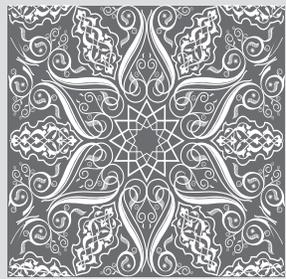
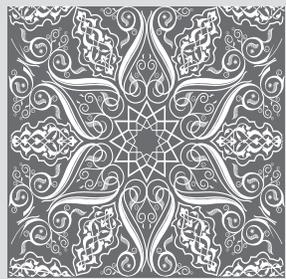
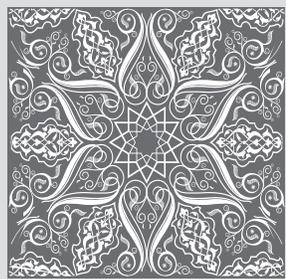
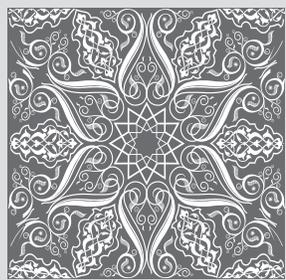
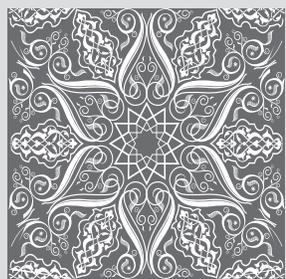




**USAID**  
FROM THE AMERICAN PEOPLE

**HEALTH POLICY  
INITIATIVE**



# HIV Principles and Stigma Reduction Training Curriculum:

Addressing HIV and Stigma in the  
Healthcare Setting in the  
Middle East and North Africa Region

Investing in PLHIV Leadership  
in the Middle East and North Africa—Volume 4

This publication was produced for review by the U.S. Agency for International Development. It was prepared by staff of the Health Policy Initiative, Task Order 1.



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*Investing in PLHIV Leadership in the Middle East and North Africa —  
Volume 4*

**JULY 2010**

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This curriculum was developed because people living with HIV in the MENA Region wanted to create a specific workshop that provided space for PLHIV and their supportive physicians to discuss stigma in the healthcare setting and unite in their responses to HIV. After piloting the workshop, participants wanted the opportunity to share sessions and information in their home countries.

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## ABBREVIATIONS

AIDS	acquired immune deficiency syndrome
ANC	antenatal care
ARV	antiretroviral
ART	antiretroviral therapy
CEDPA	Centre for Development and Population Activities
FGC/M	female genital cutting/mutilation
GIPA	greater involvement of people living with HIV
HCV	hepatitis C
HIV	human immunodeficiency virus
IDU	injection drug user
MCH	maternal and child health
MENA	Middle East and North Africa (Region)
MIPA	meaningful involvement of people living with HIV
MTCT	mother-to-child transmission
NAPs	national AIDS programs
NGO	nongovernmental organization
PLHIV	people living with HIV
PMTCT	prevention of mother-to-child transmission
PPT	PowerPoint
PTCT	parent-to-child transmission
SGBV	sexual and gender-based violence
STI	sexually transmitted infection
TB	tuberculosis
USAID	United States Agency for International Development
VCT	voluntary counseling and testing

## INTRODUCTION TO THE CURRICULUM

HIV is one of the greatest challenges of our lifetime. Since HIV was first discovered nearly 30 years ago, 60 million people worldwide have been infected with HIV and 25 million people have died from HIV-related diseases.<sup>1</sup> These statistics reflect the difficulty healthcare workers face in managing the complexity of HIV disease, which can easily overwhelm a person's immune system, especially without access to appropriate treatment and care.

In addition to the science of the disease, it is important to understand the sociocultural and development issues that can both fuel the spread of HIV and must be addressed to prevent it. These include poverty, gender disparity, human rights, and governance. We are all at risk of acquiring HIV, regardless of religion, where we live, what language we speak, the family to which we belong, or our sex or sexual orientation.

HIV affects not only individuals but also entire families and communities, weakening the social structures on which people depend. Because HIV usually affects people in their most productive years (between the ages of 15 and 49)—school teachers, port workers, truck drivers, traders, tea sellers, business professionals, doctors and healthcare workers, as well as mothers and fathers—the disease has affected the productivity of entire countries. In many countries, it has also left an orphaned generation as parents die, leaving elderly relatives to shoulder the burden of care.

HIV has also been described as a complex set of epidemics, including a parallel epidemic of stigma and discrimination. People living with HIV often face self-stigmatization, in addition to discriminatory practices that cause harm and violate their basic human rights. These practices can include being denied housing, marriage, a job, healthcare services, or community acceptance, leaving some HIV-positive people without support and hope for the future.

However, many ways exist to prevent stigma and discrimination, along with preventing HIV transmission and managing HIV as an individual; caring family; or member of a mosque, church, school, workplace, and community. One of the first steps in addressing HIV and limiting both stigma and infection, while promoting greater health, is creating a better understanding of HIV. This complex understanding is best brought to light by people living with HIV themselves, who have proven in many regions, including MENA, that they can provide key leadership in creating a sustainable HIV response.

### HIV and Stigma in MENA

**Denial, stigma, and discrimination** are major barriers to health and happiness for people living with and most vulnerable to HIV. To avoid discrimination and ostracism,

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<sup>1</sup> UNAIDS. 2009. *AIDS Epidemic Update*. Geneva: UNAIDS.

many people living with and vulnerable to HIV do not seek counseling and testing, services, and treatment and may not disclose their HIV status. Individuals may face partner, family, and social exclusion and violence, in addition to rejection, even within the healthcare setting. HIV prevention programs, including activities and support groups led by people living with HIV, face a difficult time reaching individuals who most need this support. This problem is further complicated by the social status of many women and girls in the region, who face strict family and social regulation that often leaves them with little of the control over their own bodies necessary to maintain health and well-being. Their status can make accessing any services—especially HIV-related services—almost impossible. Further, even if people living with HIV are able to reach local clinics, not all healthcare providers in the MENA Region will accept them.

Only 14 percent of those people in the MENA Region who need treatment are receiving antiretroviral drugs. When provided at all, antiretroviral treatment (ART) regimens are limited, as are combination therapies. Stockouts are not uncommon. Necessary testing, including CD4 and viral load that is crucial to effective treatment, often is not available. Added to this situation are high levels of stigma and discrimination people living with HIV face when trying to access what treatment and care is available. PLHIV have reported being rejected by hospitals and clinics and for prenatal, delivery, and postnatal care.

In addition, women and girls often face gendered stigma-related barriers to treatment, such as finding providers who will treat them when they are not accompanied by male relatives or who show a willingness to respect confidentiality and nondisclosure to husbands and other relatives. Women often face higher levels of stigma and discrimination, as do other vulnerable groups, including Men who have Sex with Men (MSM), Injecting Drug Users (IDU), and Sex Workers (SW), whose behavior is criminalized in the region.

Experience around the world proves that societies cope best with HIV and prevent its spread when governments are open; actively provide accurate information and services to all people; are gender aware and sensitive; and collaborate with organizations that represent affected communities, including people living with HIV and those most at risk, to limit both infection and stigma and discrimination.

The Greater Involvement of People Living with HIV (GIPA) is a basic principle that has been incorporated into national and international program and policy responses and has been adopted as a model of best practice in the response to HIV. But GIPA is also a broad and dynamic process that must be linked to PLHIV social movements, organizations, networks, support groups, and individuals. As increasing numbers of women and men come forward as leaders in the MENA HIV response, the GIPA principle that has guided national and regional responses worldwide is surfacing.

## Curriculum Overview

The purpose of this curriculum is to support a truly sustainable HIV response in the MENA Region, centered on positive leadership, prevention, education, and mentorship, as well as gender equity and sensitivity. It is the first curriculum of its kind to be implemented by and for people living with HIV in the MENA Region and their supportive physicians. In this way, it marks a shift in power from PLHIV as beneficiaries, imparters of testimonies, and workshop participants to experts taking a more active role in the response to HIV, in cooperation with healthcare workers they identify as making a difference in the local HIV response. The authors of the curriculum include people living with HIV in the MENA Region and elsewhere, as well as healthcare professionals and supporters who have worked on the HIV response in the region. Global practitioners, more than 30 people living with HIV, and 15 doctors from 16 countries in the MENA Region have provided inputs to this curriculum. In partnership with AMSED, it has been pilot-tested in trainings in Morocco.

The curriculum is intended to be implemented by and for people living with HIV and their supportive physicians. Facilitators should have a fairly high level of baseline knowledge of HIV and understanding of stigma and discrimination. Some sessions are designed specifically for facilitation by skilled healthcare practitioners, such as physicians, including sessions on **prevention of mother-to-child transmission (PMTCT), hepatitis C (HCV) and TB co-infection, and adherence and treatment.** For this reason, it is critical that the training include healthcare professionals, such as doctors, counselors, pharmacists, and others, who can serve as session designers, facilitators, and participants during the workshop and as advocates and champions afterward. The Health Policy Initiative workshops used a unique methodology to select healthcare providers, by asking PLHIV with whom they have worked to nominate supportive providers. PLHIV chose healthcare providers who could be champions and supporters after the workshop. The participant selection process ensured that PLHIV already active in the HIV response and who knew the environment in their countries, could partner with providers they knew and trusted, who often themselves were pioneers in the HIV response. Individual patient-physician relationships then expanded to institutional relationships between support groups and/or NGOs led by PLHIV with national AIDS programs (NAPs) and research centers led by supportive physicians and other healthcare providers.

The curriculum provides a basic program designed to engage participants regarding stigma and discrimination and HIV in the MENA Region and, in particular, healthcare settings. It is primarily discussion based. The aim is to draw the most knowledge about people living with HIV, healthcare providers, and stigma and discrimination in MENA from the participants themselves—using them as experts sharing knowledge with each other, in lieu of the facilitators simply transferring knowledge. The program is divided into four full-day sessions and a fifth half day; however, the length of both days and sessions can be modified as needed. For example, workshop facilitators also can set

aside time for sessions that feature local experts or visits to local service providers, NGOs, and support groups, as well as time for informal discussion and group activities.

The curriculum aims to raise awareness about stigma and discrimination within the healthcare sector; provide an opportunity for positive leaders and healthcare providers to learn and work together as partners in the HIV response to reduce stigma and discrimination; and provide an opportunity for these groups from the MENA Region to learn about the latest clinical advances in HIV related to treatment, parent-to-child transmission (PTCT), co-infection, fertility, and other context-specific information, as requested by participants.

The curriculum is based on the following adult learning and GIPA principles:

- **Learning is self-directed.** Adults can share responsibility for their own learning because they know their own needs.
- **Learning fills an immediate need and is highly participatory.** Motivation to learn is greatest when it meets the learner's immediate needs. The most effective learning is from shared experience; learners learn from each other, and the trainer often learns from the learners.
- **Learning is experiential.** Again, participants and the trainer learn from one another; learning is based on doing and on a collection of experiences.
- Time in training is allowed for **reflection and corrective feedback.** Maximum learning from a particular experience occurs when a person takes the time to reflect back on it, draw conclusions, and derive principles for application to similar experiences in the future.
- A **mutually respectful environment** is created between facilitators, resource staff, and participants.
- A **safe atmosphere** and comfortable environment are provided.
- Positive **leadership, prevention, education, gender equity, and mentorship** are critical components of the HIV response.

Training techniques used in this manual include the following:

- **Presentations** – activities conducted by the facilitator to convey information, theories, or principles. The facilitator will provide some PowerPoint presentations, but for those participants without access to PowerPoint, the facilitator can hand out copies of presentation slides or use the slides as a guide for main points outlined on flip chart paper;
- **Case study scenarios** – written descriptions of real-life situations used for analysis and discussion;
- **Role plays** – two or more individuals enacting parts in scenarios as related to a training topic;
- **Small group discussions** – participants sharing experiences and ideas and problem solving together; and
- **Hands-on application** – learning skills through hands-on training and practice.

It is the facilitator's role to present each session's background material, objectives, and activities as clearly as possible. Skills used to enhance communication include key verbal and nonverbal communication skills. Effective facilitation also includes the following:

## **Setting the Learning Climate**

- Read each session and review all materials and activities before each training session so that as the facilitator you are fully comfortable with the content and process;
- Start on time and clearly establish yourself as the facilitator by calling the group together. Remember, the facilitator does not play a supervisory role, but rather is someone who is facilitating the learning process of the group. If punctuality is an issue—as it often is in our region—do your best to start on time but perhaps with a less critical session, such as a review of the previous day, an evaluation, or an energizer to start the day.
- Organize all of the materials you need for the session and place them close at hand. You should make any handouts, flip charts, or PowerPoints beforehand during the preparation week. These always take longer to prepare than we think!
- Stay within suggested timeframes. If you see that the group is processing and learning, allowing a bit more time is appropriate, but with group work, one group often will be rather fast, while another will need more time. Be sure to strike a balance so no one feels either rushed or bored.
- Gain participants' attention and interest by creating comfort between yourself and them. Make them feel welcome at all times. Encourage any questions and never criticize participants for their questions or work.
- Anticipate questions. It is always best to be able to answer all questions participants may have but if there is a question you don't know the answer to, don't pretend you do. Let the participant know you'll research the answer and get back to them.
- Prepare responses and examples to help move the discussion forward. It is always best to provide an example or illustration of the answer you are providing. Stories based on work and life experiences are helpful.

## **Presenting the Objectives**

- Provide a link between previous and current sessions to ensure consistency and that the participants understand and experience progression in the learning process.
- Use the background notes to introduce the topic or prepare for the session.
- Inform participants of what they will be doing during the session to meet the session's objectives. Write objectives on a flip chart and review them for each session. Review them again at the end of each session and include them in your evaluation.

## **Initiating the Learning Experience**

- Introduce as appropriate an activity in which participants experience a situation relevant to the objectives of the session.
- Let participants use the experience as a basis for discussion during the next step.
- If you begin a session with a presentation, follow it with a more participatory activity.

## **Reflecting on the Experience**

- Guide discussion of the experience.
- Encourage participants to share their reactions to the experience.
- Engage participants in problem-solving discussions.
- Provide feedback to participants on their work from each other and from you.

## **Applying Lessons Learned to Real-life Situations**

- Encourage participants to discuss how the information learned in the activity will be helpful in their own work.
- Discuss problems participants might experience in applying or adapting what they have learned to their own or different situations. However, the conversation should not get bogged down with potential problems; instead, focus on realistic solutions and adaptations.
- Discuss what participants might do to help overcome difficulties they encounter when applying their new learning.

## **Providing Closure**

- Summarize the activities at the end of each day.
- Refer to the objective(s) and discuss whether and how they were achieved.
- Discuss what else is needed for better retention or further learning in the subject area.
- Provide linkages between the sessions of the day and the rest of the workshop.
- Help participants leave with positive feelings about what they have learned and accomplished.
- Consider providing a certification; a closing session 'graduation' can provide a great means of closure, acknowledgement of learning and hard work, and legitimacy for participants to implement their own local or country-level sessions. It can also be provided to local co-facilitators and partners to demonstrate accomplishment.

## **Covering All Details**

- Prepare all training materials (resources for research, reference materials, handouts, visual aids, and supplies) and deal with logistics (venue, tea breaks,

- and audiovisual equipment—including making sure the equipment is working) well in advance.
- Clarify everyone’s roles and areas of responsibility if other facilitators are helping to conduct the training. Meet with co-facilitators daily to monitor the progress of the workshop and provide each other with feedback. Create a team spirit, an environment where everyone feels valued and invested in the goals and objectives of the workshop.
  - Ask participants to evaluate the training both daily and at the end of the workshop.
  - Plan follow-up activities and determine additional training needs.

As mentioned earlier, this participant-centered workshop format uses interactive and experiential activities, including small group discussion, role plays, interpersonal skills practice, personal and group assessment, training and knowledge-sharing tools, and open discussion formats.

For maximum effectiveness and group interaction, we recommend the group size be limited to 20–30 participants. Generally, we recommend a mixed group of women and men of different ages and backgrounds. However, facilitators should ensure that participant meet the participant criteria so that you can meet basic workshop expectations and objectives. A survey of needs and expectations from participants ahead of time will also help set the final agenda.

This curriculum is a living document, open to changes, input, and modification by local and regional participants to serve women and men in their own countries and community contexts, as well as global practitioners with lessons to share. We thank those women and men in the region who have provided their valuable time and inputs and look forward to more feedback as stigma and discrimination is fought via awareness raising, planning, and policy-level activities in the MENA HIV response.

## WORKSHOP AGENDA

Day	Morning	Afternoon
<b>Day 1</b>		
<b>Introduction, Overview of Stigma and Discrimination</b>	Introductions and Goals of Training	Gaps in Stigma, Parts I and II
	Group Norms and Ground Rules	Overview of HIV Stigma and Discrimination in the Healthcare Setting, with Case Discussions
	Parachute and Judgment	Closing and Evaluation
	General Overview of Stigma and Discrimination	
<b>Day 2</b>		
<b>Personal and Professional Perceptions of Stigma and Discrimination</b>	Welcome and Review	Impact of HIV on Our Personal and Professional Lives, Part II
	Setting the Stage/Exploring Our Thoughts, Beliefs, and Attitudes	Case Studies
	Impact of HIV on Our Personal and Professional Lives, Part I	Moving Beyond Us and Them Closing and Evaluation
<b>Day 3</b>		
<b>The Patient-Physician Partnership</b>	Welcome and Review	Counseling and Testing, Part II
	Resistance and Adherence	Closing and Evaluation
	Counseling and Testing, Part I	
<b>Day 4</b>		
<b>Technical Updates on Key HIV and Stigma-related Issues</b>	Welcome and Review	Treatment, Care, Support, and Stigma Mapping
	Parent-to-Child Transmission	Closing and Evaluation
	Hepatitis C and TB Co-infection	
<b>Day 5</b>		
<b>Ethical Issues</b>	Welcome and Review	
	Ethical Issues	
	Closing and Final Evaluation	

## DAY 1: INTRODUCTION, OVERVIEW OF STIGMA AND DISCRIMINATION

### Schedule

<b>Session 1: Introduction and Goals of Training</b>	1 hour 20 minutes
<b>Session 2: Group Norms and Ground Rules</b>	40 minutes
<b>Session 3: Parachute Fear and Judgment</b>	40 minutes
<b>Session 4: General Overview of Stigma and Discrimination</b>	1 hour 25 minutes
<b>Session 5: Gaps in Stigma, Parts I and II</b>	1 hour
<b>Session 6: Overview of HIV Stigma and Discrimination in the Healthcare Setting, with Case Discussions</b>	1 hour
<b>Session 7: Closing and Evaluation</b>	1 hour

\*Please be sure to factor in time for a coffee/tea break in the morning and afternoon, as well as a lunch break.



## SESSION ONE: INTRODUCTION AND GOALS OF TRAINING

**Time:** 1 hour 20 minutes

**Materials:** Flip chart, tape, markers, sticky pads (Post-it notes) of different colors

**Prepared Materials:**

**Prepared Flip Charts:** On the flip chart, use one page each for the following headings:

1. Introduction: Name, Home Country, How long and Why I've been involved/working with HIV
2. Expectations
3. Concerns
4. Goals and Objectives of Workshop

**Handouts:** Workshop Agenda (tailored) (**Annex I**)

### Welcome!

**Time:** 2–5 minutes



### Instructions for Facilitator

Thank the participants for traveling and taking time out of their busy family and/or work lives to spend this week so we can all learn from each other.

## Introductions

Time: 35 minutes



### Instructions for Facilitator

1. Introductions of facilitators (2–3 minutes each):
  - a. Name
  - b. How long and WHY we have been working with HIV
  - c. Why we developed this workshop
  - d. What we expect to share, learn, and take home from the workshop
2. Introductions of participants (about 1 minute for each participant = 30 min. total):
  - a. Name
  - b. Home Country and City
  - c. How long and WHY I decided to work in the HIV field
3. Introduction of resource persons, interpreters, logistics people, and others
4. Introduction of note takers

## Expectations

Time: 10 minutes



### Instructions for Facilitator

1. **Ask** participants to write on colored Post-it notes their learning expectations and hopes.
2. **Ask** them to write any concerns or fears they might have related to the workshop on Post-it notes of another color.
3. Then **ask** them to post their papers on a flip chart with this title at the top:  
*“EXPECTATIONS: What are your expectations/ hopes?”*
4. **Ask** participants to place Post-its of the other color on another flip chart paper titled: *“CONCERNS/ FEARS: What are your concerns/fears?”*
5. **Pick** a participant to read out some of the expectations and concerns; this can lead to a conversation regarding group expectations and concerns (see below).

## Review Goals and Objectives of the Workshop

Time: 10 minutes



### Instructions for Facilitator

1. **Read** the overall goals of the workshop (see below). Then **select** volunteers to read one training objective each (see below).
2. **Ask** participants to compare the objectives with the groups' expectations to see if they match.
3. **Highlight** that, although not all expectations of the workshop will be met, facilitators will offer suggestions for how in the future those expectations *could* be met. Further, any issues can be placed in a 'parking lot' for discussion later.
4. Make a parking lot by **posting a piece of flip chart paper** with the heading 'Parking Lot' on top.
5. **Explain** to participants that they can write any questions or issues to discuss later or at the end of the day on the 'parking lot' flip chart paper.

### Overall Goals

- Enhance the capacity of the network of people living with HIV and their supportive healthcare providers in the MENA Region to provide accessible resources for support and mentorship and a platform for sharing experiences and ideas.
- Implement country- and community-level activities and projects that strengthen the HIV response, promote positive leadership, and foster greater involvement.

### Training Objectives

- To raise awareness about stigma and discrimination within the healthcare setting.
- To provide an opportunity for HIV-positive leaders and their physicians to learn and work together as partners in the HIV response for the purpose of reducing stigma and discrimination in their countries and region.
- To provide an opportunity for healthcare providers and people living with HIV from the MENA Region to learn about the latest clinical advances in HIV related to treatment, parent-to-child transmission (PTCT), co-infection, and other context-specific information based on the participants' needs.

## Review Agenda

**Time: 10 minutes**



### Instructions for Facilitator

The agenda should be tailored to suit the particular training and audience. **Explain** each day's agenda to participants; you can also **copy the day's agenda** and hand it out. **Read** it each day (or nominate a participant to read it) and provide a short overview.

## Logistics

**Time: 10 minutes**



### Instructions for Facilitator

Also have the **logistics staff introduce themselves** and **review** the following:

1. Bathroom location
2. Water—if the water is safe to drink from the tap and other related digestion/safety issues
3. Meals (if provided)
4. Tea break(s) (time and place)
5. Per diem
6. How to reach a doctor if needed
7. Location of first aid kit
8. Miscellaneous housekeeping issues

**Ask** participants if there are any questions. If individuals have specific questions during the workshop week, **ask** them to see the logistics staff at breaks, during mealtimes, or after the sessions.



## SESSION TWO: GROUP NORMS AND GROUND RULES

**Time:** 40 minutes

**Materials:** Flip chart, tape, markers

**Prepared Materials:**

**Prepared Flip Chart:** On the flip chart, use one page each for the following headings:

1. Group Norms/Ground Rules
2. Roles of Participants

**Handouts:** Subject Release Form/Photo Consent Form (**Annex 2**), Interpreter Confidentiality Agreement (**Annex 3**)

### Objective:

- Establish a way of working together that will allow us to work freely and productively throughout the workshop.



## Activity: Group Norms/Ground Rules

**Time: 15 minutes**



### Instructions for Facilitator

**Ask participants to establish the group norms or ground rules** they want the group to use during the workshop.

1. **Write** all participant suggestions on the flip chart.
2. After all suggestions are put forth, **ask** the group to confirm which suggestions they all agree should be included in the group norms and rules.
3. **Cross out** those suggestions with which the group does not agree.
4. **Put the flip chart paper** with the Group Norms and Ground Rules in a prominent place so that all participants can refer to them throughout the workshop.
5. **Examples** of ground rules may include no mobile phones, confidentiality, respect, arriving on time, keeping to the agenda.



## Activity: Establish Roles of Participants

**Time: 10 minutes**



### Instructions for Facilitator

**Establish functional roles of participants** by selecting the following:

- One new participant each day to serve as time keeper
- One new participant to provide a morning review of the previous day's work
- One new participant to lead the wrap-up at the end of each day

**Post** the participant roles on the prepared flip chart. Put this in a prominent place.



## Trainer Notes

Try to **select** a new participant each day for these roles so as to involve all participants in the logistics of the workshop itself. This also will encourage participation among quieter people and provide an example of balanced participation and roles between men and women.

## Confidentiality Overview and Photography Discussion

**Time: 15 minutes**

### Explanation of Interpreters

1. **Explain** that interpreters have signed a *confidentiality agreement* for our training (see **Annex 3**). This means that interpreters will keep all information from the meeting confidential and will not share this information with anyone else. Interpreters are often asked to sign agreements in advance of political meetings, business negotiations, or community meetings where sensitive information is being shared.

### Explanation of Note Takers

1. **Explain** that the note taker will take training notes that will be shared with participants after the meeting to ensure that any promises and plans are documented and followed up when we all go back to our respective homes.
2. **Explain** that the note taker will take notes throughout the training; however, any participant can ask the note taker to *stop taking notes*—for example, because the participant will be providing confidential information. The note taker—as with everyone in the room—will respect rules of confidentiality.

### Confidentiality

1. **Remind participants** that no one's name or picture from the group will be used in the report or any other documents, without expressed, written permission from the participant (introduce the Subject Release Form/Photo Consent Form, **Annex 2**).

### Photographs

1. **Discuss** photo taking and ask how the group feels about it.
2. **Explain** that, if the majority of the group is not comfortable, then photo taking will not be allowed.
3. If the majority is comfortable, then **explore the rules for photos**, how they will be used if they're taken (for example, in a training CD, for internal reporting, for

publications that reach a wider audience, to share via email with participants to remember the workshop), and whether those in the photo will be identified in any way.

4. For those who are comfortable having pictures taken, **ask them to sign** the Subject Release Form/Photo Consent Form.



## SESSION THREE: PARACHUTE FEAR AND JUDGMENT

**Time:** 40 minutes

**Format:** Role play activity

### Objectives:

- To explore fears, beliefs, and internal stigmas.
- To illustrate how attitudes and values affect our behavior.



### Activity: What Color Is Your Parachute?

**Time: 40 Minutes**



### Instructions for Facilitator

1. **Ask** for four volunteers. Take the four volunteers out of listening range of the rest of the group. **Explain** to the volunteers that they are going to pretend to be on airplane, which is about to crash. However, there is only one parachute on board the plane so only one person can use this parachute to get to safety. Explain to the volunteers that they are going to play a role and must convince the rest of the larger group as to why they should get the parachute.
  - **Person 1** should pretend to be an elderly man on his way to visit his family. He is over 72 years old, married with two children and grandchildren.

- **Person 2** should pretend to be a young boy. He has recently lost his mother to illness and his father abandoned the family when he was a small baby. He is on his way to live with his grandmother.
  - **Person 3** should pretend to be a young woman of 28. She is the only person in her family who is earning a living and she supports four siblings and her elderly parents.
  - **Person 4** should pretend to be a middle aged man who is on his way back from a work related trip. He is recently divorced and has no children.
2. After the volunteers are comfortable with their roles, **bring them** in front of the group. **Give each volunteer one minute** to make their case to the larger group that they should be the one to have the only parachute, and then **ask the group** to vote for the person who should get the parachute. **Tally** the votes on the flip chart. **Ask** a few participants to explain their vote.
  3. Now **reveal the following additional information** about each of the four actors:
    - **Person 1:** the old man is in fact Amr Moussa (or another famous, older person; use a woman from the MENA Region or a leader or famous person from your own community);
    - **Person 2:** the boy's mother died from an HIV-related illness and the child may have contracted the virus, although we don't know for sure;
    - **Person 3:** the young woman is in fact a sex worker who feels she supports her family by engaging in sex work;
    - **Person 4:** The man is a policeman and although he is no longer married, he supports his sister and her four children.
  4. **Ask** the group to vote again. **Tally the votes** on a flip chart. **Ask** the participants if they changed their vote, and why. **Ask them** to justify their responses.



### Trainer Notes

Chances are that many participants will change their vote. For example, those who voted for the young woman may be less inclined to vote for her when they know that she supports her family via sex work and is comfortable with this choice.

**Explain** that such changes occur as a result of beliefs, attitudes, and values. What we believe and feel about sex work and what we have been conditioned to think about it influence how we respond to the person. For example, by changing our vote, we are actually stigmatizing and discriminating against the sex worker – we are reacting negatively toward the sex work on the basis of **preexisting beliefs and values** rather than knowing the person herself.



## SESSION FOUR: GENERAL OVERVIEW OF STIGMA AND DISCRIMINATION

**Time:** 1 hour 25 minutes

**Materials:** Stigma example handout or PowerPoint (PPT), note cards (1 per participant), ballot/suggestion box

**Handout:** Four Types of Stigma (**Annex 4**)

**Format:** Guided Discussion

### Objectives:

- To define stigma and discrimination.
- To link the definition of stigma and discrimination to personal experiences.



### Activity: Introduction to Stigma and Discrimination

**Time:** 1 hour



### Instructions for Facilitator

1. **Ask** the following questions:
  - What do we mean by “stigma”?
  - What do we mean by “discrimination”?
  - What is the difference?
2. **Lead a guided discussion** on the following:
  - Types of stigma
  - The stigma process
  - Examples of stigma from the participants’ experiences
  - Examples of discrimination from their experiences
  - Ask participants to differentiate between stigma and discrimination

## Discussion Points

All of the examples below are common for many of us who are living with HIV:

- Deep feeling that makes me feel disrespected or unloved;
- Feeling that work as an AIDS educator is difficult because people tease me about distributing condoms;
- Being blamed as a person living with HIV—blamed for the infection and being told I deserve it;
- People running away from me because of a disease I have;
- Feeling ashamed because I have HIV/AIDS or tuberculosis (TB);
- Fear of disclosing my status to others; and
- Self-stigma—as a person living with HIV or a healthcare provider who works with positive people, I react to and begin to accept negative judgments from society.



### Trainer Notes

**Guide** participants to give examples of stigma and discrimination, such as the ones above. **Provide** other examples to stimulate discussion. **Provide** the handouts (**Annex 4** and **Annex 5**) at the end of the session or adapt information to a PowerPoint or flip chart.



### Activity: Anonymous Questions

**Time: 25 minutes**



### Instructions for Facilitator

**Inform** participants that this activity is called “**Anonymous Questions.**” We will replicate this activity throughout the workshop to generate discussion after key sessions and allow participants to ask any questions they like, even if the questions seem embarrassing.

This is your opportunity to answer participants’ questions about HIV and AIDS.

**Encourage** participants to write their questions anonymously and in private. **Ask** them to put the questions into a suggestion box when they’re finished and **explain** that you will answer the questions for all to hear, share, and discuss further.

**Provide one index card** to each participant.

- **Ask participants** to think about everything they have ever heard or read about HIV and AIDS, not only today but also in previous months and years. **Ask** them to think about any question they have ever wanted to ask on this topic. Again, they can ask a broad question or something specific to the session; it's up to the participant.
- **Ask participants** to write in private in some way (some may want to move to another part of the room for increased privacy) and to write their questions very clearly. **Make sure** participants do NOT put their names on the card.
- **Inform participants** that they have about 7 minutes to think of questions and can ask as many questions as they like within this timeframe. **Bring the suggestion box** around for participants to submit their cards.

Once participants have either put their cards in the suggestion box or have given them directly to you, shake the box or shuffle the cards while turned away from the group. Then, with the cards placed face down, **pick up each card, read the question, and provide an answer**, allowing time for group discussion.

If there are participants who have problems writing out their questions, they can choose to pair up with a participant they trust or with the facilitator to better articulate their questions in writing.



## **Trainer Notes**

**Try to keep answers brief and consider whether some questions will be answered in later sessions of the training.** If so, please tell participants that they can look forward to receiving more information on this topic later. Some questions will be sensitive and will lead to laughter or confused looks, but try to answer each question honestly and carefully. If you don't know an answer, admitting that you do not know but will try to find out the answer later demonstrates your truthfulness. You can also put questions into the 'parking lot.' As mentioned earlier, this is usually done by posting a blank piece of flip chart paper in a designated place in the room. Then, key questions can be written on the paper or posted with sticky notes for later discussion.



## SESSION FIVE: GAPS IN STIGMA, PARTS I AND II

**Time:** 1 hour

**Materials:** Flip chart, tape, markers

**Format Activity One:** Brainstorm activity and guided discussion

**Format Activity Two:** Small group role plays and plenary guided discussion

### Objectives:

- To explore how and why stigma is associated with people living with HIV.
- To examine stigma and discrimination from the perspective of someone who is HIV positive.



### Activity: Brainstorming

**Time:** 30 minutes



### Instructions for Facilitator

1. **Provide an introduction of stigma** from the perspective of someone who is HIV positive. **Ask:** What do we mean by stigma faced by people living with HIV?
2. **Ask** participants to **brainstorm the following questions:**
  - What are some of the concerns that an HIV-positive person in your community might have?
  - What concerns might an HIV-positive person have about coming to a healthcare facility in your community?
3. Take time for participants to share answers and discuss the local-level context of stigma and discrimination.



## Activity: Stigma Case Scenarios

**Time: 30 minutes**



### Instructions for Facilitator

1. **Divide** participants into small groups of four or five people. **Ask each group** to develop a 5-minute skit/role play to demonstrate HIV discrimination in healthcare settings. (Refer to **Annex 7** for basic role play guidelines.)
2. Each group will develop one skit. **Remind participants of the following:** select scenarios that most closely reflect your reality. Create a skit based on your own experiences.
3. Each skit should portray personal scenarios and how the situation could be addressed to reduce stigma and discrimination in the healthcare facility. As many group members as possible should assume a role in the skit (patient, colleague, staff person, or family member). If there are not enough roles for each group member to have a part in the scenario, participants also can choose to be “actors” or “directors.” (Group members who are not acting in the role play can provide suggestions and ideas to those who are.)
4. **Give the groups** 15 minutes to prepare. After that, all the groups will come back together and present the skits.
5. **Ask participants** to observe the skits carefully and answer the following questions:
  - Do you think these are realistic scenarios?
  - What ethical and rights dilemmas did these scenarios explore?
  - What did you observe in the behavior of the healthcare staff that did *not* reflect discrimination against the patient/colleague known or presumed to be infected with HIV?
  - What did you observe in the behavior of the healthcare staff that *reflected discrimination* against the patient/colleague known or presumed to be infected with HIV?
  - What would you do differently to ensure that people living with HIV, or those presumed to be HIV positive, do not face discrimination?



## SESSION SIX: OVERVIEW OF HIV AND STIGMA AND DISCRIMINATION IN THE HEALTHCARE SETTING, WITH CASE DISCUSSIONS

**Time:** 1 hour

**Materials:** Computer, projector, display screen

**Prepared Materials:**

**PPT:** MENA HIV Stigma and Discrimination Workshop

### Part: I

The following pages are an example of a presentation by a medical provider on stigma and discrimination in the healthcare setting, with case study examples and discussions. Keep in mind that the medical provider should present the information without medical jargon so that everyone can understand. Make sure that you allow enough time for questions and comments.

## ACTIVITY: PowerPoint Presentation and Case Discussions



**MENA HIV Stigma & Discrimination Workshop**  
Marrakech, Morocco, 2009

### Goals of this session:

- Examine the role HIV/AIDS related stigma plays in
  - HIV testing and care seeking behavior
  - the disclosure of positive serostatus
  - entry into HIV/AIDS care as well as quality of care.
- Examine the impact HIV/AIDS related stigma has on different population groups.
- Educate providers and communities on strategies to address HIV/AIDS related stigma and to develop plans to effect stigma reduction.

### Starting Exercise – what does Stigma feel like?

- **Part 1: Individual & pairs activity**
- Recall a time when you felt rejected for seeming different from others
- Define for yourself what the key perceived difference was
- Find a partner and share your thoughts
- **Part 2: Individual activity**
- Recall a time when YOU had negative thoughts about another person or a patient because they were different from you
- Keep this for the discussion

### Terminology

BELIEFS	STIGMA
• <b>Stereotype</b> -	Negative feelings, beliefs, and behavior directed toward an individual or group due to a particular label or characteristic.
• <b>Prejudice</b> -	
• <b>FEARs</b>	
• <b>Homophobia</b> -	
• <b>Addictophobia</b> -	
• <b>Xenophobia</b> -	
• <b>ACTIONs</b>	
• <b>Discrimination</b>	
• <b>Sexism</b> -	
• <b>Racism</b> -	

### Stigma & Discrimination in HIV/AIDS

Discrimination, prejudice and negative attitudes towards those with a stigmatizing health condition have been well documented throughout our history (e.g., mental health disorders, STIs, disfiguring conditions, congenital disorders etc).

HIV/AIDS stigma is manifested through **discrimination** and **social ostracism** directed against:

- individuals with HIV/AIDS (*primary stigma*)
- groups of people perceived to be infected
- individuals, groups, and communities with whom these individuals interact (*secondary stigma*)

### Examples of S&D in Healthcare & Work

#### In health care

- Refusing care or providing poor quality of care
  - Not seeking out available options for intervention
- Violating confidentiality
- Using infection-control or different procedures only with PLWH/A

#### At work

- Requiring testing before employment
- Being dismissed because of HIV/AIDS status
- Violating confidentiality

## Impact on testing timing

- Study of 828 gay and bisexual men unaware of their HIV status showed that **66%** of the respondents indicated **HIV/AIDS stigma as the reason for not seeking an HIV test or counseling.**

Study shows link between stigma-driven delayed/refused testing and positive serostatus.

- Individuals who refused an HIV test when one was offered were **5 to 8 times more likely to test positive** than those who agreed to testing.

## Case Study #1

- 28 year old sexually active gay man in Casablanca.
- Has not always been able to use condoms
- Closeted to family
- Has been feeling ill for some months but tells people that he has a prolonged cold
- Feels he should go in for testing but not sure where
- Family doctor not an option since he knows the family
- Not sure how to approach friends for help.

## Case Study #2

- 36 year old married woman in Marrakech.
- Husband has informed her that he may be HIV infected
- Has never had a medical exam outside of pregnancy
- Is 4 months pregnant and having first antenatal visit
- Wants to ask for an HIV test but not sure how
- Overheard clinic staff making negative comments about HIV and people who get it.
- Has no one to ask for advice.

## Many THANKS for Your Attention

Siyabonga Asantesana  
Dziękuję Dakujem dhanya-waad Дзякую  
bedankt ありがとう go raibh maith agat  
tesekkürle Спацеба شكراً Thank you  
谢谢 Merci köszí tack så mycket  
Thank you faleminderit  
Shukriyâ Danke hvala díky kiitos  
takk Obrigada Mulțumesc nandri  
Ευχαριστώ Grazie anugurihiitosumi תודה  
Muchas gracias dhanya-waad tack köszönöm  
너를 감사하십시오 ačiû Terima Kasih  
aitäh dėkuji vam mange tak salamat



## SESSION SEVEN: CLOSING AND EVALUATION

**Time:** 1 hour

**Materials:** Post-its (sticky pads) of various colors, flip chart

### Objective:

- To share feelings and feedback about the day.



### Activity: Process Group Evaluation

**Time:** 30 minutes



### Instructions for Facilitator

1. **Ask** participants to regroup in a circle, seated.
2. **Let them know** that they will participate in a process group and **review** the objective above.
3. The aim of a process group is to express one's personal feelings and **ask for feedback** from the group or to share one's personal perspective—in this case, regarding the first day of the Stigma Reduction workshop.
4. We also learn about ourselves when we receive feedback from other people.

#### **The co-facilitator will explain the following steps in the process group:**

1. Anyone from the group can share his or her feelings and/or thoughts from the day.
2. When someone is speaking, there should be no interruptions, and everyone should focus on good listening skills.

3. To practice, the person can start her sentence by saying, “I feel...” Members are specifically asked to phrase sentences as “I” rather than “you” to ensure that the statement remains centered on that person’s feelings. This should be done by both those requesting and providing feedback.
4. For example, a participant may say, “I feel happy to be among people living with HIV from my region for the first time, along with our physicians, but I am nervous about going back home...”
5. **Ask** that group member if she would like feedback from the group.
6. If she answers yes, **let her know** that feedback can be obtained from anyone in the group.
7. When another group member gives feedback, it should not be advice or solutions unless those are requested.
8. The person receiving feedback should acknowledge the feedback. The receiver can rephrase the feedback to ensure clear communication.
9. As mentioned earlier, there should be no putting down of others’ values.
10. No person’s question or idea is dumb.
11. It is okay to feel embarrassed.
12. No one should ask personal questions.
13. No one needs to justify his/her behavior.
14. Everyone in the circle has the right to participate or pass.
15. Everyone in the group should feel they have an opportunity to speak but are not forced to do so.
16. **Ask** all members to speak from the heart.



### **Trainer Notes**

Process groups often bring out different emotions that can be both intense and difficult to deal with. Be sure to focus this process group on what participants have experienced with this workshop and how they feel about the workshop. It is best to have someone with counseling skills on hand.



## Activity: Closing and Evaluation

**Time: 30 minutes**



### Instructions for Facilitator

1. **Ask** participants to fill out an evaluation for the day (see **Annex 8** and modify). (15 minutes)
2. **Adjourn** and announce any evening events, reminding people what time we will start in the morning. Close with a song, dance, prayer, or another short activity to end the day on a positive note.
3. **Co-facilitators should meet** in the evening to review evaluation forms, discuss the day, and review and prepare for the next day.

## DAY 2: PERSONAL AND PROFESSIONAL PERCEPTIONS OF STIGMA AND DISCRIMINATION

### Schedule

<b>Session 1: Welcome and Review</b>	30 minutes
<b>Session 2: Setting the Stage/Exploring our Thoughts, Beliefs and Attitudes</b>	45 minutes
<b>Session 3: Impact of HIV in Our Personal and Professional Lives, I</b>	1 hour
<b>Session 4: Impact of HIV in Our Personal and Professional Lives, II</b>	1 hour 40 minutes
<b>Session 5: Moving Beyond Us and Them</b>	1 hour 25 minutes
<b>Session 6: Case Studies</b>	1 hour 30 minutes
<b>Session 7: Closing and Evaluation</b>	1 hour

\*Please be sure to factor in time for a coffee/tea break in the morning and afternoon, as well as a lunch break.



## SESSION ONE: WELCOME AND REVIEW

**Time:** 30 minutes

**Materials:** Flip chart, tape, markers, prizes for game

**Prepared Flip Chart:** Day 2 Agenda

### Objectives:

- To provide a time for participants to lead an activity and warm up the group with an upbeat and fun start.
- To review housekeeping issues and the agenda for the day.



## Activity: Welcome and Review of Yesterday

Time: 30 minutes



### Instructions for Facilitator

1. **Select a participant to lead** a warm-up exercise. (15-20 minutes)  
Example Exercise: **Six Degrees of Separation**
2. **Assemble materials:** Prizes (such as candy)
3. **Give the background and the following instructions to participants:** It happens all the time: we meet someone who knows someone we know. It's a small world, that's for sure. The object of this game is to see how small the world really is!
  - First, find a partner. Introduce yourselves and make a list of five to ten things that you have in common with each other—where you went to school, year you were born, number of years with the company, favorite food, favorite sports, etc.
  - Once you have completed your first list, you must find someone else in the room that also has one of those five to ten things in common with you already on your first list. When you have found that person, repeat step one and develop a new list.
  - Repeat step two.
  - Continue until you have met five other people or time is called by the facilitator.
  - A prize will be given to the first person able to complete the game by finding five people and completing five lists. When you are done, let the facilitator know that you have finished.
4. **Set the time**—allow approximately 15–20 minutes for game. Once most people have finished, call time. Ask your winner to reveal his/her chain of separation by introducing those interviewed.
5. **Review** the agenda for the day. **Review** highlights from yesterday. (15 minutes)



## SESSION TWO: SETTING THE STAGE/EXPLORING OUR THOUGHTS, BELIEFS, AND ATTITUDES

**Time:** 45 minutes

**Materials:** Flip chart, tape, markers

**Format:** Values clarification

**Prepared Materials:**

**Handout:** How Do You Feel about HIV and AIDS? (**Annex 5**)

### Objectives:

- To set the tone for participants to explore the impact and attitudes toward people living with or believed to be infected with HIV.
- To analyze why different people are judged differently.
- To open a non-judgmental space for sharing and examining the reasoning behind our feelings.



## Activity: How Do You Feel about HIV?

**Time: 45 minutes**



### Instructions for Facilitator

#### Rapid Survey

1. **Post** three half-size pages of flip chart paper on the wall in consecutive order; these will serve as a continuum. The headings should read:
  - **Strongly Agree**
  - **Strongly Disagree**
  - **Undecided**
2. **Read** a value-based statement (see 'statements' below) and **ask** participants to choose their answer to the statement by getting up and standing under one of the three signs to represent their opinion. (Make enough room between signs so that about 10 participants can stand under each.)
3. Now **ask** a few participants at different points in the continuum to explain their views. Then **provide a quick summary** (or ask a willing participant to do this) and **introduce the next issue** (read the next value-based statement). Don't let this session drag—keep participants moving and thinking!
4. **Tabulate the results** for each question (for example: 15 Agree, 10 Strongly Disagree, 3 Undecided).
5. **Conduct a plenary discussion** by taking one statement at a time. **Ask** one person to read the statement and the tabulated result. Then **ask one person who agrees** to explain why and **one who disagrees** to explain why.
6. **Discuss and then move** to the next statement.

### Statements

- People living with HIV should keep it to themselves and not talk about it.
- A PLHIV should eat and sleep separately from the rest of the family.
- People with HIV deserve it because they have been doing bad things.
- If one partner gets AIDS, the other partner should look after him/her.
- Family members should be told when a member tests positive for HIV.
- Women living with HIV are all promiscuous.
- Antiretrovirals (ARVs) should be freely available to anyone living with HIV.
- Condoms should be available only to married couples.
- I believe there are innocent and guilty victims of HIV/AIDS.
- People living with HIV should not be allowed to have children.



## SESSION THREE: IMPACT OF HIV ON OUR PERSONAL AND PROFESSIONAL LIVES, PART I

**Time:** 1 hour

**Materials:** Flip chart, tape, markers

**Format:** Small group discussions

### Objectives:

- To allow participants an opportunity to explore how HIV has affected them personally and professionally.
- To encourage participants to consider different types of responses to HIV and AIDS within their communities and countries.
- To foster empathy among participants for those living with HIV and AIDS by enabling participants to imagine how they would feel if they were infected.
- To demonstrate how fears and worries about HIV and AIDS can affect quality of care for patients.



## Activity: Group Discussions

**Time: 1 hour**



## Instructions for Facilitator

**Ask** participants to **sit in small groups** of 5 or 6. Groups should be mixed as to country; role (doctors, healthcare staff, and patients); and gender. **Ask each group** to choose a facilitator, recorder, and reporter. **Provide the questions** below to the facilitators. **Request** that each small group discuss the questions for 30 minutes and report key discussion points in a 30-minute plenary.



## Trainer Notes

**Ask** participants to make note of the discussions; this will help them implement the next activity, the reverse doctor-patient role plays.

## Suggested Questions about the Personal and Professional Impacts of HIV and AIDS

### Personal Experiences with HIV and AIDS

- When was the first time you heard about HIV and AIDS? What was your reaction, and how did you feel about it?
- Do you know anyone who is living with HIV? If yes, how did you react to that person when you first found out? Have your reactions or feelings changed over time? If yes, in what way?
- Has your life changed because of HIV? How? If it has not changed, why not?

### What if you were diagnosed HIV positive?

- If you were HIV positive, would you want to know?
- What would motivate you to want to know your HIV status?

- How would you feel if someone conducted an HIV test without your knowledge or permission?
- If you were told you were HIV positive, in what ways would it change your life?
- If you were told you were HIV positive, with whom would you want to share that information? How would you want to share that information with them?
- If you were told that you were HIV positive, from whom would you want to keep that information a secret? Why would you want to keep the information secret from them?
- How would you feel if other people spread the information that you were HIV positive without your knowledge or permission?
- What would happen to your job if your boss or co-workers found out that you were positive?
- If you were living with HIV, how would you want to be treated by others.
- If you were living with HIV, how would you want to be treated at a healthcare facility?

### **Professional Experiences with HIV and AIDS**

- If you work directly with patients or clients, recall the first time you interacted with a patient who you knew was HIV positive. How did you feel providing health services for that person? Did you treat him or her differently than other clients? Why or why not? Thinking back, what things would you do differently now than you did then?
- Do you think HIV-positive patients should be treated differently from patients who are not positive? Why or why not?
- What are your fears or concerns about providing health services for clients who are or might be HIV positive?
- What led you to become an HIV specialist?
- Do you feel stigma from others for being an HIV doctor?
- When was the first time you heard about HIV/AIDS?
- What was your reaction, and how did you feel about it?
- Do you know anyone who has died from AIDS? If you do, how did you react to that person when you first found out they were HIV positive?
- Have your reactions and feelings changed over time? If yes, in what way?
- Has your life changed because of HIV? How? If it has not changed, why not?



## SESSION FOUR: IMPACT OF HIV ON OUR PERSONAL AND PROFESSIONAL LIVES, PART II

**Time:** 1 hour 40 minutes

**Format:** Reverse role plays

### Objective:

- To demonstrate how fears and worries about HIV and AIDS can affect quality of care for patients.
- To look at how we communicate stigma through body language and words. At times, we unconsciously show emotions and feelings about people through our faces, hand movements, or the way we hold our bodies.



### Activity: Reverse Role Plays

**Time:** 1 hour



### Instructions for Facilitator

**Ask** doctors and patients to pair up. **Ask** them to create and practice a skit related to a personal experience with stigma in the healthcare setting. The skit should last no longer than 5 minutes. The doctors should act out the patient roles, and the patients should act out the doctor roles. Give the pairs 10–15 minutes preparation time and have them spend the final 45–50 minutes presenting their skits. You can refer to **Annex 7** for some basic role play instructions.



## Trainer Notes

This activity can be done either with doctors and patients who know each other and are from the same countries or with those who do not know each other and are from different countries. Sometimes it is good to have women and men work together on roles and even exchange gender roles.



## Activity: Body and Word Language Activity

**Time: 40 Minutes**



### Instructions for Facilitator

**Ask** the participants to get into small groups. **Give each group** a stigmatizing word or phrase (for example: drug user, sex worker, sexually transmitted infection, unmarried woman living with HIV). **Ask participants** to act out actions or practices they might see in the healthcare setting that stigmatize or discriminate against HIV-positive patients.



## SESSION FIVE: MOVING BEYOND US AND THEM

**Time:** 1 hour 25 minutes

**Materials:** Flip chart, tape, markers, sheets of paper or large cards (two per participant), pen or pencil for each participant, ballot/suggestion box

**Format:** Case studies cards

**Adapted from:** Engender Health. 2004. *Reducing Stigma and Discrimination Related to HIV and AIDS: Training for Health Care Workers*. New York: Engender Health, pp. 35-36.

### Objectives:

- To better articulate the perspective of people living with HIV and AIDS.
- To describe the impact of healthcare workers' behaviors on HIV-positive patients' health and well-being.



## Activity: Seeing the World with HIV

**Time: 1 hour**



### Instructions for Facilitator

1. **Introduce** the exercise by **reviewing** the session objectives and **explaining** that, in this session, we will be attempting to see the world from the perspective of a person living with HIV.
2. **Distribute** two sheets of paper or cards with the case studies to each participant. **Explain** that they are to write one response on each card and *should not* write their names on the cards. **Instruct** them to write responses to the following (read the questions and post them on the flip chart); and
3. **Briefly describe** a situation you have witnessed or experienced, either at your own healthcare facility or elsewhere, where you or an HIV-positive client was treated poorly because of their HIV status.

### Example Card 1:

A woman came to the hospital in labor. At a certain point in her care, her doctor found out that she was HIV positive and refused to assist the delivery. He didn't say anything to her, he just left the hospital. She was forced to seek care elsewhere.

### Example Card 2:

A man came to the health post because he had a troublesome cough that would not go away. He worried all the way there about telling the nurse that he was HIV positive. He thought they might tell him to go away. In the end he told her, and she praised him for doing so, as it was important for the staff to know this. She treated him just like she would any patient, with dignity and respect, in a caring manner.



### Trainer Notes

**Read** the examples from the cards and **tell** participants that if they have not personally witnessed situations such as these, they can either recount stories they have heard or make them up.



## Activity: Anonymous Questions

**Time: 25 minutes**



## Instructions for Facilitator

**Inform** participants that you will once again facilitate the **Anonymous Questions** activity. As mentioned earlier, we will replicate this activity throughout the workshop to generate discussion after key sessions and allow participants to ask any questions they want, even if the questions seem embarrassing.

**Answer** participants' questions about HIV and AIDS. **Remind** them to write their questions anonymously and in private. **Ask** them to put the questions in the suggestion box when they're finished and **explain** that you will answer the questions for all to hear, share, and discuss further.

\*Please note: See **Day 1, Session 4** for a review of the Facilitator Instructions on this activity.



## Trainer Notes

**Try to keep answers brief and consider whether some questions will be answered in later sessions of the training.** If so, please tell participants that they can look forward to receiving more information on these topics later. Some questions will be sensitive and will lead to laughter and confused looks, but **try to answer** each question honestly and carefully. If you don't know an answer, admitting that you do not know but that you will try to find out the answer later demonstrates your truthfulness. You can also put any questions into the 'parking lot.' Then, key questions can be written on the flip chart paper or posted with sticky notes for later discussion.



## SESSION SIX: CASE STUDIES

**Time:** 1 hour 30 minutes

**Format:** Small mixed group discussions with groups of doctors and patients, men and women, followed by larger group report

### Objectives:

- To show how ethical principles apply to practical problems.



## Activity: Case Studies

**Time: 1 hour 30 minutes**



### Instructions for Facilitator

**Ask** participants to sit in small mixed groups of 5 or 6. Groups should be mixed by region and by roles as doctors and patients. **Ask** each group to choose a facilitator, a recorder, and a reporter. **Give case studies** below to the facilitators ahead of time for this activity. **Ask** each small group to discuss the cases for 30 minutes and report back key discussion points as part of a 30-minute plenary.

#### Case 1:

Hashem has attended the genito-urinary clinic at his local hospital. Hashem is seen by Dr. Sayed, who informs him that he is HIV positive. Dr. Sayed counsels Hashem to contact his sexual partners and inform them of his status. After checking his CD4 count and other blood tests, Dr. Sayed starts Hashem on antiretroviral therapy.

For the last 18 months, Hashem has been in a relationship with Noha. They are expecting a baby in 2 months. Before this relationship, Hashem had a series of sexual partners and unsafe sex.

On a subsequent visit to the clinic, Dr. Sayed realizes that Hashem has not told Noha of his HIV status. Dr. Sayed is aware of the impending arrival of their baby and tells Hashem that steps should be taken to assess whether Noha is HIV positive and whether the baby is at risk so that treatment can be started if necessary.

Hashem adamantly refuses to tell Noha and says that if she is told without his consent, he will stop his course of treatment. What should Dr. Sayed do? Can/should he inform Noha or Hashem's General Practitioner?

#### Case 2:

Fatima was pregnant and found out she was HIV + when she was required to take an HIV test. When she went to the hospital to deliver her baby, she was told she would not receive care unless she signed a document. Fatima did not understand the document but, being desperate for care, signed anyway. The document was a consent form to implement an operation to sterilize Fatima so that she could not get pregnant again.



## Trainer Notes

**Allow** small groups the opportunity to give their own real-life examples instead of the cases provided. **Call on** participants to define ethics and as a group, **come to agreement** on a shared definition of ethics. **Write definitions** on the flip chart. Keep the definitions posted so that you can refer to them during other sessions. **Inform** participants that they will discuss ethics on the morning of Day 5.



## SESSION SEVEN: CLOSING AND EVALUATION

**Time:** 1 hour

**Materials:** Post-its (sticky pads) of various colors, flip chart

### **Objective:**

- To share feelings and feedback about the day.



## Activity: Process Group Evaluation

**Time: 1 hour**



### Instructions for Facilitator

1. **Ask** participants to regroup in a circle, seated.
2. **Let participants know** that they will participate in a process group and **review** the objective above.
3. The aim of a process group is to express one's personal feelings and **ask for feedback** from the group or to share one's personal perspective—in this case, regarding the second day of the Stigma Reduction workshop.
4. We also learn about ourselves when we receive feedback from other people.

\*Please note: Review the steps for running a process group from the **Closing and Evaluation Session on Day 1**.



### Trainer Notes

Process groups often bring out different emotions that can be both intense and difficult to deal with. Be sure to **focus this process group** on what participants have experienced with this workshop and how they feel about it. It is best to have someone on hand with counseling skills.

- **Ask** participants to fill out an evaluation for the day (see **Annex 8** and modify). (15 minutes)
- **Adjourn** and announce any evening events, reminding people what time we will start in the morning. Close with a song, dance, prayer, or another short activity to end the day on a positive note.
- **Co-facilitators should meet** in the evening to review evaluation forms, discuss the day, and review and prepare for the next day.

## DAY 3: THE PATIENT-PHYSICIAN PARTNERSHIP

### Schedule

<b>Session 1: Welcome and Review</b>	30 minutes
<b>Session 2: Resistance and Adherence</b>	2 hours 25 minutes
<b>Session 3: Counseling and Testing, Part I</b>	1 hour 15 minutes
<b>Session 4: Counseling and Testing, Part II</b>	1 hour
<b>Session 5: Closing and Evaluation</b>	1 hour

\*Please be sure to factor in time for a coffee/tea break in the morning and afternoon, as well as a lunch break.



## SESSION ONE: WELCOME AND REVIEW

**Time:** 30 minutes

**Materials:** Flip chart, tape, markers, prizes and recipes for “What’s Cooking?”

**Prepared Flip Chart:** Day 3 Agenda

### Objectives:

- To provide a time for participants to lead an activity and warm up the group with an upbeat and fun start.
- To review housekeeping issues and the agenda for the day.



## Activity: Welcome and Review of Yesterday

**Time: 30 minutes**



### Instructions for Facilitator

1. **Select a participant to lead** a warm-up exercise. (15-20 minutes)  
Example Exercise: **What's Cooking?**
2. **Assemble materials:**
  - Recipes—**cut** the recipes into strips. **Separate** the title, ingredients, instructions, baking times, any notes.
  - Several small **prizes** for the winning team
3. **Arrange groups** the groups ahead of time according to country if it is a regional workshop, or region in a country if it is a local workshop, and **provide a recipe** they should be familiar with.
4. **Give the background:** Your family (group) just inherited a successful restaurant from Chef Amina, a long-lost relative. The only problem: Amina was very disorganized. The only recipes you have found are on torn strips of paper. You have to make sense of it all—and quickly! The restaurant is opening tonight, and you have to have the food ready.
  - Each member of the group will be given part of recipe (an ingredient, instruction, etc.).
  - Your job is to put yourselves in order as quickly as possible. Your recipe must make sense.
  - When your group is done, loudly announce “bon appetite” to signal the end of the game.
5. **Set the time**— allow 10–12 minutes for the game. Once a team calls “bon appetite,” have them introduce themselves and read their recipe in order.
6. **Think of variations:**
  - For an added challenge—**make this game more difficult** by not pre-designating groups before the recipe pieces are distributed. Participants must then not only find the correct order but the correct recipe as well.
  - Just for fun—at the end, **ask** if anyone has a modification to the recipe, since everyone cooks recipes a little differently.
7. **Review** the agenda for the day. **Review** highlights from yesterday. (15 minutes)



## SESSION TWO: RESISTANCE AND ADHERENCE

**Time:** 2 hours 25 minutes

**Format:** Presentation and plenary guided discussion

**Prepared Materials:**

**PPT:** Preparing and Maintaining Our Patients on Their ART Medications:  
“Are” vs. “How Are” You Adherent?

### Objectives:

- To understand the clinical science around ARV drug resistance in HIV-positive patients and the importance of adherence to antiretroviral therapy (ART) regimens.
- To understand the difference between resistance and adherence and their relationship to each other.



## Activity: ARV Adherence PowerPoint Presentation and Discussion

**Time: 2 hours**



### Instructions for Facilitator

This session includes a technical talk by a medical provider on the principles of treatment adherence and HIV. Below is an example of a presentation that could be adapted. Adaptation is key. Not all slides will be appropriate, so **be sure to get a review from a local medical provider** to ensure they are accurate for the local context. There will be different regimens available in different countries and consequently different guidelines to follow. **Give the information** in a way that everyone can understand and use technical terms only when you can explain them clearly. **Make sure** to allow time for questions and comments.



### Trainer Notes

**Start the talk**, using slides to help explain drug resistance and provide an introduction as to why adherence is important. **End** your adherence presentation **on a positive note** to spur discussion on how to overcome the negative aspects of adherence.

At the end of the presentation, **include questions and answers** for PLHIV. **Make sure** you have a medical provider facilitating the session to ensure that PLHIV are included in the discussion. **Consider** doing a role play ahead of time to see what questions PLHIV might ask.

## ACTIVITY: PowerPoint Presentation and Case Discussions



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### Preparing and Maintaining Our Patients on Their ART Medications: “Are” vs. “How” are you adherent?

### We know that:

- No matter how sick (or well), taking drugs daily is tiring.
- Multiple barriers to adherence exist for individuals with HIV/AIDS.
- Improving and maintaining adherence is hard.
- Adherence support can focus on one aspect, or address multiple barriers, in a multi-disciplinary, holistic approach.

### Overview

- What is adherence?
  - Factors affecting adherence
  - Health care providers perceptions of adherence
  - Optimize long-term adherence
- Patient Adherence Confidence Level
  - Counseling + supporting your patient
    1. Treatment Readiness & Preparation
    2. ART Initiation
    3. ART Monitoring & Maintenance

### What is adherence?

When patients take their drugs correctly:

- Right dose
- Right frequency
- Right time
- A behavior that includes:
  - Engagement + participation of patient in their treatment plan
  - Implies understanding, consent, + partnership
  - Adherence to care + adherence to treatment
- Sticking to ART care + treatment = adherence

### Medication Adherence in Chronic Diseases

- Adherence to long-term therapy for chronic diseases - diabetes, hypertension, asthma - averages only 50%
- Consequences of poor adherence
  - Poor health outcomes
  - Increased health care costs
- Solutions
  - Don't blame patient; support them
  - Adherence = dynamic, multi-factorial process
  - Tailor strategy to assist and follow-up patient
  - Team approach best = health care providers, family, friends need adherence training + support
  - Multidisciplinary approach required

WHO 2003; Adh to Long Term Therapy

### Common Adherence Questions

- What is adherence and why is it important?
- What is drug resistance; how does it work?
- What is a treatment plan? How can I make one that works for me as someone living with HIV?
- Can I get a written copy of my treatment plan?
- What about possible side effects, what can I expect and how can I manage problems?
- Can I talk to my doctor about challenges I face regarding adherence?
- **\*Ask people living with HIV what are their challenges and questions related to Adherence?**

## Adherence Objectives

- Develop treatment plan suitable to patient's hospital, clinic, community, + home environment
- Ensure long term success to first-line therapy
  - decreases overall costs + complexities of care
  - guard against transmission of ARV resistance virus in community

## How smart is the HIV virus?

*First: Reproduces quickly, abundantly*

- HIV virus half-life = 30 minutes
  - About 1 – 10 billion viruses created in single day
- Within all this new growth, ~1 mutation per viral copy occurs in one day
  - About 1 - 10 million mutations in a day
- The birth of drug resistance...

## Second: Mutates fast - resistance can develop quickly, depending on the viral load

Viral Load	Days Before Mutation Arises
300,000	0.1
30,000	1
3,000	10
300	100

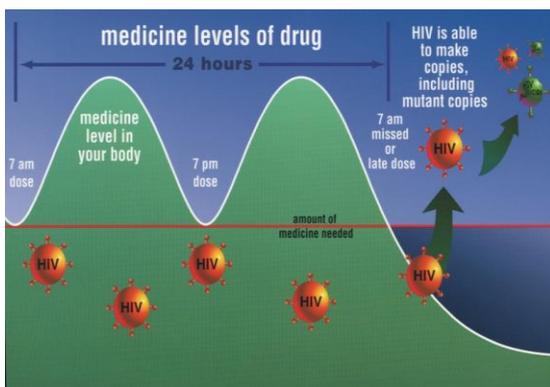
Siliciano, 2002

## Adherence Objectives

- Develop treatment plan suitable to patient's hospital, clinic, community, + home environment
- Ensure long term success to first-line therapy
  - decreases overall costs + complexities of care
  - guard against transmission of ARV resistance virus in community

BODY NEEDS A CERTAIN AMOUNT OF MEDICINE TO SUPPRESS THE VIRUS

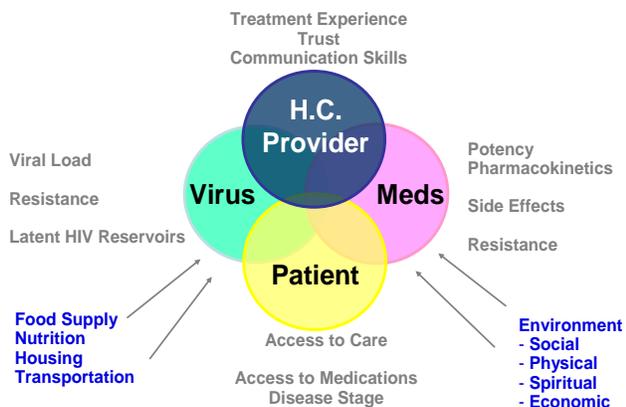
**Non-adherent patient = potential viral load increase and development of ARV resistance**



## What is 95% adherence?

- 95% or greater adherence needed:
  - Obtain ARV effectiveness and durability
  - Maximize viral suppression
  - Prevent emergence of resistance
- For a 12 hourly dosing schedule (2 doses in a day):
  - Non - adherence
    - = miss 3 doses (1.5 days) in 1 month
    - = 2 days in a month
  - NOT much room for error!

## FACTORS AFFECTING ADHERENCE



## Keeping Up with Life...

- Patient's life changes over time
  - Understanding of disease, treatment
  - Stigma, disclosure
  - Behaviors, motivation fluctuates
- Adherence changes over time
  - Identify and mitigate these changes



## Common Barriers to ARV Adherence

- Gendered barriers including ability to travel to health care provider/pharmacy alone or with children; ability to pay for medication; fear of family members finding out HIV status due to finding medication at home and resulting violence or family rejection;
- Not made part of daily routine, forgetfulness
- \*for example: can be distracted by a sick child or relative or by a busy family life;
- \*when going on holiday or away from home we can forget since we are not in our daily routine
- Depressed or overwhelmed; resulting in alcohol and drug abuse which makes adherence even more difficult
- Side effects- real and anticipated
- Literacy issues
- Cultural issues, social myths
- **What else have you faced?**

## As a health care provider, how do you help?

- Ask what are their barriers?
  - "Are" vs. "How"
- Detect perceived emotional, psychological, informational gaps
- Skill in asking + resolving issues
- Non-adherence is complex: you can't do it all!

## Work with a Team = Clinic, Family, Friends

- Adherence changes when patient
  - Symptomatic vs. asymptomatic
  - Encounters stigma or disclosure issues, again
  - Motivation level
- Helping and supporting your patient
  - Time consuming
  - Take effort
  - Requires follow-up
- Discuss, LISTEN, educate...again & again

## Framework for adherence counseling

- State adherence expectations clearly
- Assess resources
- Emphasize benefits + challenges
- Emphasize communication, feedback
- Remove obstacles to adherence
- Provide refresher education



## Education: How to Manage Side Effects

- Discuss
  - Potential side effects + how to manage them
  - Reactions, feelings about adherence during first few days
  - Sometimes all they need is to talk
- Follow-up 1-2 weeks AFTER starting new medications
  - Adherence problems occur during this period
  - Daily calls or visits

## Facilitating Patient Adherence

- Have a discussion; test various counseling techniques
- ASK the right question: “Are” vs. “How” are you taking your ARVs?

### **Multi-dimensional:**

- **Patient:** understand, want it, capable of strict adherence? Accept status? Sense of self-worth.
- **Environment:** anchor to daily activities
- **Socially:** family and friends. Treatment partner or coach
- **Reminders:** Use pill box, alarm, text messaging

## ADHERE!

- **A** nchor to daily activities & use reminder aids
- **D** isclose; seek social support
- **H** ome Treatment Partner
- **E** ducate & listen
- **R** evisit & resolve barriers over time
- **E** nable & adjust

Thank You!



## Activity: Anonymous Questions

**Time: 25 minutes**



### Instructions for Facilitator

**Inform** participants that you will once again facilitate the **Anonymous Questions** activity. As mentioned earlier, we will replicate this activity throughout the workshop to generate discussion after key sessions and allow participants to ask any questions they want, even if the questions seem embarrassing.

**Answer** participants' questions about HIV and AIDS. **Remind** participants to write their questions anonymously and in private. **Ask** them to put the questions in the suggestion box when they're finished and **explain** that you will answer the questions for all to hear, share, and discuss further.

See **Day 1, Session 4** for a review of the Facilitator Instructions on this activity.



### Trainer Notes

**Try to keep answers brief and consider whether some questions will be answered in later sessions of the training.** If so, tell participants so that they can look forward to receiving more information later. Some questions will be sensitive and will lead to laughter or confused looks, but **try to answer** each question honestly and carefully. If you don't know an answer, admitting that you do not know but that you will try to find out the answer later demonstrates your truthfulness. You can also put any questions into the 'parking lot.'



## SESSION THREE: COUNSELING AND TESTING, PART I

**Time:** 1 hour 15 minutes

**Materials:** PPT

**Format:** Presentation and guided discussion

**Prepared Materials:**

**PPT:** Counseling and Testing

### Objectives:

- Review the basic elements of voluntary counseling and testing (VCT) and the meaning of test results.
- Understand the difference between routine, coerced, and mandatory testing.
- Explore the challenges of scaling up testing.
- Explain the impact of stigma on testing.
- Explore practical and ethical issues related to testing that may arise in the healthcare setting.
- Share patients' and healthcare providers' experiences of getting or administering an HIV test.
- Explore ways in which fears of stigma could be tackled at an early stage.



### Activity: Counseling and Testing PPT

**Time:** 1 hour 15 minutes



### Instructions for Facilitator

1. **Use** the prepared PowerPoint **Counseling and Testing**

Introduction to Counseling and Testing—**Ask:** What do we mean by “voluntary, coerced, and mandatory testing”?

- Voluntary Counseling and Testing is the predominant model for testing in the MENA Region.
- Other methods of testing include home-based testing; workplace confidential testing; mandatory testing for jobs (e.g., for the military); mobile testing centers; and testing at specific places, such as young adult recreation centers or during special events.

**2. After you present the slides, lead a discussion** on stigma and counseling and testing.

- **Explain** VCT basics by reviewing the elements of VCT and the meaning of test results. **Describe** the differences between routine, coerced, and mandatory testing. **Explore** the meaning of the ‘window’ period and explaining the 3 Cs of testing (see PowerPoint).



### Trainer Notes

**Ask** the group: “How does POWER affect the way in which people are stigmatized?” **Explain** that the dominant or privileged group(s) has/have the power to:

- Institutionalize and systematize stigma and discrimination, and that the person/group lacking power—such as people living with HIV or women—must accept condemnation and labeling by the dominant group. What effect could this have on testing or on the doctor-patient relationship?

This session is divided into two parts:

- The first part is a technical talk by a medical provider on the principles of HIV-related counseling and testing (using the PowerPoint presentation). **Provide** information so that everyone can understand and use technical terms only when they can be explained clearly. **Make sure** you leave time for questions and comments.
- The second part of the session should be given by a person living with HIV, ideally someone with health education experience. This part of the session should include a reverse role play during which doctors and patients divide into mixed pairs; they will create a role play where a person is being tested and receives a positive outcome. Use **Annex 7** for basic role play instructions.

## ACTIVITY: PowerPoint Presentation: Counseling and Testing



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### HIV Counseling and Testing

### HIV Test for Antibodies

- Elisa
- **Western Blot (WB) assay** a *confirmatory* test: it is only performed if ELISA or rapid test is positive.
- Indirect immuno fluorescence assay (IFA)
- **Rapid Tests for HIV**
- Rapid testing results in as little as 20 minutes

### Window Period

- The "window period" is the time it takes for a person who has been infected with HIV to react to the virus by creating HIV antibodies. This is called seroconversion.
- During the window period, people infected with HIV have no antibodies in their blood that can be detected by an HIV test, even though the person may already have high levels of HIV in their blood, sexual fluids, or breast milk.
- "Antibodies generally appear within 3-6 months after infection with HIV, but may take up to six months in some persons."
- individuals are often most infectious during this time (shortly after they have been exposed to HIV).

### Testing 101

- What kind of test
  - Blood test
  - Oraure saliva swab
  - Oraquick finger prick
- What does the test measure
- What is the window period

### Testing Rights

- What are the 3 C's
  - Confidentiality
  - Consent
  - Counseling

### Testing Policy

**Explain the difference between:**

- VCT
- Routine testing
- coerced testing
- mandatory testing
- opt vs. opt out
- provider initiated vs. patient initiated

## Testing and Stigma

- Testing as self disclosure
- Confronting the truth
- Links to Treatment Care and Support
- Challenges to sexual and reproductive Rights
- Denial or acceptance
- The Status quo or change



## SESSION FOUR: COUNSELING AND TESTING, PART II

**Time:** 1 hour

**Format:** Role play

### Objectives:

- Review the basic elements of voluntary counseling and testing (VCT) and the meaning of test results.
- Understand the difference between routine, coerced, and mandatory testing.
- Explore the challenges of scaling up testing.
- Explain the impact of stigma on testing.
- Explore practical and ethical issues related to testing that may arise in the healthcare setting.
- Share patients' and healthcare providers' experiences of getting or administering an HIV test.
- Explore ways in which fears of stigma could be tackled at an early stage.



## Activity: Reverse Role Plays

**Time:** 1 hour



### Instructions for Facilitator

1. **Ask** doctors and patients to divide into mixed pairs. **Ask** the pairs to create role plays in which one person being tested is receiving a positive diagnosis. (For basic role play directions, see **Annex 7**.)
2. **Explain:** Participants can share testing experiences or stories to fuel the creative process.
3. **Ask:**
  - What does the person who has not been tested or who has tested negative believe receiving a positive diagnosis will be like?
  - What was it like for the person who tested positive to give a positive test result to someone else?
  - Role play how you would like the diagnosis delivered and how you would *not* like it delivered.



### Trainer Notes

**Guide** participants so that they share counseling and testing norms related to issues of stigma from countries in the region.



## SESSION FIVE: CLOSING AND EVALUATION

**Time:** 1 hour

**Materials:** Post-its (sticky pads) of various colors, flip chart

### **Objective:**

- To share feelings and feedback about the day.



## Activity: Process Group Evaluation

**Time: 1 hour**



### Instructions for Facilitator

1. **Ask** participants to regroup in a circle, seated.
2. **Let participants know** that they will participate in a process group and **review** the objective above.
3. The aim of a process group is to express one's personal feelings and **ask for feedback** from the group or to share one's personal perspective—in this case, regarding the second day of the Stigma Reduction workshop.
4. We also learn about ourselves when we receive feedback from other people.

\*Please note: Review the steps for running a process group from the **Closing and Evaluation Session on Day 1**.



### Trainer Notes

Process groups can bring out different emotions that can be both intense and difficult to deal with. Be sure to **focus this process group** on what participants have experienced with this workshop and how they feel about the workshop. It is best to have someone with counseling skills on hand.

- **Ask** participants to fill out an evaluation for the day (see **Annex 8** and modify). (**15 minutes**)
- **Adjourn** and announce any evening events, reminding people what time we will start in the morning. Close with a song, dance, prayer, or another short activity to end the day on a positive note.
- **Co-facilitators should meet** in the evening to review evaluation forms, discuss the day, and review and prepare for the next day.

## DAY 4: TECHNICAL UPDATES ON KEY HIV AND STIGMA-RELATED ISSUES

### Schedule

<b>Session 1: Welcome and Review</b>	30 minutes
<b>Session 2: Prevention of Parent-to-Child Transmission</b>	2 hours
<b>Session 3: Hepatitis C and TB Co-infection</b>	1 hour 40 minutes
<b>Session 4: Treatment, Care, Support, and Stigma Mapping</b>	1 hour 30 minutes
<b>Session 5: Closing and Evaluation</b>	1 hour

\*Please be sure to factor in time for a coffee/tea break in the morning and afternoon, as well as a lunch break.



## SESSION ONE: WELCOME AND REVIEW

**Time:** 30 minutes

**Materials:** Flip chart, tape, markers

**Prepared Flip Chart:** Day 4 Agenda

### Objectives:

- To provide time for participants to lead an activity and warm up the group with an upbeat and fun start.
- To review housekeeping issues and the agenda for the day.



## Activity: Welcome and Review of Yesterday

**Time: 30 minutes**



### Instructions for Facilitator

1. **Select a participant to lead** warm-up exercise. (10 minutes)  
Example Exercise: **Race for the Truth**
2. **Assemble the materials**
  - 2 long pieces of string for the start and finish lines
  - List of statements related to the group
3. **Give the background:** You and the other “runners” in the room are about to embark on a race for the truth. Your goal is to cross the finish line as quickly as possible by truthfully answering questions about yourself as you follow the facilitator’s directions.
  - Line up on the starting line, as directed by the facilitator.
  - In a moment you will hear a statement. If it is true about you, move forward one step. If it is false, remain at the starting line. (Facilitator: **Keep** the statements light and interesting.)
  - Once all first moves have been made, the facilitator will make another statement. Again, if it is true, move forward one step. If it is false, remain on the starting line if you have not yet advanced. If you have advanced past the starting line, take one step back.
  - Repeat step three until the first “runner” completes the race.
4. **Set the time**—allow 5–10 minutes for this activity.
5. **Think of variations**—narrow the scope of the statements to relate to issues at work or to the materials being covered.

**Review** the agenda for the day. **Review** highlights from yesterday. (15 minutes)



## SESSION TWO: PREVENTION OF PARENT-TO-CHILD TRANSMISSION

**Time:** 2 hours

**Format:** Presentation and guided discussion

**Prepared Materials:**

**PPT:** Overview of HIV Prevention in Mothers, Infants, and Young Children

### Objectives:

- To describe the comprehensive approach to prevention of HIV infection in infants and young children.
- To discuss mother-to-child transmission (MTCT) of HIV infection.
- To describe the four elements of a comprehensive approach to the prevention of HIV infants and young children.
- To describe the role of maternal and child health (MCH) services in the prevention of HIV in infants and young children.



### Activity: PPTs on Prevention of MTCT

**Time:** 2 hours



### Instructions for the Facilitator

**Present** the prepared PowerPoints **Prevention of Mother-to-Child Transmission**

This session is a technical talk by a medical provider on prevention of mother-to-child transmission (PMTCT). See the generic PowerPoint presentation below; this must be adapted by a professional to fit the local context in which it will be presented. The speaker should engage with the audience—both providers and people living with HIV—by asking questions around key technical terms, allowing time for questions and comments.

**Source:** The PPT on PMTCT is adapted from *Women, Children and HIV*. Available at: [www.womenchildrenhiv.org/wchiv?page=pi-60-00](http://www.womenchildrenhiv.org/wchiv?page=pi-60-00)

# Prevention of Mother-to-Child Transmission PPT



## DAY 4 SESSION 2

### Overview of HIV Prevention in Mothers, Infants and Young Children

PMTCT Generic Training Package

Module 2

Slide 1



## Session 2: Objectives

- Describe the comprehensive approach to prevention of HIV infection in infants and young children.
- Discuss mother-to-child transmission (MTCT) of HIV infection.
- Describe the four elements of a comprehensive approach to the prevention of HIV in infants and young children.
- Describe the role of maternal and child health (MCH) services in the prevention of HIV in infants and young children.

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Module 2

Slide 2



## Overview of HIV Prevention in Mothers, Infants and Young Children

### Part 1

### Comprehensive Approach to Reducing HIV Infection in Infants and Young Children

PMTCT Generic Training Package

Module 2

Slide 3



## Scope of HIV

*Insert current regional, country or local data on HIV here. If you need help getting current information, go to your local NAP office or UNAIDS office.*

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Module 2

Slide 4



## Scope of HIV

*Insert country or local data on MTCT. If you need help getting current information, go to your local NAP office or UNAIDS office.*

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Slide 5



## Comprehensive Approach to Reducing HIV Infection in Mothers, Infants and Young Children

- **Element 1** Primary prevention of HIV infection
- **Element 2** Prevention of unintended pregnancies among women infected with HIV
- **Element 3** Prevention of HIV transmission from women infected with HIV to their infants
- **Element 4** Provision of treatment, care and support to women infected with HIV, their infants and their families

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Module 2

Slide 6



## Language of HIV/AIDS

- MTCT – mother-to-child transmission of HIV infection
- PMTCT – prevention of MTCT
- PLWH – people living with HIV
- Local slang for HIV infection. Is any of this stigmatizing? Have you ever heard it mentioned in a health care setting?

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Module 2

Slide 8



## Overview of HIV Prevention in Mothers, Infants, and Young Children

### Part 2

## Mother-to-Child Transmission (MTCT) of HIV Infection

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Slide 7



## Estimated MTCT Rates

### Without intervention

During pregnancy	5–10%
During labour and delivery	About 15%
During breastfeeding	5–15%

**MTCT infection rates = up to 40%**

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Slide 9



## PMTCT Interventions to Decrease Risk of HIV Transmission to Infant

### During pregnancy

- Decrease viral load by using ARV prophylaxis and treatment
- Monitor and treat infections
- Support optimal nutrition



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Module 2

Slide 10



## PMTCT Interventions to Decrease Risk of HIV Transmission to Infant

### Safer delivery practices

#### Avoid

- Routine rupture of membranes
- Invasive delivery techniques
- Unresolved infections such as STIs

#### Provide

- Elective caesarean section when safe and feasible

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Module 2

Slide 11



## PMTCT Interventions to Decrease Risk of HIV Transmission to Infant

### Promote safer infant feeding

- Replacement feeding
- Exclusive breastfeeding for limited time
- Avoidance of mixed feeding

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Module 2

Slide 12



## Overview of HIV Prevention in Mothers, Infants, and Young Children

### Part 3

#### Four Elements of a Comprehensive Approach to Prevention of HIV Infection in Infants and Young Children

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Module 2

Slide 13



## A Framework for a Comprehensive Approach to PMTCT

Prevention of Primary HIV Infection

Prevention of Unintended Pregnancies among Women Infected with HIV

Prevention of HIV Transmission from Women Infected with HIV to their Infants

Provision of Treatment, Care, and Support to Women Infected with HIV and Families

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## Element 1: Prevention of Primary HIV Infection

ABCs of primary HIV prevention for parents-to-be:

A = Abstain

B = Be faithful to one HIV-uninfected partner

C = Condom use – use condoms consistently and correctly

Adapt approach to local culture and target groups at risk; explain why HIV+ couples should also use condoms.

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Module 2

Slide 15



## Element 2: Prevention of Unintended Pregnancies Among Women Infected with HIV

- Access to counselling and referral for family planning
- Safe, consistent, effective contraception

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Module 2

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## Element 3: Prevention of HIV Transmission from Women Infected with HIV to Their Infants

### Core Interventions

- HIV testing and counselling
- Antiretrovirals
- Safer delivery practices
- Safer infant-feeding practices

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## Element 4: Provision of Treatment, Care and Support to Women Infected with HIV and their Families

- Prevention and treatment of opportunistic infections
- ARV treatment
- Palliative and non-ARV care
- Nutritional support
- Reproductive healthcare
- Psychosocial and community support

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## Overview of HIV Prevention in Mothers, Infants, and Young Children

### Part 4

#### Role of Maternal and Child Health Services in the Prevention of HIV Infection in Infants and Young Children

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## MCH Programmes Offer Services that Facilitate PMTCT

- Antenatal care
- Family planning services
- ARV prophylaxis and treatment
- Family planning
- Safer delivery practices

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Module 2

Slide 20



## Session 2: Key Points

- A comprehensive approach is needed to prevent HIV infection in infants and young children.
- The four elements of the comprehensive approach to PMTCT are:
  - Primary prevention of HIV infection
  - Prevention of unintended pregnancies among women infected with HIV
  - Prevention of HIV transmission from women infected with HIV to their infants
  - Provision of treatment, care and support to women infected with HIV, their infants and their families

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## Session 2: Key Points

- Without intervention the risk of MTCT is 25–40%.
- Combination interventions can reduce the MTCT rate by up to 40% in breastfeeding populations.
- Because ARV prophylaxis alone does not treat the mother's infection, ongoing treatment, care, and support are needed.

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## Session 2: Key Points

- MCH services can act as an entry point to the range of services that can provide care and support to the woman who is HIV-positive and affected family members.
- Linkages to community services can provide enhanced treatment, care, and support.

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## Trainers Notes on Pregnancy and Babies: Mother-to-Child Transmission

### Prevention of MTCT involves the following:

- 1. Prevention of primary HIV infection**—Decreasing the number of mothers who are HIV positive is the most effective means for reducing MTCT. HIV infection will not be passed on to children if parents are not positive.
- 2. Prevention of unintended pregnancies among HIV-positive women**—In the MENA Region, the risk of MTCT is exacerbated by unintended pregnancies. A major cause of unintended pregnancy is the limited access to family planning services. Stockouts of contraceptive supplies also present a problem—this includes condoms, which also help prevent HIV. In addition, HIV-positive women on highly active antiretroviral treatment (HAART) may be more vulnerable to unintended pregnancy because, while HIV might suppress fertility, HAART reduces viral loads and is likely to increase fertility.<sup>4</sup> In developing countries, maternal mortality is nearly double in HIV-positive women compared to those who are not positive.
- 3. Prevention of HIV transmission from HIV-positive women to their infants**—Specific interventions to reduce HIV transmission from an HIV-positive woman to her child include VCT, antiretroviral prophylaxis and treatment, safer delivery practices, and safer infant-feeding practices.
- 4. Provision of treatment, care, and support to women living with HIV and their infants and families**—If a woman is assured that she will receive adequate treatment and care for herself, her children, and her partner/husband, she is more likely to accept VCT and, if HIV positive, interventions to reduce MTCT. Other services also may be needed, such as palliative care, nutritional support, and reproductive health—which, importantly, includes family planning and counseling—as well as psychosocial support. Further, children whose mothers are HIV positive are at higher risk than other children for illness and malnutrition and so should be included in comprehensive care.
- 5. Promotion of safe breastfeeding practices**—In resource-constrained settings, some healthcare providers suggest exclusive breastfeeding.<sup>5</sup> Exclusive breastfeeding may provide benefit by protecting the infant's intestinal mucosa, thus allowing for a better barrier against HIV, and by diminishing the mother's risk for breast-health problems, which are associated with increased breast milk viral load. However, it is important for the mother to check with her healthcare provider regarding the kind of breastfeeding practice that is best for her circumstance, including formula-based options that could mitigate HIV transmission.

**7. Risk reduction during pregnancy and delivery**—Many MENA women can plan delivery to take place in an antenatal care (ANC) setting, supported by healthcare staff. ANC improves the general health and well-being of mothers and their families. By integrating PMTCT services into essential ANC services, healthcare programs can improve care and pregnancy outcomes. This can ensure that both delivery and treatment are provided to limit HIV transmission. For example, interventions in Somalia are being supported to incorporate midwives into safer delivery practices for mothers who are HIV positive.

**8. Antenatal care** improves the general health and well-being of mothers and their families and is a main source of healthcare for women of childbearing age. By integrating PMTCT services into essential ANC services, healthcare programs can improve care and pregnancy outcomes for clients. Antenatal interventions can reduce the risk of MTCT and can support women living with HIV to have healthy, longer lives and care for their children to adulthood. When mothers die prematurely, children face much higher rates of vulnerability themselves, including illness and death. ANC should include the following in PMTCT programs:

- Health information and education
- Education about safe sex and HIV
- Confidential VCT for HIV Partner HIV testing and counseling
- Interventions to reduce the risk of MTCT
- Infant-feeding counseling and support
- Support for safe motherhood, including malaria and TB treatment
- Diagnosis and treatment of sexually transmitted infections (STIs)

<sup>2</sup> Population Action International. 2007. *Family Planning—A Crucial Intervention for HIV-positive Women*. Available at [www.populationaction.org/Publications/Fact\_Sheets/FS35/Summary.shtml#notes].

<sup>3</sup> In South Africa, a 2007 study was conducted in which pregnant women were enrolled in a nonrandomized cohort study to assess HIV transmission and infant survival by type of infant feeding. They received single-dose nevirapine, counseling about feeding options, and postnatal home visits by counselors. The feeding options were exclusive breastfeeding, starting from birth; replacement feeding (nonhuman milk, with or without solids); and mixed breastfeeding (breast milk plus nonhuman milk, other liquids, or solids). For more information, see full article: Coovadia, H., et al. 2008. “Mother-to-Child Transmission of HIV-1 Infection during Exclusive Breastfeeding in the First 6 Months of Life: An Intervention Cohort Study.” *The Lancet* 369(9567): 1107–1116.



## SESSION THREE: HEPATITIS C AND TB CO-INFECTION

**Time:** 1 hour 40 minutes

**Materials:** Flip chart, tape, markers

**Format:** PowerPoint presentation, followed by guided discussion

**Prepared Materials:**

**PPT:** Hepatitis C (HCV)

**PPT:** Tuberculosis (TB)

### Objective:

- To gain better understanding of clinical and experiential information about HIV co-infections with HCV and TB.



## Activity: PPTs on Co-infection

**Time: 1 hour 15 minutes**



## Instructions for the Facilitator

**Present** the prepared PowerPoints **HCV and HIV Co-infection; TB and HIV Co-infection**

This session includes a technical talk by a medical provider on the principles of HCV and HIV co-infection and TB and HIV co-infection. See the generic PowerPoint presentations below; these should be adapted by a professional to fit the local context. The speaker should provide information that everyone can understand and use technical terms only when they can be explained clearly, allowing time for questions and comments.

### **Directions for HCV/HIV Presentation**

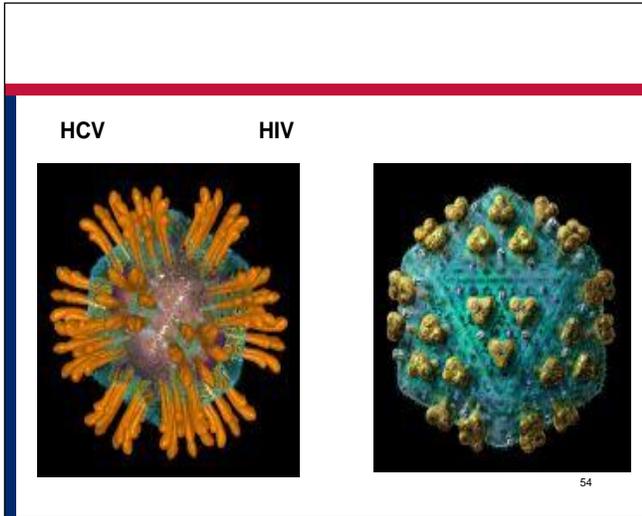
**Present** slides and **lead a guided discussion** that encompasses the life experience of living with HCV/HIV co-infection. **Allow time** for questions and answers. The facilitator should be someone who has been treated for HCV themselves, is a healthcare provider, or should have access to experienced participants to call on to help facilitate an informed discussion.

### **Directions for TB/HIV Presentation**

**Present** slides and **lead a guided discussion** that encompasses the life experience of living with HCV/HIV co-infection. **Allow time** for questions and answers. The facilitator should be someone who has been treated for HCV themselves, is a healthcare provider, or have access to experienced participants to call on to help facilitate an informed discussion.

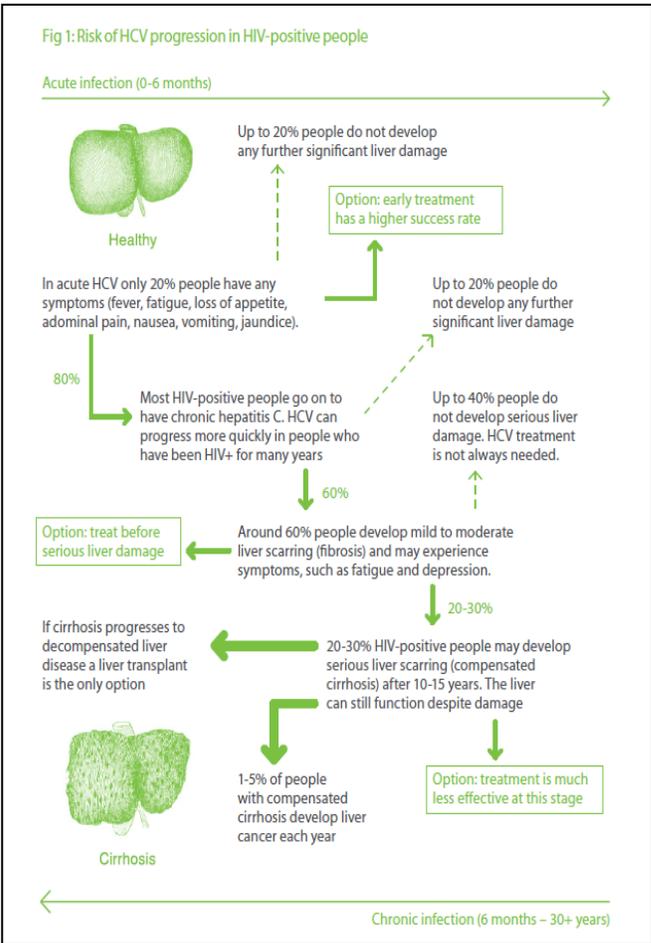
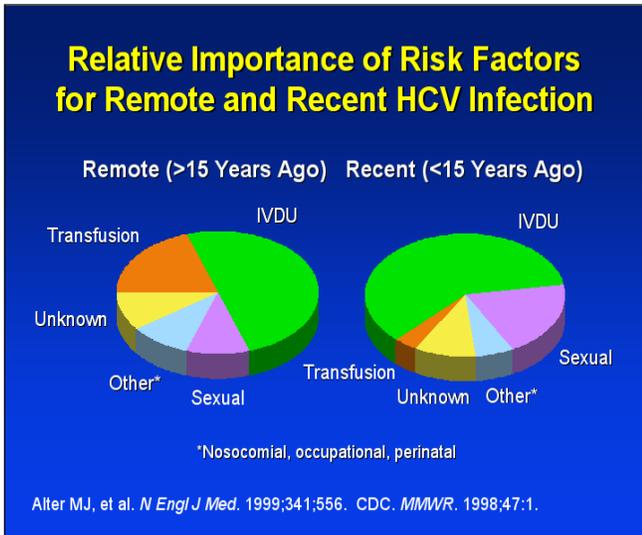
\*Please Note: The TB/HIV PPT was adapted from the presentation *Action AIDS Care and Treatment in Nigeria*.

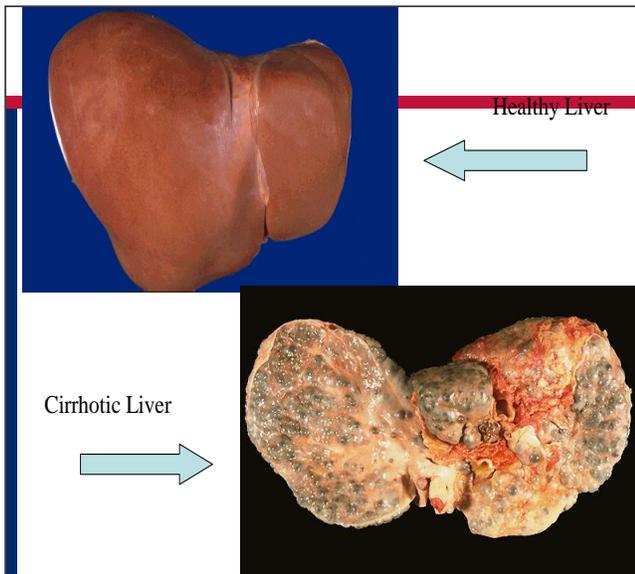
# PowerPoint: HCV HIV Co-Infection



## What is Hepatitis C?

- Hepatitis C is liver disease caused by the hepatitis C virus (HCV).
- The virus mainly lives in the blood, and in liver cells where it can cause damage.
- HCV can cause liver inflammation, and scarring (known as fibrosis, or when more serious, cirrhosis).
- This can reduce the liver's ability to perform essential functions. Liver damage from HCV usually takes many years.





## How Can You Protect Your Liver?

1. Getting hepatitis A and hepatitis B vaccines. Having another viral infection in your liver can worsen hepatitis C.
2. Drinking less, or stop drinking alcohol—the less you drink, the better for your liver. Sometimes drinking less, or not at all, is more important than treating HCV.
3. Maintaining normal weight; being overweight increases your risk for fatty liver.
4. Drinking plenty of water, to help your liver filter out waste and toxins.
5. Eating fewer fatty, salty and high sugar foods.
6. Trying to eat more fresh fruit and vegetables, complex carbohydrates (whole grains, breads, rice, pasta, cereals, vegetables, fruits, beans, nuts and seeds), low-fat foods, high-fibre foods and an adequate amount of protein.
7. Using HCV treatment to reduce liver damage.
8. Asking questions & getting support
9. Talking with other people who are living with hepatitis C or HIV and HCV.



## Trainers Notes on HCV and HIV Co-infection

**HCV Overview** – Explain the following:

- Persons with HIV, especially injection drug users (IDU), may also be infected with HCV.
- HCV infection is more serious for people living with HIV.
- Many persons with HCV don't have any symptoms.
- HCV infection can be treated.

Injecting drugs is one of the main ways people become infected with HIV, even in the Middle East and North Africa. The majority of injection drug users (IDU) who are HIV positive are men but there also are female IDU who are HIV positive.

HCV infection is more serious in HIV-positive persons. (It is not known yet whether co-infection with HCV makes HIV disease progress faster.) It leads to liver damage more quickly. Co-infection with HCV may also affect HIV treatment. It is important for HIV-positive people to know whether they also are infected with HCV and if they are not, to take steps to prevent infection.

Many people with hepatitis C do not have any symptoms of the disease. So your doctor or other healthcare provider will need to test your blood to check for the virus. If you test positive, he or she may also conduct a liver biopsy to determine the amount of damage to your liver.

Chronic hepatitis C can be treated successfully, even in HIV-positive persons. ("Chronic" means having the disease for a long time.) Treatment for chronic hepatitis C usually is done with a single drug or combination of two drugs. Treatment usually takes 6–12 months. You should drink little or no alcohol during treatment and may be advised not to have alcohol again. Vaccination against hepatitis A and hepatitis B is also recommended. Hepatitis E is common in MENA and should be discussed with your doctor.

### **Other Ways of Becoming Infected with HCV**

There are other ways of becoming infected with HCV. Persons with hemophilia who received clotting factor concentrates before 1987 often have HCV infection. Becoming infected through sexual contact is possible, but the risk is much lower than the risk for HIV. Mothers can pass the infection to their newborn babies, but here too, the risk is less than that for HIV.

### **How to Prevent HCV Infection**

The best way to prevent infection with HCV is to stop injecting drugs or never start. Substance abuse programs may help. If you continue to inject drugs, always use new, sterile syringes and never reuse or share syringes, needles, water, or drug

preparation equipment. Do not share toothbrushes, razors, and other items that might be contaminated with blood. Tattooing or body piercing may also increase risk for infection with any blood-borne pathogen if dirty needles or other instruments are used. Practice safer sex.

Female Genital Cutting/Mutilation (FGC/M) is very common in some countries in the MENA Region. This is a very dangerous and damaging practice in any setting; it can have many life-long effects, including contraction of HCV, chronic pain, infection, difficulties during sexual intercourse, and complications during childbirth.

**Please pause and ask** if people have any questions related to this subject. **Explain** that, even in the healthcare setting, the act of FGC is dangerous and damaging. It is also prohibited by law in most countries because it is considered a human rights issue but traditional practices regarding FGC/M continue. Mothers, even if they have experienced the practice themselves, must protect their daughters from this practice, as should responsible fathers who care about their daughter's emotional and physical well-being.

### **Liver Biopsy**

During a liver biopsy, a tiny piece of your liver is removed through a needle. The tiny piece (or specimen) is then checked for liver damage.

### **Treating HCV Infection**

Alpha interferon or pegylated interferon alone, or one of these in combination with ribavirin are some common drug regimens given to patients with chronic hepatitis C who are at greatest risk for progression to serious disease. Treatment is not always successful, but even HIV-positive patients may benefit from treatment. Your doctor or other healthcare provider will need to make the final decision about if and when you should receive treatment.<sup>6</sup>

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<sup>4</sup> Sources: <http://www.cdc.gov/hiv/resources/factsheets/coinfection.htm>;  
<http://www.cdc.gov/tb/topic/tbhivcoinfection/default.htm>

## PowerPoint: TB HIV Co-Infection

### HIV and TB Co-infection Overview

- Among HIV-infected individuals, lifetime risk of developing active TB is 50%, compared to 5-10% in persons who are not HIV-infected
- In a person infected with HIV, the presence of other infections, including TB, allows HIV to multiply more quickly. This may result in more rapid progression of HIV infection
- HIV-related TB can present typical or atypical clinical and/or radiological features. Atypical features are usually found in HIV-infected individuals with severe immunosuppression

### Overview, Continued

- Initial signs of TB disease may become apparent at any time during the evolution of HIV-infection
- Can come well before other manifestations of HIV infection or after patient has become symptomatic
- May be pulmonary or extra-pulmonary

Pulmonary TB is most common form—presentation depends on degree of immunosuppression

### Signs and Symptoms

#### Most important symptoms

- Cough lasting more than 3 weeks and not responding to usual antibiotic treatment
- Production of purulent, sometimes blood-stained sputum
- Evening fevers
- Night sweats
- Weight loss

### Treatment

HIV infected patients should be treated according to national guidelines and in cooperation with local authorities such as the district medical officer (DMO) and the district TB supervisor.

#### Aims of treatment

- To cure the patient of TB
- To prevent death from active TB or its late effects
- To prevent TB relapse
- To decrease TB transmission to others

### Treatment, Continued

#### Drug regimens

- Initial phase—first 2-3 months
  - During the initial phase, there is rapid killing of TB bacilli
  - Three or more drugs are used in combination
  - Infectious patients become non-infectious within about 2 weeks and symptoms usually improve

### Treatment, Continued

- Continuation phase—additional 4-6 months
  - Fewer drugs are necessary (usually 2), but longer time
  - These drugs eliminate the remaining bacilli

## DOTS

- **Directly Observed Treatment Strategy (DOTS)**  
DOTS is a strategy for TB control which aims to detect 70 percent of active TB cases and to successfully treat 85 percent of them. The essential features of DOTS include:
  - Government commitment to sustained TB control activities
  - Case detection by sputum smear microscopy among symptomatic patients self-reporting to health services
  - Directly observed, standardized treatment regimen of six to eight months

## DOTS, continued

- Efficient information systems for monitoring and reporting treatment outcomes
- A regular, uninterrupted supply of all essential anti-TB drugs

## WHO Recommended TB Treatment Regimen for each Treatment Category

Treatment Category	Patients	Alternative TB Treatment Regimens	
		Initial Phase (Daily or 3 x/Wk)	Continuation Phase
I	New smear-positive PTB; new smear-negative PTB with extensive parenchymal involvement; new cases of severe forms of extra-pulmonary TB	2 EHRZ (SHRZ) 2 EHRZ (SHRZ) 2 EHRZ (SHRZ)	6 HE 4 HR 4 H <sub>3</sub> R <sub>3</sub> <sup>b</sup>
II	Previously treated smear-positive PTB; relapse; treatment failure; treatment after interruption	2 SHRZE/1 HRZE 2 SHRZE/1 HRZE	5 H <sub>3</sub> R <sub>3</sub> E <sub>3</sub> 5 HRE
III	New smear-negative PTB (other than category I); new less severe forms of extra-pulmonary TB	2 HRZ 2 HRZ 2 HRZ	6 HE 4 HR 4 H <sub>3</sub> R <sub>3</sub>
IV	Chronic case (still sputum positive after supervised re-treatment)	NOT APPLICABLE: refer to WHO guidelines for use of second-line drugs in specialized cntrs	

## WHO Recommendations for ART

- WHO recommends that people with TB/HIV complete their TB therapy prior to beginning ARV treatment unless there is high risk of HIV disease progression and death during the period of TB treatment (i.e., a CD4 count <200/mm<sup>3</sup> or the presence of disseminated TB).

## Prevention

### TB Preventive Therapy

- Evidence shows it is effective in HIV-infected people
- Can be given to people with HIV who:
  - have been screened to exclude active TB
  - are PPD positive (Mantoux test ≥5mm)
  - have not been BCG vaccinated
  - have a high TB risk

## Prevention, Continued

In a setting where it's not practical to do a PPD skin test, consider TB prophylaxis for the following individuals if they are HIV-infected:

- Individuals living in population with high prevalence for TB infection (>30%)
- Health care workers
- Household contacts of TB patients
- Prisoners
- Miners
- Other selected groups at high risk for acquisition or transmission of TB



## Trainers Notes on TB/HIV Co-infection

TB remains a serious threat, especially for HIV-positive persons. In fact, TB is one of the leading causes of death worldwide among PLHIV.

People living with HIV are more likely than uninfected people to get sick with other infections and diseases. TB is one of these diseases.

- Without treatment, as with other opportunistic infections, HIV and TB can work together to shorten the life of PLHIV.
- Someone with untreated latent TB infection and who is HIV positive is **much more** likely to develop active TB disease during his or her lifetime than someone who is HIV negative.
- Among people with latent TB infection, HIV infection is the strongest known risk factor for progressing to active TB disease.
- A person who is both HIV positive and has active TB disease has an AIDS-defining condition.

The good news is that HIV-positive persons with either latent TB infection or active TB disease can be treated effectively. The first step is to ensure that HIV-positive persons get a test for TB infection and any other needed tests. The second step is to help those found to have either latent TB infection or active TB disease get proper treatment. Rapid progression from latent TB infection to active TB disease can easily be prevented.



## Activity: Anonymous Questions

**Time: 25 minutes**



### Instructions for Facilitator

**Inform** participants that you will once again facilitate the **Anonymous Questions** activity. As mentioned earlier, we have replicated this activity throughout the workshop to generate discussion after key sessions and allow participants to ask any questions they want, even if the questions seem embarrassing.

**Answer** participants' questions about HIV and AIDS. **Remind** them to write their questions anonymously and in private. **Ask** them to put the questions in the suggestion box when they're finished and **explain** that you will answer the questions for all to hear, share, and discuss further.

See **Day 1, Session 4** for a review of the Facilitator Instructions on this activity.



## SESSION FOUR: TREATMENT CARE, SUPPORT, AND STIGMA MAPPING

**Time:** 1 hour 30 minutes

**Materials:** Flip chart, tape, markers

**Format:** Break-out groups by country

### Objectives:

- Identify different contexts in which HIV stigma occurs in the community.
- Identify some of the common features of stigma.



## Activity: Mapping

**Time: 1 hour 30 minutes**



### Instructions for the Facilitator

1. **Divide** participants into small groups by country and **ask each group** to make a quick mapping of HIV services in their respective countries, showing the major sources and institutions of prevention, care, treatment, and support services on flip chart paper.
2. The next step is to **ask the groups** to indicate places where stigma and discrimination occurs at the various treatments, care, and support institutions.
3. **Ask** a participant within each group to **report back** to the whole group.
4. **Put the maps up** on the front wall and make a list of places where stigma occurs, with a description of a stigma incident.
5. **Discuss**
  - Who gets stigmatized?
  - Who stigmatizes?
  - What forms of stigma take place in each context?
  - How do you think people who are stigmatized are affected?

#### 6. Summary

Stigma occurs in many different contexts—homes, neighborhoods, schools, clinics, workplaces, mosques, churches, souks, coffee shops, bars, buses, and other public places. In all of these contexts, it takes similar forms— isolation and rejection, name-calling and insults, shaming and blaming, stigmatizing body language.



### Trainer Notes

**Suggest** that participants try out this activity in their own communities. The community mapping of stigma could be a good start for people living in the community to publicly name the problem and start thinking about what they want to do to change it.



## SESSION FIVE: CLOSING AND EVALUATION

**Time:** 1 hour

**Materials:** Post-its (sticky pads) of various colors, flip chart

### **Objective:**

- To share feelings and feedback about the day.



## Activity: Process Group Evaluation

**Time: 1 hour**



### Instructions for Facilitator

1. **Ask** participants to regroup in a circle, seated.
2. **Let participants know** that they will participate in a process group and **review** the objective above.
3. The aim of a process group is to express one's personal feelings and **ask for feedback** from the group or to share one's personal perspective—in this case, regarding the second day of the Stigma Reduction workshop.
4. We also learn about ourselves when we receive feedback from other people.

\*Please note: Review the steps for running a process group from the **Closing and Evaluation Session on Day 1**.



### Trainer Notes

Process groups often bring out different emotions that can be both intense and difficult to deal with. Be sure to **focus this process group** on what participants have experienced with this workshop and how they feel about it. It is best to have someone on hand with counseling skills.

- **Ask** participants to fill out an evaluation for the day (see **Annex 8** and modify). (15 minutes)
- **Adjourn** and announce any evening events, reminding people what time we will start in the morning. Close with a song, dance, prayer, or another short activity to end the day on a positive note.
- **Co-facilitators should meet** in the evening to review evaluation forms, discuss the day, and review and prepare for the next day.

## DAY 5: ETHICAL ISSUES

### Schedule

<b>Session 1: Welcome and Review</b>	30 minutes
<b>Session 2: Ethical Issues</b>	2 hours
<b>Session 3: Closing and Final Evaluation</b>	1 hour 15 minutes

\*Please be sure to factor in time for a coffee/tea break in the morning and afternoon, as well as a lunch break.



## SESSION ONE: WELCOME AND REVIEW

**Time:** 30 minutes

**Materials:** Flip chart, tape, markers

**Prepared Flip Chart:** Day 5 Agenda

### Objectives:

- To provide a time for participants to lead an activity and warm up the group with an upbeat and fun start.
- To review housekeeping issues and the agenda for the day.



### Activity: Welcome and Review of Yesterday

**Time:** 30 minutes



### Instructions for Facilitator

- **Select a participant to lead** warm-up exercise. (15 minutes)
- **Review** the agenda for the day. **Review** highlights from yesterday. (15 minutes)



## SESSION TWO: ETHICAL ISSUES

**Time:** 2 hours

**Materials:** Flip chart, tape, markers

**Format:** Break-out groups by country

### Objectives:

- To define ethics.
- To identify different contexts in which HIV stigma occurs in the community.
- To identify some of the common features of stigma.



### Trainer Notes

The purpose of this session is to start a discussion around ethics and its linkages to appropriate protocol, human rights, and stigma and discrimination. **Start the session** by first defining ethics based on key words or phrases to examining sample case studies. Then **provide a safe space** where participants can provide their own examples of stigma and discrimination. To bring the session full circle, the group then will **discuss** how stigma and discrimination relates to ethics.



## Activity: Define Ethics

**Time: 1 hour 30 minutes**



### Instructions for Facilitator

1. First, **ask** participants to define ethics. You can also give a sample definition to get them started. For example, **ethics** addresses questions about morality—including concepts such as good and bad, noble and ignoble, right and wrong, justice, and virtue. Work with participants to come up with one definition of ethics the whole group can agreed with.
2. **Ask** participants to sit in small mixed groups of 5 or 6. Groups should be mixed by region and roles (doctors and patients). **Ask** each group to choose a facilitator, a recorder, and a reporter. **Give case studies** to the facilitators for this activity. **Have each small group discuss** the cases for 30 minutes and report back key discussion points as part of a 30-minute plenary.

## Example Cases

1. Hospital staff are gossiping about one of the HIV-positive patients in front of other patients.
2. There is a known HIV-positive sex worker called in to the doctor from a crowded clinic waiting room. When she goes in to see the doctor, other patients in the waiting room complaining loudly that they don't want to see the doctor or nurse who treats those sick and dirty sex workers.
3. A woman with AIDS is being tested by a doctor who does not want to touch her.
4. A surgeon who is HIV positive is dressing in the doctors' changing room when she overhears staff talking negatively about people with AIDS.
5. Fatima is an IDU. She was alone injecting drugs and had a used syringe she tried to clean with bleach and water. Fatima had a bad reaction to a subsequent injection and was worried that she accidentally injected bleach. She walked herself to the emergency room of the nearest hospital and reported what happened.
6. A nurse at the hospital ordered a blood sample taken from Leila and loudly exclaimed to other workers in the hospital, within earshot of Leila, "Be careful not to get any of that blood on you—have you ever heard of a clean junkie?" Leila was afraid to respond, suffered from low self-esteem, and never responded to the nurse's comments that she found offensive.



## Trainer Notes

**Allow** small groups the opportunity to give their own real-life examples instead of the cases provided. **Ask** participants if the scenario is an example of ethics, stigma, discrimination, or any combination of the three? **Ask** participants questions about the scenarios. These can include the following:

- Do you think these are realistic scenarios?
- What would you do differently to ensure that people who are HIV positive, or those presumed to be, do not suffer discrimination?
- What ethical and rights predicaments did these situations explore?
- What did you observe in the behavior of the healthcare staff that reflected discrimination against the client or colleague?



## Activity: Anonymous Questions

**Time: 30 minutes**



### Instructions for Facilitator

**Inform** participants that you will facilitate the **Anonymous Questions** activity for the last time. As mentioned earlier, we have replicated this activity throughout the workshop to generate discussion after key sessions and allow participants to ask any questions they want, even if the questions seem embarrassing.

**Answer** participants' questions about HIV and AIDS. **Remind** them to write their questions anonymously and in private. **Ask** them to put the questions in the suggestion box when they're finished and **explain** that you will answer the questions for all to hear, share, and discuss further.

See **Day 1, Session 4** for a review of the Facilitator Instructions on this activity.



## SESSION THREE: CLOSING AND FINAL EVALUATION

**Time:** 1 hour 15 minutes

**Materials:** Flip chart, markers, feedback box

**Prepared Materials:**

**Prepared Flip Chart:** What Is Feedback?

**Handouts:** Final Evaluation (**Annex 8**)

### Objective:

- To review the workshop objectives in light of what has been accomplished today and throughout the workshop.



## Prepared Flip Chart: What Is Feedback?

- Feedback is non-judgmental
- Feedback is constructive
- Feedback is specific
- Feedback provides alternatives
- Feedback is received non-defensively



## Activity: Closing Discussion

**Time: 1 hour 15 minutes**



## Instructions for Facilitator

1. **Ask** participants to sit in a circle.
2. **Ask** a volunteer to read from the flip chart.
3. **Provide** a brief overview of the topics covered during the workshop.
4. **Ask** the participants to think back on the workshop's activities and discuss some of the central themes.
5. **Ask** participants: What did you like? What did you learn? What will you remember?
6. **Thank** all participants for their time, energy, and commitment.
7. **Provide** a final evaluation form (modified from **Annex 8**) and **ask** participants to fill out the form. They should not put their names on the evaluations. They can return the evaluations to a designated person or table.

## ANNEX I: WORKSHOP AGENDA

WORKSHOP AGENDA		
Day	Morning	Afternoon
<b>Day 1</b>		
<b>Introduction, Overview of Stigma and Discrimination</b>	Introductions and Goals of Training	Gaps in Stigma, Parts I and II
	Group Norms and Ground Rules	Overview of HIV Stigma and Discrimination in the Healthcare Setting, with Case Discussions
	Parachute and Judgment	Closing and Evaluation
	General Overview of Stigma and Discrimination	
<b>Day 2</b>		
<b>Personal and Professional Perceptions of Stigma and Discrimination</b>	Welcome and Review	Impact of HIV on Our Personal and Professional Lives, Part II
	Setting the Stage/Exploring Our Thoughts, Beliefs, and Attitudes	Case Studies
	Impact of HIV on Our Personal and Professional Lives, Part I	Moving Beyond Us and Them Closing and Evaluation
<b>Day 3</b>		
<b>The Patient-Physician Partnership</b>	Welcome and Review	Counseling and Testing, Part II
	Resistance and Adherence	Closing and Evaluation
	Counseling and Testing, Part I	
<b>Day 4</b>		
<b>Technical Updates on Key HIV and Stigma-related Issues</b>	Welcome and Review	Treatment, Care, Support, and Stigma Mapping
	Parent-to-Child Transmission	Closing and Evaluation
	Hepatitis C and TB Co-infection	
<b>Day 5</b>		
<b>Ethical Issues</b>	Welcome and Review	
	Ethical Issues	
	Closing and Final Evaluation	

## **ANNEX 2: SUBJECT RELEASE FORM/PHOTO CONSENT FORM**

I would like permission to take your picture or video on behalf of:

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*(Enter company name, NGO, or other organization/group being represented above)*

I would also like permission to include your picture (or video) in an internal report or PowerPoint presentation, publications of limited distribution, or a password-protected website. Any information provided in this document and/or website or with your picture will not misrepresent you. Please read the statement below. If you agree with the statement, please sign your name and include today's date.

- Yes, I agree to have my picture taken, and I understand that the photo may be used in a limited-distribution document or on a password-protected Internet site for educational purposes.

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

### **ANNEX 3: INTERPRETER CONFIDENTIALITY AGREEMENT**

I, \_\_\_\_\_, as an interpreter, will be permitted to have access to participants' information in order to perform interpretation and translation work related to **investing in PLHIV leadership in the Middle East and North Africa region Training-of-Trainers and Subregional Workshops.**

I agree to keep all information that I learn about the participants from these trainings confidential. I understand that I may not discuss or disclose any information related to any participant to anyone outside the workshop setting. I further understand that I may learn personal information about a participant and/or his or her family that is private. I understand that it is my duty and responsibility to preserve and protect this privacy and confidentiality. I understand that this duty will extend after I am no longer working at the workshops. I also understand that information relating to persons who are participating at the workshop is also privileged and must be kept confidential. By placing my signature below, I hereby indicate that I understand and agree to maintain the privacy of the participant(s)' personal information.

WITNESS:

INTERPRETER:

By: \_\_\_\_\_  
Date: \_\_\_\_\_

By: \_\_\_\_\_  
Date: \_\_\_\_\_

## ANNEX 4: FOUR TYPES OF STIGMA

**Self-Stigma**—people living with HIV practice “self-stigma.” This can take the form of PLHIV isolating themselves from their families and communities and feeling self-hatred, shame, and blame.

**Stigma**—includes perceptions or feelings toward people living with HIV that are negative and based on preconceived notions and judgments.

**Enacted Stigma**—this is discrimination and can take form, for example, by kicking a person out of school, work, or the house because of their sero-status.

**Layered Stigma**—when a person experiences more than one stigma, for example for being a woman, a drug user, and HIV positive.

### **Stigma is a process that can take place in the following four steps:**

1. Something about a person that is different is pointed out or labeled, for example: He is different from us—he coughs a lot.
2. The thing that is different about the person is attributed to a negative behavior, for example: His sickness is caused by his sinful and promiscuous behavior.
3. The negative attribution makes the person different and therefore separate from “us” (meaning the family, society, workplace, religious community). This can lead to shunning, isolation, rejection, and an “us” and “them” mentality.
4. Loss of status and discrimination (loss of respect, isolation, and basic rights, including home, work, children, etc.).

### **Other Important Dimensions**

- Often people do not understand what the word “stigma” means when translated into other languages.
- Stigma differs in intensity—sometimes it is blatant, sometimes it is subtle.
- Stigma is targeted mostly at people who are assumed to be HIV positive, but sometimes it can also be targeted toward healthcare providers who treat PLHIV, as well as family members and friends.
- Stigma is targeted at stereotyped and scapegoated groups (for example, women, sex workers, and IDU).
- Other diseases (TB) are stigmatized because of HIV.
- AIDS disfigures, so stigma changes according to the stage of the disease. Stigma increases as the symptoms become more visible.
- Motives for stigma change according to the setting.

- Stigma disrupts social relations. For example, you may start dating someone you are attracted to or your parents may introduce you to someone, and when you tell them you are HIV positive, they stop seeing you.
- People fear that HIV is very contagious and are afraid of being infected in ways in which the virus is not transmitted. Stigma is always related to irrational conceptions of contagion, even in public places.
- People hide their stigmatizing attitudes; they may be judging you in a stigmatizing way but keep it to them and never say anything. For example, if you own a business and one of your customers is HIV positive, you don't let them know your thoughts of stigma because you want to keep their business.
- Discrimination often, if not always, violates human rights.

## **ANNEX 5: HOW DO YOU FEEL ABOUT HIV AND AIDS?**

HIV/AIDS is an emotionally charged subject. This exercise allows us to explore the reasons behind our emotions. Feelings are not right or wrong—but the reasons we feel the way we do may or may not be based on scientific evidence or facts. Below are statements that have often been made about HIV and AIDS.

**Read each statement** and, in a word or phrase, **describe** how hearing the statement makes you feel.

1. AIDS is a punishment from God for immoral behavior.
2. Children with AIDS are innocent victims and should receive free treatment.
3. All pregnant women should receive a mandatory HIV test.
4. Women who are HIV positive should not have children.
5. An HIV test should be required for all health workers.
6. Health workers have a right not to treat a person who is HIV positive.
7. Health workers who deny care to people living with HIV should be sanctioned.
8. People who are HIV positive have a right to continue working as long as their condition permits.
9. I would not enroll my child/grandchild/nephew in a school with a child who is HIV positive.
10. I would share my plate with a person living with HIV.
11. All PLHIV should receive free medical services and medications from the government.
12. Access to condoms increases promiscuity among adolescents.
13. Injecting drug users can and should change their behavior.
14. Injecting drug users should receive free, sterile needles to prevent the transmission of HIV.
15. I would continue to have sexual relations with my partner even if I knew s/he is HIV positive.
16. The best method for preventing HIV infection is abstinence.
17. I always use condoms.
18. I would feel safe receiving a blood transfusion.
19. I am at risk of becoming contracting HIV.
20. I am affected by HIV/AIDS.

## **ANNEX 6: BACKGROUND NOTES: WE ALL STIGMATIZE**

**Source:** *Understanding and Challenging HIV Stigma: Toolkit for Action*. Alliance, 2006.

We stigmatize when we say things such as “she is promiscuous” and “he deserves it,” and we discriminate when do things such as isolating people when they get sick or excluding them from decisionmaking.

### **Forms of stigma**

- Moral judgments—people blamed for their ‘behavior.’ HIV can be a sexually transmitted disease, so people assume that the person has had many partners [this can be especially problematic for women] or has engaged in criminalized and/or marginalized behavior, such as drug use.
- Physical isolation—being forced to eat alone. No visitors, no physical contact. Separation—‘us’ versus ‘them.’ These actions are based on ignorance and fear of HIV and AIDS.
- Self-stigma—people blame and isolate themselves as a reaction to stigmatization from society; in these ways, they are internalizing the shame and blame from society.
- Stigma by association—family members or orphans stigmatized; family status is affected.

### **The main causes of stigma include:**

- Insufficient knowledge, misbeliefs and fears about HIV transmission
- Moral judgments about people
- Fears about death and disease
- Lack of recognition of stigma

### **The main forms of stigma include:**

- Physical and social isolation from family, friends, and community
- Gossiping, name-calling, violence, and condemnation
- Loss of rights and decisionmaking power

### **Other forms of stigma include:**

- Self-stigma—when people blame and isolate themselves
- Stigma by association—the whole family is affected by stigma
- Stigma by looks/appearance/type/occupation/lifestyle

### **The effects of stigma include:**

- Being chased from the family, house, work, rented accommodation, organization, etc.
- Dropping out of school (resulting from peer pressure or insults)
- Depression, suicide, drug use, alcoholism

**For more information about stigma and discrimination, see for example:** Morrison, Ken. *Breaking the Cycle, Stigma, Discrimination, Internal Stigma and HIV*. Washington, DC: Health Policy Initiative, Task Order 1, 2006. Available at:

[http://www.policyintranet.com/PolicyArchive/General%20Reports/Breaking\\_the\\_Cycle.pdf](http://www.policyintranet.com/PolicyArchive/General%20Reports/Breaking_the_Cycle.pdf)

## ANNEX 7: ROLE PLAY GUIDELINES

### Explain the following:

1. Two or more people are usually asked to take on the roles of characters and then to act out a scene focusing on a pre-determined situation. In some cases, details might be given about how a situation should unfold, and role players are asked to create an ending. Sometimes this information is written on a card, for example, and provided to the role play group so that the audience does not know what the role play will be about.
2. Make sure that no one is forced by other participants to act in a role play; some may not feel comfortable acting. However, if a group member seems to be only a little shy, gently encourage her/him to try.
3. It is important that individuals do not play themselves or the exact situations they have experienced, especially in sensitive role plays.
4. Suggest that male participants play female roles and female participants play male roles from time to time, so that they have a chance to place themselves in situations encountered by members of the opposite sex.
5. Visit small groups as they are creating a role play to make sure they are developing a scene that does not run under 5 minutes and over 7 minutes, and to ensure that all members of the group are involved in some way.
6. Make sure that the group does not spend all of the exercise time devising a detailed script; encourage an outline. They need to *practice* their role play as well.
7. Create enough space for the performance so that all participants can see what is presented.
8. Encourage role players to speak loudly so that the whole audience can hear the dialogue.
9. If the role play goes on too long or seems to get stuck, invite the players to stop so that everyone can discuss the situation.
10. Allow the other participants to offer their observations after each group has performed. For example, you can ask the audience what they saw and then ask the actors whether they intended to portray that.
11. When doing a serious/emotional role play, it might be necessary to “de-role” so the actors can acknowledge who they are in real life—outside of the characters just played.
12. Ask participants how the role play relates to their own lives.

Role play scenarios may offer opportunities to provide information on many topics, such as stigma and discrimination, basic facts about HIV, advocacy and human rights, behavior change communication and education, psychosocial support, testing, treatment and care, disclosure, gender issues, family issues, and community issues—and much more!

## ANNEX 8: EVALUATION TEMPLATE

### Logistics

Please give your feedback on the following:

- Hotel:  
\_\_\_\_\_
- Location:  
\_\_\_\_\_
- Service:  
\_\_\_\_\_
- Meals:  
\_\_\_\_\_
- Coffee Breaks:  
\_\_\_\_\_
- Your Room:  
\_\_\_\_\_
- Meeting Room:  
\_\_\_\_\_

### Workshop Content

Please provide your feedback on the following:

Overall, what were the strengths of this workshop?

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Overall, were there any weaknesses of this workshop? If so, what? How could the workshop be improved?

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Please use the table below to rate each one of the sessions.

					
<b>Day 1: Session 1</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 2</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 3</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 4</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 5</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 6</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 1: Session 7</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 2: Session 1</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 2: Session 2</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 2: Session 3</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 2: Session 4</b>	Relevance				
	Facilitation/Speakers				
	Comments				

					
<b>Day 2: Session 5</b>	Relevance				
	Facilitation/Speakers				
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<b>Day 2: Session 6</b>	Relevance				
	Facilitation/Speakers				
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<b>Day 2: Session 7</b>	Relevance				
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<b>Day 3: Session 1</b>	Relevance				
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<b>Day 4: Session 5</b>	Relevance				
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<b>Day 5: Session 1</b>	Relevance				
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<b>Day 5: Session 2</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Day 5: Session 3</b>	Relevance				
	Facilitation/Speakers				
	Comments				
<b>Feedback Group</b>	Relevance				
	Facilitation/Speakers				
	Comments				

