



USAID
FROM THE AMERICAN PEOPLE

**HEALTH POLICY
INITIATIVE**



PROJECT SUMMARY | SEPTEMBER 2010



Photo courtesy of Health Policy Initiative in Mali

CITIZEN MONITORING IN MALI

PLHIV Promote Accountability in the HIV Response, Leverage Funds to Scale-up Citizen Monitoring Nationwide

Meaningful participation in policymaking improves the design of policies, empowers those who engage in the process, and fosters partners' ownership for new policy directives. Participation is equally crucial for policy implementation and monitoring. Engaging citizens to monitor implementation helps to make health policies and programs more responsive to client needs and strengthen relationships between clients and healthcare providers. Citizen monitoring can also enhance governance and accountability for improved health service quality and access. Engagement of people living with HIV (PLHIV) in citizen monitoring is especially important given the isolation, silence, and stigma that surrounds HIV and the need to reduce barriers to services and resources.

Citizen Monitoring Pilot Project in Mali

In 2009/10, the Mali Network of People Living with HIV/AIDS (RMAP+) undertook a pilot citizen monitoring project. The project focused on:

- Assessing quality of health services—including access to antiretroviral treatment (ART), treatment for opportunistic infections, and laboratory and social services—as well as experiences with stigma and discrimination in health services; and
- Engaging PLHIV in policy dialogue, planning, and implementation.

The USAID | Health Policy Initiative, Task Order I, provided assistance to gain stakeholder buy-in for the activity (e.g., the national AIDS program, civil society, the health sector, and international partners); design the study instruments; and train PLHIV in data collection, analysis, and evidence-based

advocacy. Strengthening organizational and leadership capacity of the PLHIV network was a central concern in the pilot design. Thus, the Health Policy Initiative ensured that PLHIV led the process and made final decisions in all aspects of the project; that the approach involved not only training but also transfer of competencies (“learning by doing”); and that the activity provided an opportunity to strengthen “social capital.” Social capital refers to the means by which a person or group can influence their environment and is often characterized by involvement in networks and partnerships. Through engagement with HIV-positive people and other partners, PLHIV gain confidence in interacting with persons of authority (e.g., policymakers, healthcare providers, law enforcement), are valued for their opinions, and are better able to exercise their rights and demand high-quality health services.

Methodology

RMAP+ carried out the pilot project in Bamako District and the region of Koulikoro, with participants representing 10 PLHIV associations. Through a series of workshops, PLHIV designed the concept and focus for the project. They drafted the questionnaire and adapted it into a low-literacy format. The questionnaire contains items on general health, ART, and quality of healthcare, among others. From April to June 2010, data collectors interviewed their associations' members and others involved in activities organized by the associations, such as home-based care. The analysis encompassed 433 overall questionnaires completed by respondents currently prescribed on ART.

“This project helped us, as PLHIV, understand our own capacities—to know that we can do something about improving our own living conditions.”

—Member, PLHIV association

Key Findings

- The majority of respondents (69%) visited a health center in the weeks preceding data collection; half of respondents (50%) visited an NGO clinic on their last visit and one-quarter (25%) had visited a hospital.
- Most respondents (87%) did not believe healthcare providers treated them more coldly due to their HIV status; however, more than half reported that they had, at some point since being diagnosed as HIV positive, been refused services.
- About one-fourth of respondents did not receive pre-test counseling.
- Nearly 1 in 5 respondents (19%) reported having some difficulty taking antiretrovirals (ARVs) at prescribed times and 3 in 5 (61%) affirmed that, at one moment or other, they were without the medications they needed to take.
- Close to one-quarter of respondents (23%) reported that the medication their doctor prescribed was not always available.
- Almost half of respondents (46%) thought expenses for medicine were too high and about 4 in 10 (42%) reported they had been denied services because they were unable to pay for services.
- A third of respondents (34%) did not know about the existence of legal documents that protect the rights of PLHIV in Mali and more than a third did not know where to turn if their rights were violated.

Outcomes and Next Steps

RMAP+ and the 10 participating PLHIV associations came together to discuss the results of their work. They were gratified to learn more about their members and their satisfaction and difficulties with health services. The group felt great pride in having come by this knowledge themselves. The study findings have helped to inform the development of a national advocacy platform for RMAP+. The national network will not only advocate for improved services but also help associations work more closely with local health services to address their needs.

Another key result has been the affirmation of the vital role of NGOs and civil society in Mali’s HIV response. This includes civil society’s roles in providing care and support, helping family and community members access services, and educating their members, families, and friends. The analysis also inspired participants to engage in policy dialogue at national and local levels. Local PLHIV organizations have discussed the results with their local service providers (many of which are NGOs)

and RMAP+ has met with representatives of the Ministry of Health to discuss implications for improving services.

In addition, the analysis brought some clarity to the work the associations could undertake with their members and with which RMAP+ could assist. This includes educating members about services, supporting treatment adherence, and raising awareness of rights and recourse mechanisms.

Finally, the national government and partners have demonstrated commitment to expand the role of PLHIV in policy formulation and monitoring. In Mali’s grant awarded by the Global Fund to Fight AIDS, Tuberculosis and Malaria, US\$36,000 has been set aside for taking the citizen monitoring process to the national level, including support for national training and assessment workshops and a data collection system.

“The Citizen Monitoring project of the national network of PLHIV is a vital part of a governance system to help ensure an effective and equitable health response to HIV in Mali.”

—Malick Sene, Executive Secretary,
High Council of the National AIDS Program

Lessons Learned for Replication and Scale-up

- A PLHIV-led process can produce high-quality results that can be used in developing an advocacy agenda.
- A participatory process that transitions leadership into the hands of a PLHIV network can appreciably increase ownership.
- Although the information gathered in such a process is extremely valuable, a more complete picture can be made by triangulating the information with the views and opinions of health service providers and deeper exploration of key themes identified by and with PLHIV.
- While funds have been identified to take this pilot to a national level, further support is needed to build strong data collection and dissemination systems and harmonize the study instrument with other national monitoring and evaluation endeavors.

LEARN MORE:

The full report is available online at:

http://www.healthpolicyinitiative.com/Publications/Documents/I309_I_Citizen_Monitoring_Mali_Final_FINAL_acc.pdf

Task Order 1 of the USAID | Health Policy Initiative, Task Order 1, is funded by USAID under contract GPO-1-01-05-00040-00 (September 2005–2010). It is implemented by Futures Group, in collaboration with the Centre for Development and Population Activities (CEDPA), White Ribbon Alliance for Safe Motherhood (WVRA), and Futures Institute. To learn more, please contact: Futures Group | One Thomas Circle, NW, Suite 200 | Washington, DC 20005 USA | Tel: (202) 775-9680 | Email: policyinfo@futuresgroup.com | Web: www.healthpolicyinitiative.com