On February 4, 2006, in Tunis, 26 participants from nine countries made history when they came together for the first leadership and networking workshop held exclusively for Arab people living with HIV (PLHIV). Arab PLHIV face high levels of stigma and discrimination, resulting in isolation. Many PLHIV who attended the Tunis workshop had never before met another person living with HIV, much less had the opportunity to disclose their status and share ideas and concerns in a safe space.

Since it was formally adopted at the Paris AIDS Summit in 1994, the greater involvement of people living with or affected by HIV (GIPA) principle has become one of the guiding principles of the global response to HIV. Worldwide, PLHIV networks have grown in size and strength and HIV-positive individuals have become engaged in the HIV response at every level. In the Middle East and North Africa (MENA) region, however, the majority of PLHIV have remained isolated and disengaged, cut off from this global movement.

To break this isolation and support PLHIV engagement in the MENA regional and global HIV response, Task Order 1 of the USAID | Health Policy Initiative and its predecessor—the POLICY Project—collaborated with the United Nations Development Program HIV/AIDS Regional Program in the Arab States (UNDP/HARPAS) to launch a ground-breaking initiative fostering PLHIV leadership and networking in the region.

The February 2006 Tunis workshop provided basic HIV information in Arabic and French, as well as networking opportunities. Increased demand from PLHIV led the Health Policy Initiative and HARPAS to host a second, longer workshop in September 2006 in Wadi Natroun, Egypt for 44 PLHIV from 14 Arab countries. The eight-day workshop began with a three day intensive skills-building session for seven attendees of the Tunis workshop, which honed participants’ training, facilitation, leadership and capacity-building skills. The remaining five days gave a new group of Arab PLHIV the chance to learn the skills covered in the initial Tunis workshop.

Through its Investing in PLHIV Leadership in the MENA Region activity, the Health Policy Initiative has continued to support the growth of a PLHIV movement in the MENA region. A training-of-trainers (TOT) workshop for 12 women and men living with HIV from Egypt, Yemen, Jordan, Bahrain, Oman, Lebanon, and Libya was held June 1–5, 2008, in
“Before, I was hesitant and closed inside my house—taking medicine only. Now I know I have something to give to people.”

—PLHIV workshop participant

Amman, Jordan. The TOT, Investing in PLHIV Leadership in the Middle East and North Africa Region: How to be a Positive Trainer to other PLHIV in the Region, aimed to provide PLHIV trainers with the skills to independently design and implement a training for fellow PLHIV in their region, countries, and/or communities. The workshop provided rigorous training on basic HIV information, public speaking and facilitation skills, adult learning, session development and evaluation, crafting effective Power Point presentations, and behavior change communication (BCC).

From June 8–12, 2008, the 12 TOT participants used their new skills to facilitate a sub-regional workshop attended by 26 PLHIV from Jordan, Egypt, Yemen, Lebanon, Oman, Libya, Bahrain, and Saudi Arabia. The workshop’s purpose was to support country and community-level activities and projects that strengthen PLHIV leadership, the HIV response, and the GIPA principle in the region. The workshop built participants’ knowledge through sessions on stigma and discrimination; treatment; advocacy; disclosure; prevention of parent-to-child transmission; human rights; history of PLHIV; GIPA; nutrition and exercise; relationships, marriage, and family; gender and HIV; positive living; support groups; stress management and reduction; and feedback groups. Conducted entirely by and for PLHIV from the region, the workshop marked a shift in the role of Arab PLHIV—from beneficiaries and recipients of knowledge to empowered experts themselves teaching and supporting others living with HIV.

During the workshop, participants launched a regional network for PLHIV. The network supports the provision of HIV resources in Arabic and offers support, mentorship, and a platform for sharing experiences and ideas. Given that members are based in different countries, the network has created an online chat room that meets at a designated time every two weeks, with a brief hiatus during the month of Ramadan. The chat room provides a space to share HIV-related information in Arabic and offer emotional support to fellow members in a ‘safe space.’ Treatment access and advocacy have been two of the most popular discussion topics in the online forum. The group has also shared scientific articles, translating them into Arabic to give all members access to the information, and discussed ideas to improve access to treatment in the MENA region.
Together, the regional network and online forum are critical new sources of support and information given the high levels of stigma in the region, the lack of information about HIV available in Arabic, and the lack of means to provide peer-to-peer support.

On June 14, 2008, the Health Policy Initiative hosted a small grants development for 10 participants from the sub-regional workshop. The Health Policy Initiative awarded three small grants to support participants affiliated with in-country NGOs to carry out activities in Egypt, Jordan, and Lebanon. This is the first time grant money has been given directly to PLHIV in the region for the management of HIV activities. The grants will support activities such as HIV awareness-raising workshops conducted in Egypt by PLHIV; development of basic, low-literacy HIV information booklets in Arabic; outreach to PLHIV in Jordan who are difficult to reach, including women living with HIV and those living in remote areas; and development of a newsletter created by PLHIV for PLHIV and other key stakeholders in Lebanon.

The strongest barrier to PLHIV engagement in MENA has been stigma-related isolation— Isolation from each other, from information about HIV, and from the regional and global PLHIV community. The work of the Health Policy Initiative and its partners has given a core group of PLHIV the tools to break the isolation PLHIV face in the region and build a network of support and a path to PLHIV leadership. Full involvement and acceptance of PLHIV in the MENA region’s HIV response will take time, but the efforts of increasingly skilled and engaged PLHIV in the region are bringing that day closer.