

APPENDIX 5: SWAZILAND PLWA INTERVIEW

Physicians for Human Rights
Swaziland PLWA Interview
5.6.05

INSTRUCTIONS:

READ if in italics

DO NOT READ if in plain text

1. **Qualitative Interviewer code** _____ (1, 2, 3, ...) ICD2

OBTAIN CONSENT:

Introduction and Purpose

- *This is a study about HIV/AIDS prevention, testing and treatment and is being conducted by Physicians for Human Rights and Women and Law in Southern Africa Research Trust, two non-governmental organizations.*
- *We are conducting a survey to help understand more about HIV and AIDS among men and women in Swaziland.*
- *You have been selected because you belong to an HIV/AIDS support group/ peer education group/ are a patient at an ARV treatment center.*
- *Your participation in the research is entirely voluntary: you can decide not to take part at all.*
- *There is no payment for participating in the interview.*

Study procedures

- *The questions will take about an hour.*
- *We will need some privacy for our conversation because some of the questions may be sensitive. If you do not understand a question, please ask me to explain it to you.*
- *You can refuse to answer any question, and are free to stop the interview at any point.*

Confidentiality

- *None of what you say will be shared with anyone else.*
- *I will not write down your name or any identifying information anywhere in my notes.*

Do you have any questions for me?

Do you agree to take part in the study?

2. Consent provided: No _____ 0 CNST
Yes _____ 1

DEMOGRAPHICS

3a. Sex

Male _____ 0 FEMALE
Female _____ 1

3b. *Where do you live?* [Circle ALL THAT APPLY]

Urban _____ 1 LIVE
Peri-Urban _____ 2
Company Town _____ 3
Rural _____ 4

3c. *How old are you now?* _____ (years) AGEN

3d. Are you **currently** married? No _____ 0 [GO TO 3f] MARR
Yes _____ 1 [GO TO 3e]
NR _____ 99 [GO TO 3f]

3e. *Is there more than one wife in your marriage?* No [one husband, one wife] _____ 0 MARR
Yes [one husband, more than one wife] _____ 1
NR _____ 99

3f. Are you **currently** living with a sexual partner? No _____ 0 SXPT
 Yes _____ 1
 NR _____ 99

3g. Have you **ever** been widowed? No _____ 0 WIDW
 Yes _____ 1
 NR _____ 99

3h. How many children or other people depend on you for support? _____ (number) NDEP

3i. What is the highest year you completed in school? Not finished primary _____ 1 SCH
 Finished primary _____ 2
 Junior certificate _____ 3
 High school (form 5) _____ 4
 Tertiary _____ 6

4. How do you believe you became infected with HIV? From caring for HIV+ person _____ 1 HOW
 Unprotected sex _____ 2
 Other _____ 3 (specify) _____

What factors, if any, made it difficult to prevent HIV infection? DIFFICULTIES_PREVENT

Tell me about your experience finding out you were HIV positive. EXPERIENCES_HIV+

5a. Where were you tested? Public Hospital _____ 1 WHERE
 Private Hospital _____ 2
 TB Clinic _____ 3
 Antenatal Clinic _____ 4
 NGO _____ 6
 VCT _____ 8
 Other _____ 9 (specify) _____
 DK _____ 88

5b. Were you tested voluntarily (did you feel you had the option to refuse the test)? No _____ 0 REFUS
 Yes _____ 1
 DK _____ 88

5c. What were the most important reasons that made **you** decide to have an HIV test? Wanted to know status _____ 1 FACT
 Was sick _____ 2
 Doctor/nurse recommended _____ 3
 PMTCT recommended _____ 4
 Worried about a sexual contact _____ 5
 Knew treatment (ARVs) was available _____ 6
 Partner/friend/family advised _____ 7
 Church advised _____ 8
 TV/Radio/billboard messages _____ 9
 Job required _____ 10
 Other (specify) _____ 11
 DK _____ 88

5d. Did you receive counseling **before** being tested for HIV? No _____ 0 COUNB

Yes _____ 1
 DK _____ 88

5e. Did you receive counseling **after** the HIV test? No _____ 0 COUNA
 Yes _____ 1
 DK _____ 88

Were your counseling experiences adequate (confidential, informative, respectful, etc.)? Please elaborate.
 COUNSELING_EXPERIENCES

5f. Did anyone tell you how to get access to AIDS treatment? No _____ 0 TRAC
 Yes _____ 1
 DK _____ 88

5g. Do you regret getting tested? No _____ 0 REGR
 Yes _____ 1
 DK _____ 88

Why or why not? REGRETS_DETAIL

5h. Do you think barriers to testing differ for men and women? No _____ 0 BARR
 Yes _____ 1
 DK _____ 88

Can you tell me more? BARRIERS_DETAIL

5i. Is access to testing a problem in Swaziland? No _____ 0 ACCES
 Yes _____ 1
 DK _____ 88

Why or why not? ACCESS_DETAIL

Do you think the following would increase or decrease testing in Swaziland? TESTS

	Increase	Decrease	No Change
5j. Introducing routine testing which means testing everyone for HIV as part of routine clinic or hospital visit, unless they say no?	1	2	3
5k. Increasing mobile testing which means testing from a vehicle that moves around to different places close to where people live or work, such as markets or community centers, and gives the test results on the same day?	1	2	3
5l. Introducing couples testing which means testing men and women partners together for HIV and giving them their results together?	1	2	3

What can be done to encourage HIV testing in Swaziland? ENCOURAGE

6a. Have you told anyone your HIV status?

No _____ 0 DISCL
Yes _____ 1
NR _____ 99

Who? TOLDWHO

6b. Did anyone tell your status to other people without your permission?

No _____ 0 DISCL2
Yes _____ 1
DK _____ 88

Please tell me more. DISCLOSURE_DETAIL

6c. What were the consequences of telling others your HIV status? [Circle ALL THAT APPLY] CONSEQ

Were any of the following a consequence?	No	Yes	NR
c. Violence (such as being hit, kicked or forced to have sex, or hurt in any way)	0	1	99
d. Shame	0	1	99
e. Poor treatment	0	1	99
f. Losing a job	0	1	99
g. Losing friend(s)	0	1	99
h. Convincing others to get tested	0	1	99
i. Getting support from your family	0	1	99
j. Emotional relief	0	1	99

Were there other consequences of telling others your HIV status?

Please tell me more. CONSEQ_DETAIL

7. Have you experienced discrimination (unequal treatment) or stigma because of your HIV status?

No _____ 0 DISCR
Yes _____ 1
DK _____ 88

If so, please tell me more. DISCRIM_DETAIL

7a. Have there been changes in your relationships, family, work environment, or friendships because of your HIV status?

No _____ 0 CHANG1
Yes _____ 1
DK _____ 88

If so, please tell me more. CHANGES_RELATIONSHIPS

7b. Have you experienced poor treatment at work, school, hospitals or in other public places because of your HIV status?

No _____ 0 CHANG2
Yes _____ 1
DK _____ 88

If so, please tell me more. CHANGES_POORTX

7c. Do you think that HIV-related stigma or poor treatment differs for HIV-positive women and men in Swaziland?

No _____ 0 STIGG
Yes _____ 1
DK _____ 88

If yes, how so? STIGMABYGENDER_DETAIL

What do you think can be done to reduce stigma surrounding HIV in your community and in Swaziland? REDUCE_STIGMA

8a. Are you getting care or treatment for HIV/AIDS?

No _____ 0 [GO TO 8c] TREAT
Yes _____ 1 [GO TO 8b]

8b. What kind of care or treatment are you getting? [Circle ALL THAT APPLY]

Traditional healer _____ 1 TREATT
Clinic/ hospital care _____ 2
ARVs _____ 3 [SKIP to 8c]
Meds for HIV/AIDS-related conditions _____ 4
Nutritional foods/supplements _____ 5
Home-based care _____ 6
Other _____ 7 (specify) _____

8c. Why are you not receiving ARVs? [Circle ALL THAT APPLY]

Lack of information _____ 1 NOARV
Lack of money for transport _____ 2
Lack of time _____ 3
Have not disclosed _____ 4
Ashamed to be seen at treatment site _____ 5
Treatment site too far away _____ 6
Lack of food _____ 7
Concern about quality/effects of ARVs _____ 8
Other _____ 9 (specify) _____

If you are receiving ARVs, what have been your experiences with treatment? ARV_EXPERIENCES

[Probes: process, treatment literacy (what understand), adherence (staying with the regimen)]

How do people get access to antiretroviral treatment (ARVs) in Swaziland? ARV_ACCESS
[Probes: process, availability, information, travel/costs/payment issues]

8d. Is access to care or treatment different for HIV-positive men and women?

No _____ 0 CAREG
Yes _____ 1
DK _____ 88

Why or why not? ACCESSBYGENDER_DETAIL

9. What are some of the main things that put women at risk for HIV in Swaziland? MAINRISKSWOMEN
[Probe cultural practices, such as polygamy, wife inheritance, other mourning customs, etc.]

9a. Is violence against women (forced sex, physical abuse) a big problem in your community?

No _____ 0 VIOLE
Yes _____ 1
DK _____ 88

If so, please tell me more. VIOLENCE_DETAIL

9b. Do women not being able to have property in their names leave them without a secure place to live or farm and put them at risk for HIV?

No _____ 0 NOPRO
Yes _____ 1
DK _____ 88

9c. Does lack of income put women at risk of HIV?

No _____ 0 NOINC
Yes _____ 1
DK _____ 88

What are other reasons women are at risk for HIV? OTHERRISKSWOMEN

What can be done to help women protect themselves against becoming infected with HIV? HELPWOMENPROTECT

FOR FEMALE PARTICIPANTS ONLY:

In order to understand more about how HIV is spread in Swaziland, we need to know more about your personal experiences. What you tell me will be completely confidential and may help make changes to policies and programs so other women will be safer and less at risk for HIV. I really appreciate your honesty and willingness to share your experiences.

9d. Do you feel like you have control over the decision of when to have sex? No ___0 IFSEX
Yes ___1
DK ___88

9e. Who usually decides whether or not to have sex in your relationship(s)?
You only _____1 DECI
Mostly you _____2
You and your partner(s) equally ___3
Mostly partner(s) _____4
Partner(s) only _____5
Other (please specify) _____6

9f. Do you feel like you have control over the decision of whether to use a condom? No ___0 IFCN
Yes ___1
DK ___88

9g. Do you feel like you have control over decisions about childbearing? No ___0 IFCHLD
Yes ___1
DK ___88

How are these decisions made and carried out? HOWSEXDECISIONS_DETAILW
[Probe use of force or other forms of control]

9h. Do you have more than one sexual partner? No _____0 PART1
Yes _____1
NR _____99

9i. Have you had more than one sexual partner at the same time? No _____0 PART2
Yes _____1
NR _____99

9j. Have any of your primary partners had more than one partner at the same time as you?
No _____0 PPART
Yes _____1
DK _____88
NR _____99

9k. Did you have more than one partner at the time you became infected with HIV?
No _____0 MPART
Yes _____1
DK _____88
NR _____99

9l. Do you feel like alcohol use (by you or your partner) played a role in your becoming infected with HIV?
No _____0 ALCU
Yes _____1
DK _____88
NR _____99

If so, please tell me more. ALCOHOL_ROLEW
[If own use, probe frequency and level of use]

9m. *Have any of your sexual partners ever hurt you or forced you to have sex when you didn't want to?*

No _____ 0 ABUSE
Yes _____ 1
NR _____ 99

If so, in what ways? ABUSE_DETAIL

9n. *Have you ever had a sexual relationship with someone 10 or more years older or younger than you?*

No _____ 0 INTERG
Yes _____ 1
NR _____ 99

If so, please tell me more. INTERGEN_DETAILW
[Probe frequency, length of relationship(s)]

9o. *Have you ever had sex with someone because he gave you food, gifts, money, or other things?*

No _____ 0 TRANSX1
Yes _____ 1
NR _____ 99

If so, please tell me more. TRANSACT_RECEIVEW
[Probe frequency, length of relationship(s)]

9p. *Have you ever given someone food, gifts, money, or other things to have sex with you?*

No _____ 0 TRANSX2
Yes _____ 1
NR _____ 99

If so, please tell me more. TRANSACT_GIVEW
[Probe frequency, length of relationship(s)]

Who owns or rents the dwelling where you live? WHOOWNS

9q. *Do you own livestock that you can dispose of as you wish?*

No _____ 0 LIVSTK
Yes _____ 1
NR _____ 99

Do you feel there are certain expectations for your behavior or living situation as a Swazi woman, such as when or whether you have sex or bear children, whether you earn an income, your roles in your family and community? Please tell me more.

EXPECT_ASWOMEN

Do you feel there are certain expectations for your partner's behavior or living situation as a Swazi man, such as when or whether he has sex or fathers children, whether and how he earns an income, his roles in the family and community?

Please tell me more. EXPECT_ONMALEPARTNER

FOR ALL PARTICIPANTS:

10. What are some of the main things that put men at risk for HIV in Swaziland? MAINRISKSMEN

[Probe migration; cultural practices such as wife inheritance, polygamy]

10a. *Is there pressure for men to have many sexual partners?*

No _____ 0 MMPAR

Yes _____ 1

DK _____ 88

If so, please tell me more. MANYPARTNERS

10b. *Is alcohol use common among men?*

No _____ 0 MALC

Yes _____ 1

DK _____ 88

10c. *Does alcohol use put men at risk for HIV?*

No _____ 0 AURSK

Yes _____ 1

DK _____ 88

If yes, how so? ALCOHOLRISK_MEN

How common is condom use among men? HOWCOMMON_CONDOM

What do you think are some reasons men do not use condoms? WHYNOT_CONDOM

What can be done to encourage men to take the steps necessary to prevent HIV infection and to get involved in HIV prevention efforts? HELPMEN_PREVENT

FOR MALE PARTICIPANTS ONLY:

In order to understand more about how HIV is spread in Swaziland, we need to know more about your personal experiences. What you tell me will be completely confidential and may help make changes to policies and programs so other men will be less at risk for HIV. I really appreciate your honesty and willingness to share your experiences.

10d. *Do you feel like you have control over the decision of when to have sex?* No _____ 0 IFSEXM
Yes _____ 1
DK _____ 88

10e. *Who usually decides whether or not to have sex in your relationship(s)?*
You _____ 1 DECIM
Mostly you _____ 2
You and your partner(s) equally _____ 3
Mostly partner(s) _____ 4
Partner(s) only _____ 5
Other (please specify) _____ 6

10f. *Do you feel like you have control over the decision of whether to use a condom?* No _____ 0 IFCM
Yes _____ 1
DK _____ 88

10g. *Do you feel like you have control over decisions about childbearing?* No _____ 0 IFCHLDM
Yes _____ 1
DK _____ 88

How are these decisions made and carried out? HOWSEXDECISIONS_DETAILM
[Probe use of force or other forms of control]

10h. *Do you have more than one sexual partner?* No _____ 0 PARTM1
Yes _____ 1
NR _____ 99

10i. *Have you had more than one sexual partner at the same time?* No _____ 0 PARTM2
Yes _____ 1
NR _____ 99

10j. *Have any of your partners had other sexual partners during the time that you were together?*
No _____ 0 PPARTM
Yes _____ 1
DK _____ 88
NR _____ 99

10k. *Did you have more than one partner at the time you became infected with HIV?*
No _____ 0 MPARTM
Yes _____ 1
DK _____ 88
NR _____ 99

10l. *Do you feel like alcohol use (by you or your partner) played a role in your becoming infected with HIV?*
No _____ 0 ALCUM
Yes _____ 1
DK _____ 88
NR _____ 99

If so, please tell me more. ALCOHOL_ROLEM
[If own use, probe frequency and level of use]

10m. Have you ever had a sexual relationship with someone 10 or more years older or younger than you?

No _____ 0 INTERM
Yes _____ 1
NR _____ 99

If so, please tell me more. INTERGEN_DETAILM
[Probe frequency, length of relationship(s)]

10m. Have you ever had sex with someone because that person gave you food, gifts, money, or other things?

No _____ 0 TSX1
Yes _____ 1
NR _____ 99

If so, please tell me more. TRANSACT_RECEIVEM
[Probe frequency, length of relationship(s)]

10n. Have you ever given someone food, gifts, money, or other things to have sex with you?

No _____ 0 TSX2
Yes _____ 1
NR _____ 99

If so, please tell me more. TRANSACT_GIVEM
[Probe frequency, length of relationship(s)]

Do you feel there are certain expectations for your behavior or living situation as a Swazi man, such as when or whether you have sex or father children, whether and how you earn an income, your roles in your family and community? Please tell me more.
EXPECT_ASMAN

Do you feel there are certain expectations for your partner's behavior or living situation as a Swazi woman, such as when or whether she has sex or bears children, whether and how she earns an income, her roles in the family and community? Please tell me more. EXPECT_ONFEMALEPARTNER

FOR ALL PARTICIPANTS:

11. Are food shortages a significant problem in Swaziland? FOODSHORTAGES

11a. *Have you been affected by lack of food or water?* Not affected _____ 0 NOFD
 Hunger _____ 1
 Access to health care _____ 2
 Ec dependence _____ 3
 Can't farm _____ 4
 Other (specify) _____ 5
 NR _____ 99

If so, how so? AFFECTED_NOFOOD

11b. *Are you receiving any assistance or support related to food needs?* No _____ 0 FDSUP
 Yes _____ 1
 NR _____ 99

If so, what type of assistance? ASSIST_FOOD

11c. *Are you receiving any assistance or support related to your HIV status?* No _____ 0 HASUP
 Yes _____ 1
 NR _____ 99

If so, what type of assistance? ASSIST_HIV

12. Has being HIV-positive changed your sexual behavior? No _____ 0 CHSX
 Yes _____ 1
 DK _____ 88
 NR _____ 99

How? [Probe number of partners, condom use, behavior towards partners] HOWSEX_CHANGED

If so, what helped you to change your behavior?/ If not, what prevents you from changing your behavior?
 HELPHINDERED_CHANGE

13. Has being HIV-positive led to other significant changes in your life or in your relationships with others?
 RELATIONSHIPS_CHANGED

[Probe experiences as a person who is HIV+ and healthy, if applicable]
 [Probe changes to drug/alcohol use, other risky behaviors]

14. What has been your experience with health care providers with respect to HIV? HEALTHPROVIDERS

14a. Has the quality of your medical care changed since you tested positive? [Circle ALL THAT APPLY]

- Better care _____ 1 QUAL
- No change _____ 2
- Worse care _____ 3
- Denial of care/treatment _____ 4
- Verbal mistreatment _____ 5
- DK _____ 88
- NR _____ 99

Please tell me more. HOWQUALITY_CHANGED

15. Have community and political leaders addressed the HIV/ AIDS problem in your community? What have they done?

COMMUNITY_POLITICIANS

[Chiefs, clergy, Members of Parliament, Ministers, etc.]

What has the king done to address HIV/ AIDS in Swaziland? KINGDONE

What should he do? KINGSHOULD

ASSESSMENT FOR MAJOR DEPRESSION

16. The following are symptoms or problems that people sometimes have. Please let me know the extent to which each of the following symptoms has bothered you or distressed you in the LAST WEEK, including today. DEPR

Statement	Not at all	A little	Quite a bit	Extremely	NR
a. Feeling low in energy, slowed down	1	2	3	4	99
b. Blaming yourself for things	1	2	3	4	99
c. Crying easily	1	2	3	4	99
d. Loss of sexual interest or pleasure	1	2	3	4	99
e. Poor appetite	1	2	3	4	99
f. Difficulty falling asleep, staying asleep	1	2	3	4	99
g. Feeling hopeless about the future	1	2	3	4	99
h. Feeling down or blue	1	2	3	4	99
i. Feeling lonely	1	2	3	4	99
j. Thoughts of ending your life	1	2	3	4	99
k. Feelings of being trapped or caught	1	2	3	4	99
l. Worry too much about things	1	2	3	4	99
m. Feeling no interest in things	1	2	3	4	99
n. Feeling everything is an effort	1	2	3	4	99
o. Feeling worthless	1	2	3	4	99

FOR PARTICIPANTS WHO REPORT THOUGHTS OF ENDING THEIR LIVES [2-4 on 16]:

Based on your response, I am concerned about your safety. I would like you to speak with one of the doctors or nurses working on this study because they may be able to help you. While you are free to refuse, I want you to know that the doctor or nurse will not tell anyone else anything that you tell them without your permission. This health worker would like to help make sure that you are safe and that you know where to go to get help. Would you like to speak with a health worker?

IF NO:

I would like to provide you with some information on counselors you can talk to about the feelings you've expressed. Can I give you some information on where you can get help?

INFORMATION HANDOUTS

I have some written information on living with HIV/AIDS and treatment, would you like these pamphlets?

In Swaziland, people sometimes don't feel safe at home because they experience domestic violence. Domestic violence means that their partners or family members physically hurt them, threaten them or force them to have sex when they don't want to. There are organizations to assist people who are being hurt. They can also help you to report domestic violence to the police. Would you like information on how you can contact these organizations?