GUIDELINES ON
HIV SELF-TESTING AND
PARTNER NOTIFICATION

SUPPLEMENT TO CONSOLIDATED
GUIDELINES ON HIV TESTING SERVICES

Annex 31. Community values and preferences regarding HIV self-testing and partner notification in Tunisia, Lebanon and Morocco: men who have sex with men, transgender people and people living with HIV

DECEMBER 2016

#Test4HIV
Contents

Acknowledgements ............................................................................................................. iv

Acronyms and abbreviations ............................................................................................. v

31.1 Background ...................................................................................................................... 1

31.2 Introduction ...................................................................................................................... 1

31.3 Methodology .................................................................................................................... 2
  31.3.1 Selection of participants .......................................................................................... 2
  31.3.2 Process ...................................................................................................................... 2
  31.3.3 Data collection and analysis ..................................................................................... 2

31.4 Results .............................................................................................................................. 3
  31.4.1 Characteristics of study population ......................................................................... 3
  31.4.2 HIV self-testing ....................................................................................................... 3
  31.4.3 Partner notification .................................................................................................. 4

31.4.4 Strengths and limitations .......................................................................................... 6

31.6 Recommendations .......................................................................................................... 6

References ............................................................................................................................. 8
Acknowledgements
This research was conducted by the Arab Foundation for Freedoms and Equality supported by WHO-Eastern Mediterranean Regional Office.
Acronyms and abbreviations

FGD focus group discussion
HIV human immunodeficiency syndrome
HIVST HIV self-testing
HTS HIV testing services
MSM men who have sex with men
PWID people who inject drugs
TG transgender people
UNAIDS Joint United Nations Programme on HIV/AIDS
WHO World Health Organization
31.1 Background
In July 2015, the World Health Organization (WHO) published the first Consolidated Guidelines on HIV Testing Services (HTS), which included some information on HIV self-testing (HIVST) and partner notification (PN). Following these guidelines, new evidence emerged and countries requested updated guidance on those two approaches to delivering HIV testing services.

WHO defines HIVST as a process in which individuals who want to know their HIV status collect their own specimen, perform a test and interpret the result, often in private. HIVST could increase access to testing and play a particularly important role for people who are unable or hesitant to attend HTS at facilities, or who require repeat HIV testing (2-4).

Partner notification services (PN) may also increase HIV testing among partners of people diagnosed with HIV, and facilitate HIV case-finding and early diagnosis and linkage to prevention, treatment and care. WHO defines HIV partner notification services as a voluntary process whereby a trained provider asks people diagnosed with HIV about their sexual and/or drug injecting partners, and then, if the client agrees, offers these partners HTS (5).

The WHO Eastern Mediterranean Regional Office, in coordination with its key partners in the region, supported two studies to assess whether the implementation of HIVST would be an acceptable approach to increasing uptake of HIV testing, and to understand the knowledge, experiences and views of the individuals who will be affected by the new guidance on HIVST and PN.

31.2 Introduction
The HIV epidemic in the Eastern Mediterranean is the region is relatively small compared to other regions. In 2015 it was estimated that 230,000 people in the region were living with HIV, and that there were 21,000 new infections that year (6). The majority of these infections are among key populations, with 69% among sex workers, their clients and other sexual partners, 18% among men who have sex with men (MSM) and 9% among people who inject drugs (6). While these numbers may appear small, they actually reflect a 20% increase in the number of people living with HIV and a 5% increase in annual infections since 2010 in that region (5). Additionally, from 2010 to 2015 while other regions have seen a decline in AIDS-related mortality, countries in the middle-east and North Africa have experienced a 26% increase in AIDS-related death; this is likely due to the low levels of testing and treatment coverage, which remains below 30% (6).

Although testing and treatment coverage is increasing in some settings, such as antenatal care clinics, the biggest gap continues to be among key populations who have limited access to services due to stigma, discrimination and criminalization of behaviour (1,7). This is a particular challenge in Lebanon, Morocco and Tunisia where adult same-sex relationships are criminalized, or members of lesbian, gay, bisexual and transgender communities have been prosecuted under other laws that criminalize their sexual identity and gender orientation. Under such conditions, MSM and transgender (TG) populations are less likely to have enough information about HIV, and they face many barriers to HIV prevention, diagnosis and care services (7). New approaches to HTS delivery are needed to reach people living with HIV who remain undiagnosed, especially those that can reach key populations.

The following report presents the values and preferences of individuals—focusing on two key populations, MSM and transgender women, and people living with HIV—in the Eastern Mediterranean region who would be affected by new guidance on HIVST and PN. This report summarizes the methodology used to develop the report, documents and analyzes the findings and proposes recommendations for consideration during the guidance development process.
### 31.3 Methodology

#### 31.3.1 Selection of participants

A total of 78 individuals participated in this study. Forty-eight participants from MSM and TG communities in Lebanon, Morocco and Tunisia were recruited by word of mouth; they were 18–30 years old and HIV-negative. Thirty people living with HIV (19-25 years old) were identified, contacted and interviewed by a trusted individual from a civil society group working with people living with HIV. All participants received a small incentive payment (US$20 for FGD participants, US$30 for interview participants).

Collection of socio-demographic information was voluntary, and confidentiality of information and anonymity of participants was respected.

#### 31.3.2 Process

Two focus group discussions (FGD), one with eight members of the MSM community and one with eight members of the TG community were conducted in each country, and 10 in-depth interviews were conducted with people living with HIV in each country. Civil society members and public health workers from HIV and sexual health NGOs facilitated FGDs and conducted interviews.

Questions used to guide FGDs addressed:

- Knowledge and awareness about HIV testing in participants’ home countries;
- Views on available tests in terms of availability, cost, acceptability, barriers to testing;
- Awareness about HIVST;
- Views on HIVST: intention to use, opinion about whether HIVST would improve HIV testing, perspectives on access, barriers and cost;
- Views on how HIVST would improve access to testing and treatment and for whom?
- Views on what people should be aware of before, during and after self-testing, including instructions on use and post-test services;
- Opinions and preferences on different approaches to partner notification including advantages, barriers and confidentiality issues;
- Views on partner notification in terms of who should be informed about HIV status;
- Cultural considerations in terms of security and effective channels of communication.

Interviews with people living with HIV covered the same topics as FGDs with additional questions about the participants’ HIV status, experience with testing and views on advantages and disadvantages of HIVST in light of their own experiences with HTS.

#### 31.3.3 Data collection and analysis

Data were collected from FGDs and interviews and transcribed for thematic analysis in order to identify areas of consensus, diverging views and personal insights on the two study topics. One interview was omitted from analysis due to errors in data collection.
31.4 Results
31.4.1 Characteristics of study population
Nearly all study participants requested that their participation be anonymous and opted not to provide any socio-demographic information. Therefore, this information was not available.

31.4.2 HIV self-testing

Focus group discussions with MSM and TG participants.

A few participants had read about HIVST online or heard about it when travelling abroad. However, most participants had not heard of HIVST prior to the FGD.

There were some differences in perspectives on HIVST across countries. In Tunisia, both MSM and TG participants were enthusiastic about the idea, noting that this approach would reduce barriers to testing and would eliminate the stigma associated with HIV, sexual orientation and the testing process itself. In Lebanon, views were more mixed. Members of the TG community expressed concerns about the potential for self-harm when testing alone and receiving a positive result. However, MSM in Lebanon were more supportive because of the privacy and security of self-testing, which they felt would ultimately lead to increased uptake of testing. Nearly all MSM and TG reported having some concerns or uncertainty about the accuracy of a self-test. Some also felt that the lack of a professional tester would discourage some people from using an HIV self-test. Similarly in Morocco, TG participants were opposed to the idea because of the lack of awareness about HIV self-testing in Morocco and because they were concerned about individuals testing without a professional tester present. However, MSM in Morocco were generally enthusiastic about HIVST because of the increased level of privacy it could provide.

Overall, all FGD participants felt that HIV self-testing should be available for free or at a very low cost. Additionally, participants suggested HIVST could be delivered at a number of locations, including hospitals/health centres, individual doctors, non-government organization (NGO) / community-based organizations, pharmacies and colleges.

When asked about important actions or information needed before, during and/or after self-testing, participants offered several considerations:¹

- Social media campaigns to promote HIVST;
- Community training on using HIVST;
- Information on how to use the HIVST;
- Information on HIV and the accuracy of the self-test;
- How to stay negative if test result is negative;
- A 24-hour telephone hotline to support individuals at any point during self-testing;
- Web links to more information about HIV and about testing;
- Mental health care referral for support;
- Distribution of condoms with the HIVST;
- Information on what is HIV, including that HIV is not a death sentence and HIV is not a crime.

¹ This list is not ranked; different groups suggested different considerations, all of which were viewed as equally important across groups.
Participants suggested the following to be included in HIVST kit packages:\(^2\)

- Storage and expiry information;
- A referral list that includes contact information for NGOs, physicians and psychological support;
- Visual information for populations that cannot read;
- How to interpret the result;
- Steps to take in the case of a positive result.

**In-depth interviews with people living with HIV**

In general, people living with HIV in Tunisia, Morocco and Lebanon were not aware of HIVST. However, most of those who were aware of HIVST were from Lebanon.

Some participants did express that they had some concerns about HIVST, particularly that it could lead to unexpected reactions and in some cases self-harm. However, many celebrated HIVST as an innovative idea for increasing access to testing and ultimately to treatment. Many of the participants reported unpleasant and, in some cases, traumatic experiences when learning of their positive status. Because of this they viewed HIVST to be a reasonable, logical and welcome step in protecting privacy and confidentiality and reducing stigma and discrimination.

Nearly all of the interviewees said that they wished that they had had the choice to learn about their status through HIVST, without the stigma, stress and humiliation they had experienced. They also noted that HIVST would give the individual the choice of how to act once he or she received a positive result. In general, participants felt that HIVST presents a new hope for access to treatment and care for populations at risk of HIV and stigma.

**31.4.3 Partner notification**

**Focus group discussions with MSM and TG**

Views on PN varied between the MSM and TG participants and across countries. However almost all participants agreed that it is important to notify all partners as this would help to reduce new HIV infections, increase early diagnosis and expand access to treatment. In Tunisia, TG participants expressed concern about security, but they agreed that all partners should be notified and stated that contract referral was preferable to provider or patient referral as it protects the individual’s privacy and supports follow-up by a health-care provider. MSM participants, in contrast, believed that only regular sex partners and stable relationship partners should be notified, as it can be difficult to stay in contact with single encounters. This is mostly due to social media dating applications that protect an individual’s anonymity and privacy. At the same time, MSM participants in Tunisia supported and encouraged promotion of HIV testing and sexual health services through these mobile channels.

Similar to the findings in Tunisia, TG participants in Lebanon also emphasized the importance of notifying all partners, though they preferred dual notification (i.e. where a provider accompanies the person with HIV to notify their partner together) as long as it is the provider who delivers the information to the client’s partner. Religious considerations were also seen as important in partner notification in Lebanon as some faith groups may be more

\(^2\) Some of these may also be useful as part of social media or other promotion and information campaigns.
tolerant than others. Among MSM, there was consensus that all partners should be notified; and some felt that it was particularly important to notify one’s partner prior to sexual activity.

In Morocco, both the TG and MSM participants were less supportive of PN. They mentioned a lack of awareness and information, due to inadequate public education campaigns, as a constraint, assuming partners would not be able to fully understand the information. Participants also expressed fear about the resulting stigma they might experience. Participants also noted cultural attitudes toward illness, which might inhibit individuals from seeking HIV testing and follow up.

In all three countries, there were some individuals who felt unable to notify their partner/s due to a fear of their status being exposed to the community and fear of the discrimination that would follow.

Regarding the mode of delivery of partner notification services, those who favoured:

- **Passive referral** expected a greater sense of freedom and autonomy in partner notification when a provider is not involved, but still expressed concern about an inability to connect with their partner and encourage testing.
- **Dual referral** was favoured by some as the presence of a professional helped to ensure safety, reduce embarrassment and maintain control of the situation. A health-care provider in this case would be able to answer questions and help partners to manage their reactions.
- **Contract referral** is seen as more protective of privacy by some participants.

**In-depth interviews with people living with HIV³**

People living with HIV from Morocco, Lebanon and Tunisia largely agreed on the importance of notifying their partners and the importance of having a professional to support this process and to help protect their privacy. In Lebanon, participants emphasized the critical roles of professionals in partner notification: information-sharing, support for testing, and helping the client manage stigma. Although some participants noted that passive referral is important for a relationship, most think that it is not advisable as self-stigma and fear can negatively affect the process and the individual’s mental health.

“I have done the passive referral and it was not the best decision I have made.”

“Passive referral might not be welcome . . . feelings of fear, anger and judgment might not make it very smooth.”

“Provider referral would reduce risk, harm, misunderstanding or even stigma, and urges people to test at the same time”.

In Tunisia and Lebanon, around half of people living with HIV participants stated a preference for contract referral, while a similar majority of participants in Morocco supported passive referral, believing that individuals should take personal responsibility. One participant suggested that provider referral could diminish an individual’s preferences about how to approach a partner about HIV status:

**Provider referral is unfair [sic] as confrontation is important.**

---

³ Interview participants are not identified by age or sex to protect their privacy.
However there were some participants in Morocco who did not support any form of partner notification. This was primarily because they were afraid of potential negative outcomes and felt these concerns outweighed the potential benefits of notifying their partner/s.

The differences in the attitudes towards HIV itself and towards partner notification may be related to different social and cultural contexts. Tunisian people living with HIV face strong stigma, thus their priority is to protect their privacy. In Lebanon the importance of having a professional involved was considered a priority especially when a client’s mental health is at stake. In Morocco, taking responsibility and facing one’s partner/s and any consequences of notification was considered very important.

31.4.4 Strengths and limitations

The short research timeline and limited resources were the main limitations of the study, and consequently researchers were not able to provide more socio-demographic information. This report covers data that were collected over a 30-day period.

31.6 Recommendations

For ministries of health and local national AIDS control programmes

HIVST

- Develop communication campaigns with information on accuracy of self-testing technology to encourage uptake;
- Authorize/facilitate a broad range of HIVST delivery points;
- Set standards for HIVST packaging to ensure complete, audience-appropriate information on usage, interpretation of results and post-test services;

PN

- Guarantee protection and confidentiality for individuals at testing centres;
- Encourage supportive laws and policies for people living with HIV and the programmes that serve them: including prohibiting mandatory or coercive HIV testing and partner notification, and revising laws and policies that stigmatize, criminalize and discriminate against people from key population groups and people living with HIV.
- Develop communication campaigns that explain the various approaches to voluntary partner notification, the importance of choice for notification type for each partner, and the option of declining partner notification altogether.

For sexual health and HIV-specific health-care providers

HIVST

- Consider using HIVST delivery as an opportunity for other interventions such as condom distribution;
PN

- Provide training for medical staff on stigma-free, sex-positive, culturally specific communication when serving key populations;
- Provide training for medical personnel on how to communicate HIV-positive news to key populations;
- Providers may require training in how to facilitate partner notification and in documenting partner notification attempt and outcomes, including on how to support passive, provider, dual and contract referral;

For civil society and activists

- Lobby local ministries of health and NACP to ensure that HIVST is affordable, practical and user friendly.
- Empower young LGBTQI and key populations on sexual health and rights.
- Advocate for supportive laws and policies that are supportive of people living with HIV and the programmes that serve them.
References


