

A NEW RESOURCE  
FOR COMMUNITIES  
FIGHTING HIV.

# GLOBAL HIV TOOLKIT FOR BEGINNERS



With helpful hints from Robin the Ribbon

## ACKNOWLEDGEMENTS

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## LEGAL

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## DISCLAIMER

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This guide is the result of a Queen's Young Leaders Programme Network Project Pilot. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of any one party or organisation.

The field of HIV is constantly changing, with new knowledge being added daily. It is therefore important to note that data in this educational tool-kit will eventually become out of date and in need of updating. Future updated versions will be made available on the website: **[www.justicedesk.org](http://www.justicedesk.org)**

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# INSTRUCTIONS FOR IMPLEMENTATION

The Global HIV toolkit is a year-long initiative led by Queens Young Leaders in South Africa, Canada and New Zealand, to educate, equip and empower young people to become HIV advocates for change.

## **The toolkit has three key chapters:**

- HIV Education
- HIV Projects
- HIV Advocacy

**This toolkit is meant to be used by young leaders across the globe who want to respond to the devastating root cause and effects of HIV/AIDS in their various homes, communities and countries.**

Drawing from collaborations with HIV resources throughout South Africa, Canada and New Zealand, the toolkit creates opportunities for young people globally to understand HIV/AIDS, how to engage in HIV advocacy movements, as well as how to produce and facilitate their own HIV/AIDS projects in their home countries.

Within this toolkit you will find “**Test Me**” pages. Use them to test what you have learnt, as well as to indicate what you should spend more time on.



# LIST OF ABBREVIATIONS

**HIV**

Human Immunodeficiency Virus

**ART**

Antiretroviral Treatment

**ARV**

Antiretroviral

**HAART**

Highly Active Antiretroviral Therapy

**AIDS**

Acquired Immune Deficiency Syndrome

**OI**

Opportunistic Infection

**STD**

Sexually Transmitted Disease

**STI**

Sexually Transmitted Infection

**RNA**

Ribonucleic Acid

**CD4**

Cluster of Differentiation

**HCT**

HIV Counselling and Testing

**HCW**

Health Care Worker

**IRIS**

Immune Reconstitution Inflammatory Syndrome

**TB**

Tuberculosis

**VL**

Viral Load

**WHO**

The World Health Organization

**UN**

The United Nations

**QYL**

The Queens Young Leaders

**ERJD**

The Edmund Rice Justice Desk – or – The Justice Desk

CH

ONE

# 01

# HIV EDUCATION

**The aim of chapter one** is to give an easy-to-understand overview of HIV and AIDS. Throughout the chapter you will become familiar with the definitions, stages, symptoms, treatments, myths and prevention strategies regarding HIV & AIDS. You can use this information in lesson plans, community-based initiatives and to increase your own understanding of HIV & AIDS.

# WHAT IS HIV & AIDS ?

## WHAT IS HIV?

HIV, or Human Immunodeficiency Virus is a virus that gradually attacks the body's immune system and specifically, the CD4+ T Cells. If left untreated, HIV reduces the number of CD4 cells in the body which makes the body more susceptible to infection.

### Q: What does it mean if a person is HIV Positive (+) or HIV negative (-)?

**HIV Positive:** If you are HIV Positive (+) it means that you have tested positive for HIV. This means that you have HIV.

**HIV Negative:** If you are HIV Negative (-) it means that you have tested negative for HIV at the time of testing. This means you do not have HIV.

If you test positive for HIV, it does not mean you have AIDS. However, when HIV is left untreated it can result in AIDS.

## WHAT IS AIDS?

AIDS is a syndrome caused by HIV which develops when an HIV infection is very advanced. AIDS is often referred to as the final stage of HIV. The individual's immune system becomes too weak to fight off infections.

### Q: What does it stand for? 'Acquired Immunodeficiency Syndrome'

**Acquired:** An infection people acquire or 'contract'.

**Immuno:** The Immune system is severely affected by AIDS.

**Deficiency:** AIDS severely weakens your immune system.

**Syndrome:** AIDS involves a set of signs and symptoms that occur together to make-up the illness.

AIDS progresses from HIV but not everyone who has HIV has AIDS.

QUESTION	HIV	AIDS
What does it stand for?	Human Immunodeficiency Virus	Acquired Immunodeficiency Syndrome
How is it transmitted?	HIV is transmitted between people through the exchange of bodily fluids such as blood, vaginal fluids, semen and breast milk.	AIDS cannot be directly transmitted. However, if a person is infected with HIV it may progress to AIDS.
How is it diagnosed?	HIV is diagnosed with a blood or oral fluid (not saliva) test that tests for HIV antibodies.	AIDS is diagnosed by measuring an individual's CD4 count. If the CD4 count is below a certain level then the individual is diagnosed with AIDS.
What is the prognosis (The likely outcome)?	With proper health care and antiretroviral treatment an individual who is diagnosed with HIV can live many years without HIV progressing to AIDS.	An individual who is diagnosed with AIDS has a severely weakened and deteriorating immune system that is prone to other infections which can cause death. Life expectancy is reduced dramatically.



### WHY IS IT IMPORTANT TO KNOW the definitions of HIV and AIDS?

- You can make informed decisions about HIV and AIDS,
- Knowledge and understanding reduces stigma and discrimination,
- You can learn about proper health care treatments, and
- Knowledge and understanding helps to prevent the spread of HIV.

# HIV 101

Adapted from [www.cdc.gov/hiv](http://www.cdc.gov/hiv)

Without treatment, HIV (human immunodeficiency virus) can make a person very sick and even cause death. Learning the basics about HIV can keep you healthy and prevent transmission.

## HIV CAN BE TRANSMITTED BY:



Blood Transfusion



Sexual Contact



Sharing Needles to Inject Drugs



Mother to Baby during pregnancy, birth or breastfeeding

## HIV IS **NOT** TRANSMITTED BY:



Air or Water



Saliva, Sweat, Tears, or Closed-Mouth Kissing



Insects or Pets



Sharing Toilets, Food or Drinks

### IS THERE A CURE FOR HIV?

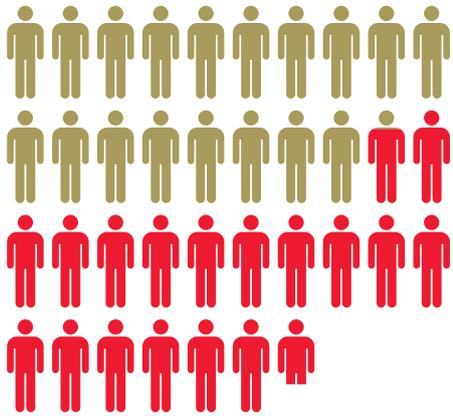
Currently there is no cure for HIV. However, with treatment and support, an individual can live a long and healthy life with HIV.

### CAN YOU LIVE WITH HIV?

Yes, with early diagnosis and effective anti-retroviral treatment, individuals with HIV can live a long and healthy life.

# HIV FACTS & STATS

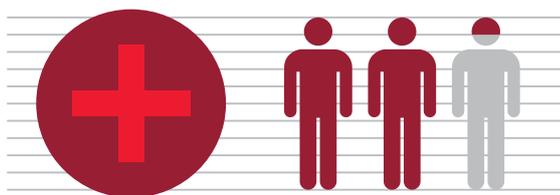
Global statistics sourced from UNAIDS.org from November 2015



In 2015 **only 50%** of people living with HIV were accessing antiretroviral therapy.

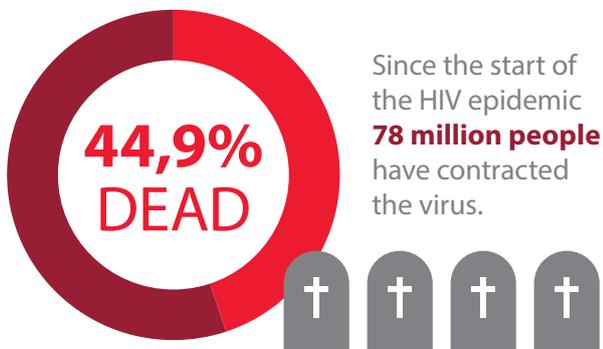
**36,7 million**  
Living with HIV

**18,2 million**  
Accessing Antiretrovirals



## 2,1 million people

became newly infected with HIV in 2015



And 35 million people have died from AIDS-related illnesses



## 77%

Approximately 77% of HIV positive pregnant women in 2015 had access to antiretroviral medicines in order to prevent transmission of HIV to their babies

## 50%



New HIV infections in children have declined 50% since 2010 from 290 000 to 150 000 children



## 0%

## 0%

Since 2010 there have been no decline in new HIV infections among adults

# HIV & THE BODY

## WHY IS HIV SO DIFFICULT FOR THE BODY TO FIGHT?

### HIV uses the CD4+ cells like a factory

- HIV is difficult for the body to fight because the cells (CD4 cells) that the body uses to fight off viral infections (in this case HIV) are used by the HIV to reproduce and replicate.
- HIV uses the CD4 cells to replicate (make copies of itself) and eventually destroys the CD4 cells in the process.
- Over time HIV can destroy so many of these cells that the body cannot fight off infections and disease.
- The HIV virus also has the ability to mutate (change its form and nature) many times, allowing the virus to evade the body's immune system.
- HIV is also difficult to completely eradicate because the virus can lay dormant (inactive) in a resting memory state in CD4 cells for prolonged periods of time.

### The cycle continues

The body responds to the increase in HIV by making more CD4 cells and HIV continues infecting other CD4 cells by using them to reproduce and replicate.

## WHAT DOES HIV DO TO THE IMMUNE SYSTEM?

### What is the immune system?

The immune system is a complex bodily system that protects the body from and provides resistance to infection, toxins and foreign substances.

It is a network of cells, tissues and organs which work together to protect the body.

- HIV weakens the immune system.
- This means that the immune system loses its ability to fight infections.
- The weakened immune system makes the body more susceptible to infections and other diseases.
- This weakened immune system explains why people who have AIDS tend to keep getting sicker, especially if they are not taking antiretroviral medications as recommended.
- Without treatment (usually after several years) the rest of the immune system is worn out. The body becomes more vulnerable to opportunistic infections.

## WHAT IS AN OPPORTUNISTIC INFECTION?

*An opportunistic infection (OI) takes advantage of a weakness in the immune system.*

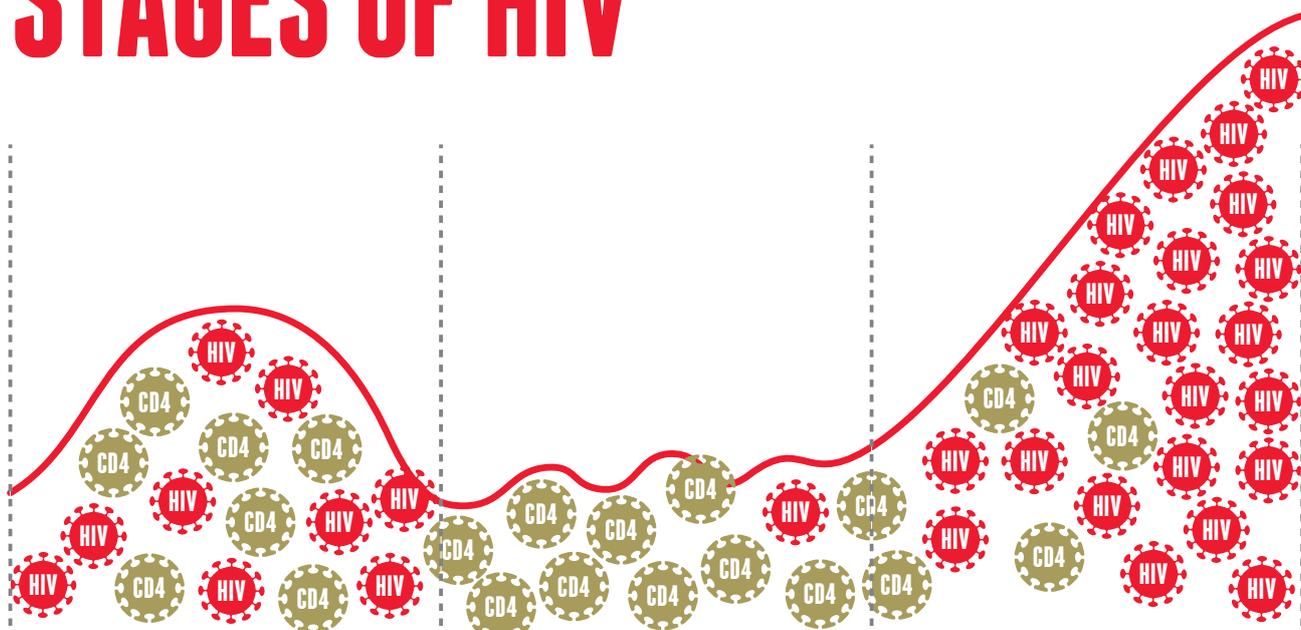
*It refers to an infection that occurs more frequently or an infection that is more severe in individuals with weakened immune systems.*

*Examples of opportunistic infections: Malaria; Pneumocystis Pneumonia (PCP); Tuberculosis (TB) and many more.*

*Rates of OIs have fallen since the introduction of ARTs. However, they are still problems, especially in individuals who do not know their HIV status and cannot take the necessary precautionary steps and treatments if they are HIV+.*



# STAGES OF HIV



## STAGE ONE: ACUTE INFECTION

Early Period of Infection

**Flu-like symptoms occur within first 2-4 weeks of contracting HIV infection**

Large amount of the virus is being produced.

The virus uses the CD4 cells to replicate itself and destroys the CD4 cell as a result

During this stage the body's immune system will eventually bring the level of the virus in the body down to a viral set point.

At the viral set point the CD4 count begins to increase (however, it may not return to pre-infection levels)

At this stage a person is at a high risk of transmitting HIV because the levels of HIV in the blood stream are very high.

## STAGE TWO: CLINICAL LATENCY

"Latency" refers to a period of time where a virus is living or developing in a person without producing symptoms

This stage is also known as "asymptomatic HIV infection" or "chronic HIV infection."

During this stage the virus is still active but continues to reproduce at very low levels

**With ART a person can live for several decades in this stage**

Without ART the clinical latency stage can last for an average of 10 years (however, progression varies from person to person)

In this stage the person is still able to transmit HIV to others (even if the person is on ART- which can reduce the risk of transmission)

## STAGE THREE: AIDS

At this stage the immune system is badly damaged and a person is more vulnerable to opportunistic infections

**When the number of CD4 cells falls below 200 cells per cubic millimetre of blood (200cells/mm<sup>3</sup>), a person is considered to have progressed to AIDS.**

Healthy immune system: CD4 counts are between 500 and 1,600 cells/mm<sup>3</sup>

**A person is also considered to have progressed to AIDS if they develop one or more opportunistic illnesses**

Without treatment, average life-expectancy, of individuals who progress to AIDS, is 3 years. 1 year if a person has an opportunistic illness.

## What are CD4 Cells?

- CD4 cells are a type of white blood cell that helps the immune system fight off infections.
- CD4 cells are also known as T-Cells or T-Helper cells.

## What function do CD4 cells have?

- CD4 cells play a major role in protecting the body from infection.
- Sends signals to activate immune response when there is bacteria/virus.

## What does CD4 stand for?

- CD4 stands for: "Cluster of Differentiation 4"

## How does the CD4 count show if a person has progressed to AIDS?

- When a person's CD4 count drops below 200 cells per millilitre of blood, they are said to have AIDS

## What is the average CD4 count of a healthy immune system?

- In a healthy immune system CD4 counts are between 500 and 1,600 cells/mm<sup>3</sup>

The CD4 count along with other health factors is used to decide when to start treatment.

## What is a CD4 count?

- The CD4 count is a laboratory test that measures the number of CD4 cells/T-helper cells in a cubic millimetre (mm<sup>3</sup>) of blood.

**Full medical name:** CD4 T lymphocyte count

**Also known as:** CD4 T cell count; T4 count

Everyone should have a CD4 count soon after being diagnosed with HIV.

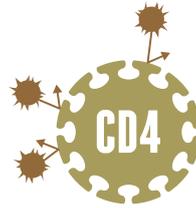
## How often should your CD4 count be tested?

The answer depends on the following:

- **Your current CD4 count:** Lower CD4 counts often require more frequent monitoring
- **Whether you are on ART or not:** When you are on ART viral load tests are more important than CD4 Counts (especially if CD4 count is above 300 per mm<sup>3</sup>)

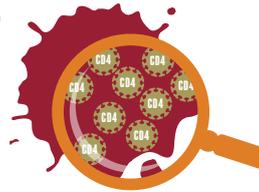
It's important for all people with HIV to have regular blood tests. The two most important blood tests are for CD4 and viral load.

1



CD4 cells are the most important cells in the immune system. Our immune system protects us against infections & illness.

2



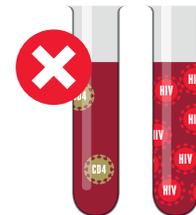
The CD4 count tells you how many CD4 cells there are in a drop of blood. The more there are, the better.

3



Viral load measures how much HIV there is in a drop of blood. You want to have as little HIV as possible.

4



When the CD4 count is low, the viral load is usually high. This situation is not good.

5



When the CD4 count is high, the viral load is usually low. This is much better.

6



The result of treatment should be the CD4 going up, and the viral load going right down.

**Important Points:** CD4 and viral load test results give essential information about the effect HIV is having on your body. The aim of HIV treatment is to have a very low (or 'undetectable') viral load and a high CD4 count.

## What is a viral load?

A viral load refers to the amount of HIV present in a sample of your blood.

Viral load tests are tests carried out regularly to monitor a person's health and help inform decisions about treatment.

## Does the CD4 count directly measure HIV?

- No.

## But then why do we use a CD4 count?

- The CD4 count is used because it is a good surrogate marker.

## What is a surrogate marker?

A surrogate marker is an indirect marker used as a measure of something else that is usually difficult to measure directly. The CD4 count is a good surrogate/indirect marker for measuring how much HIV has damaged the immune system and a person's risk of infection.

- A few weeks after being infected with HIV, the CD4 count falls.
- The immune system begins to fight back.
- The CD4 count goes back up but not as high as it was before the infection.
- The lowest CD4 count level is usually 3 to 6 months after infections (if not on ART). This is called the CD4 set point.
- Without ART, the CD4 count will gradually drop – usually over several years depending on the individual.

The aim of HIV treatment is to have a viral load that is 'undetectable'. But what does that mean and why is it important?

1



A viral load test tells you how much HIV there is in a drop of blood.

2



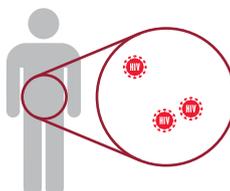
Test results give you a good idea of whether the amount of HIV is high or low.

3



However, the tests can't measure very small amounts of HIV. When you have very little HIV, you will be told that your viral load is 'undetectable'. This means that there was so little HIV in one sample of blood that the test couldn't find any.

4



It doesn't mean that HIV has disappeared entirely. It will still be present in other parts of your body, like the gut.

5



The aim of HIV treatment is to have an undetectable viral load. This means that HIV is being kept under control.

6



An undetectable viral load massively reduces the risk of passing HIV on.

**Important Points:** If your viral load result is undetectable, there is only a little HIV in your body. This means that your HIV treatment is working and is keeping the HIV under control. The risk of passing on HIV is extremely low.

## When is a person diagnosed with AIDS?

- When a person living with HIV gets an opportunistic infection they are diagnosed with AIDS.
- When an HIV positive individual has a CD4 count of less than 200 cells/mm<sup>3</sup>.

## Symptoms of HIV

**Important:** The only way to know if you have HIV is to get tested for HIV. You cannot simply rely on symptoms because they differ from person to person.

## What are the signs/symptoms of HIV?

### Symptoms vary:

- According to the individual.
- Depending on what stage of HIV the individual is in.

Not everyone will experience the same symptoms; therefore, it is not an effective way of determining if you have HIV.

Many of the symptoms that are listed here can also be caused by other illnesses so,

**“YOU MUST GET TESTED TO KNOW YOUR STATUS!”**



# REMEMBER!

## There are 3 Stages of HIV:

- Acute infection/early infection
- Clinical latency
- AIDS

### Stage 1: Acute Infection

(an individual is at a high risk of passing on HIV to others if care is not taken to prevent spreading the infection)

2-4 weeks after infection with HIV some individuals experience severe flu-like symptoms (some individuals do not feel sick at all).

Severe flu-like symptoms can include (but not always):

- Mouth ulcers
- Fever
- Fatigue (extreme tiredness)
- Night sweats
- Muscle pain
- Rash
- Sore throat
- Swollen lymph glands, mainly in the neck

### Stage 2: Clinical Latency

- An individual may not show symptoms or may have mild symptoms at this stage.

### Stage 3: AIDS

The last stage of HIV.

An individual can experience symptoms such as:

- Rapid (extreme) weight loss
- A recurring fever
- Night sweats
- Extreme tiredness
- Swollen lymph glands (armpits, neck, groin)
- Diarrhoea
- Sores: mouth and genitals
- Pneumonia
- Rash/blotches (purple, pink, red, brown) on/under skin-inside mouth, eyelids
- Memory loss
- Neurological disorders such as depression

Many of these symptoms come from opportunistic infections.

# THE IMPORTANCE OF NUTRITION

A solid foundation for a healthy lifestyle begins with good nutrition (Department of Health SA). Nutrition is the term used to describe the way the body uses food for growth, reproduction and maintaining good health.

## Problems related to poor nutrition:

- Weight loss
- Muscle wasting (loss)
- High levels of fats and sugars in the blood
- Lack of vitamins and minerals

The above can all be avoided/managed by eating well.

## If you eat well you can also have:

- A healthy immune system
- Energy
- Strength

## A healthy/balanced meal should contain:

- Water
- Proteins/amino acids
- Carbohydrates
- Lipids/fats
- Vitamins
- Minerals

## Why is good nutrition important?

According to the Department of Health South Africa, good nutrition ensures that the body can:

- Produce energy
- Have brain function
- Grow well
- Replace and repair cells and tissues
- Protect itself against diseases
- Recover from diseases

**Poor nutrition = a weakened immune system = higher risk of infection!**



# NUTRITION & THE IMMUNE SYSTEM

Nutrition plays a key role in maintaining a good immune system that can respond to and fight off infection.

The nutrients we get from food help to keep our body's immune system strong.

If a person does not get proper nutrients, viruses and bacteria are more difficult to fight and have an easier way into the body.

For example, the skin and linings of the lungs and gut provide the first line of defence by acting as physical barriers to invaders such as viruses and bacteria. These barriers are very sensitive to nutrition, especially vitamin A, and deteriorate when you do not get proper nutrition.

If a person is low on or lacks certain nutrients the body's ability to fight off infections is weakened.

# NUTRITION & HIV

Individuals living with HIV face additional challenges when it comes to maintaining good nutrition.

Nutritional needs increase for individuals living with HIV because the immune system is overworked and overused in fighting opportunistic infections and trying to handle the virus.

Good nutrition is therefore a fundamental part of an effective, holistic HIV treatment plan involving HAART (treatment).

## Food Safety:

- Check expiry dates.
- Store food correctly (what does the label say?)
- Clean your hands thoroughly before eating or preparing food.
- Clean surfaces thoroughly before preparing food or eating.
- Clean cutlery, plates and glasses.
- Correctly prepare raw meat: make sure you wash cutting boards and utensils used when preparing raw meat with hot water and dishwashing detergent.

Food safety is important for everyone but it is even more important for individuals living with HIV because HIV affects the immune system which in turn increases the chance of HIV positive individuals to risk getting food-borne illnesses.

## Scenario 1:

**A body with a healthy immune system gets an infection:**

1. Good food intake, good absorption and good nutrition.
2. The immune system manages to fight off viruses or infections with greater ease.

## Scenario 2:

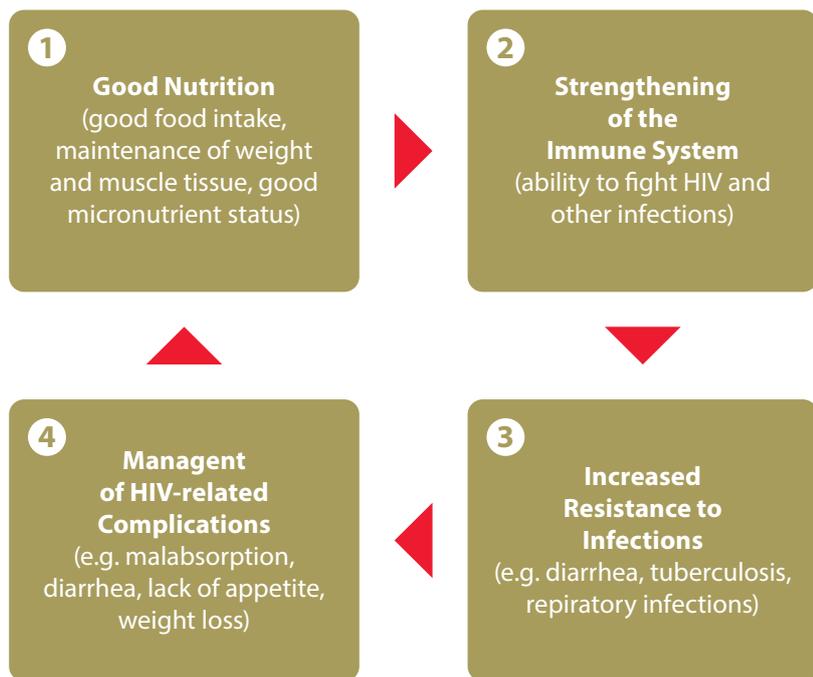
**A body with a weakened immune system (from HIV/AIDS) gets an infection:**

1. Increased need for nutrients - Poor food intake = lack of nutrients
2. Increased risk of Opportunistic Infections/Diseases (e.g. TB, Malaria, Diarrhoea)
3. Malnutrition leading to micronutrient deficiency and wasting (emaciation)
4. The body is underweight, the Immune system is weakened further and is unable to fight off the infection.

It has been recommended that in order to maintain a healthy lifestyle it is necessary to have a balanced diet and a good intake of nutritional food. A balanced diet consists of a variety of foods.



## The Cycle of Good Nutrition and Resistance to Infection in The Context of HIV/AIDS

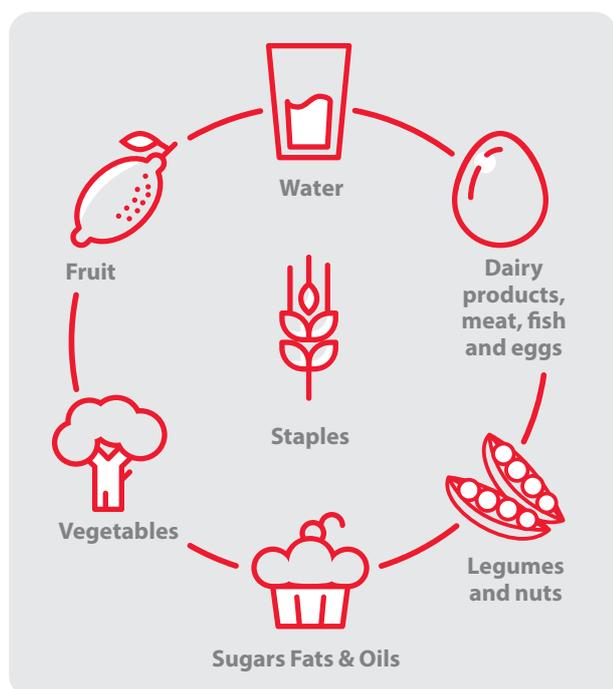


Adapted from Ellen G. Piowz and Elizabeth A. Preble, HIV/AIDS and Nutrition: A Review of the Literature and Recommendations for Nutritional Care and Support in Sub-Saharan Africa. Washington, D.C.: Academy for Educational Development (AED), 2000.

## HEALTHY AND BALANCED NUTRITION FOR GROWTH, WORK AND PLAY

(Recommendations from United Nation, Food and Agriculture Organization, Living well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS)

### Enjoy a Variety of Foods



### Eat staple foods with every meal

These foods are relatively cheap and supply not only energy and protein but also small amounts of vitamins and minerals. Staples include cereals (such as rice, maize, millet, sorghum, wheat and barley), starchy roots (such as potatoes, sweet potatoes, cassava and yams) and starchy fruit (such as plantains).

### Eat legumes if possible every day

These foods include beans, peas, lentils, groundnuts (including peanut butter) and soybeans. When eaten with staple foods the quality of protein is increased.

### Eat animal and milk products regularly

Foods from animals and fish should be eaten as often as you can afford them. They supply good-quality proteins, vitamins, minerals and extra energy. All forms of meat, poultry (birds), fish, eggs and dairy

products such as milk, sour milk, buttermilk, yoghurt and cheese should be included.

### Eat vegetables and fruit every day

The following foods are important for a person to grow well and fight infection:

#### Yellow, Orange, Red or Dark green

Green leafy vegetables (spinach, pumpkin, cassava leaves), green peppers, squash, carrots, yellow peaches, apricots, papaya and mangoes

#### Sources of vitamin A

#### Other Vegetables and Fruit

Tomatoes, cabbage, oranges, mandarins, grapefruit, lemons, guavas mangoes, passionfruit, pine-apples, mulberries and baobab fruit

#### Sources of vitamin C (help to fight infection)

### Use fats and oils as well as sugar and sugary foods

Fats, oils and sugar are good sources of energy and are important for maintaining weight or regaining weight lost. They add flavour to food, thereby stimulating the appetite.

Fats and oils include butter, lard, margarine, cooking oil (vegetable, coconut and palm oil), cream, mayonnaise and coconut cream. They are also found in avocados, oilseeds (sunflower, groundnut and sesame), fatty meat and fish, curds and cheese. Sugars and sugary foods include honey, jam, table sugar, cakes and biscuits.

### Drink plenty of clean and safe water

Drink about eight cups of water per day and even more if you are suffering from diarrhoea, vomiting or fever. You can also drink fruit juice, soups and other beverages. Collect your water from a protected source and store it in a clean container. If the water is not from a protected source it should be boiled for ten minutes and cooled down afterwards before drinking. Avoid drinking tea or coffee with a meal, as they reduce the iron the body gets from your food.

### Personal hygiene

Always wash hands with clean water and soap or ashes before, during and after preparing food or eating, and after visiting the toilet.

Cover all wounds to prevent contamination of food during preparation and handling.

## MAINTAINING WEIGHT WITH HIV

If you are sick with HIV/AIDS you need more food to recover from illness. When your body does not get enough food it uses energy and protein stored in fat and muscles. This leads to weight loss, muscle weakness and malnutrition from which it takes longer to recover. Once weight has been lost it is difficult to regain it.

### Why do people with HIV/AIDS not eat enough food?

- Illness and medicines reduce appetite, modify the taste of food and prevent the body from absorbing it.
- Symptoms such as a sore mouth, nausea and vomiting make it difficult to eat.
- Tiredness, isolation and depression reduce the appetite and the willingness to make an effort to prepare food and eat regularly.
- There is not enough money to buy food.

### Gain weight by eating more food

- Eat more staple foods such as rice, maize, millet, sorghum, wheat, bread, potatoes, sweet potatoes, yams and bananas.
- Increase your intake of beans, soy products, lentils, peas, groundnuts, peanut butter and seeds, such as sunflower and sesame.
- Eat meat, fish and eggs as often as you can afford to.
- Increase the fat content of your food by using more fats and oils as well as eating fatty foods - oilseeds such as groundnuts, soy and sesame, avocados and fatty meat. If problems with a high fat intake are experienced (especially diarrhoea),

reduce the fat intake until symptoms are over and then gradually increase it to a level the body can tolerate.

- Eat snacks regularly between meals. Good snacks are nuts, seeds, fruit, yoghurt, carrots, cassava chips, crab chips and peanut butter sandwiches.
- Add dry milk powder to foods such as porridge, cereals, sauces and mashed potatoes. However, avoid using coffee and tea whiteners, which do not have the same nutritional benefits as milk. Note that some people may find milk difficult to digest. It should be avoided if it causes cramps, a feeling of being full or skin rashes.
- Add sugar, honey, jam or syrup to your food.

### Try to eat three good meals daily with frequent snacks in between

#### Breakfast

Eg: Cereal / Eggs / Fruit / Yoghurt / Toast

#### Snack

Eg: Fruit / Crackers / Nuts / Cured Meats

#### Lunch

Eg: Chicken / Salad / Rice / Vegetables

#### Snack

Eg: Fruit / Crackers / Yoghurt / Nuts / Cheese

#### Supper

Eg: Fish / Potatoes / Vegetables / Salad / Dessert

#### Snack

Eg: Milk / Nuts / Cheese

### Keep active and stay fit

#### Exercise helps you to gain weight properly.

- Regular exercise strengthens the muscles, makes you feel energetic, helps to relieve stress and increases appetite.
- Cleaning, working in the field and collecting firewood and water may provide enough exercise.
- Find an exercise that you enjoy and can fit into your daily life.
- Walking, running, swimming or dancing are all suitable.

### Increase your intake of vitamins and minerals

#### Your immune system needs vitamins and minerals to function properly. When you are ill with HIV/AIDS you need even more.

- Eat a variety of vegetables and fruit every day, as these are a valuable source of vitamins & minerals.
- Take care not to lose vitamins and minerals when cooking your food. Boil, steam and fry vegetables only for a short time.
- Multivitamin and mineral supplements, usually in the form of pills, can help but they are expensive and leave less money for food.
- Too many vitamins and minerals can harm you. If you take supplements, follow the instructions on the label.

### During infection

- It is very important to try to eat, even though you may not feel like eating, to avoid weight loss.
- Treat infection as early as possible. If you are ill for more than a couple of days see a health worker.

---

# LOOKING AFTER YOURSELF

### Positive living

- The body needs extra rest. Try to sleep for eight hours every night. Rest whenever you are tired.
- Try not to worry too much. Stress can harm your immune system. Relax more. Relax with people you love, your family, your children and your friends. Do things you enjoy, e.g. listen to music or read a newspaper or a book.
- Be kind to yourself. Try to keep a positive attitude. Feeling good is part of being healthy.
- Take light exercise. Choose a form of exercise that you enjoy.

- Find support and get good advice. Ask for information and assistance from health workers. Many of your medical problems can be treated.
- Ask for help and accept help when it is offered.
- Stop smoking. Smoking damages the lungs and makes it easier for infections to attack your body.
- Alcohol is harmful to your body. You may forget to practise safe sex.
- Avoid unnecessary medicines. They often have unwanted side-effects and can interfere with food and nutrition. If you do take medicines, read the instructions carefully.

## CARING FOR SOMEONE WITH HIV/AIDS

**Looking after a person with HIV/AIDS is not easy. Get enough rest yourself. Take some time off. Ask a friend or family member to help.**

- Spend time with the person living with HIV/AIDS. Discuss the foods they need to maintain and gain weight and manage their illness. Get to know what kind of foods they like and do not like. Involve them in planning their meals.
- Keep an eye on their weight. If possible, weigh them regularly and keep a record. Look out for any unexpected weight loss and take action.
- Check the medicines they are taking. Read the instructions to find out when they need to be taken, what foods to be avoided and any side-effects.
- Be encouraging and loving. If they want to have food of their choice at any time of the day, try to get it for them.
- Be firm about the importance of eating but do not force the person to eat. Giving too much food at one time may cause them to refuse.
- If they are too sick to leave their beds, make sure that they have something to drink and a snack nearby.
- Keep a watchful eye. Look around to see if the house is clean, that there are no hygiene problems and there is enough food.
- If the sick person lives alone, invite them to join your family for a meal. Encourage others in the community to visit them and invite them out.



### More information

**These resources also listed in the Appendix:**

- Living Well with HIV/AIDS – A manual on nutritional care and support for people living with HIV/AIDS by United Nations Food and Agricultural Organization  
<http://www.who.int/nutrition/publications/hivaids/Y416800/en/>
- Practical Guide to Nutrition for People Living with HIV by CATIE (Canada's source for HIV and HepC information).  
<http://www.catie.ca/en/practical-guides/nutrition>
- Forms to monitor food intake and weight
- Important vitamins and minerals for people living with HIV/AIDS
- Sources of literature and information on institutions providing support for people living with HIV/AIDS

# ARV & ART?

## ARV

**“Antiretroviral”.** It is the name for the medication that is used to treat HIV. ARVs do not cure HIV but they slow down the rate at which HIV multiplies in the body.

## RETROVIRUS

**HIV is a retrovirus.** A retrovirus refers to any group of RNA viruses that attaches and inserts its genetic makeup into to a host cell and uses the host cell to replicate itself.

## ART

**“Antiretroviral Therapy”.** Antiretroviral Therapy refers to the treatment of individuals who are infected with HIV. It involves a combination of antiretroviral (ARV) medicines.

## HAART

**“Highly Active Antiretroviral therapy”.** HAART consists of a combination of several antiretroviral medications (standard treatment of includes 3 or more antiretroviral medications)

## ‘ART’ IS AMAZING!!

It dramatically slows down the rate at which HIV multiplies in the body.



## HOW DOES HIV WORK?

1. When a person is infected with HIV, the body naturally produces more CD4 cells to fight off the infection.
2. HIV attaches to CD4 cells and inserts its genetic makeup into the cells.
3. HIV infects CD4 cells and uses them like factories to multiply and produce copies of itself.
4. CD4 count drops and viral load (the amount of HIV in the body) increases.
5. This severely weakens the immune system which greatly increases the risk of opportunistic infection.

## HOW DOES ART COMBAT HIV?

1. Reduces the amount of HIV in the body by slowing down the multiplication process.
2. Protects the immune system.
3. Helps to prevent HIV from progressing to stage 3 - AIDS (some people may never progress to AIDS)
4. Helps an individual living with HIV to live a nearly normal lifespan.
5. Reduces the risk of onward transmission of HIV to others.
6. Reduces the risk of mother-child transmission before, during, and after pregnancy.

# CONTRACTING HIV

## HOW DO YOU CONTRACT HIV?

HIV is spread via direct contact with the following bodily fluids:

- Blood
- Rectal fluid
- Semen and pre-seminal fluid
- Vaginal fluids
- Breast milk

HIV is spread via direct contact with bodily fluids. This means that actions involving these bodily fluids can increase a person's risk of contracting HIV.

### Quick Fact:

If you have an STD (Sexually Transmitted Disease) you have a greater risk of contracting (getting) HIV if you have sexual intercourse with an HIV positive partner.

## WHAT ACTIONS CAN CAUSE HIV TO SPREAD BETWEEN PEOPLE?

- Unprotected sexual intercourse with an HIV positive partner (Vaginal/anal).
- Sharing needles with an HIV positive person.
- Breast feeding (if a woman is HIV positive).
- HIV can be passed from mother to child during pregnancy and birth.
- HIV can be spread via contaminated blood during blood transfusions and organ transfers.

**Challenge false information about HIV. KNOW THE FACTS!**

# FACTS & MYTHS

## YOU CANNOT GET HIV FROM:

- Someone who does not have HIV.
- Mosquito bites (You cannot get HIV from mosquito bites).
- Toilet seats (HIV cannot survive on surfaces).
- Sharing cutlery/crockery (HIV cannot survive on objects).
- Touching (HIV cannot survive outside of a person's body).
- Kissing (unless there is blood exchange from large open mouth sores and/or bleeding gums).
- Coughing or sneezing (HIV cannot survive in the air).
- Using new or properly sterilised needles.
- Water (sharing swimming pools, showering facilities or drinking water).



HIV IS **ONLY** TRANSMITTED WHEN INFECTED BODILY FLUIDS GET INTO A PERSON'S BLOODSTREAM.

# GETTING TESTED

## WHAT IS USED WHEN TESTING FOR HIV?

- Blood or oral fluid (not saliva).
- blood is more likely to help identify infection sooner than oral fluid because there are more antibodies found in blood.

## WHERE CAN A PERSON GET TESTED?

- A Clinic
- A Doctor's Office
- Mobile testing van
- At Home – Using An At-Home HIV Test

## WHAT ARE THE DIFFERENT TYPES OF TESTS AVAILABLE?

### 1. Antibody Screening Test (Immunoassay)

- The most common test used.
- Tests for particular antibodies that your body makes to fight against HIV.
- An antibody is also known as an immunoglobulin and it is used by the immune system to identify and help remove foreign bacteria and viruses.

### 2. Follow-up Diagnostic Testing

- This test is performed if the first immunoassay is positive
- It is important to get a follow-up test because it is possible to get a false positive
- This process involves an array of tests to determine more information about the individual's HIV status.

### 3. Home HIV tests (2 types)

- Home Access HIV-1 Test System
- OraQuick in-home HIV Test

### 4. RNA tests (viral load test)

- Mostly used to monitor HIV progression in individuals diagnosed with HIV.

This test is used to screen blood donations and provide information on viral loads.



# HIV TESTING 101



**“HIV TESTS ARE NOW QUICK, FREE, & PAINLESS”**

## SHOULD I GET TESTED?

- **Everyone ages 13-64 should get tested for HIV regularly throughout their life.**
- Some sexually active gay and bisexual men may benefit from more frequent testing (every 3 to 6 months).
- If you are pregnant or planning to get pregnant, get tested as early as possible to protect your baby.

## WHERE CAN I GET TESTED?

Ask your doctor for a test or for the closest testing site.

## YOU SHOULD GET TESTED AT LEAST ONCE A YEAR IF:

- You are a sexually active gay or bisexual man.
- You have had sex with an HIV positive partner.
- You have had more than one partner since your last HIV test.
- You have shared needles or works to inject drugs.
- You have exchanged sex for drugs or money.
- You have another sexually transmitted disease, hepatitis, or tuberculosis.
- You have had sex with anyone who has done anything listed above or with someone, whose sexual history you do not know.

## WHAT IF MY TEST RESULT IS NEGATIVE?

- You could still have HIV. Ask your doctor about the “window period,” a period of time after a person is infected during which they will not test positive.
- To stay negative, take actions to prevent HIV.



## WHAT IF MY TEST RESULT IS POSITIVE? **You may be given a follow-up test to confirm the result.**

- Finding out you have HIV can be scary, but you can still live a healthy life if you take action.
- If you have HIV, start medical care right away. HIV treatment can keep you healthy for many years and reduce your chance of transmitting the virus to others



**HIV testing is incredibly important for both preventing the spread of HIV infection and recognising the need for antiretroviral treatment and good health practices.**

### **Places where you can get tested include:**

- Medical Clinics and Hospitals
- Community Health Centres
- Pharmaceutical Stores
- Your Own Home or a Safe Space (take-home test only)

Special testing drives and mobile testing opportunities are further options, although they may not always be available in your community.

### **Different types of testing**

There are several different types of HIV test. Basic screening tests are the most common. The biggest advantage of these tests is that they will inform you of your HIV status within minutes. They do this by testing for the anti-bodies your body produces in response to HIV.

The biggest drawback of these tests is that they do not tell you anything more. That is why it is necessary for people who test HIV-positive to undergo more detailed tests.

More detailed tests by a laboratory have the advantage of testing not only whether you have HIV but also: how well your body's organs are functioning; how rapidly HIV is spreading; how well your immune system is coping; and whether or not you have any related diseases.

The drawback with the laboratory test is that it may take several days or even weeks to process your test results. This makes it an unattractive option for people who only care whether or not they have HIV.

### **Types of screening tests**

The most common types of screening test will test your blood for anti-bodies. Whether in a clinic, hospital, or in your own home, these tests will require a sample. Only a tiny amount of blood is necessary – the prick of a finger with a needle. An advantage of these tests is that they are 96% accurate.

Another option is to use a type of screening test that analyses a swab of fluid collected from your gums. An advantage of this test is that the swab replaces the need for a blood sample – meaning that if you are uncomfortable with needles or blood you can avoid them. A slight drawback is that these tests are marginally less accurate.

### **Take-home kits**

For people who value the confidentiality of their HIV-status above all, take-home kits present a unique advantage. These tests are easy to use and come with step-by-step instructions.

Potential drawbacks associated with take-home kit include language barriers and the necessity for reading skills. While pictured-based instructions help mitigate this weakness, the possibility of error still exists.

An additional consideration with take-home kits is whether or not they have been approved and are reliable. So long as the tests are purchased from clinic or a store, they are sure to be legitimate.

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### **GETTING TESTED:**

Get an HIV test at your local clinic, doctor or mobile test zone

#### **If the test result: HIV negative (-)**

- Continue to use preventative measures
- Get tested regularly

#### **If the test result: HIV positive (+)**

- Speak to a medical professional about treatment options
- Have a follow-up diagnostic test to confirm your test result

### **What is a window period?**

- A window period is the time between initial HIV infection and the time when the body produces enough HIV antibodies (CD4 cells) to be detected and test positive on an HIV Test.
- This means that for a period of time you could be HIV positive but your test result will show up negative because there are not enough HIV antibodies produced yet and therefore they will not show up on the HIV test.
- The window period is usually 3- 12 weeks.
- A person living with HIV has the most risk of infecting others with HIV in the first few weeks after initial infection.

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**If you test HIV+ it is important that you consult a healthcare professional about the best suitable treatment and diet to suit your body's needs to best maintain your health.**

# PERSONAL CHECKLISTS

Refer to the below HIV risk assessment questionnaire by Public Health Agency of Canada

ANSWER THE FOLLOWING QUESTIONS	CHECK YES / NO
<ul style="list-style-type: none"> <li>Are you between the ages of 13 and 64? (It is recommended that everyone is tested once regardless of perceived risk factors)</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Are You sexually active?</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Do you engage in risky sexual behaviour? (For example do you have sex without a condom?)</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Do you have multiple sexual partners?</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Have you had more than one sexual partner since your last HIV test?</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Have you got any STDs (sexually transmitted diseases)? (STDs increase chances of infection and transmission).</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Have you had sex with an HIV+ person? (if they are on medication and you use protection your risk of infection is reduced).</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Are you not sure about your partner's sexual history?</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Are you pregnant or planning to get pregnant? (Get tested so that you know your status. If you are HIV + you can take the necessary steps to ensure that the risk of transmission of HIV from mother to baby is decreased).</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Have you shared needles or injecting equipment?</li> </ul>	YES   NO
<ul style="list-style-type: none"> <li>Have you had sexual intercourse with anyone who has checked yes to any of these?</li> </ul>	YES   NO

[http://www.catie.ca/sites/default/files/EN\\_HIV-Screening-Guide-2013.pdf](http://www.catie.ca/sites/default/files/EN_HIV-Screening-Guide-2013.pdf)



“If you check yes to any of the above questions and you have not been tested for HIV, visit your nearest clinic or mobile testing site so that you can,  
**KNOW YOUR STATUS!**”

CATEGORY & ELEMENTS	IMPORTANT QUESTIONS TO GUIDE YOUR ASSESSMENT
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<b>Relationship</b>	
<ul style="list-style-type: none"> <li>• Present situation</li> </ul>	<ul style="list-style-type: none"> <li>• Do you have a regular sexual partner?</li> <li>• If yes, how long have you been with this person?</li> <li>• Do you have other partners?</li> </ul>
<ul style="list-style-type: none"> <li>• Identify concerns</li> </ul>	<ul style="list-style-type: none"> <li>• Do you have any concerns about your relationship?</li> <li>• If yes, what are they (e.g. violence, abuse, coercion)</li> </ul>

<b>Sexual Risk Behaviour</b>	
<ul style="list-style-type: none"> <li>• Number of partners</li> </ul>	<ul style="list-style-type: none"> <li>• When was your last sexual contact? Was that contact with your regular partner or with a different partner?</li> <li>• How many different sexual partners have you had in the past 2 months? In the past year?</li> </ul>
<ul style="list-style-type: none"> <li>• Sexual Partners, orientation</li> </ul>	<ul style="list-style-type: none"> <li>• Are your partners, men, women or both?</li> </ul>
<ul style="list-style-type: none"> <li>• Sexual Activities</li> </ul>	<ul style="list-style-type: none"> <li>• Do you perform oral sex (i.e. do you kiss your partner on the genitals or anus)?</li> <li>• Do you receive oral sex?</li> <li>• Do you have intercourse (i.e., do you penetrate your partners in the vagina or anus? Or do your partners penetrate your vagina or anus)?</li> </ul>
<ul style="list-style-type: none"> <li>• Sexual Activities</li> </ul>	<ul style="list-style-type: none"> <li>• Have any of your sexual encounters been with people from another country? If yes, where and when?</li> <li>• How do you meet your sexual partners (when travelling, bathhouse, internet)?</li> <li>• Do you use condoms, all the time, some of the time or never?</li> <li>• What influences your choice to use protection or not?</li> <li>• If you had to rate your risk for STI, would you say that you are at no risk, low risk, medium risk or high risk? Why?</li> </ul>

<b>STI History</b>	
<ul style="list-style-type: none"> <li>• Previous HIV/STI Screening</li> </ul>	<ul style="list-style-type: none"> <li>• Have you ever been tested for HIV/STI? If yes, what was your last screening date?</li> </ul>
<ul style="list-style-type: none"> <li>• Previous STI</li> </ul>	<ul style="list-style-type: none"> <li>• Have you ever had an STI in the past? If yes, what STI and when?</li> </ul>
<ul style="list-style-type: none"> <li>• Current Concern</li> </ul>	<ul style="list-style-type: none"> <li>• When was your sexual contact of concern?</li> <li>• If symptomatic, how long have you had the symptoms you are experiencing?</li> </ul>

CATEGORY & ELEMENTS	IMPORTANT QUESTIONS TO GUIDE YOUR ASSESSMENT
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<b>Reproductive health history</b>	
<ul style="list-style-type: none"> <li>Contraception</li> </ul>	<ul style="list-style-type: none"> <li>Do you and/or your partner use contraception? If yes, what? Any problems? If no, is there a reason?</li> </ul>
<ul style="list-style-type: none"> <li>Known reproductive problems</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever had any reproductive health problems? If yes, when? What?</li> </ul>
<ul style="list-style-type: none"> <li>Pap test</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever had an abnormal Pap test? If yes, when? Result, if known?</li> </ul>
<ul style="list-style-type: none"> <li>Pregnancy (for females)</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever been pregnant? If yes, how many times? What was/were the outcome(s) (number of births, miscarriages, abortions)?</li> </ul>

<b>Substance Use</b>	
<ul style="list-style-type: none"> <li>Alcohol</li> </ul>	<ul style="list-style-type: none"> <li>Do you use alcohol? If yes, frequency and type?</li> </ul>
<ul style="list-style-type: none"> <li>Share equipment for injection/inhalation</li> </ul>	<ul style="list-style-type: none"> <li>If injection drug use, have you ever shared equipment? If yes, when was your last sharing date?</li> <li>If inhalation drug use (e.g. crack cocaine), have you ever shared equipment like pipes or straws? If yes, when was your last sharing date?</li> </ul>
<ul style="list-style-type: none"> <li>Sex under influence</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever had sex while intoxicated? If yes, how often?</li> <li>Have you ever had sex while under the influence of alcohol or other substances? What were the consequences?</li> <li>Do you feel that you need help because of your substance use?</li> </ul>
<ul style="list-style-type: none"> <li>Percutaneous risk, other than drug injection</li> </ul>	<ul style="list-style-type: none"> <li>Do you have tattoos or piercings? If yes, were they done using sterile equipment (i.e. professionally)?</li> </ul>

<b>Psychosocial History</b>	
<ul style="list-style-type: none"> <li>Sex trade worker or client</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever traded sex for money, drugs or shelter?</li> <li>Have you ever paid for sex? If yes, frequency, duration and last event?</li> </ul>
<ul style="list-style-type: none"> <li>Sexual Abuse</li> </ul>	<ul style="list-style-type: none"> <li>Have you ever been forced to have sex? If yes, when and by whom?</li> <li>Have you ever been sexually abused? Have you ever been physically or mentally abused? If yes, when and by whom?</li> </ul>
<ul style="list-style-type: none"> <li>Housing</li> </ul>	<ul style="list-style-type: none"> <li>Do you have a home? If no, where do you sleep?</li> <li>Do you live with anyone?</li> </ul>

# AWARENESS & PREVENTION

## THERE IS CURRENTLY NO CURE FOR HIV/AIDS.

There are however, a number of ways to prevent the transmission of HIV.

### HIV is spread via direct contact with the following bodily fluids:

- Blood
- Rectal fluid
- Semen and pre-seminal fluid
- Vaginal fluids
- Breast milk

### Ways to prevent contracting and transmitting HIV:

- **The most effective way of preventing the spread of HIV through sexual intercourse is abstinence (refraining from having sex).**
- Limit your number of sexual partners.
- Use condoms correctly every time you have sexual intercourse.
- Do not share needles/sharps.
- Confirm that blood used for blood transfusions or organ transplants have been tested for HIV.
- Speak to your healthcare provider within 72 hours after possible exposure to HIV.
- Know your status!
- PrEP (Pre-exposure Prophylaxis) - daily course of ARV medication for HIV(-) individuals to prevent against the contraction of HIV.

## SEXUAL RESPONSIBILITY

If you are a person living with HIV it is important to take precautionary measures to reduce the risk of passing HIV to others.

- Take ARVs or start ART (this gradually reduces the risk of transmission).
- Do not engage in risky sexual behaviour. Always use protection.
- Get tested and treated for STDs.
- Encourage your partner to get tested.
- If you are a pregnant woman living with HIV it is important to speak to a healthcare professional and start ART to reduce the risk of passing HIV to your child during pregnancy and childbirth.

It is important to make informed decisions and practice safer sex. In doing so, you protect both yourself and your partner from HIV, Sexually Transmitted Infections (STIs) and Sexually Transmitted Diseases (STDs).

### If you choose to be sexually active, ask yourself the following questions:

- Do I understand why I am choosing to be sexually active?
- Do I know and understand sexuality and sexual health?
- Do I know what makes a healthy relationship?
- Do I feel safe speaking to my partner about sexual health?
- Do I know how to take extra precautions?
- Do I know how to protect myself and my partner?

**If you cannot answer yes to the above questions then you are not making an informed decision and you are at risk of contracting a sexually transmitted disease.**



# HOW TO USE A CONDOM CORRECTLY

## Step 1:



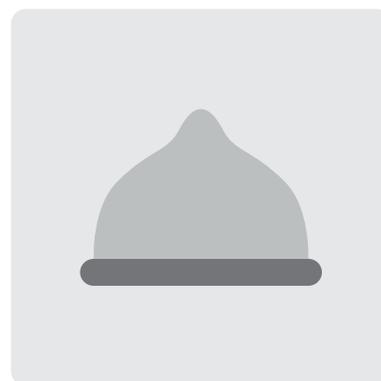
Check the expiry date on the condom packet. If it is expired it will break and will not be an effective way of protecting you against HIV, STDs and unwanted Pregnancy. If it is expired get a new one. If it is not expired, move on to step 2.

## Step 2:



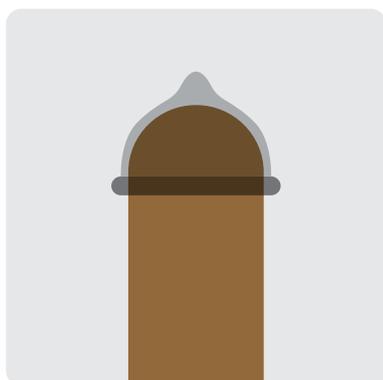
Carefully open the condom packet. Do not use your teeth - you might tear or break the condom and then it will not be an effective way of protecting you against HIV, STDs and unwanted Pregnancy. Make sure there are no tears or holes or rips. If there are get a new one. If there are none move on to step 3.

## Step 3:



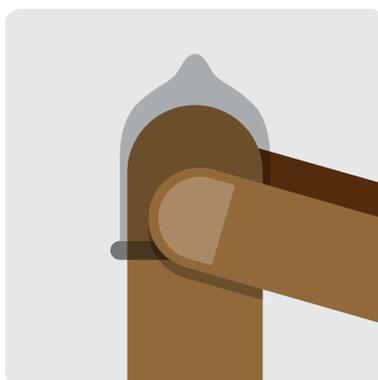
Once the penis is hard and erect take the condom out of the packet and look to see which way it unrolls. The rim should be on the outside so it looks like a little hat, and it will unroll easily. You can unroll it a little bit before putting it on to make sure it's right-side out. If you are satisfied move on to step 4.

## Step 4A:



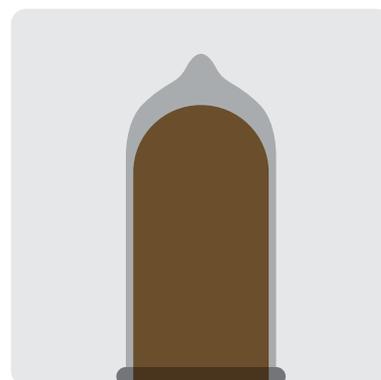
Place the condom onto the erect penis. Pinch the top of the condom between your thumb & first finger to let any air out.

## Step 4B:



Leave about 1.5cm of room at the tip to allow the condom to catch the semen when you ejaculate.

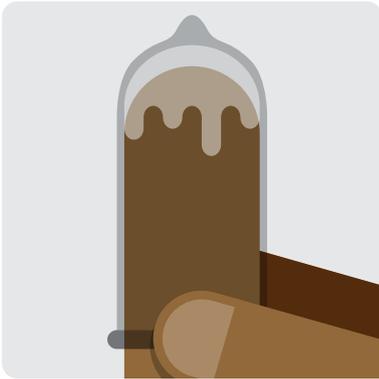
## Step 4C:



Hold the condom against the head of the penis and roll it down to the base, making sure the condom is on securely.

# HOW TO REMOVE A CONDOM CORRECTLY

## Step 1:



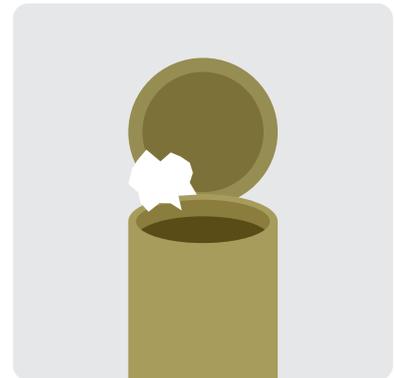
After ejaculation, take the penis out (while it is still hard). Hold the rim of the condom at the base of the penis while you are pulling out. Be careful not to spill any semen.

## Step 2:



Take off the condom, making sure you are away from your partner's body before taking it off.

## Step 3:



Throw away the condom. NEVER use a condom more than once

## USE CONDOMS CORRECTLY

- Use a condom every time you have sex.
- Put the condom on before having sexual intercourse.
- Make sure there are no tears or rips.
- Use water or silicon-based lubricants.
- Check the expiry date (if a condom is expired it will break).
- Store condoms in a cool dry place.
- Use latex or polyurethane condoms.

**“REMEMBER  
NEVER USE A CONDOM  
MORE THAN ONCE!!”**



# HIV STIGMA

## SPREAD AWARENESS - NOT STIGMA

### What is Stigma?

Stigma refers to a set of attitudes and beliefs that cause people to reject, avoid, and or discriminate against individuals or groups of individuals with a particular condition or attribute (for example: a person with an illness such as HIV).

A lack of knowledge about how HIV is transmitted leads people to make assumptions about individuals living with HIV because of fear around 'contagion'.

False beliefs about HIV lead to more fear towards individuals living with HIV which results in stigma and discrimination.

MYTH + IGNORANCE + FEAR = STIGMA



## WHAT IS DISCRIMINATION?

Discrimination is the unjust behavioural response that results from stigma that is directed towards particular categories of people - in this instance people living with HIV.

### Silence & Shame:

Anxiety, fear, poor well-being, fearing lack of support

Incorrect assumptions about HIV transmission lead to irrational behaviour and attitudes about personal risk of infection which leads to stigma and discrimination.

Silence + Ignorance + Fear = Stigma & Discrimination

## NEGATIVE ATTITUDE?

If you have a negative attitude towards an individual or a group based on a particular condition or attitude they have, then you need to ask yourself:

- **WHY?**
- **What is it that is causing me to feel this way?**  
(Often you will find your answer is related to fear and ignorance.)



**“DO NOT  
DISCRIMINATE!!”**



# TYPES OF STIGMA

TYPE OF STIGMA	HOW DOES STIGMA AFFECT A PERSON LIVING WITH HIV?
Public Stigma	<p>Ill-informed views held by the general public about HIV and individuals living with HIV lead to negative assumptions and discriminatory actions. This contributes to the HIV epidemic as it reinforces stigma in a variety of social sectors and prevents individuals from getting tested, disclosing their status and accessing proper medical care and social support.</p>
Governmental stigma	<p>Discriminatory policies, laws and rules could reinforce stigma around HIV and those living with HIV.</p>
Healthcare stigma	<p>Healthcare professionals play a significant role in providing necessary information and medical care to individuals living with HIV. Therefore, when stigma is present and discriminatory practices are taking place it can lead HIV positive individuals to be reluctant to disclose their status and access proper health care for fear of discrimination.</p> <ul style="list-style-type: none"> <li>• Many healthcare professionals are still ignorant about HIV transmission.</li> <li>• Some healthcare practitioners have been found to have refused to help HIV positive individuals or offer only substandard treatment.</li> <li>• There are negative attitudes and judgement towards HIV+ individuals.</li> <li>• Betrayal of confidentiality and disclosure of HIV+ individuals' status to others</li> </ul>
Employment stigma	<ul style="list-style-type: none"> <li>• Co-workers and employers may isolate, avoid and discriminate against a co-worker who has disclosed their status.</li> <li>• Unfair/ unjust dismissal or termination of employment as a result of an individual's HIV status.</li> <li>• Refusal of employment based on an individual's HIV status.</li> </ul>
Community and household level stigma	<ul style="list-style-type: none"> <li>• Isolation and discrimination experienced by family, friends and community members based on the individual's HIV status.</li> <li>• This can affect an individual's level of social support.</li> <li>• It can cause an individual to feel as though they "have nowhere to go".</li> </ul>
Restrictions travelling, visiting and residing	<p>In some countries individuals are not allowed to travel to, enter or live in the country if they are HIV+.</p>
Self-stigma (internalised stigma)	<ul style="list-style-type: none"> <li>• Internalised stigma effects an individual's mental well-being</li> <li>• Fear of discrimination results in a fear of seeking help, support, medical services and employment.</li> <li>• Individual's can begin to believe the misconceptions around HIV and internalise the negative beliefs.</li> </ul>

# THE NEGATIVE EFFECTS OF STIGMA:

- Limited access to medication-If people do not feel safe disclosing their status or seeking medical help they cannot access proper medication.
- Limited access to necessary information due to discrimination from healthcare staff
- Fear of stigma and discrimination means that people living with HIV do not demand access to medication and healthcare services.
- Feeling isolated
- Fear of discrimination results in a fear of getting tested for HIV
- Loss of income and livelihood as a result of employment stigma
- Fear of not being hired or dismissed/fired from work if status is disclosed
- Lowered feelings of self-worth
- Lack of hope
- Loss of 'reputation'
- Prevents individuals from protecting themselves and providing support to those who are living with HIV
- Increases the fear of disclosing one's status to partner/s
- Fear as a result of stigma prevents individuals from accessing family planning
- Individuals are less likely to engage in prevention behaviours and are more likely to be afraid of asking about prevention methods
- Increases violence towards an individual's status

## SPREAD AWARENESS NOT STIGMA

### EDUCATE

Educate yourself and those around you about HIV & AIDS. Do not rely on false information or myths

### DO NOT DISCRIMINATE

Do not treat anyone unjustly or unfairly based on their HIV Status!

### KNOW YOUR RIGHTS & RESPECT THE RIGHTS OF OTHERS!

### SUPPORT COMMUNITY GROUPS

Or form new ones if necessary

### RETHINK & REPHRASE

Be careful, the words we use often reinforce stigma

### GET TESTED REGULARLY

Know your status! Break the stigma around getting tested!

# UNDERSTANDING CONTEXT:

Understanding the context allows civil society, NGOs and governments to engage in clear, effective HIV advocacy initiatives instead of creating solution-based responses based off of the assumptions that all communities and contexts respond to HIV in the same way.

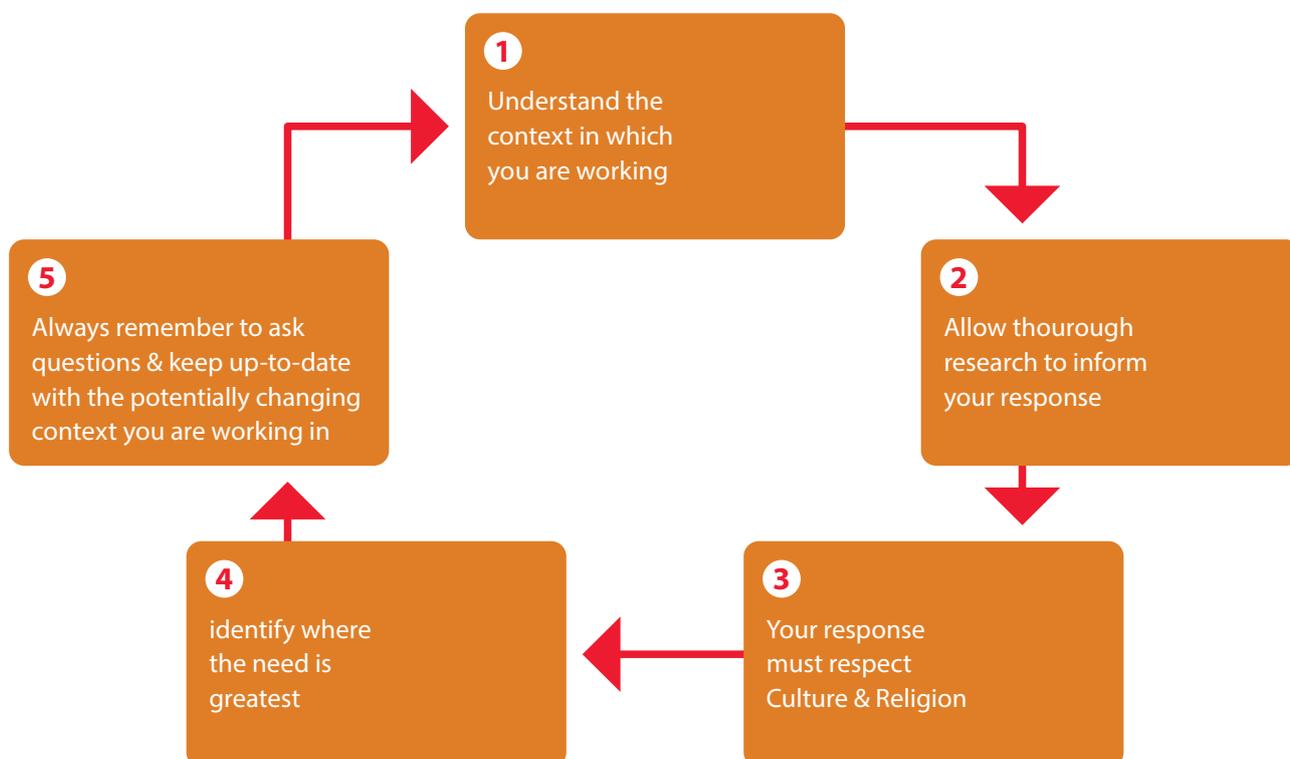
Here are some examples of the many questions to ask when beginning to work in the HIV Advocacy Sector:

<b>UNDERSTANDING MY OWN CONTEXT- CONSIDERATIONS</b>	<b>CHECK YES / NO</b>
Am I working in a First world Country?	YES   NO
Am I working in a Third world Country?	YES   NO
Is there a high rate of HIV prevalence within the context in which I work and/or live?	YES   NO
Are there potential partner organisations to work with, within my context?	YES   NO
Are there high risks of adherence?	YES   NO
Is there access to ART and ARVs?	YES   NO
Is there access to knowledge and educational materials about HIV, AIDS, and Treatment etc within your working context?	YES   NO
Is there access to proper nutrition within your working context?	YES   NO
Are there high levels of adherence in your country?	YES   NO
Are there issues regarding stigma, access, faith healing etc?	YES   NO
Are there sufficient distribution, access to, and an understanding of how to use condoms?	YES   NO

<b>ADDITIONAL CONSIDERATIONS</b>
Who are the key affected population groups?
What current initiatives, if any, are there in relation to HIV awareness raising and advocacy work?
Where is the need greatest, in response to the HIV epidemic, in your working context?

The above tables serve as an example of the many questions one needs to ask oneself when attempting to understand one's working context in relation to HIV and AIDS. Once you have established the questions to ask and the most appropriate answers, you can begin to formulate your response to the particular need within your working context.

# UNDERSTANDING YOUR CONTEXT BEFORE CREATING A RESPONSE.



For example, in an attempt to understand the phenomenon of HIV ARV Treatment Adherence, a local Zambian HIV Advocate called Namakau Muketoi uses her knowledge as a women living with HIV to spread awareness.

She was approached and interviewed. As an expert within her community, she was able to answer the question regarding adherence with ease.

**Below is a summary of her response to the following question:**

**What is your experience with adherence to treatment? Are ordinary Zambians following treatment guidelines and are they able to do so without obstacles?**

- Namakau believes ordinary Zambians are following guidelines – which she says is informed by high literacy levels.
- The respondent says stigma and discrimination are the greatest obstacles to adherence.

- The respondent adds poverty can be an obstacle because ARTs are strong and should not be taken on an empty stomach.
- The respondent notes that based on the evidence of her defaulter tracing programme, most HIV positive persons do not disclose their status to their spouse – which creates an obstacle and thereby discourages adherence.

As this response shows, not only is the issue of adherence confirmed, but other issues and concerns have emerged (i.e. poverty, lack of nutrition and stigma).

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Whilst this is a single good example, it is of fundamental importance that the information and research used to inform your response should come from multiple sources in order to achieve a greater understanding of the need and the different needs that emerge.

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# TEST YOURSELF 01

A	W	A	R	E	N	E	S	S	M	D	N	W	A	N
I	K	V	W	O	A	B	E	Y	T	O	B	N	V	O
M	D	E	T	S	E	T	V	S	I	I	T	L	M	I
M	Z	A	N	A	T	M	X	T	U	I	G	Q	G	T
U	E	M	A	O	E	N	C	L	R	T	M	M	U	N
N	U	P	I	S	I	E	E	E	S	H	A	A	A	E
E	P	S	E	E	F	S	T	Y	V	C	R	T	F	V
I	V	D	C	N	F	R	S	I	Y	U	M	E	S	E
Q	A	B	I	Y	O	T	H	I	D	G	I	N	S	R
U	O	Y	J	V	E	L	K	I	M	W	D	T	D	P
G	E	X	I	M	M	C	Z	B	V	S	V	R	I	L
I	S	R	C	C	U	B	Y	G	T	E	N	U	A	I
Y	A	R	K	K	D	Z	C	W	H	B	L	A	H	V
L	M	H	M	F	S	W	C	S	P	I	Z	R	R	A
Y	T	I	L	I	B	I	S	N	O	P	S	E	R	T

## FIND THE FOLLOWING WORDS

AIDS

Antiretroviral

Awareness

Hiv

Immune

Infection

Prevention

Responsibility

Status

Stigma

System

Tested

Transmission

## TRUE OR FALSE

There is a cure for HIV.	TRUE?	FALSE?
You cannot live a long and Healthy Life if you Have HIV.	TRUE?	FALSE?
If HIV is left untreated it can progress to AIDS.	TRUE?	FALSE?
An opportunistic infection is an infection that takes advantage of a weakness in the immune system.	TRUE?	FALSE?



**“CHECK YOUR KNOWLEDGE!”**

# TEST YOURSELF 02

Y	B	V	Y	C	N	S	B	X	G	O	O	N	G	V
E	I	B	C	D	L	E	X	L	P	L	O	B	U	I
H	G	Q	N	H	M	F	G	A	S	I	M	I	H	A
N	T	O	E	S	Y	Z	Z	A	T	N	J	C	S	I
L	M	D	I	R	D	K	J	C	T	Q	Z	J	X	M
U	M	E	C	F	T	I	E	J	L	I	H	U	R	M
P	U	R	I	O	U	F	A	I	A	F	V	B	Y	U
B	O	U	F	Y	N	S	R	I	B	M	L	E	V	N
F	D	C	E	I	F	T	P	O	S	I	T	I	V	E
G	W	O	D	F	H	S	U	R	I	V	P	A	X	C
H	X	M	T	E	J	D	W	O	E	A	N	I	K	F
P	H	W	A	T	J	B	X	G	H	A	U	I	Y	U
R	H	L	P	J	J	D	R	T	U	R	X	Q	K	C
D	T	U	Z	P	A	B	R	K	J	C	F	U	M	I
H	L	U	Q	R	D	S	E	G	X	E	Q	R	P	H

## FIND THE FOLLOWING WORDS

AIDS

Cure

Deficiency

Health

HIV

Immune

Infection

Negative

Positive

Virus

## MULTIPLE CHOICE

### 1. When are you considered to have progressed to AIDS?

- A. When you are infected with HIV
- B. When the number of your CD4 cells falls below 200 cells per cubic millimetre of blood
- C. When your CD4 counts are between 500 and 1,600 cells/mm<sup>3</sup>

### 2. What is stage 2 of HIV called?

- A) Acute infection
- B) AIDS
- C) Clinical Latency

### 3. What Does HIV stand for?

- A.) Human infection Vaccine
- B.) Human Immunodeficiency Virus
- C.) Hyper Immune Visual

### 4. The immune system is:

- A.) A type of hospital
- B.) A complex bodily system that protects the body from and provides resistance to infection, toxins and foreign substances
- C.) The brain

### 5. How is AIDS transmitted?

- A. AIDS cannot be directly transmitted, HIV can progress to AIDS
- B. AIDS is transmitted when you hold hands with someone
- C. Neither of the above

### 6. What Does HIV stand for?

- A. Human infection Vaccine
- B. Human Immunodeficiency Virus
- C. Hyper Immune Visual

# TEST YOURSELF 03

G	B	S	C	B	Q	N	I	M	P	T	C	S	X	T
C	K	Y	Y	Z	M	G	M	O	T	R	O	Y	O	S
N	Z	H	Y	M	A	P	C	C	V	A	W	B	I	B
E	E	I	P	B	P	C	E	L	D	N	P	X	T	Q
T	O	P	P	O	R	T	U	N	I	S	T	I	C	O
A	L	E	R	H	O	G	O	T	J	M	V	M	E	S
L	O	P	M	R	X	P	C	M	E	I	I	K	F	C
D	K	M	P	Z	F	P	W	N	S	S	R	Y	N	L
Y	L	Y	N	V	F	V	R	E	Z	S	U	F	I	I
R	E	P	L	I	C	A	T	E	Q	I	S	H	T	N
T	R	M	A	E	R	T	S	D	O	O	L	B	R	I
P	C	H	N	R	Z	N	O	T	W	N	S	I	Y	C
I	M	M	U	N	E	M	V	W	O	I	S	G	S	A
D	E	N	E	K	A	E	W	U	N	K	F	K	F	L
E	W	U	G	R	R	V	E	D	V	D	B	D	A	B
K	N	L	P	O	N	G	O	L	A	K	W	F	O	I

## FIND THE FOLLOWING WORDS

- Acute
- Bloodstream
- Clinical
- Immune
- Infection
- Latency
- Opportunistic
- Protect
- Replicate
- Risk
- Symptoms
- Transmission
- Virus
- Weakened

# CRYPTOGRAM

Use the KEY to decode the sentence. The KEY lists all the letters from A to Z. Below each letter is a random corresponding number. Start by filling in all the letters you can that correspond to the numbers below the blanks. Then, fill in the missing numbers in the KEY and crack the code!! A letter may occur more than once in the sentence.

KEY

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T	U	V	W	X	Y	Z
				21		26	2	8						1	9		25			10		16		24	

P	_	E	_	E	_	_	I	O	N		I	_		_	E	_	_	E	_
9	25	21	3	21	15	17	8	1	15		8	13		5	21	17	17	21	25

T	H	_	_		C	U	_	E.		E	_	P	E	_	I	A	_	_	Y		W	H	E	_
17	2	14	15		19	10	25	21		21	13	9	21	19	8	14	6	6	24		16	2	21	15

_	O	M	E	_	H	I	_	G		H	_	_		N	O		_	U	_	E.
13	1	22	21	17	2	8	15	26		2	14	13		15	1		19	10	25	21

CH  
—  
TWO

# 02

# HIV PROJECTS

**Chapter two** takes a look at existing HIV & AIDS project initiatives. It will give you the opportunity to learn from case-studies based on real-life responses to HIV/AIDS. It includes helpful hints and powerful initiatives that will inspire you to begin to engage in HIV/AIDS projects and campaigns.

# 01. HIV & YOUNG WOMEN

## HIVSA

<b>Location</b>	Gauteng, South Africa (Soweto, Orange Farm & Sedibeng Region)
<b>Website</b>	<a href="http://www.choma.co.za">www.choma.co.za</a>

### Introduction to HIVSA

The aim of HIVSA is to empower people at an individual, community and organisational level through developing their capacity, increasing their resilience, and addressing the health, socioeconomic and psychosocial issues that they face as a result of HIV/AIDS. Since 2002, HIVSA has played a key role in advocating for access to HIV treatment for all.

### Raising Awareness through Social Media: CHOMA MOBILE MAGAZINE

HIVSA increases awareness about HIV and AIDS using social media and mobile technology to promote HIV & AIDS prevention.

The CHOMA mobile magazine is an interactive mobile phone magazine that shares information on sexual & reproductive health, HIV & AIDS, and prevention.

HIVSA makes use of youth-focused means of communication in order to engage with their target audience, South African adolescent girls and young women between the ages of 15 and 25.

The aim of this project is to prevent new infections by targeting a vulnerable population group that accounts for 40% of new HIV infections in this age range in South Africa.

### Helpful Hints:

- Advocacy requires strategizing if you want to raise awareness successfully.
- Ask yourself who is your target audience?  
If your target audience is young women, offer youth-friendly spaces and girl-friendly programming that attracts and retains the interest of this group.

- Be clear about the message you want to get across. The main objective of CHOMA is to engage with South African girl adolescents in order for them to stay free from HIV. However, it also provides young women with relevant and engaging content about love and relationships, inspiration, health, fashion and beauty .
- Think about how will you communicate your message successfully. What communication tools do you have available to you? Using relevant communication tools such as Facebook, Mxit, Twitter and Mobi, CHOMA has already reached over one million users in a way that inspires and empowers them to be the next HIV-free generation.
- Leverage existing digital and communication technology and networks to help run your awareness campaign. Use social media platforms to reach your target audiences.



# 02. HIV & SENIORS

## HIVSA

<b>Location</b>	Gauteng, South Africa (Soweto, Orange Farm & Sedibeng Region)
<b>Website</b>	<a href="http://www.hivsa.com">www.hivsa.com</a>

Gogo is a local slang term referring to grandmother and Mkhulu refers to grandfather.

### The Gogo/Mkhulu Champion's Project

HIVSA recognised that elders and senior citizens in various communities are greatly respected and are often viewed as being wise members of the community. As a result, senior citizens within various communities are often approached for guidance and advice on different topics, including those related to health.

In order to harness this, HIVSA offered basic HIV information training to 1500 senior citizens from their local area so that they could relay important information about HIV and AIDs within their own communities. HIVSA then selected 30 individuals to become 'Champions'. The Champions were further trained to share even more information with community members and offer support and care. The community members that these elders belonged to trusted and responded to these champions who encouraged community members to be tested. Much needed support and guidance about HIV statuses, medication, protection and prevention are now common knowledge shared by all.

### Helpful hints:

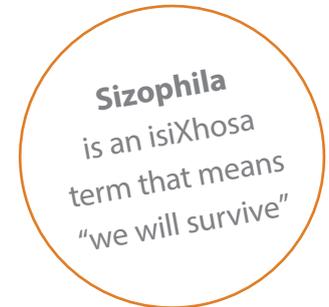
- Recognise the effectiveness of working with members from a particular community, particularly working within the existing cultural and community structures.
- Upskill from within. Do not assume that the answers to a problem lie outside of a community.
- Harness the power of intergenerational sharing of knowledge. Senior citizens are not only often the custodians of wisdom and culture within the community, but also often the caregivers within the household. Empowering them with HIV knowledge and tools helps them make and advise safe choices in the community such as encouraging young people to get tested, helping with medication and making better nutritional choices.
- Advocacy involves the creation of a platform for individuals whose voices are not listened to, so that they can be heard.



# 03. HIV & MENTAL HEALTH

## THE DESMOND TUTU HIV FOUNDATION

<b>Location</b>	Mitchell's Plain/ Klipfontein Cape Town South Africa
<b>Website</b>	<a href="http://www.desmondutuhivfoundation.org.za">www.desmondutuhivfoundation.org.za</a>



### Introduction to The Desmond Tutu HIV Foundation (DTHF)

The Desmond Tutu Foundation is a non-profit organisation (NPO) that started in 2004 and forms part of the Desmond Tutu HIV Centre which is housed at the University of Cape Town (UCT). Its core focus is on HIV and AIDS research, treatment, training and prevention. Their overarching aim is to lessen the impact of the HIV epidemic on individuals, living with and affected by HIV/AIDS.

### The Sizophila Counsellor Project

As the HIV epidemic began to take hold in South Africa, it was apparent that there would never be a sufficient number of professional health workers to provide for the clinical and emotional needs of clients coming to test for HIV. The Sizophila Counsellor Project was initiated in 1999 when antiretroviral therapy (ART) first became available in South Africa through participation in clinical trials. The group grew to twenty-eight dedicated women and men trained by the DTHF to have full understanding of all aspects of HIV, the names of the drugs, and the side effects that might be expected. They called themselves The Sizophila Therapeutic Counsellors. This marked the onset of peer support and peer education and a new cadre of health care workers - founded upon a very real spirit of Ubuntu. Many of the counsellors were living with HIV themselves and therefore had empathy with clients through their own experience. This model for HIV support-care came to be adopted throughout the Western Cape and was eventually instituted as national policy.

### Helpful Hints

- Try to involve people living with or who had been personally affected by HIV/AIDS to be part of the peer counselling group. This programme employs counsellors and community care workers most of whom are undergoing HIV treatment themselves. These lay workers are able to empathize with the fears and concerns of their patients and are living proof that the HIV drugs do work.
- Where possible use the right aged people to engage their peers.
- Peer educators are a tremendous untapped resource for educating communities about HIV and performing treatment readiness assessments, treatment preparedness education and treatment support through conducting home visits.
- Look out for counsellor burn-out. Ensure a strong training and support network for the peer educators. When supporting the emotional needs of clients, it is important to ensure the peer counsellors also have necessary support through ongoing training and debrief.



# 04. HIV & MOBILE HEALTH

## THE DESMOND TUTU HIV FOUNDATION

<b>Location</b>	Mitchell's Plain/ Klipfontein Cape Town South Africa
<b>Website</b>	<a href="http://www.desmondtutuhivfoundation.org.za">www.desmondtutuhivfoundation.org.za</a>

### The Tutu Teen Truck

According to the DTHF, the drivers of new HIV infections are adolescents between the ages of 15 and 24, who may be prone to risky behaviour. This age group is said to be difficult to reach out to as young people may avoid attending clinics which are unfriendly and judgmental in nature. In response, the DTHF launched the Tutu Teen Truck mobile clinic in 2015. The Tutu Teen Truck has brought accessible, free, efficient and youth-friendly health screening and health risk-reduction counselling to over 8,000 young people in high disease burden areas.

Anonymity is important to adolescents when accessing sexual and reproductive health care services. The DTHF developed a biometric, tablet-based application, which securely captures client data. This system has streamlined sessions for clinic visits by eliminating paper records, preventing co-enrolment at different sites and real-time tracking of client registrations and medical records. Young people were involved in designing the TTT to optimally provide a youth-friendly, integrated sexual and reproductive health service that is culturally appropriate, respectful and confidential.

The TTT has moved healthcare from “reactive” treatment to “proactive” case-finding and linkage to care. The sexual risk behaviour assessment allows for tailored, in-depth risk-reduction counselling and wellness promotion, as an alternative to disease focused intervention. Each session ends with the client setting a health goal, which is revisited at subsequent visits.

### Next steps

Mobile services have improved the DTHF's understanding of how to provide care among adolescents in a hyper-endemic setting, which is critical to HIV eradication in this key population. The Teen Truck will continue to improve the technology and science needed to reach more adolescents while they are still healthy as well as optimally assisting those who have been exposed to HIV, STI's or other health issues.

### Helpful Hints

- Youth who reside in communities where HIV is stigmatized can make use of anonymous youth friendly health services.
- It is important to ensure a trustworthy service that will attract young people to make use of the service.
- Bringing HIV services directly to a community and making them as user friendly as possible could encourage more people to access these services.
- Mobile health services are a great alternative to a traditional health clinic for young people in limited-resource and high-disease burdened communities.
- The Tutu Teen Truck tries to tailor the mobile clinic for youth by offering after-school operational hours and non-judgemental staff, and situating itself in spots where youth gather, like sports fields and shopping centres.



# RUBEN CENTRE

<b>Location</b>	Mukuru, Kenya (East Africa)
<b>Website</b>	<a href="http://www.rubencentre.org">www.rubencentre.org</a>

## Introduction to Ruben Centre

The Ruben centre is a non-profit faith-based organisation that strives to empower the community of Mukuru in Kenya by improving access to healthcare, social services and education. The Ruben centre is located in a slum/township area and can therefore provide access to those most in need of basic services.

## Rapid Results Initiative

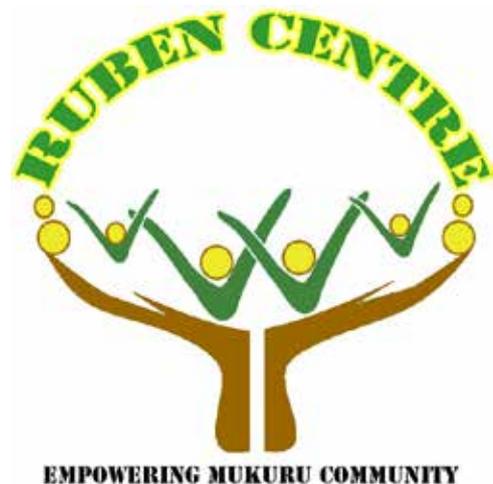
The Rapid Results initiative was a mobile door-to-door HIV counselling and testing outreach programme which targeted youth and adolescents aged between 15 to 24 years. This age group was selected after the Ruben team found that youth rarely used the various HIV/AIDS services offered by the Ruben Medical Centre. The facility identified youth from Diamond, Egessa and Ruben Mpya for the focus of this activity.

The initiative took place over two days and the objectives were to provide HIV tests to as many people as possible in these three communities. Those who tested negative were directed towards their health facilities where they were exposed to various preventative services and techniques, such as proper condom use and distribution, as well as prevention demonstrations. Those who tested positive were given counselling and directed to Rubens medical clinic for access to proper health care.

The door-to-door testing drive involved a team of seven counsellors and four community health volunteers (CHV) from various areas, and the visits were supervised by a management team. Debriefing and distribution took place each morning. The counsellors and CHVs divided themselves into various teams and headed out to the several areas where the CHVs mobilized clients and counsellors provided their services.

## Helpful Hints

- The Ruben Centre continually notes those who are using their services.
- This allows them to identify which members of the community are not accessing their services, and therefore where they should be directing more of their attention.
- Who are your target groups? Who are not using your services? It is important to be able to adapt and recognize when plans must change.
- The door to door mobile health model allows the program to work in collaboration with the community to deliver tailor made solutions to the very needs of the people.



# 05. HIV & FAITH-BASED NETWORKS

## FIKELELA AIDS PROJECT

<b>Location</b>	Cape Town, South Africa
<b>Website</b>	<a href="http://www.fikelela.org.za">www.fikelela.org.za</a>

**Fikelela** is an isiXhosa term that means "reach out"

### Introduction to Fikelela AIDS Project

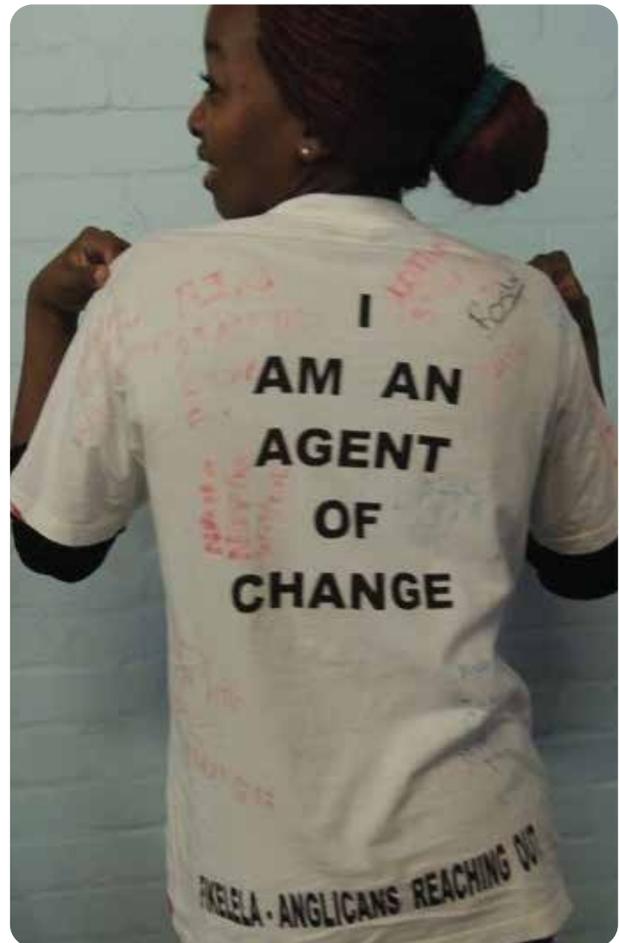
The Fikelela AIDS initiative is an outreach project of the Anglican Diocese of Cape Town, it started in 2000 to mobilise the Anglican community to respond to the HIV epidemic. They recognised an immediate need for a sustained and positive contribution to reduce new HIV infections through HIV and AIDS education.

### The Agents of Change Initiative

Fikelela found that youth vulnerability to teenage pregnancy and HIV infections is very high and because of this, they launched the Agents of Change initiative. This programme teaches young people to "live the message as well as give the message". Each 'Agent of Change' is elected by their peers to become a peer educator and role model in their communities. Fikelela trains these peer educators through 20 sessions in a specially catered life skills programme. In addition, Fikelela has parenting workshops to help parents talk about sexuality with their children to ensure that children and youth are well informed at home.

### Helpful Hints

- This project was mobilised through a large church group.
- Think of groups and networks in your community or context that you could mobilise together in order to advocate for and educate about HIV and AIDS prevention, treatment and anti-stigma.



# 06. HIV & CHILDHOOD EDUCATION

## FIKELELA AIDS PROJECT

<b>Location</b>	Cape Town, South Africa
<b>Website</b>	<a href="http://www.fikelela.org.za">www.fikelela.org.za</a>

**Fikelela**  
is an isiXhosa  
term that means  
"reach out"



### The Jerry Giraffe Initiative

Fikelela adapted the Sunday School Curriculum to teach children ways to protect themselves from child abuse and learn about HIV and AIDS. The name of the initiative is inspired by a Jerry giraffe toy, which is used to make the topics more age appropriate and engaging for a younger audience. It consists of 10 lessons over a period of 10 weeks. The lessons promote good choices, kindness and compassion and includes basic HIV facts, the information on transmission, anti-stigma and how to keep yourself safe from HIV infection. The aim of the initiative is to create an HIV free generation but also a generation that respects those who are HIV Positive.



### Helpful Hints

- Advocacy work can never start too young.
- Strategies such as using a toy giraffe can help young learners have fun while learning.
- Teaching about compassion and the importance of acceptance can help shape the way in which young people think about justice, advocacy and the issues faced by individuals living with HIV/AIDS.
- Healthcare, education and empowerment methods go hand-in-hand. There is no use only providing medical treatment once a person has tested positive for HIV. It is necessary to educate and empower groups of people with life skills, prevention techniques, and HIV & AIDS treatment in order to strengthen their knowledge, resilience and response to the HIV epidemic.

# CHAMP ZAMBIA

<b>Location</b>	Lusaka, Zambia
<b>Website</b>	<a href="http://www.champzambia.org">www.champzambia.org</a>

## Introduction to CHAMP Zambia

CHAMP is a non-profit organisation that was started in 2002 in response to the growing need for corporate HIV/AIDS programmes and initiatives in Zambia. CHAMP offers support to several institutions and communities, providing HIV related services, HIV educational programmes, and sensitisation programmes focused on employees and communities which work in the field of HIV. They also focus on HIV and AIDS policy development.

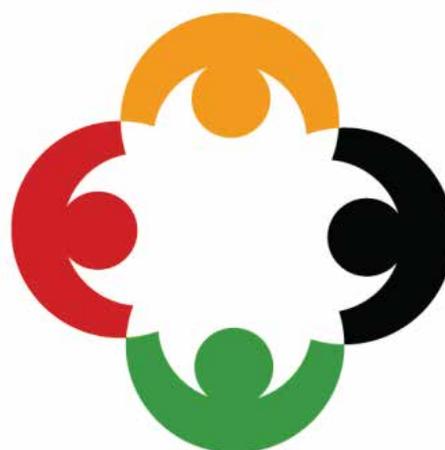
## CASH

One of the initiatives of CHAMP is a Save The Children project called Child Advocacy on Sexual and Reproductive Health (CASH). This initiative focuses on advocating for the sexual and reproductive health rights of children, with the target group being adolescents. Through CASH, CHAMP aims to provide and increase access to age appropriate non-judgemental comprehensive sexuality education and information on sexual, reproductive health and rights. Reproductive services and access to knowledge about sexuality has been shown to lessen the number of new HIV infections.

The aim of CASH is to advocate for the promotion of children's rights and increase access to information about HIV/AIDS Prevention strategies for children and ensure that children have access to age-appropriate material to help them keep themselves safe.

## Helpful Hints

- Young people's HIV risk is increased when they have limited knowledge about the means to protect themselves and they are not supported to access and utilize them.
- One third (4 million) of the Zambia population is aged 15-24 years; every hour, 3 of these young people will become infected with HIV. Less than 40% of young people in Zambia have comprehensive HIV knowledge, with lower levels among females.  
In order to improve the ability of young people to mitigate AIDS impact at an individual and community level, it is important to promote youth and adolescent participation in HIV response and get their opinions on issues that affect their vulnerability and risk for HIV.
- Access to child friendly and age appropriate SRH services is critical to facilitate and increase knowledge on HIV/AIDS prevention strategies in children.



# 07. HIV & PEER EDUCATION

## HUMANA PEOPLE TO PEOPLE IN SOUTH AFRICA

<b>Location</b>	South Africa
<b>Website</b>	<a href="http://www.hpp-sa.org">www.hpp-sa.org</a>

### Introduction to HUMANA People to People South Africa

HUMANA people to people in South Africa is a non-profit organisation that started in 1995. The main aim of HUMANA is to work alongside those most affected by the various issues facing their society such as HIV/AIDS. The organisation promotes listening to the experiences of community members and together coming up with viable solutions to combat their problems.

### The Total Control of the Epidemic (TCE) Initiative

In response to the HIV/AIDS epidemic, HUMANA launched Total Control of the Epidemic (TCE) in the year 2000. TCE is a community mobilisation and educational program that aims to strengthen communities in the fight against the spread of HIV and AIDS. The key focal points are prevention, care and support. The TCE initiative works to ensure that local communities and institutions are well informed within their nineteen TCE areas in South Africa. Each TCE area consists of 100 000 people. They run door-to-door campaigns that consist of educating every household within the TCE area, offering counselling and mobilising the community to be aware of prevention methods and treatment options. HUMANA also recruits and employs members of the community to become peer educators as they believe that “only the people can liberate themselves from HIV”.

### Helpful Hints

- Working alongside those most affected by HIV/AIDS to discover what concerns exist and what possible solutions can be put in place is very important.
- This gives greater insight into what the community believes should be advocated for, as well as the best way in order to go about it.
- Never assume that you know what a community needs.
- Work alongside those most affected by an epidemic, for they know what it is like from a grassroots perspective.



# 08. HIV & HEALTH SYSTEMS CHANGE



## TREATMENT ACTION CAMPAIGN (TAC)

<b>Location</b>	South Africa
<b>Website</b>	<a href="http://www.tac.org.za">www.tac.org.za</a>

### Introduction to TAC

The Treatment Action Campaign (TAC) is a civil society organisation that started in 1998. TAC promotes rights-based local activism that is informed and monitors health and service delivery at a local level and demands quality healthcare. TAC is a highly successful organisation whose campaigns have influenced the South African constitutional court to rule that the South African government should be providing anti-retroviral medication to the general public, especially in order to prevent mother-child HIV transmission during birth.

### Treatment Literacy programme

The Treatment Literacy Programme disseminates educational materials on how HIV and AIDS affects the body and the importance of prevention and treatment to promote informed grassroots level activism. It is necessary to understand and have knowledge about HIV and AIDS in order to know what you are advocating for and the approach you need to take with your campaigns.

### Health system strengthening campaign and building local activism

TAC represents those who use the public healthcare system in South Africa and monitors thousands of clinics and hospitals to ensure that there is accessible, quality healthcare.

TAC has a network of over 200 branches and 8000 members that they represent. The members receive basic HIV, TB and healthcare rights training and form part of the local activism initiatives. Members make use of the public healthcare system and therefore they are the ones who will notice when the system is failing them and what changes need to be made. Through national campaigns and the local activism of the TAC's members, their concerns can be addressed and their failing healthcare system can be challenged from the ground up.

### Stop Stockouts Project (SSP)

The TAC monitors the availability of medication in healthcare across South Africa, as it is a severe health risk to run out of essential medicines such as anti-retroviral drugs. Access is incredibly important and TAC forms part of the Stop Stockouts Project (SSP) alongside five other civil society organisations. The SSP monitors medicine availability and advocates for systemic solutions to ensure that essential medications are available when needed.

### Helpful Hints

- In order to mobilise grassroots communities to challenge injustice or infringements on their healthcare rights; it is vital that they be made aware of what these rights are in the first place.
- Getting feedback from members who are direct users of the public healthcare systems is an effective strategy to identify shortcomings and gaps in the current system.
- It is essential to engage multiple stakeholders such as healthcare facilities, healthcare workers, patients, civil society organizations and government, to advocate for continuous and ongoing access to essential affordable and quality medications such as ART.

# 09. HIV & LEGAL & HUMAN RIGHTS

## AIDS LEGAL NETWORK

<b>Location</b>	Cape Town, South Africa
<b>Website</b>	<a href="http://www.aln.org.za">www.aln.org.za</a>

### Introduction to AIDS Legal Network:

AIDS Legal Network (ALN) is a Human Rights organisation which was started in 1994 with the aim to promote and protect the rights and fundamental freedoms of people living with and affected by HIV and AIDS. ALN responds to the legal and ethical challenges faced by those living with HIV. They document and respond to human rights violations and abuses using a rights-based approach. ALN advocates for law reform in policy and practice where laws do not fairly consider individuals living with HIV and/or AIDS.

ALN runs and forms part of national, regional and global advocacy activities. One of their campaigns is the “who have you discriminated against lately?” campaign. The aim of this campaign is to challenge stigma and discrimination against people living with HIV.

### Human Rights & Legal Literacy Training Initiative and Legal Advice Desk

ALN runs human rights and legal literacy training programmes to increase awareness and understanding about HIV risk and vulnerabilities, human rights and fundamental freedoms. They believe that it is vitally important for those who are living with HIV to be able to recognise when their rights are being violated in order to challenge such injustices. ALN also offers a Legal Advice Desk which documents and responds to violations of human rights and fundamental freedoms for those living with HIV.

### Helpful Hints

- Knowledge about HIV is incredibly important but it goes hand in hand with knowledge about your legal rights and fundamental freedoms, especially when advocating for justice.
- Knowledge and training about human rights in the context of and response to HIV helps facilitate critical human rights discourse, challenge gender and human rights barriers, and to ultimately transform the societal contexts defining HIV risks and vulnerabilities.  
The ultimate focus of a legal and human rights campaign is the promotion and advancement of the principles of equality, non-discrimination, human dignity, and the equal enjoyment of all rights and freedoms, irrespective of a person’s sex, gender, sexual orientation, gender identity and/or HIV status.



**AIDS  
LEGAL  
NETWORK**

# THE JUSTICE DESK

<b>Location</b>	Cape Town, South Africa
<b>Website</b>	<a href="http://www.justicedesk.org">www.justicedesk.org</a>

## Introduction to The Justice Desk

The Justice Desk is a Human Rights focused non-profit organisation which was started in 2013 in response to severe human rights violations and injustice faced by people across South Central Africa. The Justice Desk works to empower ordinary people to understand and defend their Human Rights, so that they can transform society and create a more just and equal world. To achieve this the Justice Desk develops and offers education, training, and advocacy initiatives across South Africa, Zambia and Zimbabwe. They work alongside civil society, NGOs, businesses, and governments to challenge and eliminate the root causes of injustice.

## Global HIV Campaign and Educational materials

The Justice Desk runs international and national Justice Campaigns and launches them within schools and communities at both a local and international level. Their Global HIV campaign addresses issues around access to HIV treatment and medication as well as issues around the prevalence of stigma and discrimination experienced by those living with HIV/AIDS. By getting schools and communities involved in campaigns such as letter-writing campaigns, petitions and demonstrations, many young people are getting more involved in government processes.

The Justice Desk mobilises their network to spread awareness and challenge stigma and promote prevention methods and a clearer understanding of HIV treatment. HIV educational trainings are offered to various communities in order to increase awareness about the HIV epidemic. The Justice Desk creates African-context specific educational materials on various topics, including HIV and AIDS and disseminates information in easy to read manuals, posters and infographics that are age appropriate, relevant and informative.

## Helpful Hints

- Mobilise your networks of schools and their communities. These consist of students, teachers, staff and parents.
- It is important recognise that we have power in numbers.
- Do not forget about the influence of schools and their communities!



# 10. HIV & IV DRUG USE

## SUPERVISED CONSUMPTION FACILITIES, MIDDLESEX-LONDON HEALTH UNIT

<b>Location</b>	London, Canada
<b>Website</b>	<a href="http://www.healthunit.com/opioids-faqs">www.healthunit.com/opioids-faqs</a>

### Introduction to Supervised Consumption Facilities

Supervised Consumption Facilities are health services that provide a hygienic environment for people to inject pre-obtained drugs under the supervision of a nurse. This service is provided for people who inject-drugs. In addition to supervised injection, individuals are provided with sterile injection supplies, education on safer injection, overdose prevention and intervention, medical and counselling services, and referrals to drug treatment, housing, income support and other services.

**FACT:**  **“People who inject drugs are around 28 times more likely to be living with HIV than the general population”**

### Supervised consumption facilities have four main goals:

1. To reduce spread of infectious diseases (HIV and hepatitis C);
2. To reduce the number of drug overdose deaths;
3. To bring people who inject drugs into contact with other health and social and treatment services; and,
4. To reduce issues in the community such as drug use in public places, and discarded needles.

### The Harm Reduction Approach

Almost 1/3rd of Global HIV Infections outside of Sub Saharan Africa are caused by injecting drug use.

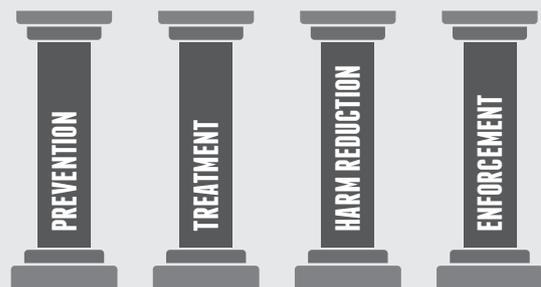
People who use and inject drugs are among the groups at highest risk of exposure to HIV, but remain marginalized and out of reach of health and social services.

People who inject drugs need urgent access to harm reduction interventions, including needle-syringe programmes and opioid substitution therapy. There is irrefutable evidence that new HIV infections drop sharply when people who inject drugs have access to harm reduction and other public health programmes. People who inject drugs, including people in prisons and other closed settings, need access to harm reduction services to prevent HIV infection, including needle-syringe programmes, opioid substitution therapy, antiretroviral therapy and nalaxone.

Evidence shows that harm reduction approaches such as needle-syringe programmes reduce the health, social and economic harms of drug use to individuals, communities and societies. They do not cause increases in drug use.

UNAIDS is calling for the global adoption of a people-centred, public health and human rights-based approach to drug use and for alternatives to the criminalization and incarceration of people who use drugs.

### 4 PILLARS OF DRUG STRATEGY



**“Four countries account for around half of all people who inject drugs globally: China, Pakistan, the Russian Federation and the United States of America”**



### Prevalence

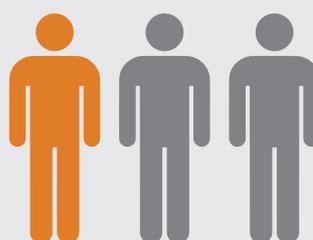
The first supervised injection service opened 30 years ago in Switzerland. Today there are more than 90 Supervised Consumption Facilities worldwide, including in Europe, Australia and Canada. In Canada, there are Supervised Consumption Facilities in Vancouver, Surrey, Kamloops, Kelowna and several in Montreal. Sites are currently being proposed in London, Ontario.

### UNAIDS Five Policy Recommendations

1. Recognize that the overarching purpose of drug control is first and foremost to ensure the health, well-being and security of individuals, while respecting their agency & human rights at all times.
2. Ensure accountability for the delivery of health services for people who use drugs by including public health and human rights pillars in the framework of The UNGASS outcome document that incorporate clear objectives for reducing new HIV infections & protect and promote the rights of people who inject drugs.
3. Commit to fully implement harm reduction and HIV services, as outlined in the World Health Organization’s consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. commit to treating people who use drugs with support & care, rather than punishment.
4. UNAIDS believes that this objective can be achieved only by implementing alternatives to criminalization, such as decriminalization and stopping incarceration of people for the consumption & possession of drugs for personal use.
5. Ensure integration of HIV services with other health and social protection services for people who use drugs.

### Useful Tips

1. Ensure that your campaign or programme is contextualised to your local reality.
2. Translate materials and programmes into the local language(s) to ensure access to vulnerable groups.
3. Build a sound network of organisations that might be able to assist your clients or your organisation.



**“Almost one third of global HIV infections (excluding Sub-Saharan Africa) are caused by injecting drug use.”**

# TB HIV CARE

<b>Location</b>	Cape Town, Durban and Pretoria in South Africa
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<b>Website</b>	<a href="http://www.tbhivcare.org">www.tbhivcare.org</a>
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## Step Up Project

Reducing and preventing the spread of HIV among people who inject drugs in South Africa

## Background

TB HIV Care, a national non-profit company, works to prevent, find and treat TB and HIV in South Africa. TB HIV Care is committed to protecting the health of all communities; this includes key populations such as high-risk groups who are the most vulnerable to HIV and other diseases.

In the global response to HIV, interventions focused on key populations (including inmates, sex workers, men who have sex with men and people who use and inject drugs) are both a public health and human rights imperative.

TB HIV Care's Step-Up project, launched in 2015, aims to reduce HIV infection and improve health outcomes for people who inject drugs (PWID) in South Africa. The project provides the World Health Organization's comprehensive package of HIV interventions for PWID (including HIV counselling and testing, condom distribution and risk reduction counselling). It prioritises harm reduction services; meaningful engagement with (and advocacy on behalf of) PWID; accessible, non-judgemental healthcare services and peer-led interventions. The project is run through two drop-in centres in Cape Town and Durban, as well as a unique, integrated key-populations clinic in Pretoria.

## Consultation and engagement

Even in its development, TB HIV Care (and partners) knew that for the Step-Up project to be successful and sustainable; it had to be guided by the fundamental principle of 'nothing about us, without us'. Ongoing consultation and engagement with PWID helped shape the project – ensuring that PWID needs and experiences inform the services on offer.

## Accessible services

In many countries, key populations are marginalised and, as a result, are unwilling (or unable) to access healthcare services. As a result, HIV is left untreated and unchecked. In South Africa, it is no different. The criminalisation and stigmatisation that PWID experience has led to a fear of visiting clinics and hospitals. Step Up's drop-in centres are safe spaces where PWID can 'drop-in' and access healthcare services. These include HIV testing, hepatitis screening, screening for TB and STIs (Sexually Transmitted Infections), basic health checks (diabetes and blood pressure) and basic wound care. Importantly, the centres also provides appropriate treatment (for example, antiretroviral therapy) as well as psychosocial counselling and support. In addition, Step Up makes use of mobile outreach teams. Literally taking healthcare onto the streets, reaching PWID with the services they need, where they are.

## Harm reduction services

PWID are susceptible to HIV and other blood-borne viruses through the re-use and sharing of needles. Step Up offers a needle/syringe programme, which provides PWID with sterile injecting equipment. It also collects and disposes of used needles in a safe manner. By engaging with PWID during needle exchange, TB HIV Care educates and encourages PWID to look after their health, make positive decisions concerning their well-being and counsels them around testing for HIV and hepatitis.

**MORE THAN**  
**150 000**

**"More than 150 000 people who inject drugs were newly infected with HIV in 2015"**

## Peer-led education and support

People who use drugs are directly and meaningfully involved in outreach and service delivery and are critical to the success of the project. The inclusion of PWID as staff is vital to Step Up's work with PWID as this provides a broader understanding of the needs and circumstances of people who use drugs, and provides legitimacy and credibility to their services and intentions (to a group who are understandably wary).

## Impact

Step Up was borne out of a need for rights-affirming, evidence-based interventions aimed at improving health outcomes for the PWID community.

### To date it has:

- Ensured a continuous supply of sterile injecting equipment to approximately 4 000 PWID in South Africa
- Tested more than 300 PWID for HIV, per month, since inception
- Provided a non-judgemental space for PWID to access basic healthcare and support in three centres around South Africa
- Provided hepatitis screening for over 400 PWID and, when necessary, successfully linked them to further treatment
- Contributed to the representation and involvement of people who use drugs in national policy decisions, including the development of the National Strategic Plan & National Drug Master Plan
- Hosted SA Drug Policy Week
- Educated more than 1 000 medical professionals and trainees on harm reduction
- Presented at international conferences and contributed to the academic literature through peer reviewed publications

**Many PWID have now found acceptance and care, gained dignity and have real hope for their future.**

The Step-Up project continues to grow and evolve. If we are ever to see the end of the HIV epidemic in South Africa, key populations cannot be left behind.

# 13%

**(1.6 million) of the 12 million people worldwide who inject drugs are living with HIV**

# 50%

**(6.1 million) of people who inject drugs are living with hepatitis C**

# 60 000

**In 2015, 60 000 people who inject drugs died of aids-related illnesses**

# 33%

**The rise in new HIV infections among people who inject drugs. (2011 - 2015)**

Statistics sourced from UNAIDS.org

# 11. HIV & INDIGENOUS HEALTH

## YOUTHCO HIV & HEP C SOCIETY



<b>Location</b>	Vancouver, Canada
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<b>Website</b>	<a href="http://www.youthco.org">www.youthco.org</a>
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### Introduction to Yúusnewas at YouthCo

Yúusnewas is an Indigenous peer-led education program that provides workshops on HIV, Hepatitis C, Sexual Wellbeing, Harm Reduction and Sexual Health in urban and rural communities across British Columbia, Canada. Yuusnewas approaches the topic of sexual health by highlighting Indigenous perspectives and incorporating traditional teachings. All of their workshops are led by Indigenous youth, and are culturally responsive, fun and free.

### The Yúusnewas Team

The Yuusnewas team consists of three people, an Urban Outreach Educator, a Provincial Outreach Educator, and a Program Manager. These are all indigenous youth under 30. One of the unique values at YouthCO is shared leadership. Working through this value they provide a staff orientation, and work with educators at their own pace to ensure an understanding of workshop materials. They also have a facilitation guide that peer educators can look to for tools for facilitation.

### Incorporating Indigenous Perspectives

Everyone on the Yúusnewas team is Indigenous, each with unique teachings and culture. The program encourages educators to share their knowledge with youth during workshops. For instance, some of the educators have teachings around coming-of-age ceremonies, or what sex meant for their ancestors. Yuusenewas has 6 different workshops they offer -

- HIV 101
- Taking Care of Communities
- Taking Care of Ourselves (Hep C & Harm Reduction)
- Sexual Wellbeing
- Decolonizing our Health, and
- HIV+ Harm Reduction Bingo

For example, the 'Decolonizing our Health' workshop that is a self-reflection tool to look at Indigenous health holistically and incorporate sexual health as an important influence to other parts of wellbeing. They have also recently started a program called "Culture is Healing". Through this program they bring youth from all over the Vancouver lower mainland to share, teach, and learn traditional teachings in a safe and inclusive space.

## Helpful hints

Some considerations when hosting an HIV and sexual health training in Indigenous communities:

- Creating low-barrier workshops that are community-based and reflect the needs of the community are important.
- Catering workshops to the needs of the community will result in the right, and relevant information being shared.
- Land acknowledgements and thanking the nation for allowing us on their territory is important.
- Prompt youth in your workshops to share their teachings if they feel comfortable. We share some of our teachings, they share some of theirs.
- When possible, peer-education should be utilized (Indigenous people living with HIV should be the ones teaching, or at least Indigenous people who hold knowledge about HIV and sexual wellbeing). If settlers are the only ones available to facilitate then it is important that they prioritize Indigenous voices and perspectives and should learn about the nation before presenting.
- Keep in mind that Indigenous people have their own teaching which may differ from western teachings and perspectives. As guests in a community we must be respectful of Indigenous knowledge even if it is different than what we have been taught.
- It is important to be mindful that most Indigenous people in Canada are marginalized and have a complicated and traumatic colonial history.
- Young parents are common in Indigenous communities as well as drug use and STI prevalence, educators must be sensitive, respectful, and non-judgemental of this reality.
- When working in rural communities be open to adapting your suggestions for resources to accommodate for the fact that some communities may not have the same access to resources as urban centres (i.e. Instead of recommending youth clinics as a good place to get tested, recommend the nurse at the band office). It is important for you to do a bit more research of available services before presenting in rural communities.

## ADVICE FOR HIV YOUTH ADVOCATES

Our advice is to always be open to learning opportunities. HIV education is always changing, and it's important to keep up-to-date and create spaces that are inclusive and anti-oppressive. It's important to centre the voices of those most affected by HIV. Many Indigenous communities have a person at their health station or nurses station that works specifically in HIV/AIDS education, and getting involved may start with connecting with them!



# 12. HIV & LGBTQ2+ HEALTH

## REGIONAL HIV AIDS CONNECTION (RHAC)



<b>Location</b>	London, Canada
<b>Website</b>	<a href="http://www.hivaidconnection.ca">www.hivaidconnection.ca</a>

### Introduction to Open Closet at RHAC

Open Closet (OC) is a social support group for youth between 14 and 18 years of age who identify as lesbian, gay, bisexual, transgender, two-spirit, queer or questioning their sexual orientation and/or gender identity (LGBTQ2+). The group started in early 2002 and has served more than 1,100 youth since its inception. OC is open to youth from each of the six counties serving youths from Ontario - Perth, Huron, Lambton, Elgin, Middlesex and Oxford.

The group facilitates discussions related to coming out, queer identities, LGBTQ2+ histories, survival strategies, safer sex and healthy relationships. They also bring in guest speakers, do arts-based activities, and provide information about HIV/AIDS and other sexually transmitted infections (STIs), harm reduction, and community services/resources according to participants' individual needs.

### The Open Closet Approach

The Open Closet team consists of trained group facilitators. All facilitators have previous experience leading youth groups. The facilitators are closely involved with developing and planning the session topics every week. The style of facilitation is informal and peer-led with semi-structured activities that promote self-awareness, respect, self-esteem and self-confidence. Some examples of session structure include a group check-in asking preferred pronouns, developing and reviewing group guidelines and a closing checkout after the planned activities for the day.

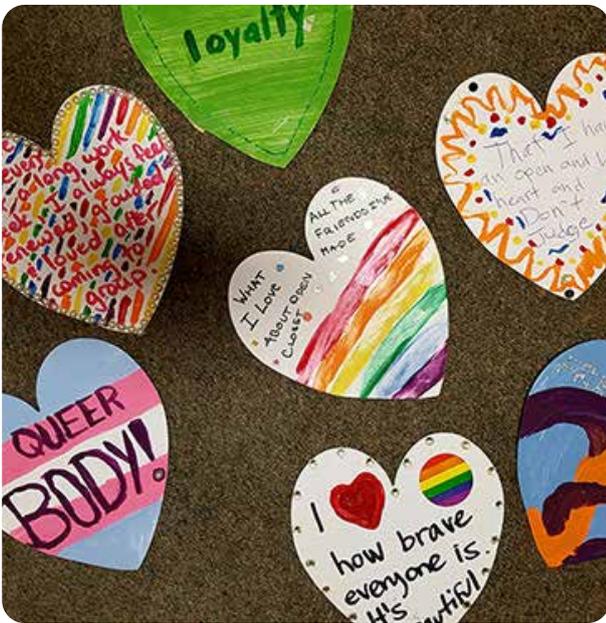
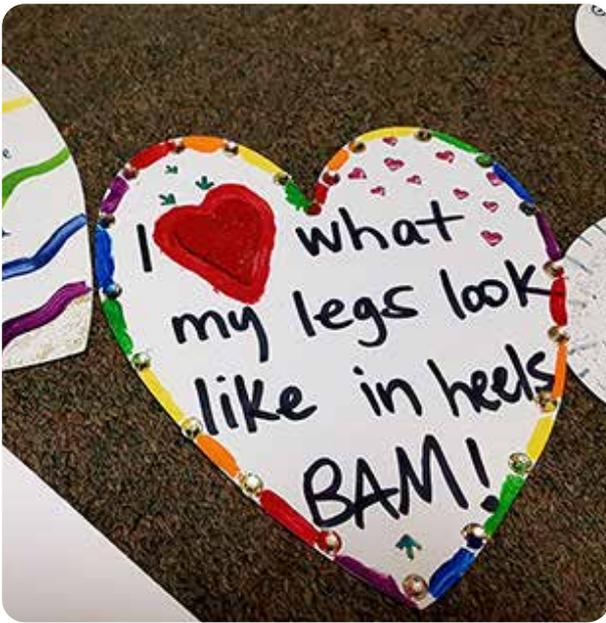
### Examples of Open Closet program include:

- Safer sex, HIV/AIDS and other STI information
- Coming out to parents, family, and friends
- Gender identity
- Culture, religion, & spirituality
- Dealing with depression and isolation
- Who am I in this community
- Internalized homo/bi/transphobia
- Self-acceptance and self-esteem

### Incorporating LGBTQ2+ Perspectives

The goal of the Open Closet Program is to create a safe space for youth to participate in discussions and receive support while dealing with matters related to sexual orientations and/or gender identity. It also offers an opportunity to connect with one another as a community and educate each other about the impact of internalized homo/bi/transphobia.

The program recognizes the need for connection, alliances and pride for a healthy self-concept and aims to identify factors that support the development of healthy LGBTQ2+ relationships within the context of oppressive social environments. The support group also offers youth an opportunity to practice communication skills, how to share thoughts and feelings in a way that promote connection, and discuss relevant social issues that both pertain to the define greater LGBTQ2+ communities.



## Helpful hints

Some considerations when hosting an HIV and sexual health training in LGBTQ2+ youth groups:

- Support, share, learn and listen to each other!
- To develop trust, it is important to establish confidentiality at the beginning of the sessions. Whatever is said in the group, stays in the group.
- Provide stickers or nametags where youth can indicate their preferred pronouns at the beginning of each session. This provides reassurance that the youth will not be misgendered by the facilitators and other group members and also gives flexibility so that youth may change their pronouns as they wish.
- Providing food, if possible, at the sessions is a good way to encourage attendance and provide a shared bonding experience.
- Providing transport allowance, if possible, is a good way to encourage attendance by youth who may live farther away.
- Drop-in style sessions work well. However, be prepared for fluctuating group sizes and reviewing group guidelines with new members.
- Encourage youth to provide ideas for activities at future sessions.
- Ensure facilitators are relatable, and comfortable with sexual health topics (eg. Can provide condom demos, lead conversations about sex, etc. from a non-judgemental perspective).
- Be mindful of challenges with group dynamics such as interrupting group members and conflicts within group members.
- Alternate group facilitators to respect facilitator time and commitment and prevent facilitator burnout.
- During the check-out activity, it is safe practice to ask youth where they are heading next, especially if groups are held in the evening or after school.

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THREE

# 03

# HIV ADVOCACY

**The aim of chapter three** is to help you to develop HIV/AIDS campaigns and initiatives using a human-rights based advocacy approach. By the end of the chapter you will have a greater understanding of human rights, social justice, community-based responses to injustice and how to successfully plan and implement an advocacy response.

# SECTION 1:

# HUMAN RIGHTS

# – A GLOBAL FRAMEWORK

## Understanding the Global framework

There has been significant progress made in the fight against the global HIV/AIDS epidemic through advocacy and justice. The levels of awareness around the issue of HIV/AIDS have in general increased and public campaigns have been implemented globally. Yet the numbers are not showing any behavioural changes (UNAIDS, 2018). Although the amount of new infections is slowly decreasing, there are still more and more people living with the illness each year (UNAIDS, 2017). This provides all states with the increasing challenge of having to provide medication for many more people living with HIV/AIDS. National programmes set by individual states, which focus on raising awareness about HIV/AIDS are usually the most visible in various developing countries. However, there are other global campaigns such as the United Nations “Blind spot - Reaching out to men and boys” and “Zero Discrimination Day” which are globally recognised and engaged with (UNAIDS, 2017). Many experts believe that in order to truly challenge the HIV/AIDS pandemic, we need to engage in advocacy and justice work at both the national and international levels. A strong focus on the protection and promotion of human rights is said to have the potential to truly end HIV/AIDS for future generations.

## WHAT IS ADVOCACY?

### **‘ADVOCACY’ (VERB):**

**Advocacy is the act or process of supporting a cause or proposal: the act or process of advocating**

## WHAT ARE HUMAN RIGHTS?

### **‘HUMAN’ (NOUN):**

**A member of the Homo sapiens species; a man, woman or child; a person.**

### **‘RIGHTS’ (NOUN):**

**Things to which you are entitled or allowed; freedoms that are guaranteed.**

### **‘HUMAN RIGHTS’ (NOUN):**

**The rights you have simply because you are HUMAN.**

### **What is Advocacy?**

Advocacy is about speaking out and alongside those whose voices have been silenced. It means standing up and demanding that the rights of all people (and not just yours) are respected, protected and fulfilled. Advocacy is about recognizing our common humanity, and using our positions and influences in society to speak out for the rights of others.

Advocacy in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to:

- Have their voice heard on issues that are important to them.
- Defend & safeguard their rights.
- Have their views and wishes genuinely considered when decisions are being made about their lives.

### **What are Human Rights?**

Human rights are rights inherent to all human beings, whatever our nationality, place of residence, sex, ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.

Universal human rights are often expressed and guaranteed by national and international law. International human rights law lays down obligations of governments to act in certain ways or to refrain from certain acts, in order to promote and protect human rights. Human rights are also often guaranteed in the constitutions and other legislations of national governments.

At the international level, the most widely recognised document concerning human rights, is known as The Universal Declaration of Human Rights (UDHR). It was adopted by the United Nations General Assembly in 1948 and consists of 30 fundamental human rights that were accepted by all member states of the UN as being natural rights inherent to all human beings. Many countries around the world have ratified human rights through signing what are known as treaties. By signing a treaty, a member state agrees to uphold that particular human right in their country and incorporate it into law.

# THE THIRTY FUNDAMENTAL HUMAN RIGHTS

## As Featured In The UDHR (Universal Declaration Of Human Rights)

- Article 1** Right to Equality
- Article 2** Freedom from Discrimination
- Article 3** Right to Life, Liberty, Personal Security
- Article 4** Freedom from Slavery
- Article 5** Freedom from Torture and Degrading Treatment
- Article 6** Right to Recognition as a Person before the Law
- Article 7** Right to Equality before the Law
- Article 8** Right to Remedy by Competent Tribunal
- Article 9** Freedom from Arbitrary Arrest and Exile
- Article 10** Right to Fair Public Hearing
- Article 11** Right to be Considered Innocent until Proven Guilty
- Article 12** Freedom from Interference with Privacy, Family, Home and Correspondence
- Article 13** Right to Free Movement in and out of the Country
- Article 14** Right to Asylum in other Countries from Persecution
- Article 15** Right to a Nationality and the Freedom to Change It
- Article 16** Right to Marriage and Family
- Article 17** Right to Own Property
- Article 18** Freedom of Belief and Religion
- Article 19** Freedom of Opinion and Information
- Article 20** Right of Peaceful Assembly and Association
- Article 21** Right to Participate in Government and in Free Elections
- Article 22** Right to Social Security
- Article 23** Right to Desirable Work and to Join Trade Unions
- Article 24** Right to Rest and Leisure
- Article 25** Right to Adequate Living Standard
- Article 26** Right to Education
- Article 27** Right to Participate in the Cultural Life of Community
- Article 28** Right to a Social Order that Articulates this Document
- Article 29** Community Duties Essential to Free and Full Development
- Article 30** Freedom from State or Personal Interference in the above Rights



### Important Notes:

The Universal Declaration of Human Rights is not a treaty, so it does not directly create legal obligations for countries. However, it is an expression of the fundamental values which are shared by all members of the international community. And it has had a profound influence on the development of international human rights law(1).

Most countries that are part of the United Nations(2) have incorporated the UDHR into their constitutions. Thus, the legal effect of these rights is guaranteed at the national level, where it is enforceable. In all instances, the state is the primary defender of human rights, however all institutions and agencies that form part of the fabric of any society are collectively responsible for the realisation of human rights.

However, the incorporation or ratification of these rights has not always translated into the realisation of these rights. In many contexts around the world, many people's rights are violated by those in their communities, in their government, or by other institutions and businesses.

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1.) Australian Human Rights Commission. (2017). Is the Universal Declaration Legally Binding? Available: <https://www.humanrights.gov.au/publications/what-universal-declaration-human-rights>.

2.) Tom Ginsburg, Zachary Elkins & Beth Simmons, "Getting to Rights: Treaty Ratification, Constitutional Convergence, and Human Rights Practice," 54 Harvard Journal of International Law 61 (2013).

## Why are we talking about Human Rights?

We talk about a human rights based approach to HIV advocacy because although human rights are universal and inalienable, not all people enjoy them. Throughout our world, we have seen examples of how people, especially young people, have been denied access to HIV prevention, diagnosis and treatment services. Often there are policy and legal barriers to providing services for young populations. In some cases, certain behaviors and sexual orientations are criminalized. In other cases, there are restrictive education policies or conditions such as requirements for schools to disclose the HIV status of learners or there is a lack of educators with training to provide counselling or support to positive youth.

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*“The right to life and the right to exist trumps everything. The duty of the state is to ensure that the rights of its people are supreme”*

**Zachie Achmat** – Social Justice Activist, and Founder of the Treatment Action Campaign

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Given the marginalized social position of youth and their reluctance to attend diagnostic and treatment services due to fears of stigma including possible legal consequences, adolescents remain less likely than adults to be tested, access HIV care, remain in care and achieve viral suppression.

Therefore, raising awareness about human rights is a priority because people do not know that they are entitled to these rights and are being robbed of their rights because of it.

(Reference: WHO 2013 HIV and adolescents: Guidance for HIV testing and counselling and care for adolescents living with HIV)

# HIV/AIDS AND HUMAN RIGHTS

The issue of HIV/AIDS is multi-layered and requires a collective response. By its nature, HIV/AIDS is not only an issue of access to quality health care, but also an issue of poverty and lack of education and lack of provision of basic social services by government.

This is where HIV/AIDS intersects with human rights issues. The fundamental challenge when one considers the issue of HIV/AIDS through the lens of Human Rights is that HIV is often a symptom of the injustice caused by poverty and inequality at both the national and international levels.

For example, access to education (or the lack thereof) is a major contributing factor to either the increase or decrease of new HIV infections. When dealing with HIV/AIDS infections, it is important to share relevant information with children as young as 10 years old. In South Africa, children as young as 12 years of age are sexually active, while in countries like Zambia, child marriages are a common practice, often exposing these young people to possible HIV infection (Shisana, O et al, 2014).

The question is how do we engage, interact and advocate for people living with HIV and how do we prevent new infections?

The Right to Life (article 3 of the UDHR) and the Right to Health Care (Article 25) intersects when relating to HIV/AIDS. These two rights form the foundation of the need for governments, institutions, companies and NGO's to be working together to reduce the rate of new infection and to increase access to medicine.

# THE RIGHT TO LIFE

The most fundamental of Human Rights is the right to life, without which no other right can exist. The inability of the individual to access health care severely limits the right to life. In some instances, without the right to health care, it would mean the end of a life. In the case where a person has been diagnosed with HIV/AIDS, access to life saving medication is vital.

The disparity between nations and their ability to provide for the rights of their people, as indicated in the UDHR, manifests at the community and grassroots level, where people access their rights.

For example, due to the inequality at the international level, HIV medication is bought at cheaper prices and sold at very high prices (The Guardian, International Edition, 2011). The increased price of medications causes high levels of inaccessibility meaning that the poor and vulnerable are often unlikely to have access to medication, simply because they cannot afford them. Countries in the developing world are often placed in difficult positions where they must incur debt to provide for their citizens (if the government is willing to incur the debt). In countries battling high levels of poverty, inequality and debt, the right to access adequate health care becomes nothing more than a dream. Therefore, inequality at both national and international levels has a direct impact on the ability of the individuals to access adequate health care services. The interconnectedness of global economic and political systems perpetuates the cycle of inequality at all levels of society. The rights of individuals must be protected by the state, however due to the levels of inequality within states, the individual rights can only be realised with a global effort to reduce the price of health care globally.

The interconnectedness of the UDHR rights requires that we look at our systems both globally and nationally, in order to ensure that rights within and across borders are protected at all costs.

## Helpful hints:

- To advocate for the right to access essential medicines, not only would it be beneficial to engage people who are HIV positive and require the medication, but also to engage the Health Ministry or department to understand the challenges they face.
- Engaging the service providers and the recipients will give you a clearer understanding of the challenges of all parties concerned. It will also allow you to better channel your energy and campaign message.

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## Anti-Stigma

Many people living with HIV/AIDS are still discriminated against and as a result have received limited access to resources and opportunities in their communities. For example, many people refuse to go to local clinics to receive medical care, in fear of the stigma associated with those seen entering clinics. The issue of stigma is multi-faceted especially among youth. The multifaceted nature of stigma is that it can be borne out of cultural, racial, ethnic and nationalist under tones. Therefore, understanding the root cause rather than assuming is important to insure intended outcomes.

# THE RIGHT TO HEALTH CARE

For people living with HIV/AIDS, being able to access health care may mean the difference between life and death. Therefore, if the state (government) is not able to provide decent primary health care services, they are violating the Universal Declaration of Human Rights.

Primary Health is part of any healthcare system's ability to combat preventable diseases such as HIV/AIDS. Some primary health care systems also focus on preventing HIV/AIDS through raising awareness and educating people on the virus.



## What is Primary Health Care?

The ultimate goal of primary health care is better health for all. WHO has identified five key elements to achieving that goal:

- reducing exclusion and social disparities in health (universal coverage reforms);
  - organizing health services around people's needs and expectations (service delivery reforms);
  - integrating health into all sectors (public policy reforms);
  - pursuing collaborative models of policy dialogue (leadership reforms); and
  - increasing stakeholder participation.
- [http://www.who.int/topics/primary\\_health\\_care/en/](http://www.who.int/topics/primary_health_care/en/)

## Rights & Responsibilities

Since we have established that all human beings have inherent human rights that are provided for in international and local legislative frameworks, let us review, who has what responsibility?

Just because every person has certain rights, does not mean they do not have responsibilities.

## Rights Holders

- People who are entitled to Rights (everyone!)
- People who are entitled to claim their Rights.
- People who are entitled to hold their duty bearers accountable.
- People who have the responsibility to respect the rights of others.

## Duty Bearers

- People who support rights-holders to claim their rights.
- People who speak out and advocate for the rights of others.
- E.g. Politicians, local authorities, institutions, public servants, parents, teachers, civil servants, students, educated people, etc.

People, not just laws, uphold Human Rights. It is up to fellow human beings to respect the human rights of those around them.

## This can take place in several ways:

- By respecting people's Human Rights through your behaviour. For example in respecting a person's right to privacy.
- By choosing not to support political parties that infringe upon certain people's Human Rights.
- By withholding support and speaking out against businesses that do not uphold Human Rights, such as businesses that do not provide fair and equal working conditions for their employees.
- By reporting Human Rights abuses to the Police.

# WHAT IS SOCIAL JUSTICE?

Social justice is defined as "... promoting a just society by challenging injustice and valuing diversity." It exists when "all people share a common humanity and therefore have a right to equitable treatment, support for their human rights, and a fair allocation of community resources." (Toowoomba Catholic Education, 2006)

Social injustice is when individuals, families and communities are deprived of their basic human rights. Human rights represent the basic necessities needed to live a healthy, adequate standard of living. People are deprived of their human rights for a variety of reasons. Governments and oppressive laws may deprive certain groups of people from accessing opportunities and services such as education or fair employment. Factors such as corruption, economic crisis, natural disasters and violence can result in the violation of human rights for a short or extended period of time. Societal structures and institutions can marginalize and disempower groups of people through denying them access to basic rights such as housing, water and nutrition.

Societal structures often favour certain groups over others, making it easier for them to access opportunities and succeed. People may be discriminated against on the basis of their race, gender, ethnic origin, nationality, religion or other factors. This inequality can be so deeply embedded that we see it as normal or acceptable. The denial of human rights deprives individuals, families and communities from developing their capacities, accessing opportunities and services as well as every day needs that some people take for granted. Denial of human rights not only inhibits their ability to thrive but sometimes even to survive.

Suffering as a result of not having one's human rights can seem normal or acceptable because communities have been experiencing it for so long. Poverty, unemployment, and children not receiving an acceptable standard of education are some of the most prevalent forms of social injustices in our society today.

While issues such as poverty may seem inevitable, it is not justified or "natural". The inability to gain employment, have running water or access to basic nutrition is a violation of fundamental human rights.

## Systemic Injustice

Injustice often embeds itself into the very way that we operate as a country and community, therefore making it systemic. Systemic injustice can be found in the interpretations of our laws, the running of institutions, organizations and companies, as well as in the ways in which we interact with each other. Many, if not most, people operating within this system are unaware of the injustice caused by their daily interactions. However, there are others who are aware, but who do not wish to sacrifice the benefits they receive from the system, in order to correct it. An example of systemic injustice was the Apartheid system of South Africa.

However, systemic injustice does not only exist in past systems of oppression. Historical patterns of unfairness, discrimination and unfairly distributed allocations of social, political and economic goods, within the various social and economic structures, are all problems of injustice faced within many countries today. If we consider the ways that economic, political and social assets are allocated in society today we can clearly see that certain structures are set in place to favour certain groups of people.

Injustice by nature is systemic and this is why it is important that we become aware of the structural injustice that are inherent in our daily lives and begin to challenge and change the unjust structures that favour certain individual over others. In order to truly start to change we need to break down the core systems that keep the cycle of injustice thriving.

# CHARITY VS. JUSTICE

When we see suffering and injustice, there are two types of action we can take, charity-driven action and justice-driven action. It is important to distinguish between the two:

	CHARITY	JUSTICE
PURPOSE	Charity aims to provide solutions to the effects of injustice and its symptoms	Justice aims to deal with the root causes of social problems and addresses the underlying structures or causes of the problems
GOAL	Charity responds to immediate needs and looks for immediate solutions.	Justice responds to long-term needs and looks for long-term solutions.
METHOD	Charity provides direct services like food, clothing and shelter.	Justice promotes social change in institutions or political structures.
WHO	Charity is often private, individual acts.	Justice involves public, collective actions.

(Edmund Rice International, 2013)

Charity is responding to immediate suffering and aiming to meet these needs without delay. This is important, especially when there are emergencies, conflict or natural disasters. Charity can sometimes be the difference between life and death. When someone is starving, feeding them can save their life. We can work for justice, but it is equally vital that we cater to the immediate needs of those around us.

However, if we only focus on charity work, problems will never be solved. The hungry person may be fed but the factors that led them being hungry in the first place will still be there. Justice work attempts to address the root causes of issues so that the problem will be resolved. Justice work asks the question ‘Why is that person hungry?’ and focuses on addressing the core issue so that they will not ‘go’ hungry again.

The importance of justice work also lies in the relationship it facilitates between the person receiving services and those who give them. Those engaged in charity often hold all of the power, those engaged in justice ensure the equal standing of all those engaged in the development process.

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*“Overcoming poverty is not a task of charity, it is an act of justice.”*

**Nelson Mandela**

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### Helpful hints:

- Charity work alleviates a problem so that the symptoms are not as bad.
- Justice work attempts to eradicate a problem so that it no longer exists.

# SECTION 2:

# BEING AN ADVOCATE FOR CHANGE

When we witness or experience human rights violations, we may feel an urgency to do something about it. In many circumstances, outrage at injustice is the catalyst for change. This passion is an important component of working towards change. However, it is only the starting point for advocacy. Unfortunately, many advocacy efforts driven by outrage fail in the first few years of existence. While passion and outrage is important, strategic, collaborative and peaceful planning is essential if you want to see success in both the short and long term.

The following steps can assist you with setting up your advocacy work so that it is strategic, sustainable and effective.

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**Note:** Before you begin planning social justice and advocacy work, it is necessary to be well informed about social injustice and the particular issue you wish to address. A well informed, well thought out plan can help to ensure the successful implementation of your intervention.

# KNOW YOUR CONTEXT

When starting with advocacy work it is essential that you take the time to build relationships within the community. You may have lived in the community for many years and so you may know the community well. However, it is important to take time to get to know other members of the community who may have different lived experiences. Important things to clarify and determine are:

- What is the history of the community? How was the community formed and how did the people end up living in the community?
- What are the main concerns of different groups such as the elderly; parents; young adults and school learners?
- What change would the different age and social groups like to see in their community?
- Is the community close-knit? Is there social cohesion and trust? Or are there divisions among race, class, religion, gender and ethnic origin?
- What advocacy work is currently taking place in the community? Has it been successful? Is the community supportive? How can you partner with this work?
- What community forums exist? Are these having an impact? How can you partner with these forums?
- Are there community resources available such as centres, parks etc.? How are these managed and used?

**Social Group Concerns?**

**Community History?**

**KNOW YOUR COMMUNITY**

**Existing Advocacy Work?**

**Existing Community Structures?**

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**There are several tools provided in this chapter to help you through this process. They include:**

1. Social Analysis
  - a. The Problem Tree method
  - b. Focus Group Interviews
  - c. Salt Methodology
2. Table to systematically identify issues within the community and the resources available.

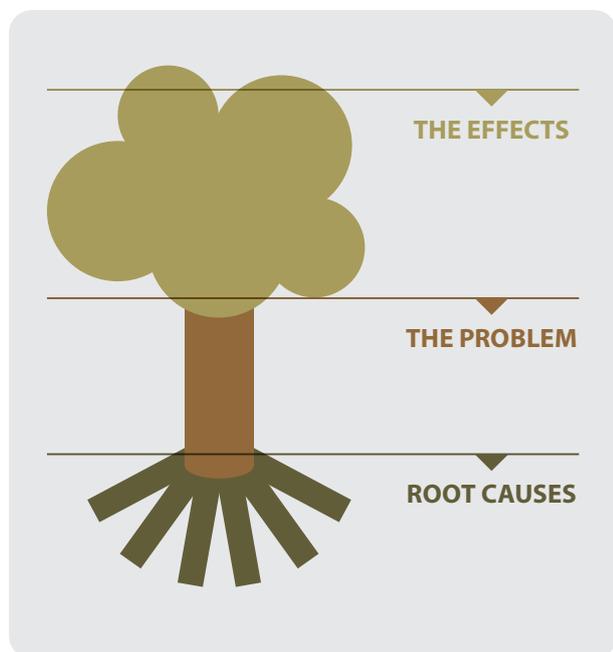
# SOCIAL ANALYSIS

Social Analysis is crucial to any advocacy campaign. It is when a person systematically examines a social issue, problem, trend, movement or subject, to recommend changes that could be made to address

that issue. You cannot claim to be talking on behalf of a community when you do not know how the issue has impacted the people. Here are three ways in which you can conduct social analysis.

## A. Using a Problem Tree

The Problem Tree method helps you to illustrate the root causes of a problem/issue and visually examine how the effects of the problem manifest themselves in your community. The Problem Tree method is a planning method based on needs, however it is not a mechanical translation of problems into objectives. While going through the process, taking the different steps, there should be continuous room for opportunities, new ideas and contributions from the involved parties. Once you clearly identify the root causes, it becomes easier to address the problem and its effects.



### Helpful hint:

Use the basic diagram below as a guideline and work through it in small groups.

## B. Focus Group interviews

A good focus group has the following characteristics:

- Carefully recruited participants,
- A comfortable environment for participants to interact in,
- A skilful moderator, and
- A process of systematic analysis in order to report on the outcomes of the interviews.

A safe space where participants are encouraged to speak their minds will likely result in you and your team better understanding the various issues faced by each community. In some instances, your personal bias may influence you into believing that one issue takes precedence over another, however, it is important to recognise that the community may have a different priority area to yours. In small communities, you may consider arranging a community meeting to initiate a broader conversation.

## C. The SALT Methodology

An extension of the group interview is the guided conversation, aimed at understanding the underlying issues of injustice rather than the superficial ones. Let us take a look at the SALT methodology which is a useful tool that could be used in order to guide community conversations. The basis of this methodology is the understanding that all communities should be viewed from a strength point of view. This encourages practitioners to change the way in which they engage with a community, as it's point of departure is always from a positive standpoint. It is important to never adopt the role of the "saviour of people", but rather a partner in change. It is important to include as many community members as possible from the very start of such conversations, as they should be the ones identifying all their major priorities. At all times listen to the community members as they will often know what is needed and who is needed to fulfil or to achieve a goal (Campbell, C; Campbell, M; and Blair, S. 2010).

### Practicing SALT

SALT is a way of thinking and working for communities engaged in advocacy work. It is based on the principles of participation, facilitation and the appreciation of the strengths of the community. It is a way of walking alongside a community in order to move forward as a collective.

Practising SALT, a facilitation team will invite individuals and families to gather and share a conversation in the home or neighbourhood environment. These conversations will focus around the concerns, hopes for the future, and community ways of working/relating. Typically, as these conversations accumulate amongst many households and stakeholders over time, common themes emerge in a way that naturally link homes and families to one another, and become the basis for a community-informed and community-agreed response – an action for change. Furthermore, increased community responses to common issues identified through the SALT process creates awareness of locally available resources (\*).

It is this "learning from local action and experience" component that makes SALT particularly effective in reorienting communities and institutions from within.

### Questions that can be asked during these conversations include the following:

- What are your concerns for your community?
- What is your hope/vision for your community?
- What are the strengths of the community?
- How does the community work together?

### Helpful hints:

#### Conceptualise with Communities

- Create the space for communities to explore their challenges
- Draw themes from their conversations
- Let the community decide on the next step

### The acronym reminds SALT-practitioners of the direction of the approach, which is:

- S:** **support/stimulate** (through presence and strategic questioning)
- A:** **appreciate/acknowledge/affirm** strengths (as opposed to problem-identification)
- L:** **learn/link** (from local action and experience, so as to adapt and become more responsive)
- T:** **team** (working together relationally in community – not as individual experts), **/transfer** (working through relationships to connect, influence and expand the community's response).

1. Based in a recognition and affirmation of the innate human capacities of people, the disciplined attitude of **appreciation** of what people in a community are already doing, and their lives. This is contrary to a more familiar development paradigm of entering a community to conduct a needs-assessment, based on the assumption of weaknesses.

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(\*) Krueger, R., Casey, M., Donner, J., Kirsch S. and Maack, J. (2001). *Social Development Papers: Social Analysis - Selected Tools and Techniques*. Washington: Social Development Family of the World

2. Based on the assumption of local strength and capacity within individuals and families to respond, the attitude of **learning**: to enter into life with others in their environment, where they are the experts, and the work of the visiting team is to learn, and to understand, and resist the urge to instruct or advise or impose technical knowledge over local experience and expertise.

3. Based on the belief that response is possible by people who have innate strength, the attitude to **support** – through presence with people that encourages and affirms and inspires, particularly in environments where people may feel suppressed or unaware of their own capacity.

4. The practise – as in a counselling paradigm - to **stimulate** home and neighbourhood reflection through careful, active listening and with sensitively probing questions to support a community to make the connections between prevailing issues in a

community – that may initially be seen simply as problems or needs to be met externally - and their own more personal concerns related to risk and vulnerability, as well as vision for an alternative experience. Over a series of encounters, SALT has the ability to progressively deepen the analysis of concern and vision by a local community itself.

5. The practise of **linking** – through inclusion, and opportunities for participation – community members to one another in conversation and action around issues of shared concern, in so doing building a local team over time, and across multiple streams of conversation that gradually become joined up.

6. The practise of supporting and stimulating **transfer**, both of lessons learned by teammates back into their respective organisations, and of community members who seek to link to others in influential ways inside their own community, and outside their own community often through extended family links.

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**S** Strength, Support  
Sustainability

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**A** Access  
Achievable

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**L** Learning  
Laughing

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**T** Transfer  
Trust

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### Conversational

1. What are your concerns?
2. What is your hope/vision for the your community?
3. What are the strengths of the community?
4. How does the community work together?



# IDENTIFY THE CORE ISSUES

One of the first steps in designing HIV advocacy work is identifying what the core issues are. When working in a community there are often a myriad of HIV issues that are interconnected. When you are starting out with justice and advocacy work, you will not be able to challenge every issue. Trying to fight too many issues limits your ability to drive substantial change. It will also leave you feeling overwhelmed and frustrated. Before you step into action, you need to clearly identify what advocacy issues you will be working for. The diagram below presents questions you can ask to help determine the core challenges facing the community.

## Helpful Hints:

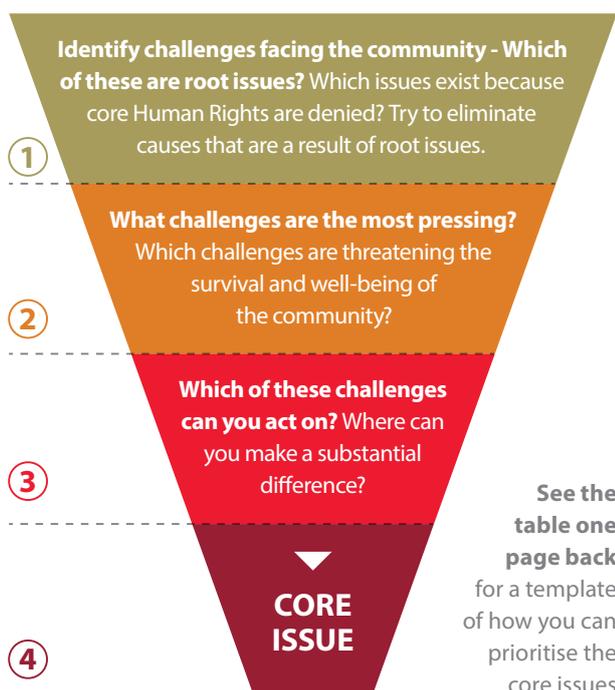
- The process of trying to focus on an advocacy issue should not be done in isolation, but should be carried out with the community.
- This can be done informally over food and conversation.
- This can also be done formally in a community forum setting. When engaging with the community, ensure that you are inclusive and that you have not ignored or excluded certain peoples' voices.



Once you have identified the core issues that you will act on, you need to identify the Human Rights Violations creating these challenges.

It is helpful at this stage to also identify why these Human Rights are being violated.

## See the diagram below:



- 1 Identify the core challenges that will drive advocacy.
- 2 What Human Rights are being violated/denied?
- 3 Who are the primary duty bearers responsible for upholding these Human Rights?
- 4 Why are these Human Rights being violated?

# WHAT WOULD YOU LIKE TO SEE HAPPEN?

Once you have identified the HIV issue that will be at the centre of your advocacy work, you need to clearly identify what change you would like to see happen. This step will often take place naturally. However, when planning strategic advocacy work, it is essential that you identify clear, specific outcomes. If you are campaigning for change, but your demands are too vague you are less likely to see tangible results. As you can see in the example below, vague goals can result in frustrations, unnecessary challenges and ultimately undermine the success of your advocacy work.

## Example:

*There are not enough HIV Testing and Counselling (HTC) services in the community and there are several health risks and other hazards because of this. Basic Human Rights of community members are being denied, particularly right to Health Care. The local government are responsible for ensuring health services. The change you would like to see is that more HTC services are created and placed in this community. This goal is obvious, but it is too vague. If you are simply demanding more HTC services, the local government can put in a few testing and counselling services and say that they have fulfilled the demands. Or they can put the services in locations that are not safely accessible to the community. Or they can put in services that do not meet basic quality standards, i.e. inadequate supplies at the testing centres or inadequate staff or trained and equipped counsellors.*

*A more tangible goal would be to identify HOW many HTC services are needed, WHERE the services are needed, WHEN the services should be installed by and any other SPECIFICATIONS.*

*For example, we want one HIV Testing and Counselling centre in every 5 blocks of this community by December 2018. The centre should be adequately equipped with medications, staffed with trained confidential counsellors, and provide resources that help the community practice preventive behaviours to reduce the risk of transmitting HIV.*

It is vital to be as clear as possible when selecting your goals. In some cases, when an organisation is vague with their goals, the community may be confused as to what the organisation actually does. This can threaten the legitimacy of the movement as key stakeholders may not be able to determine what the purpose of the movement is.

## Example:

*In 2015, a student campaign was started in South African Universities called #FeesMustFall. This was a powerful movement that rapidly gained momentum. Initial goals were specific, such as demanding that there be no fee increases for the year 2016. However, as the movement has grown, their goals seemed more vague and broad. The movement now represents issues on fees, the decolonisation of higher education and workers' rights on University Campuses. While these are all important issues, people now find it difficult to participate as the movement is unclear as to what their real purpose is. Moreover, the initial focus on University Fees is no longer the centre of the movement. The capacity of the movement to impact the cost of Higher Education is lower as the focus is on more than three different issues.*

## Helpful Hint:

Use 'THE FOUR W's' as a guide for setting clear goals with a community:

- **What** would you like to see happen? Make this as specific as possible by including details such as quantity and quality.
- **Who** is this for? Who are the beneficiaries of the movement? Is it for the entire community or a specific set of people? This is not to exclude people from the movement but rather to focus your goals i.e. mothers with children under the age of five years.
- **Where** should this change take place? Is this happening in a specific community? What are the geographical boundaries? Is it online?
- **When** would you like this done by? Set a time by when you would like to see partial or full results.

# IDENTIFY YOUR CORE VALUES

An essential component of any advocacy work is to identify what the core values and principles are. Values and principles form part of the foundation of the movement and can have profound positive or negative effects on the life and longevity of a movement. If you do not identify and prioritise values and principles, a movement can be influenced or shaped by many differing voices. Establishing a set of values and principles will help guide an advocacy movement and its different methods to bring about change. As you grow in your advocacy efforts, your core values will enable you to review whether you are using the right methods and are on track towards achieving your goals.

## Example:

*As movements gain momentum and grow, they are likely to attract a variety of people who will have differing beliefs, behaviours and opinions. Diversity is important and this is not a bad thing. However, if you have not established core values and principles, differing voices can start to dictate the nature of the movement when the movement should dictate the nature of the participant's behaviour.*

*Examples of how this occurs is when protests and movements turn violent. Non-violence is an important value if we want to advocate for the Human Rights of all people. We know that any form of violence will ultimately violate the basic Human Rights of another person or group. We cannot fight for Human Rights while at the same time denying other people their Human Rights. If you establish non-violence as a core principle and value it at the beginning, it should shape how the movement operates.*

## Values to Consider:

Non-Violence	Honesty & Transparency
Innovation & Creativity	Empowerment
Collaboration	Participation & Inclusion

# IDENTIFY YOUR ALLIES

Advocacy work cannot be done alone. If we want to run successful advocacy work, we need to have a group of people running the campaigns and projects. Furthermore, you should have a wider network of partners, allies and people that you can call on for support. When starting advocacy work, take some time as a team to sit down and discuss who your allies are. It may be helpful to create a mind map where you can map out organisations, community groups, people and churches that could be considered 'allies'. Allies could be anyone who shares your same beliefs, does similar work to you, works in the same community or would be able to provide any form of support. Through identifying these people, you can be intentional in strengthening these relationships and possibly partnering together. When you encounter challenges, it is helpful to have an accessible list of people you may be able to call on for assistance.

By adding multiple organisations/groups of people to your movement, you will have a stronger, more powerful voice. Your voice alone is powerful, but many voices together are much more powerful.

## Helpful Hint:

- Use the Strategic Template below to help you identify your core issue, your plan of action, your allies and the resources available for your advocacy campaign.

# CAMPAIGN PLAN OF ACTION STRATEGIC TEMPLATE

Print this  
page & use it  
as a working  
resource

Use this template to consolidate all your ideas and plans before taking action.  
It will save you time in the long run.

Group/Name:	Date:
Individual Names:	
<b>Issue or Problem:</b> The name of the issue or problem at hand.	
<b>Problem Statement:</b> Brief description of the problem and how it effects your community.	
<b>Action Plan:</b> What do you plan on doing to address this issue? A step-by-step action plan.	
<b>Core Values:</b> What are the core values of your campaign?	

**Allies:** What people or organisations will you work with?

Where will your campaign take place?

What timeframe are you working with?

What resources will you need?

Who will you have to get permission from first?

What are the costs? How can you access funds if you need them

# WORKING WITH YOUR COMMUNITY

One of the most fundamental parts of community advocacy work is WORKING WITH your community versus WORKING FOR your community.

**‘PANEL’** is a set of human rights principles that can be used as a guide for community advocacy. These principles assist in:

- 1) Ensuring that your work is based on a human rights approach.
- 2) Ensuring your work creates participation and inclusion among community members.
- 3) Ensuring that your advocacy campaign equips and empowers community members to carry out advocacy work.

---

## P

**Participation:** Community advocacy must be participatory at every step / level. Space and opportunities must be facilitated where the community can actively participate in the advocacy work. As many community members, as possible, should be involved in decision-making processes. Participation must be free, especially from barriers, such as language or access to information.

## A

**Accountability:** We need to monitor human rights – whether they are being implemented, denied or accessed. Accountability is essential in community advocacy. There are various forms of accountability in community advocacy.

- 1) Monitoring of human rights standards in the community should continually occur.
- 2) Advocacy programs should be monitored so that you can identify what works and does not work.
- 3) Your advocacy work should be accountable to the community; they should continually be consulted on and informed about what action is taking place.
- 4) At all levels of advocacy, appropriate laws, policies, institutions and administrative procedures need to be set in place to assure accountability.



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## N

**Non-discrimination:** All forms of discrimination should be strictly prohibited. Your advocacy work should focus on preventing and eliminating any form of discrimination in a community. This is to ensure the realization of human rights of all community members. Your advocacy work should stand up for and prioritize those whose rights have been violated the most.

## E

**Empowerment:** All community members should be educated about and fully understand their human rights. They should be empowered with the knowledge of human rights so that they can defend, demand and protect their human rights. Community members should be supported and equipped so that they can participate in policy making processes.

## L

**Legality:** Your community advocacy work should be grounded in human rights that can be found in domestic and international law. Where rights are not recognized in domestic legislation, advocacy work may need to campaign for the adoption of international human rights standards. Human rights must be recognized in national law so that they can be legally enforced. Your advocacy campaign should never undermine the legal structures in your country (unless legal structures like Apartheid actively violate the human rights of people).

# WORKING WITH GOVERNMENT STRUCTURES

All advocacy work must be done from a Rights Based Approach. A rights based approach acknowledges that all people have human rights and that they must access and enjoy these rights. This belief forms the foundation of Human Rights advocacy work.

Under the rights based approach, all of your advocacy work should be geared towards ensuring the realization of human rights. Working from a rights based approach means that our advocacy work must uphold the rights of all people. We cannot discriminate against or deny the rights of people who are in opposition to us. Moreover, we have to work within legal structures. Human Rights cannot be realized outside of legislation and government practices. This means we cannot use deviant or illegal methods to try carry out our advocacy work.

Government has the primary responsibility to implement human rights through legislation and fair structures. Where possible we need to build strong, positive relationships with government members. There are several ways to do this:

## **Work with your Local Government**

Zambia has 9 provinces. Each province is divided into districts. Within your district you will have a council. The council works hand in hand with the District Administration. Each council has 28 wards and 5 constituencies. Each ward will have a ward councillor who will be supported by a ward committee. Their role is to facilitate a healthy communication process between the community and the Council. The ward councillor acts as a spokesperson for the people in their ward. Generally, your easiest point of call in local government is your ward councillor.

If you do not know who your ward councillor is, find out who it is and go meet them. Try to build a positive relationship with them. Invite them to participate in any community forums or meetings. If you are planning a program, invite them to take part. When you have concerns, see if you can set up a meeting with them to discuss it. Ask them how you could support them in their initiatives. The healthier your relationship with your ward councillor is, the higher the probability that they will support your initiatives.

## **Support Positive Government Initiatives**

When Government runs positive initiatives, show your support. See if there are ways that you could partner with government in rolling out the initiative. If there are no ways to officially partner with government in this, see if there are ways that you can promote the initiative or utilize materials from the initiative. If your government sees you supporting their initiatives, they are less likely to see you as a threat.

## **Get to Know Your Local Police**

While the law enforcement system is not perfect and can, at times, be difficult to work with, they are the primary mechanism through which the government enforces the rule of law. They are essential to the realization and protection of human rights. Where possible, get to know your local police. Set up a meeting with the police station, introduce yourself and your dream for your community. Praise the police when they do a good job and let them know that you appreciate their work. Ask them if there are ways that you can be of service to them. This will build a healthy and supportive relationship between the police and the community.

## **Participate in Government Forums**

When there are government forums that are open to the public, attend them. Whenever there is an occasion to participate in government trainings and forums, make sure that there is a community representative present.

## **Build Bridges between Government and Community Members**

An effective means of empowering community members is through teaching them about government structures and procedures as well as how they can participate in these structures.

At times government may be responsible for the violation of peoples' human rights. Your advocacy work may have to be directed at changing government legislation and structures so that these human rights violations can come to an end.

However, we should not always see the government as an enemy in advocacy work. They play a vital role in the protection and realization of Human Rights. Where possible we must build positive, effective and meaningful relationships with government members to achieve our goals.



## IMPROVE YOUR VOCABULARY

### “Legislature”

- a deliberative body of persons, usually elective, who are empowered to make, change, or repeal the laws of a country or state;
- the branch of government having the power to make laws, as distinguished from the executive and judicial branches of government.

### “Legislation”

- the act of making or enacting laws.
- a law or a body of laws enacted.

### “Policy”

- a definite course of action adopted for the sake of expediency, facility, etc.
- a course of action adopted and pursued by a government, ruler, political party, etc.

# HOW TO INFLUENCE POLICY

## Questions to consider:

- What rights does your Constitution grant the citizens of your country?
- What is the national health policy?
- What other laws affect the ability of your fellow citizens accessing adequate health care?

## Step I:

### Know the Policy or Law

Most legislatures around the world aim to cover most foreseeable situations that the law or policy is dealing with. In doing so they cover all but a few, meaning the aim is not necessarily to exclude anyone but this may happen. Laws and policies often overlap in their application. Therefore, when a law or policy tries to deal with a specific issue, without considering other areas of the law or society that its covering, it leads to a gap. Different stakeholders may exploit these gaps in legislation for their gain. It is, therefore, important that when you are advocating for a change in policy, that you know all aspects of the policy and what it aims to do.

## Step II:

### What are you saying?

Your message must be very clear and precise when advocating for change. Your focus should not be exclusive to the extent that the change you seek infringes on the rights of others. For you to be clear on what you are saying, consider the following:

### • Do your research:

Where HIV/AIDS is concerned, you must know what your national legislation says about the treatment for those living with HIV/AIDS. For instance, some countries have a national health insurance policy that may cover HIV/AIDS related illnesses. Whereas other countries only provide emergency medicine as the first line of defence. This means that if an insurance provider does not

cover you, some hospitals can refuse you medical treatment. It is therefore very important to see who, if you have a national insurance policy, is excluded and on what basis.

**Who is also concerned about the policy you are talking about?**

Access to medication may be an issue in some countries. In countries where the health sector is unionised, you may find support with the unions concerned with the welfare of their members, who may not be insured, and therefore may not have access to HIV/AIDS medication.

One of the most important exercises is to conduct a stakeholder analysis. This will give you an indication of who may have an impact on your campaign or who your policy change may affect. This gives you a basic understanding of what you can do and who might be supportive.

**The Stakeholder Concept**

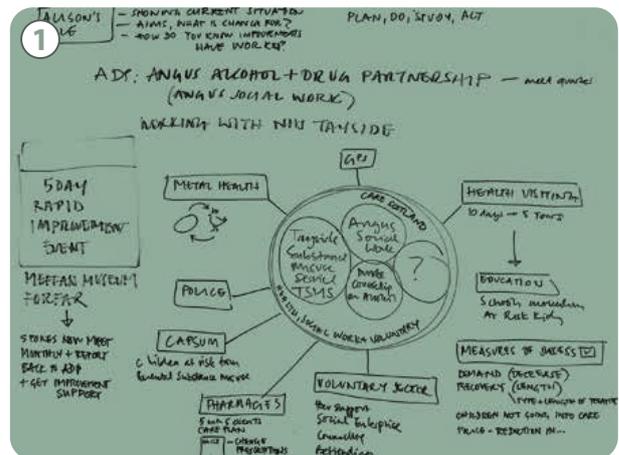
Stakeholders can be defined as all parties who effect or are effected by the project. They can be individuals, groups, a community, or an institution – all those with an interest in an organisation and its activities.

An organisation’s project or programme activities engage with various stakeholders and are not isolated entities. These projects must, therefore, be sensitive to the various issues and perspectives that exist in that particular context. Engaging with the experiences of various stakeholders when planning activities helps ensure that the activities benefit and positively impact the users.

**What is Stakeholder analysis?**

Stakeholder analysis helps an organisation identify and define all the parties who have an interest in their work in a more systematic way than merely responding to the different and sometimes conflicting demands they may make. It can also help identify any previously unrecognised factors. This information is important in many different aspects of project management, such as project planning, strategic assessment, monitoring and evaluation, and relationship building.

A stakeholder map (also known as a relationship map) is a visual representation of relationships and connections between different stakeholders.



**Stakeholder Map Example 1**

This lo-fi map was created on an office whiteboard during a meeting about a new drug and alcohol support program – showing the connected organisations and initiatives.

**Stakeholder Map Example 2**

This hi-fi stakeholder map from QYL Akshay Jadhao showing the people and organisations with a vested interest in the running of a coffee shop business.

**Step III: Change the whole policy or parts of it?**

You must be very clear about which aspects of legislation or policy you want to change. In most instances, your legislature will not be able to remove an entire act but would be empowered to address the short falling of a section of the legislation.

**Step IV: What are you proposing?**

Asking your legislature or government to amend or repeal a policy or legislation will only be helpful if you have a proposal as to how they can fix the defect in the policy or legislation. Consider all the people your suggestion might effect and how you propose to deal with the unintended causalities of the change.

# SECTION 3:

# PLANING SOCIAL JUSTICE & ADVOCACY WORK

When planning your social justice and advocacy work you need to consider the following:

1. Purpose
2. Goals
3. Timeframe
4. Method of your campaign
5. Monitoring and Evaluation

Throughout this planning process, ensure that you are in communication with your community. This is to ensure that they understand the campaign, agree with it and can fully participate in your campaign work. This section will help you plan the specifics of your social justice and advocacy campaign.

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# PURPOSE

You need to identify the purpose of your intervention/campaign as this will shape how you plan and carry out your campaign. Your purpose will help you determine what the goals or the outcome of the campaign should be.

**There are three underlying purposes of HIV Justice and Advocacy Campaigns.**

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## 1. Raising Awareness

Raising awareness campaigns aim to increase awareness and understanding about HIV/AIDS. The goal of the intervention/campaign is for the community to be informed on what a particular issue is, why the issue exists and what can be done to address the issue.

### **Example:**

*HIV rates are increasing in your town but many people do not know that is happening, what it is, or why it is happening. Your school is running HIV awareness month with the purpose of increasing awareness on the issue.*

*The goal of the campaign is that by the end of the month, each learner in the school will know*

- 1) what HIV/AIDS is,*
- 2) how it is transmitted, and*
- 3) ways to prevent the spread of infection.*

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## 2. Charity or Acts of Service

Acts of charity / service campaigns aim to meet a physical need that you have identified. This type of intervention /campaign is focused on short term, material goals and is often driven by an emergency or suffering. Most charity campaigns have the purpose of meeting basic needs through providing goods.

**Note:** These campaigns are important because without them, people may go without the necessities they need to survive. However, these campaigns do not address root causes of inequality and poverty.

While people may receive basic necessities through this type of campaign, their livelihoods are not improved in the long-term. As a result, we cannot do these types of campaigns in isolation.

### **Example:**

*A local safe house for children orphaned by HIV has run out of funding and cannot afford to buy food. Your school runs a drive to collect food parcels for them. Learners and teachers donate food which is given to the orphanage.*

---

## 3. Justice and Advocacy

Justice and advocacy interventions/campaigns aim to address or challenge a specific human rights/social justice issue. Justice and advocacy work has the purpose of trying to tackle an issue so that it may be improved or resolved. These types of interventions/campaigns are focused on action and being a part of the solution.

### **Example:**

*Your community has come to know about the increasing prevalence of criminal charges being laid against people living with HIV in your community. Currently, your country does not have any legislation (laws) prohibiting criminalization of HIV. Your community decides to take on a letter writing campaign urging the government to adopt legislation outlawing HIV criminalization. By doing this, police are forced to protect your people, perpetrators are properly sentenced for their crimes, and government will have to cater to the needs of survivors/victims.*

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# GOALS

Once you have identified the purpose of your intervention/campaign, it is time to set goals. These are things that you hope to achieve by the end of the campaign.

**When setting goals, keep the following two important things in mind:**

## 1. Are they Realistic?

When setting goals ask yourself/your team whether this can realistically be achieved by the end of the intervention/campaign? Setting goals that are unlikely or too big can be discouraging as they may feel too big to achieve. There may be feelings of disappointment if the goals aren't achieved. At the same time, do not underestimate the power of your campaign and set goals that are too small.

### **Example:**

*If your community is doing a letter-writing campaign to urge your government to adopt HIV non-disclosure decriminalization legislation, it may be unrealistic to expect that by the end of the campaign, HIV non-disclosure will be decriminalized. Legislation takes years to happen. More realistic goals would be: to get a response from government to promise to look into establishing these laws.*

## 2. Are they Practical?

As far as possible, try to ensure that your goals are practical. The more practical a goal is the easier it is to measure whether the goal was achieved or not.

### **Ways to make your goals practical:**

- *Identify the number of people that you would like to have participated or benefited from the campaign.*
- *If it is a charity-drive, determine how much food/goods/money you would like to raise.*
- *If it is an awareness campaign, identify the types of knowledge or information people should have by the end of the campaign.*
- *If it is a justice & advocacy campaign, identify what activities or actions should have taken place by the end of the campaign.*



# TIMEFRAME

Once you know your purpose and have set your goals, a timeframe for the intervention/campaign must be established. The number of people involved in your advocacy work will determine what you are able to achieve in a certain timeframe.

# METHODS

Once you have set your purpose, goals and timeframe for the campaign it is time to start designing the campaign. Below are different methods that you can use to run your intervention/campaign. They are split up according to the different purposes.

**When running HIV advocacy work in a community, you may use a variety of methods.**

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## 1. Raising Awareness

### Social Media Campaigns

Social media can be used to raise awareness on a particular issue. This can be done through getting groups of people/learners to post pictures, news articles and information. Effective ways of using social media include making profile pictures an awareness image or using specific hashtags when posting on social media.

### The Creation and Usage of Visual Materials

Awareness can be raised through the creation of visual materials such as posters, banners and artwork. Learners can creatively engage in the campaign through the creation of materials. Posters and artwork can raise awareness on an issue in a powerful, emotive manner. You can also use visual materials to raise awareness through wearing specific solidarity bands.

### Workshops and Dialogue Sessions

Hosting workshops and presentations within the community can be a powerful way of raising awareness and educating community members on issues. Moreover, these spaces can be powerful for facilitating dialogues on such issues.

### Silent March / Walk Around

A walk around the community with posters and visual representations can be a powerful way of raising awareness about an issue, particularly to the surrounding community.

This is different to a protest; this method is about standing in unity together to shine a light on a specific human rights violation/social injustice.



## 2. Charity or Acts of Service

### Food/Goods Drive

A food or goods drive mobilizes the community to collect foods or goods for a community in need. This is generally a response to an emergency.

### Raising Money

If there is a project/organisation that requires funds, you can raise the funds and donate money to that project or organisation. If your campaign is to buy something specific for a community in need (i.e. an orphanage) you can do various activities to raise funds.

### Acts of Service

If your intervention/campaign is focused on uplifting or improving a community in need, you can offer your practical skills and time to do this.

**Ways you could do this (these are only some ideas, you can come up with your own):**

- Giving spare time to tutor younger learners from a vulnerable school.
- Going after school or on a Saturday to paint or repair buildings.
- Visiting the elderly.

## Justice and Advocacy

### Letter-Writing Campaign

A letter-writing campaign can be used to urge the government or local community to take action against a specific human rights violation/social injustice issue.

#### Ways that you can use a letter writing campaign:

- Community members can be mobilized to write letters to a specific government department requesting them to act on a specific human rights violation/social injustice issue.
- Community members can be mobilized to write letters to companies/businesses requesting them to change their behavior so that it is not harmful to people or the environment.
- Community members can be mobilized to write letters to newspapers, community members, NGOs, encouraging them to act against a specific human rights violation / social injustice issue.

#### When doing a letter-writing campaign, ensure the following:

- Community members are well informed on the issue before they write a letter.
- Community members request similar action be taken.
- Community members' letters are written in the correct format. (*You can find an example of a letter in the Annexures.*)

### Protests/Demonstrations

Protests are a powerful representation of people coming together to stand against an injustice. Protests show the government, companies and the community that there are people who will not tolerate human rights violations/social injustices.

Protests are used to object to specific behaviors and demand that action be taken by the government/companies/community.

#### Identify the following before the protest:

- Clearly identify the problem/harmful actions before the protests.
- Clearly identify solutions to the problem/harmful actions

#### Planning a protest:

- Ensure permission from police before the protest.
- Make sure the protesters are clearly informed on the issue.
- Create visual materials such as banners, posters and t-shirts.
- Gather as many people as possible to attend the protest.
- Protest in an area that will gather the attention of the people the protest is aimed at.

### Petitions

A petition is a letter condemning specific actions and demanding change. Petitions are used to raise objections to specific actions of the government/companies/community. It is accompanied by signatures of people. The more signatures on the petition, the more powerful and reputable the petition.

#### Planning a petition:

- Be clearly informed on the issue.
  - Write a clear, concise letter.
  - Create a table for the names and signatures of people.
  - Ensure that people are aware of the issue before signing the petition. (Never write someone's name on the petition without their permission)
-

# PLANNING

It is time to plan your intervention/campaign. Involve community members in the planning of the campaign as much as possible.

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## Tips for Planning:

1. Be as specific as possible.
2. Plan all aspects of your campaign, set dates and delegate tasks.
  - a. Ask yourself and Plan: What, When, Where, Who
    - i. Who is affected by the issue and who can you involve in the campaign. Conduct a thorough stakeholder analysis to inform you of all parties that can positively or negatively impact your campaign.
  - b. Organize logistics ahead of time
  - c. Do not forget to identify venues, decide on times etc.
3. Identify what resources you will need and how you will obtain them
4. Make sure you have permission for all aspects of your campaign
5. Communicate with all people that will be involved or effected by the campaign
  - a. Communication is necessary for buy-in, participation and ultimately the success of the campaign.
6. Think ahead!
  - a. Are there possible challenges or obstacles you need to account for or plan around?
7. Be realistic.
8. Do not plan to do too much in too little time. In the run up to the date when you will be launching or running your campaign, based on your assigned duties, always check you have enough time to complete your plan.



**Once you have set your purpose, goals & timeframe & once your planning is complete...**

**IT IS FINALLY TIME TO**

**RUN YOUR  
CAMPAIGN**

**BE CONFIDENT  
BE PASSIONATE  
DO YOUR BEST  
& ENJOY  
THE PROCESS.**

# CAMPAIGN COMPLETE!!

Once you have completed your intervention/campaign, it is important to take some time to reflect on what has taken place. It is helpful to sit with community members and discuss the following:

- What worked?
- What did not work?
- How can you improve the next campaign?

## Discuss

Discussing and answering the above questions will enable you to identify the strengths and weaknesses of the campaign. This is a great learning process and will help you improve future campaigns.

## Acknowledge

It is important that you acknowledge and thank those who participated and assisted in the intervention/campaign. Write them a letter or email thanking them. When people feel appreciated and recognized, they are more likely to support future campaigns.

## Celebrate

It is important to celebrate what went well. Both small and big achievements should be recognized and celebrated.

# MONITORING AND EVALUATION

Monitoring and evaluation may seem like a lot of work, but in fact, is one of the most exciting and important aspects of your work. Do note that Monitoring and Evaluation starts before your project implementation. It is important to always keep track of your budget, the impact and the change resulting from your project as it is happening, rather than wait till the end.

It is through monitoring and evaluation that you will be able to identify whether your advocacy work is a success. It will also help you to improve in avenues that may need strengthening. By doing monitoring and evaluating your campaign well, you will ensure that your funder, supporters and community are happy with your work.

## Carrying out monitoring & evaluation can assist in:

1. Determining when your campaigns / programs have been successful in achieving your goals.
2. Determining if there is buy-in and participation from community members in your advocacy work.
3. Determining if your advocacy work is having a meaningful impact in the lives of community members/beneficiaries.
4. Determining what actions are working and what actions are not working.
5. Determining where there is need for change.

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There are several different ways you can carry out monitoring and evaluation. What follows are different models for monitoring and evaluation:

## The 'Most Significant Change' (MSC) Technique

The monitoring and evaluation model MSC is about gathering the stories of those who are involved and benefiting from the advocacy work. MSC is essentially about gathering and capturing stories from your advocacy work. It is putting a name, face and story to your advocacy work. It is asking those people whose lives have been impacted by your advocacy work how they have been impacted in their own words. This tool is highly valued by funders in advocacy work. There are nine steps in this process. This may sound long and complex but it is quite simple:

### 1. Become Familiar with the Approach and Identify Key Players:

This step is about becoming comfortable with the monitoring process. Who will be primarily responsible for leading this monitoring process? Identify who will assist in gathering data and capturing the stories. This could be staff members, community members or members of your team.

### 2. Map out the current reality of the community:

In this step, you need to do a needs assessment which will summarize the key challenges that your community faces. You may have already carried this out in your advocacy work. This does not need to be long or complex, it is simply to get a context and better understanding of your community. Information that you can gather includes:

- The quality of people's lives – what Human Rights are being accessed, denied or violated?
- The level of participation in the community – how involved is the community in decisions concerning their livelihood, community etc.
- What is the role and involvement of duty bearers?
- Have any changes happened in the community recently?
- Who are the key stakeholders in the community?

### 3. Map out your current advocacy work:

- What action have you been taking?
- Who has been involved?
- Who has been benefiting?

### 4. Identify whose stories to capture:

Identify which beneficiaries/community members you want to interview/meet. You want to collect stories from people who have been involved or benefitted from your advocacy work. What was their life like before the advocacy work? What has their involvement in the advocacy work been?

#### People you can meet with include:

- Individuals
- Families
- Community Groups
- Schools
- Any social group i.e. church

#### You must have ensured that the following people have been interviewed:

- A story from a staff member
- A story from a beneficiary
- A story from a community leader
- A story from a volunteer

If you are meeting with groups, you can capture this data in group settings. It does not need to be one-on-one. This can be done simply and can be informal or formal. For example. meeting with someone over a cup of tea.

### 5. Identify a Time Frame:

Identify the time frame in which these interviews need to be carried out. Make sure it is realistic and sustainable. Consider travelling, people's availability and any possible delays. Most time frames vary between 3 – 6 months of collecting stories (testimony and narrative).

**It is helpful to create a time planner to help plan your data gathering/interviewing:** See the next page for an example of a useful time planner.

**Create a basic time planner like this example to help plan your data gathering/interviewing:**

Who collects?	When? Dates?	Hours involved	Resources	Data entry – Who?

### 6. Collecting Stories:

**Now it is time to collect stories.** If there are language barriers, try to use a trusted interpreter. If people do not feel comfortable in an interview setting or you think that by asking these questions, the answers will be shaped, you can give the questions in written format. The participants can then write their answers in written story form. There are lots of other ways you can do this. For example you can use a diary, photo diary, mood or reaction chart, video diary etc.

### 7. Analyze Findings:

Once you have all of your stories, you need to type them up. Before doing that ask the following questions:

- What do you think was the most significant change in the quality of people’s lives in the community?
- Why is this story significant for you?
- What difference has this made now or will it make in the future?
- What are the important changes that have occurred in the community as a result of this project?
- What aspects of our advocacy work are working well?
- What aspects of our advocacy work can we strengthen?
- Are there aspects of our advocacy work that is not working well? If so, why?
- What problems occurred?
- Overall, how can we improve our work?

This needs to be written up. It is vital that storytellers give you written consent to use their stories.

### 8. Verification of Stories for Accuracy:

Check that the stories you have gathered are accurate and are not fictional, exaggerated or a misinterpretation of the truth. You can use triangulation (see point on triangulation below) for this.

### 9. Feedback:

Once you have your results, you can provide feedback to storytellers, the community, supporters and your funders.

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### Triangulation

Triangulation is a tool used to prove that your change is really happening. This can be done through selecting a minimum of three sources (i.e. letters) which you then compare and contrast to determine if transformation is occurring. This model is to ensure that your findings are representative. This prevents findings that are highly subjective or only reflective of a group of beneficiaries.

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### Evaluation Forms

When you carry out any meetings, workshops or trainings, using evaluation forms are a great way to monitor the success of your work. Evaluation forms allow you to gather data immediately after projects and on a continuous basis.

### Helpful hints for effective evaluation forms:

- Evaluation forms should be anonymous. Do not ask people to put their names on evaluation forms. They are less likely to be completely honest.

- Make sure your questions are clear and simple. Do not ask questions that are long or include more than one question in them. If your questions are complex, participants are less likely to provide comprehensive answers.
- Always ask how you can improve your work. Do not be afraid of criticism or constructive feedback – it is one of the best learning tools.
- Ask people how they were impacted or effected by the project. If you can gather data on how your work has impacted or affected people, this will help you to show the transformative power of your work. It will also show funders/supporters/ community members, the importance and success of your work.
- Do not ask too many questions. Pick your questions carefully and do not put an endless list of questions down. If there are too many questions, participants will be less likely to put effort into answering the questions. Your form should not be longer than 1 page or 3 pages maximum.

### Pre & Post Forms

If your intervention/campaign is aimed at equipping or educating community members, you can use pre-and post-registration forms to gauge their level of knowledge. This is to show the increase in learning among the participants. The pre-and post-training form will show any change in knowledge before and after the training..

#### **Example:**

*If you are doing a training on HIV you could ask participants to indicate their level of knowledge prior to the training.*

### Registration Forms

Whenever you carry out any meeting or training, take registration forms along with you. Registration forms are a helpful way of data capturing. You will be able to determine how many participants there were, identify regular participants and identify trends among participants i.e. age or gender.

#### **Helpful categories that you can put in your registration form include:**

- Name
- Region they live in
- Their gender (for example: male, female, other)
- The grade if participants are in school
- Their job if you will be having participants coming from different areas of work
- An email address or telephone number so that you can keep in touch.

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FOUR

# 04

## APPENDIX

**In the following appendix** you will find useful tools to help you on your advocacy journey. For more resources you can visit [www.justicedesk.org](http://www.justicedesk.org).

# RESOURCE 01:

## Letter-writing template

Planning and executing a letter writing drive is a great way to allow large numbers of people to be part of a campaign while making your voices heard at multiple levels.

### PART A: Planning the Letter

1. Define: Work with your participants to identify the issue, which you plan to write about it.  
Read newspaper articles, talk to people involved and do the necessary research to have a clear understanding of the issue.
2. Strategize: Working in small groups, strategize about who to write to:
  - Is this a local, state, national, or international issue?
  - Is this an issue that needs to be more widely known? Would a letter to the editor of a newspaper be effective? What community response is desired?
  - Is this an issue that needs attention from government agencies? Which agencies are involved? What kind of response is desired?
  - Is this an issue about which legislation is needed? Who are the legislators that this issue should concern?
3. Research: Work cooperatively to gather the information needed to write an effective letter.
  - Verify and expand your information.
  - Identify the best person(s) to write to and gather the necessary contact information.

**Sample Letter to the Editor**

No 28 Nelson Mandela Street  
Khayelitsha  
Cape Town  
7783  
December 10, 1998

To the Editor:  
Cape Times,  
Box 11,  
Cape Town 8000

I like the comic section of the Cape Times very much, but lately I have become upset with the comic strip "Gatiep." In the last few days, "Gatiep" has been making fun of people infected by and affected by HIV/AIDS.

I don't think being HIV positive is funny. In fact, it's a human rights violation. Article 1 and 2 of the Universal Declaration of Human Rights says everyone has the – Right to Equality and Freedom from Discrimination.

I think the cartoonist, Iggy-G, is very inconsiderate to make fun of HIV positive people. I don't find it the least bit amusing or entertaining. The problem of the HIV/AIDS is serious and people living with HIV/AIDS have right to be treated with dignity

Themba Goba

Grade 8  
Masiphumelele High School  
Khatelistha  
Cape Town

# RESOURCE 02:

## Petition Template

Petitions are a great way to show support for your efforts, get the attention of the community and of decision makers, and bring about change. Petitions demonstrate group strength. Officials may ignore you, but the more names you have on your petition, the harder it will be to ignore it.

### The following tips will help to make your petition as effective as possible:

1. **Appearance:** Use and A4 paper, or if you want to make a statement, a big banner!
2. **Title:** Give the petition a title so that both the signers and the receivers know immediately what it is about.
3. **Purpose Statement:** Write a statement describing the problem your petition is addressing, the solution you are proposing, or the response you would like to get from officials. This should appear at the top of every petition page so that people know what they are signing.
4. **Blank Lines:** Provide blank lines for people to write any or all of this information: Name, grade, age, or group to which they belong, their school or hometown, address and telephone number.
5. **Number the lines** for easy totalling.
6. **Plan:** Strategize the times and places where you are likely to collect the most signatures.
7. **Smile:** The better you treat the people you approach, the more likely they are to sign!
8. **Stay Calm:** Some people you ask to sign may disagree with your ideas and try to argue with you. Be ready to explain your ideas clearly, but remain polite and respectful.
9. **Photocopy:** When you've finished collecting signatures, photocopy all the pages. Keep them in a safe place. You may need proof of the signatures, and the addresses may form the basis of a mailing list.
10. **Present the Petition:** Choose the recipient carefully. It should be someone who has the power to act on your ideas. Try to arrange to present it in person. Bring along a camera or the press!

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**Note:** Always take adult supervision with you when collecting signatures from people's homes, businesses or in public spaces.

**Source:** Lewis, 1991



# RESOURCE 03:

## Ideas for Global Advocacy Campaigns

### 1. Red Letter Campaign

The Red Letter Campaign is a global letter writing campaign to share and highlight stories of youth living with HIV around the world. This campaign enables youth without access to internet to connect using pen and paper and creates a network of HIV knowledge through shared stories.

Leveraging existing youth-led pen-pal programs such as the Common Story Program by the Office of Inclusion and Engagement of the Commonwealth Youth Council, the Red Letter Campaign enables youth living or affected by HIV to discuss the similarities and differences of their HIV/AIDS experience around the world and has the potential to connect all walks of life.

After registration, youth will be sent a starter kit with all the information they need to be connected to a partner in a different commonwealth country. Support and guidelines will be offered for the letters but the rest is up to the youth.

All of these letters will be sent within a red envelope, symbolizing HIV/AIDS awareness.

The youth may choose to share their personal stories through social media and will be supported and shared through the campaign social media channels.

More information about the CommonStory pen-pal program can be found at:  
<http://commonstorycyc.wixsite.com/penpal>

### 2. HIV World Cafe

The HIV World Café is a multi-country, internet-based advocacy dialogue around HIV and how to prevent it.

Specifically, this will take the form of video chats or webinars between groups of young people across the Commonwealth connecting for small sessions during which they will share ideas and stories around advocacy and reducing the stigma of HIV.

Online platforms and technology of existing local youth HIV organizations can be leveraged to connect groups of youth HIV advocates.

Some sessions may invite local experts, and draw from the wealth of local stories to create exposure about the lived experiences of HIV in different global communities.

# RESOURCE 04:

## Important vitamins and minerals for people living with HIV/AIDS

<b>Micronutrient</b>	<b>Role</b>	<b>Source</b>
<b>Vitamin A</b>	Makes white blood cells - essential for vision, healthy skin and mucosa, teeth and bone development. Protects against infection associated with accelerated HIV progression, increased adult mortality, increased mother to child transmission, higher infant mortality and child growth failure	All yellow and orange fruit and vegetables, dark green leafy vegetables, alfalfa, liver, oily fish, dairy products and egg yolks
<b>Thiamine Vitamin B1</b>	Important for energy metabolism, supports appetite and nervous, system functions	Whole-grain cereals, beans, meat and poultry and fish
<b>Riboflavin Vitamin B2</b>	Important for energy metabolism, supports normal vision, health and integrity of skin	Milk, yoghurt, meat, green leaves and whole-grain cereals
<b>Niacin Vitamin B3</b>	Essential for energy metabolism, supports health and integrity of skin, nervous and digestive systems	Milk, fish, eggs, meat, poultry, peanuts, whole-grain cereals
<b>Vitamin B6</b>	Facilitates metabolism and absorption of fats and proteins, helps to make red blood cells	Sweet potatoes, white beans, maize, avocados, cabbage, whole-grain cereals, seeds, Brazil nuts, walnuts, eggs, leafy green vegetables, alfalfa, bananas, legumes, meat and fish
<b>Folate</b>	Required for building new cells, especially red blood cells and gastrointestinal cells	Liver, red meat, green leafy vegetables, fish, oysters, legumes, groundnuts, oilseeds, whole-grain cereals, egg yolks and avocados
<b>Vitamin B12</b>	Important for new cell development and maintenance of the nerve cells	Red meat, fish, poultry, seafood, sardines, cheese, eggs, milk, whole-grain cereals and seaweed
<b>Vitamin C</b>	Helps the body to use calcium and other nutrients to build bones and blood vessel walls. Increases non-haem iron absorption. Increases resistance to infection and acts as an antioxidant. Important for protein metabolism	Citrus fruits (such as baobab, guava, oranges and lemons), cabbage, green leaves, tomatoes, sweet peppers, potatoes, yams and cooking plantains. Vitamin C is lost when food is cut up, reheated or left standing after cooking
<b>Vitamin E</b>	Protects cell structures and facilitates resistance to disease	Leafy vegetables, vegetable oils, peanuts, egg yolks, dark green vegetables, nuts and seeds, whole-grain cereals
<b>Calcium</b>	Builds strong teeth and bones Aids heart and muscle functions, blood clotting and pressure and immune defences.	Milk, green leaves, shrimps, dried fish (with bones), nuts, beans and peas
<b>Iodine</b>	Ensures the development and proper functioning of the brain and the nervous system	Fish, seafood, milk and salt with iodine
<b>Iron</b>	Transports oxygen to the blood, eliminates old red blood cells and builds new cells	Red meat, poultry, liver, fish, seafood, eggs, peanuts, beans, some cereals, green leafy vegetables, seeds, whole- grain cereals, dried fruit and alfalfa
<b>Magnesium</b>	Strengthens the muscles and is important for proper functioning of the nervous system. Involved in bone development and teeth maintenance	Cereals, dark green vegetables, seafood, nuts and legumes
<b>Selenium</b>	Prevents impairment of the heart muscle	Seafood, liver, meat, carrots, onions, milk, garlic, alfalfa, mushrooms and whole-grain cereals
<b>Zinc</b>	Reinforces the immune system, facilitates digestion and transports vitamin A	Meat, chicken, fish, cereals, leafy green vegetables, seafood, oysters, nuts, pumpkin seeds, milk, liver, whole-grain cereals, egg yolks, garlic and legumes



**THANK  
YOU!!**