Regional Capacity-Building Workshop for TB Survivors
10 – 13 April 2017, New Delhi
Narrative Report
TB survivors and champions from six countries in South-East Asia - India, Indonesia, Vietnam, Cambodia, Bangladesh and the Philippines – came together to participate in the Regional Capacity Building workshop for TB Survivors, organized by REACH, the Stop TB Partnership and USAID. This was held between 10 and 13 April 2017 in New Delhi, India.

The workshop brought together 30 people from six countries who, over the course of four days, shared personal experiences on TB, documented the societal and systemic barriers they faced, translated the barriers they faced into concrete advocacy goals and strategies and discussed the power of collective community-driven advocacy to change the status quo in TB.

Aiming to build the capacity of potential TB Champions from across South-East Asia, the workshop focused on strengthening their knowledge of TB, contextualizing their personal experiences of TB within a broader public health perspective and helping participants develop advocacy and communication skills, learn to tell their stories more impactfully and build effective partnerships.

This narrative report -
- Details the processes involved in organizing the workshop including identifying participants and developing the agenda;
- Describes the workshop proceedings and key highlights of each day;
- Documents outcomes from the workshop including the development of a series of short videos featuring TB Champions and the formation of a coalition of people affected by TB;
- Outlines next steps and the roll-out of an advocacy mentorship programme.
What they said...

“I lost my father to TB. And a few years ago, I was diagnosed with TB as well and I could never speak about it. It’s a huge burden to suffer alone. That is why this workshop just clicked for me. People wanted to listen to our stories, and I have learnt how to tell my story even better.”

- Mr Arun Singh Rana, TB survivor & Champion from India

“The voice of the survivor becomes the voice of India. In TB, there is a dual stigma – one is the disease itself but the other is poverty. This dual stigma can be explained best by the TB survivors. The TB fight is not finished – but survivors will help us get there. TB survivors at different levels can be great ambassadors and pass the message very efficiently so that TB loses, and we all win.”

- Dr Sunil D Khaparde, Deputy Director General, TB, Central TB Division, Ministry of Health and Family Welfare, Government of India

“If we are serious about ending TB, engaging those who have experienced TB first hand in a meaningful way is vital.”

- Dr Lucica Ditiu, Executive Director, Stop TB Partnership.

“It is critical that we actively engage TB champions in designing and implementing programs and advocating for policy change. Their experiences can guide the way forward as we move toward a TB-free India and world.”

- Mr Xerses Sidhwa, Director, Health Office, USAID/India

“The energy brought in by the TB Champions who won the fight against TB including MDR and XDR-TB was palpable. The TB response across the world is missing passion and if we want to end TB in our lifetime, we need their lived experiences, their passion and their energy to truly bend the curve and win the fight against TB.”

- Ms Blessina Kumar, TB Advocate and lead facilitator at the workshop
BACKGROUND AND RATIONALE

South-East Asia bears almost half the world’s TB burden, with close to half a million annual deaths due to TB. The region also bears one-third of the drug-resistant TB burden, with an estimated 99,000 cases. TB remains a grave public health concern in the region and in India, which has the highest TB burden in the world, with a quarter of cases worldwide.

Globally and in South-East Asia, the TB crises demands a concerted and comprehensive response from both government and non-government actors including the private healthcare sector, business and industry leaders, civil society and most of all, those directly affected by TB – patients, survivors and their families. However, responses to TB have remained top-down and TB survivors, patients and their families have had little or no role to play in the fight against TB. Their potential role as powerful advocates with the capacity to increase visibility for TB, improve public understanding of the disease and destigmatize the TB experience has been largely ignored. As a result, there are few personal narratives in the public domain and few trained TB advocates and spokespersons who can demand changes to how we respond to TB.

In India, the last few years have witnessed capacity building efforts to identify and support TB-affected communities to become effective advocates for TB. However, these efforts have however remained sporadic and there is a need to establish mechanisms that offer long-term support to TB advocates and champions.

In May 2014, the World Health Assembly passed a resolution approving the new post-2015 Global End TB Strategy, which if achieved, its targets will herald an end to the TB epidemic as a global threat. Central to the strategy is a call for integrated, patient-centered care and strong coalitions with civil society. Reflective of the End TB Strategy and in response to the habitually slow slide towards TB elimination, the Stop TB Partnership Global Plan 2016-2020 challenges the traditional biomedical approaches to TB and identifies 8 fundamental changes that must be implemented as part of the needed paradigm shift to end TB. One of those shifts is community- and patient-driven approaches. Following on from the first global meeting of people affected by TB in November 2015 the Stop TB Partnership has been supporting a number of regional workshops to strengthen the capacity of TB activists who can meaningfully engage in the fight to end TB both at regional and national levels.

In India, REACH is currently implementing the TB Call to Action project, with support from USAID, which envisages transforming our approach to ending TB. At the core of the proposed change is ensuring that those affected by TB are integral to our response, extending beyond tokenism to involving affected communities. REACH envisages a long-term role for trained, committed advocates in policy advocacy, overseeing program implementation, community monitoring and addressing stigma.

In this context, REACH and the Stop TB Partnership came together, with support from USAID, to organize the Regional Capacity-Building Workshop for TB Survivors for the South-East Asia region.
WORKSHOP OBJECTIVES

- To identify and engage a pool of potential TB Champions in India and select South Asian/South-East Asian countries
- To build the capacity of potential TB Champions to engage in the response to TB
- To support TB Champions to develop short, powerful video/written testimonials for wide dissemination
- To discuss and identify key advocacy opportunities for TB Champions over a six-month period

It was agreed that the workshop would focus on two key intertwined aspects:
- **Knowledge-building**: Supporting participants to contextualize their personal experiences of TB in the broader Indian/Asian context, thereby identifying key advocacy focus areas
- **Skills-building**: Helping participants develop advocacy and communication skills, specifically focusing on the ability to tell their stories in an impactful manner and identify and build effective partnerships.

IDENTIFYING PARTICIPANTS

A formal call for applications was issued on 6 February 2017 and widely disseminated via email, Twitter and Facebook. In response, a total of 80 applications were received, and the country-wise breakup was as follows:

<table>
<thead>
<tr>
<th>Country</th>
<th>Applications received</th>
<th>Participants selected</th>
</tr>
</thead>
<tbody>
<tr>
<td>India</td>
<td>49</td>
<td>15</td>
</tr>
<tr>
<td>Indonesia</td>
<td>14</td>
<td>4</td>
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<tr>
<td>Philippines</td>
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<td>Bangladesh</td>
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<td>Vietnam</td>
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<td>1</td>
</tr>
<tr>
<td>Cambodia</td>
<td>2</td>
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</table>

The applications were reviewed by a team from REACH and the Stop TB Partnership and in some instances, skype calls were scheduled with shortlisted applicants. In all, over 60% of applicants were contacted via phone/skype during the reviewing process.
**Challenges**

- Several applications were from individuals who were associated with organizations working on TB but were not TB survivors themselves. A decision was taken in consultation with the Stop TB Partnership to restrict participation to those individuals whose lives had been directly affected by TB.

- Among those who were eligible for selection, language was a barrier. Given that the workshop would include participants from six countries, it was decided that sessions would be held in English and therefore basic fluency and understanding of English was a pre-requisite for participation in the workshop. Several applicants, who were otherwise eligible, did not meet this criteria. REACH will be inviting these applicants, who were otherwise eligible, to attend state-level workshops scheduled for later this year.

Annexure A contains a complete list of participants.

**WORKSHOP AGENDA**

The workshop agenda was developed through a two-month long consultative process, involving REACH, the Stop TB Partnership, USAID and workshop facilitators, with inputs from the participants as well. All confirmed participants were sent a list of possible topics for inclusion in the agenda and asked to identify their priorities.

Sessions were designed to be as inclusive and interactive as possible, reflecting a two-way learning process. The emphasis was on participatory learning and on providing participants and facilitators with an opportunity to share stories with each other, rather than a one-way transfer of knowledge from facilitator to participant.

**Workshop facilitators**

The workshop was led by Ms Blessina Kumar, Public Health Consultant and Patient Advocate who has worked extensively with disempowered communities in India, Sudan, Indonesia and other countries. She was supported by Ms Caoimhe Smythe from the Stop TB Partnership and Ms Anupama Srinivasan from REACH.

Several external facilitators were invited to present or lead sessions at the workshop:

- Dr K S Sachdeva, Deputy Director General, National AIDS Control Programme, Ministry of Health and Family Welfare, Government of India
- Ms Mercy Annapoorni, Blossom Trust India
- Ms Prabha Mahesh, TB Survivor and Advocate
- Ms Rhea Lobo, TB Survivor and Advocate, Journalist and Filmmaker
- Dr Indira Behera & Ms Sukriti Chauhan, Global Health Strategies
- Mr Subrat Mohanty, The Union
In keeping with the workshop’s focus on creating powerful communication materials featuring the participants, a comprehensive communications plan was developed. This included the hiring of a professional photographer and videographer to document the proceedings of the workshop and to record individual interviews with participants, which would subsequently be edited into short, impactful videos. Informed consent procedures were strictly followed and all participants were allowed to opt-out of this component of the workshop.

Annexure B includes the full agenda of the workshop.
WORKSHOP SUMMARY

DAY 1: 10 April

Inaugural Session
The workshop began with an address by Dr Nalini Krishnan, Director, REACH. Welcoming the participants, she pointed out the significance of a gathering of TB Survivors and Champions and how they had the potential to end the ‘silence’ around TB. Dr Lucica Ditiu, Executive Director, Stop TB Partnership joined the workshop via Skype and reiterated the Stop TB Partnership’s commitment to meaningful community engagement and ensuring that those affected by the disease are at the center of our response. Ms Sarah Rugnetta, Programme and Policy Advisor, USAID, also welcomed the participants and endorsed the need for more inclusive policy and programme design that incorporates the views of those affected by TB.

Participants then had the opportunity to introduce themselves and answer one question: “why are you here?”. Their responses set the tone for the open, forthright and candid conversations that would ensue over the next few days.

Ms Anupama Srinivasan, Deputy Project Director, REACH presented the objectives of the workshop to the group and sought their feedback, based on their expectations. She explained the agenda and drew attention to the need for active participation throughout the sessions. Ms Blessina Kumar outlined some basic rules that all participants and facilitators would follow during the workshop, including the need to listen to each other’s views, no matter how different with an emphasis on respectful dialogue.
The first formal session of the workshop was “Who wants to be a TB Millionaire?”, an interactive quiz that addressed the science of TB. Divided in teams, participants were quizzed on the basics of TB symptoms, diagnosis and treatment. The quiz was followed by a presentation on the Global and Regional Burden of TB by Ms Kumar. She also explained the broad epidemiology of TB in the region, resource gaps to address the burden of TB and the End TB Strategy and its components to the group. This session was an opportunity for the participants to contextualize their personal experiences of TB within a broader, global health perspective.

It was circle time post-lunch. In this session titled “Your Story”, participants spoke freely, emotionally and movingly of how TB had affected their lives. For many in the group, this was the first time they had openly shared their experiences and the first time they heard how TB had affected the lives of others.

The final session of the day was led by Ms Gouri, Gender Advisor at USAID/India. Ms Gouri spoke of the need to incorporate a gendered approach to all aspects of public health including TB and the importance of viewing advocacy efforts through a gender lens. Participants received a resource-guide to engendering advocacy plans.
DAY 2: 11 April

The second day of the workshop began with a brief recap of the previous day by Ms Mildred Pancho from the Philippines. This was followed by a presentation by Ms Caoimhe Smyth on the ‘paradigm shift’ and the increased prioritization of work related to communities, key populations, human rights and gender by the Stop TB Partnership.

The main focus of the day was on “Pathways through Care”, a group work session designed to seek inputs from participants on the barriers they had faced at different stages through the treatment process. Seven stages were defined on chart papers that were displayed along a long wall. Participants were divided into seven groups and each group was asked to focus on a specific stage, although they were free to give inputs to the other stages as well.

The seven stages were:
- Developing symptoms
- Seeking care
- Getting a diagnosis
- Starting treatment
- Completing treatment
- Getting cured
- Getting back on track

In less than one hour, the chart papers were filled with post-it notes that described both systemic barriers and individual barriers. The next two hours saw animated discussion, facilitated by Ms Blessina Kumar, on barriers they had personally experienced, examples of specific moments in their individual pathways they wanted to share and cross-cutting obstacles such as stigma and lack of clear information that pervaded every stage of the process. Several participants identified
this session as the most rewarding and stimulating session of the workshop – for many of them, it had been the first opportunity to reflect on their individual pathways and the first time they had been able to share the challenges they had faced with a peer group.

Annexure C presents a summary analysis of the barriers identified by participants and this will form the basis for further reflection and discussion.
Ms Blessina Kumar facilitated the final session of the day, a formal introduction to the basic principles of advocacy. Through an interactive presentation, she defined the nature of advocacy, the people and processes it usually involves, the different kinds of advocacy and shared examples of advocacy for TB. She spoke of the importance of creating demand for high-quality services and a rights-based approach to TB. Finally, she encouraged participants to consider each barrier they had identified in the previous session as an advocacy opportunity.

The second day of the workshop ended at 3pm, so as to provide participants with an opportunity to explore New Delhi through a guided city tour.

Homework: Participants were asked to think about and identify the one aspect of TB advocacy they felt most passionately about. What was the one issue they wanted to continue working on?
DAY 3: 12 APRIL

The third day of the workshop began with a recap of the previous day by Ms Paransarimita Winarni from Indonesia.

Close your eyes.
Try and remember your favourite story, one you may have heard as a child.
Who told you the story?
Where were you sitting when you heard it?
What clothes were you hearing?

The first session of the day was on *Personal Narratives and Effective Storytelling* by Ms Anupama Srinivasan from REACH. This session focused on the importance of good storytelling, what a good story can achieve and some simple, practical ways to tell your story effectively and powerfully. Participants volunteered to tell their own stories using the ‘story spine’ structure discussed in the session and received feedback from their peers.

Continuing with the focus on storytelling, the next speaker was Ms Rhea Lobo, journalist and filmmaker, and a TB survivor herself. Ms Lobo spoke evocatively of how she had been affected by TB. She described how she had originally told her TB story, several years ago and contrasted it with how her storytelling has evolved. She shared the short film she had made several years ago (for a competition on TB organized by REACH) and critiqued it, along with the participants. Finally, Ms Lobo emphasized the importance of honest yet sensitive storytelling and urged participants to only share their stories when and if they felt comfortable, and not feel compelled to do so under any circumstances. All participants were then given time to begin the process of developing their personal narratives.
Even the most experienced advocate will concur that advocating to government requires special skills. This was the focus of the next session, led by Dr K S Sachdeva, Deputy Director General, National AIDS Control Programme, Ministry of Health and Family Welfare, Government of India. In his brief session, Dr Sachdeva addressed several key issues including the building and sustaining of community networks, the relevance of social protection schemes and the need for all stakeholders to contribute to the creation of a supportive environment.

In the penultimate session of the day, participants had an opportunity to learnt about advocating to parliamentarians and other elected representatives. Facilitated by Dr Indira Behera and Ms Sukriti Chauhan from Global Health Strategies, the session addressed how best to advocate effectively to parliamentarians, given their ability to influence how programmes and policies are both designed and implemented.

The final session of the day saw participants begin the process of developing their individual advocacy plans, based on a framework developed by REACH. The framework required them to clearly identify -

- An advocacy goal
- The stakeholders they needed to address
- The activities they needed to undertake in order to achieve the goal
- Their desired or anticipated outcomes
- The resources/support they would need
- The challenges they anticipated
Participants received support from each other and from Ms Kumar, Ms Annapoorni and Ms Mahesh, who provided feedback and offered suggestions to strengthen their plans.
DAY 4: 13 APRIL

The final day of the workshop began with a brief recap of the previous day by Mr Tieng from Cambodia.

In the first session of the day, participants gathered in small groups for peer review of their draft advocacy plans. They shared their goals and activities and sought inputs from others on how realistic their plans were and how they could be improved. Some participants also seized the opportunity to practice effective storytelling and get feedback from their peers on how they could tell their stories more powerfully.

Network building was the focus of the next session, through a panel discussion moderated by Ms Mona Balani and featuring Ms Paran from Indonesia, Ms Maricel from Philippines and Mr Subrat Mohanty from The Union South-East Asia Office. Each panelist spoke briefly about networks they had been part of and their relative strengths and weaknesses. Mr Mohanty drew attention to the immense value of a powerful community network and its potential contribution to the response to TB. The robust open discussion that followed addressed a range of issues including the reasons for the failure of networks, how networks could work with the government (rather than as adversaries) and the role of those affected by TB in network-building.

The final session of the day, saw participants reflecting on the workshop and offering valuable feedback to REACH.
VALEDICTORY SESSION

The valedictory session of the workshop was held at Hotel Ambassador in New Delhi.

Speaking at the valedictory session, Dr Sunil D Khaparde, Deputy Director General, TB, Central TB Division, Ministry of Health and Family Welfare, Government of India said, “The voice of the survivor becomes the voice of India. In TB, there is a dual stigma – one is the disease itself but the other is poverty. This dual stigma can be explained best by the TB survivors. The TB fight is not finished – but survivors will help us get there. TB survivors at different levels can be great ambassadors and pass the message very efficiently so that TB loses, and we all win”.

Also addressing the group, Mr Xerses Sidhwa, Director of Health at USAID/India, said: “USAID is proud to support this workshop, which helps TB survivors to become powerful agents of change in India and other regional countries. It is critical that we actively engage TB champions in designing and implementing programs and advocating for policy change. Their experiences can guide the way forward as we move toward a TB-free India and world.”

Dr Khaparde and Mr Sidhwa presented certificates to all the participants. A short video on the workshop, developed by the Stop TB Partnership, was screened. Four participants – Mr Arun Rana and Mr Dean Lewis from India, Ms Cherry Florida from the Philippines and Ms Lusiana Aprilawati from Indonesia shared their TB stories and reflected on their experience of participating in the workshop.
Advocacy Mentorship Programme
In keeping with the Call to Action project’s mandate to support a long-term role for trained, committed TB advocates, REACH launched an advocacy mentorship programme at the workshop. This is open to TB survivors and those who have been directly affected by the disease, and those who are keen to assume the role of advocates. Eleven of the 14 participants from India signed up for the programme and have each been subsequently linked to a mentor. Over the next six months, all 11 advocates will be supported to develop and execute a strategic advocacy plan, with clear goals, activities and intended outcomes. Mentors will provide individual, customized support to each advocate s/he mentors and act as a guide and sounding board to the advocate to ensure that s/he is able to carry out their advocacy effectively. REACH is committed to expanding this mentorship programme and envisages a rolling system where this year’s advocates become mentors for the next batch and so on, thereby contributing to a pool of well-trained and effective advocates in India.

The TB Champions Video Series
The ‘silence’ around TB is, in part, related to the paucity of public testimonials from those who have been affected by the disease. Subsequently, a key objective of the workshop was to develop a series of short videos as well as photographs featuring workshop participants. Personal narratives have the immense potential to both improve general awareness of TB and destigmatize the TB experience. In addition, participants felt the process of telling their stories would be a learning experience for them and would encourage them to speak more boldly and openly.
A series of 12 short films has been developed and will be widely disseminated in the coming months. This document will be updated with the video link once it is available.

**Network Formation**

During the workshop, participants from India held several discussions on the urgent need for a network or coalition of those affected by TB. This has since resulted in the formation of *Touched by TB: The Coalition of TB People in India*. At the first ‘official’ meeting held on the last day of the workshop, the group identified national coordinators as well as regional focal points.

In keeping with their self-identified mandate to support the TB programme in India, they agreed on several key objectives:

- To create and sustain a coordinated and capacitated national coalition of people affected by TB
- To ensure that the voice and the wisdom of the lived experience of the community is heard across all platforms including health policy, service delivery and resource distribution
- To ensure treatment literacy and awareness for people living with TB
- To build the capacity of TB advocates
- To overcome barriers to TB treatment and diagnostics
- To advocate for acceptable, accessible, compassionate, comprehensive, rights-based services for people irrespective of age or gender
- To network with and build linkages with other agencies and groups across the country, regionally and globally
- To network with and support the Ministry of Health and the RNTCP and its partners to achieve the goal of ending TB in India by 2025.

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**Announcing the formal launch of**

*Touched by TB*

One person dies of TB in India every single minute. TB is a silent killer that is preventable and curable, if society at large comes together to fight it.

Keeping this in mind, and the urgent need to make affected voices heard from varied groups to fight TB, the coalition of TB people in India - *Touched by TB* was formed. The first meeting took place on April 13, 2017 in New Delhi at the Regional Capacity Building workshop for TB Survivors organized by REACH.

The participants were from different states who recognized the gap of a national level body and expressed the urgent need and desire to form a national coalition of people who have survived TB. The network decided that in line with the RNTCP commitment, the goal of *Touched By TB* is "TOWARDS A TB-FREE INDIA"

To meet this goal, following commitments were articulated which will translate into the aims and objectives of the Coalition:

- To create and sustain a coordinated and capacitated national coalition of people affected by TB
- To ensure that the voice and the wisdom of the lived experience of the community is heard across all platforms including health policy, service delivery and resource distribution
- To ensure treatment literacy and awareness for people living with TB
- To build the capacity of TB advocates
- To overcome barriers to TB treatment and diagnostics
- To advocate for acceptable, accessible, compassionate, comprehensive, rights-based services for people irrespective of age or gender
- To network with and build linkages with other agencies and groups across the country, regionally and globally
- To network with and support the Ministry of Health and the RNTCP and its partners to achieve the goal of ending TB in India by 2025

The Coalition has 5 regional focal points:

- North East – Mr. Tilak Muntun
- East – Dr. Santosh Kumar Giri
- North – Ms. Monu Salani
- West – Ms. Priyanka Mahesh
- South – Mr. Rama Pandian

Any resident of India who has had TB and would like to be part of the efforts to end TB, please email us at touchedbytbindia@gmail.com to join the membership.
Feedback from participants

Overall, 28 participants offered their feedback on the workshop.

- On a scale of 1-5, 1 being the lowest and 5 the highest, 96% of participants rated the overall content of the workshop as 4 and above.
- The four sessions participants found most useful were:
  - Pathways through Care
  - Developing Advocacy Plans
  - Network building: Opportunities & Challenges
  - Personal Narratives: An introduction to storytelling
- 97% of participants judged the workshop sessions to be highly participatory in nature and felt they had adequate opportunities to voice their opinions.
- The majority of participants felt all the important TB issues had been addressed in the workshop.
- Over 65% of participants felt the workshop had exceeded their expectations.
- Participants identified issues and topics they felt could have been included or addressed in greater detail including:
  - Engagement of the private sector;
  - Discussion on medical curriculum;
  - An enhanced focus on network-building;
  - Capacity-building for policy and programme analysis.
ANNEXURE A: LIST OF PARTICIPANTS

Bangladesh
1. Mr Golam Mourtoza
2. Mr SK Anwar Hossain
3. Mr Isbat Azmary Rifat

Vietnam
4. Ms Pham Thuy Duong

Indonesia
5. Ms Paransarimita Winarni
6. Ms Lusiana Aprilawati
7. Mr. Erman
8. Ms. Farida Ari Kusuma

Philippines
9. Ms Maricel Rovillos Buen
10. Mr John Stuart Pancho
11. Ms Mildred Fernando Pancho
12. Mr Mark Aethen Gallano Agana
13. Ms Cherry Ramos Florida

Cambodia
14. Mr. Chhoeut Sarun
15. Mr. Choeurn Tieng

India
16. Mr Mutum Tilak Singh, Manipur
17. Mr Ramasamy Pandian, Tamilnadu
18. Mr. Yogesh Balkrishna Bhalerao, Maharashtra
19. Mr. Cedric Gregory Fernandes, Maharashtra
20. Mr Dean Savio Peter Lewis, Maharashtra
21. Ms Alma Ram, Punjab
22. Dr Reeta Sahoo, Odisha
23. Ms. Amrita Limbu, Tamilnadu
24. Ms. Mona Balani, New Delhi
25. Mr. Arun Singh Rana, New Delhi
26. Mr. Amogh Mangalore, Maharashtra
27. Dr Gopakumar, New Delhi
28. Mr Chinmay Modi, New Delhi
29. Mr Faiz Anwar, Jharkhand
30. Dr Santosh Giri, West Bengal
## ANNEXURE B: WORKSHOP AGENDA

### 10 APRIL, DAY 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Session Title</th>
<th>Session Facilitator/Speaker</th>
</tr>
</thead>
<tbody>
<tr>
<td>08:45 – 09:15</td>
<td>Registration</td>
<td>REACH team</td>
</tr>
<tr>
<td>09:15 – 10:00</td>
<td>Welcome &amp; Opening Remarks</td>
<td>Dr Nalini Krishnan, Director, REACH&lt;br&gt;Sarah Rugnetta, Programme and Policy Advisor, USAID&lt;br&gt;Lucica Ditiu, Executive Director, Stop TB Partnership</td>
</tr>
<tr>
<td>10:00 – 10:15</td>
<td>Workshop Overview &amp; Objectives</td>
<td>Anupama Srinivasan, REACH</td>
</tr>
<tr>
<td>10:15 – 12:45</td>
<td>Participatory Session &lt;br&gt;Your Story &lt;br&gt;(Break for Tea/Coffee during the session)</td>
<td>Facilitated by Blessina Kumar</td>
</tr>
<tr>
<td>12:45 – 13:45</td>
<td>Lunch</td>
<td></td>
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<tr>
<td>13:45 – 15:00</td>
<td>Quiz &lt;br&gt;Basic Science of TB</td>
<td>Blessina Kumar</td>
</tr>
<tr>
<td>15:00 – 16:30</td>
<td>Presentation &amp; Discussion &lt;br&gt;The big picture: An overview of Key Issues in TB &amp; The Global Plan to End TB &lt;br&gt;(Break for Tea/Coffee during the session)</td>
<td>Blessina Kumar&lt;br&gt;Caoimhe Smythe</td>
</tr>
<tr>
<td>16:30 – 17:00</td>
<td>Open discussion &lt;br&gt;My role in the response to TB</td>
<td>Blessina Kumar&lt;br&gt;Caoimhe Smythe</td>
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<tr>
<td>18:30 onwards</td>
<td>Welcome Dinner</td>
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## 11 APRIL, DAY 2

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<tr>
<th>Time</th>
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<th>Session Facilitator/ Speaker</th>
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<tbody>
<tr>
<td>09:00 – 09:15</td>
<td>Recap Day 1 and outline of Day 2</td>
<td>Participants</td>
</tr>
<tr>
<td>09:15 – 10:30</td>
<td>Group Work&lt;br&gt; Pathways through Care</td>
<td>Blessina Kumar&lt;br&gt; Caoimhe Smythe&lt;br&gt; Anupama Srinivasan</td>
</tr>
<tr>
<td>10:30 – 10:45</td>
<td>Morning Tea/Coffee</td>
<td></td>
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<tr>
<td>10:45 – 12:00</td>
<td>Presentation &amp; Discussion&lt;br&gt; Advocacy for TB: First steps</td>
<td>Blessina Kumar</td>
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<tr>
<td>12:00 – 13:30</td>
<td>Group work&lt;br&gt; From Barriers to Advocacy</td>
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<td>13:30 – 14:30</td>
<td>Lunch</td>
<td></td>
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## 12 APRIL, DAY 3

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<td>09:00 – 09:15</td>
<td>Recap Day 2 and outline of Day 3</td>
<td>Participants</td>
</tr>
<tr>
<td>09:15 – 11:30</td>
<td>Presentation &amp; Individual work&lt;br&gt; Personal Narratives: An introduction to storytelling</td>
<td>Anupama Srinivasan, REACH&lt;br&gt; Rhea Lobo, Journalist, Filmmaker &amp; TB Advocate</td>
</tr>
<tr>
<td>11:30 – 11:45</td>
<td>Morning Tea/Coffee</td>
<td></td>
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<tr>
<td>11:45 - 12:30</td>
<td>Presentation &amp; Discussion&lt;br&gt; Advocating to Government</td>
<td>Dr K S Sachdeva, MoHFW</td>
</tr>
<tr>
<td>12:30 – 13:15</td>
<td>Presentation &amp; Discussion&lt;br&gt; Advocating to elected representatives</td>
<td>Indira Behera &amp; Sukriti Chauhan, Global Health Strategies</td>
</tr>
<tr>
<td>13:15 – 14:15</td>
<td>Lunch</td>
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<tr>
<td>14:15 – 17:00</td>
<td>Interactive Session&lt;br&gt; Introduction to Mentorship Programme and Developing Advocacy Plans</td>
<td>Blessina Kumar&lt;br&gt; Prabha Mahesh&lt;br&gt; Mercy Annapoorni&lt;br&gt; REACH Team&lt;br&gt; Stop TB Team</td>
</tr>
<tr>
<td>Time</td>
<td>Session Title</td>
<td>Session Facilitator/Speaker</td>
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<td>---------------------------------------------</td>
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<tr>
<td>09:00 – 09:15</td>
<td>Recap Day 3 and outline of Day 4</td>
<td>Participants</td>
</tr>
<tr>
<td>09:15 – 10:45</td>
<td>Panel discussion</td>
<td>Chaired by Subrat Mohanty, The Union</td>
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<tr>
<td></td>
<td>Network-building: Opportunities &amp; Challenges</td>
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<tr>
<td>10:45 – 11:00</td>
<td>Morning Tea/Coffee</td>
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<tr>
<td>11:00 – 12:30</td>
<td>Circle Time</td>
<td>All participants and facilitators</td>
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<tr>
<td></td>
<td>Our Plans</td>
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<tr>
<td>12:30 – 13:15</td>
<td>Lunch</td>
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<tr>
<td>13:45</td>
<td>Departure from Tivoli</td>
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<tr>
<td>15:00 – 17:00</td>
<td>Valedictory Programme</td>
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<td></td>
<td>(At Hotel Ambassador, Vivanta by Taj)</td>
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</tbody>
</table>
## Annexure C
### Pathways Through Care: A Summary Analysis of Barriers & Obstacles

#### Barriers at the System Level

<table>
<thead>
<tr>
<th>Developing Symptoms</th>
<th>Seeking Care</th>
<th>Getting a Diagnosis</th>
<th>Starting Treatment</th>
<th>Completing Treatment</th>
<th>Getting Cured</th>
<th>Getting Back on Track</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited availability of clear information on TB within the health system or for the general public</td>
<td>Lack of clear information on what to do</td>
<td>Lack of clear information on where to go</td>
<td>Lack of counseling</td>
<td>Service delivery system not flexible ( timings)</td>
<td>Inadequate information on impact of missing doses</td>
<td>No employment</td>
</tr>
<tr>
<td>Lack of support from family/employers</td>
<td>Limited access – nearest centre often too far</td>
<td>Limited access – nearest centre often too far</td>
<td>Treatment centres far away</td>
<td>Poor communication by health staff</td>
<td>No counseling received</td>
<td>No social security</td>
</tr>
<tr>
<td>Financial restrictions</td>
<td>Financial restrictions</td>
<td>Financial restrictions</td>
<td>Availability of drugs occasionally an issue</td>
<td>Lack of nutritional support</td>
<td>Adverse drug reactions</td>
<td>No support group</td>
</tr>
<tr>
<td>Insensitive and unfriendly health workers</td>
<td>Quality of diagnosis</td>
<td>Quality of diagnosis</td>
<td>Unavailability of trained manpower at labs</td>
<td>Inability to support treatment financially</td>
<td>Loss of employment</td>
<td>No contact with counselor</td>
</tr>
<tr>
<td>Poor explanation of diagnosis</td>
<td>Unavailability of trained manpower at labs</td>
<td>Poor explanation of diagnosis</td>
<td>Poor explanation of diagnosis</td>
<td>No counseling received</td>
<td>Migration</td>
<td>Poverty</td>
</tr>
</tbody>
</table>
### BARRIERS AT THE INDIVIDUAL/COMMUNITY LEVEL

**DEVELOPING SYMPTOMS**
- Poor understanding of TB
- Lack of support from family
- Superstitious or religious beliefs
- Tendency to self-medicate
- Opioid use

**SEEKING CARE**
- Lack of clear information
- Poor health-seeking behavior (health often not a priority)
- Fear of stigma
- Lack of support from family
- Financial restrictions

**GETTING A DIAGNOSIS**
- Financial restrictions
- Tendency to seek care in a private facility
- Difficulty in producing sputum

**STARTING TREATMENT**
- Lack of counseling
- Fear of side effects
- Forgetting to take medication
- Difficulty swallowing all the pills

**COMPLETING TREATMENT**
- Poor nutritional status
- Inability to support treatment financially
- Loss of employment
- Migration

**GETTING CURED**
- Unhealthy lifestyle
- No motivation to complete treatment

**GETTING BACK ON TRACK**
- No employment
- No social security
- No support group
- Poverty

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**BARRIERS AT EVERY STAGE**

*Lack of clear information*  
*Stigma and discrimination*  
*Fear of losing family/partner/friends/jobs*
This report is, in part, made possible by the support of the American People through the United States Agency for International Development (USAID). The contents of this report are the sole responsibility of REACH and do not necessarily reflect the views of USAID or the United States Government.