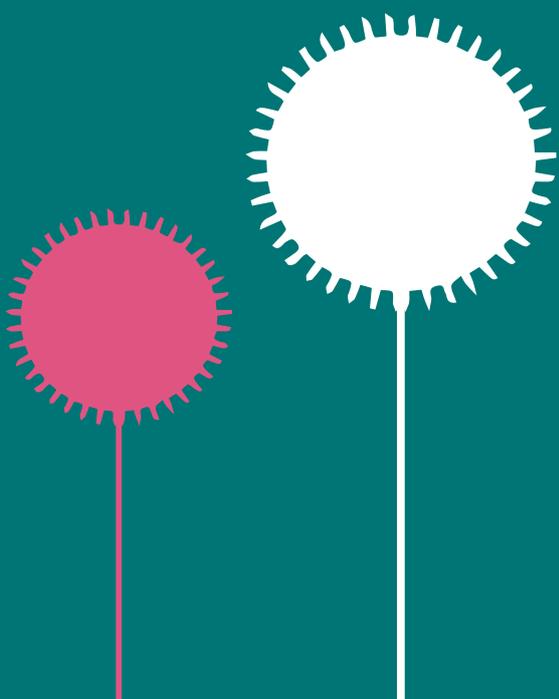


# FACT SHEET

HIV stigma, disclosure and  
the right to confidentiality



CHILDREN'S RADIO  
FOUNDATION

# Fact Sheet

## Definitions

- ★ **Confidentiality** is when information is private. Confidential information can only be shared when permission (or consent) is given. ([Merriam-Webster Dictionary](#))
- ★ **Consent** is to give permission or approval for something to happen. ([Kids.WordSmyth.com](#))
- ★ **Disclosure** is when someone makes private information known. ([Merriam-Webster Dictionary](#))
- ★ **Stigma** refers to negative and unfair beliefs that a society or group of people have about something. ([Merriam-Webster Dictionary](#))
- ★ **HIV-related stigma** is the negative and unfair beliefs a society or group have about people living with HIV (PLHIV).

## Did you know...

There are different kinds of stigma:

- **External stigma** is when people have negative attitudes and act unfairly toward people living with HIV. This includes insults, rejection, intolerance, stereotyping, discrimination, avoiding contact and physical violence aimed at people living with HIV.
- **Internalized stigma** is when people living with HIV begin to believe the negative things that people around them say or think about them. Internalized stigma refers to a person's own negative thoughts about him/herself based on his/her HIV status.
- **Anticipated stigma** is the expectation that one will be treated differently or poorly because of the stigmatized identity of people living with HIV.

([People Living With HIV Stigma Index](#))

## Stigma on top of stigma...

HIV-related stigma often happens together with other forms of social stigma connected to race, gender, class, sexual orientation, nationality, drug use, mental and/or physical disability and more.

*For example, a young girl in a wheelchair, who is living with HIV, may experience HIV-related stigma as well as the social stigma associated with disability. She will face the challenges that those negative and unfair beliefs create.*

([Report: The People Living With HIV Stigma Index – South Africa 2014](#))

"I have HIV, but it's stigma that makes me sick."  
Karen Fratti  
([Dustie](#))

"Many of the people most vulnerable to HIV face stigma, prejudice and discrimination in their daily lives. This pushes them to the margins of society, where poverty and fear make accessing healthcare and HIV services difficult."  
([AVERT](#))

# Fact Sheet

## Basic Rights of People Living with HIV

The Constitution of South Africa protects the rights of people living with HIV or AIDS to have the same rights that apply to all citizens of the country. Here are some highlights:

### Privacy and confidentiality:

- Everyone, including children, has the right to confidentiality and privacy about their health and HIV status.
- This means ALL information about HIV test, results, treatment and medication will be kept private.
- Health care professionals are ethically and legally required to keep all information about clients or patients confidential.

### Freedom of movement:

- No restrictions should be placed on the free movement of people living with HIV.
- It is illegal to discriminate, segregate or isolate people living with HIV (in schools, hospitals, prisons or elsewhere) based on their status.

### Rights in the workplace:

- No person may unfairly discriminate against an employee on the grounds of his or her HIV status. In the workplace, this can include recruitment, appointment, remuneration, training and development, promotion, transfer and dismissal.

### The right to safer sex

- People have a moral obligation to tell their sex partners if they are living with HIV. They must also ensure that their sex practices are safe by using condoms. Disclosing HIV infection to sex partners is a part of one's duty to protect others from potential exposure to the period after virus.

([Basic Rights of People Living with HIV, Health24](#))

## Age, consent and confidentiality

### Children 12 years of age or older...

- Can consent to an HIV test.
- Can consent to disclosing their HIV status.

### Children under 12 years of age...

- Cannot consent to an HIV test alone or disclose their HIV status.
- Can consent to an HIV test and disclose their HIV status **if they demonstrate that they are mature enough to understand the benefits and risks of the test and of disclosure.**

If the child cannot give informed consent for an HIV test or disclose their status, consent may be given by:

- A parent or caregiver of the child
- The provincial head of Social Development
- A designated child protection organisation arranging placement for the child
- Where there is no parent, caregiver or designated child protection organisation, informed consent may be provided by a superintendent or person in charge of a hospital

([Human Sciences Research Council](#))

# Fact Sheet

## When should a parent/caregiver disclose to their child?

- There is evidence of the positive outcomes for children who are made aware of their status, including greater adherence to treatment.
- Disclosure to children is a process, not an event. That means that support is needed before and after disclosure.
- The World Health Organization recommends that in circumstances where the parents or caregivers know their children's HIV-positive status, children of school age should be told their HIV status and younger children should be told in a manner appropriate to their developmental stage.

(Repsi)

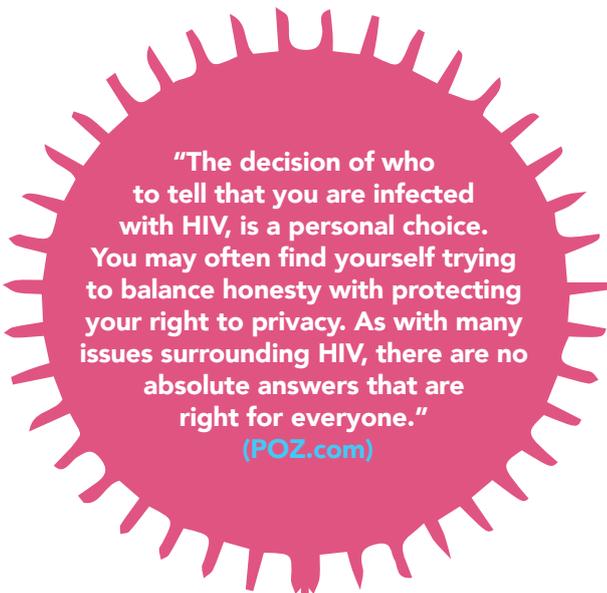
## Thinking about disclosing?

Disclosure, or deciding to share your HIV status with someone, is a personal choice. You will have to decide whether to share that information with other people, and—if so—whom you should tell.

Consider the following:

- Think about the people you look to for support, like family and friends.
- What kinds of relationships do you have with these people?
- What are the pros and cons of telling them you are living with HIV?
- What is that person's attitude and knowledge about HIV?
- Why do you want to disclose to this person?
- What kind of support can this person provide?
- For each person you want to tell, ask yourself if the person needs to know now—or if it's better to wait.

(AIDS.gov)



**"The decision of who to tell that you are infected with HIV, is a personal choice. You may often find yourself trying to balance honesty with protecting your right to privacy. As with many issues surrounding HIV, there are no absolute answers that are right for everyone."**  
(POZ.com)

## HIV Resources

- AIDS Legal Network: LEGAL ADVICE DESK: 021 447 8435 or 083 978 5357
- National HIV and AIDS Helpline: 0800 012 322
- **Guidelines for HIV disclosure counselling for children up to 12 years of age**
- **To disclose or not to disclose: HIV testing for children**
- **Find out more about stigma, discrimination and HIV**

## Internet Resources

- **Phindile Sithole-Spong: HIV Activist**
- **A South African mother living with HIV talks about disclosure and overcomes stigma**
- **A Positive Champion**
- **Positive Youth**
- **HIV Disclosure: Time Right Time is in Your Time**

# Radio Production Guide

## Preparing for the show

### Ways to talk about HIV-related stigma, disclosure and confidentiality:

- ★ Discussing rights of privacy and confidentiality
- ★ How to evaluate when to disclose or not.
- ★ Disclosure: it's a personal process
- ★ Parents disclosing (or not) to their children
- ★ Discrimination around disclosure

Choose an angle

Disclosure:  
It's a personal  
process

### Ways to talk about 'Disclosure: It's a process':

- ★ What are your rights to privacy and confidentiality?
- ★ What are your responsibilities to your current and past sexual partners?
- ★ Who are the people you look to for support?
- ★ What are your relationships with these people?
- ★ What are the pros and cons of telling them you are living with HIV?
- ★ What is that person's attitude and knowledge about HIV?
- ★ Why do you want to disclose to this person?
- ★ What kind of support can this person provide?

# Radio Production Guide

# Radio Production Guide

## RADIO FORMATS

### Vox Pop

Vox Pop aim: to get many opinions on one topic  
Who do you Talk To: Anyone in the community.

Question: When should a person disclose their HIV status?  
OR  
What does confidentiality mean?

### Audio commentary

Audio commentary aim: To get people's opinion about a topic that they care deeply about.  
Who do you talk to: A healthcare worker who can talk about the pros and cons of disclosing your HIV status.

### Audio profile

Audio profile aim: To get a first person account of someone's experience, passion and journey. Audio profiles often aim to inspire.

Who do you talk to: A young person or adult who has disclosed their HIV status, are living openly positive and are comfortable being interviewed. OR talk to a healthcare worker who can talk about their experience supporting and counselling people living with HIV in their disclosure process.

- ★ What motivated you to disclose your status?
- ★ How did you decide who you wanted to tell about your HIV status?
- ★ How did they react?
- ★ How did you feel when they reacted?
- ★ What are the challenges of disclosing a positive HIV status?
- ★ What are the benefits of disclosing your status?

### PSA

The aim of a PSA: to create a public awareness message

Voice 1: Pst! Xolani, check it out. Look there goes Bandile again. Man, every day he leaves the game... Same time every day. He's probably off to take those HIV meds.

Voice 2: What are you talking about?

Voice 1: I bet he's sick, you know infected. And he's playing football with us - putting us at risk of catching his disease.

Voice 2: Lay off, man, it's none of your business. Even if he's living with HIV, he's doing exactly what he needs to do - taking care of himself. And you can't "catch" HIV like a cold! Educate yourself, relax and pass the ball!

Character: HIV is a virus. Stigma is the deadly social disease. Ending stigma begins with you.

## How to present your show

Use your produced radio features, your research and the suggested script and questions to write your own script.

### Suggested questions for your interview with a healthcare worker (nurse, doctor, healthcare counsellor)

- ★ What are the basic rights of people living with HIV?
- ★ Do young people have the same rights to privacy as adults?
- ★ What does disclosure in relation to HIV mean?
- ★ Who has the right to disclose a person's HIV status?
- ★ Is disclosure ever a legal requirement?
- ★ What is pre and post-disclosure support?
- ★ What factors should be considered when thinking about disclosing?
- ★ When should parents, who know their child's positive HIV status, tell their child?

[INTRO:]

Host 1: It's just gone [TIME] and you're just in time for the [NAME OF SHOW] on [RADIO STATION]. My name is [NAME]...

Host 2: And my name is [NAME], and today's show is all about HIV stigma, disclosure and the right to confidentiality!

Host 1: That's right! We'll be talking about everyone's right to privacy concerning their health and HIV status. HIV is not curable, but it is treatable. People who get treated early can live long and healthy lives. But HIV-related stigma, or negative and unfair beliefs towards HIV-positive people, have severe consequences that often prevent people living with HIV from getting the care and services they need. It can feel like a very big deal when making the personal choice to disclose a HIV-positive status.

Host 2: Yebo, that's why we'll be focusing on HIV disclosure as a process. This includes conversations about our rights to privacy and how people figure out to whom, when and how they choose to disclose their status.

Host 1: Let's hear more about what people have to say about disclosure.

[PRESENT WHO IS BEING INTERVIEWED]  
[PLAY THE INTERVIEW]

[Outro:]

Host 1: Today, we've learnt so much about HIV disclosure and rights to privacy.

Host 2: Yes, it's amazing to learn how disclosure is not just a one-time event, but can take time to figure out what's right for you. Disclosure is a journey for a lot of people. That's given me a lot to think about how we all can work to support each other's journey.

Host 1: Next week on [DAY] at [TIME] we'll be talking all about [NEXT WEEK'S SHOW TOPIC]. Until then, it's bye from us!

Once you've finalised your script, produced your radio features and finalised your "show clock" it's time to go live on air!

Prepare to present your show

# Radio Production Guide

## Show outline

General Intro
Intro Vox Pop
Vox Pop
Outro Vox Pop
Music transition
Intro audio commentary
Audio commentary:
Outro commentary:
Music transition & jingle:
Intro interview (or Intro audio-profile)
Interview (or Audio-Profile)
Outro interview (or (Outro audio profile)
Music transition & Jingle
PSA
General outro
Music end

## Ethics and consent

This is a sensitive topic, so make sure you inform your interviewees properly and get their full consent.



**You must always introduce your show and radio features. Then once you've played your features, have a concluding statement for each one. Don't forget a final conclusion for the very end of the show.**

**Use links (facts, tips, did you knows, music) to glue it all together.**



**Now write your radio script**

# Outreach Guide

## Outreach Formats

### Interview

**Interview aim:** An interview is a one-on-one conversation where questions are asked by the interviewer and answers are given by the interviewee.

Suggested questions for an interview:

- What motivated you to disclose your status?
- How did you decide who you wanted to tell about your HIV status?
- How did they react?
- How did you feel when they reacted?
- What are the challenges of disclosing a positive HIV status?
- What are the benefits of disclosing your status?

### Impact Jingle

**Impact jingle aim:** A jingle is a short song or tune that is easy to sing along to and remember, it has a clear message.

### Guest Speaker

**Guest speaker aim:** A guest speaker is someone who can share expert knowledge about the impact statement or tell a personal story related to the impact statement.

Some questions for the guest speaker to think about ahead of time:

- Is it compulsory that a person living with HIV disclose their status to family, friends or colleagues?
- What are the pros and cons of disclosing your HIV status?
- What are the ways we can help minimise the stigma HIV minimise the stigma that people living with HIV face?
- What does confidentiality mean?

### Roleplay

**Roleplay aim:** To provide a scenario that allows the audience to "act out" a point about the impact statement. Decide how many characters are needed and set the scene for the 'actors' to flesh out the statement. It is really an improvisation, and the audience 'actors' make it up as they go along.

- A young person or adult discloses their HIV status and is open about living positively, but faces stigma in the community
- A healthcare worker supports and counsels people living with HIV through their disclosure process

### Panel Discussion

**Panel discussion aim:** A panel discussion involves a group of people discussing one topic in front of an audience. There is usually time for questions from the audience afterwards.

Examples of opening questions for the panel:

- How can we constructively challenge people about their stigmatising behaviour?
- What are the ways stigma can be dangerous for those living with HIV?
- What are the ways that we can encourage friends and family living with HIV to live positively?

Who is on the panel: Health care professionals, community nurses, counsellors, youth, gender activists, parents.

# Outreach Guide

## [INTRO]

Host 1: Hello and welcome everyone! It's just gone [TIME] and my name is [ NAME OF HOST 1] and I am a [TITLE OF HOST] from [NAME OF ORGANISATION]. You're just in time for an awesome show all about a topic that probably one way or another has affected us.

Host 2: And my name is [NAME], I am a [TITLE OF HOST] from [NAME OF ORGANISATION] and today's show is all about HIV stigma, disclosure and the right to confidentiality!

Host 1: That's right! We'll be talking about everyone's right to privacy concerning their health and HIV status. HIV is not curable, but it is treatable. People who get treated early can live long and healthy lives. But HIV-related stigma is real. These negative and unfair beliefs towards people living with HIV have severe consequences that often prevent them from getting the care and services they need. It is a big deal to make the choice to disclose an HIV-positive status.

Host 2: Yebo, that's why we'll be focusing on HIV disclosure as a process. It's not one 'event' and you just tell all. It's way more complex. We'll be talking about our rights to privacy and how people figure out who, when and how they choose to tell others about their status.

Host 1: Let's hear more about what people have to say about disclosure.

## [INTRO TO INTERVIEW]

### [INTERVIEW]

Suggested questions for your interview with someone who has disclosed their HIV status and is openly living with the virus.

Suggested interview questions:

- What was your reaction when you discovered your HIV positive status?
- Have you ever faced stigma because of your status?
- Why did you decide to disclose your status and how did you do it?
- Do you ever regret disclosing?
- If you disclose to one person, does that mean you have to disclose to everyone?
- What is it like to live positively?

## [OUTRO TO INTERVIEW]

Host 1: Wow! That was really interesting and really personal! We have to remember that HIV is the virus and stigma of HIV is the social disease. Ending stigma begins with you.

Host 2: Exactly right! We each have to do our bit to end stigma in our communities. It helps when we have the correct information about HIV so that we can put a stop to the myths. When we have the facts about HIV we can support people with HIV to live positively.

Host 1: Definitely! Now let's get that correct information from our guest speaker today who is a healthcare professional. She will help us understand more about HIV and bust those myths that may linger in our minds. She will also talk about this word confidentiality. Later on, we will have a quiz about that word and much more! Don't go away!

# Outreach Guide

[INTRO TO GUEST SPEAKER]

[GUEST SPEAKER]

Suggested questions for your interview with a healthcare worker (nurse, doctor, healthcare counsellor)

- Are the rights of people living with HIV threatened in any way?
- Do young people have the same rights to privacy as adults?
- What does HIV disclosure mean?
- Who has the right to disclose a person's HIV status?
- Is disclosure ever a legal requirement?
- What is pre and post-disclosure support?
- What factors should be considered when thinking about disclosing?
- When should parents, who know their child's HIV positive status, tell their child?

[OUTRO TO GUEST SPEAKER]

[PLAY IMPACT JINGLE]

Host 1: We've learned a lot from our guest speaker and our interviewee. Now let's hear from you with a quick quiz. This is how it works.

[INTRO QUIZ RULES]

[DO THE KNOWLEDGE QUIZ - You can create by asking questions about the content that has been shared during this outreach]

[OUTRO QUIZ]

[PLAY IMPACT JINGLE]

[Here, continue with your own script according to the outreach outline below]

[OUTRO:]

Host 1: Today, we've learnt so much about HIV disclosure and rights to privacy.

Host 2: Yes, it's amazing to learn how disclosure is not just a one time event, but can take time to figure out what's right for you. Disclosure is a journey for a lot of people.

Host 1: That's right! It really is something to think about and not treat lightly. Now it's time for us to say goodbye. Don't forget to catch us next month on [DAY] at [TIME] and [VENUE]. We'll be talking all about [TOPIC FOR NEXT SHOW]. Thank you for joining us and we hope to see you next time!

Host 2: Until then, it's bye from us!

# Outreach Guide

## Outreach Outline:

An outreach outline is a map to help you stay on track during your event. It is a list of the items and the order in which they will happen in the outreach activity. Below is an example of an event that is one hour long.

Music
Intro
Intro the Interview
Outro the Interview
Intro Guest Speaker
Guest Speaker
Outro the Guest Speaker
Impact Jingle
Intro Quiz
Quiz
Outro Quiz
Impact Jingle
Music/Performance
Intro Roleplay
Roleplay
Outro Roleplay
Impact Jingle
Outro



Ethics and consent  
This may be a sensitive topic for some, so make sure you inform your audience to respect those who share personal stories in the space



If any incorrect information comes up in any of your formats, like the quiz, role play or panel discussion, you must correct it. Don't let your audience leave with myths



Once you've finalised your script, your performance artists, your outreach outline and prepared all your formats, it's time to start your live event!