

## YOUTH AS KNOWLEDGE PRODUCERS – TOOLKIT

### Arts-based approaches and ethics

If you use arts-based approaches for research or teaching ethics become a crucial issue. It is important that you protect the rights of the participants in your class or workshops. For example, if you conduct a Photovoice project and the learners produce pictures showing people, it is important to make sure that you have the consent of all the people in the photographs. Particularly HIV and AIDS is a sensitive topic often related to stigma. You must be extra careful when doing a project on HIV and AIDS that you have consent from all participants and that the participants know what your project is focused on. The consent form needs to be specific about how and where you plan to use the pictures. You must make it clear to your informants (those participating in your project) that they may at any time withdraw their consent. In case the learners are youth the guardians might have to sign the consent form. We have listed some of the principles included in the “Universal Declaration on Bioethics and Human Rights”, which refer to research and will be relevant for you when using arts-based approaches in the context of HIV and AIDS. It is important that you always reflect about ethics and the rights of your informants or participants and that you also engage your learners in discussions about ethical issues.

- **(Article 6, 2.) “Scientific research should only be carried out with the prior, free, express and informed consent of the person concerned.** The information should be adequate, provided in a **comprehensible form** and should include modalities for withdrawal of consent. **Consent may be withdrawn by the person concerned at any time** and for any reason without any disadvantage or prejudice.”
- **(Article 8) [...] “Individuals and groups of special vulnerability should be protected** and the personal integrity of such individuals respected. For example, when working with children, you will require the consent of the person that cares for them.”
- **(Article 9) “The privacy of the persons concerned and the confidentiality of their personal information should be respected.** To the greatest extent possible, such information should not be used or disclosed for purposes other than those for which it was collected or consented to [...]” When participants give their consent to have their picture taken or to be videotaped, you must explain what exactly you will be using these materials for. You cannot use the photos or video for any purpose outside of what you have told your participants they will be used for.”

UNESCO (2006) *“Universal Declaration on Bioethics and Human Rights”*, Paris: United Nations Educational, Scientific and Cultural Organization Division of Ethics of Science and Technology

## GUIDELINES FOR DRAWING UP AN INFORMED CONSENT DOCUMENT

The Informed Consent document could either be

1. in the form of a letter to the participant, containing information on the items listed below and concluding with a declaration allowing for the name of the participant, signature and date, or
2. drawn up as a declaration with a separate information sheet containing information on the items listed below

### NOTE:

in the case of 1 above, a copy of the signed consent has to be given to the participant.

## INFORMATION TO BE INCLUDED IN THE INFORMED CONSENT DOCUMENT

- The project title understandable by the lay person.
- A statement of the projects aims, in terms understandable by the lay person,
- The names, affiliations and contact details of the investigator/s, with qualifications where appropriate,
- Name, contact address or telephone number of an independent person whom potential subjects may contact for further information, usually the project supervisor, team leader or school director,
- A brief explanation of how the subject was identified,
- A clear explanation of what is required of the subjects who agree to participate, including descriptions of any procedures they will undergo and any tasks they will perform, together with an indication of any possible discomfort or any possible hazards involved. The estimated total time of involvement and the number of occasions or duration of time over which this involvement is spread should be stated.
- Potential benefits to be derived from participating in the study should be stated,
- An indication of payments or reimbursements of financial expenses incurred by subjects,
- A statement on the use of any written, audio or video recordings made,
- An indication of how and when the gathered data will be disposed of,
- A statement assuring confidentiality or anonymity as appropriate,
- A statement that a decision not to participate will not result in any form of disadvantage,
- A statement that participation is voluntary and that subjects are free to withdraw from the study at any stage and for any reason.

## EXAMPLE OF DECLARATION

I.....(full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

.....  
**SIGNATURE OF PARTICIPANT** **DATE**

**NOTE:**  
Potential subjects should be given time to read, understand and question the information given before giving consent. This should include time out of the presence of the investigator and time to consult friends and/or family.

## GETTING THE FACTS STRAIGHT – FACTSHEET

You might feel more comfortable having the necessary information at hand during lessons or activities about HIV and AIDS or when discussing the quiz results of the activity 2.1.A. So if you are unsure about certain aspects of transmission during moderating, check on this factsheet:

### **HIV (Human Immunodeficiency Virus)**

Your immune system keeps your body strong and free from infections. It is like a guard against disease. When you get infected with HIV, your immune system can be weakened, making you more vulnerable to infections and diseases. HIV infects and kills the cells that help your immune system detect infection and disease and fight against it. These cells are called CD4, or t-cells.

HIV lives in the bodily fluids (like blood, pre-ejaculate fluid, vaginal secretions and semen) and is transmitted if your fluids or an open sore come in contact with fluids from a person with HIV.

The main ways that HIV is transferred is through sexual contact without a condom. To protect against this happening, you must use a male or female condom every time you have sex, or abstain from sex. There is also risk of transmitting HIV through unprotected oral sex, although the risk is lower. Oral sex can be risky for the person using his/her mouth when there are open sores in the mouth or bleeding gums, or when semen enters the mouth and when any secretions are swallowed.

Other ways that HIV is transmitted is through:

- Blood Contact
- Sharing unclean needles
- Mother-to-child transmission (MTCT)

Blood Contact can occur through sharing needles and equipment used for injection drugs, through organ transplants or blood transfusions, and through sharing tattoo or skin piercing equipment. To avoid these transmission routes, you should never share needles or any equipment that comes in contact with blood.

While mother-to-child transmission of HIV occurs, including through breastfeeding, the actual mechanisms of transmission from mother to child are not well known. A minority (small amount) of infants being breastfed by HIV positive mothers become infected. HIV can be transmitted through breast milk, but women who exclusively breastfeed (defined as frequent feeding day and night, with no other food or drink, and no use of formula feeding) can reduce this risk significantly, increasing HIV-free survival for their children. The actual rates of mother-to-child transmission are influenced by many factors, some known and some unknown.

**If you are pregnant and HIV positive or want to get tested, you should speak with a health care provider or AIDS clinic to find out what you can do before the baby is born to reduce the risk of infection. There are some drugs available, which are taken before your baby is born and can greatly reduce the chances of your baby being born with HIV.**

Even if you have HIV, you can keep your immune system strong by staying healthy, exercising and eating well. Having HIV doesn't mean your life is over. You can still enjoy a happy, healthy life if you take good care of yourself and keep your immune system strong.

## AIDS (Acquired Immune Deficiency Syndrome)

AIDS stands for **Acquired Immune Deficiency Syndrome**. AIDS itself is not a single disease but rather a group or combination of illnesses that develop because the body can no longer fight disease as it normally would. Treatments now available (such as anti-retroviral) cannot cure HIV but can delay the development of AIDS for many years. Some hospitals give treatment to people who were raped in order to prevent HIV that must be taken shortly after the incident in order to decrease the risk of HIV infection. Please see the backside of this booklet for helpline numbers.

### Ways to avoid HIV infection:

- **Sexual Contact:** There are several ways to avoid infection through sexual contact: Abstain from sex, or if you do have sex, use a male or female condom every time. You can also reduce your risk by avoiding having multiple sexual partners.
- **Blood and blood products:** Do not share needles or injection drug equipment with others; or make sure that any equipment, including tattoo, piercing and circumcision equipment, is properly sterilized.
- **Mother-to-Child Transmission:** Women can be tested for HIV during the antenatal (before birth) period, and if she is HIV positive (or if her partner is HIV positive), there are different things that can be done. She can be counseled on her options and may receive treatment that could reduce the risk of transmission to the child. There are also things that can be done during the baby's delivery to minimize the risk of infection, such as having a Caesarean section, or receiving certain drug treatments.

Delaying when you start having sex is one of the best forms of protection for young people. You can also avoid HIV infection by practicing safe sexual activities like masturbation, using hands to stimulate your partner or dry humping and safer sex like deep kissing or oral sex on a man or woman using a condom or a plastic protector or vaginal penetration using a condom or anal penetration using a condom. A water-based lubricant also helps to reduce the risk of HIV transmission by decreasing the tearing of the vaginal tract or anus.

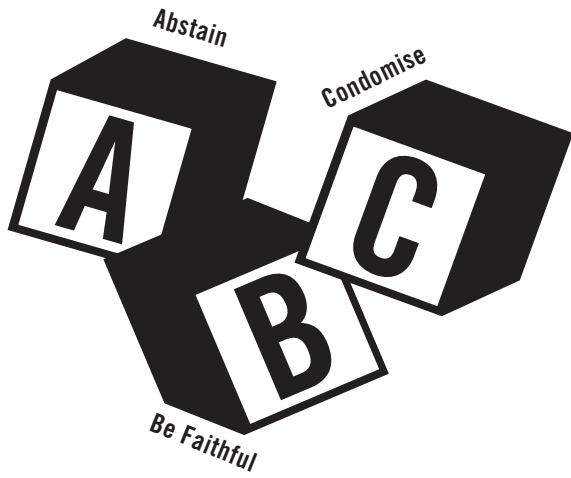
It is important to know your status and the only way to be certain of this is to get tested. There are a lot of testing sites which offer free HIV testing and counselling in South Africa. For more information please see the helpline numbers at the back of this toolkit.

## QUIZ: TESTING YOUR KNOWLEDGE ABOUT HIV/AIDS

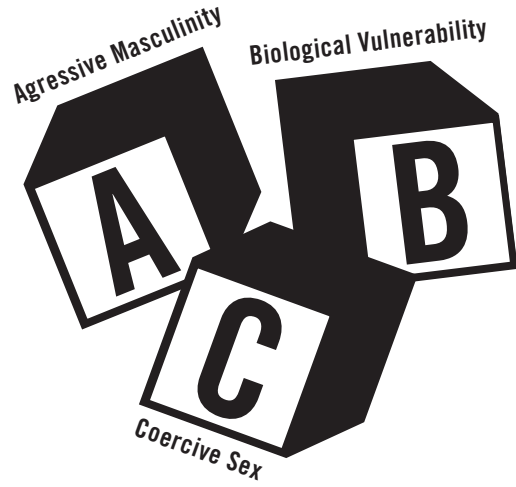
### TRUE OR FALSE?

1. You can get HIV by sharing a meal or drinking from the same cup as an infected person.
2. The HIV incidence rate among girls is three-four times higher than for boys.
3. A woman's biology increases her chances of getting HIV and AIDS.
4. A woman in a committed relationship doesn't have to worry about getting HIV and AIDS.
5. You should not be allowed to attend school if you have HIV.
6. If you teach sexuality education in schools, you encourage young people to have sex.
7. AIDS weakens your immune system so it has difficulty fighting other diseases.
8. People living with HIV and AIDS look very sick and are skinny.
9. Abstaining from sex will reduce your risk of getting HIV.
10. Girls who carry condoms are asking for it.
11. If a guy beats his girlfriend, it is because he loves her too much.
12. It's alright to delay or refuse sex if you are not ready.
13. If you go to a boy's house, it means that you want to have sex with him.
14. The female condom protects as well as the male condom against HIV.
15. Learners are our best resource in AIDS prevention programs.

**THE ABC'S OF HIV/AIDS PREVENTION**



**GENDERING THE ABC'S OF HIV/AIDS PREVENTION**



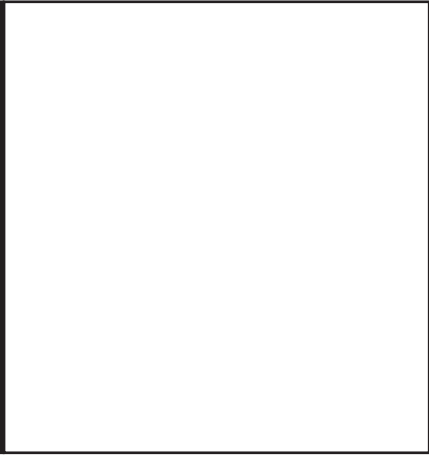
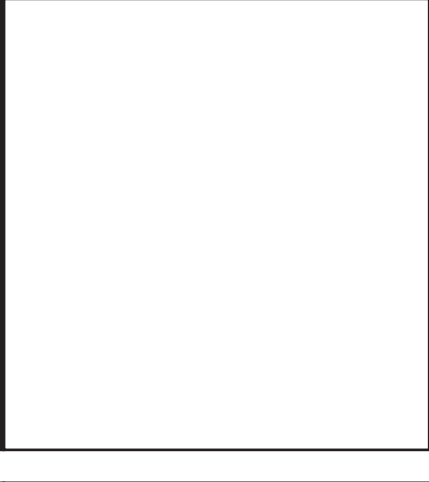
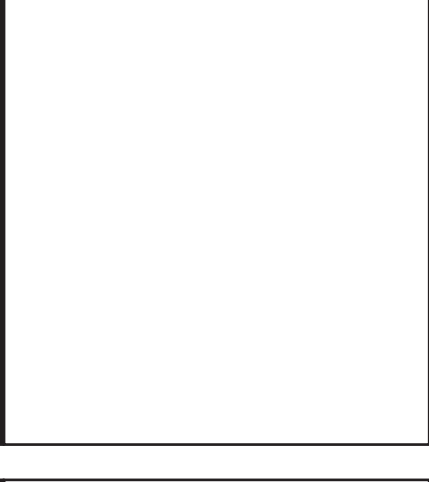
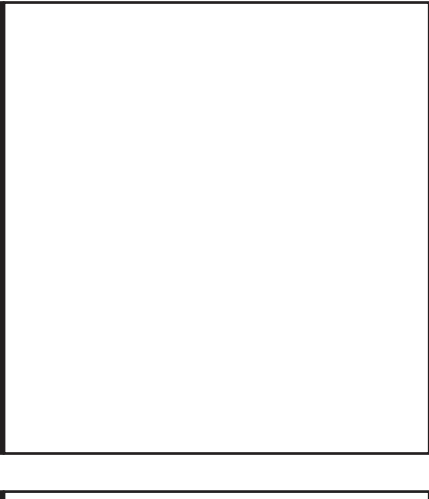
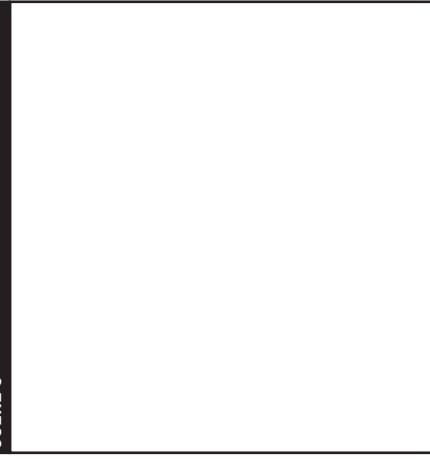



**GENDERING THE ABC'S OF HIV/AIDS PREVENTION**

Three 3D block outlines are stacked vertically, each followed by a horizontal line for writing.

What is meant by “gendering the ABC’s of HIV/AIDS”?  
Write your answers on the lines and in the spaces provided on the blocks above.

### STORYBOARD TEMPLATE

Use the storyboard technique to moderate the writing of a story to be filmed or acted. In each box of the storyboard the participants draw the skit of one scene with a short explanation. Later they add the name of the acting learners and the camera person for this scene. You can also develop the storyboard on the chalkboard and use this as an example.

<p><b>SCENE 1</b></p> 	<p><b>SCENE 2</b></p> 	<p><b>SCENE 3</b></p> 	<p><b>SCENE 4</b></p> 
<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>
<p><b>SCENE 5</b></p> 	<p><b>SCENE 6</b></p> 	<p><b>SCENE 7</b></p> 	<p><b>SCENE 8</b></p> 
<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>	<p>What happens?</p> <hr/>