

Report of a WHO consultation on strengthening the active engagement of civil society organizations in the global TB prevention, care and control efforts

September 30 – 1 October 2010

Geneva, Switzerland



Civil society organizations are nonprofit organizations that aim to further the interests of the communities they serve. Driven to protect and empower the vulnerable, these organizations work in areas such as community development, service provision, advocacy, activism and research. They include international and national nongovernmental organizations, faith-based, community-based and patient-based organizations delivering health services and advocacy organizations, which play a pivotal role in garnering political support and catalysing implementation. The Stop TB Department of the World Health Organization (WHO) convened a consultation of selected civil society organizations at WHO headquarters in Geneva, Switzerland, on September 30 – 1 October 2010. The objective of the meeting was to exchange experiences and share innovative ways of working together to strengthen efforts for prevention, care and control of tuberculosis (TB) worldwide. The meeting was attended by more than 70 participants representing 38 organizations, including international, national and local nongovernmental, faith-based, community-based and patient-based organizations working on health and development, patient support and advocacy. Participants from the Global Fund to Fight AIDS, Tuberculosis and Malaria and the Joint United Nations Programme on HIV/AIDS (UNAIDS) also attended the meeting. Plenary presentations, commentaries and interactive discussions held during round tables were used to describe best practices, experiences, challenges and solutions for strengthened involvement of civil society organizations in TB prevention, care and control efforts at global, national and local levels.¹



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¹ Presentations from the meeting and list of participants are available at http://www.who.int/tb/features_archive/civil_society_meeting30sep_01oct2010/en/index.html



The meeting was chaired Dr Mario Raviglione, Director of the WHO Stop TB Department, who emphasized that engaging civil society organizations in TB prevention, care and control efforts is a departmental priority. Dr Hiroki Nakatani, Assistant Director-General for HIV, TB, Malaria and Neglected Diseases, declared the meeting a “pathfinder” in recognition of its importance for WHO’s overall work with civil society organizations.

The participants noted that the mandate and policies of WHO and the work of civil society organizations should be anchored on the principles of human rights and the values of social justice, which serve as a basis for fruitful collaboration between WHO and civil society organizations. Throughout the meeting, representatives of civil society organizations and WHO staff expressed mutual willingness and interest in collaborating at all levels to improve TB prevention, care and control efforts worldwide.

The following items were discussed and conclusions and action points suggested during the meeting.

1. Removing critical barriers to global and national TB responses and civil society involvement.

The participants noted the limited involvement of civil society organizations and the almost total absence of organizations of TB patients in global and national responses to TB, despite the acknowledgment of their crucial role at all levels reflected in WHO policies and guidelines. These include the Stop TB Strategy and the 2008 guidance document on community involvement in TB care and prevention. Lack of understanding and implementation of existing WHO policies, mainly by national TB control programmes, was cited as one of the critical barriers for meaningful involvement. This had generated a lack of recognition of civil society organizations and their representatives as legitimate partners in planning, monitoring and evaluation of TB prevention, care and control efforts at national levels. Also described as critical barriers were lack of financial resources for community-based and patient-based TB initiatives; absence of consistent and targeted TB messaging as well as advocacy strategies both globally and nationally; limited visibility of TB civil society organizations in structures of the Global Fund to Fight AIDS, Tuberculosis and Malaria; and insufficient involvement of WHO staff in brokering civil society involvement at all levels, especially in countries.

Absence of visibility of TB in initiatives for development, social justice, and maternal and child health as well as the lack of collaboration between national TB control programmes and other line ministries (e.g. the Justice Ministry for prison health services) are additional barriers. The absence of TB on the development agenda limits the engagement of development agencies. The perception that ministries of health and their national TB control programmes are the primary stakeholders in national efforts to control TB, combined with the assumption that TB control is being addressed effectively, were given as reasons for zero or delayed involvement in TB control activities by some international nongovernmental organizations attending the meeting.

Action points:

- *WHO to provide clear and simplified policy guidance to national TB control programmes on the roles and mechanisms of engagement for civil society organizations in national TB prevention, care and control efforts based on the principles expressed in previous WHO documents and expedite implementation.*
- *WHO to facilitate the mobilization of highly visible TB ambassadors who could also advocate for increased involvement of civil society organizations and other line ministries along with partners in the Stop TB Partnership and civil society organizations.*
- *WHO to define a strategy that will help to mainstream TB into the broader development agenda and into maternal and child health initiatives.*
- *WHO to play a brokering role to enhance the engagement of other line ministries in TB prevention, care and control activities.*
- *WHO along with other partners in the Stop TB Partnership including civil society organizations to facilitate the development of context-specific messages and an advocacy strategy for the global TB response.*



2. Comparative advantages and collaborative areas of work for WHO and civil society organizations.

The meeting participants discussed the core functions and comparative advantages of WHO and civil society organizations in advancing global TB prevention, care and control efforts. WHO's core functions, as set out in its constitution, include developing policy, norms and standards; providing technical support and its coordination to countries; monitoring and evaluation; fostering partnership and alliances; and promoting research. The civil society organizations have the following core functions: protecting the rights and health of civil society sectors through nongovernmental interventions and programmes; fostering partnerships with governments to ensure effective and efficient programmes (including research and policy) that reflect community priorities and concerns; holding international organizations, and governmental and nongovernmental programmes accountable through measures of transparency; and participating in monitoring and evaluation.

WHO has the comparative advantages of influencing the implementation of policy and programmes; technical capacity; monitoring and evaluation; access to decision-makers; and technical impartiality. Civil society organizations have the comparative advantages of autonomy; bidirectional influence on both community and government institutions; capacity to reach out to inaccessible and remote areas including conflict

zones; knowledge and understanding of local circumstances; and flexibility and adaptability to local situations. Presentations highlighted that civil society organizations are the sole providers of TB care and control activities in some conflict zones and countries (e.g. Somalia).

Civil society organizations can contribute to all core functions of WHO. Similarly, WHO can contribute to the core functions of civil society organizations through its facilitation and brokering role at global and national levels. It was emphasized that the comparative advantages of WHO and civil society organizations need to be cross-fertilized to exploit the huge potential that would benefit global and national TB prevention, care and control efforts. The brokering and leveraging role of WHO in enabling national TB control programmes to recognize the role of civil society organizations is crucial and is noted as a fundamental action that is possibly expected from all levels of the Organization.

Action points:

- *WHO to explore including a specific activity item on enhancing civil society organizations involvement in the terms of reference of its staff working on TB at all levels.*
- *WHO to promote and conduct context-specific international, regional and national meetings that convene higher level decision-makers within ministries of health (e.g. permanent secretaries or directors), national TB programme managers, civil society organizations and WHO staff to develop global, regional or country-specific roadmaps to engage civil society organizations in TB prevention, care and control efforts.*
- *WHO to continue including civil society organizations in its global and regional TB policy and programme guidance development processes and decision-making bodies.*
- *WHO to encourage the participation of civil society organizations in national TB control programme reviews.*



3. Strengthening national response and creating linkages.

The meeting participants underlined the importance of enhancing the involvement of civil society organizations in national TB control efforts. Civil society organizations need to be involved in the national policy and guidance development processes more proactively. The diversity of civil society organizations in terms of size, capacity, scope, geographical coverage, funding, area of work and interest needs to be recognized, while establishing a collaborative work with national TB control programmes or WHO at all levels. The facilitation and brokering roles of WHO in building linkages between the often underfunded and less visible community-based and patient-based organizations with well-funded and structured international nongovernmental and civil society organizations are particularly important to advance national responses.

civil society organizations in national TB control programmes activities in selected pilot countries as soon as possible; and to demonstrate action that can serve as a model for scaling up activities in other countries. Strong commitment from WHO country offices is a prerequisite for effective implementation of such actions.

Action points:

- *WHO to facilitate and broker the engagement of civil society organizations in national TB policy processes, including monitoring and evaluation activities.*
- *WHO to provide capacity building (e.g. training) and technical support for national civil society organizations to promote their involvement in national TB control activities.*
- *WHO to encourage and broker linkages among community-based and patient-based organizations and international NGOs, including on enhancing their access to resources and technical assistance.*
- *WHO to identify pilot countries in which pilot projects will be carried out to strengthen the involvement of civil society organizations, demonstrate effectiveness, and garner experiences and best practices for scaling up activities in other countries.*



The role of WHO in networking and helping to establish and revitalize innovative national mechanisms (e.g. effective national Stop TB partnerships) needs to be fully exploited. The focus on community and patient-based organizations will facilitate the delivery of comprehensive care for patients and also help to streamline TB interventions with other important health and livelihood interventions (e.g. nutrition). WHO's leadership is needed at national levels to promote the engagement of

4. Removing the bottlenecks to accessing funds for civil society responses.

The meeting participants noted the lack of earmarked financial resources for civil society organizations for TB prevention, care and control activities as a key barrier. Bottlenecks to access existing funding streams (e.g. Global Fund) further inhibit the engagement of civil society organizations. The lack of adequate and strong representation of TB civil society organizations in functional bodies of the Global Fund (including country coordinating mechanisms) and the requirement for approval from country coordinating mechanisms for grant applications, especially for international nongovernmental organizations, were cases in point. Similarly, the funding needs of civil society organizations working on TB are ignored by private foundations and donors. The lack of capacity in writing successful grant proposals particularly by national and small community-based organizations presents another barrier to accessing funding mechanisms. WHO offers technical assistance for civil society organizations in applying for grants from the Global Fund. This role of WHO, although unfunded by the Global Fund, was hailed as best practice that needs to be scaled up. Such crucial roles by WHO and other technical partners to advance the engagement of civil society organizations in global TB control efforts should be funded. TB REACH, a funding stream of the Stop TB Partnership Secretariat that aims to increase early detection of TB cases, provides opportunities for civil society organizations who are interested in working on TB control activities.

Action points:

- WHO to organize a high-level meeting with Global Fund authorities (including selected civil society participants from the consultation meeting) to discuss the stronger representation of civil society organizations working on TB in Global Fund functional bodies including country coordinating mechanisms.
- WHO to continue and strengthen its technical assistance to civil society organizations during the Global Fund application process and explore the availability of funds for this activity from the Global Fund and other donors.
- WHO to advocate for the availability of resources for engaging civil society organizations in TB control activities at all levels as part of its resource mobilization work.

5. Mechanisms to enhance the advisory role of civil society organizations.

The meeting reiterated the importance of having a mechanism to enhance the advisory role of civil society organizations for WHO's work on TB at all levels, as well as the need for an accountability and follow-up mechanism for such collaborative activities. However, there was no final consensus among participants on the structure, composition and roles of a global body that systematically advises WHO in its TB-related activities. Particular areas identified for advice from civil society organizations include developing simplified guidance for national TB control programmes; developing global and national advocacy messages for TB; and accelerating implementation of evidence-based policies in countries. There are difficulties and challenges posed by the unique positions of WHO as an organization of Member States and of civil society organizations as independent autonomous entities in establishing an accountability system for collaborative work. Furthermore, there is limited knowledge and awareness of WHO's roles and functions among civil society organizations.

Action points:

- WHO to continue consulting and exploring best mechanisms for enhancing the advisory role of civil society, and follow up on collaborative areas of work.
- WHO to disseminate information on its functions and roles in TB prevention, care and control efforts to civil society organizations (e.g. through attendance and presentations of conferences and meetings conducted by civil society organizations) to raise awareness and solicit interest for collaborative activities.

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