

Mzantsi Wakho Follow Up Giraffe Questionnaire



Interviewer name: _____

Interview date: _____

Serial Number: _____

Participant's Birth Date: _____



Thank you for meeting with us again. We have interviewed over 1500 teenagers and your stories have been incredibly helpful to our government and healthcare providers. By participating in Mzantsi Wakho, YOU have the power to influence what services and support will be provided to young people in South Africa.

MZANTSI WAKHO is a study about young people in South Africa and how they think about their bodies, their health and their lives.

We are part of a research team from the Universities of Oxford and Cape Town that is trying to learn more about the lives and health of young people in the Eastern Cape. You (the participant) have been invited to participate in our study. We want to learn from you, share ideas so that we can help government provide better support and services for teens.



***What will happen to the results of the study?**

The results of this study will be used to help the government, and health and welfare organisations, to make better policies for young people and their families.

***Why should I take part in this study?**

Your story is important! This study will help us to learn more about how to help young people in South Africa.

***Do I have to take part?**

Not at all. You can decide if you want to take part again or not. If you don't want to, it won't affect any help you are getting and you won't get into trouble. If you decide to take part, you are still free to stop at any time and you won't have to give a reason. In one year's time, we will visit you again to see how you are doing. You can choose then whether you want to talk to us again!

***What will I have to do?**

If you decide to take part, you will sign this consent form, and then spend a couple of hours talking together and doing activities with a researcher. Sometimes we will need to understand things about your health or about school. You might not know these things. With your permission, we might ask your school and clinic for additional information.

***Will what I say be kept confidential?**

Anything you tell us about yourself will be kept strictly confidential, and will not be told to anyone else. The questionnaire will not include your name and it will be completely anonymous. But during our chat it may become clear that you are suffering from serious challenges. If so, our researchers will explain to you, in private, possibilities for further help. If there is a safety issue, we might contact an organization that can help you. But we will talk to you about it first.

***What if the questions upset me?**

You can stop at any point, and you don't have to give a reason. You can also contact the research team at any point and say that you want your answers about certain questions to be removed, which we will do straight away.

***What if I have a complaint?**

If there is anything to do with the research that you are unhappy with, you can contact:

- Dr Lucie Cluver at the University of Oxford (lucie.cluver@spi.ox.ac.uk)

- Send a 'Please Call Me' to 0783079507



1. Please choose if the participant is a boy or a girl:

☐ Boy

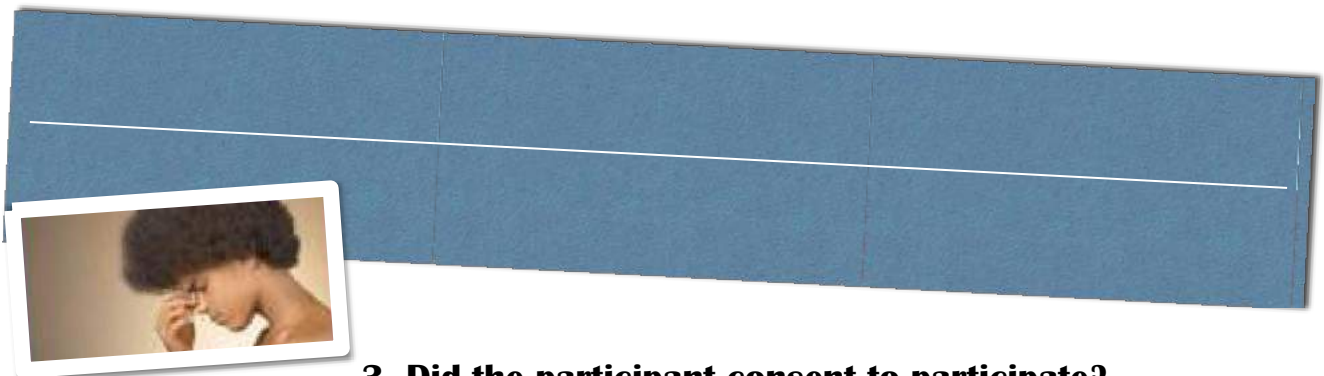
☐ Girl

2. Please select the participants animal:

☐ Elephant

☐ Giraffe

☐ Bear



3. Did the participant consent to participate?

☐ Yes - please continue

☐ No - stop the interview

5. Where are you conducting the interview?

☐ Participant's Home

☐ Clinic

☐ Hospital

☐ School

☐ Church

☐ Community Centre

☐ Other: _____

☐ Please write address: _____



Introduction

This questionnaire has 13 parts, each of which will take about 10 minutes. There will be a short break after each part and we will play a small game together. Your answers will be kept confidential and your name will not be written anywhere on this questionnaire. Your experiences will be incredibly helpful to our government and healthcare providers.



If you need a break, just tell the person that is helping you and they will do some activities with you. This is not a test. There are no right or wrong answers! This research aims to help young people in South Africa. Thank you for taking the time to help.



1. What nickname would you like us to call you? _____
2. How old are you? _____
- 3 Have you moved since we last met?

4. Please tell us what type of house do you live in now? [please check one]

- ☐ house made of brick or concrete
- ☐ hut made of traditional materials (cow dung, mud, etc.) or a rondavel on its own plot
- ☐ living on the street
- ☐ shack in a back yard or a separate plot
- ☐ children's home or shelter for kids
- ☐ other (what kind?) _____

5. When were you born?

SECTION 1 - ABOUT YOU

Your answers are important and will help government and other organisations to design better services for young people. But if we need to use something you have said, we will never use your real name. Everything you say is confidential. Can you make up a pretend name that we can use? It can be any name, such as **Lerato** or **Akhona** or **Beyonce** or **Zola**



7. WHAT IS THE NICEST THING THAT SOMEONE HAS SAID TO YOU ABOUT YOURSELF?

SECTION 2: My school

1b. What kind of school do you go to?

- ☐ we pay school fees
- ☐ the school charges fees but we cannot afford to pay them, so we owe them
- ☐ it's a free school but we are still asked to pay something
- ☐ a totally free school, we don't have to pay anything
- ☐ other kids pay school fees but I have an special permission from the principal
- ☐ I don't go to school – go to question 1c.

2. WHAT IS THE NAME OF YOUR SCHOOL?

3. WHAT GRADE ARE YOU IN?

1a. Have you changed school since we last spoke? _____

If yes, please answer all questions. If no, please start at question 3.

1c. If you are NOT currently attending school, what is the MAIN REASON for not attending school? [PLEASE CHOOSE ONLY ONE] REASON]

- | | |
|--|--|
| <input type="checkbox"/> I finished matric | <input type="checkbox"/> I was suspended or expelled |
| <input type="checkbox"/> I didn't have enough money to pay fees or uniform | <input type="checkbox"/> I got married |
| <input type="checkbox"/> I had to stop going to school to help at home | <input type="checkbox"/> I got pregnant or had a child |
| <input type="checkbox"/> I stopped going because I was too unwell | <input type="checkbox"/> I was bullied or treated badly by teachers or friends |
| <input type="checkbox"/> I had to stop going because my parent/guardian died | <input type="checkbox"/> I did not like school |
| <input type="checkbox"/> I had to repeat a grade and I didn't want to | <input type="checkbox"/> I moved to another place and could not register |
| | <input type="checkbox"/> Other: _____ |

Now go to question 4!

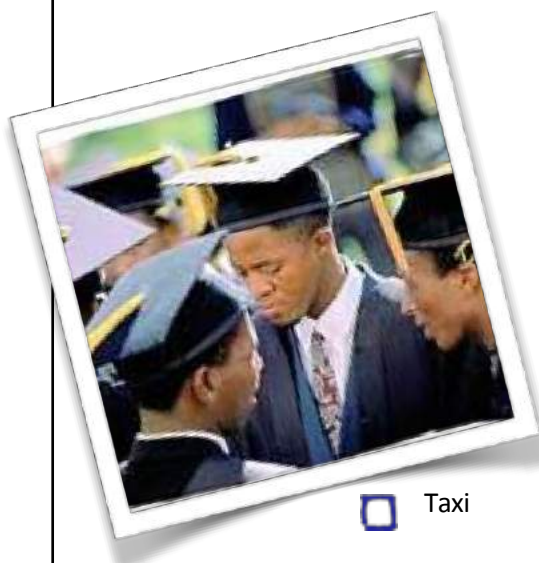
4. WHAT IS THE HIGHEST GRADE YOU HAVE PASSED?



5. Did you pass your grade last year?

...

6. If you've ever repeated a grade, Why?



☐ Taxi

☐ Bicycle

☐ Walk

☐ Driven

10. How long did it take you to get there?

_____ hours _____ minutes

MY SCHOOL

Please think about **THE LAST FULL TERM YOU WENT TO SCHOOL**. If you are not sure when this was, please chat with the research assistant.

7. In the last full term of school, how many days did you miss school (not including weekends, holidays or public strikes)?

☐ Less than a week in total

☐ About 3 weeks in total

☐ About a week in total

☐ More than a month in total

☐ About 2 weeks in total

8. In the last term of school, which meals did you have for free at school?

☐ Breakfast

☐ Other food

☐ Lunch

☐ I don't have any free food at school

9. How did you get to school during the last term of school?

☐ Bus



10. Did you ever receive free food every day from your school or your teacher during the holidays? _____



We would like to know a bit more about your experiences at school. If you are not in school now, please think about when you last went to school. Please tell us how true these statements are for you:

11. I like school

13. I look forward to going to school

14. I try hard to do well in school

15. I have been hit, beaten or slapped by a teacher at school

16. I like the way my school looks

17. I feel safe at school

Never

Sometimes

Always



This is the
end of
Section 2!!!



Section3: Me and My Health

We all get sick sometimes. This section asks about how your health has been in the past 12 months.

1. How has your overall health been in the last 12 months?

- ☐ Very poor health
☐ It has been OK (not too good, not too bad)
☐ Excellent health



The next questions are about problems you might have while doing certain activities because of your health, in the past 12 months. [Please check the boxes below:](#)

In the last 12 months...	No, no difficulty	Yes, some difficulty	Yes, a lot of difficulty	Cannot do it at all
2. Did you have difficulty seeing, hearing, walking or climbing steps, washing yourself or getting dressed, speaking or being understood?				
3. Did you have difficulty remembering things or following a story or conversation?				



Which one of the following illnesses have you had in the past 6 months?
Please tell us how often you have felt them: never, sometimes or often.



In the past sixth months...	Never	Sometimes	Often
4. Asthma, lung problems and trouble breathing for more than two days			
5. Ear problems: pains and infections			
6. Fits or epilepsy			
7. Shingles or rash on the skin			
8. Sores on the hands, mouth, feet or other parts of the body			
9. A cough where you spit up green or yellow stuff			
10. A bad cough lasting three weeks or longer			
11. Pains in your chest			
12. Night sweats			
13. Coughing up blood			
14. Ulcers, white patches on your mouth or problems swallowing food			
15. Diarrhoea or a runny tummy for more than 2 days			
16. Nausea or vomiting			
17. Headaches			
18. Back pain/ aches			
19. Fever			
20. Tire easily, little energy			
21. Stomach problems/ difficulties with digesting food			
22. Dizziness			
23. Bad dreams or problems sleeping well			
24. Lost a lot of weight, or could not put on weight			



In the past six months...	Never	Sometimes	Often
25. Sores or warts in your private parts			
26. Burning while urinating/ peeing			
27. Itching and redness in your private/ intimate parts.			
28. Itching, soreness or bleeding from your bum			
28(b). Smelly or unclear discharge from vagina or penis			

29. Have you ever received any of these tests for TB in the last year?

- ☐ They pricked my skin with a needle to see a reaction
- ☐ I coughed sputum into a little bottle or container
- ☐ I had a chest x-ray
- ☐ I received one of these tests but it a more than a year ago
- ☐ I have never received one of these tests



30. What where the results of your last TB test?

- ☐ It was negative ☐ It was positive, and I'm still sick
- ☐ It was positive but I took medicine and I'm better
- ☐ I don't know

31. Have you ever been given medicine to take every day for TB?





32. Have you ever had an HIV test?

- ☐ Yes
- ☐ No
- ☐ I don't know

32a. How old were you when you had your first test?

_____ years old

33. What were your HIV test results?

- ☐ I was told I was HIV-positive
- ☐ I was told I was HIV-negative
- ☐ I don't know, I didn't get my results



33a. Did you get initiated on HIV treatment? In other words, after your test, did the nurse or doctor give you pills to take for the rest of your life?

- ☐ Yes ☐ No

33b. When was the last time you had your bloods taken in the clinic/hospital?

- ☐ In the last week ☐ In the past 2 weeks
☐ In the past months ☐ In the past six months
☐ In the past year ☐ More than a year ago
☐ I don't remember having my bloods taken the clinic/hospital
☐ I don't know the results

33c. Did the nurse or doctor tell you the results of your bloods?

- ☐ Yes, but it was confusing I didn't understand what it meant
☐ Yes, but they were angry at me and shouted at me about the results being bad
☐ Yes, and I understood what it meant
☐ Nobody spoke to me about my bloods after they took them

33d. Did you have your CD4 count taken in the past year?

- ☐ Yes ☐ No

33e. What is your most recent CD4 count?

33f. Did you have your viral load taken in the past year?

- ☐ Yes ☐ No

33g. What was the result of your most recent viral load?

- ☐ There is still some virus in my body
☐ The doctor or nurse said my viral load is low
☐ I don't know my viral load results



Sometimes when we are not feeling well, we go to see a doctor or a nurse. Sometimes we go straight to the pharmacy or we visit a sangoma or a herbalist

33. In the last year, where have you gone to get help? Please choose all options that apply.

- | | |
|---|--|
| <input type="checkbox"/> Chemist/Pharmacy | <input type="checkbox"/> Healer at church, medicines from church or spiritual healer |
| <input type="checkbox"/> Public Clinic | <input type="checkbox"/> Traditional pharmacy or herbalist |
| <input type="checkbox"/> Private Doctor (Ugqirha) | <input type="checkbox"/> Public Hospital |
| <input type="checkbox"/> Traditional Healer (Sangoma) | <input type="checkbox"/> Private Hospital |

34. How do you usually get to your local clinic/ hospital?

- | | |
|--------------------------------|---------------------------------|
| <input type="checkbox"/> Walk | <input type="checkbox"/> Bus |
| <input type="checkbox"/> Taxi | <input type="checkbox"/> Driven |
| <input type="checkbox"/> Other | |

34a. If "other", how do you get there?

35. How long does it take you to get there?

_____ hours _____ minutes

36. How much does it cost to get to your clinics (in Rand)? If you don't pay any money, please write 0 (zero): _____

37. Who goes to the above places with you usually?

CHOOSE ONLY ONE ANSWER

- ☐ I don't go - someone else goes instead of me to pick up my medicine
- ☐ I go alone
- ☐ My parent/ caregiver goes with me
- ☐ Another family member goes with me
- ☐ My friend goes with me
- ☐ My boyfriend/ girlfriend goes with me
- ☐ My village or community healthcare worker goes with me
- ☐ Someone else goes with me



AT THE CLINIC

38. Who did you talk to about your health at the clinic during the last year? Choose as many as apply.

- | | |
|---|--|
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Village or community healthcare worker |
| <input type="checkbox"/> Doctor | <input type="checkbox"/> Someone else who works at the clinic who is living with HIV |
| <input type="checkbox"/> Counsellor | <input type="checkbox"/> Data Capturer |
| <input type="checkbox"/> Pharmacist | |
| <input type="checkbox"/> Social Worker | |
| <input type="checkbox"/> Patient Advocate | |

39a. How long do you wait to see someone at the clinic usually?

_____ hours _____ minutes



39.b Which clinic do you go to most often when you are sick?



Going to the clinic/ hospital in the last year

Now we would like to hear about your experience at the clinic or hospital where you went to get help or where you go when you are sick. Your answers will be completely confidential and will not in any way impact the help or support you are getting.



<u>Please tell us how often you experienced these in the past year:</u>	Never	Once or twice	Several Times	Most of the time
40. I didn't have enough money for transport to get to the clinic				
41. No one was available to go with me				
42. It was not safe for me to go to the clinic/ hospital				
43. I did not get the help I needed				
44. The clinic/hospital staff were too busy to give me the help I needed				
45. I felt my information would be kept safe and confidential				
46. They did not know the answers to my questions				
47. They got angry with me about how I take my pills and they scolded me				
48. I had to miss school to go to the clinic				
49. I felt comfortable talking to the healthcare worker about getting something to prevent pregnancy				
50. They got angry with me because I am having sex and they shouted at me				
51. I could get condoms if I needed them				



52. Nobody helped me because I didn't have my health card				
53. They could not find my patient file				

Does your family have a person who visits you at least once a month to help with health issues, who is not a family member, like a nurse, community health worker, home-based carer, village health worker or social worker?

☐ Yes ☐ No



Part 4: You and your medicine



Sometimes we get sick and we need to take medicine to get better. Other medication helps us stay healthy.

We'd like to ask you some questions about any medicine you might be taking, or have taken in the past. We know that taking medicine regularly can be a big job, and that it is challenging.

Do not worry about telling us if you are not taking any or all of your medicines. We need to know what is really happening, not what you think we may want to hear.



So you can have some privacy, we're going to give you the questionnaire if you like. Now it can be your turn! But if you would like some help reading and answering the questions then we can continue as normal!

Remember, if you have any difficulties, ask the Research Assistant for help.



We know the questions that we are going to ask you are difficult to answer, everyone finds them hard. But it is really, really important that you tell us the truth in order to help other young people like yourself in South Africa.

If you are not honest with us, we can't help. So please help other teens and policy-makers by being totally truthful.



1. We'd like to know if you are currently taking any of the following forms of medicine:	Yes	No
Are you taking any pills?		
Are you taking any injections?		
Are you taking any other form of medicine?		
IF all your answers for number 1 are "No", please skip to Section D		

2. We'd like to understand why you are taking these medicines:	Yes	No
a)Are you taking these medicines for your chest?		
b)Are you taking these medicines for diarrhea?		
c)Are you taking the medicines for tuberculosis (TB)?		
d)Are you taking these medicines to prevent getting pregnant?		
e)Are you taking these medicines for treating HIV/AIDS?		

f)Are you taking these medicines for epilepsy?		
g)Are you taking these medicines to prevent your child from getting HIV/AIDS?		
h)Are you taking these medicines for your ears?		
i)Are you taking these medicines for ONE MONTH ONLY to prevent HIV infection (this would happen after a severe injury or rape and the medicine probably made you feel very ill)?		
j)Are you unsure why you are taking these medicines?		
k)Have you ever taken any antiretrovirals (ARVs) or HIV medicine in the past?		
l)Are you currently taking any antiretrovirals (ARVs) or HIV medicine?		
If the answers for 2.e) onward are “No”, please skip questions 3 and 4. If the answer to 2.k) was “yes” but 2.i) is “no” then please skip to section D.		

WELL DONE!



You're doing great! We'd would like to ask you specific questions about your ARVs or your HIV medicine.

3. Please answer each question with a number:	Number:
How old were you when you started taking these antiretrovirals (ARVs) or HIV medicine?	
How many ARVs or HIV pills do you have to take every day?	
How many times a day do you have to take your ARVs or HIV medicine?	

4. Well done, let's continue, please tick one box per question:	YES	NO	I DON'T KNOW
Do you know when in the day you need to take your ARVs or HIV medicine?			
Do you need to take your ARVs or HIV medicine in the morning?			
Do you need to take your ARVs or HIV medicine during the day?			
Do you need to take your ARVs or HIV medicine in the evening?			
Do you change the time of day you take your ARVs or HIV medicine, for example, sometimes you take them in the morning and sometimes in the evening?			

WELL DONE

Sometimes people get busy and forget to take their ARVs or HIV medicine.

We would like to understand if you have similar experiences when you take your ARVs or HIV medicine so we can help other teens.

We need to know what is really happening, not what you think we want to hear. Nobody will get angry at you and your answers. Please be honest.

5. Please answer each question with a number:	Number:
How many times did you take your ARVs or HIV medicine yesterday?	
How many times did you take your ARVs or HIV medicine the day before yesterday?	
How many times did you take your ARVs or HIV medicine three days ago?	



Sometimes unexpected things get in the way and prevent people from taking their ARVs or HIV medicine at the same time. Some days people do not take their ARVs or HIV medicine at all or don't take them at the right time.

This is not their fault.

We would like to ask you about the times you were not able to take your ARVs or HIV medicine. We simply want to better understand why teens have a hard time taking their ARVs or HIV medicine.

6. How many days did you take all of your ARVs or HIV medicine at the right time last week?

Remember, your answers to our questions will help us understand what makes it easier and harder to take pills or medicine. Please answer as truthfully as you can. Your answers are completely confidential and you will not be judged.

7. Please tick one box per question:	YES	NO	DON'T KNOW
Have you ever missed a pill or medicine?			
Did you miss taking any of your ARV pills or HIV medicine in the last year?			
Did you miss taking any of your ARV pills or HIV medicine in the last month?			
Did you miss taking any of your ARV pills or HIV medicine in the last week?			
In the past year, have you changed the type of ARVs or HIV medicine treatment you take, for example: name of medicines, number of pills, times you had to take them?			

8. How many times have you changed the type of ARVs or HIV medicine treatment you take?

9. Please tick one box per question:	YES	NO	DON'T KNOW
Do you usually go yourself to get your ARV pills or HIV medicine from the clinic or hospital?			
Do you know who collects your ARVs or HIV medicine from the clinic or hospital?			

10. Please tick one box per question:	YES	NO	DON'T KNOW
Does someone in your family usually go without you to get your ARV pills or HIV medicine from the clinic or hospital?			
Do you usually go together with someone from your family to get your ARV pills or HIV medicine from the clinic or hospital?			
Does a health worker usually bring the ARVs or HIV medicine to your home?			
Does a treatment buddy usually collect your ARVs or HIV medicine from the clinic or hospital?			
Are your ARVs or HIV medicine delivered straight to your home?			
Do you get your ARV pills or HIV medicine every month?			
Do you get your ARV pills or HIV medicine every 2 months?			
Do you get your ARV pills or HIV medicine every 3 months?			
In the last year, were you always able to get your ARVs or HIV medicine from the clinic?			

11. How many times in the last year were you not able to get your ARVs or HIV medicine from the clinic?

12. In the last year, were you always able to get to your clinic appointment?

- ☐ Yes ☐ No ☐ Don't Know

13. In the last year, how many times were you not able to get your ARVs or HIV medicine because the clinic had run out of medication (stock-out)?



Sometimes we have trouble getting our medication and cannot take them for a few days in a row. Other times, we must visit family and cannot take our medication with us.

14. In the last year, how many times were you not able to take your medication for more than 2 days in a row?

15. Since you started taking your medication, have you had to stop taking it for more than a month?

- ☐ Yes ☐ No ☐ Don't Know

You're doing a great job! Thank you!



Taking ARVs or HIV medicine can make us feel better or worse. It can also change over time.

The next set of questions ask how often you have felt or thought the following about your ARVs or HIV medicine in the last year. You can answer 'Never', 'Sometimes' or 'Often'.

16. Please tick one box per question:	OFTEN	SOMETIMES	NEVER
In the last year, how often have you felt that you don't need ARVs or HIV medicine anymore, because you can stay healthy without it?			
In the last year, how often have you felt that you remember to take your ARVs or HIV medicine when you do something else, for example, brush your teeth or eat breakfast?			



17. Please tick one box per question:	OFTEN	SOMETIMES	NEVER
In the last year, how often have you felt that taking ARVs or HIV medicine caused you to have other physical symptoms (e.g., rash, headache, getting fat in unusual places, nausea, vomiting, diarrhoea)?			
In the last year, how often have you felt that taking ARVs or HIV medicine makes you feel stronger and healthier?			
In the last year, how often have you not taken your ARVs or HIV medicine because you ran out of them?			
In the last year, how often did you forget to take your ARVs or HIV medicine?			
In the last year, how often have you felt that you remembered to take your ARVs or HIV medicine because a soapie or a TV programme started on TV?			
In the last year, how often have you felt that your ARVs or HIV medicine got in the way of your daily life, school and friends?			
In the last year, how often have you felt fed up with taking your ARVs or HIV medicine and needed a break?			

18. Please tick one box per question:	OFTEN	SOMETIMES	NEVER
In the last year, how often have you felt that it has been hard to take your ARVs or HIV medicine when you have changed homes or schools?			
In the last year, how often have you felt that taking your ARVs or HIV medicine is hard because you are worried people would find out about your HIV?			
In the last year, how often have you felt you needed to use an alarm to remember to take your ARVs or HIV medicine?			
In the last year, how often have you felt that you struggle to take your ARVs or HIV medicine when you get sick with another illness?			
In the last year, how often have you felt that it is hard to take your ARVs or HIV medicine when your family and/or friends don't help you remember?			
In the last year, how often have you carried your ARVs or HIV medicine with you all the time?			
In the last year, how often have you felt that you do not have anywhere to keep your ARVs or HIV medicine e.g. at school or home?			

19. Please tick one box per question:	OFTEN	SOMETIMES	NEVER
In the last year, how often have you felt that you understand why you have to take your pills?			
In the last year, how often have you felt that you keep getting sick even when you do take your ARVs?			
In the last year, how often have you felt that your girlfriend/ boyfriend helps you to remember to take your ARVs?			
In the last year, how often have you felt that taking your ARVs reminds you of HIV?			
In the last year, how often has your doctor/ nurse told you to stop taking ARVs for some time?			
In the last year, how often have you felt that it has been difficult for you to take your ARVs when you haven't eaten?			
In the last year, how often have you felt like the ARVs are toxic or harmful?			
In the last year, how often have you felt that you have had too many ARVs or HIV medicine to take?			

20. Please tick one box per question:	OFTEN	SOMETIMES	NEVER
In the last year, how often have you felt that, when you have a boyfriend/ girlfriend, you struggle to take your ARVs?			
In the last year, how often did you use a cellphone to remember to take your ARVs?			
In the last year, how often did you feel that, when you were in circumcision camp, it was hard to take your ARVs?			
In the last year, how often have not been able to take your ARVs because your pills got damaged or lost?			
In the last year, how often did you feel that it was difficult to take your ARVs because you drank too much alcohol?			
In the last year, how often did someone at the clinic/ hospital tell you that you should not take ARVs when you drink alcohol or take other drugs?			
In the last year, how often could you not take your ARVs because someone robbed you?			

GREAT WORK!



SECTION D

Previously you said you took ARVs or HIV medicine in the past, but not now. This is totally okay.

We would still like to ask you about the time when you were taking antiretrovirals (ARVs) or HIV medicine in the past.

First, we'd like to ask you about any medicine that you've ever taken for longer than 2 weeks.

1. Please tick all that apply.	YES	NO
Have you ever taken any medicine for your chest for longer than 2 weeks?		
Have you ever taken any medicine for diarrhoea for longer than 2 weeks?		
Have you ever taken medicine for tuberculosis (TB) for longer than 2 weeks?		
Have you ever taken medicine to prevent getting pregnant for longer than 2 weeks?		
Have you ever taken medicine for treating HIV/AIDS for longer than 2 weeks?		
Have you ever taken medicine for epilepsy for longer than 2 weeks?		
Have you ever taken medicine to prevent your child from getting HIV for longer than 2 weeks?		
Have you ever taken medicine for ONE MONTH ONLY to prevent HIV infection (this would happen after a severe injury or rape and the medicine probably made you feel very ill)?		
Have you ever taken medicine for your ears for longer than 2 weeks?		
Have you ever taken any other medicine for longer than 2 weeks?		
Do you know how old you were when you first started taking ARVs or HIV medicine?		
Do you know how old you were when you first started taking your pills?		

2. How old you were when you first started taking ARVs or HIV medicine?

3. Please tick one box per question:	YES	NO
Do you remember when you last took your ARVs or HIV medicine?		
Was the last time you took your ARVs or HIV medicine a long time ago?		
Have you taken your ARVs or HIV medicine in the last year?		
Was the last time you took your ARVs or HIV medicine more than a year ago?		



Taking ARVs or HIV medicine can make us feel better or worse. It can also change over time. Please tell us how you felt about taking your ARVs or HIV medicine?

4. Please tick one box per question:	YES	NO
Did you feel that you didn't need ARVs or HIV medicine anymore, because you could stay healthy without it?		
Did you feel that taking ARVs or HIV medicine caused you to have other physical symptoms (e.g., rash, headache, getting fat in unusual places, nausea, vomiting, diarrhoea)?		
Did you stop taking your ARVs or HIV medicine because you ran out of them?		
Did you sometimes forget to take your ARVs or HIV medicine?		
Did you feel that your ARVs or HIV medicine got in the way of your daily life, school and friends?		
Did you feel fed up taking your ARVs or HIV medicine and felt you needed a break?		
Did you feel it was hard to take your ARVs or HIV medicine when you changed homes or schools?		

5. Please tick one box per question:	YES	NO
Was taking your ARVs or HIV medicine hard because you were worried people would find out about your HIV?		
Did you struggle to take your ARVs or HIV medicine because you got sick with another illness?		
Was it hard to take your ARVs or HIV medicine when your family and/or friends didn't help you remember?		
Do you feel that you did not have anywhere to keep your ARVs or HIV medicine at school or home?		
Did you feel like you didn't understand why you had to take your ARVs or HIV medicine?		
Did you feel that you kept getting sick even when you did take your ARVs or HIV medicine?		
Did you feel that taking your ARVs or HIV medicine reminded you of HIV?		



6. Please tick one box per question:	YES	NO
Did your doctor/ nurse tell you to stop taking your ARVs or HIV medicine for some time?		
Did you feel that it was difficult for you to take your ARVs or HIV medicine on an empty stomach?		
Did you feel like the ARVs or HIV medicine was poisonous or harmful?		
Did you feel you had too many ARVs or HIV medicine to take?		
Did you get a new boyfriend/girlfriend, and did you struggle to take your ARVs or HIV medicine around them?		
Did you feel that when you were in circumcision camp, it was hard to take your ARVs or HIV medicine?		
Did you struggle to take your ARVs or HIV medicine because they got damaged or lost?		

7. Please tick one box per question:	YES	NO
Did you feel it was difficult to take your ARVs or HIV medicine because you drank too much alcohol?		
Did someone at the clinic/ hospital tell you that you should not take ARVs or HIV medicine when you drink alcohol or take other drugs?		
Did you struggle to take your ARVs or HIV medicine because someone robbed you?		

Part 4: You and your medicine (continued)



21. How do you take your medicine? (please tick one)

- ☐ I take my medicine myself
- ☐ An adult at home gives me my medicine
- ☐ Sometimes I take them myself, sometimes an adult gives them to me
- ☐ I do not take any medicine

22. Which clinic do you go to when you get your ARVs?

Sometimes we take other medicines to make our body and soul feel better. We visit sangomas, healers, preachers or local doctors and pharmacists to help us.

Sometimes they give us medication or advice to help us feel better.



23. In the last year, how often did you go to a sangoma, traditional healer or a healer in your church?

- | | |
|--|--|
| <input type="checkbox"/> I did not go to a sangoma or healer | <input type="checkbox"/> Once |
| | <input type="checkbox"/> 2-3 times |
| | <input type="checkbox"/> 4 or more times |

24. If you went to a sangoma or a traditional healer in the last year, did they tell you to:

- | | |
|--|---|
| <input type="checkbox"/> I did not go to a sangoma | <input type="checkbox"/> Take ARVs together with traditional meds |
| <input type="checkbox"/> Take ARVs | <input type="checkbox"/> Stop taking your ARVs |

25. If you went to a healer at church in the last year, did they tell you to:

- | | |
|---|--|
| <input type="checkbox"/> I did not go to a healer | <input type="checkbox"/> Take ARVs with prayer |
| <input type="checkbox"/> Take ARVs | <input type="checkbox"/> Stop taking your ARVs |

26. Have you taken any other medicine to help keep you healthy and happy over the last year?

- | | |
|---|--|
| <input type="checkbox"/> Medicine my sangoma gave me | <input type="checkbox"/> Vitamin pills |
| <input type="checkbox"/> Herbal medicine to eat or drink | <input type="checkbox"/> Nutritional supplement |
| <input type="checkbox"/> Herbal medicine to use on my skin as a cream | <input type="checkbox"/> I have not taken any medication |

27. Now we would like to test adolescents' general knowledge of HIV medicine...

Andiwe is confused about how to take his ARVs.

Can you please help him and tell him whether he is doing the right thing?



	Right	Wrong
. It is important that Andiwe takes his ARVs at the exact time.		
. It is ok for Andiwe to share ARVs with other people in his family or friends.		
. Andiwe is two hours late in taking his ARV medication. He should still take it.		
. Andiwe has gone out and has had some drinks with his friends. He shouldn't take his ARVs.		
. If Andiwe misses his ARVs one day, it is ok to take two doses the next day.		
. Andiwe just vomited up his ARV pill. He should take another pill.		



28. How often do you go to a support group?

- ☐ Weekly ☐ Monthly ☐ Every year ☐ Once in a while
☐ I don't go to one / I don't have a support group

29. What kind of support group do you go to?

- ☐ A group for anyone who is HIV-positive ☐ A group for HIV-positive youth/ teens only
☐ The group changes

30. Would you like to go to a support group?

- ☐ Yes ☐ No

31. Who would you like the support group to let in?

- ☐ Only HIV-positive teens ☐ HIV-positive and HIV-negative teens
☐ Anyone who is HIV-positive including adults

32. Where would you like the support group to happen?

- ☐ In a hospital / clinic ☐ Somebody's home ☐ At church
☐ At school



A treatment buddy is someone who was there when you started medication, who often attends clinic appointments with you, knows information about pills, reminds you to take your treatment, and the clinic contacts them when they need to contact you.

They can be your parent/ caregiver, friend, sibling, support group member or another patient.

They can be taking ARVs or they can be HIV-negative.

33. Do you have a treatment buddy?

- ☐ Yes ☐ No

34. What is your relationship?

- ☐ My treatment buddy is a friend of mine
- ☐ My treatment buddy is my parent or caregiver
- ☐ My treatment buddy is a sister/brother of mine
- ☐ My treatment buddy is a mentor mother at the clinic

35. Has your treatment buddy talked to you about your ARVs in the last month?

- ☐ No
- ☐ Yes once
- ☐ Yes more than once

Let's Take A Break!

Who is your favourite sports player?



Do you support a team?



What are your
favourite soapies?

1. _____
2. _____
3. _____



Which soapie star are you most like?



Why are you like them?



Section 5: More About You

Now we would like to ask you a bit about your body.

Please tell us how often have you felt these things about your body in the past year?



1. I look as good as others my age

- ☐ Never
☐ Sometimes
☐ Always

2. I like how my skin looks

- ☐ Never
☐ Sometimes
☐ Always

3. My body is small for my age

- ☐ Never
☐ Sometimes
☐ Always

4. I would like to put on weight

- ☐ Never
☐ Sometimes
☐ Always

5. Other young people think I am sexy/ attractive

- ☐ Never
☐ Sometimes
☐ Always

6. Some of my body parts have changed

- ☐ Never
☐ Sometimes
☐ Always



7. What is your favourite soapie? _____

How you Think and Feel

This part of the questionnaire looks at sadness and challenges that all of us face in our lives sometimes. For each group of 3 statements, pick out which best describes how you have felt in the last 2 weeks.

8.

- ☐ Nothing will ever work out for me
- ☐ I am not sure if things will work out for me
- ☐ Things will work out for me OK

13.

- ☐ I do most things OK
- ☐ I do many things wrong
- ☐ I do everything wrong

9.

- ☐ I am sad once in a while
- ☐ I am sad many times
- ☐ I am sad all the time



14.

- ☐ I have enough friends
- ☐ I have some friends but wish I had more
- ☐ I don't have any friends



10.

- ☐ I look ok
- ☐ There are some bad things about my looks
- ☐ I look ugly

15.

- ☐ I feel like crying every day
- ☐ I feel like crying many days
- ☐ I feel like crying once in a while



11.

- ☐ I hate myself
- ☐ I do not like myself
- ☐ I like myself

16.

- ☐ Nobody really loves me
- ☐ I am not sure if anybody loves me
- ☐ I am sure that somebody loves me

12.

- ☐ I do not feel alone
- ☐ I feel alone often
- ☐ I feel alone all the time

17.

- ☐ Things bother me all the time
- ☐ Things bother me many times
- ☐ Things bother me once in a while



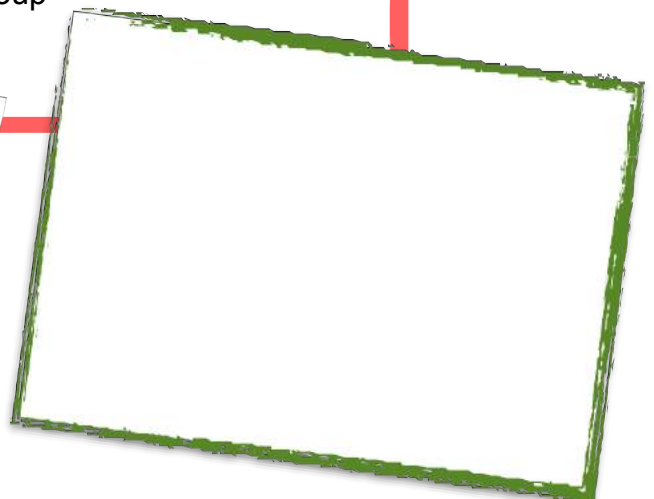
Sometimes we get extremely sad. In the past month did you

		Yes	No
18.	Wish you were dead?	<input type="checkbox"/>	<input type="checkbox"/>
19.	Want to hurt yourself?	<input type="checkbox"/>	<input type="checkbox"/>
20.	Think about killing yourself?	<input type="checkbox"/>	<input type="checkbox"/>
21.	Think of a way to kill yourself?	<input type="checkbox"/>	<input type="checkbox"/>
22.	Try to kill yourself?	<input type="checkbox"/>	<input type="checkbox"/>

23. Are you a member of any youth and/or health organisations, political or activist groups? Tick as many as apply.

- ☐ A youth centre where I can do things like use computers and play sports
- ☐ A youth club or homework club at school
- ☐ Gospel Choir/ Singing Group
- ☐ Sports team
- ☐ Music/ Arts performance group
- ☐ Volunteering
- ☐ Career Development and advice
- ☐ Other/ Ezinye _____
- ☐ No, I am not a member of a group

24. What is the name of your club or group or activity?



WEEKENDS

On weekends, Andiwe spends time with friends and family. Sometimes he travels to visit family members, or stays out late with his friends. Some weekends he stays at home, goes to church and helps out his parents and grandparents. It is not always easy for him to take his medication during Saturdays and Sundays, but he does his best. Think about last weekend – Saturday and Sunday.

25. What did you do last weekend?

- ☐ Stayed at home
- ☐ Visited relatives
- ☐ Played sports with friends
- ☐ Go out with friends
- ☐ Other:

26. How many times did you not take your medication last weekend (Friday night, Saturday and Sunday)? _____ times

27. How many days in the last month did you want to take your ARVs but you couldn't? _____ days

31. Think back to Andiwe, who is struggling to take his ARVs regularly. What advice would you give him to make it easier to take his ARVs?



28. Were there times in the past (when you were younger) that you couldn't take your ARVs?

- ☐ No
- ☐ Yes

29. Were there times in your life when it was easy to take ARVs?

- ☐ No
- ☐ Yes

30. Can you tell us a bit more about what made it easier?



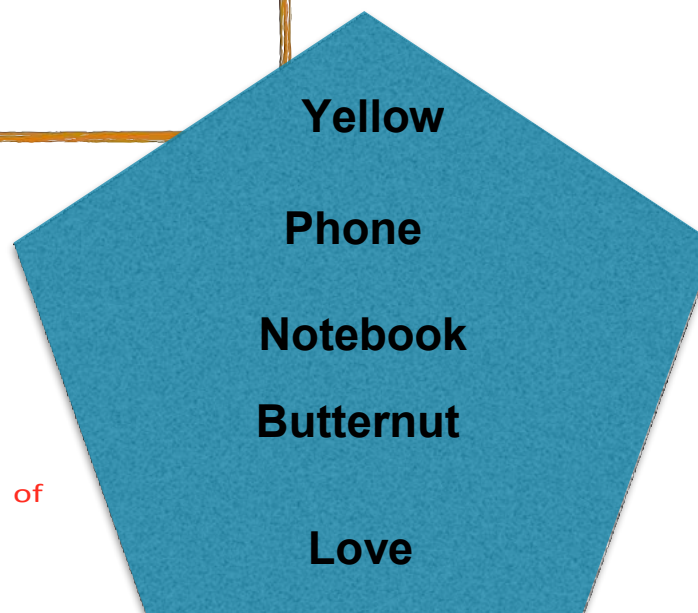
Akhona loves going to school and helping out at home. But sometimes it is difficult for her to sit still, concentrate or finish the work that she has been asked to do by her teacher or parents. Some days, she can get bored or tired or even angry. Could you tell us a bit more about whether you have felt these in the last 6 months?

In the last sixth months...	Not true	Somewhat true	Certainly true
32. I am restless, I cannot stay still for very long.			
33. I am constantly moving around and turning.			
34. I am easily distracted, I find it difficult to concentrate.			
35. I think before I do things.			
36. I finish the work I am doing. My attention is good.			

37. Memory Game

During this questionnaire we are going to play a couple of games. They will last a few minutes but don't take any of this too seriously, just see what you can do.

We will tell you 5 words. Please repeat them as you read them. We will ask you for them in a little bit of time.





38. Would you rather be Beyonce, Justin Beiber, Mandela or Miriam Makeba?

MEMORY GAME: Please write down any of the words that you remember from our word game

1. _____
2. _____
3. _____
4. _____
5. _____

39. How many of the words did you need help remembering?
_____ words

MY FRIENDS AND FREE TIME

Thobeka likes to spend her free time with friends from school, while Sipho likes to play sports with his friends to relax. Sometimes, Thobeka likes to go to a shebeen or a party with her friends. Sipho also goes to the shebeen after soccer games.

1. What do you like to do with your friends in your free time or when you are not in class?

1.a Cellphones

What type of cellphone do you have?	Tick all that apply:
Basic	
Smartphone	
Apple (iPhone)	
Blackberry	
Sim	
I have no cellphone	

What to you use your phone for?	Please tick only one of three:
SMS only	
Whatsapp	
Facebook	

What to you use your phone for?	Please tick only one of three:
Mixit	
Checking email	
Health information	

What to you use your phone for?	Please tick only one of three:
Information about jobs	
information about sex	
Listening to music	

What to you use your phone for?	Please tick only one of two:
HIV information	
Games	



Andiwe likes to go out and he meets friends in a shebeen almost every night. Sizwe does not like going out too much, she prefers to stay home and play with her little sister.

Please tick one box:	A few times a week	Every week	Once in a while	Never
1.b) How often do you go out to a night club, tavern or shebeen?				



Sipho has gotten drunk in the past. Thobeka smokes dagga sometimes. A few of their friends also use drugs: dagga, sniff glue or petrol, use pills, or take other drugs like tik.

2. In the last three months, have you ever drunk enough alcohol or taken enough drugs to make you forget what happened, or you couldn't walk or talk properly?

Never ☐

Often ☐

Sometimes ☐

Every day ☐

Can you tell us how your friends at school and home feel about these things?

3. How many of your friends think that having sex at my age with as many people as possible is a cool thing for a boy or girl to do?

- ☐ None ☐ Some
☐ Most ☐ All

4. How many of your friends think that using condoms is like eating sweets in their wrapper?

- ☐ None ☐ Some
☐ Most ☐ All

5. Do you have friends who have had sex because they were drunk or high on drugs?

- ☐ None ☐ Some
☐ Most ☐ All

6. How many of your friends have been pregnant or gotten someone pregnant?

- ☐ None ☐ Some
☐ Most ☐ All

Teen Confidential

Teenagers have different ideas and feelings about sex. Nobuhle often discusses with her girlfriends their thoughts about relationships, pregnancy and HIV. Sithembele and his friends sometimes chat about other teens he is attracted to and his ideas about sex.



Could you tell us a little bit about what people in your community think about HIV?

7. People in the community think that a person with HIV is disgusting.

- ☐ Never
☐ Sometimes
☐ Most of the time

8. People in my community think that HIV is a punishment from God or from ancestors.

- ☐ Never
☐ Sometimes
☐ Most of the time

9. Do you play or did you play sports at school, like soccer, netball, running, rugby, drum majorettes, or cricket?

- ☐ Yes
☐ I don't/ didn't play any sports at school
☐ I was told not to play sports at school

Other teens and you

Other kids and teenagers can be great. They can also be really mean to each other. Think about how things have been for you in the last 6 months. It would help if you answered all the questions even if you are not certain or it seems silly.

In the past 6 months have other kids:	Not at all	Once	2-3 times	4 or more times
10. Called me names or swore at me.				
11. Tried to get me into trouble with my friends.				
12. Took something without permission or stole things from me.				
13. Made fun of me for some reason.				
14. Made me uncomfortable by standing too close or touching me.				
15. Punched, kicked or beat me up.				
16. Hurt me physically in some way.				
17. Tried to break or damaged something of mine.				
18. Refused to talk to me or made other people not talk to me.				



19. Who's the best dancer?



ACTING AND REACTING



Sometimes, Buliswa and Themba get upset, or just plain angry. They react by doing things that show their anger. Can you tell us about your actions in the past 6 months?

<u>In the past six months...</u>	Not true	Somewhat true	Definitely true
20. I cut or bunk classes, or skip school.			
21. I run away from home.			
22. I drink alcohol to have a good time, without my caregivers knowing or approving.			
23. I don't feel guilty after doing something I shouldn't.			
24. I hang around with kids who get in trouble.			
25. I would rather be with older kids than with kids my own age.			
26. I steal at home			
27. I steal things from places other than home.			
28. I swear or use dirty language.			
29. I lie or cheat.			
30. I get very angry and often lose my temper.			
31. I fight a lot. I can make other people do what I want.			
32. I usually do as I am told.			
33. I try to be nice to other people.			
34. I carry a knife on me for protection.			
35. I carry a gun on me for protection.			
36. I am part of a gang.			
37. I bet money or gamble.			

Special Friends and Relationships

Now we would like to know a bit more about any romantic relationship that you might have or want to have in the future

38. Do you currently have a boyfriend or girlfriend?

☐ No ☐ Yes

38.b Does your boyfriend/girlfriend always want to know where you are?
(If you don't currently have a boyfriend, please answer this question for your most recent relationship in the past year)

☐ Yes ☐ No ☐ Sometimes
☐ I did not have a relationship last year

38.c How often did the following happen in the last year? (tick one box)	Never	Has happened but not in the last year	Sometimes	Often	I did not have a relationship last year
My boyfriend/girlfriend insulted, swore or said something to spite me					
My boyfriend/girlfriend pushed, shoved, grabbed or slapped me					

39. Do you know your boyfriend's or girlfriend's HIV status? ☐ Yes, there are positive ☐ Yes, they are negative ☐ I don't know

40. Have you ever had a romantic or sexual experience (that is more than friends) with someone of the same gender?
☐ No ☐ Yes

41. If you could choose a famous person to be your boyfriend or girlfriend, who would it be?



SHARING AND CARING

Learning about our positive status can be difficult but also valuable. We would like to know more about your experience so we can make it better for other teenagers in the future.

1. How did you learn about your HIV the first time?

- ☐ I learned it myself, nobody told me
- ☐ I was told at the clinic by a doctor or nurse
- ☐ I was told at home by my family
- ☐ I was told at the clinic by my family and a doctor or nurse
- ☐ I overheard people talking about my HIV status
- ☐ I was told by my family and a social worker



3. At which age did someone first tell you you were HIV positive?
_____ years old

2. At which age did you first suspect you were HIV-positive?
_____ years old

4. Did you ever take arvs without knowing what they are for?

☐ Yes ☐ No

5. How did you feel when you learned about your HIV status? Choose as many options as apply:

- ☐ Surprised
- ☐ Upset
- ☐ Relieved
- ☐ I didn't care
- ☐ I don't remember
- ☐ Other: _____



For boys only:

(girls skip to next page)

Remember Lundi? Living with HIV is difficult for him sometimes. Some days Lundi feels ashamed and he struggles to feel good about himself. Could you say how much these things have been true for you in the past year?



6. Lundi is very careful who he tells that he has HIV. Are you careful who you tell?

☐ Never

☐ Sometimes

☐ Most of the time

7. Sometimes Lundi feels that he is not as good as other kids because he has HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

8. Sometimes Lundi feels like he would rather die than live with HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

9. Sometimes Lundi feels like he is a bad person because he has HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

10. Sometimes Lundi feels ashamed that he is HIV-positive. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

11. Sometimes Lundi feels that it is his fault that he is HIV-positive. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

12. Sometimes having HIV makes Lundi feel contaminated and dirty inside. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

If you could say anything to Lundi to make him feel better, what would it be? You can even share with him your own difficulties and how you've overcome them.

Thank you for
answering these
difficult and
private questions.

For girls only:

This is Nosizi. Living with HIV is difficult for her sometimes. Some days Nosizi feels ashamed and she struggles to feel good about herself. Could you say how much these things have been true for you in the past year?



6. Nosizi is very careful who she tells that she has HIV. Are you careful who you tell?

☐ Never

☐ Sometimes

☐ Most of the time

8. Sometimes Nosizi feels like she would rather die than live with HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

10. Sometimes Nosizi feels ashamed that she is HIV-positive. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

12. Sometimes having HIV makes Nosizi feel contaminated and dirty inside. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

7. Sometimes Nosizi feels that she is not as good as other kids because she has HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

9. Sometimes Nosizi feels like she is a bad person because she has HIV. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

11. Sometimes Nosizi feels that it is her fault that she is HIV-positive. Do you ever feel this way?

☐ Never ☐ Sometimes ☐ Most of the time

If you could say anything to Nosizi to make her feel better, what would it be? You can even share with her your own difficulties and how you've overcome them.

Thank you for answering these difficult and private questions.

For boys and girls:

Some teens have parents who were ill for some time before they died. Or their parent is unwell at the moment. It's difficult for teens to handle sometimes. Could you say how much these things have been true for you in the past year?

Because someone in my family is sick or has died...	Not at all	Sometimes	All of the time
13. I've been teased about my family member.			
14. I've been treated badly because of my family member.			
15. People have gossiped about my family behind my back.			
16. I worry about being rejected.			
17. I avoid making new friends.			
18. I feel different and alone.			



19. Which music or sport star are you most similar to?

Each of us has different people who we share secrets with and go to when we need help or support.

20. Please tell us how many people know about your HIV. Choose all answers that apply:

- ☐ Parent or person who cares for me
- ☐ Rest of my family
- ☐ Friends at home
- ☐ Friends at school
- ☐ Teachers/ Principal at school
- ☐ People at church
- ☐ Others who live near my house
- ☐ Nobody knows

We would like to know how much information about your health you share with others in your life.

Please tell us how much you have shared with each person in your life:

21. **My Parent or Caregiver...**

- ☐ I don't have a parent or caregiver
- ☐ They don't know anything about my health, illness or medication
- ☐ They suspect something/ know from other sources
- ☐ They know I am sick but they don't know what I have
- ☐ They know I am taking medication, but not what medication
- ☐ They know about my HIV status
- ☐ I talk to them about my HIV status
- ☐ They know that I am taking ARVs
- ☐ I talk to them about my struggles with taking medicine

22. **My Best Friends...**

- ☐ They don't know anything about my health, illness or medication
- ☐ They suspect something/ know from other sources
- ☐ They know I am sick but they don't know what I have
- ☐ They know I am taking medication, but not what medication
- ☐ They know about my HIV status
- ☐ I talk to them about my HIV status
- ☐ They know that I am taking ARVs
- ☐ I talk to them about my struggles with taking medicine

23. **My Boyfriend/ Girlfriend...**

- ☐ I don't have a boyfriend/ girlfriend
- ☐ They don't know anything about my health, illness or medication
- ☐ They suspect something/ know from other sources
- ☐ They know I am sick but they don't know what I have
- ☐ They know I am taking medication, but not what medication
- ☐ They know about my HIV status
- ☐ I talk to them about my HIV status
- ☐ They know that I am taking ARVs
- ☐ I talk to them about my struggles with taking medicine

24. **My Church Leader or Priest...**

- ☐ I don't go to church
- ☐ They don't know anything about my health, illness or medication
- ☐ They suspect something/ know from other sources
- ☐ They know I am sick but they don't know what I have
- ☐ They know I am taking medication, but not what medication
- ☐ They know about my HIV status
- ☐ I talk to them about my HIV status
- ☐ They know that I am taking ARVs
- ☐ I talk to them about my struggles with taking medicine

25. **Teachers and school principal**

- ☐ I don't go to school
- ☐ They don't know anything about my health, illness or medication
- ☐ They suspect something/ know from other sources
- ☐ They know I am sick but they don't know what I have
- ☐ They know I am taking medication, but not what medication
- ☐ They know about my HIV status
- ☐ I talk to them about my HIV status
- ☐ They know that I am taking ARVs
- ☐ I talk to them about my struggles with taking medicine

Similarities and Differences

Boys:

Remember Lundi? He is having a hard time because of his HIV status. Lundi knows that people often think bad things about HIV-positive people. Sometimes people treat Lundi differently from other kids just because he is HIV-positive. This is not fair. Could you say how much these things have been true for you in the past year?

Girls:

Remember Nosizi? She is having a hard time because of her HIV status. Nosizi knows that people often think bad things about HIV-positive people. Sometimes people treat Nosizi differently from other kids just because she is HIV-positive. This is not fair. Could you say how much these things have been true for you in the past year?

26. I have been hurt by how people reacted when they found out I have HIV.

☐ Never ☐ Sometimes ☐ Most of the time

27. I have stopped spending time with some kids because of their reactions to my HIV status.

☐ Never ☐ Sometimes ☐ Most of the time

28. I have lost friends by telling them I have HIV.

☐ Never ☐ Sometimes ☐ Most of the time

29. I've been teased because of my HIV status.

☐ ☐ ☐

Great Work! Well Done!

Part 8:

Stuff that has been hard



Scary things may also happen in our neighbourhood, community or city.

Buntu has been robbed and had his things stolen.

1. How many times have you had things stolen in the last year?

_____ times.

2. Buntu was attacked and hit when he was out. Have you ever been hit or attacked outside?

☐ Yes, more than a year ago.

☐ Yes, in the last year.

☐ Never

3. Buntu saw someone in his neighbourhood being shot. Have you seen someone being shot?

☐ Yes, more than a year ago.

☐ Yes, in the last year.

☐ Never

4. Lindiwe saw someone being stabbed one evening. Have you seen someone stabbed?

☐ Yes, more than a year ago.

☐ Yes, in the last year.

☐ Never

5. If you could fly to any place in the world, where would it be?

Young people in many parts of the world experience bad treatment and violence by family members, at school, in their communities or at work. This is an important problem for youth in many places, even though many times they don't speak about this.

We would like to ask you about your experiences of violence.

How often has anyone in your family or who is living in your home or someone at school done any of these to you:	Weekly	Monthly	At least once this year	Has happened but not in the last year	Never
6. Used a stick, belt or other hard item to hit you					
7. Slap, punch, hit, pinch or pull your ear/hair so that you were hurt or had marks					
8. Threaten to hurt you.					
9. Say they would call ghosts or evil spirits, or harmful people					
10. Tell you they wished they did not have to look after you or make you feel you are a burden					
11. Make you feel unwelcome in the home.					
12. Say that you would be sent away or kicked out of the house					
13. Call you dumb, lazy, or other names					
14. Insult members of your family that have passed away					
15. Threaten to leave you and never come back.					
16. Threaten to hurt or kill a person or an animal that you care about.					
17. Withhold a meal to punish you.					



Let's take a break!

18. Has anyone made you look at their private parts or wanted to look at yours when you did not want to?

- ☐ Yes, more than a year ago
- ☐ Yes, in the last year
- ☐ Never

19. Has anyone touched your private parts, or made you touch theirs, or tried to have sex with you when you did not want to?

- ☐ Yes, more than a year ago
- ☐ Yes, in the last year
- ☐ Never

20. Has anyone had sex with you when you did not want them to?

- ☐ Yes, more than a year ago
- ☐ Yes, in the last year
- ☐ Never

If it happened in the last three days, please tell me if you would like me to help you access emergency contraception and post-exposure medication.

21. Did you tell anyone if someone touched you when you didn't want it?

- ☐ Yes
- ☐ No

22. Who did you ask for help?

23. How did the person you first told about this react? Choose all answers that apply

- ☐ They believed me and supported me
- ☐ They believed me, but did not care
- ☐ They blamed me for causing it
- ☐ They did not believe me at all
- ☐ They took me to the police, clinic or social worker

Go to next page

Responding to challenges

We'd like to know how you feel about challenges you may face, how you think about difficult problems you have faced, and how you have responded to them. Your answers will help us support other teens who might be facing the same difficulties.

Let's think about this and answer these questions.



	Not at all	A little bit true	Sort of true	Exactly true
24. I can always manage to solve difficult problems if I try hard enough.				
25. I am certain that I can achieve/reach my goals.				
26. I can stay calm because I have ways of solving problems when they come up.				
27. I can handle whatever comes my way.				

28. Remember the words we told you at the end of part 5? Let's see if we can remember them together.

- _____
- _____
- _____
- _____
- _____

29. How many of the words did you need help remembering?

_____ words.

Part 9: Home & Family

We'd like to understand what living in your home is like. Can you please answer the following to the best of your ability? If there's anything you don't understand just ask the research assistant.



1. Do you have a parent, guardian or caregiver staying with you and taking care of you at home?

- ☐ Yes
☐ No

1a. If you don't have anyone that takes care of you at home, who is the main person that supports you? _____.

2. Who is the person that takes care of you at home?

- ☐ Biological mother
☐ Biological father
☐ Grandmother
☐ Grandfather
☐ Aunt
☐ Brother
☐ Sister
☐ Uncle
☐ Other

2a. Who is the person who takes care of you at home? _____.

3. How old is this person? _____ years.

4. How many different caregivers [parents or guardians] have you had? _____.

5. How many children live in the same home as you? _____ How many adults? _____.

6. How many of them are working? _____.

7. Please tick all the things which you can afford at home (choose as many as apply):

- ☐ 3 meals a day
- ☐ School fees
- ☐ Visit to the doctor when you are ill, and all the medicines you need
- ☐ School uniform
- ☐ Enough clothes to keep you warm and dry
- ☐ Toiletries to be able to wash every day
- ☐ School equipment
- ☐ More than one pair of shoes



8. Sometimes kids don't have enough food in their home. How many days in the past 7 days did you not have enough food in your home?
_____ days.

9. Are you or your household receiving any grants?

- ☐ Yes
- ☐ No

10. How many **child support** grants does your household receive? _____

11. How many **foster care** grants does your household receive? _____

12. How many **disability** grants does your household receive? _____

13. How many **pension** grants does your household receive? _____

14. How many **care dependency** grants does your household receive? _____

15. Do you get **food parcels or free meals** at a church or clinic/ hospital at least once a month?

- ☐ Yes
- ☐ No



SOME KIDS GROW FOOD TO EAT OR HAVE ANIMALS TO TAKE CARE OF.

CAN YOU TELL US ABOUT WHAT PLANTS YOU GROW OR WHICH ANIMALS YOU CARE FOR?

16. Do you or your family grow food in a school garden, community garden or at home?

☐ Yes

☐ No

17. What is the name of your favourite soapie?



We would like to find out about experiences that happen to children at home, in the family. These questions may seem strange or hard to answer. Please try to answer them as best you can, this is not a test. There is no right or wrong answer, just say what you remember happened to you. If at any point you feel too uncomfortable to continue you can stop.

If you want to get help about any of the things we ask about, talk to the research assistant. Buntu's family has lots of arguments. Sometimes adults shout at each other and sometimes there is fighting.

18. How many days in the last week were there arguments with adults shouting in your home?_____days.

19. What were these arguments mainly about?

20. How many days in the last week were there arguments with adults hitting each other in your home?_____days.

21. If you could meet Justin Bieber or Beyonce, what would you do?

Part 10: Your past, your present and your future

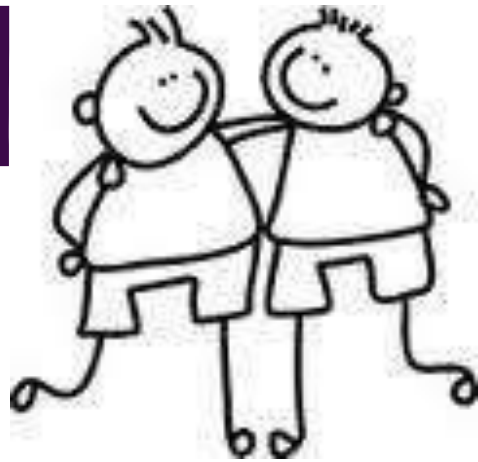
Many kids go through things that are very upsetting or frightening. Now, think about something upsetting or frightening that has happened in your life. Please tell us how often you have felt the following things when you think about what happened.



	Not at all	Some of the time	Most of the time	All of the time
1. Do you get upset when you think about what happened?				
2. When something reminds you of what happened, do you get tense or upset?				
3. Do you go over and over what happened in your mind?				
4. Do you think about (or see pictures in your head of) what happened even when you don't want to?				
5. Do you worry that it might happen again?				
6. Do you try not to think about what happened?				
7. Do you try to stay away from things that remind you of what happened?				
8. Do you feel like it's happening all over again even when it's not?				
9. Do you feel it's hard to have any feelings any more, like you feel numb?				
10. Do you make yourself very busy and do things so you won't think about what happened?				

Other teens and you

Many kids and teenagers feel nervous and anxious at times. Please say which of these is true for you:



11. I worry a lot of the time.

☐ Yes

☐ No

12. I worry about what my carers will say to me.

☐ Yes

☐ No

13. I feel that others do not like the way I do things.

☐ Yes

☐ No

14. It is hard for me to get to sleep at night.

☐ Yes

☐ No

15. I worry about what other people think about me.

☐ Yes

☐ No

16. I feel alone even when there are people with me.

☐ Yes

☐ No

17. I worry about what is going to happen.

☐ Yes

☐ No

18. Other children are happier than I am.

☐ Yes

☐ No

19. I have bad dreams.

☐ Yes

☐ No

20. I wake up scared some of the time.

☐ Yes

☐ No

21. I worry when I go to bed at night.

☐ Yes

☐ No

22. I am nervous.

☐ Yes

☐ No

23. A lot of people are against me.

☐ Yes

☐ No

24. I often worry about something bad happening to me.

☐ Yes

☐ No

Part 11: Let's talk about sex...



The following section has a lot of personal questions in it. Remember that everything is confidential, no one will know what you have said, and when you share your experiences with us we will use it to help healthcare workers and the government understand the needs of youth such as yourself better. Your answers will help us find out how to make health services better for youth.

Please answer the following questions to the best of your ability. For each sentence, please tell us if you think it is 'true', 'false', or if you 'don't know'.

	True	False	I don't know
1. If you are HIV-positive, you cannot become infected with HIV again.			
2. HIV cannot be passed from an HIV-positive mother to her unborn child.			
3. If an HIV positive adolescent has sex, they need to use a condom.			
4. People living with HIV who are using the injection, pills or implant to prevent pregnancy do not need to use condoms.			

We know that sex can mean a lot of things. Girls can have sex with boys, girls with girls, or boys with boys. Sometimes we choose to kiss, others to have sex. Sometimes we feel that we must do it for different reasons. Remember that your name is not recorded anywhere on this questionnaire.

Let's talk about sex.

First time experiences

For **boys** only:

(girls skip to question 10)

5. How old were you when you first kissed someone with tongue?

____ years old

☐ never

6. How old were you when you touched someone else's private parts because you wanted to or someone else touched your private parts because you wanted them to?

____ years old

☐ never

7. How old were you when you first had sex?

____ years old

☐ never



8. How old were you when someone first used their mouth to kiss your private parts (penis)?

____ years old

☐ never

9. How old were you when you had sex in your bum or put your penis in someone else's bum?

____ years old

☐ never

For girls only:

10. How old were you when you first kissed someone with tongue?

____ years old

☐ never

11. How old were you when you touched someone else's private parts because you wanted to or someone else touched your private parts because you wanted them to?

____ years old

☐ never

12. How old were you when you first had sex?

____ years old

☐ never

13. How old were you when someone first used their mouth to kiss your private parts (vagina)?

____ years old

☐ never

14. How old were you when you first had sex in your bum?

____ years old

☐ never

15. Are you or your partner using anything to prevent getting pregnant?

☐ Yes ☐ No



If you are not sexually active and have never had sex please skip to section 12.

16. How many people have you had sex with in the past year?



17. Think about the oldest person you had sex with in the last year. Was he or she more than 5 years older than you?

☐ Yes ☐ No

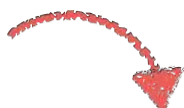
Tick one box	Never	Sometimes	Always
18. In the last year, how often did you use condoms for the whole time that you were having sex?			

19. Please tick all that apply	YES	NO
In the last year, did you or your partner use female condoms during sex?		
In the last year, did you or your partner use the birth control pill?		
In the last year, did you or your partner use the injection?		
In the last year, did you or your partner use the implant?		
In the last year, did you or your partner use the pulling out method during sex?		
In the last year, did you or your partner use an IUD?		
In the last year, were you or your partner sterilised?		
In the last year, were you or your partner having sex only with each other?		
In the last year, were you or your partner having sex only during certain times of the month?		
Did you use a condom the last time you had sex?		

Sometimes, people give or receive presents from a person because they are having sex with him or her.

Have you had any of these presents given to you because you had sex with someone OR did you decide to have sex with someone in exchange for these gifts?

- ☐ Money
- ☐ Buying you clothes
- ☐ Hair extensions or weave at the salon
- ☐ Drinks when you are out at a shebeen or club
- ☐ Cosmetics and jewellery
- ☐ Airtime
- ☐ Cellphone
- ☐ A place to stay
- ☐ Transportation: bus tickets, lifts in a car or taxi
- ☐ Better marks at school
- ☐ School fees
- ☐ Food
- ☐ Anything else
- ☐ None of the above



20. Has this happened in the last 12 months?

- ☐ Yes
- ☐ No

21. In the last year, how many times have you had sex when you were drunk or smoking dagga or any other drugs?

22. How many times have you been pregnant **or** made someone pregnant?

23. Have you been pregnant or made someone pregnant since we last spoke to you?

- ☐ Yes ☐ No

24. How many children do you have?

25. Now think back to the first time you had sex with someone. What was it like for you?
Choose as many answers as apply:

- ☐ I was scared
- ☐ I enjoyed it
- ☐ I felt shy
- ☐ It was painful
- ☐ It was something I wanted

26. The first time you had sex did you or your partner use any of the following?

- ☐ Nothing
- ☐ Male condom
- ☐ Female condom
- ☐ Birth control pill
- ☐ Injection
- ☐ Pulling out
- ☐ Having sex with only one person
- ☐ Intrauterine Device (IUD - loop)
- ☐ Implant
- ☐ Sterilisation
- ☐ Having sex only during certain times of the month

27. People use contraception for different reasons. Some want to please their partner, others want to avoid getting infected by a STI or HIV.
Why did you use contraception in the last year?

- ☐ I don't know
- ☐ To prevent pregnancy
- ☐ To prevent passing on my HIV to my partner
- ☐ To prevent getting infected with STIs
- ☐ To prevent getting re-infected by HIV
- ☐ I did not use contraception in the last year

28. Where did you get contraception in the last year?

- ☐ Shop
- ☐ Pharmacy
- ☐ Clinic/ Hospital
- ☐ HIV/AIDS treatment centre
- ☐ Other health centre
- ☐ Friends
- ☐ Shebeen
- ☐ I did not get contraception

For girls only: (boys skip to q.49)

Noxolo got pregnant when she was 16. She was not sure when it happened or how, but she decided to keep the baby with her grandmother's help. Nomvula got pregnant at 15, but decided that she could not have the baby. Some friends told her to take some herbs, other friends suggested she go to the hospital to end the pregnancy.

We'd like to know a bit more about **the last time** you were pregnant:

29. How old were you when you were last pregnant?

_____ years old

☐ I have never been pregnant

30. If you have ever been pregnant, please tell us a bit more about your last pregnancy? Choose all that apply:

- a. I was not planning to get pregnant
- b. I did not want to get pregnant
- c. I wanted to get pregnant
- d. I was planning to get pregnant



31. When did you find out you were HIV-positive?

- ☐ I am not HIV-positive
- ☐ Before I got pregnant
- ☐ While I was 0-3 months pregnant (first trimester)
- ☐ While I was 4-6 months pregnant (second trimester)
- ☐ While I was 7-9 months pregnant (third trimester)
- ☐ I don't remember, but while I was pregnant
- ☐ During or after birth

32. Can we ask about your first pregnancy? When did you start drinking antiretroviral pills (ARVs)?

- ☐ During pregnancy
- ☐ During labour
- ☐ After giving birth to my baby
- ☐ I did not start ART

33. At which clinic were you given your antiretroviral (ARV) treatment for the first time?

- ☐ ANC clinic - clinic where I saw a nurse during my pregnancy
- ☐ Labour ward - while I was waiting to give birth to my baby
- ☐ ARV clinic - the clinic where all other people get their ARVs
- ☐ I did not start ART (If you ticked this go to question 40)

34. Did you:

- ☐ stay at that clinic until you stopped breastfeeding
- ☐ or pick up your antiretroviral (HIV/AIDS) pills/ medications somewhere else

35. How long did the nurse or doctor tell you that you should drink antiretroviral (HIV/AIDS) pills for?

- ☐ To drink while I was pregnant, in labour or breastfeeding
- ☐ To keep drinking for the rest of my life

36. When you were pregnant or breastfeeding, did you ever stop taking your medication?

- ☐ Yes, I stopped completely
- ☐ Yes, I stopped and restarted
- ☐ No, I did not stop

37. What side-effects did these pills give you while you were pregnant or breastfeeding?

- ☐ None
- ☐ Nausea
- ☐ Vomiting
- ☐ Diarrhea
- ☐ Headaches
- ☐ Bad dreams/problems sleeping
- ☐ Other _____

38. How long did you take antiretrovirals (ARVs) for?

39. Where did you usually pick up your antiretroviral (HIV/AIDS) pills/medications?

- ☐ Hospital
- ☐ Clinic
- ☐ Other _____

40. What happened the last time you were pregnant?

- ☐ I am still pregnant
- ☐ I have a baby
- ☐ The fetus did not live
- ☐ I took some herbs to stop being pregnant
- ☐ I went to the hospital to stop being pregnant
- ☐ I went to a doctor's office/practice to stop being pregnant

41. How did you give birth to your (youngest) baby?

- ☐ At home
- ☐ In the hospital/clinic
- ☐ I had a caesarean (c-section)

42. Did/Does your baby take any medication, for example a syrup or tablet?

- ☐ Yes ☐ No

43. Do you know the name of this medication? _____

44. How are you feeding/ did you feed your (youngest) child in the first 6 months?

- ☐ Breastfeeding mixed with some baby formula
- ☐ Baby formula only
- ☐ Breastfeeding only

45. Now, we would like to know about all of your children. If you only have one, that is ok. Are any of your children HIV positive?

- ☐ Yes
- ☐ No
- ☐ I don't know

46. Sometimes nurses, or doctors, offer young mothers methods to help them decide when and if they want to have another baby. Which of the following were you recommended as the end of your pregnancy, during birth or just after giving birth?

- ☐ Condoms ☐ IUD ☐ Implant ☐ Injection
- ☐ Pill ☐ Sterilization ☐ None of the above

47. Did you choose to use anything to help you decide when and if you want to have another baby?

- ☐ Condoms ☐ IUD ☐ Implant ☐ Injection
- ☐ Pill ☐ Sterilization ☐ None of the above

48. Is there anything you'd like to say to support other young mother's like yourself?

For boys only:



Jongile has had a girlfriend for a long time. His girlfriend got pregnant last year. Jongile decided to support the child. Jongile's friend Fikile likes lots of girls and has had sex with many of them. Some of these girls have told Fikile they got pregnant, but he is not sure what happened with the baby. What about you?

49. How old were you when you **last** got someone pregnant?

_____ years old



I have never gotten someone pregnant

50. Please tell us a bit more about **the last time** you got one of your girlfriends pregnant. Choose all that apply:

- a. I was not planning to get my girlfriend pregnant
- b. I did not want to get my girlfriend pregnant
- c. I wanted to get my girlfriend pregnant
- d. I was planning to get my girlfriend pregnant

51. What happened **the last time** you got your girlfriend pregnant? Choose only one answer:

- a. I have a baby
- b. The fetus did not live
- c. My girlfriend took some herbs to stop being pregnant
- d. My girlfriend went to the hospital or a doctor's office to stop being pregnant.
- e. I don't know what happened
- f. Other: _____

52. Now, we would like to know about **all of your children**. If you only have one child that is ok. Are any of your children HIV positive?

- a. Yes
- b. No
- c. I don't know

For boys and girls:

Please answer these questions, whether you have had sex or not.

Remember that all your answers will kept private and that your name is not attached to this questionnaire.



53. Next time you have sex, do you plan to use a condom?

- ☐ Definitely yes
- ☐ Probably yes
- ☐ Not sure
- ☐ Probably no
- ☐ Definitely no

Khwezi uses condoms correctly but only with some girlfriends. Babalwa does not like condoms because she is embarrassed to ask her boyfriend to use them.

What about you? Can we talk about condoms? Thank you!

	Never true for me	Sometimes true for me	Always true for me	I have never used a condom
54. I can use a condom and make sure it's put on the whole way down every time I have sex.				
55. If the guy or girl I'm with refuses to use a condom, I can say no to sex				
56. I would be too embarrassed to get condoms at the local shop				
57. Condoms make sex less good.				
58. If I use a condom when I have sex this will make my partner think that I do not trust them or I am cheating on them.				
59. My religion does not support using condoms				
60. Condoms are too expensive to buy for every time I have sex				
61. Using contraception is my partner's problem and responsibility, not mine.				

For boys only:

Xolani is 18. He was invited to initiation school when he was 17. His friend Zweli decided to get circumcised at hospital when he was 18. What about you?

62. How did you get circumcised?

- ☐ I have not been circumcised yet
- ☐ I was initiated through a traditional ceremony
- ☐ I went to a clinic or hospital

For boys and girls:

Getting and using contraception

63. What are you doing to prevent getting pregnant? Choose as many answers as apply:

- ☐ Nothing
- ☐ Male condom
- ☐ Female condom
- ☐ Birth control pill
- ☐ Injection
- ☐ Pulling out
- ☐ Having sex with only one person
- ☐ Intrauterine Device (IUD-loop)
- ☐ Implant
- ☐ Sterilisation
- ☐ Not having sex at all
- ☐ Only having sex during certain times of the month
- ☐ Other: _____

6.4 Which method to prevent pregnancy do you think is best for you? Choose only one answer.

- ☐ Nothing
- ☐ Male condom
- ☐ Female condom
- ☐ Birth control pill
- ☐ Injection
- ☐ Pulling out
- ☐ Having sex with only one person
- ☐ Intrauterine Device (IUD-loop)
- ☐ Implant
- ☐ Sterilisation
- ☐ Not having sex at all
- ☐ Only having sex during certain times of the month
- ☐ Other: _____

65. If you were going to use something to prevent pregnancy, where would you feel most comfortable getting it? Choose only one answer.

- ☐ Shop
- ☐ Pharmacy/ drug shop
- ☐ Clinic/ hospital
- ☐ HIV/AIDS treatment centre
- ☐ Other health centre
- ☐ Friends
- ☐ School
- ☐ Shebeen

Andisiwe went to the clinic to get condoms last week and it was terrible. But Siphesihle said her clinic is fine and they are really nice!

What is it like for you to get condoms or the pill or other ways of preventing pregnancy?



66. What has someone at the clinic offered you to prevent pregnancy? Choose as many answers as apply

- | | |
|---|--|
| <input type="checkbox"/> Nothing | <input type="checkbox"/> Implant |
| <input type="checkbox"/> Male condom | <input type="checkbox"/> Intrauterine Device (IUD) |
| <input type="checkbox"/> Female condom | <input type="checkbox"/> Sterilisation |
| <input type="checkbox"/> Birth control pill | <input type="checkbox"/> Other |
| <input type="checkbox"/> Injection | |

67. Think back to the first time you or your partner used a method to prevent pregnancy (pill, injection, IUD, implant, condom or sterilisation). How did you first start using it? Choose only one answer.

- ☐ I asked the nurse for the method to prevent pregnancy that I or my partner wanted
- ☐ The nurse/ doctor offered me some choices and I chose one method for me or my partner
- ☐ The nurse/ doctor told me which method my partner or I should start
- ☐ The nurse gave me something without telling me what it was
- ☐ My partner or I are not using any contraception
- ☐ Other

68. How did you feel when you went to the clinic to get methods to prevent pregnancy in the last six months? Choose as many answers as apply:

- ☐ Welcomed
- ☐ Ashamed
- ☐ Respected
- ☐ Worried
- ☐ Listened to carefully and professionally

- ☐ Scared
- ☐ Scolded
- ☐ Annoyed
- ☐ Bored
- ☐ I have not been to the clinic to get contraception

69. Did anyone at the clinic ever tell you about the side effects of contraception?

- ☐ Yes
- ☐ No

70. Have you ever used contraception before?

- ☐ No
- ☐ Yes

70a. Have you experienced any of these side effects from contraception?

- | | |
|--|--|
| <input type="checkbox"/> Nausea | <input type="checkbox"/> Weight gain |
| <input type="checkbox"/> Bloating | <input type="checkbox"/> Depression or feeling low |
| <input type="checkbox"/> Headaches | <input type="checkbox"/> Sore dry or itchy vagina |
| <input type="checkbox"/> Sore breasts | <input type="checkbox"/> Not wanting to have sex |
| <input type="checkbox"/> Painful periods | |

71. Were you told to return for your next appointment for contraception at an exact time?

- ☐ Yes
- ☐ No
- ☐ I have never had contraception appointments

Every two months, Neliswa goes to the clinic to get the injection. One day she misses her appointment because she is studying for an exam.

72. If you miss your appointment (return date), what will happen?

- ☐ I will not be able to reschedule another appointment at that clinic
- ☐ I will be able to reschedule another appointment at that clinic. There will be no bad consequences
- ☐ I will reschedule another appointment but there will be bad consequences (the nurse will scold me)
- ☐ I have never had clinic appointments

73. How many children would you like to have?

_____ children.



Part 12: Needs and Support



Remember the difficult thing that we were thinking about before? Please think about it again.

Please tell us if you have felt this way 'not at all', 'some of the time', 'most of the time' or 'all the time' **in this past month**.

In the past month...	Not at all	Some of the time	Most of the time	All of the time
1. Do you get physically upset when something reminds you of what happened - like getting sweaty, shaking, your heart pounding, getting short of breath, or stomach aches?				
2. Do you have trouble falling asleep or staying asleep?				
3. Is it hard for you to pay attention - like listening to your teacher, or doing your work - because you can't concentrate well?				
4. Do you get jumpy or startle easily?				
5. Do you get annoyed (grouchy) or irritable (kind of angry) really easily?				
6. Do you get angry or upset at people for no reason?				
7. Do you feel it's hard to have fun doing things?				
8. Do you ever feel it's hard to feel happy?				
9. Do you feel alone even when other people are around?				

Sometimes the people we live with, our parents, grandparents, siblings or aunts/ uncles, they get sick and they need our help and support to get better. At other times, we need their help to get healthy again.

In this section, we will ask you about your parents, the person or people that take care of you at home.

a. Has your parent or person who cares for you been sick for more than two weeks in the last year?

i. ~~Yes~~

ii. No

b. Could we ask you about some of the symptoms of sickness your parent or person who cares for you the most have had when they are sick? Choose all the symptoms that they have.

- ☐ Lost weight and become very thin
- ☐ Diabetes
- ☐ Asthma
- ☐ Any of: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry
- ☐ Emotional problems
- ☐ Eyes yellow, and fever, or itching
- ☐ Shingles or a rash on the skin
- ☐ High blood pressure
- ☐ Sores on body
- ☐ Ulcers, white patches on mouth, or problems swallowing food
- ☐ Do they drink alcohol too much?
- ☐ Cancer
- ☐ Trouble breathing, or a cough for more than two days with fever
- ☐ TB in the past 5 years
- ☐ Arthritis
- ☐ Have they been bewitched?
- ☐ Diarrhoea or a runny tummy for more than two days
- ☐ HIV
- ☐ Other

c. Is your caregiver taking ARVs?

- ☐ Yes
- ☐ Yes, but they don't take them everyday
- ☐ No
- ☐ I don't know

d. Do you take ARVs together?

- ☐ Yes
- ☐ No
- ☐ Sometimes

Confidential Stories

Langa and Sebenzile's parents both passed away in the last three years. They don't know why their mom passed away, but they know their dad had TB and many headaches.

We would like to ask you about your mom and dad. Thank you for helping us with this. These questions are totally confidential.

e. Is your mom alive?

- i. Yes
- ii. Yes, but she doesn't live with me
- iii. I don't know
- iv. No

f. How old were you when your mom passed away? _____ years old.

g. Do you know what happened?

- i. Road accident
- ii. Illness
- iii. Attacked
- iv. I don't know
- v. Something else

16a. Could you tell us what else? _____

h. Could we ask you about some of the symptoms of sickness your mother had before she died? Please choose all the symptoms she had:

- | | |
|---|--|
| <input type="checkbox"/> Lost weight and become very thin | <input type="checkbox"/> Ulcers, white patches on mouth, or problems swallowing food |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Did she drink alcohol too much? |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Cancer |
| <input type="checkbox"/> Any of: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry | <input type="checkbox"/> Trouble breathing, or a cough for more than two days with fever |
| <input type="checkbox"/> Emotional problems | <input type="checkbox"/> TB in the past 5 years |
| <input type="checkbox"/> Eyes yellow, and fever, or itching | <input type="checkbox"/> Arthritis |
| <input type="checkbox"/> Shingles or a rash on the skin | <input type="checkbox"/> Was she bewitched? |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Diarrhoea or a runny tummy for more than two days |
| <input type="checkbox"/> Sores on body | <input type="checkbox"/> HIV |
| | <input type="checkbox"/> Other |

i. Was your mother taking ARVs?

- ☐ Yes
- ☐ No
- ☐ I don't know



j. Is your dad alive?

- i. Yes
- ii. Yes, but he doesn't live with me
- iii. I don't know
- iv. No

k. How old were you when your dad passed away? _____ years old.

l. Do you know what happened?

- i. Road accident
- ii. Illness
- iii. Attacked
- iv. I don't know
- v. Something else

21a. Could you tell us what else? _____

m. Could we ask you about some of the symptoms of sickness your father had before he died? Please choose all the symptoms he had:

- | | |
|---|--|
| <input type="checkbox"/> Lost weight and become very thin | <input type="checkbox"/> Ulcers, white patches on mouth, or problems swallowing food |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Did she drink alcohol too much? |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Cancer |
| <input type="checkbox"/> Any of: very pale, hair changing colour, legs swelling up, burning feelings in feet, skin very dry | <input type="checkbox"/> Trouble breathing, or a cough for more than two days with fever |
| <input type="checkbox"/> Emotional problems | <input type="checkbox"/> TB in the past 5 years |
| <input type="checkbox"/> Eyes yellow, and fever, or itching | <input type="checkbox"/> Arthritis |
| <input type="checkbox"/> Shingles or a rash on the skin | <input type="checkbox"/> Was she bewitched? |
| <input type="checkbox"/> High blood pressure | <input type="checkbox"/> Diarrhoea or a runny tummy for more than two days |
| <input type="checkbox"/> Sores on body | <input type="checkbox"/> HIV |
| | <input type="checkbox"/> Other |

n. Was your father taking ARVs?

- ☐ Yes
- ☐ No
- ☐ I don't know

Thank you for answering these difficult questions. Would you like to draw or write something for your parents?



People sometimes look to others for friendship and support.

How often do you have:



o. ...someone you can count on to listen when you need to talk?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

p. ...someone to give you good advice about a crisis?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

q. ...someone to share you most private worries and fears with?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

r. ...someone to turn to for suggestions about how to deal with personal problems?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

s. ...someone to help you if you were confined to bed?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

t. ...someone to take you to the doctor if you needed it?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

u. ...someone to prepare your meals if you were not well?

<input type="checkbox"/>	Never
<input type="checkbox"/>	Sometimes
<input type="checkbox"/>	Always

31. Who is the person that supports you the most with advice, help to solve problems or making sure you are ok when you are sick?

- ☐ Parent or other family member
- ☐ Friends
- ☐ Teachers
- ☐ Healthcare provider (doctor, nurse, or village/ community health worker)
- ☐ Social worker
- ☐ Someone from church
- ☐ Other: _____

Your relationship with your family

Please answer these questions about stuff that happens at home in the past two months - just choose the best answer.

How have things at home been in the past two months?



	Never	Rarely	Sometimes	Often	Always
32. Your parent or caregiver says you have done something well					
33. Your parent or caregiver compliments you when you have done something well					
34. Your parent or caregiver praises you for behaving well					
35. Your parent or caregiver tells you that they like it when you help out around the house.					
36. Your parent or caregiver rewards or gives something extra to you for behaving well					

	Never	Rarely	Sometimes	Often	Always
37. Your parent or caregiver hugs you or kisses you when you have done something well					
38. You go out without a set time to be home					
39. You stay out in the evening past the time you are supposed to be at home					
40. You fail to leave a note or let your parent or caregiver know where you are going					
41. Your parent or caregiver does not know who you are friends with					
42. You go out after dark without an adult with you					
43. Your parent or caregiver gets so busy that they forget where you are and what you are doing					
44. You stay out later than you are supposed to and your caregiver doesn't know it					
45. Your parent or caregiver leaves the house and doesn't tell you where they are going					
46. You come home from school more than an hour past the time your parent or caregiver expects you to be home					
47. You are at home without an adult with you					



We'd like to know more about how you feel talking to your parents or caregivers. Could you tell us about how much you've shared with your caregiver **in the past two months?**

	Strongly disagree	Disagree	Don't know	Agree	Strongly agree
48. I have no fear in discussing problems with my parent or caregiver					
49. I am comfortable talking about sex or medication with my parents or caregivers					
50. I am relaxed with my parent or caregiver, I can talk to them openly					
51. When I talk to my parent or caregiver, I am anxious and careful about what I say					
52. I have no fear telling my parent or caregivers exactly how I feel					



Part 13: Tell us what you think!

Thank you for taking part in our research project.

We would appreciate it if you could take an extra few minutes to tell us your thoughts about our research. We will use your answers to improve our future work.



What did you think about taking part in this research project? Choose as many answers as apply:

- ☐ It felt good to be open and honest about myself
- ☐ It helped me to share the bad things I've been through
- ☐ It made me feel distressed (sad, upset or angry)
- ☐ This research will help others
- ☐ The questions were too private/ personal
- ☐ I learnt stuff I didn't know before
- ☐ It was hard to understand the questions
- ☐ I know my answers won't be told to other people

We'd like to come back and speak to you again next year. Is that okay?

Thank you very much for your time. Please pass this questionnaire back to the research assistant so they can give you your certificate.
