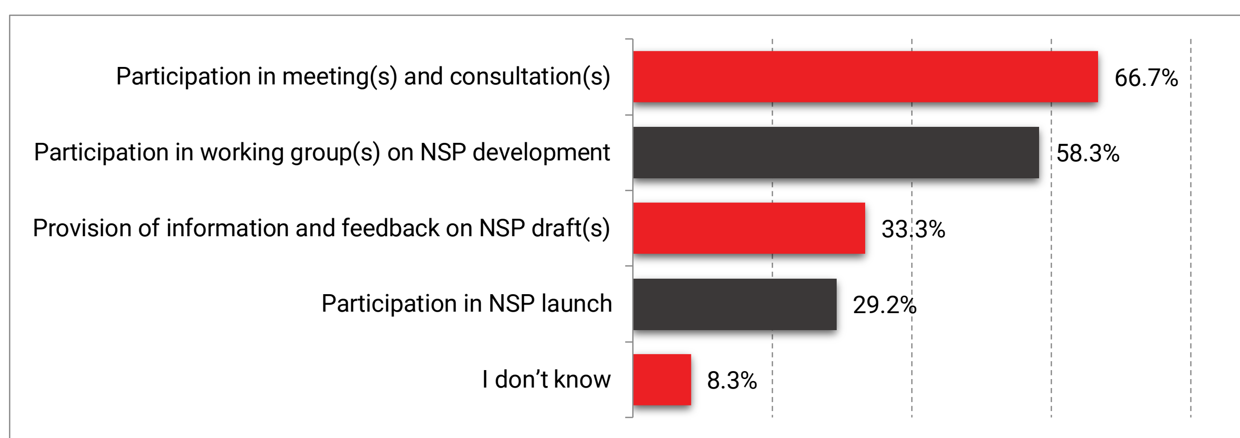
Table 32. Distribution of responses to the question “Is your organization participating (or has participated) in the development of the new NSP?” relative to the population the organization represents

	Which group does your organization represent?		Total
	People affected by TB	TB key population	
Yes	84.2%	50.0%	67.6%
No	15.8%	44.4%	29.7%
I don’t know	0.0%	5.6%	2.7%

From among the organizations, which answered the question on their participation in the new NSP development, there is a correlation between the participation and membership in coordinating mechanisms. So, an overwhelming majority of CCM/RCM members (78%) were involved in the NSP development, while for non-members this indicator was 50%.

Respondents, who confirmed their engagement in the development of the new NSP, more often mentioned participation in meetings and consultations (67%) and in working groups (58%). Provision of information and feedback on NSP draft was mentioned by only a third of respondents (33%).

Figure 11. Distribution of responses to the question “In which processes related to the development of the new NSP is your organization participating (or has participated)?”



Only 24 respondents shared their opinion on the change in the civil society and community engagement in the NSP development. But more than a half of them indicated that the situation has somewhat improved, and another quarter, that the situation has definitely improved. Only two respondents (8%) indicated that the situation either has not improved or has worsened.

Table 33. Distribution of responses to the question “In your opinion, has the situation changed in terms of involvement of NGOs and community groups in NSP development processes, and if yes, then how?”

	No.	%
Situation has definitely improved	6	25.0
Situation has somewhat improved	13	54.2
Situation has not improved	1	4.2
Situation has become somewhat worse	0	0.0
Situation has definitely become worse	1	4.2
I cannot say	3	12.5
Total responses	24	100.0

The only most frequently mentioned reason for non-participation in the development of the new NSP was that the respondent's organization was not invited (82% or 9 out of 11 respondents who answered this questions).

Table 34. Distribution of responses to the question "Why is not your organization participating (or has participated) in the development of the new NSP?"

	%
The process has just begun	9.1%
Nobody has invited us yet	81.8%
Other	9.1%

This is also supported by the findings of in-depth interviews, suggesting that representatives of NGOs and initiative groups are not offered the required technical support and information.

"We can play a meaningful role in the NSP development if we have the technical support, but without access to technical support and information our participation is meaningless"

From an in-depth interview with a representative of and NGO from the African region

5. KEY CONCLUSIONS AND RECOMMENDATIONS

5.1. Conclusions

- The sample of the study proportionately included organizations representing people affected by TB and those representing key populations; likewise, there was proportionate representation of organizations for which TB is the main area of focus and for which TB is one of the thematic areas.
- The highest number of respondents were organizations covering the territory of the country, followed by organizations working at the local and grassroots level (i.e., working below the provincial level).
- Most organizations that took part in the survey are membership-based, predominantly individual and mixed, with the median size being 50 members (though organizations representing people affected by TB were larger).
- Almost all respondents are officially registered organizations.
- Before 1996, creation of civil society organizations falling within the scope of the survey (i.e., groups and organizations representing people affected by TB and key populations) was rather sporadic. After 1996, the rate of creation of new organizations intensified, exceeding the rate of registrations. After 2000, both creation and registration of new organizations grew further. After 2010, the rate of creation of new organizations slowed down, surpassed by the rate of registration of earlier created organizations. On the average, organizations having TB as their main thematic focus and those represented on coordination mechanisms were created more recently.
- About two-thirds of respondents were members of either (and predominantly) country or regional coordinating mechanisms. Many organizations were part of other coordination forums and processes, of which country dialogue for Global Fund application development was mentioned most frequently (especially for the organizations which work nationally and are represented on CCM/RCM).
- The most common key population represented by respondents (in particular by those for which TB is not the only thematic focus) are people living with HIV. Other key populations represented by respondents were people who use drugs, prison inmates and health workers.
- Most frequently mentioned areas of work related to TB were (in descending order): raising public awareness, fighting stigma and discrimination, capacity building, psychosocial support, legal services and monitoring of access to treatment.
- According to respondents, representation and engagement of communities affected by TB is improving in many countries, though many of them still lack the required capacity and resources for strengthening their organizations and implementing TB-related activities. As a result, community networks and civil society groups continue to be regarded as unnecessary or not strong enough for being engaged in national TB response.
- National strategic plan on TB is the foundation for national efforts to end TB. For the NSP to be evidence-informed, robust and effective, all stakeholders – including people affected by TB and key populations – need to be involved at all stages, from planning to implementation and monitoring and evaluation.

- An overwhelming majority of respondents reported availability of a current NSP on TB in their country, though some indicated that their country's broader NSP also covers TB. As a rule, acting NSPs were adopted not earlier than 2014-2015 and expire in 2019-2021.
- Near half of all respondents was involved in the development of the current NSP. Most common modes of engagement were through participation in working groups and attendance of meetings and consultations. Organizations of people affected by TB and those having TB as the primary area of work were more engaged than others; for them participation in NSP development working groups was more common.
- Overall, respondents assessed positively community and civil society engagement in the development of the acting NSP. They were most positive about an opportunity to openly share their opinion, inclusion of their organizations as NSP implementation partners, and invitation to participate in NSP development process at early stages. However, they find that the time allocated for NSP development was insufficient and inadequate for ensuring wide participation in the process. Also, respondents were not too confident speaking about an open invitation to apply for the membership in NSP development working groups and about the opportunity for all key populations to participate in the process. Some respondents reported negative or critical reaction of government representatives to the comments and suggestions coming from community and civil society groups.
- While generally language was not highlighted as a barrier for participation in NSP development, it was mentioned moderately more frequently by organizations representing key populations.
- Coordinating mechanism non-members were less likely to find selection of NSP development working group fair and transparent. Organizations working mainly at the local/grassroots level more often reported an open invitation to join the working group, while those working at the countrywide level were more likely to disagree with the statement.
- According to a majority of respondents, the development of the new NSP in their country has not started yet or is at early stages; only in a minority of cases, the process was at the stage of an early draft or further.
- About two-thirds of respondents reported their engagement in the development of the new NSP (more frequently – among the organizations of people affected by TB and the organizations represented on coordinating mechanisms). Usually, such engagement takes form of being part of working groups and participation in meetings and consultations. These respondents were generally believing that the situation with community engagement in NSP development has improved. Several respondents indicated that they were not engaged in the process because they were not invited.

In-depth interviews showed the following:

- NGOs and initiative groups are very committed to fight against TB and are willing to make their contribution.
- Involvement of NGOs and initiative groups in NSP development promotes the participation of key populations.

- Civil society participation in NSP development needs to happen at all stages, from the beginning of planning to implementation, monitoring and evaluation.
- Some of the interviewees observed a positive trend with a growing number of community and civil society organizations being involved in NSP development, as compared to just one or two such organizations being invited to take part in the process just a few years ago. When participation is limited and only one community representative participates in NSP writing groups, it is difficult to monitor what is happening in other committees and working groups.
- Participation of non-governmental organizations and initiative groups in the NSP development process helped to reduce the number of patients lost to follow-up and the number of TB deaths while increasing screening rates, because their work was taken into account.
- NGOs working on TB continue to be inadequately involved in the processes related to NSP development, implementation and monitoring and evaluation.
- Participation and engagement of TB affected communities in national-level decision-making and specifically in NSP development continue to have limited impact. In spite of the efforts of the Global Fund and other international partners, community of people affected by TB is not always able to sit at the table with decision-makers to contribute to NSP planning and development; their participation is limited because of lack of information, knowledge and capacity, including funding gaps. This study found that over 90% of TB affected communities are not meaningfully engaged in processes of strategic planning and NSP development. This limits their further involvement in TB responses, including the work around prevention, treatment support, stigma reduction, human rights, community-led monitoring and other relevant areas, where the community can and should play a leading role.

5.2. Recommendations

1. Empower TB affected community groups and NGOs in the processes around national strategic planning on TB

- People affected by TB and their organizations have to be prioritized when it comes to NSP development. The study has shown that in many instances they get excluded from the process of NSP development, because many of these people do not have higher or even secondary education and lack appropriate communication skills, and some often face a language barrier. Therefore, for ensuring meaningful engagement of the community in development of country strategies, attention should be given to educating and empowering patients, and this work has to begin when they are on their TB treatment.
- There is a big need to build capacity of community of people affected by TB and NGOs and improve their knowledge and access to information about NSP related processes. Community groups sometimes lack knowledge and skills in formulating their issues – and solutions -- making training and empowerment of community activists key. Also, for their participation to be meaningful, community and civil society groups need to have access to information about NSP development. Oftentimes, they are invited in the last moment and provided with very scarce information; as a result, their contribution becomes minimal.
- Community organizations and other NGOs should have their own space and be supported to engage more of their representatives in the NSP development process and thus be able to influence on the final documents. For this, governments need to

ensure participation of the community of people affected by TB and other NGOs at all stages of NSP life cycle, including planning, coordination, implementation, monitoring and evaluation.

2. Ensure provision of information and technical assistance to communities and NGOs

- In order for the community and NGOs to take active part in the NSP development, they need to receive adequate technical assistance at both local, national and regional levels. Respondents highlighted that without technical assistance, communities of people affected by TB will not be able to meaningfully contribute to the NSP development. They also said that lack of technical support may not only limit their participation in NSP development, but also in other processes, such as development and implementation of Global Fund country grants.
- More than 98% of respondents recommended technical support to be available to the communities, but they also said that this support has to be provided in a timely manner. Besides, they noted that technical support should cover the following areas related to the NSP development:
    - Situational analysis and country approaches to the NSP;
    - Consultation with, coordination and mobilization of key affected populations;
    - Budget calculation and development of activities;
    - Coordination of strategic plan of communities of people affected by TB and NGOs;
    - Analysis of feedback at the stage of NSP finalization.

3. Improve transparency and accountability in NSP planning, coordination and development, including formation of working groups

- Communities affected by TB and NGOs have limited opportunity to participate in the NSP development. Oftentimes they are invited to attend and are not seen as an equal partner in the fight against TB, or engaged at the advanced stage of NSP development, rather than from the onset of the process. So, members of the NSP development working group are oftentimes hand-picked by representatives or leadership of the national TB program; this process may be prolonged, with new members being added even at the final stages of the NSP development.
- Another problem mentioned by respondents is that their contribution is not always reflected in the final document. Besides, several respondents noted that they were removed from among implementation partners and only found this out after the NSP was published.

4. Develop a roadmap for communication and coordination during the NSP development process

To clearly define roles and responsibilities in the NSP development process, there should be a roadmap for communication and coordination. Taking into account that NSP is developed with participation of a range of stakeholders, each of them has to know its role and how the process will be carried out. This will help improve communication and coordination among the partners and support transparency and accountability.

5. Allocate and scale up financial support to communities of people affected by TB and NGOs for participation in NSP development, implementation, monitoring and evaluation

Funding is key for the engagement and participation of communities and NGOs. Communities of people affected by TB may be innovative and actively contribute to the processes related to NSP development, implementation, monitoring and evaluation, but this cannot happen without financial support. Still, respondents highlighted limited budgets allocated for financing of the activities carried out by communities and NGOs during NSP development. Lack of such funding hampered community and civil society organizations to get engaged and participate at all stages of strategy development. 100% of respondents spoke in favor on adequate funding, which would allow communities and NGOs to fully realize their potential.

Selected recommendations from survey participants, received during in-depth interviews:

> *"Expand the use of social media and such tools as U-report to account for the contribution of stakeholders, including young people"*.

> *"Presently, our participation is formal. Community does not participate in implementation of any items of the Plan, we operate in a certain parallel universe, which is there only for people affected by TB. Only by ensuring real participation in activities related to NSP implementation would make all stakeholders to jointly work on strategies and policies"*.

> *"In my opinion, there should be closer contacts for cooperation with representatives of TB affected communities in TB-related policy- and decision-making. All barriers to working with local healthcare authorities have to be removed"*.

> *"Our participants need to be meaningfully engaged, and not a handful of people allegedly from the TB affected community, who in fact do not even belong to any community. But for some reason they believe they are TB experts. Interestingly enough, they are actually supported by public officials, international organizations, and even large international networks"*.

> *"National TB Program has to be more open to dialogue, it has to change its approach, it has to engage more relevant NGOs and representatives of people affected by TB, and to spread information about its work more widely"*.

> *"…to organize joint meetings with NGO representatives, doctors, academia and the ministry [of health] to discuss strengths and weaknesses of the previous program and come to a consensus as to what needs to be changed"*.

> *"…to identify Members of Parliament, who are interested in this topic and who would represent interests of NGOs and their proposals in the Parliament"*.

> *"…to unite all NGOs in line with the work they do, and together they can present their suggestions on the changes in the new program"*.

> *"For increasing the engagement of TB affected communities in decision-making on TB-related issues, communities have to be part of public councils under the Ministry of Health, local health departments and local authorities. Public councils are consultative and supervisory body, members of which participate as quality assurance experts even at the stage of policy-making on different issues before these policies get adopted, which allows public councils to influence on the final decision. Unfortunately, being the only active patient group, we are not part of any of the public councils. But they include some NGOs, which are far from the interests of people affected by TB"*.

TBPEOPLE