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PATHS TO LEADERSHIP FOR PEOPLE LIVING WITH HIV IN THE MIDDLE EAST AND NORTH AFRICA



AUGUST 2010

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EXECUTIVE SUMMARY

HIV is a growing but silent challenge in the Middle East and North Africa (MENA) region. There are an estimated 310,000 people living with HIV (PLHIV) in the region and about 35,000 new cases of HIV annually (UNAIDS, 2009a). Levels of stigma and discrimination toward HIV-positive people are high. Women constitute more than half of people living with HIV in MENA, and married women account for four out of five female HIV infections (UNDP, 2009). Youth ages 15–24 are at increased risk of HIV, due to risk behaviors such as injecting drug use and unprotected sex (PRB, 2008).

In many ways, the response to HIV in the MENA region is only beginning to emerge. In particular, social movements that 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 people living with HIV 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 the Middle East and North Africa (MENA) initiative. The POLICY Project and, subsequently, the USAID | Health Policy Initiative, Task Order 1, have implemented the activity in partnership with PLHIV and key stakeholders in the region.

The initiative’s approach included three key pillars that involved (1) building the social capital of people living with HIV, (2) investing in the capacity of people living with HIV, and (3) fostering policy dialogue and accountability. This approach recognized that involvement in networks and enabling people living with HIV to have meaningful involvement in decisionmaking processes are essential to sustaining the HIV response in the region. The Investing in PLHIV Leadership in MENA initiative based activities on the expressed needs of people living with HIV, working in collaboration with international, national, and local partners. The initiative, with its partners, fostered a shift in the region—from people living with HIV serving as beneficiaries to being increasingly and more meaningfully involved in the HIV response.

From 2005–2010, the Investing in PLHIV Leadership in MENA initiative strengthened the capacity of people living with HIV in the region through capacity building, awareness raising, advocacy, small grants, and establishment and support of informal PLHIV networks. Often, training workshops marked the first time participants had ever met with other women and men living with HIV in the region and the first time they participated in and/or conducted trainings led by and for PLHIV in the region. The workshops strengthened training skills and understanding of HIV basics among PLHIV, built capacity of HIV-positive women and men, focused attention on reducing HIV stigma and discrimination in healthcare settings, and strengthened advocacy for access to treatment and stronger resource mobilization by local groups led by and for people living with HIV. These training workshops also provided a safe place for PLHIV to exchange ideas, express their concerns, form networks for mutual support, and strengthen their leadership skills. Moreover, the small grants awarded to people living with HIV in Jordan, Lebanon, and Yemen marked the first time funding was provided directly to nongovernmental organizations (NGOs) and support groups led by people living with HIV, in partnership with local NGOs, to design, implement, and manage local HIV activities. Together, capacity building, awareness raising, advocacy, small grants, and networking have helped put women and men living with HIV on the path to greater and more meaningful involvement and leadership in the MENA region’s HIV response.

Some key accomplishments of the Investing in PLHIV Leadership in MENA initiative include

- Training of more than 170 people living with HIV from 16 countries (local facilitators living with HIV trained by the project have reached an additional 300 people in five countries);

- Design and dissemination of four curricula in English and Arabic (on training-of-trainers, HIV basics, HIV-positive women’s issues, and stigma and discrimination in healthcare settings), plus translation of 25 key HIV resources into Arabic;
- Replication and adaptation of the initiative’s materials in at least 30 instances by in-country counterparts for use in awareness raising, support groups, and workshops;
- Award of small grants to people living with HIV in Lebanon, Jordan, and Yemen, resulting in production of a trilingual newsletter on HIV issues in Lebanon; a multisectoral workshop to begin the process of improving coordination of the HIV response in Yemen; and improvements in referrals from voluntary counseling and testing sites for most-at-risk populations and the Jordanian support group, which in turn, provided access to legal aid and other key services;
- Formation of a regional network led by and for PLHIV, named MENA+, which is currently gaining consensus on its mission, setting up organizational structures, and clarifying operational procedures; also formation of regional private website and chat room to alleviate isolation, provide access to HIV materials in Arabic, and promote dialogue and sharing of experiences among PLHIV in the region;
- Creation of two support groups for HIV-positive women, in Jordan and Bahrain, as well as commitment from the Ford Foundation and the International Community of Women Living with HIV (ICW) to support the formation of a regional network for HIV-positive women in MENA;
- Strengthened in-country partnerships among PLHIV, national AIDS programs (NAPs), and NGOs, as well as increased country ownership demonstrated by NAPs of Jordan, Bahrain, Oman, and the Kingdom of Saudi Arabia; all NAPs pledged support and funding for participant costs and country-level activities;
- In addition to USAID funding through the Health Policy Initiative and AIDS Alliance, an additional \$150,000 leveraged through the Investing in PLHIV Leadership in MENA initiative—from partners including UNDP’s HIV/AIDS Regional Program in the Arab States, Catholic Relief Services (CRS), ICW, Ford Foundation, NAPs, and local NGOs; and
- Increased participation of people living with HIV from the MENA region in national, regional, and global HIV forums and in key decisionmaking positions including Country Coordinating Mechanisms (CCMs).

Key partnerships have been made to ensure sustainability of gains from the Investing in PLHIV Leadership in MENA initiative and to ensure that the path to greater PLHIV leadership continues. Among these steps are a pledge by the Jordan NAP to support the MENA+ website; resources and support provided by Ford Foundation and ICW to establish a regional women’s network; and additional funding by NAPs for country-level activities led by and for people living with HIV.

By exemplifying the principle of GIPA, the Investing in PLHIV Leadership in MENA initiative has supported the transformation of HIV-positive people as engaged leaders working with their peers, health officials, political leaders, and other stakeholders to improve HIV prevention, care, and treatment programs in the MENA region.

ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
ART	antiretroviral treatment
ATL	Association Tunisienne de Lutte Contre les Maladies Sexuellement Transmissibles et le SIDA
CCM	Country Coordinating Mechanism
CD4	Cluster of Differentiation 4
FGC	female genital cutting
GFATM	GlobalFund to Fight HIV/AIDS, Tuberculosis, and Malaria
GIPA	Greater Involvement of People Living with HIV/AIDS
GNP+	Global Network of People Living with HIV/AIDS
HARPAS	HIV/AIDS Regional Program in the Arab States
HIV	human immunodeficiency virus
ICW	International Community of Women with HIV/AIDS
IDP	internally displaced person
IDU	injecting drug user
IFRC	International Federation of Red Cross and Red Crescent Societies
LAS	League of Arab States
LDC	least developed country
M&E	monitoring and evaluation
MENA	Middle East and North Africa
MSM	men who have sex with men
NAP	National AIDS Program
NGO	nongovernmental organization
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
PRB	Population Reference Bureau
RBAS	Regional Bureau for the Arab States
SGBV	sexual and gender-based violence
SIDC	Soins Infirmiers et Développement Communautaire
SW	sex worker
TOT	training-of-trainers
UN	United Nations
UNGASS	UN General Assembly Special Session on HIV/AIDS
UNDP	United Nations Development Program
USAID	U.S. Agency for International Development
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	voluntary counseling and testing
WHO	World Health Organization

I. INTRODUCTION

The Greater Involvement of People Living with HIV/AIDS (GIPA) principle has been incorporated into national and international program and policy responses worldwide and adopted as a model of best practice in the response to HIV. This principle aims to realize the rights and responsibilities of people living with HIV (PLHIV), including the right to self determination and participation in decisionmaking processes. GIPA goals include improving the quality and impact of the HIV response through meaningful PLHIV engagement, participation, and leadership. GIPA also encompasses a broad and dynamic process that must be linked to PLHIV social movements, organizations, networks, support groups, and individuals to ensure meaningful involvement. This involvement in policy dialogue and decisionmaking leads to meaningful involvement in programming implementation and, in turn, the quality of the HIV response.

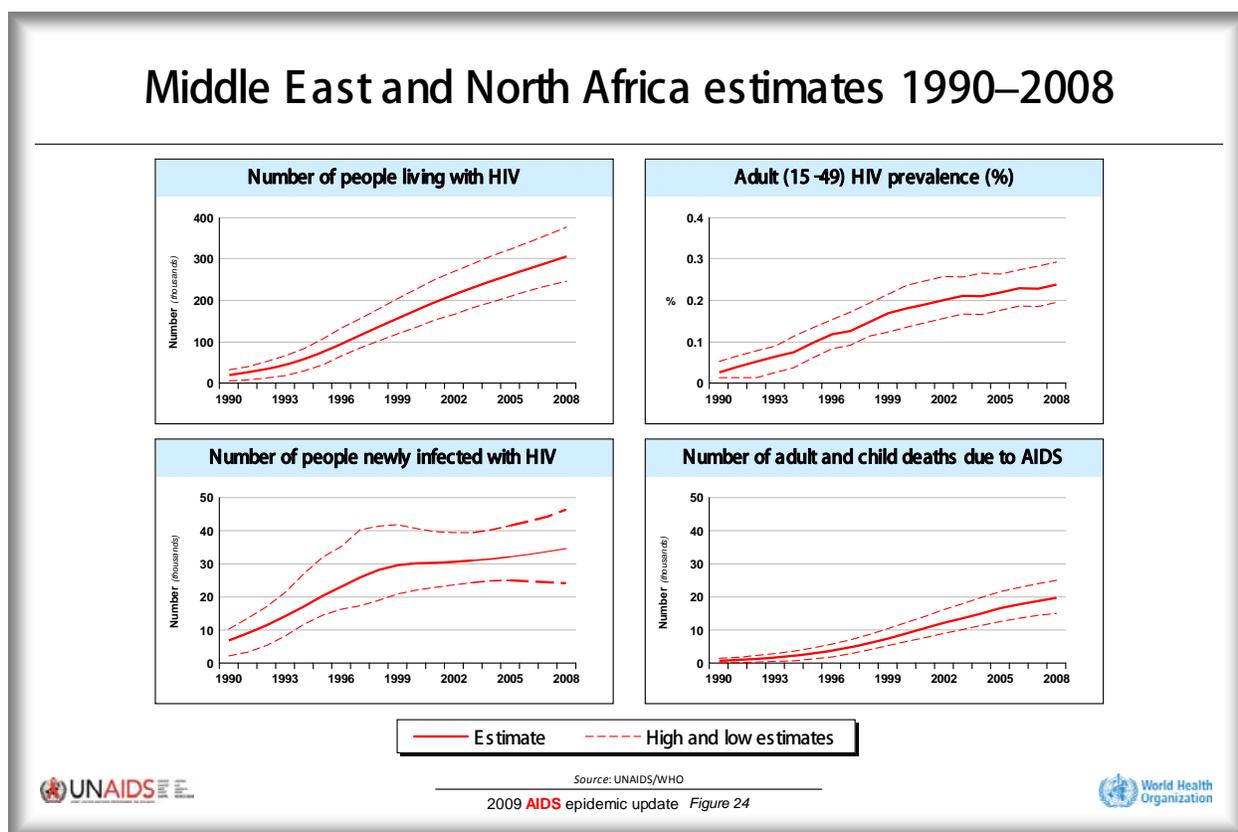
As the global GIPA movement gained momentum, however, the Middle East and North Africa (MENA) region was largely left behind. The GIPA principle is new to most people living with HIV in the MENA region. In the global, regional, and country-level responses to HIV, people living with HIV from the MENA region have too often been excluded from the decisionmaking processes that affect their lives. In response, in 2005, the U.S. Agency for International Development (USAID) launched the Investing in PLHIV Leadership in MENA initiative (hereafter referred to as “the initiative”), which was implemented by the POLICY Project and, subsequently, the follow-on USAID | Health Policy Initiative, Task Order 1. Key questions first asked when developing the initiative were: “Where are PLHIV from the Middle East and North Africa in the HIV response?” and “Why have their voices not been heard?” Introducing this relatively new phenomenon in the region provided people living with HIV an opportunity to incorporate the best GIPA ideas into their own work—based on an understanding of what works from GIPA’s long history—and strengthen GIPA within the context of the need for a more comprehensive response to HIV in the region.

II. HIV IN THE MENA REGION

The Status of the Epidemic

The MENA region experiences a cycle of risk and HIV infection that must be broken. Although experts and national statistics report that the region has low HIV prevalence, the rate of new infections remains high (see Figure 1). According to the Joint United Nations Program on HIV/AIDS (UNAIDS), there were an estimated 310,000 people living with HIV and 35,000 new cases of HIV in MENA in 2008 (see Table 1). More than 20,000 adults and children in the region died from AIDS-related causes in 2008 (UNAIDS, 2009b). Estimated numbers of those living with HIV in the Maghreb (Algeria, Morocco, and Tunisia) are higher than those in the Mashreq (Egypt, Jordan, Lebanon, Syria, and the Occupied Palestinian Territories). This difference may be due to greater access to high-quality HIV counseling and testing and other surveillance methods in the Maghreb.

Figure I. UNAIDS estimates for HIV and AIDS trends in the MENA region, 1990–2008



Source: UNAIDS, 2009a.

Table I. HIV and AIDS data for the MENA region, 2001 and 2008

	2008	2001
Number of people living with HIV	310,000 [250,000–380,000]	200,000 [150,000–250,000]
Number of new HIV infections	35,000 [24,000–46,000]	30,000 [23,000–40,000]
Number of children newly infected	4,600 [2300–7500]	3,800 [1,900–6,400]
Number of AIDS-related deaths	20,000 [15,000–25,000]	11,000 [7,800–14,000]

Note: Brackets indicate the low and high estimates.
 Source: UNAIDS, 2009b.

HIV in the region affects most-at-risk populations (MARPs), including sex workers and their clients, injecting drug users (IDUs), men who have sex with men (MSM) and their female partners, prisoners, and girls who marry before the age of 18 years old—particularly those who marry significantly older men (UNDP, 2009). Women and girls are the majority (54%) of PLHIV in the region (WHO, 2008; UNAIDS, 2007). Furthermore, vulnerable children are increasingly at risk for HIV infection region-wide (UNAIDS, 2009b).

Globally, HIV often is addressed only when it has become too visible to ignore. Lessons learned from high-prevalence countries that once faced low-prevalence/high-risk situations, such as those in neighboring sub-Saharan African countries, further demonstrate the need to address HIV in the MENA region now, before risk factors and concentrated epidemics develop into a generalized or intensified regional pandemic.

Challenges in a Low Prevalence and High-risk Context

Alongside the “loud emergencies” in the MENA region (e.g., armed conflict, political instability, and water insecurity), HIV is a growing but silent challenge to human security. HIV vulnerability and infection are fueled by the following mutually reinforcing risk factors:

- Limited access to treatment and high-quality services
- High levels of HIV-related stigma, discrimination, and human rights abuse
- Gender inequality and increased feminization of the epidemic
- Limited number of independent community-based civil society organizations, support groups, and people living with HIV networks
- Armed conflict resulting in disrupted health services and vulnerable populations, including refugees, internally displaced people (IDPs), and other mobile populations
- Large youth populations
- Lack of reliable, high-quality data about HIV in the region, as well as informational material for people living with HIV and populations at risk for infection

All regions, countries, and communities bring to the epidemic context-specific complexities that make the HIV situation both unique and challenging. However, as described in more detail below, each of these risk factors is perhaps more acute in the MENA region, due in part to the region being left behind in the HIV response. In many respects, the MENA HIV response is still in its beginning stages.

Limited access to treatment and high-quality services

In 2008, only 14 percent of those people in the region in need of treatment were receiving antiretroviral drugs (WHO, 2009b) (see Table 2). In 2008, treatment coverage in MENA was less than half of the global average for low- and middle-income countries, standing as the lowest treatment coverage in the world (UNAIDS, 2009b). When provided at all, the regimens for antiretroviral treatment (ART), including combination therapies, are limited. Stock-outs are not uncommon. In particular, many mothers living with HIV do not have access to ART to prevent mother-to-child transmission (PMTCT); only 1% of mothers are projected to have access to this care (WHO, 2009). Further, stigma and discrimination in the region increase risk; for example, HIV-positive mothers have reported refusal by hospitals and clinics to support child birth as well as pre- and postnatal care (WHO, 2010).

For most people in the region, voluntary counseling and testing (VCT) is inaccessible. Furthermore, as many as 90 percent of PLHIV in the MENA region are unaware that they are HIV positive (Obermeyer,

2006). When VCT is available, necessary testing—including CD4 count and viral load testing—which is crucial to effective treatment, often is not available.

The MENA region has made significant strides in its health indicators in recent decades, with a marked decrease in infant mortality rates and rising life expectancy in many countries. There are still many challenges within the region's health systems, however, especially in the least developed countries (LDCs) in the region. These challenges are serious for people living with HIV, many of whom do not have access to basic healthcare. In addition, women and girls often face gender-related barriers to treatment, such as finding providers who will treat them when they are not accompanied by male relatives or respect confidentiality and nondisclosure to husbands and other relatives. This is especially difficult for HIV-positive women, who must rely heavily on often overstretched systems that do not recognize indirect health determinants, such as gender and social class.¹ Health systems in the region often are restricted by underfunding, bloated bureaucracies, need for improved professional capacity, and lack of appropriate protocols or implementation of protocols and policy, including those on confidentiality as well as appropriate follow-up support for people living with HIV. This lack of access to high-quality healthcare and support creates a barrier to testing and consistent treatment, especially among the region's most vulnerable groups.

Table 2. Antiretroviral Treatment Coverage in Low- and Middle-income Countries, Adults and Children Combined, December 2008

Geographical region	Estimated number of people receiving ARV therapy	Estimated number of people needing ARV therapy	Antiretroviral therapy coverage
Sub-Saharan Africa	2,925,000	6,700,000	44%
Latin America and the Caribbean	445,000	820,000	54%
East, South and South-East Asia	565,000	1,500,000	37%
Europe and Central Asia	85,000	370,000	23%
North Africa and the Middle East	10,000	68,000	14%
Total	4,030,000 [3.7–4.4 million]	9,500,000 [8.6–10 million]	42% [40–47%]

Source: WHO, 2009

Table 3. PMTCT Coverage in Low- and Middle-income Countries, December 2008

Geographical region	Reported number of pregnant women living with HIV receiving ARVs for PMTCT	Estimated number of pregnant women living with HIV needing ARVs for PMTCT	Prevention of mother-to-child transmission coverage
Sub-Saharan Africa	576,800	1,280,000	45%
Latin America and the Caribbean	17,100	32,000	54%
East, South and South-East Asia	21,700	85,000	25%
Europe and Central Asia	12,600	13,400	94%

¹ Important factors accounting for health disparities within MENA countries are income level, place of residence (urban or rural), and mother's educational level. For more information, see WHO, 2009.

North Africa and the Middle East	<200	13,400	1%
Total	628,400	1,400,000 [1.1–1.7 million]	42% [40–47%]

Source: WHO, 2009

High levels of HIV-related stigma, discrimination, and human rights abuse

HIV stigma and discrimination include travel policies restricting people living with HIV from legally entering countries and deportation policies based on HIV status; school expulsions; house evictions; forced family separation; and rejection within the community. It is not uncommon for healthcare providers to stigmatize people living with HIV and refuse to provide them with services. As a result, people who are possibly HIV infected may not seek the necessary tests and treatment due to shame, fear, and potential stigma and discrimination. In addition, stigma and discrimination have led to egregious human rights abuses throughout the region, ranging from domestic to state-sponsored abuse (Human Rights Watch, 2005 and 2008).

Gender inequality and increased feminization of the epidemic

The feminization of HIV is becoming particularly acute in the MENA region. Women are the majority of PLHIV in the region; currently they account for 54 percent of the HIV-positive people in the MENA region (WHO, 2009; UNAIDS, 2007). An estimated 80 percent of female HIV infections in the region occur within marriage (UNDP, 2009), which reflects the limited negotiating power many women have within marriage and vulnerability due to their partners' high-risk behaviors. Studies have also found that girls and women ages 15–24 are twice as likely to be HIV positive as their male counterparts (PRB, 2008).

Gender-related risk factors increase women's vulnerability to HIV infection. The region has the lowest literacy rate among women worldwide (UNDP, 2005). Women's access to economic power is limited, as the region also has the world's highest unemployment rate among women (UNDP, 2009). Marriage laws fuel women's vulnerability inside relationships in which they have little power, as most confirm a husband's custodial rights over his wife. Further, male supremacy within the family is reinforced by Personal Status laws; under these laws, most women in MENA countries neither have the right to ask for a divorce, nor can they legally oppose polygamy, marital rape, or other forms of subordination and abuse. Girls and women face harmful traditional practices, including early marriage and female genital cutting (FGC), which is widespread in several MENA countries. (In Egypt, more than 90 percent of the women and girls over age 10 experience FGC; in Yemen, more than 20 percent of the female population is affected [UNDP, 2009]). While FGC creates greater emotional vulnerability to HIV by perpetuating women's and girls' lack of control over their own bodies, including advocating for safer sex, it also heightens their physical vulnerability to bad health outcomes due to this injurious practice. FGC is often carried out with unsterilized instruments by midwives, hairdressers, and barbers who have the cultural, traditional, and local legitimacy to perform "circumcisions." Further, this practice typically takes place just before marriage to ensure chastity and can compromise a woman's health during childbirth. As mentioned above, gender-related barriers also limit women's access to necessary care.

In general, normative societal ideals for the interaction between women and men and gender expectations related to both can put both men and women at risk. For men, cultural and traditional norms are less prohibitive with respect to having multiple sexual partners than are the norms for women. Men are usually the first in a marriage to become HIV positive (UNDP, 2009); thus men need to be tested, educated, and have access to prevention methods. Furthermore, men need to be actively engaged in the response, because in many countries, their consent is required to permit their wives and female relatives to seek health services; additionally, male engagement to support women and girls human rights is essential for realization of their rights.

Limited number of independent community-based civil society organizations, support groups, and networks led by and for people living with HIV

All MENA countries support the right to form civil associations to some extent. However, most legal systems regulating the civil sector involve a wide range of restrictive measures that affect freedom of expression, assembly, and implementation of such activities, including restrictions on forming and operating organizations. In many countries, the state and its affiliates can dissolve organizations, boards, and groups and subject donors to stringent controls. The situation is complicated further for people living with HIV and vulnerable groups, such as MSM, sex workers, and IDUs, who are often criminalized for their behavior and stigmatized for HIV status. In other regions, the HIV response has seen rapid expansion of NGOs working in HIV, support groups, and positive networks. These structures and partnerships are essential for providing education; fostering access to testing, treatment, care, and support; as well as engaging people living with HIV in the policy process. However, this has not been the case in the MENA region where the number of NGOs and networks involved in the HIV response is limited and restricted.

Armed conflict resulting in disrupted health services and vulnerable populations, including refugees, IDPs, and other mobile populations

The MENA region has experienced decades of conflict and, thus, faces increased HIV vulnerability. Conflict and HIV reinforce each other, creating deeper destabilization and a general weakening of public structures and services.² The various armed conflicts in the region and border disputes in almost all countries have created greater vulnerability to HIV due to lack of access to necessary services, especially for “non-citizens” of a state, including refugees, migrants, and nomadic groups. Exacerbating the situation is the increase in sexual and gender-based violence (SGBV), which has been used as a means of warfare, leaving many women and children particularly vulnerable to HIV.

The MENA region has the highest rate of mobility in the world—largely fueled by conflict and poverty. The region is home to 46.8 percent of the world’s refugees (7.5 million out of 16 million). IDPs account for 9.8 million people in MENA, who share many of the same insecurities as the region’s refugees, including loss of livelihood, status, and family and increased HIV vulnerability among other health status risks (UNDP, 2009). Migrant labor also increases risk; people living away from home may have disposable income and access to high-risk sexual relationships, including unprotected sex with sex workers or multiple partners, and drug use.

Large youth populations

The MENA region has one of the youngest populations in the world, with a median age of 22, and people between the ages of 15 and 24 represent one-fifth of the total population (UNAIDS, 2009b). Algeria has the highest youth unemployment rate, at 43 percent (UNDP, 2009). Idleness and lack of job security among youth can contribute to high-risk behaviors, including injecting drug use and high-risk sexual practices, such as unprotected and transactional sex with multiple partners.

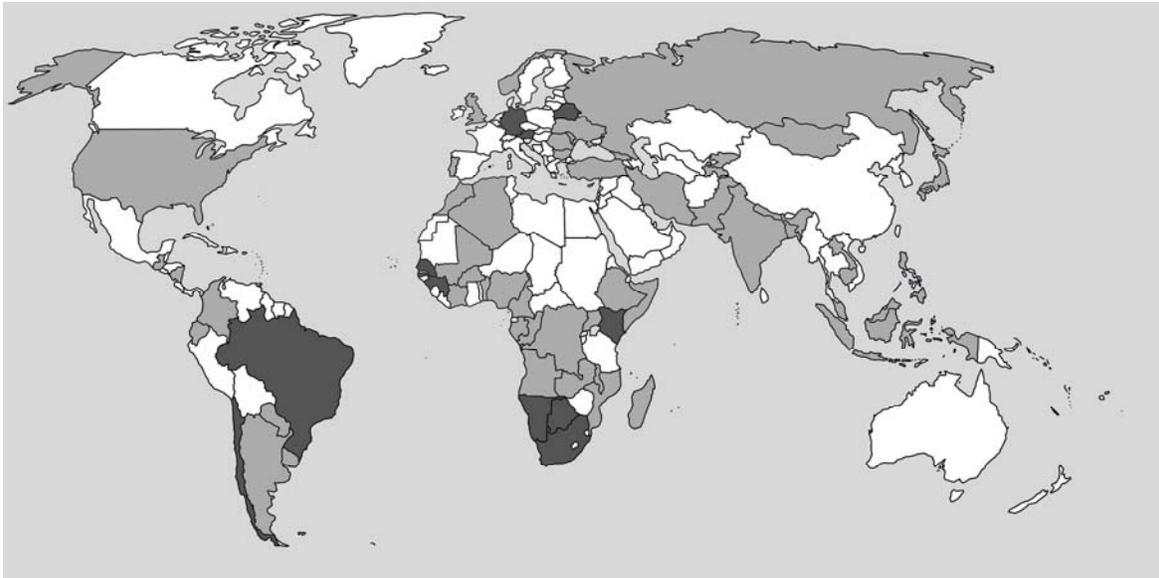
Lack of reliable, high-quality data about HIV in the region, as well as informational materials for PLHIV and populations at risk of infection

The MENA region does not lack expert researchers with the capacity to conduct the necessary surveillance. However, countries still need the political will, donor support, access to key populations, coordination, and local expertise to obtain clear and accurate data regarding the region’s HIV situation. The risk factors discussed earlier, including conflict and inadequate health funding, further complicate research processes and access to reliable data. Further, as illustrated in Figure 2, there has been no noticeable strengthening of monitoring and evaluation (M&E) systems in the region, according to the

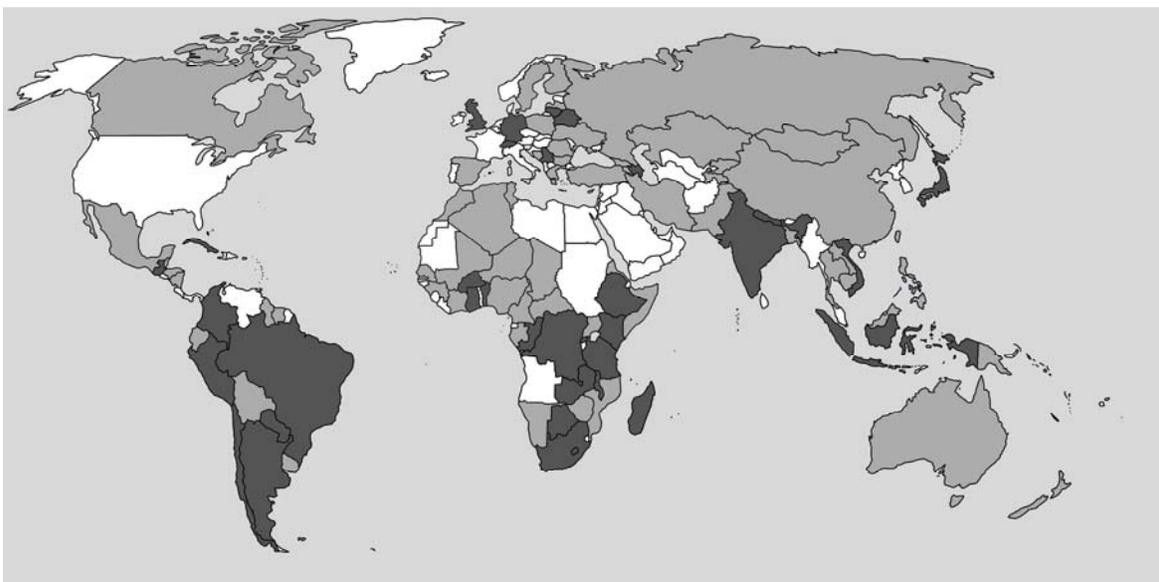
² Links between HIV and conflict should be recognized, reiterating UN Resolution 1308, which states “the HIV/AIDS pandemic is also exacerbated by conditions of violence and instability, which increase the risk of exposure to the disease through large movements of people, widespread uncertainty over conditions and reduced access to medical care...” (S/RES/1308 2000).

“Three Ones” principle: (1) a national M&E plan, including budgetary requirements and secure funding; (2) a functional national M&E unit and/or working group; and (3) a central national HIV database.

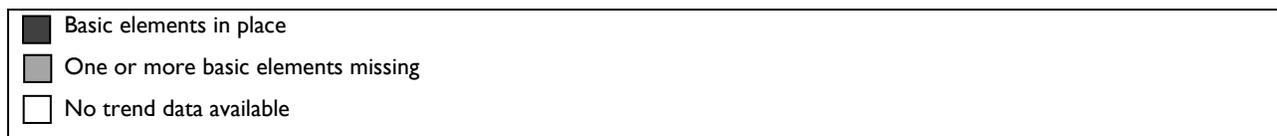
Figure 2. No change in MENA global M&E system strengthening—comparison between 2005 and 2007



Global monitoring and evaluation system strengthening, 2005



Global monitoring and evaluation system strengthening, 2007



Source: UNGASS Reporting, 2006 and 2008.

Although efforts have been made to develop high-quality educational materials, the MENA region still has little in terms of current, high-quality information about HIV in Arabic or information, education, and

communication materials available in local languages or low-literacy formats and via online platforms. The information gap is filled with myths, misinformation, and damaging stigma related to HIV that perpetuates risk, shame, and blame.

III. HISTORY OF GIPA IN THE MENA REGION

Globally, the movement by and for people living with HIV has been marked by several key milestones that have led to worldwide implementation of the GIPA principle. At the 1983 “Health Pioneering in the Eighties” Conference in Denver, Colorado, people living with HIV gave voice to the idea of personal experiences shaping the HIV response. This led to the development of the landmark Denver Principles, which first gave momentum to the GIPA movement. The GIPA principle, formalized at the 1994 Paris AIDS Summit, was supported by 42 countries, including two from MENA: Morocco and Tunisia. Signatories to the Paris Declaration agreed to support the greater involvement of people living with HIV at all levels by creating supportive political, legal, and social environments. As discussed below, the MENA region has lagged behind in reaching the key milestones that have defined the GIPA movement and fundamentally changed the HIV response.

Ten years ago, public dialogue about HIV in MENA had been limited to discussions among ministries, agencies, and clinical experts regarding the biomedical implications of HIV in the region. Due to the stigma and significant consequences for disclosure, public disclosure was rare. In 2002, United Nations agencies, notably the United Nations Development Program (UNDP) HIV/AIDS Regional Program in the Arab States (HARPAS), initiated a multisectoral approach to breaking the silence surrounding HIV. This led to greater dialogue about the cultural, social, traditional, and personal aspects of HIV in the MENA region. Since then, HARPAS has had significant success enrolling key stakeholders from the region, including female and male Christian and Muslim religious leaders, legal experts, parliamentarians, private sector professionals, media experts, and regional counterparts, such as the League of Arab States (LAS) as well as key regional figures and leaders such as the Sheikh El-Azhar and Amr Moussa. As more sectors became involved in the regional discourse, people living with HIV were engaged to share their testimonies. Testimonies from people living with HIV served to raise awareness about HIV through engaging directly with key stakeholders and providing a human element to a stigmatized disease (IFRC, 2004).

In 2002, media coverage supported by UNDP and UNAIDS included a groundbreaking documentary featuring an Algerian woman living with HIV who openly disclosed her status. This marked one of the first known public disclosures of seropositive status in MENA to a regional audience. Thereafter, people living with HIV started to directly engage key leaders, most notably the region’s religious leaders, via courageous testimonials. This directly affected the development and signing of the landmark 2004 Cairo Declaration by more than 80 religious leaders and subsequent 2006 Tripoli Declaration, signed by the region’s female religious leaders. Both declarations marked some of the first open and official acknowledgements of people living with HIV and vulnerable groups, as well as support of human rights and anti-stigma and discrimination efforts within the context of HIV and vulnerable groups.

Until very recently, people living with HIV in the MENA region were not organized and engaged in support groups, networks, and NGOs, but remained fairly isolated. People living with HIV in the region are extremely difficult to reach because they face huge risks disclosing their status, including human rights abuses. This has been such a pervasive problem that the international organizations that were partners in this initiative mentioned this as a major reason for not having fully engaged in MENA responses to HIV. UNDP/HARPAS, through the efforts described above, had built trusted relationships with people living with HIV in the region as well as key supportive NGOs. This trust led to opening up of avenues for legal aid, home care, and psychosocial support provided by individuals, and engagements with local support groups, NGOs and government ministries, in addition to the religious leaders. These

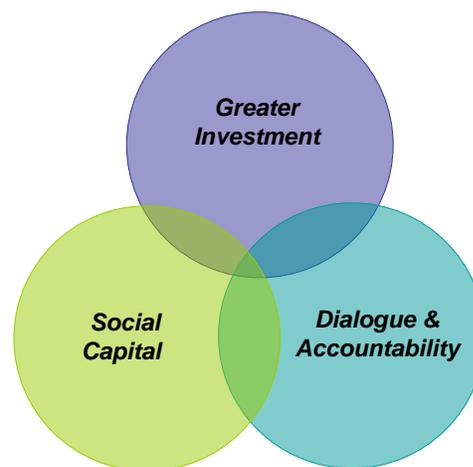
engagements began shaping the policy environment; by 2006, most states in the region prepared their own national AIDS plans and all countries signed on to the 2001 UNGASS (United Nations General Assembly Special Session) Declaration of Commitment.

IV. THE “INVESTING IN PLHIV LEADERSHIP IN MENA” INITIATIVE

It was against this backdrop that in 2005, USAID launched the Investing in PLHIV Leadership in MENA initiative. This focused, multiyear initiative was designed to take the next step in the GIPA process, by building the capacity of people living with HIV as leaders and engaging them as experts to shape the region’s emerging HIV response. Despite the progress above, it was still extremely challenging to engage women and men living with HIV in MENA. Faced with possible house eviction, job loss, forced family separation, physical abuse, social rejection, lack of access to treatment and decent care, jail sentences, deportation, and forced HIV testing, people living with HIV were reticent to engage in an HIV response. Other organizations, such as Global Network of People Living with HIV (GNP+) and the International Community of Women with HIV/AIDS (ICW), had found it difficult to start networks at regional or country levels. With concerted effort and lessons learned from global-level dialogue and engagements around GIPA—the Investing in PLHIV Leadership in MENA initiative helped to usher in a new path to PLHIV leadership in the MENA region.

Our Approach: Build Social Capital, Make Greater Investment, and Foster Dialogue and Accountability

The MENA initiative sought to involve people living with HIV; invest in HIV-positive, local leaders and organizations; and build their capacity to influence the decisions that affect their lives and health. The project’s approach to this initiative had three key pillars: building **social capital** of PLHIV, making **greater investment** in avenues for PLHIV leadership, and fostering **dialogue and accountability**.



Social Capital

Social capital refers to the means by which a person or group can influence his or her social environment and is often defined as involvement in different networking mechanisms (Baker, 2000) and characterized by trust and interdependence among the members of the networks. Key to the initiative’s approach and success was to support a burgeoning group of the region’s people living with HIV to come together as a collective and find the courage to step out of isolation based in fear, stigma, and discrimination. Further, the initiative recognized the long-term value that people living with HIV would find by building relationships, trust, and sense of cohesion in a network led by and for them. Therefore, building social capital and facilitating networking amongst people living with HIV at country and regional levels were crucial. Often, people living with HIV who participated in the first regional activity were nominated to attend via clandestine support groups and low profile NGOs. The early workshops of the *Investing in PLHIV Leadership in MENA* initiative, described below, solidified existing informal networks of support among people living with HIV and brought HIV-positive women and men together who had been living in isolation within their own communities and countries. As PLHIV had more opportunities to meet, discuss their concerns, and design a response around their priorities, they

formed a network. As described further below, the network is still defining its way forward, but now people living with HIV in the region have the opportunity to join a network formed exclusively by and for people living with HIV and led by HIV-positive women and men in the region.

Greater Investment

The global response to HIV has recognized the need for and has committed significant financial and human resources to address the epidemic at all levels—from government leadership, to health systems strengthening, to civil society and community group support, as well as support provided to people living with HIV themselves. Indeed, making financial investments in PLHIV-led efforts is key to ensuring that greater, meaningful involvement of people living with HIV is sustainable. Expanding the definition of GIPA to encompass “greater investment” recognizes that financial and other resources must be paired with capacity building to attain meaningful and lasting involvement and leadership. Thus, a fundamental component of the Investing in PLHIV Leadership in MENA initiative was to hire and mentor people living with HIV from the region as consultants, who—along with the senior technical staff—led the capacity building and ongoing technical assistance for leadership, stigma reduction, website development, workshop facilitation, and peer-to-peer education. As described below, the initiative put resources in the hands of groups led by and for people living with HIV from MENA through small grants. These investments mark some of the first people living with HIV in the region who have been hired as experts in the HIV response, as well as the first grants provided directly to groups led by and for people living with HIV to carry out local and national activities that they design, implement, and lead.

Dialogue and Accountability

Inclusive dialogue and greater accountability were central components of the Investing in PLHIV Leadership in MENA initiative. The initiative’s approach was to (1) build the skills of people living with HIV to engage effectively in policy dialogue; (2) support people living with HIV to make connections in their own countries with trusted allies in health, civil society, and policy circles; and (3) facilitate opportunities for women and men living with HIV and their allies to jointly plan for future collective action for greater accountability and positive leadership in the region’s HIV response.

Methodology

The initiative’s approach was anchored by a strong methodology. This included: (1) informing program decisions based on needs assessments conducted by people living with HIV; (2) working in partnership with international, regional, or local partners at every stage; (3) supporting a paradigm shift from GIPA to more meaningful engagement of people living with HIV (MIPA) in the region; and (4) planning for regional and in-country sustainability of leadership and capacity of people living with HIV.

PLHIV Needs Assessments

A simple but important element of the initiative’s methodology was to listen to what people living with HIV in the region faced, recognize what they knew they needed, and inform programming based on these needs to fill gaps and create sustainable solutions. Through the needs assessment process, people living with HIV provided valuable information, particularly about the barriers faced in-country related to living with HIV. From the first activity to the last, people living with HIV were, in essence, co-designers of the initiative. As the initiative progressed in capacity building, knowledge sharing, and partnerships, more people living with HIV expressed the need for high-quality information in Arabic; stated their desires to build their own capacity for awareness raising, education, NGO support, and advocacy; and requested support to share information among other people living with HIV in their local communities who, like them, had been living with little information or support regarding their HIV status and their families’ health.

Working in Partnership

Key to the success of the initiative were strategic partnerships. Local and regional partners were linked with global-level partners and decisionmaking processes. The initiative's partnership with UNDP/HARPAS was fundamental to enrolling a regional group of people living with HIV willing to join in the response early on. UNDP/HARPAS also cost-shared activities and workshops, provided regional technical expertise, and expanded the country coverage of the program. The regional partnership and approach had a multiplying effect. As more people living with HIV benefitted from the initiative, they enrolled more positive people from their countries to join in the response; this was particularly the case with bringing in more women living with HIV.

Every workshop in the initiative was conducted in partnership with an international alliance or coalition, a local NGO working in HIV, and/or a National AIDS Program (NAP) (see Appendix A). Local partners provided support for participants attending regional workshops, including access to free testing (including CD4 count and viral load), childcare services during the workshops to address gendered barriers to participation in particular, and links to local organizations, leaders, and healthcare providers. Over the years, the number of partners engaged at regional, country, and community levels continued to grow, and additional international donors joined in and provided support. Altogether, the total number of partners engaged in the Investing in PLHIV Leadership in MENA initiative was no less than 35, including NAPs, support groups, NGOs, international NGOs, and UN agencies.

Paradigm Shift from GIPA to MIPA

The groundbreaking Investing in PLHIV Leadership in MENA initiative was one of the first initiatives to address positive leadership based on the GIPA principle in the region. Building on the momentum that UNDP/HARPAS has fostered to engage people living with HIV, the initiative furthered engagement with people living with HIV by building their capacity as advocates, champions, and experts, themselves able to promote meaningful and effective leadership and sustainability in the region's HIV response.

Planning for Sustainability

The initiative's approach and methodology described above all supported the a priori goal of planning for sustainability. The sustainable results of the initiative were based on core needs and gaps identified by people living with HIV, developing and growing strategic partnerships at all levels in the region, and fostering local leadership and a sense of ownership among people living with HIV and their partners. As described below, this strategy is taking root and shows promise for continued growth.

Workshops and PLHIV-led Activities At-a-Glance

Box 1. First Time Milestones in the Region—a New Path

- The first **regional workshop facilitated by and for PLHIV** (February 2006, Regional Leadership and Networking)
- The first **training-of-trainers workshop for PLHIV** (June 2008, How to be Positive Trainer in the MENA Region)
- The first **workshop facilitated entirely by and for PLHIV from the MENA region** (June 2008, Sub-Regional Training in Leadership and Networking)
- The first **country-level small grants entirely developed, implemented, and managed by PLHIV** (2008–2010, Jordan, Yemen, Lebanon)
- The first **women-centered workshop implemented by and for women living with HIV** (May 2009, Addressing HIV among Women and the Gender Dimensions of HIV in the MENA Region)
- The first **country-level peer-to-peer workshops led by and for PLHIV from the region** (2009–2010, Bahrain, Beirut, Sana'a, Aden, Muscat, Riyadh)
- The first **workshops where PLHIV nominated supportive physicians as advocacy partners** (December 2009, Stigma and Discrimination in the Healthcare Setting and Advocacy workshops)

The initiative progressed through a series of workshops, each of which built on the previous one, drew upon lessons learned, and leveraged new opportunities for increasing the capacity and leadership role of people living with HIV in the region. Workshops often 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 (see Box 1 above). Additional details on the attendance, workshop objectives, and implementing partners are summarized in Appendix A. Workshop reports are available upon request and the curricula for the four key workshops are available at online at www.healthpolicyinitiative.com.

Regional leadership and networking workshops

The first Investing in PLHIV Leadership in MENA workshop was held in Tunis, Tunisia in February 2006, under the POLICY Project. This workshop brought together 26 participants from nine countries in the regions and was the first in the region to be facilitated by and for people living with HIV. This marked a first step on the path toward an HIV response led by and for people living with HIV. The workshop provided a safe space for people living with HIV to exchange ideas and concerns and gather new information and skills around networking and addressing stigma and discrimination. For many participants who had lived in isolation, this was their first opportunity to meet other people living with HIV in the region, disclose their status, access another level of support at the regional level, and engage in the networking process regionally. POLICY partnered with GNP+ and UNDP/HARPAS to facilitate this workshop.

Honestly, I benefitted a lot from this workshop and thanks for the steps we made for PLHIV ... It will help the PLHIV in the Arab world and will really make a difference. I feel a stronger, newer energy and I have more qualifications to communicate the data than I did before.

—Male, Libya

I know that I have a family and I feel now, if we share what we know and learn, we can accomplish a lot. I also feel a big responsibility provided and I'm hopeful.

—Male, Jordan

Thanks to communication and informal networking among participants after the Tunis workshop, the second Leadership and Networking workshop, held in Wadi Natroun, Egypt in September 2006, welcomed almost twice as many participants as the Tunis workshop and five new countries were represented. The workshop was also held in partnership with UNDP/HARPAS and local partner Freedom Center. The first

I am very happy with the participation, especially as the colleagues acting as our trainers who are also PLHIV. This has given me a great boost. This has given me great support that there is hope in this life. I am motivated and I see that this course yields great potential and that we'll be able to convey the message to our colleagues back home. I hope to be in the trainer's shoes one day.

—Male, Yemen

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

three days of the Wadi Natroun workshop focused on training, facilitation, and additional leadership and capacity-building skills for seven of the Tunis workshop participants identified by their peers as potential leaders. The remaining five days of the Wadi Natroun workshop provided a new group of men and women living with HIV from MENA with the HIV basics and leadership/networking skills covered in the Tunis workshop. A new step made with this workshop was that people living with HIV from the region co-facilitated workshop sessions for the first time in the region. This was a small but important step along the path to positive leadership and a sustainable HIV response in the region. And it was one of many steps that facilitated the transition of people living with HIV from beneficiaries to becoming HIV leaders and experts. Finally, of the 70 people living with HIV from 13 MENA countries who participated in these workshops, two HIV-positive female leaders were identified to serve as project staff consultants to support the growing cadre of people living with HIV engaged through the Investing in PLHIV Leadership in MENA initiative.

Training-of-trainers (TOT) workshop

In June 2008—having piloted initial facilitation and training skills sessions in Wadi Natroun—the initiative held a formal TOT workshop in Amman, Jordan, to build the training and facilitation skills of 12 people living with HIV from seven MENA countries to design and implement trainings in their own countries and to effectively network with other people living with HIV nationally, regionally, and globally. The participants

engaged in rigorous sessions to strengthen their technical skills related to HIV content, as well as public speaking, adult learning, session development and facilitation, leading feedback groups, contextualizing information to the region and their locality, and evaluation. Most of the sessions at the TOT were facilitated by the two women living with HIV from the region, who were mentored as trainers from the time of the previous workshop until implementation of the TOT. Women living with HIV leading a regional forum to build the skills of a cadre of future HIV-positive leaders was remarkable not only for breaking gender norms in a traditionally male-dominated society, but also for the inspiration their role gave to female as well as male participants who then aspired to engage more fully in the region's response as leaders themselves who supported the rights of women and girls. (Training-of-Trainers Curriculum: Building the Training Skills of PLHIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 1.)

The leadership also is something good, to have PLHIV lead the sessions. I would hope this would be the case, always to see PLHIV taking the lead.

—Male, Bahrain

Subregional leadership and networking workshop

With just two days to prepare after finishing the TOT, the newly minted trainers led the third leadership and networking workshop for 26 of their peers from eight countries; this marked a clear shift in power from people living with HIV as receivers of HIV knowledge, to HIV-positive regional leaders transferring knowledge and skills to other people living with HIV in the region. Session designs were refined from the previous workshops based on lessons learned, participant inputs, and assessments. Sessions built participants' knowledge and capacity related to: stigma and discrimination;

treatment; disclosure; prevention of mother-to-child transmission (PMTCT); nutrition and exercise;

I am the happiest person today and I think the members of my family have increased. I am concerned that I will lose any one of you and so I will fight to protect and assist you, and we will work together.

—Male, Saudi Arabia

relationships, marriage, and family; gender and HIV; positive living; support groups; stress management and reduction; human rights; GIPA; and advocacy. The enabling environment at the workshops also created a platform for people living with HIV to discuss challenges and their own lack of action to formalize their informal network, starting with networks of communication. This meeting started the network development process. As described below, through several meetings and online discussions, the burgeoning network has made significant strides in consolidating the terms, norms, and communication channels—all of which has been led by people living with HIV, and further, have been engaged by regional counterparts to establish partnerships and further support. The MENA+ president and network members were invited as network representatives to the WHO Regional Office for the Eastern Mediterranean (EMRO) and World Bank policy workshop: “Policy Dialogue Towards Achieving Universal Access to HIV Prevention, Treatment, Care, and Support in the MENA.” This meeting took place in Dubai from June 28–29, 2010. (Subregional Curriculum: HIV Basics for PLHIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 2.)

Small grants workshop

Immediately following the TOT and subregional workshop in Amman, 13 participants from Egypt, Lebanon, and Jordan stayed on for a small grants development workshop to plan country-specific activities. The initiative provided each country team with a small, US\$2,000 grant and guidance on the small grants application process, activity implementation, and grants management skills. This marked the first time funding had been given directly to PLHIV-led groups and in MENA for the management of any HIV activity. As described in Section V, the small grants supported country-level awareness-raising and networking activities and contributed to important partnerships with and decisions by national decisionmakers.

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 we are applying for another grant to continue the work we accomplished with the first.
—Male Jordan

I feel strength I didn't have before. I feel I am able to communicate better. I was shy—I didn't know how to speak. But after this training, I'm strong.
—Female, Egypt

I feel very proud to be surrounded by strong women who really want to do something and we are breaking the wall of silence. We can be strong even within the limits we have. We need peer-to-peer education ... Now that we have the information, we need to tailor it even more to our culture and region.
—Female, Lebanon

Women-centered workshop

In May 2009, the initiative partnered with ICW to bring together 23 women living with HIV from 12 countries to focus specifically on issues affecting HIV-positive women and serodiscordant couples. Described in more detail in Box 2, the workshop included sessions on pregnancy, childbirth, and breastfeeding; communicating with children; relationships, sex, and sexuality; grief and loss; caregiver support; HIV-positive women changing and connecting; and networks of support. (Women-Centered Curriculum: Addressing HIV among Women and the Gender Dimensions of HIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 3.)

Stigma and discrimination in the healthcare setting and advocacy workshops

In December 2009, the initiative and several partners' including ICW, International AIDS Alliance and its linking partner in Morocco, AMSED, and the Moroccan NAP, designed and delivered a workshop focused on stigma and discrimination in healthcare settings. This was followed on by an advocacy workshop to design strategies for reducing stigma and discrimination at country levels. Using a unique approach, people living with HIV were asked to nominate supportive physicians who could serve as advocates with them in-country to limit stigma and discrimination. This was a valuable opportunity for the region's doctors—who also faced stigma and discrimination as providers for people living with HIV—to share their own concerns and challenges. Many of the physicians nominated were also NAP

staff, which bolstered stronger links among PLHIV, their support groups and NGOs, and the NAPs to work in partnership. The country teams of local physicians and people living with HIV (a total of 31 people from 12 countries) developed advocacy goals, all of which were related to treatment. Recognizing the burning need expressed by people living with HIV and physicians for increased attention to treatment access, the topic of the next workshop was set. (HIV Principles and Stigma Reduction Training Curriculum: Addressing HIV and Stigma in the Healthcare Setting in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 4.)

Treatment advocacy and resource mobilization workshops

In May 2010, in collaboration with ATL, ICW, and the International AIDS Alliance, 39 healthcare providers and people living with HIV in from 11 countries gathered for five days to focus on treatment advocacy, with one day dedicated to a network meeting. Immediately following, donor representatives from USAID, Ford Foundation, and the GFATM MENA Portfolio, joined for two days on resource mobilization skills building. The treatment advocacy workshop was the first to bring together people living with HIV and their supportive doctors to specifically address the limited treatment coverage in MENA and explore ways that physicians and patients—in a new relationship as partners and experts in the national HIV response—could work together on treatment issues. The workshop featured medical and technical updates on related HIV and treatment issues in the MENA region. The resource mobilization workshop was a rare opportunity for HIV-specific donors in the MENA region, people living with HIV, and supportive physicians to discuss the donor environment in MENA, particularly as it relates to people living with HIV who are increasingly involved in civil society responses to HIV in their own communities and countries. The workshop also provided valuable time for people living with HIV to ask questions related to obtaining funding and the new round 10 prioritization for the GFATM.

Peer-to-peer workshops

The peer-to-peer workshops represent another first—the first of such workshops to be implemented by and for people living with HIV in the region. These workshops in Bahrain, Lebanon, Oman, and Yemen were based on modules from the subregional, women’s, and advocacy workshops for use at the country level. As a result, increased numbers of people living with HIV have been reached and engaged to join in civil society activities and support groups. Local HIV-positive trainers are working directly with people living with HIV in-country and engaging NAPs to ensure national support and follow-up.

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

Box 2. Where Are the Women? Involving Women Living with HIV in MENA

The need. The feminization of HIV is becoming particularly acute in the MENA region. Women constitute more than half of the HIV-positive population, and married women account for four out of five female HIV infections. Gender-related risk factors also increase women's vulnerability to HIV infection and ability to seek care. Sociocultural norms in the MENA region often regulate a woman's travel locally and certainly to another country, complicating efforts to network. Thus, a focus of the Investing in PLHIV Leadership in MENA initiative has been to meaningfully engage women living with HIV as participants, consultants, authors, experts, and networkers.

The response. Key to the engagement of women living with HIV was to ask those women who had served as participants and grew into leaders to actively reach out to as many HIV-positive women as possible through face-to-face contact, phone calls, text messages, and e-mail. To address the travel-related barriers, our staff, consultants, and local partners, in some cases, contacted male support group members to connect with male relatives they knew well, to legitimize and provide permission for women to attend workshops on their own or, if needed, with their children. As the initiative progressed, and trust increased among participants and the technical team, more men living with HIV requested that their wives and other relatives attend workshops with them so as to benefit from the information, networking, and support. By May 2009, enough engagement and trust had been built to organize the first regional workshop by and for women living with HIV in MENA. The Women-Centered Workshop: Addressing HIV among Women and the Gender Dimensions of HIV in the MENA Region was a turning point; 23 HIV-positive women from Algeria, Bahrain, Egypt, Jordan, Lebanon, Libya, Morocco, West Bank, Saudi Arabia, Tunisia, and Yemen attended the workshop. True to our methodology, participants were interviewed in advance by other HIV-positive women to assess their specific needs and desired outcomes from the workshop. Participants had varying levels of HIV knowledge and experience. Some women had never been outside of their villages before and knew very little about HIV. Other women were actively involved in a support group or an NGO. Some were single women, some were mothers of HIV-positive children, and others were spouses of HIV-positive partners. Thus, those with more experience in certain areas were asked to co-facilitate sessions and mentor other women in the group. Our local partner for this workshop, Association Tunisienne de Lutte Contre les Maladies Sexuellement Transmissibles et le SIDA (ATL), ensured that women's special barriers to participation were addressed, including arranging for ATL volunteers to provide childcare on site.

The outcomes. Within one month of the workshop, participants formed national women's support groups in Jordan and Bahrain. In Jordan, the women's support group has met with the Minister of Health to advocate for stronger support of women living with HIV; this resulted in NAP funding women's participation at the 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 (CCM). The Bahrain women's support group remains small, but it meets regularly with and is supported by the NAP.

Based on this initial boost to women living with HIV in MENA, and the outcomes of their continued networking efforts, the Ford Foundation, Egypt, announced at the May 2010 donors meeting that it will provide further funding. The first round of funds will support a regional meeting to establish a network for women living with HIV, which will also be supported by ICW.

Importantly, the two HIV-positive women from MENA who served as consultants throughout have had a positive impact regarding the status of women within this initiative and the broader regional response and burgeoning regional network. These women have represented MENA at regional and global levels including the International AIDS Conferences in 2008 and 2010.

The future. Women living with HIV in the region face many barriers, including limited access to medication to prevent mother-to-child transmission. These barriers, among other major challenges in the region, must be addressed.

V. OUTCOMES AND RESULTS

Beyond the number of people living with HIV trained, the Investing in PLHIV Leadership in MENA initiative made significant progress along the path to increased leadership, more meaningful involvement of people living with HIV, and future sustainability via the increased capacity of people living with HIV from MENA. Key outcomes and results are highlighted below.

Strengthened capacity. More than 170 PLHIV from 16 countries participated in one or more trainings. Facilitators who were men and women living with HIV from the region, 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 are 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.

- Training-of-Trainers Curriculum: Building the Training Skills of PLHIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 1.
- Subregional Curriculum: HIV Basics for PLHIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 2.
- Women-Centered Curriculum: Addressing HIV among Women and the Gender Dimensions of HIV in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 3.
- HIV Principles and Stigma Reduction Training Curriculum: Addressing HIV and Stigma in the Healthcare Setting in the Middle East and North Africa Region: Investing in PLHIV Leadership in MENA—Volume 4.

In addition, 25 key HIV resources previously unavailable in Arabic have been translated and are accessible via a private website created by and for people living with HIV in the region; these include reports on HIV transmission and prevention, human rights, universal access, treatment, PMTCT, women and HIV, and other issues.

Trainings adapted and replicated. In at least 30 instances, in-country counterparts have adapted and used curricula, session plans, and tools developed throughout this initiative for awareness-raising meetings, support groups, and workshops that they designed and led in their own countries.

Small grants lay the groundwork for country-level dialogue. The Health Policy Initiative awarded seed grants of US\$2,000 each to enable groups led by and for people living with HIV to design, implement, and manage their own country-level activities. This is the first time money has been given directly to such groups in the region for management of any HIV activity. In Lebanon, Vivre Positif in partnership with SIDC 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, Al-Amal Jordanian and Bushra Research Center carried out advocacy and policy dialogue to advise staff at the NAP and VCT sites to develop a coordinated plan to strengthen referrals for MARPs. With a second grant, Al-Amal Jordanian organized a meeting with a delegation of lawyers to establish linkages to provide legal aid to people living with HIV at medical centers and hospitals, resulting in appointment of a primary legal advisor who will help create a medical/legal plan for people living with HIV within the next year. In Yemen, AIDS Yemen and Life Impulse Association organized a workshop in partnership

participate in the global-, regional-, and national-level HIV response. This has included PLHIV involvement in public discussion of positive prevention, stigma reduction, and resource allocation. Moreover, the MENA region is being recognized at international HIV forums and on donor agendas (e.g., the 2008 International AIDS Conference had the largest representation of PLHIV from the MENA region participating in activities, presenting posters, and giving presentations, and the 2010 contingency was similar in scope), and more resources are being allocated in the region to sustain and inform the HIV response (e.g., advocacy, awareness raising, conducting research) in the region.

VI. LESSONS LEARNED AND KEY RECOMMENDATIONS

Lessons learned. According to our participants, their support groups and NGOs, and our own experience in the region the following lessons learned can inform next steps:

- Building capacity requires different processes of mentorship, network and coalition forming, awareness raising, and skills building and several years' time to sustain momentum and progress.
- Given the MENA region's cultural context and its limited level of past participation in the global HIV response, training and informational materials are best taken up when tailored to the region.
- Close partner ties at national, regional, and international levels are crucial. Partnerships with regional and national programs have provided access to key populations and mediated trusted relationships, offered local insights to problem solving, built human connections for the future, and shared lessons learned from other regions.
- To maintain a growing circle of trust, it is crucial that people living with HIV reach out and mentor other HIV-positive people via networking, peer-to-peer workshops, the private website, and local NGOs and support groups to build capacity, confidence, successful outcomes, and scale-up.

Key recommendations. The Investing in PLHIV Leadership in MENA initiative has built a strong cadre of HIV-positive leaders ready to raise awareness, build formal networks of support among and effectively represent HIV-positive people in the region at all levels through meaningful advocacy and broader dialogue. As successful as this initiative has been, challenges remain in enrolling a silent majority of Arab people living with HIV, particularly women (as the feminization of HIV takes root in the region), and in developing a comprehensive response to HIV in the region. The participants in this effort have underscored that the following areas and related skills must be addressed and developed with increased leadership by people living with HIV.

Box 3. Going Forward, Treatment Access is Key

- **Treatment access, advocacy, literacy and policy dialogue**
 - Research related to a comprehensive understanding of treatment, testing, and care access and coverage in the region based on government statistics and research conducted in collaboration with people living with HIV.
 - A transition from general to more content-specific training to support treatment access, especially related to (1) treatment literacy; (2) human rights; (3) women's rights; (4) advocacy; and (4) national- and regional-level negotiations with private sector pharmaceutical companies.
 - As an interim measure, establishment of a regional treatment center where people living with HIV can access treatment, care, and support if country-level support is not provided, provided inconsistently, marginally, exploitatively, at great cost, or with other barriers to access.
- **Gender, family, and community**
 - Region-specific issues related to gender, including how gender-based violence and harmful traditional and cultural practices contribute to HIV vulnerability, must be better understood and addressed.
 - Addressing the serious stigma and social exclusion faced by women and men living with HIV via advocacy, awareness raising, and translating policies and agreed upon human rights-based frameworks and commitments into action on the ground.
 - Focus on the family, including serodiscordant couples and seropositive couples who would like to have children and access to safe, professional childbirth services, and healthy child feeding and rearing practices, as well as the inclusion of key supportive family members in awareness-raising and advocacy efforts.
 - Means to address the growing number of children living with HIV in the MENA region.
- **Mechanisms and resources**
 - Access to donors and funding mechanisms, including CCMs and Global Fund resources for qualifying countries in the region, as well as countries that have concentrated epidemics, limited political will and support, and middle-income status that do not normally qualify for GFATM.
 - Capacity building for resource mobilization, proposal development, reporting, donor relations, and appropriate donor reporting.
 - Advocacy to address the GFATM Round 10 prioritization that will eliminate support to MENA for this round, with the exception of the potential to support MARPs.
- **Vulnerable populations**
 - A clear strategy for reaching vulnerable groups must be designed with PLHIV input, reviewing best practices and taking careful consideration of cultural norms and traditions, yet in a way that further grows and unifies PLHIV leadership rather than fragmenting the response. MARPs including MSM, IDUs, and sex workers must be supported, but also integrated into a broader HIV response when necessary that expands the positive leadership engendered through this initiative and its strategic partnerships.
- **Networking and civil society**
 - Accessible networking platforms for sharing knowledge, information, and tools in Arabic, as well as the means to reach low-literacy and isolated PLHIV.
 - Key partnerships leveraged, while providing autonomy to PLHIV network and networking process.
 - As more support groups transition into NGOs, capacity-building support must be provided to ensure effective NGO institutional leadership, management, partnerships, and sustainability.

VII. THE PATH CONTINUES: SUSTAINABILITY AND OWNERSHIP

GIPA aims to realize the rights and responsibilities of PLHIV, including the right to self-determination and participation in decisionmaking processes. 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 and care.

The initiative has strengthened the region's emerging HIV response by building PLHIV social capital through networking, making greater investments in people living with HIV, and fostering public dialogue and accountability by and for people living with HIV in the region. Power is shifting to people living with HIV; throughout this effort, the scope of engagement has gone beyond biomedical issues and beyond engaging men and women via their testimonies about living with HIV to taking the next step and engaging them as leaders and experts on HIV in the region. In addition to fostering burgeoning networks, the initiative has also supported the broader goal of a stronger civil society in MENA by supporting local support groups as they transition into NGOs led by and for people living with HIV and stronger partnerships with other local NGOs, service providers, and government.

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

- A delegation of about 16 PLHIV from MENA attended and shared their lessons learned at the XVIII International AIDS Conference in July 2010, 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 people living with HIV, who now have greater capacity and expertise.
- People living with HIV 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.

As the GIPA movement gains momentum in the region, it is crucial that investments continue to sustain the response. As more country-level partners are identified and capacity among people living with HIV is built, gains made in this seminal work must be leveraged to move the developing regional HIV response forward.

APPENDIX A. SUMMARY OF WORKSHOPS AND PARTNERSHIPS

Event	Objectives (abbreviated)	Number of participants	Countries attending and Partners
<p>Training for Leadership and Networking in the Middle East and North Africa</p> <p>February 4-8, 2006</p> <p>Tunis, Tunisia</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1) Provide opportunity for HIV positive people in the region to work together on issues that are important in their lives; 2) Present specific examples and tools that can be utilized for the formation of PLHA support network; 3) Strengthen participants' ability to return to their country and deal with some of the challenges they face, such as stigma and discrimination, and access to work and education; 4) Support linkages between and among participants so that country-specific and region-wide networks can be built. 	26	<p>POLICY Project Supported: Algeria (3), Jordan (2), Lebanon(2), Mauritania (2), Morocco (3), and Oman (1)</p> <p>UNDP/HARPAS Supported 13 participants: Libya (4), Tunisia (5), and Sudan (4)</p> <p>Partners: United Nations Development and Population Program/HIV/AIDS regional Programme for the Arab States (UNDP/HARPAS), The Global Network of People Living with HIV/AIDS (GNP+), The International Community of Women Living with HIV/AIDS (ICW), UNAIDS MENA Regional Support Team (RST), Association Tunisienne Lutte Contre Les Maladies Sexuement et le SIDA (ATL), Muslim religious Leaders</p>
<p>Leadership and Facilitation Skills-building Workshop</p> <p>September 1-3, 2006</p> <p>Wadi Natroun, Egypt</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1.) To capacitate PLHIV with leadership and technical skills about the basics of HIV-related educational topics 2.) To provide PLHIV leaders with facilitation and communication skills 	7	<p>Tunisia (2), Egypt (1). Lebanon (1), Sudan (1), Morocco (1), Algeria (1)</p> <p>Partners: UNDP/HARPAS, the Freedom Center</p>
<p>2nd Training for Leadership and Networking in the Middle East and North Africa</p> <p>September 4-8, 2006</p> <p>Wadi Natroun, Egypt</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1) Provide opportunity for HIV positive people in the region to work together on issues that are important in their lives; 2) Present specific examples and tools that can be utilized for the formation of PLHA support network; 3) Strengthen participants' ability to return to their country and deal with some of the challenges they face, such as stigma and discrimination, and access to work and education; 4) Support linkages between 	44	<p>Health Policy Initiative supported 30 participants: Egypt (12), Bahrain (4), Morocco (5), Lebanon (1), Libya (2), Tunisia (2), Algeria (3), Kuwait (1)</p> <p>UNDP/HARPAS supported 14 participants: Sudan (6) Jordan (6), Saudi Arabia (2)</p> <p>Partners: UNDP/HARPAS, the Freedom Center, Muslim Religious Leaders, Catholic Religious Leaders, Protestant Religious Leaders</p>

Event	Objectives (abbreviated)	Number of participants	Countries attending and Partners
	and among participants so that country-specific and region-wide networks can be built.		
Investing in PLHIV Leadership in the Middle East and North Africa Region: How to be Positive Trainer in the MENA Region June 1-5, 2008 Amman, Jordan	Objectives of the TOT were to: 1. Understand concepts of behavior change and adult learning related to training and education methods as they pertain to our work with HIV. 2. Acquire accurate information about HIV that PHIV leaders can share with others. 3. Develop public speaking and communication skills for training, education, and raising awareness about HIV within their respective countries. 4. Develop session development skills to design and implement country level awareness raising workshops.	12	Egypt (3), Yemen (1), Jordan (2), Bahrain (2), Oman (1), Lebanon (2), Libya (1).
Sub-Regional Training: Investing in Leadership in the Middle East and North Africa Region June 8th-13th, 2008 Amman, Jordan	Objectives of the Sub-Regional Workshop were to: 1. Provide opportunity for PLHIV in the MENA to work together on issues that are important in their lives. 2. Present tools that can be used for the formation of a PLHIV support network, trainings, and small-grant-funded country projects. 3. Strengthen participants' ability to address challenges they face as PLHIV, such as stigma and discrimination. 4. Create a foundation for greater networking and support by and for PLHIV in the region.	26	Jordan (6), Egypt (4), Yemen (3), Lebanon (3), Oman (2), Libya (3), Bahrain (3), and Saudi Arabia (2)
Small Grants Training June 14, 2008 Amman, Jordan	Small Grants Training Objective: 1. Practice the skills related to the small grants application process including budgeting, setting goals and objectives, and outlining project steps	13	Lebanon (3), Jordan (6) and Egypt (4) Partners: Soins Infirmiers et Developpement Communautaire, Lebanon (SIDC), The Bushra Center, Jordan, Vivre Positif, Lebanon, Catholic Relief Service, Lebanon (CRS), Group for Life, Egypt, El Amal, Jordan, Yemen AIDS, Bahrain NAP, Yemen NAP.

Event	Objectives (abbreviated)	Number of participants	Countries attending and Partners
<p>Women-Centered Workshop: Addressing HIV among Women and the Gender Dimensions of HIV in the MENA Region</p> <p>May 17 -21, 2009</p> <p>Tunis, Tunisia</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1. Provide an opportunity for women living with HIV and affected by HIV in MENA to work together on issues that are important in their lives; 2. Strengthen participants' ability to address challenges they face as women living with HIV, as parents of HIV+ children, and spouses of HIV+ partners; and 3. Create a foundation for greater networking and support by and for women living with and affected by HIV in the region implemented by and for women living with HIV from the MENA region. 	<p>23</p>	<p>Algeria (1), Bahrain (2), Egypt(2), Jordan (3), Lebanon (2), Libya (2), Morocco (1), West Bank (1), Saudi Arabia (2), Tunisia(4), and Yemen(3)</p> <p>Partners: ICW, ATL, Tunisienne Midwives</p>
<p>Stigma and Discrimination in the Healthcare Setting Workshop</p> <p>December 7-11, 2009</p> <p>Marrakech, Morocco</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1. To raise awareness about stigma and discrimination within the healthcare sector; 2. To provide an opportunity for PLHIV leaders and healthcare providers to learn and work together, to reduce stigma and discrimination in their countries and region; 3. To provide an opportunity for healthcare providers from the MENA region to learn about the latest clinical advances in HIV related to treatment, PMTCT, co-infection and other context specific information based on participant feedback; 4. To develop a stigma and discrimination curriculum for the healthcare setting, specific to the needs and issues in the MENA region. 	<p>31</p>	<p>Bahrain (2 PLHIV, 1 doctor), Egypt (2 PLHIV, 1 doctor), Iraq (1 PLHIV, 1 doctor), Palestine (1 PLHIV, 1 doctor), Jordan (2 PLHIV), Lebanon (2 PLHIV, 1 doctor), Tunisia (2 PLHIV, 1 doctor), Morocco (2 PLHIV, 1 doctor), Oman (1 doctor), Libya (2 PLHIV, 1 doctor), Saudi Arabia (2 PLHIV, 1 doctor), Yemen (3 PLHIV, 1 doctor)</p> <p>Partners: Association Marocaine de Solidarité et de Développement (AMSED), Bahrain National AIDS Program (NAP), , Moroccan NAP, Moroccan Ministry of Health, Omani NAP, Palestine NAP, Shady Grover Fertility Center, Physicians from: Egypt, Oman, Palestine, Lebanon, Libya, Saudi Arabia, Bahrain, Morocco, Tunisia, Iraq</p>

Event	Objectives (abbreviated)	Number of participants	Countries attending and Partners
<p>MENA Advocacy Workshop</p> <p>December 12-14, 2009</p> <p>Marrakech, Morocco</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1. To ensure participants understand the definition of advocacy and the advocacy process; 2. To provide participants an opportunity to work on an advocacy issue of their choice with a country level partner for implementation in-country; 3. To support effective advocacy at regional and country levels 	<p>23</p>	<p>Lebanon (2), Egypt (2), Saudi Arabia (2), Yemen (3), Libya(3), Bahrain (3), Iraq(2), Jordan (2), Morocco (2), Tunisia (2)</p> <p>Partners: AMSED, ICW, Bahrain NAP, Palestine NAP, Physicians from: Palestine, Libya, Saudi Arabia, Bahrain, Morocco, Iraq</p>
<p>MENA Treatment Advocacy, Networking and Resource Mobilization Meeting</p> <p>April 28-May 5, 2010</p> <p>Hammamet, Tunisia</p>	<p>The Objectives of the Treatment Advocacy, Networking and Resource Skills Building workshops are:</p> <ol style="list-style-type: none"> 1. To address the low treatment coverage in the MENA region; 2. To build the skills of PLHIV to serve with supportive stakeholders in-country, as treatment advocates; 3. To provide an opportunity for PLHIV to network at regional level; 4. To raise awareness among PLHIV regarding the local, regional and global donor environment; 5. To provide basic awareness and skills regarding resource mobilization basics and the proposal development process. 	<p>39 and 24</p>	<p>MENA Treatment Advocacy Meeting: Morocco, (2 PLHIV), Tunisia (2 PLHIV, 1 doctor, 2 NGO leaders, ATL), Libya (2 PLHIV). Egypt (2 PLHIV, 1 doctor), Jordan(5 PLHIV, 2 NAP Managers), Lebanon (3 PLHIV, 1 doctor), Bahrain (2 PLHIV), Saudi Arabia (1 PLHIV, 1 doctor), Yemen (3 PLHIV, 1 NGO Manager from YemenAIDS), Algeria (1 PLHIV), Oman (1 PLHIV, 1 doctor), Palestine (1 PHIV, 1 doctor), USAID (1 Rep), Ford Foundation (1 Rep), Global Fund (1 Rep), World AIDS Campaign (1 rep)</p> <p>MENA Networking Meeting: 24 PLHIV Participants</p> <p>MENA Resource Mobilization Meeting: 40 Participants: Morocco, (2 PLHIV), Tunisia (2 PLHIV, 1 doctor, 2 NGO leaders), Libya (2 PLHIV). Egypt (2 PLHIV, 1 doctor), Jordan(5 PLHIV, 2 NAP Managers), Lebanon (3 PLHIV, 1 doctor), Bahrain (2 PLHIV), Saudi Arabia (1 doctor), Palestine (1 doctor/NAP Manager)</p> <p>Partners: USAID, HIV/AIDS Alliance, ATL, ICW, Global Fund, Ford Foundation, World AIDS</p>

Event	Objectives (abbreviated)	Number of participants	Countries attending and Partners
			Council, NAP managers from Yemen, Jordan, Palestine. Physicians from: Oman, Palestine, Tunisia and Lebanon, Saudi Arabia.

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Health Policy Initiative, Task Order I
Futures Group
One Thomas Circle, NW, Suite 200
Washington, DC 20005 USA
Tel: (202) 775-9680
Fax: (202) 775-9694
Email: policyinfo@futuresgroup.com
<http://ghiqc.usaid.gov>
<http://www.healthpolicyinitiative.com>