

**Supporting community action on AIDS in developing countries**

**Facilitators' guide**

**LET'S TALK ABOUT  
HIV COUNSELLING  
AND TESTING**

**Tools to build NGO/CBO capacity to mobilise communities  
for HIV counselling and testing**

# Acknowledgements

## What is the International HIV/AIDS Alliance?

Established in 1993, the International HIV/AIDS Alliance (the Alliance) is a global partnership of nationally based organisations working to support community action on AIDS. Our shared mission is to reduce the spread of HIV and meet the challenges of AIDS.

To date, over \$140 million has been channelled to more than 40 developing countries in support of over 3,000 projects, reaching some of the poorest and most vulnerable communities with HIV prevention, care and support, and improved access to treatment.

For more information about the work of the Alliance, please visit our website [www.aidsalliance.org](http://www.aidsalliance.org)

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## Acknowledgements

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- the Care and Impact Mitigation team, Prevention team and Asia team at the International HIV/AIDS Alliance secretariat, United Kingdom
- Red Mexicana de Personas Viviendo con VIH, Mexico.

## The International HIV/AIDS Alliance global policy on provider-initiated testing

As this publication goes to press, a number of significant policy changes to models of HIV testing have occurred. The American Center for Disease Control, Atlanta, has recently issued guidance which recommends that all individuals between the ages of 13-64 be offered an HIV test as a routine part of general medical care. The World Health Organization is also soon to issue guidance on provider-initiated testing. The Alliance acknowledges that different models of testing are required and has adopted the following statement as its position:

While the Alliance remains committed to voluntary counselling and testing and opposed to mandatory testing, in the effort to increase access to comprehensive services, we support 'provider-initiated testing', on the condition that the provider ensures that:

- The individual retains the right to opt out after counselling
- Testing is confidential and accompanied by counselling that stresses the need to protect partners, subject to considerations of personal safety
- It is accompanied by efforts to reduce stigma and discrimination
- Treatment and prevention of mother-to-child transmission services are available at or near the testing site (easily accessible)
- That provider-initiated testing doesn't exacerbate vulnerability and violence against women and marginalised groups.

This toolkit focuses primarily on supporting individuals to access voluntary counselling and testing services. With new models of testing there is even greater need for communities to be mobilised and empowered to understand the strong benefits of accepting a routine HIV test where offered, but also to be able to exercise the right to refuse. Further guidance on provider-initiated testing will be published in due course.

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## Abbreviations

<b>AIDS</b>	Acquired Immune Deficiency Syndrome
<b>ARVs</b>	antiretrovirals
<b>CBO</b>	community-based organisation
<b>EIA</b>	Enzyme Immuno-Assay
<b>ELISA</b>	Enzyme-Linked Immuno-Sorbent Assay
<b>HIV</b>	Human Immunodeficiency Virus
<b>IDU</b>	injecting drug user
<b>MSM</b>	men who have sex with men
<b>NGO</b>	non-governmental organisation
<b>OI</b>	opportunistic infection
<b>PEP</b>	post-exposure prophylaxis
<b>PMTCT</b>	prevention of mother-to-child transmission
<b>STI</b>	sexually transmitted infection
<b>TB</b>	tuberculosis
<b>UN</b>	United Nations
<b>UNAIDS</b>	United Nations Joint Program on AIDS
<b>VCT</b>	voluntary HIV counselling and testing
<b>WHO</b>	World Health Organization

## What is this toolkit?

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This toolkit is designed to help non-governmental organisations (NGOs), community-based organisations (CBOs) and other civil society organisations responding to HIV/AIDS in developing countries increase their knowledge and improve the quality of their work on HIV counselling and testing.

The resource is intended for use by NGOs and trainers who support such groups, and has been designed to be used flexibly, either in capacity-building workshops or during technical support visits.

The toolkit is not limited to any specific country, region or epidemic trend. The Alliance works in many different countries around the world, all presenting differing challenges to responding to HIV. Some of our learning from working with different communities is shared here.

*Let's talk about HIV counselling and testing* has eight sections covering different aspects of HIV counselling and testing. Each section begins by providing essential information comprising key definitions, concepts and messages, after which participatory activities are included for carrying out with NGO and CBO staff.

It is important to note that the toolkit is not a training manual for counsellors, nor is it a guide to setting up your own HIV counselling and testing service. A number of such resources already exist and references to them are listed at the end of the toolkit.

## Who is this toolkit for?

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*Let's talk about HIV counselling and testing* is aimed specifically at NGOs and CBOs who are:

- mobilising communities to improve awareness about HIV counselling and testing, as well as to increase the uptake of HIV counselling and testing services
- advocating for increasing access to quality HIV counselling and testing, care, treatment and prevention services
- interested in providing HIV counselling and testing services.

For managers and those already implementing voluntary HIV counselling and testing in the community, see the World Health Organization (WHO) and Alliance authored toolkit *Scaling up HIV testing and counselling services* (2005).

## Why was this toolkit developed?

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The WHO estimates that “in many parts of the world most severely affected by HIV/AIDS, fewer than one in ten people with HIV know that they are infected” (WHO, 2003). This situation is very serious because people who

do not know that they are HIV positive do not seek access to care and support at an early stage of the infection, and tend to find out about their condition only once they become very unwell. They may therefore, without knowing, also infect other people and re-infect themselves.

A large number of people unaware of their HIV status also means that key prevention opportunities are being missed. HIV counselling and testing is therefore an important prevention tool, as well as opening up opportunities for treatment, care and support for people who test HIV positive.

This is particularly relevant, since the target announced by WHO in September 2003 of providing access to antiretroviral (ARV) treatment for three million people in resource-limited settings by 2005, and the commitment later in 2005 by the G8 and United Nations (UN) member states to providing universal access by 2010\*, require many more millions of people to be counselled and tested for HIV. In order to meet these demands, HIV counselling and testing services urgently need to be scaled up and improved.

The involvement of more NGOs and CBOs in the delivery of HIV counselling and testing services will be critical to the scaling up of these services. Many NGOs and CBOs already provide health services to a significant part of the population in many countries, and have the added advantage of working directly with community groups on matters that the community care about. NGOs and CBOs also often serve communities that the public or private for-profit sectors do not reach easily, such as young people, gay men and other men who have sex with men, sex workers or injecting drug users.

All NGOs and CBOs working on HIV/AIDS should be able to raise the awareness of the communities they work with on the importance of HIV counselling and testing for community HIV prevention, and care and support for people infected with or affected by HIV. It is also important that NGOs and CBOs should have the capacity to advocate for good-quality HIV counselling and testing services.

Sensitising community members about HIV counselling and testing and encouraging those at risk of being infected to seek HIV counselling and testing services are therefore crucial components of community action on HIV/AIDS. It is very important for NGOs and CBOs working with communities to understand the facts and issues around HIV counselling and testing before they sensitise community members about these issues.

\*In July 2005, the G8 nations endorsed a goal of working with WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to develop an essential package of HIV prevention, treatment and care with the aim of moving as close as possible to universal access to HIV prevention, treatment and care by 2010 – a target subsequently endorsed by the United Nations General Assembly in June 2006.

This includes an understanding of the different types of HIV testing – voluntary counselling and testing (VCT), diagnostic HIV testing, the routine offer of HIV testing and mandatory HIV screening of blood products.

In response to this need, this toolkit has been developed to increase NGO and CBO knowledge of HIV counselling and testing issues and their capacity to share that knowledge with other groups.

## How was this toolkit developed?

The toolkit was originally developed and field-tested by the Alliance in collaboration with several local NGOs and CBOs in Zambia. It was subsequently adapted and used with other Alliance partners in Asia. The toolkit was also adapted in Latin America with the Alliance linking organisation Kimirina, along with other local NGOs in Ecuador in preparation for a Spanish version of the resource, *Asesoría prueba voluntaria del VIH – Paquete de herramientas* (2006), produced by the Mexican Network of People Living with HIV and the Alliance.

## How can this toolkit be used?

The toolkit can be used by NGOs and CBOs as an information resource, as well as an awareness-raising training resource about HIV counselling and testing within their organisation and with other groups. Some of the activities can also be used to do a situation assessment or analysis with a given community; for example, to understand what services exist, what awareness there is of these services, what issues exist around accessibility and quality, and what gaps remain.

Each section provides essential information on definitions, concepts and key messages relating to HIV counselling and testing, as well as participatory activities for use with groups.

The participatory activities involve participants in discussing and exploring the issues themselves rather than ‘teaching’ them. The activities can be used to train NGO staff and volunteers involved in programmes such as outreach education, advocacy or care and support.

The toolkit also contains information sheets that provide further information on issues relating to HIV counselling and testing.

Depending on the situation, context and time available, organisations may be able to work through all of these different tools with an individual group, or they may need to select or combine some of the activities.

We recommend that the tools are integrated into an organisation’s ongoing work on HIV/AIDS rather than being used to start a separate project, such as a specific workshop on HIV counselling and testing.

## To use the tools with members of NGOs, facilitators will need to have:

- Good knowledge about HIV/AIDS and HIV counselling and testing in their community, such as what voluntary HIV counselling and testing involves and where quality support and services can be found. Personal experience of the process of HIV counselling and testing can also be a very powerful facilitation tool.
- Good knowledge and understanding of the populations most vulnerable or at risk of HIV. Each country is different. In some countries with concentrated epidemics, it may be important to reach sex workers or men who have sex with men; in other countries, young people may be most vulnerable or at risk. In high-prevalence settings and generalised epidemics you may want to reach as many people as possible. There are also differences in epidemic trends within countries that need to be considered.
- Basic skills in participatory training. This includes actively involving participants in activities by asking questions and encouraging them to discuss, draw or act out situations.
- Basic materials for participatory training. This includes paper and marker pens.
- An awareness of the literacy levels of the participants is important in order to adapt activities that involve reading and writing appropriately.
- Involvement of people living with HIV in training should be encouraged where possible. During a well-run workshop or meeting, a person may also choose to disclose their HIV status. The facilitator should never act alarmed and should ensure that the group respects that person’s confidentiality. HIV-positive people whose capacity has been built have an important role as counsellors and also, for example, as educators and advocates for HIV counselling and testing and ‘positive living’.

\* ‘Positive living’ is a way of living positively with HIV that includes coming to terms with your HIV status and taking care of your physical health and psychological well-being through having good nutrition, doing physical exercise, adopting and maintaining safer sex practices, etc.

## How is this toolkit structured?

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Following the introduction, the toolkit is divided into eight sections.

### **Section 1: What is HIV? What is AIDS?**

This section aims to clarify information and ideas about HIV and AIDS so that people have accurate information with which to go on to talk about HIV counselling and testing.

### **Section 2: What is involved in HIV counselling and testing?**

This section discusses the basic principles of HIV testing and counselling, including different types or models of HIV testing.

### **Section 3: Who is providing HIV counselling and testing services in the community?**

This section looks at the availability of HIV counselling and testing services in the community, where and how they are being provided and who is accessing them.

### **Section 4: Who is HIV counselling and testing for?**

This section discusses individual risk of contracting HIV and looks at the option of HIV counselling and testing for community members.

### **Section 5: What are the advantages of and barriers to HIV counselling and testing?**

This section is divided into two key parts addressing the reasons why it may be helpful for us to know our HIV status and what prevents us from getting tested for HIV.

### **Section 6: What are the issues around stigma, discrimination, and confidentiality?**

This section outlines the three concepts of HIV/AIDS-related stigma, discrimination and confidentiality, and discusses what's involved in disclosing your HIV status.

### **Section 7: What are our needs after we test for HIV?**

This section address the different medical, social, psychological and economic needs of people who test both negative and positive for HIV.

### **Section 8: Ideas for an activity in the community**

This final section offers ideas for activities that NGOs and CBOs can carry out in community settings when time is limited and contact with a community group is restricted.

**Information sheets** and a list of useful **resources** follow.

## Section 1: What is HIV? What is AIDS?

### Introduction

The first step in helping us to develop our understanding about HIV counselling and testing is to make sure we understand what HIV and AIDS are and how HIV is passed on from one person to the next. There are many myths and misconceptions about HIV and AIDS, and it is important that we have accurate information. Lack of information often leads to stigma, and fear of stigma and discrimination, preventing us from having open and frank discussions about HIV and AIDS.

This section provides basic information about how HIV may be transmitted, the difference between HIV and AIDS, how HIV is not transmitted, and how to tell if we are HIV positive or not.

### What is HIV?

HIV is a virus that attacks the defence system of human beings. This defence system is known as our immune system. The immune system helps the body to fight off infections. HIV attacks the immune system, making it weaker over time and therefore increasingly unable to fight off infections as efficiently. HIV is a special kind of virus called a **retrovirus** (see **Glossary**).

If we are infected with HIV, our body tries to fight the infection by producing HIV antibodies. If we have a blood test for HIV, it will detect whether these antibodies are present in our body. People who have HIV antibodies are HIV positive. Being HIV positive is not the same as having AIDS.

<b>H</b>	=	<b>HUMAN</b>
<b>I</b>	=	<b>IMMUNODEFICIENCY</b>
<b>V</b>	=	<b>VIRUS</b>

### What is AIDS?

A person is said to have AIDS when their immune system has been weakened over a period of time by HIV and they develop a combination of symptoms and illnesses. These illnesses are called **opportunistic infections (OIs)** (see **Glossary**) as they take advantage of the fact that the immune system is progressively getting weaker and cannot protect the body. Some OIs experienced by people with HIV include tuberculosis (TB), oral thrush, diarrhoea, genital herpes and toxoplasmosis. Many people who are HIV positive do not get sick or develop AIDS for many years.

<b>A</b>	=	<b>ACQUIRED</b>
<b>I</b>	=	<b>IMMUNE</b>
<b>D</b>	=	<b>DEFICIENCY</b>
<b>S</b>	=	<b>SYNDROME</b>

### How is HIV transmitted?

HIV is transmitted through the blood, vaginal fluid, semen and breast milk of people with HIV. Only by intimate exposure to such fluids may we be exposed to risk of HIV. Most people become infected with the virus by:

- having unprotected penetrative sex, either vaginal or anal, with an HIV-positive person
- having unprotected oral sex, if we or they have open sores in our/their mouth or bleeding gums
- being born to an HIV-positive mother, or being breastfed by an HIV-positive woman
- having a transfusion of blood that is infected with HIV
- using a sharp piercing instrument that contains the body fluid (for example, blood) of someone who is HIV positive – for example, sharing needles, tattooing.

Many people have, at some stage in their lives, been in a situation where they might have been at risk of HIV. This might have been through their own behaviour or that of their partner, and it might have been through something that they did many times or something that they did just once.

If we are to prevent HIV, it is important that we are honest with ourselves. This involves personalising HIV and means that we have to think about our own life and whether we have been in situations of risk. This will be an important step in helping us to decide whether to find out our HIV status.



## How is HIV not transmitted?

HIV cannot be transmitted by:

- shaking hands or hugging
- kissing
- tears or sweat
- sneezing or coughing
- using other people's utensils, towels or bed linen
- eating from the same plate
- using a toilet
- insect bites, such as mosquito bites
- caring for someone who is sick with advanced HIV infection
- sharing a house with someone who is sick or dying from HIV-related illnesses.

## How do we know if we are HIV positive?

The only way to know whether we are HIV positive is by having the HIV test. Many people live with the virus in their body for years before developing symptoms of HIV infection. Others may develop flu-like symptoms such as fever, headaches, sore muscles and joints, or other symptoms, such as stomach ache, swollen lymph glands or a skin rash, one or two weeks after they have become infected with the virus.

The HIV virus multiplies in the body for a few weeks or even months before our immune system responds. During this time, we will not test positive for HIV but we can pass the virus on to other people. When our immune system responds, it starts to make antibodies. When we start making detectable levels of antibodies, we will test positive for HIV. The time between the moment when the virus enters our body and when our body produces enough antibodies is called the **window period** (see **Glossary**). It can last up to three months.

After the first flu-like symptoms, some people with HIV stay healthy for ten years or longer. Although we can look fit and well during this time, HIV is damaging our immune system. As our immune system weakens, we might start having symptoms like fever, night sweats, diarrhoea or swollen lymph nodes. For those of us who become HIV positive, these problems may last more than a few days and probably continue for several weeks.

## Is there a cure for HIV/AIDS?

Once HIV enters the body, there is no way of completely getting rid of it. There are anti-HIV medicines known as **antiretrovirals (ARVs)** (see **Glossary**) that can slow down the virus and delay the damage to our immune system (see also **Glossary** for **post-exposure prophylaxis**). These medicines, when taken correctly, can improve the quality of our life and help us to stay healthy and live longer. But there is no way to remove all the HIV from our body. So taking measures to prevent HIV re-infection from others and passing on HIV to others is always important.

There are other medicines that we can take to prevent or treat OIs, such as TB and oral thrush. Preventing and treating TB can significantly improve the quality of life of people living with HIV. We can also help our immune system by getting plenty of rest, taking regular exercise, healthy eating and managing stress and emotions such as fear, guilt and shame.

### Key messages

- **HIV/AIDS is a real issue that does not only affect other people in other communities.**
- **HIV testing and counselling is a way to find out accurate information about our HIV status and to stop worrying about the possibilities of being infected with HIV. We all need to be honest with ourselves and to consider why it can be a good thing to know our HIV status.**
- **Having unsafe sex with one person who is HIV positive one time can be enough for someone to become HIV positive.**

# What is HIV? What is AIDS?

## Participatory activity 1: What is HIV? What is AIDS?



### Aim

To clarify information, address and dispel misconceptions, and increase participants' knowledge about HIV and AIDS.



### Preparation for facilitators

- Get to know the information presented in **Section 1**.
- Prepare a series of statements about HIV and AIDS (see **Information sheet 1**).
- Prepare three cards (A4 paper) or flip charts with the headings "True", "False" and "Don't know" (one heading per A4 paper or flip chart).
- Make sure that you are confident about discussing the statements and giving clear explanations.
- Read other resources about the basics of HIV and AIDS if you are not sure about some of the issues you will have to explain.
- In some cultures and contexts there may be locally constructed beliefs about HIV transmission. Find out what these are so they can be addressed during the exercise.



### Instructions

1. Explain the aim of the activity.
2. Divide the space in which you are working into three areas, "True", "False" and "Don't know", by sticking the correspondingly entitled A4 papers or flip charts on the walls or by putting them on the floor.
3. Explain the following methodology:
  - the facilitator will read statements about HIV and AIDS
  - for each statement participants will have to move to one of the three areas according to their opinion about the statement
  - if the participants agree with the statement, they will move to the area that says "True", if they disagree they will move to the area that says "False", if they are not sure they will move to the area that says "Don't know".
4. Make sure that participants understand what they have to do by demonstrating the exercise.
5. Read a first statement about HIV/AIDS and ask participants to move quickly to one of the three areas.

6. Ask participants from each area to explain the reasons why they have moved to this specific area.
7. Facilitate discussion about the statement between participants from the various areas. Ask participants why they agree or disagree.
8. Clarify any issues that arise.
9. Repeat the same method with the remaining statements.



### Facilitators' notes

- Participants should move quickly after each statement.
- Allow time for all participants to express their opinions during the activity but do not spend too long on each statement by asking each participant what they think.
- Do not give the explanations and right answers yourself. There will always be participants who know the answers and are able to give clear explanations. Use them as a resource. Your role is to clarify explanations if needed and make sure that there are no participants left with doubts about the answer to any of the statements.
- When working with groups where literacy is not an issue, write on flip charts the "technical" words that not all participants know so that they can see them as well as hear them. This will help them understand better and learn more.
- By the end of this activity make sure that every participant has a clear understanding of the basic facts about HIV/AIDS by asking some "recap" questions about what was discussed. Basic facts can include information such as how HIV is and is not transmitted; what activities most put us at risk; how transmission can be prevented; and the difference between HIV and AIDS.
- Make sure you are familiar with the national HIV/AIDS law and HIV counselling and testing guidelines in the country you are working in.



### Materials needed

- A series of statements about HIV/AIDS
- Three cards (A4 paper) or flip charts with the headings "True", "False" and "Don't know" (one heading per A4 paper or flip chart).



### Estimated time needed

- Approximately 1 hour 30 minutes.

## Notes

## Section 2: What is involved in HIV counselling and testing?

### Introduction

HIV counselling and testing services are a gateway to HIV prevention, care, treatment and support in high-, medium- and low-prevalence settings. Because they are adaptable to clients' needs, HIV counselling and testing services can be tailored to meet the needs of specific groups, such as young people, pregnant women, injecting drug users, men who have sex with men, and sex workers. HIV counselling and testing is also increasingly being offered in more places (see **Section 3**), such as antenatal clinics, sexually transmitted infection (STI), TB and family planning clinics, specially designated VCT clinics, needle exchange clinics and mobile outreach clinics. Through HIV counselling and testing, more people can know their HIV status, get accurate information on HIV transmission, have a better understanding of their own risk or vulnerability to HIV infection, and have access to information and services.

This section will discuss the key elements and guiding principles of HIV counselling and testing, outlining the VCT approach and discussing other approaches to HIV counselling and testing and what they involve.


### The key elements of HIV counselling and testing

#### HIV counselling

HIV counselling means that we receive **information**, **support** and **referral** through a dialogue with a trained counsellor before and after the HIV test.

#### Before the HIV test

**Pre-test HIV counselling** is the dialogue we have with a counsellor before we take an HIV test. This dialogue is aimed at discussing possible exposure to HIV, providing clear information regarding how HIV is transmitted, explaining the HIV test and how we would cope with knowing our HIV status, which leads to an informed decision on whether to have the test\*.


 For more information on pre-test counselling, see Information sheet 2.

#### After the HIV test


**Post-test HIV counselling** is the dialogue we have with a counsellor when we receive the result of our HIV test. The dialogue is aimed at discussing the HIV test result and providing appropriate information, support and referral. It is also aimed at encouraging behaviour that reduces the risk of becoming infected if the test is negative, or reduces the risk of HIV transmission and of re-infection if the test is positive\*\*. Where the test is positive, post-test HIV counselling is also aimed at helping us cope with the result and its consequences in our life and the lives of our loved ones.

\* Adapted from UNAIDS/WHO (2000).

\*\* Ibid

 For more information on post-test counselling, see Information sheet 3.

Should the result of our HIV test prove positive, we may require **ongoing HIV counselling**. If this is the case, the counsellor who gave us the result may offer us further counselling support or refer us to other counsellors. Ongoing HIV counselling may continue for as long as the individual needs.

 For more information about ongoing support needs, see Information sheet 4. For information about what makes counselling good or bad quality, see Information sheet 6.

#### The HIV antibody test

In order to diagnose whether or not we have HIV in our blood, an HIV antibody test is carried out. The HIV antibody test is the most common way to diagnose HIV infection.

When the HIV virus enters our body, our immune system responds by making proteins called **antibodies** (see **Glossary**). The HIV antibody test detects these antibodies in our blood and indicates whether we are infected with HIV. The test does *not* tell us if we have AIDS or if (or when) we may develop AIDS.

There are now several different tests available for HIV antibodies in adults. Depending on your country and the type of test being used, it can be either carried out by a doctor, a nurse, laboratory technician, counsellor or community health worker. The most common HIV antibody tests are blood tests, but there are also oral and urine tests available.

#### Blood test

The blood test involves drawing a small amount of blood from our arm through a clean (new or sterilised) syringe and following **universal precautions** (see **Glossary**). The blood is put in a specimen bottle that is then carefully labelled. In some places, a code number is linked to the client's name and the client is given this number to present when they come back for the result. The blood from the specimen bottle is then tested in a laboratory, either in the place where counselling was held or somewhere else.

The most common screening tests used today are the **ELISA** (Enzyme-Linked Immuno-Sorbent Assay) and the **EIA** (Enzyme Immuno-Assay). The ELISA test is very sensitive and can give a positive result for blood that does not actually have HIV antibodies. This is called a 'false positive'. For this reason, the blood is tested twice to make absolutely sure that the result is correct. Before a positive ELISA test result is reported, it is confirmed by another test called a **Western Blot** (see **Glossary**).

# What is involved in HIV counselling and testing?

However, the Western Blot is an expensive test and it is not always available. When the Western Blot is not available, another ELISA test may be used. All the information should be kept confidential.

Depending on the local services, the test results might be ready in one or several days (weeks in some cases). When the EIA or ELISA is used in conjunction with the Western Blot confirmation test, the results are more than 99.9% accurate.

## Rapid tests

Rapid tests involve testing whole blood from finger-prick samples. This method of testing offers many advantages. Like the ELISA and EIA tests, the rapid test is very accurate. But unlike these tests, rapid HIV testing does not require expensive laboratory equipment, a constant electricity or water supply, or skilled laboratory staff. Rapid testing involves fewer steps and can be performed by health care workers and counsellors so long as they have been appropriately trained. Test results can be obtained in as little as 20 minutes. Again, like the ELISA and EIA tests, if a positive result is seen then the test is repeated using a different test. However, rapid testing is still not available in many resource-constrained settings.

## Oral fluid tests

Oral fluid tests were approved in 2002 but are not yet widely available. Oral tests are done with samples of mucus from inside the cheeks and gums rather than with blood. They are as accurate as blood tests. They also detect the presence of HIV antibodies, not the virus itself.

## Urine tests

Urine tests also detect HIV antibodies but have not been widely evaluated in the field. Specific testing procedures have to be followed very carefully because the level of antibodies is lower than in blood.

## Testing for HIV antibodies in babies

Tests for adults cannot be used on babies born to HIV-positive mothers, as all these babies have the antibodies that were transmitted from their mother during pregnancy. All babies born to HIV-positive mothers would therefore test positive if tested with standard tests that detect HIV antibodies. However, this does not mean that all are actually infected with the virus. The mother's antibodies stay in the baby's blood until the baby is about 15 months old. At that time, the baby can be tested with the same tests used for adults. There are some specific tests that can be used to detect HIV directly (not the antibodies) in babies during the first 15 months of their life. However, these tests are more complex to use and expensive so they are not available in all settings.

## Client-initiated counselling and testing


### Key steps

1. **Counselling before the test, known as pre-test counselling.**
2. **Testing.**
3. **Counselling after the test, known as post-test counselling, which is focused on the test results and any recommended behaviour changes for healthy living.**

## The guiding principles of voluntary HIV counselling and testing

There are a number of fundamental principles that should guide HIV testing and counselling:

- HIV testing should always be **voluntary**. This means that a person makes their own choice about whether to go for HIV counselling and testing. They should not be forced to do so. The choice is based on information and support.
- HIV counselling and testing should be **confidential**. This means that the counsellor will not share any information with anyone else without the express and informed permission of the person who takes the HIV test.
- HIV counselling should be based on **self-determination\***. This means that the counsellor believes that the person they counsel (the client) is able to make their own informed decisions about their own life.
- HIV counselling should be **client-centred**. This means that it is focused on the client's specific needs and situation.
- HIV counselling should be **non-judgemental**. This means that the counsellor provides information and support without making judgements about the person they counsel.

 For information about issues around confidentiality, see Information sheet 7.

\* Some people and organisations use other methods to provide information, psychosocial support and referral to people who want to be tested for HIV or who have already been tested. For example, some faith-based organisations provide spiritual support that follows religious teachings and guidance. This kind of support may be extremely useful. However, it cannot be described as HIV counselling because the people who provide information and support are likely to be prescriptive by aiming to influence the decisions made by the person who receives information and support from them. This goes against the principle of self-determination.

## What is involved in HIV counselling and testing?

### Other approaches to HIV testing

#### Provider-initiated testing: the routine offer of an HIV test

As we have seen previously, central to VCT is the principle that it is initiated by the individual. However, with global initiatives to increase the number of people accessing HIV treatment, and an increasing demand for access to care and prevention services, an additional approach has emerged that advocates that HIV testing and counselling services should be offered to all those who might benefit from knowing their HIV status (WHO, 2003), even if they did not originally seek these services. This 'right to know' approach involves people being routinely offered an HIV test – for example, at antenatal clinics or at diagnosis and treatment centres for TB and STIs – whether their visit is HIV related or not (UNAIDS/WHO, 2004).

This approach moves beyond the VCT model of provision that relies upon concerned individuals seeking out information and support for themselves. Although increased rates of HIV testing would bring many health and HIV prevention benefits to many people, implementation of provider initiated routine HIV testing needs to be carefully managed to mitigate the risk of it becoming mandatory or compulsory HIV testing. Indeed the UNAIDS/WHO 2004 policy highlights the continued need for a rights-based approach (see box below).

#### Mandatory or compulsory HIV testing

Mandatory or compulsory HIV testing is when people are tested for HIV without having any choice. Sometimes mandatory HIV testing is carried out without informing the people who are tested.

“Mandatory HIV testing is neither effective for public health purposes nor ethical, because it denies individuals choice, and violates principles such as the right to health, including the right to privacy and the ethical duties to obtain informed consent and maintain confidentiality.” (WHO, 2003)

Mandatory HIV testing is ineffective for preventing the spread of HIV for the following reasons:

- The test does not detect HIV in people who have been recently infected (see **window period** in the **Glossary**) and therefore needs to be carried out several times and on a regular basis in order to know for sure whether an individual is HIV positive or not. This is why mandatory pre-recruitment testing or testing for migrants, for example, cannot be effective.
- People who suspect that they are HIV positive will tend to avoid any situation where mandatory testing could be carried out because they will fear that the results of the test will be used against them. This will prevent them from seeking advice on what to do, and care and referral services if needed.
- People who are tested without their consent are not likely to change their behaviour, even if others with whom they are intimate are exposed to risk.

Mandatory testing is a violation of human rights because it denies individuals the right to decide about their health and is used with the purpose of discriminating against those who test HIV positive.

### Ensuring a rights-based approach (UNAIDS/WHO, 2004)

The global scaling up of the response to AIDS, particularly in relation to HIV testing as a prerequisite to expanded access to treatment, must be grounded in sound public health practice and also respect, protection and fulfilment of human rights, norms and standards.

The voluntariness of testing must remain at the heart of all HIV policies and programmes, both to comply with human rights principles and to ensure sustained public health benefits.

The following key factors, which are mutually enforcing, should be addressed simultaneously.

1. Ensuring an ethical process for conducting the testing, including defining the purpose of the test and the benefits to the individuals being tested; and assurances of linkages between the site where the test is being conducted and relevant treatment, care and other services, in an environment that guarantees confidentiality of all medical information.
2. Addressing the implications of a positive test result, including non-discrimination and access to sustainable treatment and care for people who test positive.
3. Reducing HIV/AIDS related stigma and discrimination at all levels, notably within health care settings.
4. Ensuring a legal and policy framework within which the response is scaled up, including safeguarding the human rights of people seeking services.
5. Ensuring that the health-care infrastructure is adequate to address the above issues and that there are sufficient trained staff in the face of increased demand for testing, treatment and related services.

# What is involved in HIV counselling and testing?

Mandatory testing is also usually conducted without pre- and post-test counselling. It can be extremely harmful to individuals who find out that they are HIV positive and do not receive any information, support and referral.

## One-to-one HIV counselling versus couple, family and group counselling

HIV counselling has traditionally been implemented on an individual basis, particularly in Western countries. However, there are other forms of counselling that involve people being counselled as a couple, family unit or other group.

One-to-one counselling and couple or family counselling are not mutually exclusive. They can be combined. For example, a man who finds out that he is HIV positive during one-to-one post-test counselling may be willing to receive further counselling with his partner/spouse.

In countries where HIV prevalence is high, general information about HIV/AIDS provided during pre-test counselling may be given to groups rather than individuals. It is important to note that group counselling applies only to pre-test counselling and never to post-test counselling.

## Requirements for group pre-test counselling\*

- Informed consent for group pre-test counselling.
- Adequate privacy.
- No more than six people per group.
- If possible, group members of similar age and gender.
- Pre-test covers:
  - basic facts about HIV infection and AIDS
  - meaning of HIV test, including the window period
  - testing policies, and policy on written results
  - preventive counselling (that is, individualised risk assessment).

\*Adapted from Family Health International (2004).

## Community counselling

The Salvation Army has developed the concept of community counselling, which has been tested in various high-prevalence countries. Teams of community counsellors visit homes and facilitate community discussions in which feelings and issues are explored and acknowledged, norms and actions are assessed, choices are considered, and decisions and commitments are made about the life of the community. Community counselling is based on principles similar to the ones described above, although with some major adaptations. Confidentiality is shared within the group, and decisions are made by the community and not by individuals on their own. It is important to note that in the case of community counselling, counselling is not directly associated with the HIV testing process.



For further information on different types of counselling, their goal, client group and what they involve, see **Information sheet 5**.

## Key messages

- HIV counselling and testing is a process that involves several different steps. It is not just about having an HIV test. It is the ideal standard to have access to pre- and post-test counselling when considering taking an HIV test, and testing should always be placed in a wider context of prevention.
- Counselling after the HIV test does not always stop when a counsellor gives the test results. Ongoing counselling may be necessary in various situations.
- HIV testing should always be voluntary. It should be our choice whether to take an HIV test or not, based on appropriate information and support that has been given to help us make the best decision for ourselves.
- If we decide not to test, our decision is respected and we should be encouraged and supported to test at a time when we feel ready to do so. We should never be persuaded or forced to test.
- HIV counselling and testing should always be confidential. The counsellor should not discuss any of the information – including the test result – with anybody else (except for professional purposes) unless we give our express permission to do so. The counsellor should also make sure that the record-keeping is done in such a way that confidentiality is maintained.
- HIV counselling and testing is for any one of us who wants to know our HIV status. It is not just for pregnant women, people who are already sick or those who have multiple sexual partners or who inject drugs.
- One-to-one counselling can be combined with couple, family, group and community counselling.
- Mandatory HIV testing is ineffective for prevention. It is unethical and it can be harmful to individuals who find out that they are HIV positive.

# What is involved in HIV counselling and testing?

## Participatory activity 2: What is HIV counselling and testing?

### Aim

- To increase understanding of how the HIV antibody test is carried out.
- To increase understanding of the different steps involved in HIV counselling and testing.
- To increase understanding of people's needs before and after the HIV antibody test and how counselling can meet those needs.

### Preparation for facilitators

- Get to know the essential information, definitions and concepts in **Section 2** and **Information sheets 2 to 7**.
- Prepare flip charts:
  - how we feel before the HIV test
  - how we feel when the test result is positive
  - how we feel when the test result is negative
  - HIV testing and counselling – the key steps
  - instructions for work in small groups
- Photocopy **Information sheets 2 to 4**.

### Instructions

#### Part 1

1. Explain the aim of the activity.
2. In plenary, ask participants what they know about the HIV test. You can help participants with questions such as:
  - How does the test result indicate that a person has HIV in their body?
  - How can you be sure that the result of the test is accurate?
  - How much time does the test take?
  - How long must you wait after taking the HIV test before receiving the result?
  - Is the test the same for everybody, including babies and adults?

For each comment or answer by a participant, ask other participants whether they agree or not. Correct any misconceptions and summarise.

### Estimated time needed

- Part 1 should last approximately 30 minutes.

#### Part 2

3. In plenary, give each participant three small pieces of blank paper.
4. Ask participants to imagine that they are going to take an HIV test. Make it absolutely clear that no one will be expected to reveal anything about their own HIV status.
5. Ask them to imagine how they would feel just before the test, and to write on one of the pieces of paper three words describing their feelings and thoughts (words can be adjectives, nouns or verbs). Tell participants that this is anonymous and that they should not write their name on the paper.
6. Circulate a bag and ask participants to put their piece of paper in the bag. Collect the bag.
7. Next, ask participants to imagine that they have been tested, that they receive the test result from a counsellor and the result is positive. Ask them to write on a second piece of paper three words that describe how they might feel when they receive the positive result.
8. Circulate a second bag and ask participants to put their piece of paper in the bag.
9. Finally, ask participants to imagine that they have been tested, that they receive the test result from a counsellor, but this time the result is negative. Ask them to write down on a third piece of paper three words that describe how they might feel when they receive the negative result.
10. Circulate a third bag. Make sure that the bags are different, or if they are similar, identify each bag with a distinguishing mark.
11. Tell participants that you are now going to analyse how people feel before the HIV test.
12. Open the first bag, ask one of participants to pick out the pieces of paper and read what is written on them. Write the words on a flip chart entitled "How we feel before the HIV test". If a word is repeated, write it only once on the flip chart.
13. Ask participants if they have any comments. Stress that the feelings expressed are how most people feel before they take the HIV test.
14. Tell participants that now you are going to look at how people feel when they receive their test result and the test is positive. Open the second bag and ask another participant to read out the pieces of paper.
15. Write the words on a flip chart entitled "How we feel when the test result is positive". If a word is repeated, write it only once on the flip chart.



# What is involved in HIV counselling and testing?

16. Ask participants if they have any comments.
17. Finally, tell participants that you are going to look at how people feel when they receive their test result and the test is negative. Open the third bag and ask another participant to read out the pieces of paper. Write the words on a flip chart entitled “How we feel when the test result is negative”. If a word is repeated, write it only once on the flip chart.
18. Ask participants if they have any comments.

It is important to include a debriefing activity before closing the session to help participants step out of an experience that, for some, may have been difficult.



## Estimated time needed

- Part 2 should last approximately 1 hour 40 minutes.

## Part 3

19. Explain that because of all the feelings and thoughts that people have before and after the HIV test, the test should never be carried out without counselling. Ask participants how they would explain the word “counselling”. Discuss the explanations given by participants and give a brief definition of counselling (see page 10).
20. Explain that there are several steps in the HIV testing and counselling process (see page 11). Answer any questions and make sure you explain clearly the differences between post-test counselling and ongoing counselling after the test.
21. Explain that participants will be divided into three groups. Each group will focus on one type of counselling:

- **Group 1** on pre-test counselling
- **Group 2** on post-test counselling when the test result is positive
- **Group 3** on post-test counselling when the test result is negative.

For each type of counselling, the corresponding group should brainstorm and list the following:

- The themes they think should be explored by the counsellor; for example, client’s knowledge of HIV transmission, health condition of the client, issues of sexuality and violence, etc.
- The kind of information that should be given by the counsellor; for example, how to reduce risks of infection or transmission, healthy nutrition for people who are HIV positive, etc.

- Other tasks that should be carried out by the counsellor; for example, providing emotional support, checking what kind of family or other support the client has, referring the client to other sources of support, etc.

Instructions for group work should be summarised on a flip chart prepared in advance. Tell participants that they should also look at the flip charts from the previous session: “How we feel before the HIV test”, “How we feel when the test result is positive” and “How we feel when the test result is negative”. Explain that what happens during counselling should address the feelings and thoughts that were identified by participants in that session. Ask participants to make notes on a flip chart while they brainstorm.

22. Divide participants into the three groups and give each group flip charts and markers. Give them up to 30 minutes to brainstorm.
23. Ask the groups to come together in plenary and share the result of their work. Each presentation, including comments and questions, should last no more than 20 minutes.
24. Hand out copies of **Information sheet 5** and complete the discussion with information from the table.
25. Hand out copies of **Information sheets 2 to 4**. Allow some time for individual reading and questions.



## Estimated time needed

- Part 3 should last approximately 3 hours depending on the number of groups.



## Facilitators’ notes

- Some participants may want to share their own experience if they have taken an HIV test and received counselling. This needs to be managed carefully and you should stress that nobody is expected to talk about their own experience if they don’t wish to.



## Materials needed

- Flip charts
- Markers
- Small pieces cut from A4 paper
- Three bags (plastic, paper or any material)
- Prepared flip charts (see **Preparation for facilitators**)
- Photocopies of **Information sheets 2 to 4**.

# What is involved in HIV counselling and testing?

## Participatory activity 3: What are the key principles of HIV counselling and testing?

### Aim

To explore the key principles of HIV counselling and testing and the rationale for these principles.

### Preparation for facilitators

- Get to know the guiding principles of HIV counselling and testing outlined in **Section 2** and **Information Sheet 7**.
- Prepare a flip chart with the key principles of HIV counselling and testing (see below).
- Photocopy **Information sheet 7** (enough for one for each participant).

### Instructions

1. In plenary, explain to participants that there are some key principles for voluntary HIV counselling and testing. Show these principles on a flip chart (see below).

HIV counselling and testing	Voluntary
	Confidential
HIV counselling	Based on self-determination
	Client-centred
	Non-judgemental

2. Start with “Voluntary”. Ask participants:
  - What does it mean?
  - Why should HIV counselling and testing be voluntary?
  - What can happen if they are not voluntary?
  - What are the possible consequences for the person taking the test, others who are willing to take the test and for the community?
  - What is the opposite of voluntary HIV counselling and testing?

3. Proceed with “Confidential”. Ask participants:
  - What does it mean?
  - Why should HIV counselling and testing be confidential?
  - What can happen if it is not confidential?
  - What are the possible consequences for the person tested, other people willing to be tested and the community?
  - What is the difference between confidential and anonymous HIV counselling and testing?
  - Are there situations where HIV counselling and testing cannot be confidential?

Hand out copies of **Information Sheet 7**.

4. Ask questions about “self-determination”.
5. Ask questions about “client-centred”.
6. Ask questions about “non-judgemental”.

### Materials needed

- Flip chart with key principles outlined on this page.
- Photocopies of **Information sheet 7**.

### Estimated time needed

- Approximately 1 hour 30 minutes.

## Notes

## Section 3: Who is providing HIV counselling and testing services in the community?

### Introduction

Depending on where you live and work, you may have access to a range of HIV testing and counselling services. In some cases, there may be only one place where it is possible to access these services. Unfortunately, in some settings there won't be any services available. In that case you will have to travel somewhere else if you want to receive counselling and be tested for HIV.

This section discusses the different types of HIV counselling and testing services that may be available in your community and who may be providing them.

### Who is providing HIV testing?

Blood samples can be taken by medical doctors, clinical officers, nurses or laboratory technicians. All of them should have received training to respect universal precautions and take blood through a clean (new or sterilised) syringe. The health care workers who screen the blood and read the results of the tests have received further training to do so.

### Who is providing HIV counselling?

All people who provide HIV counselling should have received specific training, even if they are health care workers with experience. Trained counsellors can include:

- **professional health care workers** – medical doctors, clinical officers, nurses, laboratory technicians
- **social workers**
- **lay counsellors** – NGO and CBO staff and volunteers who are community members, including people living with and affected by HIV/AIDS.

In many countries, community members infected with and affected by HIV/AIDS belong to NGOs and CBOs, and some of them provide HIV counselling. People living with and affected by HIV/AIDS may decide to disclose their own situation to the person they counsel during a counselling session. Other people infected with or affected by HIV/AIDS may choose not to disclose their HIV status to the people they counsel, even if they use their personal experience in the information, support and referral they provide to other people during counselling sessions.

### What is peer HIV counselling?

When HIV counselling is provided by people living with HIV to people who have tested HIV positive, and the counsellor who is HIV positive discloses their HIV status to the client, it is called peer counselling. This means that both the counsellor and the client to some extent share a common experience.

Peer counselling has several advantages:\*

- In settings where the level of stigma is high, including among health professionals, people may prefer HIV-positive peer counsellors because they are less likely to have judgemental attitudes.
- People who are counselled by a person who is also HIV positive and has been living with HIV for some time, realise that being HIV positive is not a death sentence and that they can live with HIV.
- They also realise that they are not alone and feel less isolated.

Peer counsellors should respect the basic principles of counselling and they should not try to impose solutions on others based on their own experience. Other forms of formal and informal peer support between HIV-positive people exist – for example, peer support groups – but they should not be confused with peer counselling.

\* Based on International HIV/AIDS Alliance and Population Council/Horizons (2003).

### Where are HIV counselling and testing services available?

There are currently a number of different models of HIV counselling and testing service delivery. The availability of each will depend on context, HIV prevalence, national government plans, the presence of implementing international NGOs, available funds and demand. The three main types of client-initiated HIV counselling and testing services that you may have access to are:

- integrated voluntary counselling and testing (VCT) sites
- voluntary counselling and testing (VCT) centres
- mobile/outreach services.

# Who is providing HIV counselling and testing services in the community?

## Integrated voluntary counselling and testing (VCT) sites

In many countries, government health services now offer HIV counselling and testing within their clinics, hospitals and health centres. These services can be found in general hospitals, STI clinics, TB clinics, family planning clinics or antenatal settings\*. The counselling staff will usually have undergone a special training course in pre- and post-test counselling, referral and follow-up support. The counsellors are often nurses, clinical officers, social workers or doctors from the health services. These types of services generally use the ELISA testing method (see Section 2), but this may vary depending on the country and location.\*\*

Benefits	Challenges
<ul style="list-style-type: none"><li>• Promote HIV counselling and testing as part of general health services, allowing the normalisation of HIV.</li><li>• Involve health care workers directly in HIV prevention activities.</li><li>• Allow direct referral to other relevant care, such as antiretroviral therapy, management and prevention of OIs, TB, mother-to-child-transmission, family planning or welfare support.</li><li>• High volume of potential clients who visit public facilities.</li><li>• High potential for replication and scaling up.</li><li>• Ability of staff to provide services beyond the basic HIV counselling typically available at stand-alone sites.</li></ul>	<ul style="list-style-type: none"><li>• Often see those who are already sick with HIV/AIDS and therefore do not have the opportunity to counsel and offer testing to those who are still well.</li><li>• Stretching of already busy health staff could affect the quality of other services as well as the quality of HIV counselling and testing service delivery.</li><li>• Need to ensure HIV counselling and testing services have dedicated staff.</li><li>• Recognising the value that non-health care workers/volunteers – such as people living with HIV, teachers, community-based counsellors, etc. – could bring to the service.</li><li>• Allocation of appropriate space for confidential services.</li><li>• Low motivation in public sector employees.</li><li>• Difficulty in enforcing quality assurance measures.</li><li>• Limited administrative and managerial capacity to run these complex services.</li><li>• Long waiting times and inconvenient hours of operation.</li></ul>

\* The antenatal care setting has received special focus since it is integral to prevention of mother-to-child transmission (PMTCT) interventions.

\*\* Based on Family Health International (2006).

## Who is providing HIV counselling and testing services in the community?

### Voluntary counselling and testing (VCT) centres

These are often stand-alone services led by NGOs. They are more common in high prevalence settings, where they are often very visible and easily accessible to the communities or people they hope to reach; for example, they are located in busy places in cities or towns, such as bus terminals, market places or near a main hospital. These centres are not associated with an existing medical institution and usually have a staff solely devoted to VCT.

Benefits	Challenges
<ul style="list-style-type: none"> <li>• Well-trained staff focusing only on VCT.</li> <li>• Attract population groups that would not otherwise attend a clinic or hospital.*</li> <li>• Flexible opening hours and adequate staffing.</li> <li>• Usually located in areas of high population and HIV prevalence.</li> <li>• Usually provide a welcoming environment.</li> <li>• Cost-effective.</li> <li>• Linkages with support groups for people living with HIV.</li> </ul>	<ul style="list-style-type: none"> <li>• Usually not associated with existing medical infrastructure and difficult to ensure medical follow-up.</li> <li>• High establishment and operating costs, usually requiring longstanding external support.</li> <li>• Can be seen initially as stigmatising because the facilities are associated only with HIV.</li> <li>• Need advertising and awareness-raising campaigns so people learn of their existence.</li> </ul>

### Mobile/outreach services

These services are usually NGO led and are often made available through a 'mobile unit' van offering services at designated places and dates. In some places, a team of counsellors moves in and sets up a temporary VCT facility to serve rural or remote areas of 'hard-to-reach' groups, such as injecting drug users, sex workers, truck drivers, street children or homeless people.

Benefits	Challenges
<ul style="list-style-type: none"> <li>• Improved access for 'hard-to-reach' and rural populations.</li> <li>• Can adapt to needs of target community or population group.</li> </ul>	<ul style="list-style-type: none"> <li>• Expensive.</li> <li>• Difficult to keep services confidential and ensure follow-up after post-test counselling.</li> <li>• Limited capacity.</li> <li>• Requires good forward planning and logistics.</li> <li>• Requires engagement with key community leaders to ensure acceptance of and support for the mobile service.</li> </ul>

\* Studies have indicated that young people and men do not access VCT services when they are located at medical facilities.


# Who is providing HIV counselling and testing services in the community?

Other approaches to HIV counselling and testing delivery include:

## NGO model

In this model, the NGO integrates HIV counselling and testing into its other established activities or provides VCT services as its only activity.

Benefits	Challenges
<ul style="list-style-type: none"><li>• Better management due to a more limited focus.</li><li>• Capacity to provide HIV counselling and testing services in a private and confidential manner.</li><li>• Ability to influence waiting times and clinic hours.</li><li>• Easy to reinforce quality standards.</li><li>• Can be set up within a public health facility (partially stand-alone).</li></ul>	<ul style="list-style-type: none"><li>• Contingent upon donor assistance.</li><li>• Limited capacity to scale up.</li><li>• Potential for stigma if seen as a facility associated with HIV or AIDS.</li><li>• Diversion from NGO core activities if integrated with other services.</li></ul>

 For case studies of HIV counselling and testing service provision, see Information sheet 9.

## Private sector model

In most countries, private laboratories offer HIV testing. Anybody can go to one of these facilities and take an HIV test with a medical prescription, or even without a prescription, providing they pay for the service. However, in many cases no pre- and post-test counselling is available. The result may be given to the person who has been tested without any information, support and referral. Sometimes it is even handed over in an envelope or sent by mail to the person's home. The absence of counselling can be very harmful to a person who takes an HIV test and to their sexual partner(s).

Benefits	Challenges
<ul style="list-style-type: none"><li>• Perceived as providing high-quality service.</li><li>• Perceived as private and confidential.</li><li>• Responsive to client needs.</li></ul>	<ul style="list-style-type: none"><li>• Inaccessible to the poor and uninsured.</li><li>• Adherence to government and international standards for quality testing and counselling.</li><li>• Less control over prices and fees.</li><li>• Time-consuming counselling often does not fit in with a direct fee model.</li></ul>

## Public sector/NGO partnership approach

An NGO provides HIV counselling and testing services in a public sector facility, such as a hospital or clinic, where both parties contribute to the management of the services. This capitalises on the strengths of both models. Success depends greatly on the quality of the partnership.

## Workplace VCT

Particularly in high-prevalence settings, many large private sector companies now provide VCT within the workplace as part of an overall HIV programme for their employees. This can be seen in some of the large mining companies or in commercial agriculture.

## Who is providing HIV counselling and testing services in the community?

### Broadening the approach to the delivery of HIV testing and counselling services

As we saw in Section 2, because HIV counselling and testing must be implemented in many more settings and on a much larger scale than has so far been the case, many authorities, including WHO, are now advocating for a broader approach. In this approach, HIV counselling and testing would be implemented in most existing health care settings, where health care workers would routinely offer HIV counselling and testing to all those who might benefit from knowing their HIV status.

There are two types of provider-initiated testing:

- **routine testing** occurs in a clinical setting as part of a standard programme of medical services. In high prevalence settings, the provider offers testing during the consultation. Routine testing is increasingly the approach used in settings where pregnant women receive PMTCT services, and in TB and STI clinics.
- **diagnostic testing** takes place as part of the diagnostic work-up and clinical management of individuals with symptoms possibly attributable to HIV or an illness associated with HIV. When these symptoms are present, diagnostic HIV testing should be offered as part of standard care. The chief purpose of diagnostic testing is to identify HIV-positive individuals so that they can receive comprehensive care in health care settings. It should be accompanied by prevention counselling.

Benefits	Challenges
<ul style="list-style-type: none"> <li>• Promotes HIV counselling and testing as part of a standard of care and general health services, allowing for the normalisation of HIV.</li> <li>• Allows for early diagnosis of individuals who may not know or suspect that they are HIV positive, thus providing timely access to treatment and care, leading to improved health.</li> <li>• Involves health care workers directly in HIV prevention activities.</li> <li>• Allow direct referral to other relevant care, such as management and prevention of OIs, TB, PMTCT, family planning or welfare support.</li> <li>• High volume of potential clients who visit public facilities.</li> <li>• High potential for replication and scaling up.</li> <li>• Ability of staff to provide services beyond the basic HIV counselling typically available at stand-alone sites.</li> </ul>	<ul style="list-style-type: none"> <li>• HIV testing becomes a routine part of health care but often without counselling, as health care workers may argue that they have no time or skills to provide counselling.</li> <li>• Dilution of the quality of other services and lower quality of HIV and testing services.</li> <li>• Large numbers of health care providers need to be trained.</li> <li>• Clients may feel that they cannot decline the 'offer' of a test.</li> <li>• Appropriate spaces need to be allocated for confidential services.</li> <li>• Regulations disallowing the use as counsellors of non-health care workers, such as people living with HIV, teachers, social workers, community workers, volunteers.</li> <li>• Low motivation in public sector employees.</li> <li>• Difficulty in enforcing quality assurance measures.</li> <li>• Limited administrative and managerial capacity to run these complex services.</li> <li>• Possible negative perception by clients regarding quality of care.</li> </ul>



# Who is providing voluntary HIV counselling and testing services in the community?

## Knowing what's going on in our community

Before going for HIV counselling and testing or referring others, it is important to know what is available in our local community. This means finding out:

- Where are the HIV counselling and testing services available?
- What HIV counselling and testing services are available?
- Who can use the HIV counselling and testing services?
- What days and times are the HIV counselling and testing services available?
- Is there a charge for the HIV counselling and testing services, and if so, how much is it?

It is also important to consider the quality of the voluntary HIV counselling and testing services. This means finding out:

- Who is providing the HIV counselling and testing services?
- Is the counselling given by qualified, trained counsellors?
- Does the same counsellor provide the pre- and post- test counselling?
- Does the service guarantee confidentiality?
- Is the service 'person-centred', based on meeting the person's particular needs?
- Does the service provide ongoing follow-up and support?

Knowing this type of information will help a community member to decide whether they want to go for HIV counselling and testing. It will also help them to decide which HIV counselling and testing services will be best for them.

## Key messages

- Quality HIV counselling and testing should be available to all members of the community.
- Quality HIV counselling and testing should be available in different places in the community, not only in designated VCT centres.
- Where possible, there should be different HIV counselling and testing services available. It is important to select a quality service that will best meet our needs. Some groups of people may have specific needs, such as young people, sex workers, gay men and other men who have sex with men, and injecting drug users. Services should be tailored according to those needs.
- All counsellors should receive proper training in HIV counselling and testing, regardless of their professional experience and the place where they work.
- HIV testing should not be offered without people having access to the provision of quality information, regardless of the place where it is carried out.
- Peer counselling may be effective for people who find out that they are HIV positive.

## Who is providing HIV counselling and testing services in the community?

### Participatory activity 4: Who is providing voluntary HIV counselling and testing services and where?

#### Aim

To identify:

- where a person can access voluntary HIV counselling and testing in the community and what services are available
- who can use them
- when they are available
- how much they cost.

#### Preparation for facilitators

- Get to know the **key messages** and information in **Section 3**.
- Do some research about HIV counselling and testing services in the local community. Remember to think about the range of needs around voluntary HIV counselling and testing. Find out where the services are, what services are available, who can use them, when they are available and how much they cost.

#### Instructions

1. Explain the aim of the activity.
2. Divide participants into several groups. Depending on the context, ask each group to consider one of the following types of people in the community:
  - young person
  - pregnant woman
  - heterosexual man
  - gay man
  - man who has sex with other men
  - sex worker
  - injecting drug user.
3. Ask participants to draw maps of their local community, identifying:
  - where HIV counselling and testing services are available
  - what days and times HIV counselling and testing services are available
  - how much HIV counselling and testing services cost.

Ask them to discuss in their group whether these services are really accessible to the type of person they have chosen.

4. Ask each small group to present their work to other groups. Invite them to compare and discuss what services are available and accessible to different types of people, by asking:
  - what are the differences?
  - for what reasons is it more difficult for some categories of people to access voluntary HIV counselling and testing services?

#### Facilitators' notes

- Correct any false information that participants give. For example, it is very important that people have the correct times that voluntary HIV counselling and testing services are available, and correct details about what costs are involved.
- Encourage participants to think of the full range of organisations that contribute a variety of voluntary HIV counselling and testing services in their community – not just public and private health facilities, but also NGOs, the church, etc.

#### Materials needed

- Flip charts
- Markers.

#### Estimated time needed

- Approximately 2 hours, depending on the number of participants and small groups.

# Who is providing HIV counselling and testing services in the community?

## Participatory activity 5: Where would I go for voluntary counselling and testing services?



### Aim

To identify the benefits and disadvantages of different models of provision of HIV counselling and testing services.



### Preparation for facilitators

- Get to know the **key messages** and information in **Section 3**.
- Find out what HIV counselling and testing services are available locally, where the services are, who can use them, when they are available and how much they cost.



### Instructions

1. In plenary, ask participants to think about the question "Imagine you want to take an HIV test and you can choose from the following facilities. Where would you go?"
  - A. A private laboratory
  - B. A VCT centre run by an NGO (at the NGO's headquarters)
  - C. A family planning clinic
  - D. The local hospital
  - E. A health care centre specialised in the treatment of STIs
  - F. A centre to donate blood
  - G. A mobile VCT unit.Options A–G should be written down on a prepared flip chart. If participants are not able to read, use pictures or drawings.
2. Ask all participants who chose option A to form a small group, those who chose option B to form another group, and do the same with the other options. If one of the options has been chosen by only one person, this person will work on their own.
3. Ask each group to discuss the benefits and disadvantages of taking an HIV test in the option they have chosen. Ask participants to write down or visually represent the benefits and disadvantages of the option on flip charts. Give participants between 40 and 50 minutes for discussion and preparation of the flip chart.

4. Ask participants to come back as a large group and present the result of their discussions.
5. Ask if some of them have changed their mind regarding where they would take the HIV test after listening to the explanations given by other participants.
6. Ask participants if there is another option they would prefer.



### Materials needed

- Flip charts
- Prepared flip chart (see below) or use pictures or drawings
- Markers.

### Options for the HIV test

- A. A private laboratory
- B. A VCT centre run by an NGO (at the NGO's headquarters)
- C. A family planning clinic
- D. The local hospital
- E. A health care centre specialised in the treatment of STIs
- F. A centre to donate blood
- G. A mobile VCT unit



### Estimated time needed

- Approximately 2 hours 10 minutes, depending on the number of participants and small groups.

## Section 4: Who is HIV counselling and testing for?

### Introduction

We may think HIV counselling and testing is only for those who are sick; for people with TB or those who have lost a lot of weight, for example. We may also think that it is only for those who have many sexual partners or for pregnant women, sex workers, gay men or injecting drug users.

NGOs and CBOs play a critical role in community-level awareness and advocacy work to ensure that the benefits of HIV counselling and testing, and those it hopes to support, are well understood.

In relatively low HIV-prevalence settings there are populations that are key to the epidemic dynamics because they have been disproportionately affected by HIV\*. However, it is important not to consider these populations as a 'problem' but rather as a fundamental part of the solution. Involving people living with HIV, men who have sex with men, sex workers, young people and injecting drug users in the design and delivery of services (including HIV counselling and testing services) and in community mobilisation efforts, is essential to effective HIV work.

Such an approach helps to move away from the idea of 'them' and 'us', which is the notion that leads people to think that services such as HIV counselling and testing are only for certain groups of people. One of the challenges for HIV counselling and testing services is to consider and meet adequately and appropriately the needs of the different kinds of people who could be their users.

Knowing our HIV status will help us to have a fuller picture of our health, understand the sickness or death of a child or partner, or understand our HIV risk in sex or injecting drug use.

In many settings, the provision of quality HIV counselling and testing services to different types of populations continues to be a challenge. It is therefore crucial that providers of HIV counselling and testing services develop the specific knowledge and skills to counsel and test all those who require the service, be they young people, women, heterosexual men, gay men or other men who have sex with men, sex workers or injecting drug users.

\* 'Key population' is a concept used in the Alliance's Frontiers Prevention Project (FPP) for its work in relatively low-prevalence countries. It is considered that by focusing prevention efforts on people living with HIV and the people most likely to be infected, it will be possible to have a dramatic impact on the epidemic in low-prevalence settings. The two most critical factors relevant to defining groups as key populations are numbers of sexual partners (for sexual transmission) and likelihood of direct exposure to HIV, or directly exposing others to HIV. FPP also emphasises the importance of creating a favourable environment for prevention and the empowerment of the key populations. See International HIV/AIDS Alliance et al. (2002).

### HIV testing and counselling for couples

When people are married or involved in a stable relationship, it is often better for couples to talk about and go for HIV counselling and testing together.

This is because couples can:

- support each other while deciding whether to have an HIV test, and also during their pre- and post-test counselling
- get the full story about their HIV status at the same time
- help each other to cope with and understand the results of their tests, whether their HIV status is the same or different
- plan together for the future of their relationship; for example, they may decide to have safer sex by using condoms and non-penetrative sexual activity
- plan together for the future of their family and their children, if they have any
- share any feelings of upset, anger or blame with the support of a trained counsellor.

### Key messages

- **HIV counselling and testing is an important option for everyone in the community at various stages in their life, not just those who have many sexual partners or who are already sick.**
- **Any of us who want to know our HIV status should consider voluntary HIV counselling and testing.**
- **It is usually better for couples to go for HIV counselling and testing together. However, each person must make their own individual decision about whether to have an HIV test or not.**
- **Each person needs to be prepared for both their own result and that of their partner. They also need to know that their results might be the same or different.**
- **Couples need to be committed to working as a team. Knowing their HIV status might bring them closer together, but it might also cause upset and anger.**

# Who is HIV counselling and testing for?

## Participatory activity 6: Who is HIV counselling and testing for?

### Aim

To build understanding that HIV counselling and testing is an important option for many different types of people.

### Preparation for facilitators

- Get to know the key messages in Section 4.
- Prepare several fictitious case studies of 'typical people' in the community, including details such as
  - first name and/or surname
  - age
  - sex
  - family status
  - community status
  - occupation
  - characteristics of the typical person's family.

Adapt the 'typical people' to the type of participants you are working with. Try to avoid creating stereotypes when you create the case studies. Examples (to be adapted):

### Typical person 1

**Name:** X (include a name that is commonly used in your community)  
**Age:** 40  
**Sex:** Female  
**Family status:** Married with two children  
**Occupation:** Housewife  
**Characteristics of the typical person's family:**  
X has been married to her husband for 20 years. They are quite well off as her husband is a high-ranking civil servant. He travels a lot because of his job. Sometimes he is away for several weeks. X is in very good health. Her only problem was a very difficult delivery when she had her second child.

### Typical person 2

**Name:** X (include a name that is commonly used in your community)  
**Age:** 46  
**Sex:** Male  
**Family status:** Married  
**Occupation:** Truck driver  
**Characteristics of the typical person's family:**  
X has been married for 15 years. He is a truck driver and often travels inter state. He is frequently away for weeks at a time. He has a helper, X (include male name that is commonly used in your community), with whom he engages in unprotected sex.

### Typical person 3

**Name:** X (include a name that is commonly used in your community)  
**Age:** 18  
**Sex:** Female  
**Family status:** Single  
**Occupation:** Occasionally sells sex on the street  
**Characteristics of the typical person's family:**  
X is pregnant and lives near the general hospital. She is very poor and as a result sells sex on the street occasionally. She often has unprotected sex with clients.

### Instructions

1. Explain the aim of the activity.
2. Ask one of the participants to read out the first case study of a 'typical person' from their community.
3. Ask the participants to spend five to ten minutes discussing the 'typical person', adding further details to their lives such as where they live, what they do and what they are interested in.
4. Ask the participants if the 'typical person' from their community might have been at risk of HIV. Ask them to explain why.
5. Ask the participants if the 'typical person' from their community should think about going for HIV counselling and testing. Ask them to explain why.
6. Repeat the activity for the other case studies.
7. End the activity by emphasising the key messages about who should think about going for HIV counselling and testing.

### Facilitators' notes

- Make sure that the case studies are of everyday community members and are not too exaggerated. This is because it is important that the participants can make connections between the people in the case studies and themselves, their family and friends.
- Encourage participants to be non-judgemental in this activity. For example, help them to see why some people might go for HIV counselling and testing, but not to judge whether their behaviour has been right or wrong.

### Materials needed

- Prepared flip charts with case studies
- Flip charts
- Markers.

### Estimated time needed

- Approximately 1 hour 30 minutes.

## Section 5: What are the advantages of and barriers to HIV counselling and testing?

### Introduction

For some of us, HIV counselling and testing might be a frightening idea. However, there are many reasons why it might be helpful for us as individuals, and for our partners, families and communities, to know our HIV status.

This section looks at why it is helpful for us to know our HIV status and discusses why we may not want to be tested for HIV or know our HIV status.

### Why is it helpful to know our HIV status?

It helps those of us who **test HIV positive** to:

- find out our HIV status in a safe place with someone who is trained and can support us
- know our HIV status early in the infection, otherwise, we might not find out until we are seriously ill, when less can be done to help us
- protect ourselves from re-infection with HIV if partners are HIV positive and make sure we protect others from the virus; for example, by practising safer sex and STI treatment and prevention
- take steps to live positively with HIV, such as eating healthy food, taking proper rest and having a healthy lifestyle and outlook
- be put in touch with individuals and organisations that provide psychosocial support, such as counselling, spiritual support and self-help groups of people living with HIV
- get treatment to prevent or treat illnesses related to HIV, like TB or STIs
- get ARV treatment if we need it
- plan for our future and the future of our loved ones, such as taking care of our children, deciding on family planning and making a will.

It helps those of us who **test HIV negative** to:

- have a clear understanding of our own risk factors with regard to HIV
- take steps to protect ourselves from becoming HIV positive in the future; for example, by practising safer sex, STI prevention and treatment if needed, speaking openly to our sexual partners (especially when it is a new sexual relationship) and encouraging them to consider HIV counselling and testing.
- personalise the issues around HIV and to be more understanding towards those living with HIV.

It helps **pregnant mothers who test HIV positive** to reduce the risk of passing HIV to their baby during:

- **pregnancy** – for example, they might be able to take ARVs to prevent transmission of HIV to their baby
- **birth** – for example, they could try to ensure a safe hospital delivery attended by a qualified staff member, or in some cases they might be able to have a Caesarean section
- **the baby's first months** – for example, immediately after the birth the baby may be given a single dose of the ARV the mother has had. Informed decisions can also be made around whether to breastfeed exclusively or, depending on the local context, exclusively feed the baby with infant formula
- learn how to protect themselves from getting re-infected with HIV, care for their newborn baby while looking after their own health needs, consider carefully future family planning methods, discuss hopes and desires for more children, and learn where to go for support.

It helps **pregnant mothers who test HIV negative** to:

- learn how to protect themselves from becoming HIV positive in the future.

So, it is important for us to see HIV counselling and testing as an important opportunity rather than a threat.

People living with HIV can play an important role in encouraging others to access HIV counselling and testing services and educating them on how to live a healthy and productive life with HIV.

### What stops us wanting to know our HIV status and taking the HIV test?

There are many benefits to knowing our HIV status. But there are also many reasons why we feel we cannot or why we do not get tested. These barriers to voluntary HIV counselling and testing are different for each of us, depending on our situation.

The barriers to HIV counselling and testing may include:

- not feeling able to admit to having been at risk
- fear of finding out that we are HIV positive
- fear of the counsellor telling people about our private life and HIV status, which may lead to stigma and discrimination
- thinking that HIV counselling and testing will be expensive

## What are the advantages of and barriers to HIV counselling and testing?

- not wanting to be seen going for HIV counselling and testing because of fear of stigma and discrimination
- not wanting to go for HIV counselling and testing alone
- the HIV counselling and testing facility is not easy to get to
- not wanting to take the HIV test because the quality of pre-test counselling was poor
- legal/employment/insurance implications
- fear of violence, abandonment or homelessness.



For further information on barriers to seeking HIV counselling and testing, see Information sheet 10.

### Key messages

- It is better to know our HIV status than to worry about the possibilities. Once we have the facts, we can do something about our situation – whether we are HIV positive or negative.
- If we find out that we are HIV positive, we will not be alone. The counsellor can assist us to get the care and support we need to help us to live a longer, healthier and happier life. Visible involvement of people living with HIV in the community may also lead to a reduction of stigma and discrimination.
- If we find out that we are HIV negative, we can stop worrying and take action to prevent ourselves becoming HIV positive in the future.
- Whether we are HIV positive or negative, HIV counselling and testing is a chance to plan for our future and that of our family.
- Although some barriers to HIV counselling and testing are very challenging, there are ways to overcome them. Some barriers can be overcome easily. Others take time and effort on our part and on the part of other community members.
- Despite barriers to HIV counselling and testing, there are still many good reasons to know our HIV status.
- Even if there are no barriers to HIV counselling and testing, it is still our *personal* decision and *individual* choice whether to test for HIV or not. We should not be persuaded or forced to do it.

# What are the advantages of and barriers to HIV counselling and testing?

## Participatory activity 7: Why is it helpful to know our HIV status?



### Aim

To raise awareness about the benefits of knowing our HIV status.



### Preparation for facilitators

- Get to know the **key messages** and information in Section 5.
- Prepare four to six small pieces of paper with one benefit of knowing our HIV status written clearly on each. Examples of benefits include:
  - knowing the truth about whether we are HIV positive or negative gives us relief from worrying about the possibilities
  - if we test HIV positive, we can get social support and medical help so that we can lead a healthier and longer life
  - if we test HIV positive, we can take certain steps to improve our quality of life; for example, positive living
  - if we test HIV negative, we can stop worrying and take action to protect ourselves from becoming positive in the future
  - knowing if we are HIV positive or negative helps us to plan better for our future and that of our family.



### Instructions

1. Explain the aim of the activity.
2. Ask for a volunteer to pick one of the pieces of paper. Ask them to read out the benefit of knowing our HIV status and say whether they agree or not, and explain why. Explain that they should look at the benefits not only for the person who takes the test, but also for their partner(s), friends and the rest of the community. Note the benefits mentioned on a flip chart.
3. Ask for another volunteer and repeat the activity. Keep doing this until all of the pieces of paper have been used.
4. Ask participants if they can think of other benefits of knowing our HIV status. Add any benefits that they do not mention to the flip chart. You may wish to list the benefits according to the person who knows their HIV status, their partner(s), their family, etc.
5. Facilitate a discussion about what has been learned from the activity, asking questions such as:
  - What are the two to three most important benefits of knowing our HIV status?
  - Are these benefits relevant to most community members? Why?
6. End the activity by emphasising the **key messages** about the benefits of knowing our HIV status.



### Facilitators' notes

- Encourage participants to think about the benefits of HIV testing and counselling from the point of view of both the person taking the test and their partner(s), family and friends.
- Remind participants that even though there are many reasons to know our HIV status, it is still our *choice* whether to go for HIV testing and counselling. We should not be persuaded or forced to go.



### Materials needed for the activity

- Prepare small pieces of paper with one benefit of knowing our HIV status written clearly on each one
- Flip charts
- Markers.



### Estimated time needed for the activity

- Approximately 1 hour 10 minutes.



# What are the advantages of and barriers to HIV counselling and testing?

## Participatory activity 8: What stops us wanting to know our HIV status and taking the HIV test?



### Aim

To help identify and understand barriers to HIV counselling and testing.



### Preparation for facilitators

- Get to know the **key messages** in Section 5 and **Information sheet 9**.
- Prepare sheets of A4 paper or card. Fold them in half lengthways so that they stand up (like a tent) when put on the floor.



### Instructions

1. Explain the aim of the activity.
2. Divide participants into pairs.
3. Ask participants to think about the reasons that people in their community give for not going for HIV counselling and testing. Imagine how those people would finish the sentence: "I won't go for HIV counselling and testing because ..."
4. Give each pair of participants about four to five sheets of A4 paper or card folded in half lengthways and ask them to write one reason on each folded sheet of paper lengthways on one of the outward-facing panels.
5. Ask participants to stand all the folded sheets of paper, ridge upwards, in a line along the floor. Explain to participants that the reasons are like "barriers" or "road blocks" because they slow down our journey towards HIV counselling and testing but do not stop it.
6. Ask participants which reasons for not going for HIV counselling and testing seem to be the most common.
7. Take each of the most common reasons or barriers one at a time. Discuss what could be said in response to each to overcome the barrier (see **Information sheet 9** for some suggestions). Responses should be written on flip charts either by facilitators or participants.
8. End the activity by emphasising the **key messages** about what stops people from seeking HIV counselling and testing services.



### Facilitators' notes

- Encourage participants to think broadly about the different types of personal, social and financial reasons why people might not go for HIV counselling and testing.
- Make sure that participants spend as much, if not more, time developing responses as identifying the reasons why people do not go for HIV counselling and testing.



### Materials needed

- Prepared folded sheets of paper
- Flip charts
- Markers.



### Estimated time needed

- Approximately 1 hour 40 minutes, depending on the number of participants.

## What are the advantages of and barriers to HIV counselling and testing?

### Participatory activity 9: HIV status – to know or not to know?\*



#### Aim

To help participants to understand the risk of HIV and how it might feel to be infected themselves.



#### Preparation for facilitators

The decision about whether to use this activity in particular will have to be guided by the local context, by some knowledge of the participants and by the level of experience of the facilitator. The facilitator needs to be experienced in dealing with sensitive issues, as well as knowing the facts about HIV. It may be helpful to practise the exercise with a few colleagues before doing it with trainees.



#### Instructions

- Ask the participants to stand in a circle. Then shake one person's hand, explaining that during this activity a handshake means having unprotected sexual intercourse. Scratching the other person lightly on the palm while shaking their hand means that their body has been exposed to HIV. Demonstrate this to the person you are shaking hands with and ask them to pass it around the circle. Remind participants that, as with all viruses, being exposed to HIV does not always mean that a person becomes infected. However, there is a strong chance that exposure will lead to infection.
- Ask everyone to close their eyes and explain that you are going to walk around the circle several times and touch one person on the shoulder. Say that for the rest of the exercise this person "has HIV". The person who is touched should not tell anyone in the group.
- After you have touched one person, ask everyone to open their eyes and then ask them if they know who has HIV. Remind them that it is not possible to tell who has HIV by looking at them. What did they feel while you walked around them?
- The activity begins. Explain that participants can walk around and talk to each other and, if they choose, shake hands. Each person can shake hands with up to a maximum of three people for a group of 10 to 15 or four people for a group of 16 to 25. The person who "has HIV" has to scratch the palm of everyone they shake hands with. These people should then scratch the palm of every hand they shake.
- When the handshaking stops, ask people to form a circle again. Ask all of those who had their palm scratched, and the person whose shoulder was touched, to step into the centre of the circle. Anyone who has not had their palm scratched can sit down in an outer circle. Ask if there was anyone who chose not to shake hands.
- Ask people in the inner circle to sit down where they are, keeping the circle. Remind them that in the activity their body has been exposed to HIV, but they do not yet know if they are infected. Ask what it feels like to know that they might be infected? Would they tell anyone? Who? What support would they want? Would they continue to have unprotected sexual intercourse? What do the people in the outer circle think of those in the inner circle? Would they continue to have unprotected sex?
- Remind people of the differences between HIV infection and AIDS, about how HIV testing works, and about the need for pre-and post-test counselling. Ask what people feel about having an HIV test. Why might they decide to have counselling and be tested or not?
- Ask people in the inner circle to imagine that they have chosen to have the test. Make sure they know the facts about local HIV counselling and testing services, such as how many days or weeks people wait for their results. Hand out one card with either "positive" or "negative" on it to each person, but ask them not to look at it yet. How do they feel while waiting for their results? (Cards can be put in envelopes to make sure that participants do not read what is written on them.)
- Ask each person to read their card silently and inwardly. Those who have 'negative' cards can join the outer circle. What do the people who have had a negative result feel? Discuss whether it would be possible to reduce their risk and how they might do this. What support would they need?
- Ask the people in the inner circle with "positive" cards what they are feeling. Would they tell anyone? Who? Would they change their behaviour? How easy or difficult would this be? What could they do and what support might they need?
- After this discussion, finish by reminding everyone that this was only a training exercise. Ask everyone to say what they felt about the game in a few words. Tell participants where they can get more confidential information or counselling if they wish.
- Use a debriefing exercise to help everyone come out of their roles.

\*This exercise was originally developed by the Family Planning Association in Australia, and has been widely used to sensitise health care providers and communities around the world.

# What are the advantages of and barriers to HIV counselling and testing?



## Facilitators' notes

- This activity should be conducted only by an experienced facilitator as people often experience strong emotional reactions to this exercise. It is therefore very important that the facilitator is able to manage these reactions in a sensitive way.
- Some people in the group may know that they, or a relative or friend, are HIV positive. Emphasise that people do not have to talk about their own HIV status or other personal details.
- Encourage people to say what they feel rather than simply giving them information, but be careful to answer questions and clarify any confusion.



## Materials needed

- One card for each participant, half with "positive" (or "+") written on them and half with "negative" (or "-")
- Envelopes.



## Estimated time needed

- Approximately 1 hour 30 minutes.

## Section 6: What are the issues around stigma, discrimination and confidentiality?

### Introduction

Stigma and discrimination seriously impede the effectiveness of HIV prevention and care efforts. Many people do not access HIV counselling and testing services because they are afraid of revealing their HIV status to their partner, family, colleagues or other community members.

This section looks at stigma, discrimination and confidentiality, and the importance of tackling these issues in order to improve HIV counselling and testing services and increase the number of people accessing them.

### Stigma

People experience stigma when they feel, or are made to feel, ashamed about HIV/AIDS. They may worry that if they are seen at a facility where HIV counselling and testing services are available, others will assume that they are HIV positive or have AIDS. They may feel ashamed for this reason. When people access HIV counselling and testing services, know their HIV status and are made to feel comfortable about talking openly about HIV in the community, the stigma around HIV can be reduced.

### Discrimination

When people with HIV are treated unfairly as a result of their HIV status, they suffer discrimination. Discrimination against people with HIV can mean a loss of work or home, being denied health care, or their children may be stopped from going to school. Fear of stigma and discrimination prevents them from accessing HIV counselling and testing services. If they feel secure that there will be no discrimination on the basis of their HIV status, they are more likely to seek HIV counselling and testing services. There is always some risk that those who test positive may experience discrimination, abandonment, violence or serious emotional reactions. These consequences can be reduced through the provision of ongoing counselling, support and sensitive discussion around disclosure of HIV status.

### Confidentiality

The fear of stigma and discrimination is why people want their HIV status and related personal information to be kept confidential. Confidentiality means keeping a person's personal information private. Service providers, such as counsellors and other health care workers, must respect a person's wishes (regardless of their age) about sharing their personal information. Wherever possible, the person with HIV should be encouraged to disclose or share the information with those who can offer support. Confidentiality can be extended to other members of the person's health care/counselling team only with the person's consent. Consent can normally be gained if the person receives an appropriate explanation and understands the benefits of shared confidentiality with other care/counselling team members. If they feel assured

that their HIV status and other personal information will remain confidential, they will be more likely to seek counselling, testing, treatment and support. When an HIV-positive person feels that they are ready to disclose their HIV status, it is important that they are supported in this and are prepared for the consequences. It is essential to choose the right person, the right time and the right place for disclosure of HIV status.

### Stigma and discrimination: barriers to HIV counselling and testing

High levels of stigma and discrimination, both in the medical establishment and the general public, continue to act as powerful barriers to HIV counselling and testing. The risk of unfair treatment and physical and social isolation from family members and the community prevents people from seeking HIV counselling and testing. The issue is compounded even further for many women as, in addition to the fact that they often lack the autonomy to make decisions about HIV testing, stigma and discrimination can actually be dangerous for them, often resulting in violence, abandonment and homelessness.

For men who have sex with men, commercial sex workers and injecting drug users, testing for HIV can be equally threatening and dangerous. Sex workers who are 'routinely tested' commonly experience discrimination and violence. Male-to-male sex in many countries is also highly stigmatised. Men who have, or are suspected of having, sex with other men are often rejected by family members and the community, and discriminated against in their work and social lives, as well as being subjected to violence. Injecting drug users routinely experience persecution by the police. They are often rejected by their families, and discriminated against in health care settings, the workplace and in the broader community.

# What are the issues around stigma, discrimination and confidentiality?

## Key messages

- Fear of stigma and discrimination can prevent us from talking openly and honestly about HIV/AIDS. The same fears can also prevent us from finding out about our HIV status.
- We may worry that being seen somewhere where HIV counselling and testing services are available will mean that others may assume that we are HIV positive or have AIDS. But knowing our status means that we can be supported to talk openly and frankly about HIV/AIDS, helping to reduce stigma and discrimination in the community.
- HIV counselling and testing must be confidential. The counsellor should not discuss any of the information, including the test result, unless we give our consent. They should also make sure that the record-keeping is done in a way that confidentiality is maintained. If we are reassured that voluntary HIV counselling and testing is confidential, we are more likely to seek these services.
- Discussions around disclosure should be handled with sensitivity and with the individual's situation in mind. Disclosure of HIV status should be voluntary, regardless of the person's age. It is important to choose the right time, place and person for disclosure of your HIV/AIDS status.

# What are the issues around stigma, discrimination and confidentiality?

## Participatory activity 10: Identifying stigma and discrimination

### Aim

- To explore why stigma and discrimination are two of the greatest barriers to people voluntarily seeking counselling and taking an HIV test.
- To define stigma and discrimination and explore how and when stigma is associated with people who live with HIV/AIDS.
- To look at how HIV/AIDS-related stigma affects the lives of people living with HIV, as well as those who think they are positive or at risk of infection.

### Preparation for facilitators

- Before starting this activity, you need to be familiar with the **key messages** relating to stigma, discrimination and confidentiality in **Section 6**.
- Write definitions of stigma and discrimination on a flip chart.
- Prepare a drawing of a tree trunk entitled “HIV/AIDS-related stigma and discrimination.”
- Cut 20 to 25 pieces of paper into leaf shapes, approximately hand sized.
- Cut 20 to 25 pieces of paper in root shapes, approximately 5 cm wide and 20 cm long.
- Prepare small pieces of paper for each of the participants, half of which should have “leaf” written on them and the other half “root”. Fold the papers in half and put them in a bag for the participants to pick them out.

### Instructions

1. Explain the aim of the session.
2. Facilitate a brainstorm on what stigma and discrimination mean for the participants.
3. Summarise the brainstorm and then, if you find it necessary or useful, present the definitions of stigma and discrimination opposite.
4. Explain that HIV/AIDS-related stigma will be explored using the image of a tree. The tree will represent the **problem**, which is HIV/AIDS-related stigma. The tree's roots will represent the **causes** of stigma (cultural, economic, social) and the leaves and branches will represent the **consequences**.
5. Circulate the bag with the papers with “leaf” and “root” written on them. Each participant should take a piece of paper. Form groups. All of the participants who chose a piece of paper with the word “leaf” should go into one group and those with “root” should form another group.
6. Give each group markers and paper, and ask them to choose one person to write down the ideas and another to present them.
7. The “leaf” group should brainstorm about the consequences of HIV-related stigma, emphasising the barriers that stop people from wanting to know about their HIV status. The “root” group will brainstorm about the problem's causes. Each point on the respective lists should be written on a paper leaf or root. Thirty minutes should be allowed to complete the task.
8. Encourage the “root” group to explore underlying causes of discrimination in depth. For example, one of the roots of HIV stigma could be the link with “sex work”. The causes for this could be poverty, lack of money to look after a family, or men who see women as sexual objects. A more in-depth analysis may reach ideas like restrictive government policy, lack of resources in the community, cultural restrictions for women to access educational and work opportunities, or inequality in resource distribution.
9. Encourage the “leaf” group to consider the consequences at different levels. For example, some of the leaves could include the ideas that health services discourage people from taking an HIV test, people are losing their jobs, women lose their homes, the community blames men who have sex with men, or women are beaten up by their partners. Each one of the branches should include a number of consequences – for example, people who die, orphaned children, children with no support, inadequate education or training for work – that results in poverty, etc.
10. Ask each group to present their work by explaining and sticking each root and leaf onto the tree trunk.

### Stigma reflects an attitude

### Discrimination is an act or behaviour

**Stigma** refers to unfavourable attitudes and beliefs directed towards someone or something. It can occur as a result of a visible physical characteristic, such as the obvious symptoms of an illness, or it can be manifested through negative attitudes to a group's behaviour; for example, men who have sex with men, sex workers or injecting drug users. HIV-related stigma is directed towards people living with HIV or those perceived to be infected, as well as their loved ones, close associates, social groups and community.

**Discrimination** is the treatment of an individual or group with partiality or prejudice. It is often defined in terms of human rights and entitlement, and may impact on health care, employment, the legal system, social welfare, reproductive and family life.

# What are the issues around stigma, discrimination and confidentiality?

11. Facilitate a group discussion exploring the issues in greater depth, taking into account important consequences that were not considered before.
12. Once the tree is complete, end the activity with the following questions, using the tree as a reference:
  - How does stigma lead to discrimination?
  - How is stigma related to HIV and AIDS?
  - What are the greatest barriers related to stigma and discrimination that prevent people from seeking counselling and taking an HIV test?
  - Are there groups of people in your community that are stigmatised because it is thought that they are more likely to have HIV or AIDS?
  - Is there HIV-related discrimination in health centres where HIV counselling and testing is offered? If this is the case, can you give some examples?
  - How does discrimination affect the quality of services given to users who request HIV counselling and testing?



## Materials needed

- Flip chart and colour markers
- Definitions of stigma and discrimination written on a flip chart
- Drawing of a tree trunk entitled “HIV/AIDS-related stigma and discrimination”
- 20 to 25 pieces of paper cut into leaf shapes, approximately hand sized
- 20 to 25 pieces of paper cut in root shapes, approximately 5 cm wide and 20 cm long
- Small pieces of paper for each of the participants, half of which should have “leaf” written on them and the other half “root”.



## Estimated time needed

- 1 hour 30 minutes

### Role play







The role play includes two characters, named X and Y. The facilitator should give each character a name, making sure that the two names are different from participants' names.

X tells his friend Y that he's heard a radio programme about HIV and why it's important for young people to know their HIV status. He's also heard people in the community talking a lot about HIV and AIDS. X wants to go for an HIV test but he is afraid to go alone. He asks Y to accompany him. Y warns X that if he is seen going to a HIV counselling and testing centre people will think he has AIDS. Y also tells X that if he is HIV positive everyone in the community will find out and his girlfriend will abandon him. X tells him that the HIV counselling and testing service is confidential even for young people and that it is provided by trained counsellors. X also says he heard that it would be up to him if he wanted to tell someone about his HIV status. Y laughs and says that young people don't have those kinds of choices. Y doesn't believe anything X has said and refuses to accompany him to the HIV counselling and testing centre. Y is worried about what people may think if they see him at a HIV counselling and testing centre.




\* The HIV status of a person should only be shared with other health care professionals with the informed consent of the individual concerned. However, there are situations where confidentiality is often not maintained. One example of this is when personal information about a person, including their HIV status, is shared among a small group of health care providers in a hospital or clinical setting when the information is essential to the effective treatment of the person. Confidentiality is also, in very rare occasions, breached without the consent of the person if it is believed that a 'third party' may be harmed by the actions of the person. For further discussion on this subject see UNAIDS/WHO (2000).

# What are the issues around stigma, discrimination and confidentiality?

## Participatory activity 11: Issues, stigma and discrimination

-  **Aim**
- To identify issues of stigma, discrimination and confidentiality related to HIV counselling and testing.
-  **Preparation for facilitators**
- Before starting this activity, you need to be familiar with the **key messages** relating to stigma, discrimination and confidentiality in **Section 6**. You will also need to develop/adapt a role play about an individual in the community going for HIV counselling and testing. The role play should highlight issues of stigma, discrimination and confidentiality. An example of a role play is given below.
-  **Instructions**
- Explain the aim of the activity.
  - Give two participants the outline of the role play and ask them to act it out. Allow some time for preparation.
  - Facilitate a group discussion about what issues were highlighted by the role play.
  - Facilitate a group discussion about what has been learned from the activity, based upon questions such as:
    - In the case of HIV counselling and testing, are there any situations where it is appropriate not to respect a person's right to confidentiality?\*
    - If yes, which ones?
    - Are there any situations where it is appropriate not to respect a young person's right to confidentiality? If yes, which ones?
  - Emphasise the **key messages** about stigma, discrimination and confidentiality.
-  **Facilitators' notes**
- Select enthusiastic participants who will feel comfortable acting out the role play, and give them an outline of the story in advance so that they can prepare.
  - Encourage those acting out the role play to be creative – for example, wearing costumes or using props – in order to bring the situation to life.
  - Remember to keep the role play and acting realistic so that participants can relate it to their own situation/community.
-  **Materials needed**
- Outline of role play
  - Props.
-  **Estimated time needed**
- Approximately 1 hour.

## Participatory activity 12: Facing and addressing stigma and discrimination issues

-  **Aim**
- To identify how to deal with stigma and discrimination after the test.
  - To identify strategies to avoid and/or face stigma and discrimination.
-  **Preparation**
- Before starting this activity, familiarise yourself with the **key messages** about stigma, discrimination and confidentiality in see **Section 6**.
-  **Instructions**
- Explain the aim of the activity.
  - Ask participants to imagine that they took an HIV test and the test result came back positive. With the help of a counsellor, they choose one person (for example, a relative, a friend, a religious leader, etc.) they will share the news with.
  - Individually, participants should think of:
    - how they will share the news
    - what they will tell the person
    - what they will say if the person has a negative reaction to the news.



# What are the issues around stigma, discrimination and confidentiality?

Allow enough time for all participants to reflect on the situation. In groups where people are literate, participants may want to write down their thoughts.

4. Ask each participant to tell the group who they have chosen to share the news with.
5. Form pairs and ask participants to perform the situation where one of them discloses their HIV status to the person they have chosen, who in turn listens and reacts to the news. Each pair should exchange roles after ten minutes.
6. When each pair has performed the two role plays, ask participants to come back as a large group.
7. Ask participants how they felt while they were thinking about how they would disclose the news and afterwards when they had to role play the scenario. Ask also how they felt when they had to listen to somebody who was disclosing their HIV status to them.
8. Facilitate a discussion around the following questions:
  - Are there strategies to avoid stigma and discrimination when disclosing your HIV status?
  - What kind of help/support may be useful to have prepared for disclosure and the possible negative consequences of disclosure?

- What would be the benefits of a person sharing the information with a family member or friend?

9. De-briefing activity.



## Facilitators' notes

- Emphasise that people should not share their own HIV status or other personal details.
- People may experience **strong emotional reactions** to this exercise. It is therefore very important that the facilitator manages these reactions in a sensitive way.
- Focus the discussion on ways to prevent and address stigma and discrimination; on practical strategies rather than general theories. For example, in a national workshop for HIV positive women in Mexico in 2002, participants came up with the following strategies to help clients in their decisions around disclosure:



## Estimated time needed for the activity

- Approximately 1 hour.

## Strategic questions to ask

Why disclose HIV status?  
Who to disclose to?  
What to say and how to say it?  
Where to say it?  
When to disclose?

Why not disclose HIV status?  
Who not to disclose to?  
What not to say?  
Where not to say it?  
When not to disclose?

## When to disclose

For example, when:

- you feel prepared and have correct information
- you are feeling calm
- it is necessary or when it is an opportune moment
- you are feeling confident

## When not to disclose

For example, when:

- you are angry
- you are sad or depressed
- you don't feel in control of your emotions
- you feel you are being forced
- you are feeling guilty

## Section 7: What are our needs after we test for HIV?

### Introduction

Some of us may be worried that if we test HIV positive there will be no hope and no help for us. This is not the case. There are many different types of support and services available after testing for HIV, whether we are HIV positive or negative.

The needs of people after 'post-test' counselling can change over time and are ongoing. For example, if we test HIV positive, our immediate needs might be for emotional support. But later on we might need help in coping with illness, getting money for medicines and planning for the future of our family.

This section discusses the different medical, social, psychological and economic needs of people who test both negative and positive for HIV.

### Post-test clubs

In some settings, those of us who take the HIV test can become involved in our communities, whether our result is positive or negative. We can join support groups of affected and/or infected people or 'post-test clubs'. Post-test clubs have been set up in many high-prevalence countries, mainly in Africa. They cater for both negative and positive clients. The criteria for membership is having received counselling and testing at a VCT centre. The working assumption is that post-test clubs, where avoiding sexual risk is reinforced and 'healthy living' attitudes are fostered, help clients maintain focus and motivation" (Family Health International, 2004) and are important in deconstructing societal stigma and discrimination towards HIV-positive people.

### Community volunteers

We can also play a role as community volunteers and advocate for HIV counselling and testing. With training, we can become counsellors or HIV/AIDS educators. Depending on our skills and experience, we can be involved in many different ways. If we are positive, we can *choose* whether this involvement is 'visible', that is, whether we disclose our status or not. If more HIV-positive people are visibly involved, this will help to reduce stigma and discrimination around HIV.

### Key messages

- We have many different needs after an HIV test – whether we are positive or negative. Money and medicines are important, but they are not the only needs. Ongoing counselling is an important part of HIV counselling and testing.
- Post-test support and services are not just for people who are seriously ill. People who are HIV positive and are well also need help – including ongoing counselling and other kinds of support. People who are HIV negative may also need access to support and services such as counselling.
- Post-test support and services can be provided by many different types of groups, including NGOs, churches, people living with HIV/AIDS, government and employers. These groups need to work in close collaboration.
- It is very important for HIV counsellors and other people providing information, support and treatment to HIV-positive people to set up effective referral systems to ensure a good continuum of care and support.

# What are our needs after we test for HIV?

## Participatory activity 13: What are our needs after we test for HIV?



### Aim

- To identify the needs of people who test HIV positive.
- To identify the needs of people who test HIV negative.



### Preparation for facilitators

- Get to know the **key messages** in Section 7 and Information sheet 10.



### Instructions

1. Explain the aim of the activity.
2. Divide participants into small groups.
3. Ask each group to think of a 'typical' member of their community and to draw them in the middle of a large piece of paper.
4. Ask participants of some of the groups to think about what type of needs that a 'typical' person would have after testing **HIV positive**. Ask them to write those needs around the person (see **Information sheet 10** for an example).
5. Ask participants in the other groups to think about what type of needs the "typical" person would have after testing **HIV negative**.
6. Ask each small group to report in plenary.
7. End the activity by emphasising the **key messages** about what happens after testing for HIV.

If community members are literate, the methodology does not need to be adapted. Otherwise the activity could be adapted by using picture cards of 'typical' people from the community and discussing rather than writing down ideas. Each group will need to nominate someone to summarise the discussion for reporting back in plenary.



### Facilitators' notes

- Encourage participants to think of the full range of needs that people have after testing for HIV – not just their medical needs, but also their emotional and financial ones.



### Materials needed

- Flip charts
- Markers
- Picture cards of 'typical' people from the community prepared by the facilitator (only with community members who are not literate).



### Estimated time needed

- Approximately 1 hour 20 minutes, depending on the number of participants and groups.

## Participatory activity 14: Responding to the needs of people after they test for HIV



### Aim

- To identify how the needs of people who test HIV positive can be met in the community.
- To raise awareness that there is support and hope after testing for HIV.



### Preparation for facilitators

- Get to know the **key messages** and information in Information sheet 10.
- Find out the range of 'post-test' care and/or support services in the community for people testing positive and those testing negative. Find out who provides the support services, what is available and where.



### Instructions

1. Explain the aim of the activity.
2. Ask participants to use the map they drew in **Participatory activity 4** (see page 26) of their local area, indicating where voluntary HIV counselling and testing services are available, and to add on the map places where the needs of the people after the test (those identified in **Participatory activity 13**) might be met. Work in small groups.
3. Ask each small group to report in plenary.
4. Assist the group in identifying gaps in the response to the needs of people who take the HIV test; that is, services that would be needed and are not available in the community.



### Facilitators' notes

- Stress that VCT is not an end in itself. It is an entry point to prevention, care, support and treatment. Effective referral is an important element of good-quality counselling.



### Materials needed

- Flip charts
- Markers
- 'Community maps' drawn by participants during **Participatory activity 4**
- Drawings from **Participatory activity 13** showing the needs of people after the HIV test.



### Estimated time needed

- Approximately 1 hour 30 minutes, depending on the number of participants and groups.

## Section 8: Ideas for an activity in the community

### Introduction

This tool is designed to be used in countries or settings where community drama or street theatre is part of the way awareness around issues such as HIV is commonly raised.

The tool can be used by NGOs in community settings such as market places when they have very limited time and contact with a community group. It aims to address the key issues about HIV counselling and testing covered in the previous sections and should be used in conjunction with these (see the **key messages** in each section).

This drama is a suggested *outline* and should be changed or adapted according to the context of the specific community that you are working with. It can be made more colourful and entertaining. The drama should be realistic so that community members can relate it to their own situation/community.

### List of characters

- Several people (who should be 'typical' people from the community) who are coming to a health centre for HIV counselling and testing.
- Narrator.

All characters should be played by NGO or CBO members.

### Act 1

#### Scene 1

The waiting area of a local health centre, which provides many health services to the community, among them VCT. There are posters promoting VCT, as well as HIV awareness posters on the 'walls'. You can have a few people in the audience hold the posters up during the first scene if the play is performed in an open space where there are no walls.

The characters enter one by one. Without revealing why they are at the health centre and without disclosing their HIV status, each person introduces themselves briefly to the audience of community members only and then sits down with their back to the audience.

#### Scene 2

The narrator enters and asks the audience of community members which of the characters they think is HIV positive and why.

At this point, there is a pause in the drama to allow for some discussion among community members about the issues that have been raised. The narrator should use this opportunity to address the audience's misconceptions and attitudes about HIV and AIDS, in particular about how you can and cannot get HIV, who can get HIV and if you can tell whether someone is HIV positive by looking at them.

### Synopsis

#### Act 1

A group of people meets in the waiting area of a health centre. They do not tell each other (or the audience of community members) why they are there, but start a conversation. Prompted by some HIV/AIDS awareness and posters promoting HIV testing and counselling, they talk about HIV/AIDS. The narrator then pauses the drama and engages the audience of community members in a discussion about some of the issues raised.

This part of the drama provides an opportunity to cover key issues, such as what HIV is, what AIDS is, how HIV is transmitted, how it is not transmitted and who can get it. It also provides an opportunity to address community members' attitudes and misconceptions about HIV/AIDS and to emphasise that the only way to know a person's HIV status is to have an HIV test.

#### Act 2

The narrator explains that the characters have come to the health centre for voluntary HIV counselling and testing. They explain what VCT is and summarise the steps that are involved in the process of VCT. They point out that the characters are all at different stages of this process. Each of the characters then comes on "stage" in turn and tells the audience of community members about themselves: what has motivated them to go for VCT and what stage of the process they are at. Each character then sits down in turn with the counsellor and acts out the particular step of the VCT process that they themselves are undergoing. As one character exits, the next enters.

This part of the drama provides an opportunity to go over the different steps involved in VCT and to address community members' concerns about VCT. It also provides community members with information about where and when in their community they can access VCT.

#### Act 3

This takes place a few months later in a post-test club meeting, where the different characters share with the audience of community members what has happened to them since they have found out their HIV test result. The post-test club is for those people who have tested positive and those who have tested negative.

This part of the drama provides an opportunity to discuss the needs of people after the test for HIV. It looks at the needs of those who test positive and the needs of those who test negative, and at what services are available.

## Ideas for an activity in the community

The narrator should also be aware of and clarify any other general misconceptions about HIV and AIDS.

After some minutes, when the discussion is over, the narrator should conclude by emphasising that the only way to know your HIV status is to have an HIV test.

### Act 2

The second act also takes place in the community health centre. First of all, the narrator asks the audience of community members where in their community they could go to get an HIV test. This is an opportunity for the narrator to try to encourage community discussion about the places where VCT is available, the times that these services are available, etc.

The narrator says that in fact some of the characters in the drama have come to take an HIV test and others have come to get their results. They ask the audience what they think is involved in HIV testing. They then explain what VCT means and summarise the different steps, emphasising that it is confidential.

All the characters will come on one by one and introduce themselves more fully to the audience of community members. Each of them will explain their reason for deciding to go for VCT and tell the audience which steps of the VCT process they have gone through and which step they are about to go through. Then they will all act out this particular step with the counsellor. In order to avoid repetition but still go through most of the steps, the characters act out different steps.

### Act 3

#### Post-test club meeting

The narrator steps forward and addresses the audience, telling them that some of the people at the club tested HIV positive and some HIV negative. The narrator asks the audience:

- What are the needs of someone who tested positive?
- What are the needs of someone who tested negative?

At this point the drama pauses and the narrator takes the opportunity to encourage a discussion of the issues among the community members. The narrator reminds the audience of community members that the meeting of the post-test club is happening three months after they all first met to get tested/get their results.

After this, the post-test club meeting continues, with people making gestures and pretending to be speaking to each other. One by one, the different characters step out of the group in turn and, addressing the audience of community members only, share what has happened to them in the last three months. After each character has shared this information with the community members, they step back into the post-test club meeting and the next character steps out and shares their experience with the audience.

The drama should end with each character re-emphasising the **key messages** about VCT, including a reminder of what VCT stands for, what each word means, what each step in the process involves and where in the community VCT services can be accessed, alongside highlighting the individual and community benefits of VCT.

Large cards with copies of the picture cards and **key messages** used in some of the participatory activities described in this toolkit could be used here.

This section provides additional information to support some of the previous sections and activities.

These information sheets, the introductions to each section and the **key messages** provide the necessary background to prepare the facilitator for the different sessions.

The information sheets included here support sections 1, 2, 3, 4 and 6. The facilitator can use them to prepare the sessions and/or copy them as handouts for participants. If they are prepared as handouts, it is a good idea to give them to participants after the session.

They can also be used to produce visual support materials that highlight key information, such as flip charts or PowerPoint presentations. The technology or materials used will depend on the context and available resources.

The facilitator will need to check whether any of the information should be adapted to the local context and must be aware of national guidelines and practices.

# Information sheet 1: Checklist to use with the “What is HIV? What is AIDS” activity

- Here is a series of statements that you can use in the activity “What is HIV? What is AIDS?” in **Section 1**. These are suggestions only and you should adapt them to your context and the background and knowledge of the group you will be working with. This is also a good opportunity to explore local myths and beliefs around HIV and AIDS.
- After each statement you will find the correct answer and some comments to help you facilitate the discussion between participants, including explanations that should be given, issues that should be discussed and terminology that should be clarified.
- For explanations, also refer to the information given at the beginning of **Section 1** and in the **Glossary**.
- Each facilitator should feel free to choose as many statements as they want to depending on the number of participants, their level of knowledge and the time available. When time is limited it is preferable to spend longer discussing a smaller number of statements rather than speeding through a larger number of statements.

Statements	Correct answer	Issues arising and terminology
1. HIV is only transmitted through male semen.	False	Ways of HIV <b>transmission</b> – when body fluids (blood, semen, vaginal fluids, milk) enter the bloodstream of another person.
2. You can tell just by looking if somebody is infected with HIV.	False	Differences between HIV and AIDS – <b>asymptomatic</b> versus <b>symptomatic</b> .
3. You may be infected with HIV if you use the same toilet as someone who is HIV positive.	False	Ways of transmission of HIV – HIV cannot be transmitted by using the same toilet.
4. You may be infected with HIV if you shake hands with someone who is HIV positive and has a cut on their hand.	Don't know	This is unlikely to happen but the statement is a little confusing. For you to be at risk of HIV infection, the cut would need to be bleeding and your own hand would also have to have open cuts so that the infected blood could enter your bloodstream. Moreover, HIV does not survive easily when exposed to the air. However, basic hygiene requires avoiding contact with blood in general unless there is a direct need (for example, first aid) and <b>universal precautions</b> should be respected.
5. The Enzyme-Linked Immuno-Sorbent Assay (ELISA) is a test for detecting antibodies against HIV.	True	Definition of <b>antibodies</b> – various HIV tests available.
6. HIV-positive people can test HIV negative.	True	People may still test HIV negative during the <b>window period</b> .
7. If you are HIV positive you have AIDS.	False	Differences between HIV and AIDS – symptomatic versus asymptomatic.
8. People infected with HIV die from other infections and not from HIV/AIDS.	True	Definition of AIDS – <b>OIs</b> .
9. HIV/AIDS affects sex workers, gay men and people who have multiple sexual partners, therefore other people should not worry about being infected.	False	Most at-risk populations – ways of transmission.

## Information sheet 1: Checklist to use with the “What is HIV? What is AIDS” activity (continued)

Statements	Correct answer	Issues arising and terminology
10. Counselling (pre/post) for HIV test makes most people depressed, therefore should not be encouraged in HIV/AIDS management.	False	Definition of <b>pre-</b> and <b>post-test counselling</b> – role of counselling.
11. An effective public health measure is to separate people who test HIV positive from the rest of the community, as they are a great danger to society.	False	<b>Prevention</b> – role of people living with HIV in prevention. Human rights.
12. HIV/AIDS is a punishment from God, therefore nothing can be done about it.	False	Attitude of religions toward HIV/AIDS – attitudes of ignorance/compassion.
13. Some traditional practices contribute to the spread of HIV infection.	True	According to local context – for example, excision in Africa.
14. There is no known vaccine against HIV/AIDS.	True	Vaccine <b>trials</b> .
15. You can contract HIV by receiving blood from a tested source such as a blood bank.	False	<b>Blood safety</b> – the process of testing blood to see if it contains infectious agents capable of being transmitted to those who receive the blood is known as screening. WHO recommends that all blood and blood products be screened if they are to be stored in a blood bank.
16. You can contract HIV by donating blood in sterile conditions.	False	Definition of sterile conditions – use of syringes in general. Principle of universal precautions.
17. A person with HIV infection can live a long, productive life.	True	Definition of <b>positive living</b> . Importance of positive role models/leadership.
18. 30–40% of children born to mothers infected with HIV are HIV negative.	False	Ways of transmission of HIV from mothers to their babies: in the womb, during childbirth, through breastfeeding – <b>PMTCT</b> : use of ARVs, safer breastfeeding. HIV prevalence in children born to HIV-positive women varies depending on quality of PMTCT available. All babies born to HIV-positive mothers are HIV positive for around 18 months when tested with regular HIV tests because they carry their mother’s antibodies.
19. Protected sex (sexual intercourse with a condom) can prevent a person from contracting HIV.	True	Consistent correct use of condoms. Behaviour change. Alternative and non-penetrative sexual activity.
20. There are medicines that can slow down the progression of AIDS.	True	<b>ARVs</b> – role of ARVs, <b>combination therapies</b> .



## Information sheet 1: Checklist to use with the “What is HIV? What is AIDS” activity (continued)

Statements	Correct answer	Issues arising and terminology
21. If you are HIV positive and take ARVs, you won't be able to infect other people.	False	Role of ARVs – <b>viral load</b> (see <b>Glossary</b> ). HIV is still present in the body even if viral load cannot be detected, therefore there is still a risk of infecting other people.
22. People who do not want to take their ARVs are said to be resistant to drugs.	False	Definition of <b>resistant</b> and <b>resistance</b> to medicines.
23. Since everyone who is HIV positive dies of AIDS, it is better not to know if you have it.	False	Life expectancy of people living with HIV is longer when they have access to care and support.
24. Alternative therapies, including traditional remedies, can cure AIDS.	False	There is no evidence that any alternative therapy has cured AIDS. However, some alternative therapies can play a useful role in treating some OIs and boosting the immune system.
25. It has recently been proven that HIV does not cause AIDS.	False	Success of ARV treatments directly fighting HIV and consequently slowing down the progression of AIDS shows the direct link between HIV and AIDS.
26. If both sexual partners are HIV positive then they never need to use a condom when having sex.	False	Risk of <b>re-infection</b> , or <b>superinfection</b> with <b>different strains of HIV</b> .

## Information sheet 2: Pre-test counselling

Pre-test counselling should take place in a setting where privacy can be guaranteed. The counsellor should make an effort to put the client at ease.

It should be carried out by a trained counsellor and should be confidential. This means that the counsellor must not share any of the information that is told to them with anyone else, unless the individual(s) gives their express permission to do so.

The counselling should be free of charge and should take as much time as necessary to assist those undertaking the counselling towards being ready to take the test.

The counsellor should provide accurate information about HIV, such as how it is prevented, how it is passed from one person to another, and what the symptoms of HIV are. In some settings, basic facts about HIV/AIDS are explored in groups rather than on an individual basis because of the shortage of human resources and lack of time. However, some people may feel very uncomfortable in a group and refrain from asking questions that are directly related to the risk they themselves may have taken.

The counsellor should begin by exploring why the client undertaking the counselling is interested in the HIV test, helping them to identify how and when they might have been at risk of HIV infection. The counsellor should explain the window period (when a person has become infected with HIV less than three months ago but it does not show in a test). If there is a chance that the person is in the window period and they have been at risk of HIV infection, they will be advised to come back to repeat the test to make sure the result is accurate (see **Section 1**).

The counsellor should also give accurate information about how clients should look after themselves whether they decide to take the HIV test or not, such as by practising safer sex and enjoying a healthy sex life, including treatment and prevention of STIs. The counsellor should support clients to talk about their worries and help them to decide whether they want to take an HIV test or not.

The counsellor should also explore whether the client has been pressurised or forced to take the test, particularly where they have been referred by a health care worker. If HIV testing has been recommended in the context of clinical care, informed consent is required for the test (see **Glossary**).

Finally, the counsellor should explain what will happen next if the client decides to go ahead and take the test for HIV, including how the test will be done and how further information and support will be given.

The counsellor should always ensure the client understands all the information they give.

## Information sheet 3: Post-test counselling

Post-test counselling is usually carried out at the same place as the pre-testing counselling. International guidelines recommend that pre- and post-test counselling should be conducted by the same trained counsellor to ensure continuity and build trust between the counsellor and the person who is counselled. However, this does not always happen because of the lack of counsellors or other constraints of management of human resources and time. In either case, post-test counselling should always be carried out by a trained and experienced counsellor.

The length of post-test counselling should depend on the needs of the person who is counselled. Post-test counselling is usually longer when the result of the test is positive. However, the post-test counselling process is also very important when the test result is negative, and it should not be rushed.

The counsellor gives the result of the test clearly and sensitively. While giving the result, the counsellor provides emotional support to the client. They explain what the result means, make sure that the client understands it, and discuss how they will respond to its outcome. If the test result is HIV positive, the counsellor emphasises issues such as living healthily; eating well; getting early treatment for illnesses or ARV treatment if necessary or available; preventing and treating STIs; and enjoying a healthy sex life by practising safer sex (positive living).

The counsellor also explains where and how the client can get ongoing help, such as support from other people living with HIV and other people who have tested for HIV, medical care and more counselling. They might refer the client to individuals and/or organisations who will provide medical care or psychosocial support. Good referral is crucial to the quality of post-test counselling.

The counsellor supports and encourages the client to think about who they might want to share their status with (partner, family, etc.) so they can be supported. They also help them to think through the issues around the appropriate time, place and person(s) for such a disclosure. They should offer to assist them in the process of disclosure if required.

The counsellor tells the client that they may want to advise their sexual partner(s), who may have been at risk, to take an HIV test and receive counselling.

If the test result is HIV negative, the counsellor emphasises issues such as staying negative by practising safer sex. The counsellor should also explain where the client can get further information. If the client was exposed to HIV a few months before the test and tested negative, the counsellor must advise the client to come back because the test may have been carried out during the window period (see **Section 1**).

When the test result is positive, people are usually in shock and may not be able to listen properly and understand the information given by the counsellor. This is why it is very important to encourage the client to come back or refer them to another organisation in order to receive ongoing counselling.

### The meaning of HIV test results

#### Negative

A negative test result indicates that no antibodies to HIV were detected in the blood. This result can have several meanings:

- the person may not be infected with HIV
- the person may be infected with HIV, but their body has not had time to produce antibodies to the virus. In this case, the person is in the window period and should have a repeat test at a later stage.

#### Positive

A positive test result indicates that antibodies to HIV were detected in the person's blood. This result indicates that they have been infected with HIV. It does not mean that the person has AIDS.

#### Indeterminate

An indeterminate test result means one of the following:

- the person may be infected with HIV and in the process of developing antibodies to it (acute seroconversion)
- the person has other antibodies in their blood that are very similar to antibodies to HIV. These antibodies are reacting to the HIV test.

Source: Family Health International (2004)

## Information sheet 4: Ongoing support needs

It is important to keep in mind that HIV counselling and testing is never an end in itself. If referral is done properly during post-test counselling, the client who has been tested will be encouraged to seek further information and support – whether they are HIV positive or negative. This will depend on the needs of the client and what is available locally. It might include:

- ongoing counselling provided by trained counsellors, including information about HIV, healthy living, etc.
- moral support from other people living with HIV (peer support)
- moral support from others who have tested for HIV (for example, post-test clubs)
- psychological support provided by health professionals (for example, psychotherapy)
- spiritual support
- social support
- income-generating activities
- medicines for pain, OIs (including TB treatment and prevention), and ARVs
- alternative therapies, including traditional remedies for the treatment of some OIs
- STI treatment and prevention
- condoms, information about safer sex.

These needs can change over time. Whether they test positive or negative, people will have different needs at different times.

Needs of people also vary depending on gender and sexual orientation. Age can also be a determinant: children and young people will have certain needs that differ from those of adults.

Family members, community members, NGOs, people living with HIV, other people who have tested for HIV, church groups, government and employers are examples of members of the community who can provide support and services to meet these needs.

## Information sheet 5: Types of HIV counselling\*

Type of counselling	Goal	Client group	Tasks
<b>Pre-test counselling</b>	Decision-making regarding HIV testing	Those who want to be tested. Those who are referred for testing	<ul style="list-style-type: none"> <li>• Information-giving (HIV, details of the test, impact of test result on all aspects of life)</li> <li>• Risk assessment</li> <li>• Risk-reduction information</li> <li>• Assessment of social support</li> <li>• Assessment of coping mechanisms</li> <li>• Decision-making regarding undergoing the test</li> <li>• Informed consent</li> <li>• Support for action</li> </ul>
<b>Post-test counselling for an HIV positive result</b>	Integration of test result	Those who are HIV positive	<ul style="list-style-type: none"> <li>• Reassessing coping mechanisms</li> <li>• Reassessing knowledge</li> <li>• Breaking the “news”</li> <li>• Handling emotional and physical reactions to the “news”</li> <li>• Giving emotional support and helping to absorb the “news”</li> <li>• Facilitating expression of feelings</li> <li>• Bringing in a positive outlook by discussing “what can be done”</li> <li>• Motivating to prepare an action plan for an immediate future</li> <li>• Motivating to involve family members and close friends</li> <li>• Risk-reduction counselling</li> <li>• Motivation to return for counselling</li> </ul>
<b>Post-test counselling for an HIV negative result</b>	Integration of test result	Those who are HIV negative	<ul style="list-style-type: none"> <li>• Reassessing knowledge</li> <li>• Reassessing risk</li> <li>• Assessing possibility of window period</li> <li>• Breaking the “news”</li> <li>• Handling emotional and physical reactions to the “news”</li> <li>• Giving emotional support and helping to absorb the “news”</li> <li>• Referral for re-testing (if possibility of window period)</li> <li>• Risk-reduction counselling</li> <li>• Motivating to stay HIV negative</li> <li>• Motivating to prepare an action plan for an immediate future</li> <li>• Motivating to return for counselling if needed</li> </ul>

\*Based on CARAT/Tata Institute of Social Sciences (2000)

## Information sheet 5: Types of HIV counselling (continued)

Type of counselling	Goal	Client group	Tasks
<b>Ongoing counselling for a HIV positive result</b>	Living positively with HIV	Those who test positive	<ul style="list-style-type: none"> <li>• Preparing a health maintenance plan:               <ul style="list-style-type: none"> <li>– diet and nutrition</li> <li>– substance use/risk and harm reduction</li> <li>– sleep and rest</li> <li>– exercise</li> <li>– leisure</li> <li>– sexual health or safer sex</li> <li>– prevention of OIs</li> <li>– ARV therapy if necessary and available</li> <li>– prevention of transmission risk or re-exposure to HIV from others</li> </ul> </li> <li>• Disclosure issues</li> <li>• Handling crises</li> <li>• Involving family</li> <li>• Partner testing</li> <li>• Issues related to marriage, children, finance and job</li> <li>• Referral for services</li> <li>• Referral to self-help groups</li> </ul>
<b>Peer counselling</b>	Living positively with HIV	Those who are HIV positive	When HIV counselling is provided by people living with HIV to people who have tested HIV positive, and the counsellor who is HIV positive discloses their HIV status to the client, it is called “peer counselling”, as both the counsellor and the client to some extent share a common experience. All the above tasks can be provided by a trained peer counsellor
<b>Ongoing counselling for a negative HIV result</b>	Maintenance of a healthy lifestyle and remaining negative	Those who test negative	<ul style="list-style-type: none"> <li>• Risk and harm reduction (safer sex, substance use, etc.)</li> <li>• Re-orientation about lifestyle and life goals</li> <li>• Preparing a health maintenance plan</li> <li>• Involving family</li> <li>• Referral to self-help groups</li> <li>• Anticipatory guidance to avoid risky situations</li> <li>• Enabling and encouraging risk-reducing behaviours</li> </ul>
<b>Crisis counselling</b>	Assisting in successful resolution of crises that are related to HIV exposure risk/diagnosis or illness	Clients who are in crisis	<ul style="list-style-type: none"> <li>• Help to recognise and accept crisis reactions</li> <li>• Ensuring safety of client and others</li> <li>• Help to plan task-oriented strategies</li> <li>• Examining alternatives</li> <li>• Facilitating expression of feelings</li> <li>• Providing emotional support</li> <li>• Obtaining commitment for action</li> </ul>

## Information sheet 5: Types of HIV counselling (continued)

Type of counselling	Goal	Client group	Tasks
<b>Family counselling</b>	<p>Resolution of family issues related to client's HIV status.</p> <p>Providing support to deal with client's HIV status.</p> <p>Preventing family burnout</p>	Family members of those who undergo the test	<ul style="list-style-type: none"> <li>• Involving family in the plan adopted by the client</li> <li>• Handling interpersonal issues if indicated by the client</li> <li>• Enablement for giving support and home care</li> <li>• Referral for services and further support</li> <li>• Referral to self-help groups</li> <li>• Advocacy issues (e.g. adoption of child)</li> </ul>
<b>Grief and bereavement counselling</b>	Handling grief reaction associated with HIV	People living with HIV. Significant others	<ul style="list-style-type: none"> <li>• Helping to accept and verbalise grief</li> <li>• Helping to accept and verbalise loss</li> <li>• Helping to re-organise life context</li> <li>• Promoting positive outlook by recognising gains/value in relationships or experience</li> <li>• Handling feelings of survivor guilt</li> <li>• Re-establishing a lost equilibrium</li> </ul>

## Information sheet 6: Good-quality counselling

Like any other service, the quality of counselling may vary depending on organisations and health structures that provide this service. It may even vary between individual counsellors within the same organisation. Every person involved in counselling provision needs specific skills, good training and supervision.

The table below summarises what every person who goes for HIV counselling and testing is entitled to expect from a good counsellor. It also presents what a good counsellor should not do.

When the quality of counselling provided by a local organisation or institution is consistently of poor quality, NGOs and CBOs can play a role in advocating for better services.

Good-quality counselling	Bad-quality counselling
<p>The counsellor introduces themselves and accompanies you to a room where you feel that you can speak freely without fearing that other people will hear what you say.</p>	<p>The counsellor shouts your name and asks you whether you have come for the HIV test in front of all the other people who are waiting.</p>
<p>The counsellor welcomes you. They explain to you the objectives of the counselling session. They tell you that you should feel comfortable to ask any question you want. They stress that everything you will say is completely confidential. They tell you how much time approximately you will spend together.</p>	<p>The counsellor tells you that they are very busy and don't have much time for you. They leave the door open and speak loudly, even if you whisper because you don't want other people sitting outside to hear the conversation.</p>
<p>The counsellor seems accessible to you. They pay attention to what you say.</p>	<p>The counsellor answers the phone, leaves you on your own and asks you to wait, looks at their watch all the time.</p>
<p>The counsellor gives you the information you need but allows you to ask all the questions you want and express your thoughts and feelings.</p>	<p>The counsellor talks a lot and you don't have much time to say anything. They keep interrupting you when you try to explain how you feel or ask questions.</p>
<p>You feel free to ask questions about issues that may be difficult to discuss with other people, such as your sexual life or the fears you have about being sick.</p>	<p>When you ask the counsellor whether you should use condoms because you have several partners, they tell you that you should abstain from sex because it is "dirty". Counsellor uses judgemental wording.</p>
<p>The counsellor asks you relevant questions about yourself and your life. It really helps you explain how you are feeling.</p>	<p>You can only answer by "yes" or "no" to the questions the counsellor asks you. That makes you feel very frustrated because you have a lot to ask or share.</p>
<p>If you seem preoccupied or agitated, the counsellor explains in different words what you have said, which helps you reflect and also calm down.</p>	<p>The counsellor always repeats what you say. You have the feeling that they think you are completely stupid.</p>



## Information sheet 6: Good-quality counselling (continued)

Good-quality counselling	Bad-quality counselling
Thanks to these questions and explanations, you can prioritise your problems and understand better where you should start.	Things seem more and more confused during the counselling session. You have the feeling that you will never be able to deal with so many problems.
The counsellor explains things in a language that you understand. They ask you whether their explanations are clear, if there are words that are too complicated, if you want them to repeat something.	The counsellor uses lots of words you don't understand. If you ask a question about something you didn't understand, they tell you that you should know this already/make you feel very stupid.
The counsellor makes you feel that you have various options and that you have the capacity to make decisions and choose the best option for your life and the life of your loved ones.	The counsellor tells you what you should do. They act as if they are preaching, resulting in you feeling awkward.
The counsellor helps you understand what risks you have been/are exposed to.	The counsellor tells you that you are a bad person or a sinner.
If you cry, the counsellor tells you that it is normal to cry in this situation and that it may help you.	If you cry, the counsellor seems uncomfortable or annoyed and tells you that they/you will have to come back when you feel better.
The counsellor encourages you when you make decisions and take action to solve your problems.	The counsellor makes you feel that everything you do/say/feel is wrong.
At the end of the session the counsellor summarises what happened and discusses with you the next step(s) after the counselling session.	The counsellor says goodbye and you don't know exactly what will happen next.
The counsellor refers you to one or several organisations, structures and/or individuals based on your needs. They explain to you where to go, when to go, what kind of service you will get, and may even give you a letter of referral.	When you leave, you feel that there is nowhere to go and no one to talk to in order to get additional support.

# Information sheet 7: Issues around confidentiality

## Confidentiality

Confidentiality refers to the ethical and/or legal duty of the health care provider (for example, the counsellor) not to disclose to anyone else, without authorisation, information that was given to, or obtained by, the health care provider in the context of their relationship with a client.

In the context of HIV/AIDS:

- confidential information includes the client's HIV status and requires that the health care provider should seek the consent of the person infected for the disclosure of their HIV/AIDS status to others
- confidentiality also includes the expectation by a person with HIV/AIDS that their status will not be disclosed without their consent by other persons with whom that information may be shared; for example, other health care providers.

Confidentiality is the basis for an effective relationship between patient/client and health care provider. Only if a person feels sure that the health care provider will keep confidential any information provided will they come forward and share information.

All records on clients, whether or not they involve HIV-related information, should be managed in accordance with appropriate standards of confidentiality.

The principle of confidentiality is absolute and should be guided by the principle of informed consent; for example, where relevant information can be shared among health care providers. This allows a small group of health care providers to share personal information about a client, including HIV status, that is essential to their effective care and support. However, confidentiality should be maintained within this small group.\*

## Anonymous testing

- In some cases the HIV counselling and testing process can be anonymous. This means that the counsellor and the person who takes the blood (or saliva/urine) test do not know the name of the person or other details that could identify them (for example, their address). In this case, a number is usually given to the person and they have to show this number when they come back for the result.
- Anonymous testing helps keep the data on the person tested completely confidential. It can be used in VCT centres but is impossible to use in health care facilities, for example, where HIV counselling and testing is offered to people who receive care, or in diagnosis and treatment centres for TB and STIs, because in these settings people will already have medical records.
- Anonymous HIV counselling and testing does not allow for effective referral as, for example, the counsellor cannot contact the client to make sure that they have gone for an appointment at the hospital or have met people living with HIV who run a self-help group.

Anonymous HIV counselling and testing is not necessary where confidentiality is properly maintained by all health care providers involved in the process, and guided by the principle of informed consent.

\* For more information see UNAIDS (2000).

## Procedures to protect confidentiality

- Written information on clients (for example, medical records) should be controlled and accessible only to a very small number of health care providers.
- Written information on clients should be kept in a place that is not accessible to everybody, and preferably locked in a cabinet where possible.
- Names of clients can be written on one main register, with a corresponding code for each client. Only the code can then be used on all other documents.
- Health care providers should not mention any information on clients when they are in public.
- All staff and volunteers of health care facilities, NGOs and CBOs in contact with people who go through the HIV testing and counselling process should be trained on issues regarding confidentiality. Staff at the reception desk should not ask clients questions that may be embarrassing, such as "Are you coming for the HIV test?", if there are other people around.
- Counselling should be done in a place where privacy is respected, which means that counsellor and client cannot be seen or heard by other people during the counselling session.

# Information sheet 8: Some case studies of NGO involvement in voluntary counselling and testing service provision

## AIDS Concern, Hong Kong: Outreach VCT for men who have sex with men

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AIDS Concern is an NGO based in Hong Kong, whose HIV prevention projects focus on men who have sex with men, sex workers and their clients, cross-border travellers and young people at risk.

At the end of 2003, there were 2,244 recorded cases of HIV in Hong Kong. Of the 1,789 cases infected through sexual transmission, approximately one-third was through male-to-male sex. Among men who have sex with men in Hong Kong, the testing rate is relatively low at 15%. Existing VCT services in Hong Kong are very much clinic based and non-targeted, resulting in men who do decide to go for a test often fearing discriminatory or negative reactions, as well as having to conceal their real sexual identities.

Based on these findings, AIDS Concern began to tailor VCT services specifically towards men who have sex with men. They hoped that a non-judgemental approach to VCT would be more of a motivation for men to get tested, as well as helping men who have sex with men feel more comfortable about having open discussions about their sexual health and behaviour.

AIDS Concern developed an innovative outreach service, proactively reaching out to men who have sex with men in accessible and identifiable locations – specifically, saunas. Offering urine tests allowed for greater flexibility, as this type of HIV test is more suited to the sauna environment and no medical qualification is required to administer the test.

The outreach service is peer led, which has encouraged mutual understanding and more open discussion. The service is anonymous and confidential, with no real name or identification needed, only an assigned code number. The HIV test is conducted in private rooms inside the saunas and the results are given outside the sauna.

Before embarking on this original approach, AIDS Concern consulted extensively with the community, with the owners of saunas used by men who have sex with men, and with users themselves to assess their needs and attitudes to such a service. They also consulted relevant experts from existing government- and NGO-run VCT centres, and spoke to people living with HIV about their HIV testing and counselling experiences. For medical referral and case reporting, they consulted with the Department of Health, and for workers' safety they liaised closely with the police.

The project's outreach workers are people with social work training. They are trained in the administration of the HIV test, and have specialised training in pre- and post-test counselling. A counselling protocol has also been developed, coupled with regular training and supervision.

AIDS Concern has faced a number of challenges in developing VCT outreach in saunas in Hong Kong. These have included tackling the stigma individuals face in getting tested. A light-hearted promotion approach, particularly through posters showing the test as a healthy act, has been a successful way to combat this. Mobilising the community too has had its challenges. However, in targeting a few saunas at first, their successful experiences have encouraged other saunas to participate.

AIDS Concern is now looking positively to the future and aims to expand the current coverage, with more saunas participating, and services delivered in a more varied format; for example, providing HIV testing outside saunas and carrying out rapid and STI tests. AIDS Concern also intends to promote and advocate for a more supportive environment for HIV testing in the community.

## Remedios AIDS Foundation, Inc: Experience of working towards an enabling and supportive community for people living with HIV/AIDS

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Remedios AIDS Foundation, Inc., based in Manila, is the only NGO VCT service provider in the Philippines. The Foundation initiated the delivery of VCT services in 1992 through HIV testing. It then expanded its VCT activities to include HIV volunteer counsellor training workshops to deliver hotline and face-to-face counselling, and training for peer clients from communities of sex workers, men who have sex with men, people living with HIV/AIDS, and from young people.

Since then, the Foundation's VCT has been mainstreamed into the delivery of a comprehensive range of HIV/AIDS services, including counselling, training, a resource centre, the development and distribution of information, education and communication materials, adolescent reproductive health services, care services (clinical and diagnostic), community support services to people living with HIV/AIDS, and advocacy and networking.

## Information sheet 8: Some case studies of NGO involvement in voluntary counselling and testing service provision (continued)

A core strategy of the Foundation is to ensure the involvement of people living with HIV/AIDS in VCT service delivery. To this end, the Foundation works closely with the Philippine network of people living with HIV/AIDS – the Pinoy Plus Association. The Foundation provides capacity building and technical assistance to people living with HIV/AIDS who wish to become counsellors through HIV/AIDS counsellors workshops and training. They also run peer outreach programmes with sex workers, men who have sex with men, and drug users. Post-test referral mechanisms are also in place to support groups of people living with HIV/AIDS, and for follow-up counselling sessions for those recently tested HIV positive.

The Foundation has encountered challenges in maintaining their specialist VCT service. These have included the need to expand/scale up VCT services while also sustaining funding support for hotlines, counselling and clinic laboratory maintenance in a low-prevalence setting. An additional challenge is related to the fast turnover of volunteer counsellors, sometimes due to burn out or better opportunities elsewhere.

The Foundation's plans for the future include introducing mechanisms to ensure continuous VCT support through ongoing fundraising, soliciting private sector support and introducing resource generation mechanisms such as "user fees" testing. They will continue to promote their services through tri-media work within available resources in daily newspapers, free advertisement placements and websites, and plan to enhance their volunteer management programme.

### **Mexico City HIV/AIDS Programme: Mobile HIV counselling: an outreach strategy to demystify voluntary counselling and testing**

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The government-run Mexico City HIV/AIDS Programme has 33 centres that offer VCT free of charge. These centres are part of local clinics or health centres in each of Mexico City's 16 districts. In 2003, the government began a mobile VCT programme at events like concerts and festivals.

Encouraged by the success of the mobile VCT initiative, the directors of the Mexico City metro invited the HIV/AIDS Programme to participate in their science month event, held each year in October. Information about science and technology is handed out in a long tunnel that connects two of the main metro lines, taking advantage of the fact that passengers have to walk through it to change trains. A kiosk offering information about VCT to metro users proved so successful that it became a permanent feature.

The aim of the kiosk is to demystify information about HIV tests in order to confront the fears that people may have about taking a test. The pre-test counselling sessions offered at the kiosk inform metro users about what it means to take the test. Confidentiality is ensured through the design of the facility and by offering the service on an individual basis.

Each counselling session lasts around 30 minutes, giving users the chance to ask questions and clear up any worries they may have. They are then asked to sign a consent form, and a blood sample is taken by trained staff. Test results are sent to the VCT centre closest to the user's home. Counsellors also provide information about local NGOs where users can go for support while they wait for their results.

In 2003, 1,500 samples were taken at the kiosk. However, an important challenge is that only 50% of users collect their results. Counsellors become worried when they find that a person who has been diagnosed positive does not come back to pick up their results. The confidentiality guidelines mean that these cases cannot be followed up.

Initiatives such as this contribute to changing social beliefs about HIV and AIDS, and have also made early detection possible. Setting up a service in a public place allows people to access VCT when they are unable to go to a health centre. Users have indicated that they do not have enough time to take the test, that they do not know where their local health centre is, or even that their local clinic is too far away. In addition, the kiosks have provided an excellent opportunity to tackle issues related to HIV prevention and to promote condom use.

## Information sheet 9: What can prevent us from wanting to know our HIV status and taking the HIV test?

These are some examples of common reasons why a person does not go for HIV testing and counselling and some possible responses (they are suggestions only and local context and culture need to be taken into consideration).

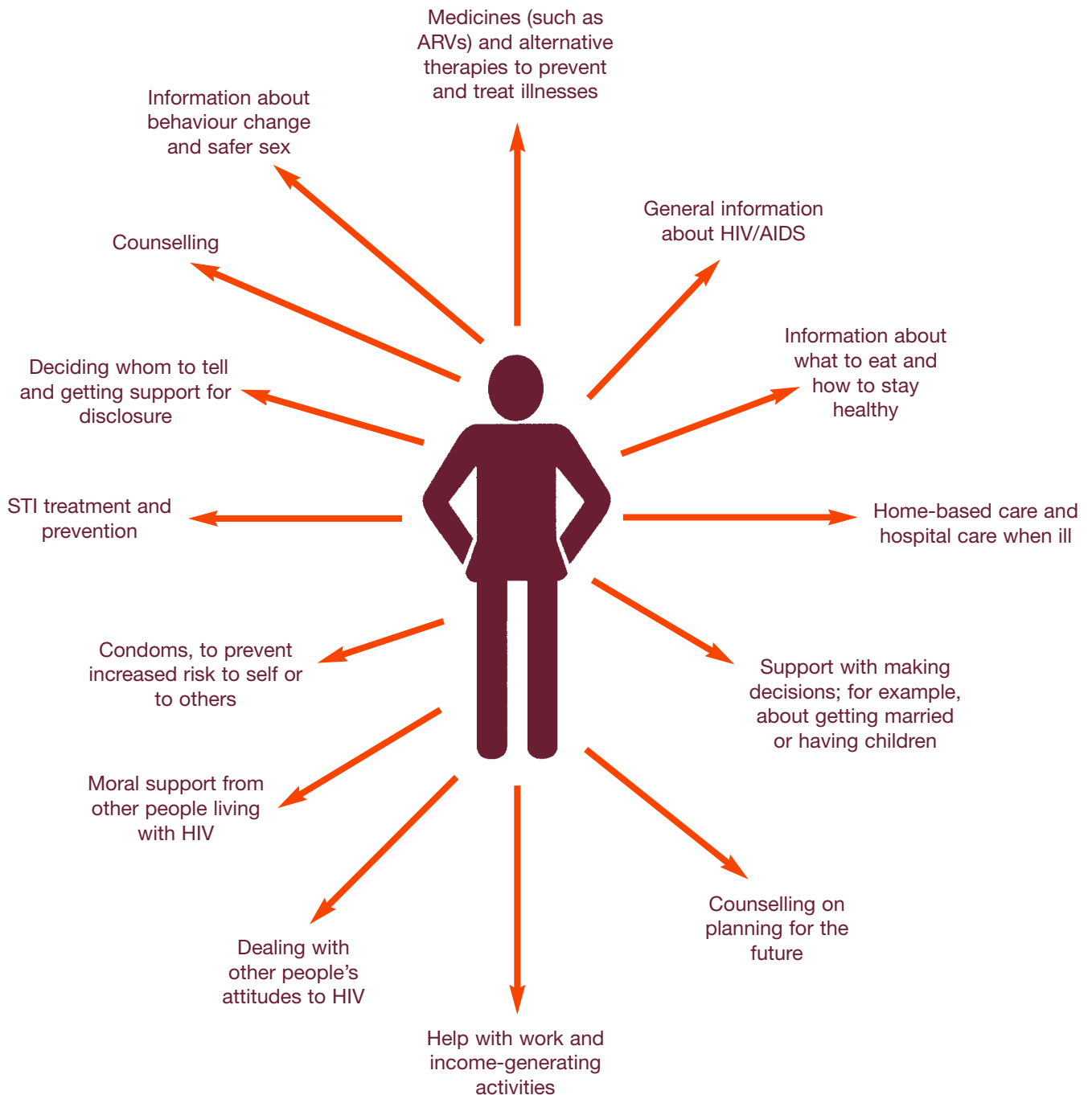
“I won’t be able to access HIV counselling and testing because...”	Possible responses to reasons why a person does not want to know their HIV status and take the HIV test
“... the facility where I could receive counselling and take the HIV test is too far away.”	<ul style="list-style-type: none"> <li>• In some settings there are more facilities where HIV counselling and testing are available than people think. For example, it might be possible to have pre- and post-test counselling at a local NGO or CBO, as well as clinics and hospitals.</li> <li>• Sometimes people may be able to combine going for HIV counselling and testing with other things that they need to do in that place, such as a check-up at the clinic or dealing with some business, going to the market, etc.</li> </ul>
“... I cannot afford it.”	<ul style="list-style-type: none"> <li>• In fact, often it is possible to find HIV counselling and testing services that are free of charge.</li> <li>• Where there is a charge for HIV testing, it can be relatively small.</li> </ul>
“... there is no point getting tested – AIDS drugs are too expensive and are not available in our community.”	<ul style="list-style-type: none"> <li>• In fact, many illnesses linked to HIV can be prevented or treated using simple drugs and remedies. If used at the right time and in the right way, these can help people to live healthier and longer lives.</li> <li>• It is true that some specific drugs for HIV are expensive. They are not available to everyone in the community. But the situation is changing gradually and some of these drugs might be available at a cheaper price in the near future.</li> </ul>
“... I don’t want people to see me going to the centre – they will think that I have AIDS.”	<ul style="list-style-type: none"> <li>• People do not have to go to a local centre for HIV counselling and testing. They could go to one in another community.</li> <li>• As more people learn about HIV/AIDS, they will see that going for HIV counselling and testing does not mean that someone has AIDS.</li> </ul>
“... If I go for a test, the counsellor will gossip to my friends and neighbours about me.”	<ul style="list-style-type: none"> <li>• HIV counsellors should have been trained to do their work, including keeping information confidential. They should not tell anyone else anything that the client says in their pre- or post-test counselling. They also should not reveal the client’s test result.</li> </ul>
“... people might tell my parents or family, friends, etc.”	<ul style="list-style-type: none"> <li>• HIV counselling and testing should be completely confidential.</li> <li>• Counsellors have been trained to keep information confidential.</li> </ul>
“... someone in my position/of my social standing cannot be seen to be HIV positive.”	<ul style="list-style-type: none"> <li>• HIV does not recognise social status, it does not discriminate and can affect people from any social group.</li> <li>• The more people are open about their status, the more obvious it will be that HIV can affect everyone, whatever their status in the community.</li> </ul>

## Information sheet 9: What can prevent us from wanting to know our HIV status and taking the HIV test? (continued)

<p><b>“I won’t be able to access HIV counselling and testing because ....”</b></p>	<p><b>Possible responses to reasons why a person does not want to know their HIV status and take the HIV test</b></p>
<p>“... if I find out that I am positive, I will be rejected by my family.”</p>	<ul style="list-style-type: none"> <li>• The test result will be confidential. It will be the client’s choice whether to tell anyone else.</li> <li>• During pre- and post-test counselling, the counsellor will help the client decide who to tell and who not to tell about the result. They will also give the client information about HIV/AIDS that they can share with those close to them.</li> </ul>
<p>“... HIV/AIDS is shameful. If I take a test, everyone will think that I have had had many different partners.”</p>	<ul style="list-style-type: none"> <li>• HIV/AIDS is a real issue for many communities and affects many different types of people. Just because a person tests HIV positive, it does not mean that they have behaved “badly”.</li> <li>• Whether a person has had one partner or twenty, being HIV positive is not shameful. People living with HIV/AIDS should be treated with respect.</li> </ul>
<p>“... if I test positive, it will mean that I am a sinner and I will be damned.”</p>	<ul style="list-style-type: none"> <li>• Being HIV positive is not a sin or the result of a sin.</li> <li>• Many church groups offer care to people living with HIV/AIDS. This often includes spiritual support and prayer to help people to come to terms with their HIV status.</li> </ul>
<p>“... I am scared to find out that I am positive as it will be too depressing.”</p>	<ul style="list-style-type: none"> <li>• A positive result can be a big shock. But it can also be a new beginning. If the person knows that they are positive, they can do something about it by taking care of themselves and leading a healthier life. In the longer term, it will be easier to know the truth than to worry about all of the possibilities.</li> <li>• There are many ways to live positively with HIV/AIDS, and many different people and organisations that can help a person to do so.</li> </ul>
<p>“... I’m not at risk.”</p>	<ul style="list-style-type: none"> <li>• HIV does not discriminate; it can affect anyone.</li> </ul>
<p>“... I have only ever had one sexual partner so I can’t possibly be HIV positive.”</p>	<ul style="list-style-type: none"> <li>• Even if a person is faithful to one partner, they might still be at risk of HIV. This is because it is possible that the partner is having other relationships and is not practising safer sex, such as using condoms.</li> <li>• Even if a partner is faithful now, they might have had other sexual relations in the past. Therefore, it is possible that they were HIV positive before they met the person.</li> <li>• A sexual partner can also have been an injecting drug user in the past and may not have shared this information.</li> </ul>

## Information sheet 10: What are a person's needs after they test for HIV?

This drawing shows some examples of the needs of a 'typical' person after they have gone through HIV counselling and testing and tested HIV positive.



AIDS	A person is said to have Acquired Immune Deficiency Syndrome (AIDS) when their immune system has been weakened over a period of time by HIV and they have a combination of symptoms and illnesses. These are referred to as opportunistic infections, because these infections take advantage of the fact that the immune system is progressively getting weaker and attack the body. Many people who are HIV positive do not get sick or develop AIDS for many years.
Antibodies	Antibodies are proteins produced by the body's immune system in response to bacteria, viruses or other foreign substances. Antibodies attach to the viruses and bacteria and attack or neutralise them.
Antiretroviral drugs (ARVs)	Antiretrovirals are drugs that fight HIV. They are called antiretrovirals because HIV is a retrovirus. There are different kinds of antiretrovirals that fight HIV in different ways. One kind of antiretroviral cannot be used alone, it has to be used with two other kinds of antiretrovirals (see <b>Combination therapy</b> ) according to international recommendations on antiretroviral therapy to treat people with HIV/AIDS.
Asymptomatic	A person who is HIV positive and has no clinical symptoms is called asymptomatic. A person living with HIV can be asymptomatic for many years after they are infected with HIV.
Blood safety	Blood safety refers to the process of testing blood to see if it contains infectious agents capable of being transmitted to those who receive the blood. It is also known as screening. WHO recommends that all blood and blood products be screened for HIV, hepatitis B and C, syphilis and, where appropriate, other markers of infection, such as Chagas disease and HTLV I/II, if they are to be stored in a blood bank.
CD4 cells/CD4 count	<p>If the HIV is left untreated, it will destroy a type of white blood cell called CD4 T-cells, which play an important role in our immune system.</p> <p>The number of CD4 blood cells that we have is called our CD4 count. The lower your CD4 count is, the more likely we are to show signs of illness. However, a low CD4 count is not an illness in itself. Some people remain well when their CD4 counts get lower, at least for a while. Other people with HIV may start developing symptoms before their CD4 count is lowered.</p> <p>A low CD4 count is less than 200 and at this stage treatment will need to be considered.</p>
Combination therapy	Combination therapy is a mix of several antiretroviral drugs that is used to treat people who have HIV/AIDS. Combination therapies should include three antiretroviral drugs according to international recommendations on antiretroviral therapy to treat people with HIV/AIDS. In some cases, they include only two antiretroviral drugs or more than three.



HIV	The Human Immunodeficiency Virus was identified in 1984. It is a virus that attacks the defense or immune system of human beings. The immune system helps the body fight off infections. HIV attacks the immune system, making it weaker over a period of time and therefore unable to fight off infections as efficiently. HIV is a special kind of virus called a retrovirus.
HIV counselling	HIV counselling provides information, support and referral through a dialogue with a trained counsellor (see <b>Section 2</b> and <b>Information sheet 6</b> ).
(HIV) Incidence	(HIV) Incidence refers to the number of new infections in a population or country over a specific period of time; for example, one year.
Informed consent	<p>The permission granted by an individual undergoing any kind of intervention (such as an HIV test) after they have received comprehensive information about the intervention.</p> <p>It is based on the principle that competent individuals are entitled to make informed decisions regarding their participation in, or agreement to, certain events in the context of a professional relationship between health care provider and patient/client. Informed consent protects the person's freedom of choice and respects their autonomy, particularly with respect to decisions affecting their body and health. In the HIV field, health care professionals have an ethical duty to obtain informed consent in order to administer HIV tests and other HIV-related health care interventions, and before disclosing to others any HIV-related information concerning a patient/client, including their HIV status (UNAIDS/WHO, 2000).</p>
Opportunistic infection (OI)	These are infections that usually do not cause disease in people with healthy immune systems. Some opportunistic infections experienced by people with advanced HIV infection include pneumocystic carinii pneumonia, Kaposi's sarcoma, cryptosporidiosis, histoplasmosis, other parasitic, viral and fungal infections, and some types of cancers.
Post-exposure prophylaxis (PEP)	<p>Post = after; Exposure = a situation where HIV has a chance to get into someone's bloodstream; Prophylaxis = a treatment to prevent an infection from happening.</p> <p>PEP is treatment to stop a person becoming infected with HIV after it has got into their body. It consists of starting a special course of anti-HIV medication (antiretrovirals) within the first 24 to 48 hours after exposure, and continuing this medication for a month in order to stop the virus from replicating. PEP should not be seen as a routine HIV prevention method as it is costly, always needs medical supervision and is not readily available. Condom use continues to be the most effective form of preventing sexual transmission because of availability, cost and ease of consistent use.</p>
(HIV) Prevalence	Usually given as a percentage, HIV prevalence is the proportion of individuals in a population who have HIV at a specified point in time (UNAIDS/WHO, 2000).

<p>Re-infection</p>	<p>Re-infection is infection with the same strain of HIV but from a different person. Since the virus changes once it is inside a person, particularly if that person is on antiretroviral therapy, it is possible to acquire the same strain with different properties from another person. It may be a “drug-resistant” strain if that person was on antiretroviral therapy. See also <b>super-infection</b>.</p>
<p>Resistance (resistant) to drugs</p>	<p>HIV reproduces itself very quickly, making billions of new copies every day. Since the virus often makes mistakes when copying itself, each new generation differs slightly from the one before. These tiny differences are called mutations.</p> <p>Some mutations occur in the parts of HIV that are targeted by anti-HIV drugs. This can result in strains of HIV that can still copy themselves when the drug is present in the body. These HIV strains are called drug resistant.</p> <p>Resistance is an important reason why an anti-HIV treatment can fail. (NAM/AIDSMAP, 2004)</p>
<p>Retrovirus</p>	<p>HIV is a retrovirus. “Retro” means “backwards” or “reverse”. A retrovirus is a type of virus that must use a substance called “reverse transcriptase” to copy itself in the cells.</p>
<p>(HIV) Seroconversion</p>	<p>The time at which a person's antibody status changes from negative to positive.</p>
<p>(HIV) Seroconversion illness</p>	<p>Before the appearance of antibodies to HIV in the blood, some people may develop symptoms following exposure to HIV. Antibodies usually become detectable at the same time as this illness. This is known as seroconversion illness. The symptoms include:</p> <ul style="list-style-type: none"> <li>• prolonged fever (4 to 14 days) and aching limbs</li> <li>• red blotchy rash over the trunk</li> <li>• sore throat (pharyngitis)</li> <li>• ulceration in the mouth or genitals</li> <li>• diarrhoea</li> <li>• severe headaches</li> <li>• aversion to the light.</li> </ul>
<p>(HIV) Strains and types</p>	<p>HIV is a highly variable virus, which changes or mutates very readily. This means that there are many different <b>strains</b> of HIV even within the body of a single infected person. Based on genetic similarities, the numerous virus strains can be classified into <b>types</b>, groups and subtypes.</p> <p>There are two types of HIV: HIV-1 and HIV-2. Worldwide, the predominant virus is HIV-1. The relatively uncommon HIV-2 type is concentrated in West Africa. HIV-1 and HIV-2 can be classified into three groups, each of which has subtypes.</p>

<p>Super-infection</p>	<p>Super-infection is infection with a different strain or type of HIV in addition to the strain or type already present in the body; for example, someone infected with HIV-1 can acquire HIV-2.</p>
<p>Universal precautions</p>	<p>Universal blood and body-fluid precautions (known as Universal precautions or Standard precautions) were originally devised by the United States Centre for Disease Control and Prevention in 1985, largely due to the AIDS epidemic and an urgent need for new strategies to protect hospital personnel from blood-borne infections. The new approach placed emphasis for the first time on applying blood and body-fluid precautions universally to everyone regardless of their presumed infectious status.</p> <p>Universal precautions are a simple standard of infection control practice to be used in the care of all patients at all times to minimise the risk of blood-borne pathogens. Universal precautions consist of:</p> <ul style="list-style-type: none"> <li>• careful handling and disposal of sharps (needles or other sharp objects)</li> <li>• hand-washing before and after a procedure</li> <li>• use of protective barriers, such as gloves, gowns, masks, for direct contact with blood and other body fluids</li> <li>• safe disposal of waste contaminated with body fluids and blood</li> <li>• thorough disinfection of instruments and other contaminated equipment</li> <li>• protected and safe handling of soiled linen.</li> </ul> <p>(ILO, 2001)</p>
<p>Viral load</p>	<p>Viral load refers to the amount (that is, the number of copies) of HIV genetic material circulating in the blood plasma (the fluid that carries blood cells). A viral load test is therefore a blood test.</p>
<p>Virus</p>	<p>A small organism that needs other organisms' cells to reproduce.</p>
<p>Window period</p>	<p>The time between when HIV enters our body and when our body produces enough antibodies to be picked up by an HIV test. It can last up to three months.</p>

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