



# Building Capacity for TB Advocacy, Communication and Social Mobilization

Workshop Report  
Doctors of the World-USA



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## BUILDING CAPACITY FOR TB ADVOCACY, COMMUNICATION AND SOCIAL MOBILIZATION

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*"I have no pension, no job. I am lucky to have my wife. There was a particularly bad month when I almost became paralyzed with the symptoms. But I left the sanatorium. I wouldn't stay longer. I couldn't handle it anymore. It was too much like prison. I came home from the sanatorium and started drinking and smoking. After five months, I was sick again and went back to the sanatorium for two months. I had trouble completing my treatment. No one would help me, I got mad. I get mad easily."*

- Romanian TB patient, former prisoner, cured of TB

*"He went to the TB dispensary but he wasn't registered there so they didn't help him. He fought with them and was made to leave. I used to know him as a child. I knew how to approach him. I told him his past crimes had nothing to do with his and his family's health today. What's done is done. Whatever happened, you don't need to die or infect other people. The most important thing was to persuade him to go, to persuade him the disease was curable."*

- Romanian nurse who eventually treated this patient  
(DOW TB Partnership Project)

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### Summary of Workshop Proceedings

Among the challenges facing the tuberculosis (TB) community, reaching patients and communities is a key recurring issue. The new Global Plan to Stop TB (2006-2015) and the country level strategic framework for advocacy, communication and social mobilization (ACSM) to support TB call for engagement from all providers and affected communities. It is clear that the TB community needs to do more to detect and cure those suffering from TB while reducing stigma and increasing resources.

Doctors of the World-USA (DOW) conducted a one-day workshop to discuss emerging topics related to ACSM for TB, present current NGO models and provide a short training on ACSM concepts. The workshop was held at the 37<sup>th</sup> Union World Conference on Lung Health in Paris and was open to all stakeholders / actors interested in expanding TB control strategies through ACSM.

The large and diverse attendance at the workshop showed the interest and commitment to using multiple and new approaches for increasing case detection and treatment completion rates while decreasing TB related stigma and discrimination. The workshop utilized both presentation format and small group exercises although the latter proved to attract fewer participants. The participation from national TB control program (NTP) staff from various countries matched that of NGO staff which was notable, as these individuals were not necessarily charged with communication and outreach approaches in their work but clearly saw the need for it. In many cases, the NTP representatives were not aware of NGOs working in their regions, suggesting the need to engage multiple channels of communication and partnerships.

Participants were well informed about difficulties faced by TB patients and programmers in their home environments and stressed the need for models and training for ACSM skills. Case study presentations showed that approaches usually applied by NGOs for greater community involvement and policy change can be applied to TB control without compromising recommended standards. Furthermore, in addition to affected communities, ACSM approaches can benefit other stakeholders including health authorities and providers.

Stigma and community mobilization including engagement of patients were recurring and important themes. The most relevant skill set needs identified by workshop participants included communication techniques for different audiences, new approaches to securing local funding sources, maintaining a consistent media focus on TB throughout the year, and mobilizing efforts for greater TB-HIV integration.

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## **Recommendations**

Based on the workshop activities, the following recommendations emerge:

- ◆ NGOs and NTPs are allies in the fight against TB. Both should make efforts to work together. Successful partnership models can be gleaned from other health areas such as maternal and child health or HIV programs which usually have greater community involvement.
  - ◆ NTPs should promote involvement of affected communities and patients through their local divisions. NTPs should ask first line health workers to invite engaged patients to working group meetings or public forums.
  - ◆ NTPs and NGOs together can create easily adaptable ACSM training guides for different stakeholders in country. These should include ways to integrate TB into ongoing advocacy and service programs.
  - ◆ Together with the Stop TB partnership, NTPs and NGOs should create a pool of diverse expert ACSM trainers in each country to implement training and consult on strategy.
  - ◆ Providers, who are often the first stop for accessing health services, can be advocates for ACSM strategy development and implementation for improved quality of care for their patients.
  - ◆ Donors should consider patient and affected community involvement as a component of TB programming.
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## **Workshop Objectives**

The workshop aimed to provide participants with tools to: 1) analyze barriers to TB care including at the policy and service levels; 2) develop public advocacy messages and methods to address barriers to access; 3) develop partnerships with community and health system representatives; and 4) train, mobilize and network community advocates.

## **Workshop Format**

The workshop was a one-day activity for program managers, NGO staff, community health workers, providers and patient advocates. The speakers were public health practitioners who presented on their personal and organizational experience in the area of ACSM as it pertains to TB. Active discussion through-out the day was encouraged. Participants were exposed to frameworks and case studies to plan and implement advocacy campaigns at multiple levels, from the national TB control program to district health centers and community settings. Strategies for the engagement of various actors in TB-related ACSM were also discussed. The morning session focused on establishing a global context with examples from specific projects at the country to regional levels in a presentation format. The afternoon session focused on skills and tools for ACSM and participants engaged in

interactive small-group exercises.

## **Attendees**

Approximately 70 people attended the formal presentation portion of the workshop in the morning and over 20 completed the intensive afternoon exercises.

Attendees were a diverse group, including representatives from international NGOs, NTPs, and bilateral agencies. International and bilateral organizations included Mercy Corps (Pakistan staff), Project Hope (Central Asia staff), the World Lung Foundation, Fidelis, the International Committee for Red Cross, the Brazil Institute in Social Health, the Centers for Disease Control – Global AIDS Program (Cambodia staff), and the IUATLD. Other countries represented included Bangladesh, Germany, India, Kenya, Malawi, Myanmar, the Philippines, Russia, South Africa, Tanzania, and Uganda.

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## **Introduction: Advocacy, Communication and Social Mobilization (ACSM)**

Alka Dev, Program Manager - DOW, opened the workshop by welcoming all participants. She followed with a brief presentation on the 10-year framework for action, published by the ACSM Subgroup at Country Level of the Stop-TB partnership. Copies of the framework were also distributed to all participants. The following working definitions were presented<sup>1</sup>:

***Advocacy:*** Advocacy for TB is to be understood as a broad set of coordinated interventions, designed to place TB high on the political and development agenda, foster political will, and increase and sustain financial and other resources.

***Communication:*** Within countries, and in the context of TB Control, communication primarily seeks to create and improve knowledge among the general public about TB (e.g. its symptoms and curability), TB control services (e.g. diagnosis and treatment) and improve interpersonal communication between patients and program providers contributing to behavioral change or to meet a particular behavioral goal.

***Social Mobilization:*** In the national and sub-national contexts, social mobilization is a process of generating public will by actively securing broad consensus and social commitment within civil society to fight stigma and eliminate TB as a public health threat. That is, social mobilization seeks to convert knowledge into demonstrable action.

Participants were asked to list what they considered to be the most pressing issues or “hot topics” for ACSM and TB at this time and issues that they wanted to bring into the discussion for the day. Listed topics have been grouped together by category below but original language is kept intact when possible:

### Information needs

- ♦ International strategies for different target groups
- ♦ Models of advocacy and communication

### TB programming

- ♦ Improving adherence to treatment and ideas to improve case finding
- ♦ Accessible care
- ♦ Improving access to public services, including TB treatment, for people living in extreme poverty
- ♦ Joint focus on Eastern European countries that are on the periphery of W. Europe

### TB/HIV linkage

- ♦ How best to bring in ASCM without one program affecting the other
- ♦ Addressing TB stigma in relation to HIV
- ♦ Encouraging people to use health services and get tested for HIV
- ♦ Social mobilization – especially with human resource constraints and increasing HIV rates

### ACSM strategy development

- ♦ Incorporating social mobilization strategies into country structure/program
- ♦ Institutionalizing ACSM within owners of programs – public sector
- ♦ Increasing community involvement
- ♦ Differentiating between A,C, and SM
- ♦ How to reach the business sector with different approaches
- ♦ Involving patients in TB care
- ♦ Community level communication to engage marginalized groups
- ♦ Country level communication and social mobilization beyond World TB Day
- ♦ The communication challenge of XDR TB
- ♦ Engendering sense of social responsibility within communities for case finding and case holding
- ♦ Finding government funding and support
- ♦ Importance of physicians willing to work with communities
- ♦ Scheme for community DOTS
- ♦ How to involve community in ACSM
- ♦ Mobilizing community in counseling and case reporting

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## **Presentation: Civil Society Perspectives on TB-HIV Policy – Public Health Watch**

Three members of the Open Society Institute (OSI)'s Public Health Watch (PHW) project presented on PHW's ongoing efforts to strengthen meaningful and sustained engagement by affected communities in the development, implementation, and monitoring of TB and HIV policies. Emily Bell, Project Officer – PHW, outlined their model of community-led monitoring as a tool for national and international advocacy. Afsan Chowdhury, Director of Advocacy and Human rights - Bangladesh Rural Advancement Committee (BRAC), highlighted examples from Bangladesh of how an NGO can work in partnership with the government to increase social mobilization around TB. Ezio Távora dos Santos Filho, a health activist from Brazil, provided a case for why HIV/AIDS and TB advocacy need to come together and integrating TB with other social problems.

Ms. Bell stressed the need to scrutinize how policy is developed, including a deeper analysis of World Health Organization (WHO) and Ministry of Health (MOH) statistics in order to monitor both government and donor policies and for understanding the discrepancy between policies and realities on the ground. Following on this, she presented on PHW's interdisciplinary approach to monitoring TB-HIV policy, which focused on five countries from 2004-2007: Bangladesh, Brazil, Nigeria, Tanzania and Thailand.<sup>2</sup> PHW partnered with civil society researchers in each country to convene a local advisory group to help shape research efforts resulting in advocacy for stronger policies and increased social mobilization efforts. For example, in Tanzania, research showed that even though treatment is free, there are many "hidden" barriers to accessing care such as days lost from work and financial choices between buying food and accessing care.

Mr. Chowdhury elaborated on PHW's approach by highlighting BRAC's activities in Bangladesh where advocacy efforts have shifted the focus on TB from a disease to a social problem. This has revealed the lack of engagement between the medical system and civil society as TB is managed by public authorities. Building on BRAC's focus on poverty alleviation, the organization promotes civil society participation at sub-national and local levels, working as a partner to the government but also acting as a direct service delivery agent. BRAC has been able to capitalize on the micro-credit model by partnering with organizations of women in each village to serve as a community volunteer member, thereby focusing on social communication as a means of engaging communities and not just

individuals. Currently, BRAC has close to 60,000 volunteer *Shastho Shebikas* or health care givers and an additional 11,000 employees to support a wide range of activities. Women trained to be *Shastho Shebikas* have received training in TB and have been able to address the accessibility of drugs through a micro-credit model while building support for treatment uptake through advocacy efforts. Empowerment of women has allowed the implementation of larger ideas for social mobilization. BRAC has also focused in recent years on media engagement by, for example, working with the media to present real stories to reflect on national data. For BRAC, civil society participation is not an add-on to national TB programming, but a key component, enabling entire villages to know the basic symptoms of TB, where to access care, and how to follow treatment for TB patients; TB becomes an issue for the entire village.

Mr. Santos Filho presented on his experience with mobilization of HIV communities in Brazil with regard to TB, which has been a challenge for physicians and program managers. Although the problem of TB had seemed to be subsiding due to the introduction of short-course therapy and integration into a medical model of care, the AIDS epidemic led to a boom in TB in the 1980's. It is likely that social mobilization for TB will not have a bottom-up approach as it has successfully had for HIV as the patients are not as mobilized to fight for greater treatment options. TB has been a neglected issue although it is the largest killer of people who are HIV-positive. Due to lack of information, people ignore the fact that TB is something that should be dealt together with HIV. In Brazil, 80 civil society organizations, mostly working on AIDS, deal with TB. So it may be most cost-effective for these established organizations to address TB-related care issues instead of establishing separate infrastructures for organizations solely dedicated to TB. It would be false to assume that civil society mobilization for TB can happen on its own due to the links between TB and poverty and the lack of resources at the individual and community level, as there are currently many misconceptions about TB. Similarly, TB managers also do not feel comfortable taking on the role of mobilizing TB patients or government resources as they have been working in a medical model. Therefore, engagement of AIDS NGOs in TB advocacy would create a necessary linkage between policy and the reduction of the TB burden at the community level.

#### **Key Messages:**

- ◆ Public Health Watch approaches monitoring as a tool for effective & informed policy advocacy.
- ◆ To generate true and sustained political will, internal pressure is necessary for engaged, well-informed individuals and communities to assess whether the government policies live up to the commitments made at the international level; to scrutinize whether and how the policy is implemented; to point out where the numbers may not reflect the full reality on the ground.
- ◆ The Public Health Watch approach aims not to duplicate official monitoring and data collection efforts, but rather to complement those primarily quantitative efforts with independent, qualitative commentary by individuals and communities of those most affected by TB.
- ◆ Civil society actors can be critical participants in health policymaking processes while offering constructive recommendations.
- ◆ TB activists can learn from and find synergistic opportunities with HIV/AIDS social mobilization efforts. In fact, in some contexts, existing HIV/AIDS activists may be the most effective partners for TB advocacy and activism
- ◆ Civil society efforts to promote social mobilization are not always at odds with governmental efforts.

## Audience Questions

Several questions were posed to Mr. Chowdhury about BRAC's experience with TB ACSM. In general, queries focused on the scope of BRAC's activities, vis-à-vis government programs, applicability of the BRAC experience in other countries, and the exact role of health workers within the organization. Mr. Chowdhury provided several useful comments:

- ♦ BRAC is one of 13 NGO partners working directly with the government in health service delivery and other efforts since the government's health delivery capacity is limited. As such, the organization supports government policy but uses a community-based model employing people from existing community networks. BRAC is highlighting the vulnerability of TB patients while many other organizations are ignoring TB.
- ♦ BRAC's experience can be replicable to other settings as village or community organizations exist most everywhere. Also effective would be training in social communication for health workers and behavior change programs at the individual, collective and institutional levels.
- ♦ BRAC's health workers (who also participate in its micro-credit program) sell medication, may screen people for symptoms of pulmonary TB and ensure DOT for diagnosed TB patients. Those who volunteer to be trained in TB are also eligible for a second loan.

Questions were also posed to Mr. dos Santos Filho about whether only HIV organization were involved with TB, specifically whether this might contribute to fewer resources being allocated for TB and whether TB-specific organizations wouldn't be more effective. Mr. dos Santos Filho stated that it is important to see TB as a co-infection due to the grave impact it has on HIV-positive people. Therefore, TB does not have to be dealt with only in isolation, but rather in its impact as a HIV co-infection. He suggested that, ultimately, there may not be an equally motivated organization of TB-affected people as with HIV since TB is curable. Therefore, mobilizing others affected by TB to include it in their agenda would boost the resources while reducing the costs of a concentrated TB effort. In addition to HIV organizations in Rio de Janeiro, other organizations also address TB, including those working with street children, associations of people living in slums, sex workers organizations, and women and children's groups. In this case, the recommended strategy is to include TB in other organizations' advocacy agendas. Notably in Rio, slum organizations have been most effective in social mobilization and applying DOTS. TB should not be removed from the agenda of non-TB groups that have chosen to take it on as an issue; but rather, more funding should be made available to them to address TB.

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## Presentation: Case Study – International Federation of Red Cross and Red Crescent Societies (The International Federation)

Dr. Lasha Gogvadze, Senior Health Officer, presented the role of National Red Cross and Red Crescent Societies in TB and HIV in affected communities. Tatyana Toichkina from the Moscow office of the International Federation joined the presentation during the discussion session.

Dr. Gogvadze presented key activities in TB advocacy, noting that the International Federation and Red Cross and Red Crescent Societies are credible partners in TB control due to their presence in 185 countries with the world's largest volunteer workforce, over 97 million people.

The International Federation and the Red Cross and Red Crescent Societies are playing a significant role to fight TB and HIV/AIDS by filling gaps rather than duplicating government efforts and serve as auxiliaries to these authorities. In addition, the main activities are taking place at the grassroots level with vulnerable people and communities. Within the framework of the Stop TB partnership, the

International Federation is focusing on the hardest to reach patients especially those in remote settings.

The key target groups include newly detected TB patients, multi-drug resistant (MDR) TB patients, continuation and ambulatory phase patients, as well as those meeting the criteria for social vulnerability. Working in partnership with health authorities, National Red Cross and Red Crescent Societies take a multi-level approach, providing TB education in communities but also giving technical assistance to authorities in diagnostic and treatment delivery, as well as at the policy level regarding compliance monitoring, social support, and patient education. Sputum testing and improved drug supply lie at the nexus of these efforts. Prevention, stigma and discrimination, as well as care and treatment form the backbones of the Red Cross / Red Crescent Societies' framework to reach people living with TB and HIV through local societies and volunteers to reach communities. Ultimately, the International Federation aims to: fill a gap in TB control programming, target the most vulnerable in the community, provide basic, standardized and targeted quality service to as many as possible and work in partnership with health authorities.

An example was provided of the Russian Red Cross Society's TB activities from 1999-2004, during which period, 82% of the 8,742 TB patients they reached were reported from different socially excluded and marginalized groups. Red Cross nurses and volunteers were able to target this group for DOT support, as well as case detection, defaulter tracing, treatment support groups and, when needed, legal aid.

**Key objectives of the International Federation's ACSM framework are to:**

- ♦ Make the TB epidemic (more) visible at country / district level.
- ♦ Advocate for internationally recommended strategies and policies.
- ♦ Mobilize the community and build its capacity to respond to the TB epidemic.
- ♦ Reach out to most vulnerable groups and challenge discrimination when it occurs.
- ♦ Understand stigma and discrimination better and learn more about effective interventions to reduce stigma and how / why they work.

## **Audience Questions**

Questions from the audience highlighted the difficulties in handling DOTS for mobile populations, the uptake of successful community and patient engagement models, and the logistics of training and informing a large number of volunteers. Dr. Goguadze noted that one of the TB project sites he reported on is dealing with almost all homeless patients, which has made DOTS implementation challenging but still possible. In terms of sustainability, Red Cross / Red Crescent Societies focus on integrating their social approaches into state budgets, as well as by replicating regionally. TB training for volunteers in particular is provided in-country through technical medical partners and national TB program; including on-the-job coaching, everyday facilitation, and a refresher course at two years. ACSM is one component of the general training.

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## **Presentation: Case Study – Doctors of the World-USA (DOW)**

David Berger, Country Director - DOW Romania, presented on DOW's experience with implementation of ACSM-related activities in the country, primarily the development of the national ACSM strategy. Following the political transition of 1989, Romania underwent a dramatic transformation of its economic and political system, leading to widespread poverty, few resources for

health care, and public health reform through transition to a private system. Many of the impacts of this transformation were felt most severely by the country's large disenfranchised minority population, the Roma, who lack primary care and confront numerous social problems.

In this context, TB is a major threat to the health of Romania's people, with an incidence of more than 10 times that of western European countries. Numbers of TB cases began steadily rising in 1990 and only recently show a sign of improvement after the implementation of a national DOTS strategy. In its program, DOW chose to work with health providers (GP and nurses), patients and their families, Roma and other vulnerable populations, as well as national and local TB control and public health actors. As an initial step to gather data that was not available in Romania, DOW implemented a baseline survey to measure the TB-related knowledge, attitudes and practices (KAP) among key target populations including TB patients, their families, providers and Roma. Detailed findings can be obtained from DOW but key results noted that:

Over half of providers surveyed recommend unnecessary practices such as having patients keep their personal articles separate from the rest of the family's belongings for TB prevention. Just as many providers mentioned a lack of patient education materials although almost all noted that patients' education was very important in order to control the spread of TB.

Many vulnerable populations (Roma, prisoners, low-income ethnic Romanians, and TB patient family members) had very low knowledge and awareness about the symptoms, illness, risks and treatment of TB. At varying levels, Romanians did not know that treatment is available.

The KAP studies served as an important source of information for planning the ACSM strategy. As part of this process, DOW focused on developing appropriate types of messages and communication objectives for different populations along with a specific strategy for the media channels to select for each target group. Concepts and materials were developed and pre-tested leading to the creation of TB informational materials and resources for providers and clinics, a TB health education campaign in Roma communities, a mass media campaign targeting vulnerable groups and general public as well as resources for schools and teachers.

In all, DOW's campaigns reached an estimated 12,000 individuals in vulnerable communities and over 600 TB suspects were referred to the appropriate health professionals/facilities for testing resulting in identification of 49 new TB patients. Over 32,000 informational materials (poster, flyers, and brochures) were disseminated and a paid media campaign about TB aired on television for three months, reaching over seven million people. Over 550 providers were trained on the DOTS strategy and patient communication skills via intensives workshops. Providers also received TB job aids and TB informational posters for their health facilities. This multi-prong approach allowed DOW to engage government authorities in providing concrete recommendations for developing a national ACSM strategy.

## **Audience Questions**

Questions for Mr. Berger focused on the process of evaluating DOW's program intervention in terms of costs, advocacy and capacity built, and the program's impact on case detection. Mr. Berger noted that ACSM effectiveness can certainly be measured through core TB indicators such as case detection, provided there is sufficient time in the program lifespan between implementation and TB data reporting. For sustainability, it is important to secure commitment from NTPs to incorporate education messages and to develop an ACSM strategy. In DOW's experience, significant increase in case detection was recorded in areas where the education activities were implemented.

Representatives from Project HOPE commented on utilizing a similar approach in central Asian countries to gain endorsement for their strategies from the Ministry of Health, and to use their

experience to develop national strategy.

**Important lessons for ACSM from DOW's program in Romania include:**

- ♦ Define needs and identifying priority audiences as well as key partners for content development and dissemination (national/local and community-based)
- ♦ Collect accurate baseline information on key indicators and utilizing pre-production formative evaluation
- ♦ Bring in partners early to develop sustainability or continuation plan

**Key challenges included:**

- ♦ Difficulty in coordination and oversight of logistics and development process for large scale programs
- ♦ Difficulty in addressing attitudinal barriers in short interventions as they require a longer horizon
- ♦ Effectively documenting outcomes of intervention at the community level without damaging trust or setting false expectations

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## **Presentation: Case Study – Population Services International (PSI)**

Dr. Aung Kyaw Linn, Franchising Manager - PSI's Myanmar presented on the ACSM strategies deployed in their Public Private Mix-DOTS (PPM-DOTS) program. Myanmar is one of the 22 high TB burden countries listed by WHO, with about 85,000 new cases of TB per year. A majority of people (75%) seek health services in the private sector which has more than 8,000 general practitioners. In order to support this broad private network, PSI launched a franchising program to work directly with providers to provide training, technical assistance and protocols, quality assurance monitoring as well as subsidized quality products and brands. Participating providers are selected based on provision of services to lower income groups, a positive attitude and good aptitude, ability to maintain records and willingness to be regularly supervised and assessed. The project is known as the Sun Quality Health Franchise (SQHF).

Launched in 2001, SQHF was initially piloted in 73 private clinics in Yangon, Mandalay and Laputta divisions with a focus on reproductive health. Subsequent expansion brought in malaria, sexually transmitted infections, and voluntary counseling and testing for HIV. At present, there are 684 active members. Selected GPs received three-day training in PPM-DOTS based on the WHO curriculum and NTP guidelines. At present, GPs provide all sputum smear examinations free of charge as well as branded TB drugs that are acquired through the Global Drug Facility by NTP. Although GPs are allowed to charge a minimal consultation fee from TB patients, most reported that these fees are usually not collected.

As of September 2006, the 313 SQHF-DOTS providers had tested 28,976 people for TB and are currently treating 14,785 registered cases. A treatment success rate of 79% has been recorded for the program in the last quarter. Central level advocacy efforts focused on presenting the Minister of Health as the role model in PPM-DOTS. PSI sought to have close collaboration and coordination with the NTP and MOH by signing a memorandum of understanding. Approval was also gained at the state, divisional and township levels to carry out the activity. Linkages were made with the Myanmar Medical Association –the only professional body in Myanmar, with over 7,000 doctors as members and WHO as well as other INGOs for collaborative work for PPM DOTS. Religious leaders were

approached for supporting people to get diagnosis and support treatment. All private sector actors including providers, clinic staff and laboratory technicians were informed of the program activities. Branded communication materials for community awareness were developed, including a DOTS sign board, posters and brochures, client kits, promotional materials and vehicles. Extensive World TB Day coverage was achieved through radio and television shows as well as community activities such as on-site sputum collection. At the community level, outreach workers made regular home visits providing psychosocial support and contact tracing as well as food incentives for low income TB patients.

**Important lessons for ACSM from PSI's program in Myanmar include:**

- ♦ Strong support of and good collaboration with the NTP is critical in the implementation of PPM DOTS in the private sector.
- ♦ Advocacy is a 'must' at different levels (particularly in highly sensitive working environments). Advocacy with local authorities is important.
- ♦ Effective demand creation activities can de-stigmatize TB and promote treatment adherence.
- ♦ Religious leaders can play a crucial role in TB control, especially in peri-urban areas.

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## **Small Group Exercises – Addressing Constraints through ACSM**

As many workshop participants did not attend the afternoon session (only 20 of 70), the group was separated into two working groups in order to have a focused discussion on ACSM. To allow for sufficient time for discussion, some afternoon sessions were collapsed to allow for longer exercise periods. Participants were asked to select one to two of the “hot topics” for ACSM from the morning session and to work toward a strategy to address it. All participants expressed an interest in the topics of improving patient involvement and reducing stigma for TB.

Workshop participants began by discussing the local situations in their countries/program areas to provide a context for stigma and lack of patient involvement. Barriers and supporting factors were identified, including the negative attitude of providers, lack of an open patient-provider communication culture, misinformation about TB, and geographical and financial constraints. Participants were then asked to brainstorm ideas about how they would solve some of these constraints using an ACSM framework.

Facilitators made efforts to move people to think beyond typical community involvement models to incorporate more innovative and cross-cutting approaches using ACSM. Overall, participants were well versed in public health approaches and understood different strategies that could be utilized for educating community members. However, in light of ACSM, there was interest in what program managers could do beyond the focus on communities for TB education and how this focus could be expanded to include politicians and health providers. Most participants agreed that media seemed to be an important and effective advocacy tool and showed an interest in learning how to engage their local media. Although some had experience reporting in media stories, there was a general lack of understanding how the media can be engaged. The lack of reporting on important health issues such as TB was seen as a 'condition' of the local media, but not one that could not be overcome.

The involvement of TB patients (in treatment and recently completed treatment) in patient and community education regarding TB was a popular intervention. However, participants were asked to

think about feasible mechanisms for engaging cured patients in an ACSM framework, as well as whom they could target in their advocacy, such as politicians, health providers and community leaders.

Furthermore, many of the workshop participants were working within NTPs and were interested in understanding their own role for ACSM vis à vis that of a civil society actor. Although most recognized ACSM to be an important part of their national strategy, or they had been asked to develop one for their GFATM application, there was limited experience with advocacy and social mobilization among this group. Actual skills-building in these two areas was identified as a need for NTP staff. Several participants agreed that a one-day workshop was insufficient to address their needs and showed interest in organizing further workshops in their home countries to learn culturally appropriate tools for media outreach, communication with patient and provider networks as well as 'thinking outside the box.' The desire to work closely with other groups that may have the expertise was also expressed. Participants felt that innovative solutions must come from in-country partnerships and collaborations with an eye to international standards.

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## **Concluding Comments from Doctors of the World-USA**

The workshop was very well attended by a diverse and rich group of TB professionals, highlighting the appeal and interest that has been generated in ACSM approaches. Through this workshop, DOW aimed to address some of the gaps and felt needs for innovative tools and strategies for ACSM programming.

Although all participants were asked to focus on these, during the workshop it became clear that it was difficult to distinguish between the different components of ACSM in community based programming as these components were often co-dependent and integrated. In the models presented by speakers, all three elements were present, though at times one component, such as communication, seemed to dominate the strategic focus. Furthermore, there was some confusion between focused advocacy and program sustainability in understanding the purpose of securing increased funding and resources for TB. Still, many good examples of NTP collaboration with civil society and community were given.

Since many NGOs already focus on community based programming, it was unclear how ongoing strategies for community based work were different from TB ACSM strategies at the community level. Therefore, in the case of TB programs that have been ongoing for some time, calling certain activities ACSM seemed to be more of a retrofit. It is important to stress the need for creating a new ACSM strategy with stakeholders that identifies specific aims for advocacy, communication, and mobilization of communities and launches activities to achieve these aims, rather than trying to manipulate ongoing activities to fulfill ACSM criteria.

Overall, the key questions that re-emerged throughout the day included: involving providers, involving patients, dealing with stigma and raising awareness of threats such as TB-HIV and XDR-TB.

The role of different actors was often discussed, including that of the NTP, civil society and TB patients themselves. This became especially evident during the afternoon session as different participants seemed to be asking for different sets of information and skills set in order to implement ACSM strategies. Civil society actors were interested in creating demand from within the affected communities themselves and liaising with the system to fulfill these needs while NTPs expressed the need for support and strategies for integrating ACSM into a TB system that may already be resource challenged.

It is clear that different actors will engage in varied ACSM strategies, with different, though complementary, aims. It is possible that NTPs could focus on mobilizing providers and provider organizations to engage as the implementing body for certain ACSM activities, such as advocacy for policy change within treatment programs. The role of TB patients and who can and should be the voice of the TB affected community was also an important point raised from Brazil. More than one profile exists for TB patients and more inclusive approaches could be more beneficial in identifying advocates, rather than focusing exclusively on TB status.

Overall, the workshop revealed how many gaps remain in understanding of ACSM at the national and local levels in many countries. But, the day's discussions also revealed a strong interest in understanding methods of ACSM and interest in case studies of effective programs, particularly those that have some hope for sustainability.

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<sup>1</sup> *Planning Framework: ACSM for TB Control*. Document handed out at the 2<sup>nd</sup> Meeting of the Subgroup on ACSM at Country Level. September 2006

<sup>2</sup> A full report on the PHW TB monitoring Project in the five countries can be found at:  
[http://www.soros.org/initiatives/health/focus/phw/articles\\_publications/publications/civilsociety\\_20061101](http://www.soros.org/initiatives/health/focus/phw/articles_publications/publications/civilsociety_20061101)

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## **Doctors of the World-USA (DOW)**

*Doctors of the World - USA projects focus on the critical nexus between health and human rights.*

DOW promotes global health through the advancement of human rights, improving the underlying conditions necessary to fulfill the right to health at the community and policy levels, and increasing awareness about the negative health consequences of human rights violations.

DOW projects increase access to health care for marginalized populations through initiatives that develop the capacity of local communities to provide health services that will be sustainable and long-lasting. Addressing health crises including HIV/AIDS and TB, women's health, orphans and vulnerable children, and human trafficking and torture, DOW projects combat the stigma, violence, discrimination, and deprivation of liberties suffered by the world's most excluded and vulnerable. Establishing local partnerships and working closely with communities, DOW projects combine direct service, system development, and advocacy to ensure the broadest possible impact.

DOW is currently active in Asia, Africa, Eastern Europe and the former Soviet Union, and the Americas, including a major human rights program in the United States. DOW has worked in over 30 countries and communities where health is diminished or endangered by violations of human rights and civil liberties, and has mobilized the health sector - in the United States and internationally - to promote and protect these rights.

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