

Tokyo Statement on Community Engagement in End TB Strategy

Asian National Stop TB Partnership Forum 2016

The Asian National Stop TB Partnership Forum 2016 was held on March 14-15, in Tokyo, Japan, with the participation of a total of 18 delegates from 8 Asian countries / territories (Cambodia, Indonesia, Korea, Myanmar, Nepal, Philippines, Taiwan, and Thailand). These participants represented the non-governmental organizations (NGO) and other civil society organizations (CSO) engaged in tuberculosis control.

The missions of the Forum were;

- To enhance people's awareness of the importance of their ownership for and commitment to tuberculosis control activities,
- To promote the effective collaboration between governmental and non-governmental sectors in the fight against tuberculosis, with special reference to the potentiality of women's roles,
- To clarify the problems and challenges of tuberculosis control of each target area or community to be addressed in their action plans, and
- To advance cooperation between partners of different groups beyond country borders.

During the two-day meeting the participants shared their experiences and views of their groups, as well as those of the Women's anti-TB Association and Western Pacific Region of WHO, and had discussions over the ways to enhance respective group' activities in the perspective of End TB Strategy. Following are the summary findings of presentations, discussions, and proposals from the forum, as agreed upon by all the participants.

Background: Paradigm shift in the fight against tuberculosis

Along with the paradigm shift from the Millennium Development Goals to Sustainable Development Goals, the global TB program has turned to End TB Strategy as endorsed in 2014. In this strategy, tuberculosis is recognized more clearly than ever as a socio-economic challenge, not merely as a medical issue, to which more engagement of communities, or non-governmental organizations, is badly needed, as

claimed throughout the pillars of the strategy. Specifically, integrated, patient-centered TB care and prevention is claimed as the fundamental element in Pillar 1. This is also stressed in the Regional Framework developed by WPRO, adapting the End TB Strategy to its regions.

Roles of NGOs in End TB Strategies: Missions, Opportunities, and Challenges

In country presentations and group discussions, the following four points were highlighted as important roles of NGOs / CSOs, each with special emphasis as supplemented in numbers 1, 2, Although the roles and challenges of NGOs/CSOs are diverse and variable according to the countries and organizations, the key issues such as community and patient-oriented approach were common, and this sharing was felt as most critical in promoting the spirit of the stop TB partnership.

1) Cooperation with the government in implementing NTP

1. Supporting TB case detection through urging symptomatic subjects, or TB suspects, to visit health facilities.
2. Encouraging patients to take medications regularly.
3. Increasing the awareness and knowledge of TB among community people on various occasions to reduce the stigma, discrimination and superstition, and to take proper action against illnesses.

2) Social support of patients and families

1. Supporting, educating, and empowering patients and their family facing financial barriers through forging UHC.
2. Providing patients with food, transport, housing, etc., as important areas of patient support.

3) Advocacy

1. Advocating voices of patients and vulnerable people.
2. Increasing awareness of TB among the community.
3. Creating patients' groups, so that they have a stronger voice for claiming better service and protection, and also enhancing community awareness of TB.
4. Creating peer support groups with high capacity to support vulnerable groups (e.g.,

the very poor, women, children, HIV-infected or elderly persons, etc.).

5. Advocating research for TB control, especially operational researches and researches involving community activities.
6. Engage other areas of the society/community with TB, such as education, agriculture and MCH, etc..
7. Empower health activists and volunteers to set up networks at grass-root level involving other community members

4) Women's roles and potentials

1. Gender equity should be addressed in TB care, including access to health services and knowledge of TB.
2. Women's potential in community activities should be fully recognized.

Fund raising issues

Many groups suffer from inadequate budgets, but few of them use specific schemes of their own for fund raising, e.g., Christmas-seal campaign, Calendar sales, donation box (in shops, etc.), and charity events, in addition to donations from individuals (group members and others) and companies.

Other funding sources include government programs, the Global Fund, WHO, Union, Stop TB Partnership, UNICEF, other bilateral plans (e.g., JATA, USAID, TBREACH), and charitable foundations.

Apart from the inadequacy of funds, possible concern may exist for receiving donations from pharmaceutical industries (in some countries, also other health-related businesses), to say nothing of donations from tobacco and alcohol industries.

Challenges

1. The high turn-over rate of volunteers is common, possibly due to inadequate incentives and lack of community recognition, or volunteers' dignity.
2. Incentives for volunteers may include privileged free access to health services, periodic meetings for reporting volunteers' activities, opportunities of training and exchange with other groups, awarding for outstanding performance, and provision of travel allowances.
3. Addressing patient's confidentiality or privacy.
4. In some cases, consensus between government and NGOs is not enough, and some

- care providers have difficulty in implementing International Standards of TB Care.
5. Low capacity of research activities, when NGO's operational research is expected as very significant, especially in UHC and social protection schemes.
 6. Documentation of success stories of community activities may be important in sharing recognition of bases of TB control such as UHC and patient-centered care.

Forum slogan

The forum decided to adopt a following slogan to be shared by member organizations as a priority message of activities.

- Women are creators of community health through family health.

Acknowledgement

The Forum acknowledges the contribution and efforts of the following individuals and organizations that made the meeting possible and successful. The Forum also expresses deep thanks to the observers for their kind interest in the meeting.

Participants

[Organization] Cambodia: National Center for TB and Leprosy control (CENAT), Cambodia Anti-Tuberculosis Association (CATA). Indonesia: Headquarters of Forum Stop TB Partnership Indonesia and Stop TB Partnership Cimahi City, Korea: Korean National Tuberculosis Association (KNTA), Stop TB Partnership Korea, Myanmar: Myanmar Maternal Welfare Association (MMWA), National Tuberculosis Program, Kachin State, Nepal: Japan-Nepal Health & TB Research Association (JANTRA), Philippines: RIT/JATA, Philippines Inc. (RJPI), Taiwan: Taiwan Anti-TB Association (TATA), National Chang-Hua Hospital MDR TB Department, Thailand: TB/HIV Research Foundation (THRF), Chiang Rai Volunteer Ladies against TB

[Member] Cambodia: Khloeung Phally, Monyrath Chry, Chharvy Ringsey Keo, Indonesia: Mariani Reksoprodjo, Fitriani Manan, Korea: Seungjoon Chang, Kanghee Kim, Hong Jo Choi, Myanmar: Tha Zin Nw, . . . , Ei Ei Chaw, Nepal: Ram Sharan Gopali, Jamuna Panthi, Philippines: Aurora G Querri, Leonardo G. Parungo Jr, Taiwan: Chih-Yun Lin, Wei-Wen Chen, Thailand: Sarmwai Luangjina, Jintana Ngamvitayapong-Yanai

Staff

[Organization] Stop TB Partnership Japan, Japan Anti-Tuberculosis Association (JATA), Research Institute of Tuberculosis, JATA, Council of Japanese Women's Anti-Tuberculosis Associations, Western Pacific Regional Office of World Health Organization

[Member] Ram Sharan Gopali, Makiko Goto, Yumi Ishikane, Nobukatsu Ishikawa, Shoji Kudo, Ayako Miyamoto, Toru Mori, Nobuyuki Nishikiori, Jintana Ngamvitayapong-Yanai Kosuke Okada, Kintaro Shibuya, Noriko Shirasu, Noriyo Shimoya, Keiji Tanaka, Tomoko Tsuji, Takeko Yamashita