# Strengthening the Involvement, Care and Support of People Living with HIV in the Middle East and North Africa: A Situational Overview

**Responding to MARPs in MENA Region Project**

**2012/2013**

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## Acronyms

| | |
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| ABCAR | AIDS Business Coalition in the Arab Region |
| AIDS | Acquired immunodeficiency syndrome |
| AJEM | *Association Justice et Miséricorde* (Lebanon) |
| ALCS | *Association de Lutte contre le SIDA (*Morocco) |
| AMPF | *Association Morocaine de Planification Familiale* (Morocco) |
| AMSED | *Association Morocaine de Solidarité et de Développement* (Morocco) |
| ANISS | Association de Lutte Contre les IST/SIDA et de Promotion de la Sante (Algeria) |
| APCS | *Association de Protection contre le SIDA* (Algeria) |
| ART | Antiretroviral therapy |
| ARV | Antiretroviral drugs |
| ATIOS | *Association Tunisienne d'Information and d'Orientation sur le SIDA* |
| ATL | *Association Tunisienne de Lutte contre les MST/SIDA* (Tunisia) |
| ATUPRET | *Association Tunisienne de Prévention de la Toxicomanie* |
| CCM | Country Coordinating Mechanism (Global Fund) |
| GCC | Gulf Cooperation Council |
| HARPAS | HIV/AIDS Regional Program in the Arab States (UNDP) |
| HIV | Human immunodeficiency virus |
| IDLO | International Development Law Organization |
| LMST | *Ligue Morocaine de Lutte contre les MST-STIs* (Morocco) |
| MARP | Most-at-risk populations (also known as key populations at higher risk) |
| MENA | Middle East/North Africa Region (USAID) |
| MENAHRA | Middle East North Africa Harm Reduction |
| MSM | Men who have sex with men |
| NANASO | North African Network for AIDS Service Organizations |
| NGO | Non-governmental organization |
| NSP | National Strategic Plan |
| OPALS | *Organisation Panafricaine de Lutte contre le SID*A (Morocco) |
| PEPFAR | Presidential Emergency Plan for AIDS Relief |
| PLHIV | People living with HIV |
| PMTCT | Prevention of mother-to-child transmission |
| PWID | People Who Inject Drugs |
| RANAA | Regional Arab Network Against AIDS |
| RST | Regional Support Team (of UNAIDS) |
| SIDC | *Soins Infirmiers et Développement Communautaire* (Lebanon) |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| UNGASS | United Nation's Secretary-General's Report to the General Assembly |
| USAID | United States Agency for International Development |
| VCT | Voluntary counseling and testing |

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## Executive Summary

The *Responding to Most-at-Risk Populations in Middle East and North Africa (MENA) Region* project is implemented by the International HIV/AIDS Alliance through the AIDSTAR-Two Project and supported by the USAID Middle East Bureau and the Office of HIV/AIDS in the Global Health Bureau. A priority for the project in 2012/2013 is to strengthen the involvement, care and support of people living with HIV (PLHIV) in the Middle East and North Africa (MENA) region. PLHIV in this region are nearly invisible. In addition, they have extremely poor access to care, support and treatment, and are affected by frequent stock-outs of anti-retroviral therapy (ART). There is also a lack of a support infrastructure, with a small number of self-help groups and associations that remain relatively isolated.

The International HIV/AIDS Alliance has long worked in HIV prevention with men who have sex with men (MSM) in the Middle East and North Africa. Support and care for people living with HIV is a new area for the program, and is an area that is generally neglected in countries across the region although groups of PLHIV across the region are increasing. Increasing support requires planning to respond to the realities on the ground, including identifying and responding to the significant challenges facing people living with HIV in the region, and introducing relevant guidance on care and support for this vulnerable group.

### The greater involvement of people living with HIV

There have been a number of initiatives to support the greater involvement of people living with HIV in MENA. However, despite these efforts, a large number of support groups and associations of people living with HIV, as well as individuals, remain isolated from the communities in which they work and live. These groups are also isolated from the greater response to HIV at the national level due to a range of factors, most notably the political and socio-cultural climates in which HIV-related stigma and discrimination pose significant barriers to the empowerment and participation of people living with HIV.

One of the key goals of strengthening the involvement, care and support for people living with HIV is to transform the role of the individual *from* a beneficiary and receiver of knowledge *to* a key expert and provider of information to others. Future programming for the greater involvement of people living with HIV should build upon the support and the interventions conducted in MENA to date. The region now has a number of strong leaders who are living with HIV in various countries and these individuals can serve as an important resource to help build upon strategies in this next phase to support the greater involvement of people living with HIV.

This report, **"Strengthening the Involvement, Care and Support of People Living with HIV in the Middle East and North Africa: A Situational Overview,"** provides a summary analysis of the response for the involvement, care and support of people living with HIV, and includes information on current activities, gaps, and stakeholders in MENA. It also identifies priorities for action and formulates a series of recommendations to be considered by technical partners and civil society organizations aiming to further engage in programming to work with people living with HIV.

The priority needs to support the greater involvement of people living with HIV in MENA that are described in this report include:

- Ensuring the involvement of people living with HIV in all areas of program design, implementation and advocacy

- Effectively addressing the material conditions of people living with HIV such as food, housing and transport costs to attend medical appointments
- Addressing the routine need for core capacity building for people living with HIV
- Addressing the human rights abuses and continuing legal violations against people living with HIV
- Providing adequate and sustainable resources to support groups and associations of people living with HIV for example seed funding to assist nascent associations
- Ensuring further evaluation and follow-up on workshops for and involving people living with HIV

The situational overview highlights four recommendations and key priorities for action which are:

1. Peer-based action, including mutual support and self-help among people living with HIV through community-based activities.
2. The meaningful involvement of people living with HIV in services and activities which affect them.
3. The availability of friendly services for people living with HIV, including clinical and non-clinical services for access to treatment, care and support.
4. Continued support for strengthening the enabling environment for people living with HIV in which the individual is aware of his/her human rights and has access to legal or other institutional resources and services if these rights are abused (e.g., HIV-related legal services and increasing support from decision-makers)

As this situational analysis concludes, considerable work has already taken place in the region and gains have been made to support people living with HIV. However, it is critical that all relevant partners work together to ensure that these gains are not undone, and that advances continue to be made for people living with HIV in the Middle East and North Africa.

## 1. Background

It is estimated that there are currently 500,000 people living with HIV in the Middle East and North Africa. With a rise in new infections since 2001, the MENA region is now among the top two regions in the world with the fastest growing HIV epidemic.[1] The rise in new infections is attributed to a growing HIV prevalence among key populations at higher risk of acquiring HIV who transmit the virus to individuals at lower risk of infection. AIDS-related mortality in the region has also increased in the last decade, with infections in both adults and children almost doubling. The estimated number of deaths due to AIDS increased from 22,000 in 2001 to 39,000 in 2010.[2] This is a result of an overall acceleration in the epidemic throughout MENA, an increase in the total number of women living with HIV, and the continued lack of adequate services to prevent new infections, particularly among children.[3] Two percent of the total estimated number of people living with HIV globally resides in MENA and the annual number of new infections has almost doubled in the past decade.[4]

Throughout the last several years, national and international partners have led and facilitated a range of initiatives to foster the involvement and leadership of people living with HIV in the Middle East and North Africa. This includes: the USAID "Investing in PLHIV Leadership in the MENA Region" Project,[5] the UNAIDS' Regional Meeting that yielded the Algeria Declaration of People Living with HIV/AIDS in the Middle East and North Africa (2005), the UNDP HARPAS (HIV/AIDS Regional Program in the Arab States) initiatives designed to open dialogue with religious leaders, media and governments on the rights of people living with HIV, the RANAA organized "Empowerment of People Living with HIV in the Middle East and North Africa towards Universal Access to HIV prevention, treatment, care and support" meeting held in Lebanon in November 2010, the UNAIDS MENA civil society mapping and development of the "Enhanced response to the HIV epidemic in the Middle East and North Africa through stronger partnerships with civil society: UNAIDS 5-year strategy," (2012), the scaling up of HIV-related legal services for people living with HIV through the International Development Law Organisation (IDLO), and more recently, the USAID funded AIDSTAR-Two project .

Despite these interventions and initiatives, many individuals and support groups of people living with HIV remain isolated from their communities and the greater response to HIV at the national and regional level. Furthermore, recent political and socio-cultural turmoil in the region may render it increasingly difficult to plan and strategize activities for the greater involvement of people living with HIV, as well as address and document issues concerning the abuse of human rights related to persistent HIV-related stigma and discrimination in the MENA region.

Associations and support groups of people living with HIV are recognized as vital safety nets for both individuals who are newly diagnosed and for longer-term survivors. Associations and support groups are also often the first point of care for those infected. The Egyptian Anti-Stigma Forum highlighted that "support groups have been recognized as a source of comfort by many people living with HIV," as they allow for open discussion among their peers.[6]

Support groups of people living with HIV are engaging more in HIV and AIDS advocacy interventions to address the importance of respecting human rights, as well as political and societal stigma and discrimination.[7] Associations and support groups of people living with HIV have been established throughout MENA, including in Algeria, Tunisia, Morocco, Egypt, Lebanon, Jordan, the Republic of Yemen, Bahrain, Djibouti, Iran, Sudan and lately in Libya.[8] A sizeable proportion of these support groups are led and run by women living with HIV—in countries such as Tunisia, Lebanon and Algeria.

The *UNAIDS Global Strategy Getting to Zero* highlights that people living with HIV and those affected by the epidemic must "...own effective HIV responses to ensure a rights-based, sustainable response and to hold national and global partners accountable." This report goes on to say that "the remarkable gains to date are largely the result of their activism, mobilization and building of alliances with other stakeholders."[9]

> *"We would like to help individuals and people living with HIV to be respected and to have their rights respected. We would like to continue to be able to give support to others. We would like to reduce stigma, to access treatment, and to give an example to other people in the region. It is necessary to give people a positive image of this virus. For example, if I am ashamed, people around me will think there is a reason to be ashamed."*
>
> *--A woman living with HIV in Algeria*

## Purpose of the situational overview

The purpose of this situational overview is to provide a detailed analysis of the response of associations and support groups of people living with HIV in the Middle East and North Africa to better understand how to effectively support the involvement, care and support of people living with HIV in the region. The overview begins by providing a brief presentation of the regional context for people living with HIV including a brief description of the socio-cultural and legal environment and an analysis of the disparities in the response throughout the different sub-regions. The overview examines available information on current initiatives and activities that have been or are being undertaken in the MENA region, priority gaps, and stakeholders in MENA in order to identify priority areas for action. Existing support for people living with HIV in four different countries in the region, namely Tunisia, Algeria, Lebanon and Morocco,* is analyzed, as are the different regional networks which operate across the region. The document outlines key priorities and makes recommendations to relevant stakeholders looking to further strengthen the involvement, care and support of people living with HIV in the MENA region. The *principal goal* of future interventions is to continue to strengthen the involvement, care and support of people living with HIV as a vital step to overall improved access to and quality of HIV-related services.

## Methodology

The situational overview includes a literature review and an analysis of the interviews conducted by the *Enhanced response to the HIV epidemic in the Middle East and North Africa through stronger partnerships with civil society: UNAIDS 5-year strategy* (2012) with 11 associations and support groups for people living with HIV in the region, including individuals in Yemen, Bahrain, Lebanon, Morocco, Tunisia, Egypt, Algeria, Djibouti, Jordan, Sudan, and Iran.

This situational overview also includes a series of interviews with key actors and people living with HIV in Algeria, Lebanon, Tunisia and Morocco, which are countries where the International HIV/AIDS Alliance, through the AIDSTAR-Two project and with the support of the USAID Middle East and North Africa Bureau and the Office of HIV/AIDS will provide short-term support to increase the involvement of associations for people living with HIV in the region. In addition, interviews were conducted with staff members involved in the implementation of the USAID PLHIV Project and UNAIDS' Country Coordinators in the region.

* The aim of USAID, AIDSTAR-Two and the Alliance is to provide further support in these four countries

## 2. Regional Context for People Living with HIV in MENA

The Middle East and North Africa currently has one of the fastest growing epidemics in comparison to other regions, with concentrated epidemics in each of the sub-regions including the *Maghreb* (Francophone North Africa), *Shaam* or *Mashriq* (Iraq, Palestine, Jordan, Kuwait, Lebanon and Syria), the MENA countries in Sub-Saharan Africa and the Horn of Africa, as well as the Gulf Cooperation Council (GCC) countries and West Asia.[10] The HIV epidemic in MENA increasingly reflects the diversity of the region with different populations more affected in various geographical areas. The diversity of the epidemic is magnified by disparate attitudes, policies, political commitments and the availability of and access to HIV services.[11] In particular, each of the sub-regions can be characterized by different epidemics among key populations at higher risk of exposure to HIV—namely men who have sex with men, sex workers, and people who inject drugs—as well as the availability and quality of health services, resources for responding to the epidemic, the role of civil society, and the degree to which people living with HIV are able to participate in the HIV response.

The sections that follow provides a summary of the epidemiological trends of affected populations across the region and describe the different spaces in which civil society groups do their work, the varying availability and access to health services, and the legal context for the involvement of people living with HIV in MENA. Moreover, it outlines the current engagement and support among associations of people living with HIV in Algeria, Lebanon, Morocco and Tunisia. The country sections provide supplementary information on the epidemiological context for each country, the involvement of people living with HIV in national strategic plans and the overall environment for civil society actors and potential partners.

### 2.1. Sub-Regional Characteristics of MENA

The quality and quantity of epidemiological and behavioral data across MENA is improving, however, within the different sub-regions it is still too limited to build concrete trends. There is a shortage of data on HIV in particular in the GCC countries, as well as countries which have recently been affected by conflict and/or socio-political turmoil including Iraq and Libya.[12] Throughout the region, women represent a highly affected group and many women living with HIV in the MENA region may have acquired the infection from their spouses. The region is divided into two sub-groups, a *core group* of the MENA countries that have more modest HIV prevalence which includes a majority of the countries in the region, and a *sub-region* of countries with considerably higher prevalence in the general population.[13] Nevertheless, many countries in the region are experiencing low to concentrated HIV epidemics among key populations, such as in Morocco where there is evidence of a concentrated epidemic among people who inject drugs in the north and among men who have sex with men in the south.[14]

Despite these disparities, there are common challenges which link the sub-regions together, including issues of political leadership as well as stigma and discrimination. Several governments in the region including Morocco and Algeria continue to publicly voice support for people living with HIV and the necessity for increased national efforts to tackle the epidemic. However, many governments do not currently back their words with effective policies or funding to address the needs of those most affected by HIV, and some still support policies which criminalize people living with HIV and their families. Stigma and discrimination continue to thwart the ability of governments and civil society to provide services and affect access to services for key populations as well as the dissemination of strategic data across the region which is necessary for evidence-based decision-making.[15]

### Spaces for civil society in the different sub-regions

One of the most significant differences among the various sub-regions in MENA is the space available for civil society organizations and actors to support the HIV response. For example, the *Maghreb* countries, including Tunisia, Algeria and Morocco, have strong civil society movements which have historically played a crucial role in supporting governments and communities to tackle HIV. In contrast, there are very few civil society organizations in the GCC countries, and in some areas civil society organizations are illegal. In these countries, the government is mainly responsible for prevention among affected populations and supporting people living with HIV. The *Mashriq* countries, including Jordan, Syria and Egypt, have varying civil society movements, which often face competition from strong state regimes which regularly expand and contract the spaces ceded to associations. In Lebanon, CSOs have a stronger presence than in other Mashriq countries and lead the response. The *Maghreb* and *Mashriq* countries have active civil society organizations working to improve access to health services and the support to affected communities. In both sub-regions (*Maghreb and Mashriq*) civil society organizations are legal, however the government may directly dictate degrees of funding permitted from international donors as well as the nature of activities in which civil society can engage.

### Availability of and access to health services

The availability, access and quality of health interventions for HIV and sexual and reproductive health throughout the region are variable. The 2011 UNAIDS MENA report on AIDS notes that between 1995 and 2008, only four per cent of HIV testing was undertaken among key populations at higher risk. Some countries provide treatment as well as diagnostic testing free of charge, while in other countries, such as Lebanon, individuals must pay for their own monitoring, including CD4 counts and viral load tests.[16] HIV testing and counseling across the MENA region is a significant challenge. In much of the region, HIV testing is still mandatory, but in locations where quality testing in conjunction with effective counseling is available, it is not always accessible to key populations at higher risk of HIV exposure.

It is vital that key populations gain access to voluntary counseling and testing to improve the overall response to HIV in the MENA region. The number of people accessing anti-retroviral therapy (ART) increased from 15,548 in 2009 to 19,483 in 2010 representing a 25% increase. However, the estimated regional coverage is low at 8%. Oman currently has the highest coverage for the region with 45% of adults and children living with HIV receiving treatment at the end of 2010, followed by 37% coverage in Lebanon, and 30% in Morocco.[17] The majority of countries in the region reported experiencing no stock-outs of antiretroviral drugs in 2010, and 13 countries demonstrated adherence to treatment after the first 12 months of initiating antiretroviral treatment.[18] Although access to treatment is free in many areas, medical counseling for people living with HIV remains inadequate, in particular in relation to treatment and resistance procedures. Medication supplies are still not consistently available in most places, and ART is not provided free of charge to migrants and refugees in most MENA countries. The quality of medication varies between countries in the region: for example, individuals in some countries have to acquire newer, more efficacious medications from other countries in the region.[19]

### The Global Fund to Fight AIDS, Tuberculosis and Malaria in MENA

Between 2002 and the end of 2010, the Global Fund approved $578 million to combat HIV in the Middle East and North Africa. At the end of 2010, Global Fund investments were providing 73,000 people in the region with antiretroviral therapy, which is equivalent to 26% of the estimated need in 2009. Between 2002 and the end of 2010, Global Fund programs in the region also distributed 87 million condoms, and provided 1.5 million HIV testing and counseling sessions. Despite major challenges, programs supported by the Global Fund delivered interventions to a cumulative 10,000 women to prevent mother-to-child

transmission (PMTCT) of HIV, although there were estimated to be at least 22,000 women in need in 2009 alone.[20] However HIV funding in the region represents the smallest share of the Global Fund HIV portfolio, receiving 5% of the cumulative approved funding between 2002 and 2009. In the nine countries of the Middle East and North Africa Region with data available for 2009, the Global Fund provided 61% of the international financing for HIV and 39% of the overall HIV funding (both international and domestic).[21] The Middle East and North Africa Region has allocated 40% of its HIV grant budgets to prevention activities: the majority for targeted behavior change communication, with lesser shares allocated to condom distribution and social marketing, HIV testing and counseling, and PMTCT (which has been significantly scaled up across the region since 2002). The large allocation to prevention reflects the HIV epidemics in the region, which remain mostly concentrated.[22] Eleven countries in the region have received Global Fund resources and at present, nine continue to implement Global Fund-supported programs (Djibouti, Egypt, Jordan, Morocco, Somalia, Sudan, Syria, Tunisia, and the West Bank/Gaza); in addition, a multi-country grant (MENAHRA) received funding from Round 10.[23]

### The participation of people living with HIV

Many countries in MENA have formal or legally registered associations of people living with HIV that are often at the frontline of psycho-social care and support for affected populations in the region. Formal associations of people living with HIV have been established in Tunisia, Algeria, Djibouti, Egypt, the Islamic Republic of Iran, Jordan, Lebanon, Morocco, Sudan, Somalia, Yemen, and recently Libya; their members have the capacity and skills to work in groups and have made notable improvements during the last decade.[24] Moreover, associations of people living with HIV in the *Maghreb* and *Mashriq* sub-regions are increasingly becoming involved in the development of National Strategic Plans (NSPs) and in the overall HIV/AIDS response. For example, in Tunisia, Morocco and Algeria, associations of people living with HIV are routinely involved in a range of national-level decision making fora, including Country Coordinating Mechanisms (CCMs) and National AIDS Programs, as well as in the implementation of Global Fund grants as Sub-Recipients (as is the case in Morocco and Tunisia). Associations of people living with HIV are also involved in the development of NSPs and participate in CCM meetings in Jordan and Yemen. In some cases, PLHIV are represented in CCMs but their representation is figurative, not effective.

Unfortunately, in the GCC countries, associations and individuals living with HIV are less involved in decision-making and are given fewer opportunities to participate in the overall response to HIV and AIDS. They are not optimally engaged in national strategic plans or in the delivery of services. Consequently there are no official (legal) HIV associations in the GCC countries and people living with HIV are often severely marginalized, barring them from receiving psycho-social and other support services. Furthermore, many of the associations and support groups currently operating in the *Maghreb* and *Mashriq* sub-regions, whose legal status varies, are also under-staffed and continually face funding and capacity gaps.

There is a need throughout the region to encourage the development of a broader pool of individuals and leaders living with HIV to not only provide greater support to affected communities, but to advocate for a strengthened response.

## 2.2. Legal context for the involvement of people living with HIV in MENA

Existing legal practices in the Middle East and North Africa can inadvertently punish vulnerability and can often promote risky behavior, hinder individuals from accessing prevention and treatment, and aggravate stigma and social inequalities to make people even more vulnerable to HIV infection. "In many countries, the law dehumanizes many of those at highest risk for HIV: sex workers, transgender people, men who have sex with men, people who use drugs, prisoners and migrants. Rather than providing protection, the law renders these 'key populations' all the more vulnerable to HIV."[25] Approximately 19 of the 21 countries in MENA criminalize same-sex activity either through existing penal codes or through the interpretation and implementation of *Sharia* law, making it a challenge to effectively reach key populations, such as men who have sex with men, with vital HIV-related interventions.[26]

Key populations, including people living with HIV, have significantly fewer legal protections. Eleven MENA countries recently reported having laws, regulations or policies that are obstacles to effective HIV prevention, treatment, care and support for vulnerable populations. However, 15 countries also report having laws and regulations to protect people living with HIV from discrimination.[27] In November 2011, participants in the Saudi Forum "Uniting Arab Countries to Fight AIDS" identified program needs including sensitizing police and judges; training healthcare workers in non-discrimination, confidentiality and informed consent; supporting national human rights sensitization campaigns; and legal literacy and the provision of legal services.[28] Furthermore, the Global Commission on HIV and the Law emphasizes that effective legal aid can make justice and equality a reality for people living with HIV, and that this can lead to better health outcomes overall.[29]

### Increasing advocacy for human rights across MENA

Stigma against key populations at higher risk of HIV exposure is a global challenge. The most recent UNAIDS MENA regional report on AIDS (2011) highlights the degree to which stigma and discrimination limit the effectiveness of the region's response to HIV, including the ability for civil society and governments to provide services, the ability for key populations to access available services, and the amount and diffusion of data available for informed decision-making.[30] At present many countries have associations of people living with HIV which offer psycho-social support as well as provide a platform for advocating respect for human rights. Some countries have come together to form regional networks to advocate with a stronger voice against discrimination and for greater protection for people living with HIV. One challenge to scaling-up regional advocacy across the different regions has been that individuals and associations often prefer to mobilize by language spoken rather than continental affinities, preventing them from effectively uniting regionally. An additional challenge is that most associations for people living with HIV globally are under-staffed and have been run by a handful of people—who are often also the same regional advocates—for many years. This handful of individuals in each region are increasingly overworked and spread too thin. The challenge therefore is to conceptualize new ways to foster leadership without relying on the former orthodox methods such as training and building the capacities of a small number of individuals. Organizations worldwide are working to create new models to empower and strengthen the leadership of people living with HIV, to foster autonomy and to reinforce a united voice to support the scale-up of the HIV response.

## 2.3. Ongoing activities with PLHIV in Algeria, Lebanon Morocco and Tunisia

### Algeria

Algeria was one of the first countries in the MENA region to establish an association for people living with HIV (*Al Hayet*). It was also one of the first countries in which the government manifested political commitment towards the HIV response and provided anti-retroviral treatment and diagnostic services to individuals infected and affected by HIV. These services continue to be offered by the state free of charge to nationals and non-nationals living in Algeria today. Algeria was also home to the first regional meeting on HIV/AIDS, whereby the *Algiers Declaration of People Living with HIV* was adopted in 2005, representing the first occasion for people living with HIV in the region to openly discuss their status. Many would argue that this meeting was the catalyst for other countries to form their own associations of people living with HIV. There are approximately 18,000 individuals estimated to be living with HIV in Algeria with low to high estimates between 13,000 to 24,000 people.[31] The populations most affected are sex workers and their clients (as 95 percent of new cases are sexually transmitted). Furthermore, there has been an increase in the prevalence among sex workers in the last decade with 2.87 percent prevalence in 2000 and 3.95 percent in 2007.[32] Other affected populations include men who have sex with men, people who inject drugs and prisoners. Migrants from the south, including some of the West African countries such as Mali and Niger, are also considered at-risk populations (in some areas of Algeria there are more than 48 nationalities) although non-nationals have access to treatment and diagnostic services.

#### *The National Strategic Plan and the involvement of PLHIV in Algeria*

The Algerian National Strategic Plan to Combat STIs/HIV/AIDS 2007-2011 aims to strengthen interventions designed to support people living with HIV to achieve the overall objective of reaching universal access. The NSP identifies two significant challenges to supporting key populations affected by HIV: (1) low levels of knowledge in the general population about the modes of transmission of HIV including general awareness on prevention and education; and (2) the broader socio-economic factors underlying migration in Algeria.

As in many countries across MENA, Algeria continues to face challenges in creating an enabling environment and social acceptance of people living with HIV. HIV-related stigma persists across all sectors including the health sector. In addition, there are still overall weaknesses in the epidemiological surveillance systems throughout Algeria, creating a challenge to definitively know the extent to which key populations in the country are truly impacted. The operational plan for the NSP outlines support to protect the rights of people living with HIV and their families; specifically, the NSP's guiding principles outline the guarantee for the protection of the rights of people living HIV and their families according to national law as well as the international conventions ratified by Algeria. The guiding principles also outline the promotion of gender equality to respond to the national priority for equality between the sexes and the participation of women, in particular to access information and HIV-related services. The core strategic objectives of the NSP indicate the necessity to strengthen interventions for people living with HIV to achieve universal access to HIV prevention, treatment, care and support and to improve conditions for people living with HIV and their families. This includes the provision of treatment for adults and children, as well as psycho-social and economic support for men, women and children affected by HIV.

The NSP also outlines specific activities to effectively address stigma. These include the development of a guide on the economic and social rights of people living with HIV, the development of a support

network to foster solidarity and exchange among people living with HIV, and programs to promote the rights of all people living with HIV with the overall goal of reducing HIV-related stigma and discrimination. It is important to highlight that in 2010, the Ministry of Health in Algeria re-activated a decree to counteract discrimination in healthcare settings. The decree emphasizes the necessity for healthcare professionals to treat and care for people living with HIV and effectively forbids doctors from refusing to aid people living with HIV who need medical support. The law also underscores that if individuals are not properly taken into care or support is withheld, the medical professional will be sanctioned.[33]

### *Civil society and associations of PLHIV in Algeria*

Algeria has five HIV associations including the *Association AIDS Algérie*, *Association de Protection Contre le SIDA (APCS)*, *Association de Lutte Contre les IST/SIDA et de Promotion de la Santé (ANISS)*, and *Association Solidarité AIDS* (these associations are all under a national network called ANAA), as well as a range of organizations which engage in some HIV-related activities throughout the year, for example *Les Scouts Musulmans* and *Croissant-Rouge Algerien*. The government continues to provide support for the specific health-related factors relating to HIV/AIDS, including treatment and diagnostic services through VCT centers. However, aspects which pertain to the social and psychological aspects of HIV are decentralized to the associations. There is currently one legally registered association of people living with HIV, *Al Hayat,* which is based in Algiers. *Al Hayat* was established in 1998 and mainly works with women living with/affected by HIV, providing them with a range of support and training opportunities. *Al Hayat* directs a range of micro-credit and income generating activities to allow women to work from their homes and run small enterprises. During *Eid*, *Ramadan* and the return to the academic school year for children *Al Hayat* also gives material support to families affected by HIV. The organization does advocacy work on stigma and discrimination in healthcare settings, in particular regarding access to healthcare for pregnant women and during surgeries, and also provides psycho-social support to people living with HIV and their children. *Al Hayat* receives funding from UNAIDS and project-based financing from the Africa Union. It is run by one-full time staff member, and two additional staff members who engage in outreach to help identify people at risk. The association's main challenges are sustainable financing to scale-up activities with people living with HIV, and capacity development, for example to regularly document activities.

In addition to *Al Hayat*, the *Association de Protection contre le SIDA* (APCS) in Oran convenes two support groups of women living with HIV (one with women living in Oran and one with women living outside Oran) called AMEL, and provides legal support and services for people living with and affected by HIV. This PLHIV group is formed of energetic and courageous women who have visibly come a long way from extremely stigmatizing and discriminatory environments and have progressed by the nurturing accompaniment and support of APCS board and staff. The dynamics of the group and the interaction with APCS has yielded a group of empowered women who have gradually lost their fear and shame and have become very vocal in their demands, which they have taken directly to government health authorities, in particular during interruptions in the provision of ARV in Oran.

## Lebanon

There are approximately 3,600 individuals living with HIV in Lebanon (estimates range from 2,700 to 4,800 people currently living with HIV).[34] Men who have sex with men are currently the key population at higher risk of HIV exposure in Lebanon, however there is limited information and surveillance on the current state of the HIV epidemic in the country. The most recent NSP for Lebanon was in place for 2004-2009 and most statistical and epidemiological information dates back to 2004.[35] Since the first NSP

was developed, Lebanon has experienced socio-political turmoil and conflict, so budget priorities have inevitably shifted away from HIV to relief and reconstruction.[36]

### *The National HIV response and the involvement of PLHIV in Lebanon*

Underreporting continues to be a critical issue for the HIV response in Lebanon as physicians, labs and hospitals only voluntarily report cases they encounter to the National AIDS Program, despite HIV reporting being a law.[37] While voluntary counseling and testing is offered free-of-charge, there are still relatively low levels of testing uptake and individuals are required to pay for lab and diagnostics testing, such as for CD4 count and viral load tests. The government does not directly fund civil society organizations working in HIV; however some local municipalities contribute small funding amounts. There are shortages in human and financial resources in particular as Lebanon is not eligible for Global Fund funding. The main funding for the country's HIV-related organizations comes from the following: UNAIDS, WHO and UNDP, DROSOS, the International AIDS Alliance, the USAID MENA Bureau through the AIDSTAR-Two project and SIDACTION in France.

### *Civil society and associations of PLHIV in Lebanon*

While there are a range of organizations working in HIV in Lebanon, their HIV work only comprises a small proportion of their overall work. Some of these organizations include: *Soins Infirmiers et Développement Communautaire* (SIDC); Vivre Positif; the Lebanon Family Planning Association; *Association Justice et Miséricorde* (AJEM); Helem; *Dar El Amal*; and Skoun. SIDC has a significant HIV/AIDS program and works in prevention with young people at risk and key populations in collaboration with other associations throughout Lebanon and also supports the association for people living with HIV, *Vivre Positif.* The Lebanon Family Planning Association works to raise awareness of HIV among youth in schools and among military communities and AJEM works in HIV education and prevention in prisons across Lebanon. Helem works with communities of men who have sex with men to raise awareness of HIV/AIDS and offers psycho-social support; it also has a mobile testing unit and is increasingly engaged in advocacy around issues related to human rights to address the legal conditions which discriminate against and criminalize homosexuality. *Dar El Amal* works with female sex workers and women in prisons to raise awareness of HIV. SKOUN works in harm reduction through an out-patient clinic in Beirut using substitution therapy and also works in prevention, education and HIV testing, which takes place at the clinic. Overall, SIDC and *Vivre Positif* are the principal organizations working with people living with HIV (there is another officially registered association called Think Positive that is working for PLHIV), and the others mainly work in HIV prevention and outreach. Nevertheless, it is important to note that some of these organizations could serve as potential future partners in more effectively supporting people living with HIV.

Stigma and discrimination are significant challenges in Lebanon, in particular at the societal and community level. Associations and support groups of people living with HIV cite stigma as a persistent obstacle to their work and to the overall HIV response in the country (there is currently a draft law regarding PLHIV under consideration in the Lebanese Parliament). Associations for people living with HIV, such as *Vivre Positif*, are not formally registered as official associations with the government, and this creates additional financing and resource challenges. Associations and support groups for people living with HIV are in general understaffed and considered under-resourced. *Vivre Positif* currently works to raise awareness and combat HIV-related stigma, particularly in health care settings and among religious leaders, through peer-related outreach. The association also utilizes the services of a psychologist and a nutritionist who provide support to people living with HIV on a weekly basis. *Vivre Postif* engages in home visits to individuals and organizes support group meetings for people living with

HIV. The association is beginning to do more advocacy for human rights and additional work on education and prevention to raise awareness of HIV in the general population. However, the IEC materials are considered outdated and require revisions; at present, only limited IEC materials are available in the country. There are two other associations that work with people living with HIV in Lebanon; however they mainly provide material support to individuals and at present do not hold support groups or meetings.

## Morocco

It is currently estimated that there are between 19,000 and 34,000 people living with HIV in Morocco, with low to concentrated epidemics in key populations, in particular among people who inject drugs.[38] According to Morocco's National Strategic Plan to Fight AIDS 2012-2016, since 1986, 6,453 cases of HIV/AIDS have been reported, with 65% of infections were reported between 2005 and 2011. Women represent almost 50% of reported infections. In Morocco, there are low to concentrated epidemics in key populations at higher risk of exposure, namely female sex workers, men who have sex with men and people who inject drugs. The number of people living with HIV on ARV therapy in Morocco doubled from 2007 to 2011, totaling 4,047. All people living with HIV are eligible for treatment and the level of coverage reached approximately 40% at the end of 2011.[39]

### *The National Strategic Plan and the involvement of PLHIV in Morocco*

The core issues of gender equality and human rights are significant cross-cutting themes throughout the current Morocco National Strategic Plan to Fight AIDS 2012-2016. Furthermore, the strategy emphasizes the vital contribution and role of key community stakeholders in the national response to HIV. The NSP outlines strategic objectives to increase the coverage of both testing and diagnostic HIV-related services for vulnerable groups at risk of acquiring HIV, as well as increase ARV coverage, permitting people living with HIV to have access to more treatment and care facilities throughout the country. The NSP underscores the goals of reducing HIV infection by 50% and reducing AIDS-related mortality by 60% in 2016. In addition, the NSP outlines a plan for operationalizing psycho-social care and support for all people living with and affected by HIV in Morocco, whereby people living with HIV themselves are involved in "positive prevention." The strategy highlights the critical importance of reducing inequalities linked to human rights and gender to allow individuals greater access to HIV-related services, as well as the necessity of further work to create an enabling environment to carry out HIV interventions. Finally, the NSP elaborates a strategy which focuses on human rights and HIV to fight stigma and discrimination with strong involvement and collaboration from the National Council on Human Rights (*Conseil National des Droits de l'Homme*).

### *Civil society and associations of people living with PLHIV in Morocco*

Morocco has received Round 10 funding from the Global Fund, which includes a significant portion of funding for community systems strengthening to continue to foster the development of civil society and community-based organizations. There are a number of different kinds and sizes of organizations in Morocco. The larger HIV associations include the *Association de Lutte contre le SIDA (*ALCS), with offices in 20 towns; the *Organisation Panafricaine de Lutte contre le SIDA* (OPALS Morocco) which is located in 15 towns across the country; and the *Ligue Marocaine de Lutte contre les MST*–STIs (LMST) with five to six offices. There are other smaller associations with lesser degrees of geographic representation, such as only one or two offices in only one or two towns. Other organizations are working in sexual and reproductive health, such as the *Association Marocaine de Planification Familiale* (AMPF). The *Association Marocaine de Solidarité et de Développement* (AMSED) is a development organization that also does work with local associations in HIV as well as with most development organizations in Morocco. The different organizations engage in various kinds of interventions, most of which are

concentrated around HIV prevention and some focused work with key populations at higher risk. Overall, very few organizations in Morocco are working directly with key populations affected by HIV; however this work will be scaled up for these populations with the funding of the Round 10 resources.

At present, there is only one formal association for people living with HIV in Morocco, the *Association du Jour*. Some civil society organizations such as ALCS, OPALS and *Association Sud contre le SIDA* offer psycho-social support to people living with HIV through their core NGO activities. *Association du Jour* is currently a member of the Country Coordinating Mechanism (CCM) in Morocco as well as a Sub-Recipient for Global Fund resources through the Round 6 and Round 10 grants. The association runs support groups for people living with HIV, with a "maison d'accueil" in Casablanca. *Association du Jour* receives support from UNAIDS, UN Women, from the SIDACTION resource mobilization campaign, as well as Global Fund resources. Nevertheless, they continue to experience capacity gaps in management specifically in the development of more democratic systems to elect members of the association. In addition, the association is limited in its reach outside Casablanca. Like many organizations across the MENA region, the association could have a greater impact on supporting people living with HIV more effectively if it could increase its partnerships with the other civil society organizations in Morocco, such as those with offices across the country.

### Tunisia

In Tunisia, from 1985 to December 2011, there were 1,706 officially notified cases of HIV in both adults and children. From these registered cases, 982 individuals acquired AIDS and 540 consequently died.[40] Although HIV prevalence is less than 0.1 per cent of the population in Tunisia, with approximately 2,400 people living with HIV, there are concentrated epidemics among key populations at higher risk of exposure to HIV.[41] Bio-behavioral surveys conducted in 2009 and again in 2011 indicated 0.43 and 0.61% prevalence respectively in sex workers, 3.1 and 2.4% in injecting drug users, and 4.9 and 13% in men who have sex with men.[42] The UNAIDS UNGASS Report (Tunisia 2012) underscores the significant impact of the revolution in Tunisia and the subsequent effect of the political and social turmoil on the overall health system. It indicates that administrative and key management functions were practically paralyzed during the majority of 2011.[43]

#### *The National Strategic Plan and the involvement of PLHIV in Tunisia*

The development of the Tunisian National Strategic Plan (NSP) for HIV/AIDS 2012-2016 took place during a critical transitional phase in the contemporary history of Tunisia—following the Revolution in January 2011 which encouraged important reforms in the country. The main challenges in the HIV response to date include stigma against people living with HIV in Tunisia, as well as continued stigma against key populations by the general society and institutional actors. The NSP, for example, highlights the incompatibility of legal texts and policies, or "repressive laws," and an effective public health response in relation to HIV. In addition, despite the introduction of free and anonymous voluntary counseling and testing in 19 health centers across Tunisia, there is a continually low uptake of HIV testing.[44] On a positive note, however, the NSP notes that since the implementation of the Global Fund grant during the period between 2007 and 2012, important initiatives have been undertaken to further support the needs and involvement of people living with HIV, including the implementation of a national strategy for psycho-social care and support (2009); the establishment of income generating activities (2009); the direct involvement of people living with HIV in the national HIV response, such as the designation of "health mediators" to participate in conflict resolution related to stigma; and the creation of a support group for people living with HIV (*Group de Soutien* ++, 2010). The NSP 2012-2016 integrates the key strategic objective of providing universal access to HIV treatment, care and support to people

living with HIV. More importantly, the NSP underscores that people living with HIV and their families will receive comprehensive psycho-social support.

### *Civil society and associations of PLHIV in Tunisia*

Traditionally, Tunisia has a strong, engaged civil society, with an active associative and community-based sector. The country's three HIV organizations—*Association Tunisienne de Lutte contre les MST/SIDA* (ATL MST/SIDA), *Association Tunisienne d'Information et d'Orientation sur le SIDA* (ATIOS) and *Association Tunisienne de Prévention de la Toxicomanie* (ATUPRET)—all work with different key populations. In addition there are now two associations for people living with HIV—Rahma, which acquired its associational visa in 2011, and *Group de Soutien* ++, which was established in 2010, acts as a support group for people living with HIV, and is currently situated in the offices of ATL Tunis.

One of the main challenges people living with HIV face in Tunisia is stigma and discrimination. People living with HIV continue to face stigma in their communities, discrimination from healthcare and medical professionals, and increasing stigma in the media. Despite a relatively hostile legal and socio-cultural context, civil society organizations and the support groups for people living with HIV have acted as a vital safety net for affected populations throughout Tunisia.

At present, the civil society organizations and associations of people living with HIV receive support from the Global Fund, the Embassy of the United States, UNAIDS, UNDP and USAID MENA Bureau through the AIDSTAR-Two project for various initiatives. The two associations of people living with HIV, in particular, struggle with minimal staff, intermittent financial resources and capacity limitations in financial management. Following a capacity assessment meeting in Tunisia in September 2012, the associations of people living with HIV expressed the need to become effective facilitators in participatory methods; to learn more about how to design and organize workshops; and to have access to practical tools to assess knowledge and attitudes of participants. They are also seeking to acquire training tools to implement a series of participatory sessions on Positive Health, Dignity and Prevention. Finally, as women are increasingly become infected with HIV across the MENA region, there is an expressed need to do more work with women who are affected by HIV, as well as enhance work in the areas of treatment literacy and education.

## 3. Initiatives to Support the Greater Involvement of People Living with HIV in MENA

No single agency can provide for the full spectrum of needs of people living with HIV. A range of partnerships is needed to ensure the inclusion of these actors for a more effective and robust response to HIV both in the MENA region and globally. People living with HIV have a great deal to contribute towards the challenges posed by HIV if they have the opportunity to articulate their needs on an equal platform with governments, technical partners and civil society organizations—"When people living with HIV put a face to AIDS, speak out and become involved in policies and programs, the impact is enormous and profound. Positive people challenge the myths and misconceptions about HIV/AIDS."[45] The critical link between promoting public health and protecting human rights is through encouraging a greater pool of positive individuals to engage more fully in the response at a range of levels, including in public health initiatives, with governmental partners, in communities and in decision-making fora.

At present, a variety of initiatives in the Middle East and North Africa are addressing the greater inclusion of people living with HIV; these initiatives are supporting capacity building, the development of training tools, institutional development to support the establishment of support groups of people living with HIV, and greater networking opportunities. This section describes some of the initiatives currently in place as well as those that have taken place in the MENA region. These include UNAIDS' regional mapping of civil society organizations from 2010-2011 and the relevant recommendations, the USAID PLHIV Project and the corresponding lessons learned, human rights and the training of lawyers initiative through IDLO and work with religious leaders undertaken through UNDP HARPAS, as well as capacity building being conducted by regional networks such as RANAA and MENARosa. All these efforts underscore key successes that foster increased involvement as well as ongoing challenges.

## 3.1. Current Priorities and Activities in the MENA Region outlined in the UNAIDS MENA Civil Society Mapping and Five-Year Strategy

In 2010 and 2011, the UNAIDS MENA Regional Support Team (RST) conducted a mapping of civil society organisations including associations of people living with HIV working across the region with the aim of developing a comprehensive strategy to better support and coordinate interventions with these stakeholders. The mapping included a quantitative (closed-ended survey) and qualitative analysis (in-depth interviews) with more than 100 participants, including representatives of the support groups and associations working with people living with HIV in MENA. The compilation of these outcomes featured in the *Enhanced response to the HIV epidemic in the Middle East and North Africa through stronger partnerships with civil society: UNAIDS 5-year strategy (2012)* highlights the fact that support groups and associations of people living with HIV are often the first point of contact and care for the recently diagnosed as well as vital safety nets for long-term survivors. People living with HIV are also best-placed to provide psycho-social support and care, such as information on treatment literacy, to provide home-based care and to advocate for the respect for human rights and against HIV-related stigma.

Several countries in the MENA region have associations and support groups for people living with HIV (see Annex A); these groups vary in size and reach between the different countries. Several of the actors in these countries have also been able to establish formal associations which are recognized through the country's national laws, permitting greater autonomy and recognition at the national level and in the communities in which people living with HIV come together.
Examples of routine activities of support groups of people living with HIV identified through the mapping are many and include: treatment support to address common side-effects and contraindications associated with anti-retroviral therapy; home-visits to people living with HIV and hospital visits; awareness-raising and sensitization among religious leaders, media and health workers; healthcare system referrals; psycho-social and moral support; HIV-related prevention and education activities targeted to key populations at higher risk of exposure; voluntary counseling and testing, for example through mobile testing units; financial support during religious festivals; micro-credit projects; and enterprise training for women in domains such as textiles and pastry making. Support groups are also key advocates for the provision of treatment and ARV stock management in their communities. Many support groups and associations for people living with HIV offer a safe space for individuals to gain mutual support and understanding to live positively and healthily with HIV.[46]

The mapping underscored that support groups and associations of people living with HIV in MENA experience significant challenges in both the implementation of activities and in advocacy to combat HIV-related stigma. The *UNAIDS 5-year strategy (2012)* highlights that the second greatest challenge

overall for civil society organizations working in HIV and AIDS-related interventions and for people living with HIV—after the lack of sustainable financing—is stigma and discrimination at the political, societal and cultural level.

The *UNAIDS 5-year strategy (2012)* identifies a range of challenges for support groups and associations of people living with HIV in MENA at present. These challenges include:

***Organizational development of PLHIV associations/support groups:***

- Support groups and associations of people living with HIV often depend on volunteers, with limited remunerated staff members; therefore assistance to the greater community can be patchy and unsustainable.
- Due to limitations in core financing, some support groups are restricted to providing moral and social support rather than material or technical support to people living with HIV.
- Most associations of people living with HIV do not have their own offices or administrative infrastructure and are housed within larger civil society organizations working in HIV; some associations consider this a key limitation in their organizational independence and fiscal autonomy.

***Institutional development and PLHIV involvement:***

- There is a lack of strategic partnership and coordination among associations of people living with HIV and other organizations working in HIV or related fields at the national level.
- Many associations, although effectively functioning and providing support to people living with HIV, are isolated from both strategic planning at the national level as well as in the communities in which they work.

***Support and follow-through:***

- Although training for the greater involvement of people living with HIV is available, there is limited follow-up to the training or financial support to take the knowledge and initiative gained in the training forward.

***Sustainability:***

- There is a lack of financial and programmatic sustainability. For example, some support groups speak about being caught in a cycle where in order to acquire additional funding, they have to prove the quality of their support to people living with HIV; however, they are unable to do this without regular financing.

***Lack of enabling environment:***

- There continue to be legal and human rights violations against the rights of people living with HIV accompanied by limited knowledge and information on avenues for recourse to address these abuses.

To this extent, one of the key pillars for strategic action identified in the *UNAIDS 5-year strategy (2012)* is: “Ensuring Healthier Communities and the Meaningful Involvement of People Living with HIV.” Key objectives for this strategic pillar are:

- To support the meaningful involvement and leadership of people living with HIV to further reduce stigma

- To enhance and strengthen the capacities of associations and support groups of people living with HIV
- To scale-up coverage for quality testing, treatment, care and psychosocial support for people living with and affected by HIV

The document also designates key actions for the implementation and operationalization of the strategic objectives to support the greater involvement of people living with HIV. The key actions and issues under consideration include:[47]

***Community-based programming to benefit PLHIV:***

- Enhance the role of support groups and associations of people living with HIV to provide peer-to-peer psychosocial support and education on treatment literacy.
- Help to raise awareness among key populations at higher risk of exposure and people living with HIV of their legal rights according to existing declarations and legal authorities.

***Inputs to strengthen the delivery of healthcare services:***

- Regularly update therapeutic guidelines to provide for better access to treatment.
- Conduct routine follow-up with governments on the forecasting of ART needs.
- Continue to train healthcare workers on quality care and treatment.

***Organizational and institutional development:***

- Support capacity building for the development of quality proposals by associations and support groups of people living with HIV and their partners to mobilize additional resources.
- Facilitate the acquisition of formal and legal status for associations of people living with HIV.

***Sustainability:***

- Advocate that support to associations of people living with HIV is reflected in the National Strategic Plans (NSP) with clear budget allocations.

## 3.2. USAID Investing in PLHIV Leadership in MENA Project

From 2005 to 2010, the USAID "Investing in PLHIV Leadership in MENA" Project (USAID PLHIV Project) worked to strengthen the capacity of people living with HIV across the region through a combination of mentoring, training and small targeted grants. The USAID PLHIV Project aimed to foster and support a cadre of in-country and regional HIV positive "champions" to become advocates and trainers themselves who could then act as agents of change in MENA.[48] This project came at a time when the HIV response and advocacy in the region were limited. In partnership with UNDP HARPAS (HIV/AIDS Regional Program in the Arab States), the project involved a range of activities over time with a group of people living with HIV and it achieved what is to be considered a range of "firsts" for people living with HIV within this context (for example: the first regional workshop facilitated by and for PLHIV in Tunisia in 2006; the first training of trainers workshop for PLHIV in Jordan in 2008; and the fact that for many participants, the workshops they attended marked the first time they had ever met with other people living with HIV in the region). Most importantly, a number of people living with HIV evolved from being beneficiaries and recipients of knowledge, to experts and providers of information themselves.[49]

The USAID PLHIV Project worked intensely to support the greater involvement of people living with HIV in MENA. Given that when the program started there were very few opportunities or spaces for people living with HIV to engage, the USAID PLHIV Project was an important investment in building the capacities of this core cadre of individuals. These individuals are now making significant gains in their home countries in the involvement, care and support of people living with HIV as well as in greater advocacy and leadership initiatives. However, the program concentrated on a regionally-specific program—through trainings and workshops—to foster individual leaders, rather than on initiatives to support challenges at the country level with associations and support groups of people living with HIV. The next steps to ensure that the real achievements of the USAID PLHIV Project are sustained should therefore focus on the national level, including mechanisms to address the enabling environment within specific countries in MENA and initiatives to support the engagement of the greater civil society structures and partners within the countries. In addition to its current work with civil society organizations and HIV prevention among MSM, the AIDSTAR-Two project has recently begun to work at the country-level with PLHIV.

The following are some of the activities and achievements of the USAID PLHIV Project:[50]

***Activities:***

- The development of three comprehensive training manuals to support people living with HIV to train peers (note: people living with HIV have gone on to train others using these tools).
- The organization of a five-day regional treatment workshop in Tunisia.
- The implementation of a two-day training on resource mobilization which also provided the opportunity for people living with HIV to better understand Global Fund processes.
- Workshops to train individuals on leadership and networking.
- The organization of a five-day workshop in Tunisia for women living with HIV to raise awareness about the feminization of HIV and provide women with the skills to address the factors which fuel HIV in MENA.
- Assistance to people living with HIV to apply to scholarships to attend additional conferences.

***Achievements:***

- Following advocacy training for people living with HIV, the successful blocking of discriminatory legislation in Bahrain which would have banned PLHIV and their relatives from working in certain professional fields.
- The introduction of newer and more effective treatment regimes through advocacy by the support group for people living with HIV in Bahrain among healthcare authorities.
- The fostering of closer linkages with National AIDS Programs (NAP). For example, some NAPs offered to financially support workshops for people living with HIV.
- Support for the start-up of the region's first regional network/support group of people living with HIV, MENA+[51] as well as a regional initiative started and formed by women living with HIV, MENARosa.
- The provision of one of the first grants to support a study on service availability for people living with HIV, to help identify barriers to accessing health services in Jordan, a study which was to be solely developed, implemented and managed by people living with HIV.
- Following the resource mobilization workshop, training participants met with Global Fund Portfolio Managers at the International AIDS Conference (2010) and staged a protest against Round 10 prioritization and advocated for the continued support to HIV programs in MENA.

- Support for the establishment of a number of support groups as well as formal associations of people living with HIV in Jordan, Bahrain and Lebanon.

The USAID PLHIV Project operated effectively over five years, allowing for a range of training and follow-up activities with this core cadre of individuals. Many of the participants are now key activists, advocates and trainers in MENA, leading their own associations of people living with HIV or forging ahead with regional HIV-related initiatives.

***Challenges***:
The project encountered challenges which could serve as key lessons learned for future initiatives. Some of the challenges cited by staff associated with the USAID PLHIV Project as well as key stakeholders from the program are:

- The overall project was resource intensive, and efforts to maintain projects and activities were made at considerable cost.
- The regional workshops also proved resource intensive and some participants reported receiving little follow-up after the trainings.
- Although the small-grant component allowed some associations and support groups of people living with HIV to become established, some of the associations have not been able to meet their operational costs in the medium and longer-term.
- After a series of capacity building workshops, some individuals living with HIV returned to their countries to face difficult political and socio-cultural environments which have prevented them from engaging more effectively in the response.
- Although the initiative was able to bring some new partners on board such as government National AIDS Programs (NAPS) and the regional network RANAA, the project could have benefited from more formalized partnerships with local and national organizations working in HIV and AIDS in the region, such as human rights organizations and women's organizations.
- The size of the region (23 countries) made it impossible to include all the countries in the project.

## 3.3. "Scaling-Up HIV-Related Legal Services," International Development Law Organization

The International Development Law Organization (IDLO) is an inter-governmental organization that provides legal expertise, resources, and professional support to governments, multilateral organizations and civil society, including in the MENA region. IDLO's core staff includes experienced jurists who are specialists in legal and judicial reform, human rights and health. At present, IDLO has members across the region in Egypt, Jordan and Tunisia and provides support in Algeria, Egypt, Jordan, Tunisia and Morocco. Throughout MENA, IDLO works to provide HIV-related legal services, and has recently developed a toolkit to help countries to scale-up HIV-related legal services. The organization supports people living with HIV and key populations to address legal issues and resolve disputes, with an emphasis on informal resolution to avoid courts, and negotiation with police and prison authorities to support public health approaches to HIV. IDLO also conducts research throughout the region on human rights and uses this research to increase advocacy for the promotion of human rights in MENA.

In **Algeria**, for example, IDLO has partnered with ANISS to support the provision of six lawyers on staff to address issues related to confidentiality, access to treatment, gender-related violence, criminal prosecution and child custody issues. ANISS offers legal education for people living with HIV and other vulnerable groups, as well as legal advice, informal dispute resolution and advocacy for law and policy reform. In addition, through the project "Permanent space for training of MARPs outreach workers," lawyers train leaders among people living with HIV and key populations to provide legal information to their communities and to provide links back to lawyers who are able to support them in resolving disputes. For example, in the case of a female sex worker living with HIV who was initially deprived custody of her child, mediation was carried out with the family to award custody after the father passed away. As a result of these initiatives, ANISS has been able to document an increase in the demand for legal aid among people living with HIV and key populations.

In **Morocco**, the organization OPALS has also partnered with IDLO and its staff currently includes two lawyers who support legal services for people living with HIV and key populations. OPALS has worked to address breaches in confidentiality, drug-use and gender-related violence, and issues related to criminal prosecution. OPALS also provides legal information and legal advice to vulnerable groups through the collaboration with a number of inter-governmental agencies and public institutions to raise awareness of issues related to human rights for people living with HIV. In addition, the organization held a series of meetings with parliamentarians aimed at supporting legislative reform. Examples of HIV-related legal services provided by OPALS include intervening on behalf of female sex workers who were detained as a consequence of carrying condoms. OPALS negotiated with police and the courts to release the sex workers and subsequently followed up with the police to sensitize them on the importance of sex workers using condoms. Finally, OPALs supports community outreach to provide HIV-related legal services such as capacity building for people living with HIV and key populations as well as awareness-raising on HIV-related rights.

In **Lebanon**, Skoun works with drug users and has been advocating for treatment over prosecution through dialogue with judges, advocacy to propose amendments to the country's Drugs Act and the establishment of a judicial referral system for drug users to the treatment center. Through collaboration with judges, SKOUN has been working to stop or suspend prison sentences if there is adherence to adequate treatment regimens.

Finally, in **Tunisia**, ATL has partnered with IDLO to protect the rights of people living with HIV and key populations who encounter legal challenges. Through this initiative, ATL has a lawyer on staff who regularly meets with people living with HIV to provide legal advice and support, as well as informal resolution of disputes. ATL is also now able to support vulnerable individuals with legal representation in the court systems. ATL also helps people living with HIV to access support from the government and social funds. Overall, the organization regularly provides awareness-raising and legal guidance on discrimination related to HIV or gender-based discrimination; problems related to attacks on the sanctity of private life and personal data; violence against women, people living with HIV and men who have sex with men; problems related to disputes over child custody or alimony; illegal practices of the police; the rights of people living with HIV in prisons; legal services related to the recovery of legal documents (such as national identity cards, birth and death certificates); and children's rights.[52]

## 3.4. The UNDP HIV/AIDS Regional Program in the Arab States (HARPAS)

In 2004, the UNDP HIV/AIDS Regional Program in the Arab States (HARPAS) was launched to raise awareness of HIV and to commit to scale up prevention efforts to combat the spread of the epidemic in the MENA region. Since its inception, HARPAS has worked with a range of partners critical to the HIV response, including religious leaders, civil society organizations, parliamentarians, media and people living with and affected by HIV. The HARPAS program has implemented initiatives across the region to support the leadership and empowerment of people living with HIV including a series of capacity building initiatives, as well as the involvement of people living with HIV in the creation and implementation of UNDP HARPAS work plans and programs. The program has also developed a guidance document entitled "Towards the Universal Protection of Human Rights for People Living with HIV" to reinforce the protection and promotion of the rights of people living with HIV.

In addition, HARPAS has worked consistently with parliamentarians throughout the region to develop and advocate for the promulgation of laws to protect the rights of people living with HIV. Anti-discrimination laws were either drafted or reinforced in Djibouti, Yemen, Bahrain, Sudan and Qatar through the engagement and collaboration with parliamentarians as well as religious leaders. Furthermore, in 2004, 80 top religious leaders in MENA signed the "Cairo Religious Leaders Declaration" calling for the eradication of stigma and the promotion of human rights for people living with HIV and vulnerable groups. The signing of the declaration was followed by the training of thousands of religious leaders in the MENA region to encourage them to more fully provide support to vulnerable groups, in particular psycho-social support to people living with and affected by HIV.

## 3.5. Regional Support and Networks

There are currently a range of regional networks and knowledge hubs providing technical support and playing a key advocacy role in HIV/AIDS. The existing regional networks facilitate coordination and provide guidance to the national networks as well as bring visibility to the overall HIV/AIDS response. Regional networks provide opportunities for training workshops on advocacy initiatives, capacity building for nascent national networks, as well as a forum for organizations and associations working on similar issues to exchange experience. At present, there are approximately 10 regional networks and forums operating across MENA, including the Regional Arab Network against AIDS (RANAA), the Middle East and North Africa Harm Reduction Association (MENAHRA), MENARosa, the North African Network for AIDS Service Organizations (NANASO), CHAHAMA and the AIDS Business Coalition in the Arab Region (ABCAR), as well as various HIV-related Parliamentarian groups, for example in Yemen. During RANAA's 4th General Assembly, a *Positive Development Network* was established among PLHIV, which replaced a network of PLHIV called MENA+.

The principal mission of the **Regional Arab Network against AIDS** (RANAA) is to reduce the spread of HIV/AIDS and improve the quality of life of people living with HIV in the MENA region through networking, advocacy and strengthening civil society. RANAA is composed of national networks of different civil society organizations, associations and people living with HIV. The main objectives of the network are to strengthen the technical and organizational capacities of CSOs working on HIV/AIDS and associations of people living with HIV in MENA; support the national HIV/AIDS networks for better coordination, consolidation and exchange among CSOs; and support greater advocacy for HIV/AIDS in the region. In 2010, RANAA convened, with the support of UNAIDS and USAID, the 3rd regional meeting for PLHIV in Lebanon. The meeting was designed around the overall theme of empowerment and aimed

to strengthen the leadership skills of PLHIV, their capacities for advocacy, and empower them in working towards a supportive and protective legal and policy environment, addressing stigma and discrimination, and maintaining and improving their health and well-being. For the first time in the region, an organizing committee of PLHIV was involved in all aspects of the meeting and an open call for participation was launched by them to identify the 60 participants who were present. In 2011, RANAA conducted a series of sub-regional training workshops with civil society on leadership and management among the different associations of people living with HIV, and it has consistently worked to strengthen associations of people living with HIV across the region. For example, RANAA recently organized exchange visits throughout 2011 among the different associations and countries in the region (Lebanon, Tunisia and Egypt) and continues to organize regular workshops to enable associations to be more active in their countries. In 2012, RANAA elaborated a new vision, and further defined its mission and strategic orientations for 2013-2018. This new five-year strategy for 2013-2018 was validated by RANAA's members during a General Assembly at the end of 2012.

**MENARosa** was launched in 2010, when a group of women infected by HIV came together to form a regional group with the main objective of providing an independent domain for infected women and girls to collectively express their needs and concerns related to their positive status—from nutritional support to psycho-social care and well-being, as well as the education of children and young people. Of the estimated 470,000 people living with HIV in the MENA region, 40% are women.[53] A recent UNAIDS report argued that stigma and discrimination against people living with HIV is greater for women than men because of societal expectations regarding women's behavior and because of a popular misconception of the link between HIV infections and unlawful or prohibited practices such as sex work and drug use.[54] During 2011-2012, MENARosa conducted a series of qualitative studies through 19 focus group discussions among women living with HIV in 10 countries across MENA. The findings demonstrated commonalities in the situation for women living with HIV across the region. Collective challenges included access to treatment, care and sexual/reproductive health services, as well as persistent stigma—specifically in the health sector. Another common issue was women's concern about frequent violations of their human rights. MENARosa now works through face-to-face meetings and networking across the region to give women the opportunity to talk about their experiences and challenges in living with HIV and though providing small grants to launch advocacy campaigns in countries of the region. More importantly, MENARosa is also aiming to raise awareness among key decision makers of the needs of women living with HIV globally.

**MENAHRA** serves as a regional knowledge hub on harm reduction and engages in training and advocacy workshops, the production of regional advocacy materials, and support for the establishment of VCT facilities across the region. Civil society organizations receiving MENAHRA's support report increased harm reduction services and increased sharing of strategic information both nationally and regionally. MENAHRA has also recently become one of the only successful regional initiatives in MENA to be the recipient of Global Fund resources (Round 10). People who inject drugs are their primary target group.

In addition, the regional network **CHAHAMA** is an initiative among Arab religious leaders which has trained and sensitized over 250 religious leaders across 19 countries in the region. It works to support the needs of key populations, including PLHIV and their families. It also assists religious leaders in tailoring their discourses to address HIV/AIDS in a manner which does not further stigmatize the illness and demonstrates compassion for PLHIV. CHAHAMA works to break the silence on HIV/AIDS by operating through mosques and churches, and offers spiritual support to PLHIV.

## 4. Key Gaps and Needs for Future Programming

As described in the previous section, a number of initiatives have supported the greater involvement of people living with HIV in the Middle East and North Africa. However, despite these efforts, a large proportion of support groups and associations of people living with HIV, as well as individuals, remain isolated from the communities in which they work and live. Furthermore, they also experience isolation from the greater response to HIV at the national-level. This isolation is due to a range of factors, most notably the political and socio-cultural climates in which HIV-related stigma and discrimination pose significant barriers to the empowerment and participation of people living with HIV. In addition, in 2011 the region experienced social and political turmoil, the outcomes of which are still being determined in several countries. Most importantly, while some spaces for creating associations and organizations are opening, others are simultaneously closing, with some countries turning a blind eye to undocumented rights abuses and ceasing or blocking programmatic funding. During such periods of socio-political turmoil and cultural upheaval, it is necessary to recognize the structural barriers some partners may face in the design and implementation of interventions and activities, and most importantly, that this situation continues to change in ways that cannot necessarily be anticipated.

The gaps and needs highlighted here were identified through interviews with: (1) individuals and associations of people living with HIV collected during the UNAIDS civil society mapping and the development of the *UNAIDS 5-year strategy 2012;* (2) staff members of the USAID PLHIV Project; (3) additional discussions with UNAIDS Country Coordinators in the MENA region; and (4) follow up discussions with associations of PLHIV in Algeria, Lebanon, Morocco and Tunisia. As such, it is important to note that they represent only a portion of the gaps and needs currently existing in the region. They inform the recommendations and priorities for action which are found in section 5.

### Enhancing the involvement of people living with HIV:

*Ensuring the involvement of people living with HIV in all areas of program design, implementation and advocacy* to guarantee that programs are designed effectively, it is important to provide opportunities for stakeholder input and clarity at the macro-level. In addition, future initiatives need country-specific analysis as countries in MENA share considerable socio-cultural attributes but are at varying stages of socio-economic development, with health and per capita income indicators at both ends of the spectrum.[55] Key priorities to further the involvement and leadership of people living with HIV therefore should address gaps in basic communication and IT training, resource mobilization, organizational and financial management, treatment literacy (how to take treatment, the different treatments available, resistance, adherence, side effects and contraindications, alternative medicines and therapy), and sexual and reproductive health (positive prevention for women, family planning, guardianship and inheritance).

The USAID PLHIV Project also identified remaining issues which should be addressed in partnership with people living with HIV such as: access to quality treatment, advocacy, and policy dialogue; gender, family, and community issues, including gender-based violence and harmful traditional practices; strategies to reach the most-at-risk and vulnerable populations with HIV prevention information and services; and networking, including platforms for sharing knowledge, information and tools in Arabic.[56]

### Material conditions, care and support:

*Effectively addressing the material conditions, care and support of people living with HIV: efforts to engage in and foster leadership and the transfer of knowledge to people living with HIV is a challenge when the basic material needs of the individual are not being met*. Individuals currently working with

people living with HIV, either through support groups or associations, underscore the structural challenge of poverty. Some support groups are able to provide small sums of material support to individuals living with HIV for food, housing and transport costs, however some individuals are still unable to afford the costs of transport to make their hospital appointments. A number of associations indicate that the moral and psycho-social support they are able to give often does not match the material needs of individuals severely affected by poverty. Future programming must seek to balance fostering the leadership and involvement of people living with HIV and the material needs of individuals affected by poverty within these contexts. Support to PLHIV also needs to include finding job opportunities or micro-credit loans to ensure that PLHIV are not a target for charity but for dignity and independence.

### Core capacity building:

*The routine need for core capacity building for people living with HIV*: A variety of trainings and capacity building workshops directed to people living with HIV in the MENA region have taken place; however, additional strengthening is needed. Some of these trainings were focused on treatment literacy, resource mobilization, sexual and reproductive health, advocacy, leadership, and mentoring, networking and partnership building and organizational management. However, some support groups and associations of people living with HIV point out that many of their members, including themselves, still do not know how to write a formal letter to a partner or donor, or how to send an email. In addition, advocacy is encouraged in training, however many actors are not aware of the functions of the different organizations and partners/donors from whom they may seek funding. Most importantly, communication, information technology and financial management remain key gaps for individuals seeking to have greater involvement in the overall response to HIV. Capacity building can take a variety of forms such as peer-to-peer mentoring, exchange visits such as those organized through RANAA in Egypt, Tunisia and Lebanon (2011), regional trainings such as the one conducted by RANAA in 2011 on leadership and advocacy in Sudan and through the provision of web resources and tools to allow actors to routinely develop their skills base.

While there is a core group of individuals living with HIV who engaged regularly through the USAID PLHIV Project, there is also a newer group of individuals who have not benefited from these trainings but who are actively working with and supporting people living with HIV in the region. They could benefit from the type of support provided by the USAID PLHIV project in the future. This gap in continued training underscores the need to consider the challenge of the geographical spread of effectively implementing and engaging in these initiatives, as well as the challenge of determining who can be included and/or prioritized for financial and technical support in relation to regional training, grants and technical support. It is necessary to distinguish in the design of activities between a core base of individuals who have been previously trained and who are now leaders and advocates themselves, and a cluster of individuals living with HIV who are currently engaging in the greater support of people living with HIV but who have not had access to this training. Peer-based action should ideally include follow-up training with the original cluster engaged in the project, as well as practical skills-building workshops for people living with HIV—ideally delivered by PLHIV who have already been trained.

### Greater human rights advocacy

*Human rights abuses and continuing legal violations against people living with HIV*: Universal access cannot be achieved without human rights. Stigma, discrimination and violence due to sexual orientation, gender identity or risk-behavior prevent individuals from accessing essential services, exacerbating their risk of HIV. The issue of stigma must continue to be linked with human rights initiatives in order to be

effective in the long-run. Several stakeholders and organizations underscore the need to develop a uniform mechanism to document legal violations against key populations at higher risk of HIV exposure.

Some organizations in the MENA region are now having notable success in defending the rights of minorities and integrating legal counseling for PLHIV into their strategic plans.[57] Organizations that are currently incorporating legal support/literacy and human rights advocacy into their core programmatic activities are found in Algeria, Tunisia, Egypt, Lebanon and the Republic of Yemen. These organizations are either working through partnerships with national human rights bodies, technical partners or through the support of professional jurists who may in some cases volunteers their support. Some organizations employ lawyers on their staff and one organization in Tunisia has recently created a human rights-watchdog, or *"observatoire,"* in collaboration with human rights lawyers to regularly document human rights abuses against people living with HIV and key populations.

However, people living with HIV still do not have adequate knowledge of their rights, or how to seek redress for rights abuses within their countries. For example, despite clear anti-discrimination and data protection laws in some countries, ensuring confidentiality among healthcare workers remains a key challenge for people living with HIV. Therefore, there are two main gaps concerning people living with HIV and human rights: (1) sensitization and awareness-raising on human rights and the avenues for legal or other institutional recourse available to people living with HIV or "HIV-related literacy and legal services" to ensure access to friendly services and (2) a pool of trained lawyers/jurists willing and able to defend people living with HIV seeking redress against such abuses. Future programming that is able to address both of these elements will support the fostering of a stronger enabling environment in MENA.

### Adequate and sustainable resources

*Adequate and sustainable resources to support groups and associations of people living with HIV*: The efforts of the USAID PLHIV Project allowed a number of support groups and associations of people living with HIV to become further established and to grow. However, a combination of factors—such as follow-through support, changes in the funding environment, rising rates in HIV infection, political and social turmoil—have meant that some of these groups remain limited in the activities they are able to engage in and support, as well as in their ability to strategize in the longer-term.

Furthermore, most of these associations only have one part-time or full-time salaried staff member, and consequently rely on volunteers for a substantial proportion of the work. Many are housed within larger civil society organizations as they are not able to acquire a legal associational status in the country in which they operate and, therefore cannot open bank accounts, hindering their ability to manage and mobilize resources from donors. Some organizations have initially sought to mentor associations of PLHIV to eventually become their own independent associations; however in the longer-term, these efforts have not been successful, either due to limited capacity and time or competition. Several initiatives have provided small amounts of seed funding to the associations, for example from the USAID PLHIV Project and RANAA. However, these "one off" efforts do not allow for the routine, sustained transfer of knowledge and capacities between support groups of people living with HIV.

### Evaluation and follow-up of capacity building and financial support

*Need for further evaluation and follow-up on workshops for and involving people living with HIV*: The USAID PLHIV Project provided a range of workshops and capacity building sessions to foster the leadership and involvement of people living with HIV across the Middle East and North Africa over a period of approximately five years. However, it is important to reiterate that the terrain for these actors continues to change. In particular, MENA is now witnessing one of the fastest growing HIV epidemics

globally, and consequently more and more individuals are seeking care, support and direct involvement in their own well-being.

From the interviews of individuals and support groups of people living with HIV conducted during and after the UNAIDS civil society mapping and the development of the *UNAIDS 5-year strategy (2012)*, a key challenge cited is that the workshops, while valuable, have little follow-up training or other support, and no requirement or commitment from the individuals themselves thereafter. There are few processes to encourage participants to outline how they will carry forward the training and knowledge gained in their own country, or how they can report back. Future planning must consider not only a range of activities and capacity building exercises but also how to make the training more sustainable in nature so that participants have a sense of regular continuity and follow-up.

## 5. Recommendations and Priorities for Action

One of the key objectives of strengthening the involvement, care and support to people living with HIV is to transform the individual as the beneficiary and receiver of knowledge to becoming a key expert and provider of information and strong advocate for the rights for quality treatment, care and support. This is in line with the principal strategy of the previous USAID PLHIV Project as well as the *UNAIDS 5-year strategy (2012)*. Future programming for the greater involvement of people living with HIV should build upon the support and interventions conducted in MENA to date. The region now has a number of strong leaders of people living with HIV in the various countries who can serve as a strong cadre of individuals to build upon strategies in this next phase to support the greater involvement of people living with HIV.

Future programming should ensure that this core cadre of individuals remain engaged on the issue of the greater involvement of people living with HIV and receive a combination of routine training, mentorship, exchanges and web-based friendly tools in order that they will be able to train and support a future cluster of leaders. Programming must also be realistic, practical, and offer careful technical support through a combination of targeted interventions and programs beyond the short-term. This includes small grants, the continued direct involvement of people living with HIV in the development of training manuals, tools and exchanges, as well as the greater involvement of key partners, such as civil society organizations working in HIV in the region, human rights lawyers and advocates, regional networks and knowledge hubs such as MENARosa and RANAA, religious leaders, media, private sector (for domestic funding), parliamentarians, relevant government ministries and multilateral technical partners.

A regional program needs to analyze how current resources are being invested in order to generate program models for future application. For example, future programming could focus on fewer countries while engaging in some regional activities to complement these programs. However, the challenge is to design an initiative which builds upon the real gains and achievements of previous projects, for example, including previous participants, while considering how to use finite resources more effectively. Given the current socio-political turmoil in the region, it is also important to identify countries where activities can be planned strategically and can be implemented in a relatively sustainable manner. Any strategy for the implementation of activities for the greater involvement of people living with HIV should initially involve a consultation meeting with the individuals who have already engaged in this work (as aforementioned) and key partners. While this is not an exhaustive list of potential interventions with countries in the region, the ideas below represent a range of

recommendations based on reflection from different sources and from individuals living with HIV in the MENA region who seek to have further engagement in their own national responses.

This situational overview identifies four core priority areas for action and recommendations within which a range of activities can be conducted to enhance the greater involvement of people living with HIV. They are:

1. Peer-based action, including mutual support and self-help among people living with HIV through community-based activities.
2. The meaningful involvement of people living with HIV to combat stigma and discrimination.
3. The availability of and access to friendly services for people living with HIV, including clinical and non-clinical services for treatment, care and support.
4. A strengthened enabling environment for people living with HIV in which the individual is aware of his/her human rights and has access to legal or other institutional recourse if these rights are abused, i.e., HIV-related legal services and increasing support from decision-makers.

## 1. Peer-based action, including mutual support and self-help among people living with HIV through community-based activities.

The USAID PLHIV project developed three training manuals to be used to train people living with HIV as trainers and facilitators themselves (see list of resources in Annex B). The design and development of these materials involved people living with HIV to ensure accuracy and utility. It is important to ensure that future planned activities utilize these materials as a solid base for capacity building in the region. Additional activities which should be addressed through these initial trainings could include: basic communication and IT training (including how to write a formal letter, how to send emails, an overview of the different multi-lateral and technical partners, and information technology basics); resource mobilization (different sources for possible grants, how to apply for funding, how to write a good proposal); organizational and financial management; treatment literacy (how to take treatment, the different treatments available, resistance, adherence, side effects and contraindications, alternative medicines and therapy); and sexual and reproductive health (positive prevention for women, family planning, guardianship and inheritance). Finally, capacity building can take a variety of forms such as peer-to-peer mentoring, exchange visits such as those organized through RANAA in Egypt, Tunisia and Lebanon (2011) and the provision of web resources and tools to allow PLHIV to routinely develop their skills base.

## 2. The meaningful involvement of people living with HIV to combat stigma and discrimination.

A persistent challenge identified by people living with HIV across the region is stigma and discrimination by healthcare professionals. Careful planning is needed to ensure that healthcare professionals responsible for care and support (at the care-level) receive sensitization and other capacity building on the needs and rights of people living with HIV. Ideally this kind of activity would take place at the national level among and between healthcare workers, people living with HIV and associations or organizational partners to train service providers in their communities to remove barriers to effective treatment, care and support. One additional suggestion was to conduct a training workshop led by both a person living with HIV and a human rights lawyer. Moreover, there are recommendations about providing assistance to support groups and associations of people living with HIV to develop their own materials, such as a guide for HIV positive women, a guide on sexuality between people living with HIV

and non-PLHIV, guides on alternative therapies and managing the side effects of treatment, and a guide to education and provide information to others.[58]

### 3. Access to friendly services for people living with HIV, including clinical and non-clinical services to treatment, care and support.

Individuals living with HIV should have a key role in service delivery, support and care for people living with HIV in their communities and act as vital advocates to ensure that rights are respected in care settings. There are two priorities. The first is to ensure that individuals have the material means to access clinical and non-clinical services, for example, the financial means to attend their appointments, attend support-groups, maintain healthy diets, and lead active lives. Some seed funding could be filtered through the existing support groups and associations of people living with HIV to assist individuals in need. Second, people living with HIV themselves need training and capacity building to be able to act and integrate into clinical and non-clinical settings, either as care givers, advocates during hospital/clinic visits, and as those who accompany others for voluntary counseling and testing.

### 4. A strengthened enabling environment for people living with HIV in which the individual is aware of his or her human rights and has access to legal or other institutional recourse if these rights are abused.

People living with HIV continue to experience stigma and discrimination, as well as harassment, physical and verbal abuse within their communities, or from law enforcement officials or healthcare professionals. Despite this abuse, individuals rarely report abuses or seek legal or other institutional recourse. This is either due to lack of knowledge of the legal process or because they do not have access to those who can help them, such as NGO staff or legal professionals. Two areas of action should be addressed. The first area is to ensure that the current group of people living with HIV (who were trained through the USAID PLHIV Project) has a strong understanding of the legal processes in the region. For example, many people living with HIV continue to experience workplace discrimination and the abuse of healthcare provider confidentiality, and they are not aware of the avenues available for people living with HIV to seek legal counseling or action. This core cadre of PLHIV is well-placed to offer training to their peers. The second area involves training legal advocates— who themselves may feel they do not have the technical knowledge necessary to file a suit or complaint on behalf of people living with HIV. At present, there are informal groups of lawyers across the MENA region (some are supported through the UNDP HARPAS Program and IDLO) who can serve as trainers for other lawyers, as well as PLHIV who can have a greater role in protecting the rights of people living with HIV. Together, these two areas for action, if addressed, can further ensure a more enabling environment for people living with HIV in the region.

Finally, careful thought must be given to the role that regional organizations can provide in further capacity building, as well as material support and small grants to support groups and associations of people living with HIV. This technical and financial support must be monitored effectively for future programming and to be considered for replication in other countries. Furthermore, future activities require a comprehensive evaluation during and at the end of the program cycle, to consider what works well and to synthesize key challenges and successes, with a view to application in other countries in MENA in the future.

## 6. Conclusion

Support groups and associations of people living with HIV are a critical element of the greater response to HIV globally as they provide vital safety nets and support for individuals who are often isolated and removed from a range of essential services. In MENA, people living with HIV continue to face significant stigma and discrimination at the political and socio-cultural levels and support for people living with HIV is paramount. There are a range of support groups and associations of people living with HIV in the region but many of the groups are still nascent, under-staffed and under-resourced. There has been a strong cadre of individuals living with HIV who have been involved in various strengthening and leadership initiatives and these individuals continue to be at the forefront in providing and advocating for support for people living with HIV. More new trained leaders are needed to complement this cadre.

To heighten the response and to further include vulnerable populations living with HIV, organizations and partners need to maintain the momentum in the region through fostering and supporting an even larger pool of individuals and organizations to lead and advocate for a more effective response, to improve and scale-up services and promote the rights of people living with HIV. New initiatives must continue to take into account the rapidly changing political and socio-economic and cultural context in which civil society organizations and associations of people living with HIV maneuver. To effectively further the involvement of people living with HIV in the Middle East and North Africa, partners and key actors will need to incorporate a combination of interventions which extend beyond trainings and workshops, to consider mentoring initiatives, web-based resources and tools, as well as more frequent exchanges between associations in different countries and support for these associations. Considerable work has already taken place in the region and significant gains have been made. However, it is critical that all relevant partners work together to ensure crucial gains are not undone, and that advances continue to be made for people living with HIV in the Middle East and North Africa.

## Annex A: Associations of People Living with HIV in MENA and Key Partners[59]

| Country | Name of Association | Additional Country Activities |
|---|---|---|
| **Algeria** | *Al Hayat*, Algiers: Association for people living with HIV supports micro-credit initiatives, home-based care and hospital visits, treatment literacy and micro enterprise training. | • Association Solidarité AIDS which works with PLHIV in Algiers and has legal counsel on its staff<br>• APCS in Oran which convenes two self-support groups of women living with HIV (one with women living in Oran and one with women living outside Oran) called AMEL and provides legal services to PLHIV<br>• Association AIDS Algérie is the key partner of *Al Hayat* as they share an office infrastructure based in Algiers. |
| **Bahrain** | *We Love Life*: run by a positive couple, the support group organizes male and female counseling sessions. The activities include treatment literacy, moral and psychosocial support. | |
| **Djibouti** | *Oui a La Vie*: association of PLHIV which mainly works in advocacy and care and support to people living with and affected by HIV/AIDS. It accompanies members on medical visits, conducts home visits, offers nutritional support, runs a support group for PLHIV, and advocates for access to treatment for PLHIV. It does considerable work with women and sex workers. | *National Network of People Living with HIV in Djibouti*: works across different districts throughout Djibouti. Its main target groups are children and young people, sex workers, migrants/ refugees and prisoners; with its main activities focusing on HIV prevention and education, outreach work with key populations, testing, psychosocial support and advocacy. |
| **Egypt** | *Friends of Life*, Alexandria: the association's main activities include some outreach work with MSM, and education and prevention work. | *Friends of Life* has partnered both with CARITAS Egypt, the Egyptian Initiative for Person Rights (EIPR) through the Anti-Stigma forum and UNAIDS MENA RST. |
| **Jordan** | *Positive Visions:* the PLHIV association engages in raising awareness with key populations, leadership, psychosocial support and capacity building. | The NAP has supported capacity building for PLHIV financially and PLHIV are on the CCM and various national forums. |
| **Lebanon** | There are approximately three different PLHIV associations in Lebanon, including *Vivre Positif* and *Think Positive*. The approaches of the associations are different with some emphasizing the provision of material | There are a broad range of partners to draw on in Lebanon in particular *Helem* and SIDC but also the Lebanese Family Planning Association, *Oui A La Vie*, Skoun, *Dar el Amal* and *Ajem*, many of which are actively engaged with key |

| | | |
|---|---|---|
| | and others, psychosocial support. | populations affected by HIV. |
| **Morocco** | *Association du Jour* works primarily in Casablanca with a "maison d'acceuil" and support groups for people living with HIV; *Association de Lutte contre le SIDA* (ALCS) has a national coordinator for PLHIV who leads on implementing "Greater Involvement of People with AIDS" (GIPA) across ALCS programs. | A range of civil society organizations in Morocco are working for the greater involvement of PLHIV. In addition, Morocco signed a Global Fund Round 10 HIV grant with a significant community systems strengthening component. |
| **Tunisia** | Tunisia has two core support groups for people living with HIV, *RAHMA* and support to PLHIV through ATL, Group de Soutien +. Because of the recent change in associational laws in Tunisia, *RAHMA* is an official association for PLHIV but relatively new. | While there are some strong associations working in HIV, not all of them are currently active. The main partner who has remained active throughout 2011 is ATL. Other possible partners include ATL, ATUPPRET and ATIOS however they are mainly working through prisons and with PWID. |
| **Yemen** | *Yemen Aid Association for PLHIV*: the association works mainly in social and medical support including HIV awareness raising activities. They provide hospital support to PLHIV, treatment literacy, and psychosocial support; they also target universities, schools and leisure parks for education and prevention activities and have a mobile testing unit for free blood tests. The association does considerable work in advocacy and has worked with the Parliamentary committee to implement an HIV anti-discrimination law; they also do some income generating activities with women. | • The *Women's Society for Poverty Alleviation* (WCAAP): the organization works mainly with women and children in Aden who are infected with or affected by HIV/AIDS. As a result of increasing stigma and discrimination against women and children infected by HIV, WCAAP began acquiring legal support to protect the rights of women.<br>• *Alkaramah PLHIV Association*: based in Hodeida, the association provides social support to PLHIV including accompanying members to the hospital and providing an enabling environment among PLHIV. |

Note: Libya has just registered its first NGO for PLHIV called Nag el Haya (Spring of Life).

## Annex B: Available Resources for the involvement and support of PLHIV in MENA

### USAID "Investing in PLHIV Leadership in MENA" Project materials

USAID. *Training-of-Trainers Curriculum: Building the Training Skills of PLHIV in the Middle East and North Africa Region (*Investing in MENA Series Volume 1), July 2010. Available at: http://www.healthpolicyinitiative.com/index.cfm?id=publications&get=pubID&pubID=1023

USAID. *Subregional Curriculum: HIV Basics by and for HIV-Positive People in the Middle East and North Africa Region* (Investing in MENA Series Volume 2), July 2010. Available at: http://www.healthpolicyinitiative.com/index.cfm?id=publications&get=pubID&pubID=1069

USAID. *Women-Centered Curriculum: Addressing HIV among Women and the Gender Dimensions of HIV in the Middle East and North Africa Region* (Investing in MENA Series Volume 3), July 2010. Available at: http://www.healthpolicyinitiative.com/index.cfm?id=publications&get=pubID&pubID=1268

USAID. *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 MENA Series Volume 4), July 2010. Available at: http://www.healthpolicyinitiative.com/index.cfm?id=publications&get=pubID&pubID=1269

USAID. *Paths to Leadership for People Living with HIV in the Middle East and North Africa, August 2010.* Available at: http://www.healthpolicyinitiative.com/index.cfm?id=publications&get=pubID&pubID=1235

### UN agencies and other donors' publications on HIV in MENA:

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[11] UNAIDS. *Middle East and North Africa: Regional Report on AIDS 2011*, p. II.
[12] In Libya, however, a recent study conducted by Liverpool University revealed that in Tripoli the prevalence of HIV among drug users is 87%
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[23] These countries have either received funding through Rounds 7-10 or are closing down Round 6; some countries such as Tunisia also received emergency funding after the cancellation of Round 11 in 2011.
[24] For many countries in MENA an association cannot be created unless it has been officially sanctioned and approved by the government. "Formal" associations refer to groups which have a legal status according to a specific county's associational laws; this however does not include informal support groups.
[25] UNDP. *Global Commission on HIV and the Law: Risks, Rights and Health*, July 2012, p. 8.
[26] See annex 4 of the UNAIDS working paper "HIV, Men who have sex with Men in the Middle East and North Africa, Regional Resource Group on Prevention among Men who have sex with Men", Beirut, 15-18 May, 2011, pp. 15-19.
[27] UNAIDS. *Middle East and North Africa: Regional Report on AIDS*, 2011, p. 62.
[28] Saudi Forum: Uniting Arab Countries to Fight AIDS. "Expanding rights-based programmes in national responses to HIV in the MENA region," Riyadh, 28-30 November 2011, workshop report, p. 1.
[29] UNDP. *Global Commission on HIV and the Law: Risks, Rights and Health*, July 2012, p. 9.
[30] UNAIDS. *Middle East and North Africa: Regional Report on AIDS*, 2011, p. 61.
[31] UNAIDS. *Middle East and North Africa Regional Report on AIDS*, 2011, p. 96.

[32] UNGASS Report, 2010.
[33] See Ministre de la Sante de la Population et de la Reforme Hospitalière, circulaire no. 003 du 06 Octobre 2010 relative a la sectorisation en matière de prise en charge des personnes vivants avec le VIH-SIDA.
[34] UNAIDS. *Middle East and North Africa Regional Report on AIDS*, 2011, p. 104.
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[36] UNAIDS. *Investing in Universal Access: To HIV Prevention, treatment, care and support in the Middle East and North Africa,* June 2010, p. 82.
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[47] It is important to note that the key actions and possible implementing partners have not been finalised and are still in the process of being approved by UNAIDS MENA RST.
[48] USAID Health Policy Initiative, Task Order 1 Country Report, April-September 2010.
[49] USAID Health Policy Initiative, *Investing in PLHIV Leadership in the MENA Region: Project Highlights June 2010.*
[50] Project Results: USAID Health Policy Initiative, Task Order 1 Middle East and North Africa (MENA), As of November 24, 2010.
[51] Note the network MENA+ still does not have an official status in the region, with its constitution and by-laws under development.
[52] IDLO and UNAIDS. *Report on Best Practices of HIV-Related Legal Services in the MENA Region*, 2011.
[53] UNAIDS. *Standing Up, Speaking Out: Women and HIV in the Middle East and North Africa*. July 2012, p. 8.
[54] UNAIDS. *Standing Up, Speaking Out: Women and HIV in the Middle East and North Africa*. July 2012, p. 8.
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[56] USAID Health Policy Initiative, *Paths to Leadership for People Living with HIV in the Middle East and North Africa: Project Highlights* (2010), p. 6.
[57] Aon, M. and Ibrahim, K. "HIV Prevention among MSM: MENA RRG Meeting Report," May 2011, pp. 4-5 and p.8.
[58] These examples are provided by the association of people living with HIV based through ATL, Tunisia.
[59] The annex comprises a list of different activities and support groups for people living with HIV in MENA developed throughout 2011-2012; this is not an exhaustive list and it should be noted that some organization's activities have changed throughout this period.