

Counselling and testing for HIV

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Introduction

If you, as a health care provider, suspect that a patient has human immunodeficiency virus (HIV), then HIV testing should be considered. In this chapter there is information on what is required to perform an HIV test. HIV testing must not be done without INFORMED CONSENT of the patient and there are several approaches as to how this can be facilitated.

HIV testing should always be conducted with pre test counselling and followed by post test counselling irrespective if the result is positive or negative. Counselling prior to and after an HIV test has many benefits including:

- providing patients with key information to make their own decision about whether to have the test
- assisting in reducing stigma and discrimination by providing factual information and increasing awareness about HIV and acquired immunodeficiency syndrome (AIDS)
- assisting the health care provider and patient to ascertain the patient's level of risk of HIV
- enabling the health care provider and patient to discuss and identify the patient's coping mechanisms while waiting for the test and the result
- promoting behaviour change to minimise HIV risk in the future for those testing negative or positive.^{1,2}

Essential aspects of HIV counselling and testing

The three Cs of HIV testing

Recognised in the UNAIDS/WHO policy statement on HIV testing, HIV testing must be conducted under the following principles:³

The process and results must be:

- **CONFIDENTIAL**
- Accompanied by pre test and post test **COUNSELLING**
- Only conducted with informed **CONSENT**, meaning that it is both informed and voluntary.

Confidentiality

Any HIV test must be confidential. The counselling session prior to obtaining informed consent should be provided in a confidential situation, preferably in a private room and one-to-one. If the patient is accompanied by a support person, then you could ask if your patient would like to have a private discussion or could offer for the patient to return at a later time to take the test independently.

Wherever possible, the test itself should be coded and not labelled with the patient's name. This de-identification is especially important in small communities where other health facility staff, such as laboratory technicians, may recognise the patient's name. This procedure should be discussed with the patient to ensure them of confidentiality.

The results must be kept confidential and, ideally, the same health care provider who provided the initial counselling should also provide the test results. The patient should be informed that the test result will be kept confidential by health care providers and the health facility, and that no one else will be informed of the HIV results unless the patient consents or, more importantly, chooses to disclose his/her status independently.

Accompanied by counselling and factual information

All HIV testing should be accompanied by counselling, giving of factual HIV information, and a personal risk assessment. Providing the client with information and facilitating discussion about HIV provides an opportunity for learning, correcting misinformation, assisting the patient in identifying personal risks and coping strategies in preparation for the result. It also provides an opportune environment to promote behaviour change, and in turn, normalises the testing process that assists in decreasing stigma and discrimination.

Please see the boxes below regarding the information that should be discussed prior to obtaining informed consent and when delivering HIV test results.

Informed consent

For patients to provide informed consent prior to HIV testing, they must be provided with HIV test counselling and information so that they have an understanding of the implications of the HIV test and the course of events that testing could set in motion.

It does not matter if the results are positive or negative, each person should be equipped to make the decision for themselves at that time, voluntarily, free from any form of overt or implied coercion.

Throughout Asia and the Pacific regions, there are different requirements for obtaining consent. In some cases consent must be provided in writing while in others verbal consent is considered adequate to proceed with testing. If you are unsure as to what procedure should be followed in your health facility, please consult with an HIV specialist or another facility that has more experience with HIV counselling and testing.

Voluntary

All HIV testing must be voluntary, which means that a patient has the right to decide, after counselling, to be tested or not. If patients are undecided, they should be informed that they can return at any time when they are prepared to take an HIV test.

This type of testing is called “opt-in” testing, that is, the patient opts to have an HIV test based on the advice and decision made during pre test counselling.

There is also another type of testing called “opt-out” testing; this means that the patient will be tested unless they choose to specifically decline a test. This type of testing still requires the health care worker to inform the client about the HIV test and provide an opportunity to decline.

Patients have the right to decline an HIV test. They should not be tested for HIV against their will, without their knowledge, without adequate information to decide whether to consent, or without arrangements to receive their test results in a post test counselling session.^{4,5}

At no time is it acceptable to coerce or perform mandatory testing. It is acknowledged however, that in some institutions and health facilities across the Asia and the Pacific Regions that this does occur.

Human rights-based approach

There is also an ethical and human rights approach to HIV counselling and testing. Due to the potential for stigma and discrimination that a patient may face just in having the test performed, it is important to provide the patient with appropriate information with which to make an informed decision.

The human rights-approach⁶

- Right to information
- Right to give informed consent after full disclosure of relevant information
- Right to respect for cultural and religious beliefs
- Right to know to whom the result will be disclosed
- Right to treatment even if the test is refused

Issues of access to counselling and testing

Attitude of the health care provider

Health care providers need to understand the effect that their own attitudes and beliefs have on the patient and the HIV counselling and testing experience. The atmosphere created by the health care provider for the pre test counselling session needs to be one of respect and mutual positive regard, remembering that the patient is the authority on his or her life and lifestyle and not the health care provider.

It is also important for the health care provider to have an understanding of cultural, social and religious factors that influence the interaction with the patient and also the implications about how people with HIV are perceived within their broader social networks.

Cultural, social and religious issues

Throughout the Asian and Pacific regions, within countries and in small communities, there are many different cultural, social and religious beliefs that affect how HIV is perceived and ultimately how people with HIV and their families and friends are viewed and treated. HIV counselling and testing has to be tailored to the patient. Some common examples of how social, religious and cultural issues affect HIV are:

- Discussion of sexuality is often taboo and patients may not be aware of even basic facts about sexuality, gender and sexual health; hence, there is an increased need for simple factual information.
- Superstitions and personal beliefs may also influence commonly held norms or activities; myths need expounding by giving factual information in a sensitive manner. For example, it is a common belief in the Pacific that it is unsafe to have sex when pregnant so men may go to sex workers and come back to their wives after the birth and possibly transmit HIV to mother and child while she is breastfeeding.

- Societal attitudes and beliefs about men who have sex with men, sex work, sex outside of marriage and injecting drug use are often discriminatory; members of these groups are usually stigmatised, marginalised and less likely to seek access to health services. Testing services for these most-at-risk groups need to be easily accessible, so that clients are safe from physical or psychological harm. This harm may occur through discriminatory practices or attitudes from the service or through the community, such as harassment from police, or discriminatory groups that may target people using the service.

Patients can decline a test

Patients, regardless of how ill they may be or how important it would be to confirm an HIV diagnosis, have the right to decline a test in any situation. The decision to decline a test may not be necessarily a wrong or bad decision and should not be used against a patient.

Patients may decline a test because they are concerned about confidentiality aspects of the service or location; they may have a family member present and prefer them not to know about the test, or they may not feel comfortable in having a test at that time. Others may be afraid to know their status. No matter what reason is given, a patient should make their own decision about having a test. If patients decline a test, the health care provider should inform them:

- that they can return at any time for further information and or testing
- of other health facilities that can offer HIV counselling and testing services
- of information that can be used in prevention and risk reduction for that individual
- that declining the test does not affect any other health service provision.³

While it may seem that the time spent discussing an HIV test was wasted, if done properly, it has equipped patients with key information about HIV and prevention of transmission, the ability to consider their own behaviours and could facilitate behaviour change, especially if a personal risk assessment has been facilitated.

Pre and post test counselling

There are many possible topics that should be included in an HIV pre or post test counselling session. However, it is important to tailor the discussion to the patient. Below is a list of items that make up the essential standards for HIV testing and counselling services in the Pacific region.⁷

Pre test counselling

- **Confidentiality:** The patient's legal rights around confidentiality are outlined and counsellors explain how confidentiality will be maintained at the HIV testing and counselling service.
- **Information about HIV:** Basic information regarding HIV infection is provided, including how it can and cannot be transmitted, disease progression, opportunistic infections and treatments available.
- **Risk assessment:** A comprehensive risk assessment is conducted to identify possible risks, and safer behaviours are discussed.
- **Transmission prevention:** Information about the prevention of HIV transmission is provided and, where necessary, problem-solving strategies around an individual patient's barriers to practising safer behaviours are discussed.
- **Window period:** An explanation is given of the window period of the HIV tests used and the limitations this places on the accuracy of the test results.
- **Reasons for testing:** The patient's motivation for attending for testing and counselling is assessed. This may expose previous risk incidents or highlight misconceptions about risk behaviours that need to be addressed.
- **Advantages and disadvantages of testing:** The advantages and disadvantages of testing are explained so the patient is capable of making an informed decision about whether or not to proceed with testing.

- **Right to decline:** The patient is made aware of his or her right to refuse to test or to withdraw from the testing procedure at any time.
- **Declining does not impact on service access:** Patients are informed that their decision regarding testing will not affect their rights to access other services within the health facility, with the exception of those services which rely on knowledge of a patient's HIV status, such as access to antiretroviral medications.
- **Follow-up services:** Patients are advised about services that would be available if they were to test positive (reactive).
- **Disclosure if positive (reactive):** Patients are encouraged to think about who would be their key supports in the event of a positive result. It is advisable to consider this aspect as part of pre test counselling as the patient may be emotionally overwhelmed and unable to think clearly about this issue during post test counselling.
- **Opportunity for questions:** The patient is provided with ample opportunity to ask questions.

At the completion of pre test counselling, the patient should be provided with relevant information education communication (IEC) materials and information on the process for obtaining results.

Post test counselling: negative result

- **Explanation of result:** It is explained to the patient that a negative test result indicates that the patient has not developed antibodies against the virus which means that the patient has not contracted HIV.
- **Window period:** The counsellor should ensure that the patient understands what the window period is, how this might impact on the interpretation of negative test results and whether a follow-up test is recommended.

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Post test counselling: negative result (Continued)

- **Transmission prevention:** Information is provided to the patient about protection from infection in the future, including the use of condoms and safer sexual practices.
- **Condom provision:** Education is provided about the importance of condom use in transmission prevention and the patient is offered condoms either free of charge, or at a subsidised cost.
- **Referral if necessary:** Information is provided regarding services available to the patient if additional support (e.g. social support networks) is needed. In the event that the HIV test counsellor feels the patient is in need of further counselling or specialist assistance, the patient should be referred to other professionals as required.
- **Opportunity for questions:** The patient is provided with ample opportunity to ask questions.

Post test counselling: positive result

- **Explanation of result:** The result is explained clearly and the patient given time to consider it.
- **Assistance to express and cope with emotions:** Patients are encouraged to explore what they may be thinking and feeling about their result.
- **Identification of immediate concerns and support person(s):** Patients' immediate concerns about their results are discussed and strategies discussed in pre test counselling, including identifying a support person, are reviewed.
- **Advice about follow-up services and referral:** Information is provided to the patient regarding services available and how to access these services (e.g. medical review for treatment and antiretroviral therapy, social support networks and ongoing counselling).

- **Transmission prevention:** Patients are educated about how to prevent transmission of HIV and to protect themselves from other types of infection in the future.
- **Condom provision:** The patient is educated about the importance of condom use in transmission prevention and offered condoms either free of charge, or at a subsidised cost.
- **Preventive health measures:** Patients are educated about steps that they may take to improve their health and well-being, e.g. healthy diet, reducing stress, quitting smoking, regular medical monitoring and practising safer sex.
- **Discussion of disclosure:** Patients are encouraged to consider how they may disclose to their sexual partner and key supports. The advantages and disadvantages of patients disclosing their status should also be reviewed and discussed and how they might react if their confidentiality is breached.
- **Opportunity for questions:** The patient is provided with ample opportunity to ask questions.

The HIV test

There are many different types of HIV tests that can be performed. Please refer to the Chapter on Microbiology Laboratory Clues for HIV Diagnosis for further information. However, there are several issues that need to be raised with the patient during pre test counselling and again at post test counselling to ensure that the patient understands the HIV test result.

The window period

Currently, most tests can only detect HIV antibodies when they reach a certain level in the blood. It may take up to three months from the time of infection for this level to occur. This does not mean that there is an absence of the virus in the blood, but that our current technology is unable to detect the virus.

This means that a person with HIV infection could pass on the virus even if the blood test is negative. The only definite way to be absolutely sure of negative status is to be tested, to use preventive measures and to engage in no-risk behaviour for three months, and then to be retested.

Indeterminate test result

When an HIV test is performed, it may result in an indeterminate test result, which means it is unclear whether it is reactive or not. This result can be due to factors with the test itself, contamination of the sample or it could be that the patient's body is beginning to make antibodies at the very early stages of infection.⁸ Usually this result will mean that the patient will need to be recalled for further testing to ensure an accurate result.

Confirmatory testing

Depending on which HIV test is available and the national guidelines that your health facility uses, in the event of a reactive test, confirmatory testing needs to occur. In some regions after an initial test is positive, further blood is taken and sent to a reference laboratory for confirmation of a positive result. The reason to confirm an HIV test is to ensure accuracy.

The type of testing conducted in your health care facility should be explained to the patient prior to the HIV test.

Positive test result

If, after confirmatory testing, the result is positive, then the patient is said to have HIV infection (to be HIV positive), but this does not necessarily mean that the patient has AIDS.⁸ Patients should be informed of their result as soon as possible. An HIV test and the result should be kept confidential. Only patients themselves have the right to decide to whom and when they will disclose their result.

Further testing, psychosocial and medical support should be discussed with the patient as should appropriate referrals. It is the patients' decision if they are to follow-up with a referral, and confidentiality should be maintained. It is not appropriate to forward patient information to a referral agency without the patient's permission or knowledge.

Negative test result

A negative HIV result means that HIV antibodies have not been detected in the blood. A negative HIV test can mean either that the patient does not have HIV infection or that he or she is in the window period (see above) and should be retested if appropriate.⁹

Contact tracing

Contact tracing is when health care providers or health facilities attempt to identify sexual contacts of the person who has been newly diagnosed with HIV, in order to refer them to testing. It is not mandatory and throughout the region it is conducted differently.

If contact tracing is agreed to, then a discussion about the procedures should be held with the patient, however, contact tracing should be carried out by experienced health care providers and a referral for psychosocial and medical support for the contact person should be made to an HIV service. If you are unsure of the contact tracing procedures, you should consult with a specialist HIV service. In the Pacific region for example, core HIV teams can be consulted.

Key points

- HIV counselling and testing must be voluntary and with informed consent
- A patient has the right to decline a test
- Maintaining confidentiality throughout the counselling and testing process should be of the highest priority.
- Health care providers can seek advice from peers or specialist services if assistance is required, especially for communicating an HIV-positive result and when referring a patient with HIV to an appropriate facility for further care and support.

References

1. Coates TJ, Kamenga MC, Balmer D, Sangiwa G, Furlonge C, The voluntary HIV-1 counselling and testing efficacy study: a randomized controlled trial in three developing countries. AIDS Research Institute, Center for AIDS Prevention Studies, University of California, San Francisco. June 2000.

Available at: <http://www.caps.ucsf.edu/pubs/reports/pdf/VCTS2C.pdf> (Cited 17 June 2009).
2. Denison JA, O'Reilly KR, Schmid GP, Kennedy CE, Sweat MD. HIV voluntary counselling and testing and behavioural risk reduction in developing countries: a meta-analysis, 1990-2005. *AIDS Behav* 2008;12:363-73.
3. UNAIDS/WHO Policy Statement on HIV testing, June 2004.

Available at: http://data.unaids.org/una-docs/hivtestingpolicy_en.pdf (Cited 21 June 2009).
4. WHO/UNAIDS. Guidance on provider-initiated HIV testing and counselling in health facilities, May 2007.

Available at: http://whqlibdoc.who.int/publications/2007/9789241595568_eng.pdf (Cited 12 June 2009).
5. WHO/UNAIDS. Provider initiated HIV testing and counselling in health facilities.

Available at: <http://www.who.int/hiv/topics/vct/PITC/en/index.html> (Cited 12 June 2009).
6. Pacific Counselling and Social Services, Basic Counselling Skills for work in the HIV and other STI's Field, Lautoka, Fiji, (Unpublished) June 2009. To obtain a copy of the training manual please contact PC&SS at training.service@pcss.com.fj
7. Secretariat of the Pacific Community. A Guide to Evaluating HIV Testing and Counselling Services in the Pacific Island Countries and Territories (PICTs) using Minimum Standards, New Caledonia, SPC.

Available at: <http://www.spc.int/hiv/downloads/prevention-and-control-meeting-may-09/> as PICTs HIV TC Guide (5) Pre pilot Cited 17 June 2009.
8. Family Health International. VCT Toolkit. HIV Voluntary counselling and testing: Skills training curriculum. Facilitator's guide. Family Health International, January 2005.

Available at: <http://www.fhi.org/en/HIVAIDS/pub/guide/vcttrain.htm> Cited 17 June 2009.
9. Finger W, Fischer S, editors. HIV counselling and testing for youth: A manual for providers. Family Health International, USA, 2007:42.