



PROJECT HIGHLIGHTS

Paths to Leadership for People Living with HIV in the Middle East and North Africa



HIV is a silent but growing epidemic in the Middle East and North Africa (MENA). An estimated 310,000 people living with HIV (PLHIV) reside in the region. There are about 35,000 new cases of HIV annually. HIV affects most-at-risk populations (MARPs)—such as men who have sex with men, sex workers and their clients, and injecting drug users—but is also making inroads into the broader population. Reflecting the feminization of the epidemic, women constitute more than half of PLHIV in the region, with most HIV infections among women occurring within marriage. Young people (ages 15–24) are at increased risk for HIV in MENA due to risk behaviors such as unprotected sex, transactional sex, and injecting drug use. Other factors that contribute to HIV vulnerability include limited access to HIV testing, prevention, and treatment; armed conflict, resulting in disrupted healthcare services and refugees living in poor conditions; and lack of accurate HIV informational materials in Arabic. Stigma, discrimination, and human rights abuses against HIV-

positive people and MARPs are common, driving PLHIV underground and preventing them from seeking needed support services.

HIV in the MENA Region (2008)

# of PLHIV:	310,000
# of new HIV cases:	35,000
# of AIDS-related deaths:	20,000
ART coverage:	14%
(Based on an estimated 68,000 adults and children in need of ART)	
PMTCT coverage:	1%
(Based on an estimated 13,400 pregnant women living with HIV needing ART to prevent transmission from mother to child)	

Source: UNAIDS, 2009; WHO, UNAIDS and UNICEF, 2009

In many ways, the response to HIV in the MENA region is only beginning to emerge. In particular, social movements to encourage the Greater Involvement of People Living with HIV/AIDS (GIPA) Principle have been slow to take hold. This poses both a challenge—to reach marginalized, isolated HIV-positive people in the region—as well as an opportunity—to adapt lessons learned and best practices from GIPA efforts from other regions. Building on initial efforts by the United Nations Development Program HIV/AIDS

Regional Program in the Arab States (UNDP/HARPAS) to involve PLHIV to share their experiences and engage other stakeholders, in 2005, the U.S. Agency for International Development (USAID) launched the “Investing in PLHIV Leadership in MENA” initiative. The POLICY Project and, subsequently, the USAID | Health Policy Initiative, Task Order 1, have implemented the activity in partnership with PLHIV and other stakeholders in the region.

A New Path for PLHIV: A Series of Firsts

From 2005–2010, the “Investing in PLHIV Leadership in MENA” initiative strengthened the capacity of PLHIV in the region through training, mentoring, and small grants. Often, the training workshops marked the first time participants had ever met with other women and men living with HIV in the region or participated in and/or conducted PLHIV-led trainings.

Investing in PLHIV in the Middle East and North Africa

February 4–8, 2006

Tunis, Tunisia

✓ **First regional
workshop facilitated by
and for PLHIV**

*I want to thank you
because this is the
first time I have
met another person
living with HIV from
another country. I
thought I was alone.*

—Male, Mauritania

*We are [from] Arab countries,
and in these 20 Arab countries,
we have almost half a million
PLHIV who need our care and
information so that they can
face people and live better.
We always need to be together
as a team ... to help others in
the whole region.*

—Female, Egypt

How to be a Positive Trainer

June 1–5, 2008

Amman, Jordan

✓ **First training-
of-trainers (TOT)
workshop for PLHIV in
the region**

Leadership and Networking Workshop

September 1–8, 2007

Wadi Natroun, Egypt

✓ **First regional
workshop to have
PLHIV from the region
as co-facilitators**

*I benefited
considerably from the
training and learned the
basics of leadership,
how a PLHIV can live a
positive life, and how to
plan a family, which is
central to our culture.*

—Male, Sudan

Our Approach to the MENA initiative had three key pillars:

Social capital. Few organizations or support groups for PLHIV exist in the MENA region. As demonstrated in other regions, such organizations play a key role in providing psychosocial support and referrals, advocating for improved policies and services, overcoming internal stigma, and empowering PLHIV leaders. Thus, an essential first step was to build the social capital of PLHIV by overcoming the isolation that many HIV-positive people face, bringing them together through consultative meetings and trainings, and helping them to coalesce into formal regional and in-country groups.

Greater investment. For PLHIV to establish and sustain independent organizations and play a role in HIV policymaking and program implementation, they need access to, capacity to use, and control over financial resources. Putting resources in the hands of PLHIV themselves was a central component of this activity and reflects the notion that greater investment in PLHIV is core to GIPA. To put this principle into practice, the Health Policy Initiative hired PLHIV as

consultants to provide their expertise and assist with designing training curricula, facilitating workshops and peer-to-peer education, carrying out stigma reduction activities, liaising with local partners, and developing a region-specific website for PLHIV. The project also awarded small grants to PLHIV groups to manage in-country activities.

Dialogue and accountability. We also made inclusive dialogue and fostering greater accountability central facets of the MENA initiative. Our approach was to (1) build the skills of PLHIV to engage effectively in high-level policy dialogue, (2) support them to make connections in their own countries with trusted allies in health and policy circles, and (3) facilitate opportunities for PLHIV and their allies to plan for future collective action for greater accountability in the region’s HIV response.

In addition, by basing program decisions on expressed PLHIV needs, collaborating with international and in-country partners, and fostering local leadership and a sense of ownership, the MENA initiative planted the seeds of sustained PLHIV capacity and involvement from the outset.

I feel that previous skills I had are now greater ... Before, I was hesitant and closed

inside my house, taking medicine only. I know I have something to give to people. ... if God has brought me here today, it is because he wants me to relay the message to others.

—Male, Egypt

Subregional Training in Leadership and Networking

June 8–12, 2008

Amman, Jordan

✓ First workshop facilitated by and for PLHIV from the region



Peer-to-peer workshops

✓ First country-level peer-to-peer workshops led by and for PLHIV from the region

Bahrain

Lebanon

Oman

Saudi Arabia

Yemen

Regional Women's Workshop

May 17–21, 2009

Tunis, Tunisia

✓ First women-centered workshop facilitated by and for women living with HIV from the region

I feel very proud to be surrounded by strong women who really want to do something and we are breaking the wall of silence ... Now that we have the information, we need to tailor it even more to our culture and region.

—Female, Lebanon

When I heard our new NGO would have the chance to implement an activity on our own, I did not believe it. We filled out the application, obtained the grant, and developed our activity. Now are we applying for another grant to continue the work we accomplished with the first.

—Male, Jordan

Regional Small Grants Workshop

June 14, 2008

Amman, Jordan

✓ First country-level small grants developed, implemented, and managed by PLHIV from the region



Empowering Women Living with HIV

In May 2009, the Health Policy Initiative, with the International Community of Women Living with HIV/AIDS (ICW), organized the “Women-Centered Workshop: Addressing HIV among Women and the Gender Dimensions of HIV in the MENA Region,” which involved 23 HIV-positive women from Algeria, Bahrain, Egypt, Jordan, Lebanon, Libya, Morocco, West Bank, Saudi Arabia, Tunisia, and Yemen. It was the first workshop in the region led by and for women living with HIV. Within one month of the workshop, participants formed national women’s support groups in Jordan and Bahrain. In Jordan, the group has met with

the Minister of Health to advocate for stronger support of women living with HIV; this resulted in the National AIDS Program (NAP) funding women’s participation at regional workshops to build their capacity as leaders and networkers. Women living with HIV have also been nominated to join the Global Fund’s Country Coordinating Mechanism. The Bahrain women’s support group meets regularly and is also supported by the NAP. In 2010, the Ford Foundation, Egypt, announced that it will provide further funding to build a regional network for positive women. The first round of funds will support a regional meeting to establish the network, also supported by ICW.

Stigma and Healthcare Providers Workshop

December 7–11, 2009

Marrakesh, Morocco

✓ **First workshop where PLHIV collaborated with physicians they nominated as advocacy partners**

We should focus on awareness raising, otherwise we [might] violate human rights. Doctors in our region have a huge role to play in this fight.

—Doctor, Tunisia

Advocacy Workshop

December 13–15, 2009

Marrakesh, Morocco

✓ **First regional advocacy workshop for PLHIV in MENA**

In our country, everything is available—treatment is available to PLHIV but they need to have a TRUE role and their voice should be heard in the community ...

—Doctor, Oman



This is the first time I attended a workshop with PLHIV and I learned so much and we have many things we can do via the [National AIDS Program] ... All the debate, questions, and issues raised, including treatment coverage, will impact positively on our program and planning.

—Doctor, Jordan



Treatment Advocacy Workshop

April 29–May 2, 2010

Hammamat, Tunisia



Resource Mobilization and Skills Building

May 4–5, 2010

Hammamat, Tunisia

The extent to which we are able to continue to build programs and services, with whatever level of resources we have, will be a key determining factor in the quality of lives of PLHIV in MENA and continuity of these programs.

—Donor

Advocating for Stigma Reduction and Treatment Access

In December 2009, the Health Policy Initiative partnered with ICW, Shady Grove Fertility Center, AIDS Alliance, and their linking partner in Morocco, *Association Marocaine de Solidarité et de Développement (AMSED)*, to implement a “Stigma and Discrimination in the Healthcare Setting” workshop followed by an advocacy workshop. Using a unique approach, PLHIV were asked to nominate supportive physicians who could serve as advocates with them in-country to reduce stigma and discrimination. Many of the physicians nominated were also NAP staff,

which bolstered stronger links among PLHIV, their support groups and NGOs, and the local AIDS programs to work in partnership. The PLHIV/physician country teams identified advocacy goals related to treatment. As a follow-up, a regional Treatment Advocacy Workshop was organized in May 2010 to further address the low treatment coverage in the region and how to advocate for high-quality reporting, consistent and effective access to treatment, and greater coverage. The teams are following up on their advocacy plans. Stakeholders in the region also plan to conduct a treatment mapping exercise to determine the availability and geographic distribution of services.

Key Achievements

- ✔ **Strengthened capacity.** More than 170 PLHIV from 16 countries participated in one or more trainings. PLHIV facilitators, trained and mentored by the project, reached an additional 300 HIV-positive people in five countries through peer-to-peer workshops and small grants.
- ✔ **Region-specific training and informational materials developed and disseminated.** The MENA initiative produced four curricula that will be available in English and Arabic. These curricula focus on training skills, HIV basics in the region, building capacity of HIV-positive women, and reducing HIV stigma and discrimination in healthcare settings. In addition, 25 key HIV resources previously unavailable in Arabic have been translated and are accessible via a private website created by and for PLHIV in the region; these include reports on HIV transmission and prevention, human rights, universal access, treatment, prevention of mother-to-child transmission (PMTCT), women and HIV, and other issues.

- ✔ **Trainings adapted and replicated.** In at least 30 instances, in-country counterparts have adapted and used the curricula, session plans, and tools developed throughout this initiative for awareness-raising activities, support group meetings, and training workshops.

- ✔ **Small grants lay the groundwork for country-level dialogue.** The Health Policy Initiative awarded seed grants of US\$2,000 each to enable PLHIV to design, implement, and manage their own country-level activities. In Lebanon, PLHIV used the funding to carry out awareness-raising and outreach activities, including developing and disseminating trilingual (Arabic/French/English) newsletters on HIV issues. In Jordan, PLHIV carried out advocacy and policy dialogue to advise staff at the NAP and voluntary counseling and testing sites to develop a coordinated plan to strengthen referrals for MARPs. With a second grant, PLHIV organized a meeting with a delegation of lawyers to establish linkages to provide legal aid to PLHIV at medical centers and hospitals, resulting in appointment of a primary legal advisor who will help create a medical/legal plan for PLHIV within the next year. In Yemen, PLHIV organized a multisectoral workshop that brought together leaders from the health, religious, and government sectors to begin initial planning for a more coordinated HIV response.



- ✔ **MENA PLHIV network formed and website launched.** PLHIV have taken the first steps to establish a regional network of people living with HIV. The network is fostering consensus on its mission, setting up organizational structures, and clarifying operational procedures. PLHIV also created a private website and chat room for women and men living with HIV. These resources help PLHIV gain access to information, share experiences, and broadcast news about HIV in the region. Due to the continuing stigma and discrimination in the region, however, information about the network and website is shared through PLHIV circles and trusted partners and is not widely publicized.

- ✔ **Strengthened in-country partnerships and ownership.** As a result of the small grants, peer-to-peer workshops, and workshops with trusted physicians, PLHIV have reported greater support from and stronger partnerships with NAPs and ministries of health. As PLHIV leadership has grown, more national programs have been willing to provide funding to ensure sustainability and build on progress made in-country. Reflecting in-country commitment and ownership of this effort, the Jordan, Kingdom of Saudi Arabia, Bahrain, and Oman NAPs have provided funding and resources for country activities.

- ✔ **Resources leveraged to promote sustainability.** Beyond USAID's support through the Health Policy Initiative and AIDS Alliance, as a result of partnerships, more than US\$150,000 has been leveraged to support the "Investing in PLHIV Leadership in MENA" activities. The MENA initiative is especially grateful to UNDP/HARPAS, Catholic Relief Services, ICW, Ford Foundation, and country NAPs for supporting participant costs and other activities. The graphic above illustrates some of the partners who have contributed to the MENA initiative.

Recommendations

GIPA aims to realize the rights and responsibilities of PLHIV, including the right to self-determination. It also seeks to improve the quality and impact of the HIV response through greater and more meaningful PLHIV engagement, participation, leadership, and investment in the HIV response. Great progress has been made regionally through the “Investing in PLHIV Leadership in MENA” initiative—from 26 HIV-positive people who met in Tunis for the first time to the growing network of hundreds of PLHIV in the region who are building momentum for a regional HIV movement to protect and promote human rights and advocate for improved access to treatment.

Challenges remain in mobilizing a silent majority of Arab PLHIV, particularly women, as the feminization of the epidemic takes root in the region, and in fostering a comprehensive regional response to HIV. Together with participants in this effort, we have identified the following issues that should be addressed in partnership with PLHIV:

- Treatment access, advocacy, literacy, and policy dialogue
- Gender, family, and community issues, including gender-based violence and harmful traditional practices
- Access and capacity to use resources from international, donor, and in-country sources
- Strategies to reach the most-at-risk and vulnerable populations with HIV prevention information and services
- Networking, including platforms for sharing knowledge, information, and tools in Arabic
- Civil society capacity, especially through effective NGO leadership, management, partnerships, and sustainability

The Path Continues: Sustainability and Ownership

In the short term, steps are underway to foster sustainability and ownership in the region.

- A delegation of about 16 PLHIV from MENA will attend and share their lessons learned at the XVIII International AIDS Conference, with support from UNAIDS and the country NAPs, marking the largest ever representation of HIV-positive people from the region at the international conference.
- The Jordan NAP has pledged funding for continuation of the regional website, and PLHIV focal points will also lead chat groups and a Facebook page established under the MENA initiative.
- The Kingdom of Saudi Arabia will fund a peer-to-peer workshop in September 2010. As the success of the peer-to-peer program has grown, NAPs have demonstrated commitment to fund awareness-raising and support activities carried out by and for PLHIV, who now have greater capacity and expertise.
- PLHIV have nominated officers who will work to formalize the regional network. The network has been introduced to regional counterparts and members will be involved in key regional HIV meetings and forums.
- The Ford Foundation will provide funding for the first regional network meeting by and for women living with HIV in MENA. ICW, which is establishing an office in the region, will also assist with this effort.
- The World AIDS Campaign will support a regional stigma campaign led by and for PLHIV.

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