

“Nothing for us without us”

Establishing a tuberculosis-free Africa through community action

IMPORTANCE AND BACKGROUND

African community activists have long recognized the need to strengthen the voices of African advocates and civil society working to improve health and wellbeing across the continent. With funding from the United States Agency for International Development (USAID), PATH helped former tuberculosis (TB) patients from five African countries to build on the previous efforts of their colleagues to create a strong core organization—the Africa Coalition on Tuberculosis (ACT!)—and then expand ACT! to link all of those committed activists under one umbrella organization that could connect their work. ACT! was launched on World TB Day 2012. Through ACT!, experienced activists band together as one voice to influence decision-makers at local, national, and regional levels. PATH has helped create a foundation and an environment for ACT! to grow.



ACT! founding members with the Executive Secretary of the WHO Stop TB Partnership

APPROACH: “NOTHING FOR US, WITHOUT US”

ACT! is a regional advocacy organization created by, for, and of people affected by TB in Africa. ACT!’s mission is to establish a TB-free Africa achieved through consolidating the power within communities to reduce the burden of this curable disease. PATH provides technical support to help ACT! establish critical infrastructure, plan for and fund its own activities, and build capacity of its members Through increasing communities’ knowledge, skills, tools, and

opportunities for advocacy, ACT! helps communities affected by TB to advocate for universal access to TB services, including quality diagnostic and treatment resources. In consolidating the efforts of numerous civil society organizations (CSOs), ACT! ultimately serves as link between communities on the ground and decision makers at the national, regional, and global levels—creating viable opportunities for community needs to be integrated into National TB Control Program (NTP) plans and implementation strategies.

IMPLEMENTATION

To support ACT! in its work:

1. PATH provided technical and financial support to founding ACT! members to establish the coalition, including support to develop internal infrastructure and operations, as well as technical support to help members develop work plans, monitor initial progress, and build technical capacities.
2. Since the initiation of ACT!, PATH has continued to provide technical support upon request for advocacy, communication, and social mobilization (ACSM) trainings to African CSOs, including training of trainers and joint CSO and NTP meetings to improve their collaboration and coordinated actions to address TB challenges. PATH’s practical approach to ACSM—which links activities closely to a gap analysis focusing on National TB Program objectives and targets—has created a platform that enables CSOs and NTPs to find a common language and common ground from which to strengthen their collaborations.
3. PATH also supports national ACT! chapters in strengthening CSO contributions to NTPs, by providing technical assistance to ACT! members in mapping how civil society can support national TB control objectives.

RESULTS

ACT! has made great strides in integrating local communities into the regional fight against TB in Africa,

helping the coalition to realize its vision of “a TB-free Africa through community action.” ACT!’s advocacy focus areas at the global, regional, and national levels include continuing funding for community work under Global Fund grants, elimination of drug stock-outs, access to diagnosis and treatment of drug-resistant TB, and attention to pediatric TB. In order to move ACT!’s advocacy efforts forward, it is necessary to establish national-level ACT! chapters in all participating countries.

Expansion of ACT!: While ACT! started its regional work in just five countries (Kenya, Nigeria, Swaziland, Uganda, and Zambia), with project support, the coalition expanded its activities to Malawi and Zimbabwe. National ACT! chapters have now been established in Nigeria, Uganda, and Zambia.

Global advocacy milestones: ACT! has a strong presence at the major global TB institutions: the Stop TB Partnership Coordinating Board, the Global Fund to Fight AIDS, TB, and Malaria Board, The International Union Against TB and Lung Diseases (The Union) Board, and the Global Coalition of TB Activists. This creates great opportunities to bring interests of communities affected by TB to the center of decision making in the fight against TB.

ACT!’s members chaired panel discussions and initiated civil society march events during the 2012 and 2013 Union World Conferences, and at the 19th Union Conference of the Africa Region (Rwanda, June 2013), in order to advocate for better engagement of civil society in future conference planning. Civil society representatives, including ACT!, met with the Executive Director of The Union to share their concerns. Ms. Carol Nyirenda, ACT!’s President and a community representative on The Union Board, presented at the Union Board retreat to ensure that community activists are represented in The Union regional governing bodies. The Union Board agreed to form a civil society commission to look into creating a civil society working group and allocated 100 free conference registrations for affected communities to attend the 2013 Union conference in Paris.

Capacity building: PATH conducted multiple trainings to support ACT!’s development regionally and within its national chapters, including:

- *ACSM skills-building trainings for CSOs and joint planning meetings of CSOs and the NTPs* (Zambia 2012, Nigeria 2013, and Uganda 2014), during which

NTP staff, technical partners, and CSOs discussed challenges and strategies to promote a collaborative response to TB and the integration of CSO activities into national TB strategic plans.

- *Regional Advocacy Training* (Kenya 2012), in which members were trained on developing TB advocacy strategies.
- *Regional Training on Monitoring and Evaluation of ACSM to Support TB Control* (Italy 2012), during which participants were trained on how to monitor ACSM activities and to evaluate their contribution to achieving NTP objectives.

LESSONS LEARNED

The growing achievements of ACT! demonstrate that:

1. The needs, perspectives and talents of communities are critical to understanding what works and what does not when trying to improve TB control outcomes. CSOs are quick to identify areas of weakness and sources of delays, making their contributions essential to disease control efforts. Engagement of the community is essential to making real progress in TB.
2. CSOs are strong and effective partners in TB control when they unite to combine forces.
3. While much progress has been made in engaging civil society in TB control, much remains to be done to ensure that TB-affected communities and CSOs can assume their rightful place at the table and develop effective and meaningful collaborations with NTPs, technical partners, and decision-making bodies (for example, Global Fund country coordinating mechanisms).
4. ACT! experience can be successfully built upon to establish similar coalitions in other regions.



ACT! Nigeria Steering Committee with the NTP Manager

Photo: PATH



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PATH is an international organization that drives transformative innovation to save lives and improve health, especially among women and children. We accelerate innovation across five platforms—vaccines, drugs, diagnostics, devices, and system and service innovations—that harness our entrepreneurial insight, scientific and public health expertise, and passion for health equity. By mobilizing partners around the world, we take innovation to scale, working alongside countries primarily in Africa and Asia to tackle their greatest health needs. Together, we deliver measurable results that disrupt the cycle of poor health.

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