

The People Living with HIV
Stigma Index
An index to measure the stigma and
discrimination experienced by people
living with HIV



QUESTIONNAIRE



THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX

**BEFORE STARTING the interview you must:**

1. Give the interviewee the information sheet and allow him/her time to read through it. If he/she is unable to read, you must read it out to him/her.
2. Read the informed consent form to the interviewee. If he/she agrees to participate in the study, complete **two** copies of the form. After both forms have been signed, give one to the interviewee for him/her to keep and you keep the other one.

ON FINISHING the interview, please complete the following:

REFERRALS AND FOLLOW-UP

1. Did the interviewee need a referral? Yes 1
No 2

2. If Yes, what kind of referral(s)?

- Legal 1
Counselling 2
Support group 3
Other 4

If Other, where did you refer them to?

3. What steps have you taken to help the interviewee with the above referral(s)?

(Tick more than one box if appropriate.)

- I have given sufficient information on the referral(s) already 1
I will send the required information to the interviewee 2
Further follow-up is needed 3

Please give details of what you promised to do about referral(s) after the interview, if anything:

4. Is this interviewee a potential candidate for a case study?

- Yes 1
No 2

5. If Yes, record the time and date of the case study meeting:

Time: Date:

QUALITY CONTROL PROCEDURES

Control panel – to be filled in **only** when your task* has been completed.

	Name	Signature	Date
Interviewer	<input type="text"/>	<input type="text"/>	<input type="text"/>
Team leader	<input type="text"/>	<input type="text"/>	<input type="text"/>
Data entry 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Data entry 2	<input type="text"/>	<input type="text"/>	<input type="text"/>

***Tasks:**

- The **interviewer** must ensure that all sections of the questionnaire are completed properly and in full, unless the interviewee does not wish to complete them – in which case this must be noted alongside the relevant question(s).
- The **team leader** must check the questionnaire carefully and query any apparent discrepancies with the interviewer. The **quality checks** section at the end of this questionnaire will help the interviewer and team leader with these tasks.
- **Data entry people 1 and 2** must enter all data from the questionnaire correctly. They must enter the data from every questionnaire independently, following the procedures outlined in the **user guide**.

PEOPLE LIVING WITH HIV STIGMA INDEX: QUESTIONNAIRE
CONFIDENTIAL AND ANONYMOUS

SECTION 1 INFORMATION ABOUT YOU

1. Sex

- Male 1
Female 2
Transgender 3

2. How old are you?

- Youth aged 15–19 years 1
Adult aged 20–24 years 2
Adult aged 25–29 years 3
Adult aged 30–39 years 4
Adult aged 40–49 years 5
Adult aged 50+ years 6

3. For how long have you been living with HIV? (Tick one box only.)

- 0–1 year 1
1–4 years 2
5–9 years 3
10–14 years 4
15+ years 5

4. Current relationship status (Tick one box only.)

- Married or cohabiting and husband/wife/partner is currently living in household 1
Married or cohabiting but husband/wife/partner is temporarily living/working away from the household 2
In a relationship but not living together 3
Single 4
Divorced/separated 5
Widow/widower 6

5. If you are currently in a relationship, for how long have you been involved with your husband/wife/partner?

- 0–1 year 1
1–4 years 2
5–9 years 3
10–14 years 4
15+ years 5

6. Are you sexually active at the moment?

- Yes 1
No 2



7. Do you belong to, or have you in the past belonged to, any of the following categories?

(Tick at least one box. You can tick more than one if appropriate.)

- Men who have sex with men 1
- Gay or lesbian 2
- Transgender 3
- Sex worker 4
- Injecting drug user 5
- Refugee or asylum seeker 6
- Internally displaced person 7
- Member of an indigenous group 8
- Migrant worker 9
- Prisoner 10
- I don't belong to, and have not in the past belonged to, any of these categories 11

8. Do you have a physical disability of any kind (not including general ill health related to HIV)?

- Yes 1
- No 2

If YES, please describe this physical disability:

9. What is the highest level of formal education you have completed? (Tick one box only.)

- No formal education 1
- Primary school 2
- Secondary school 3
- Technical college/university 4

10. Which one of these statements best describes your current employment status?

(Tick at least one box. You can tick more than one if appropriate.)

- In full-time employment (as an employee) 1
- In part-time employment (as an employee) 2
- Working full-time but not as an employee (self-employed) 3
- Doing casual or part-time work (self-employed) 4
- Unemployed and not working at all 5

11. How many people currently live in your household in each of these age categories?

	Number of people
Children aged 0–14 years	<input type="text"/>
Youth aged 15–19 years	<input type="text"/>
Adults aged 20–24 years	<input type="text"/>
Adults aged 25–29 years	<input type="text"/>
Adults aged 30–39 years	<input type="text"/>
Adults aged 40–49 years	<input type="text"/>
Adults aged 50 years and above	<input type="text"/>

12. How many of the children and youth in your household are AIDS orphans?

Number of orphans

13. Is your household in: (Tick one box **only**.)

A rural area 1
 A small town or village 2
 A large town or city 3

14. What was the average income of your household per month over the last 12 months?

(Write down the figure in local currency.)

Average income of household over last 12 months

For data capturers only:

Annual income in local currency:	<input type="text"/>
Current exchange rate from local currency to US dollars:	<input type="text"/>
Annual income in US dollars:	<input type="text"/>

15. In the last month, how many days has any member of your household not had enough food to eat?

Number of days



SECTION 2A YOUR EXPERIENCE OF STIGMA AND DISCRIMINATION FROM OTHER PEOPLE

1a. In the last 12 months, how often have you been excluded from social gatherings or activities (e.g. weddings, funerals, parties, clubs)? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 2a.

1b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4

2a. In the last 12 months, how often have you been excluded from religious activities or places of worship? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 3a.

2b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4

3a. In the last 12 months, how often have you been excluded from family activities (e.g. cooking, eating together, sleeping in the same room?) (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 4a.

3b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4

4a. In the last 12 months, how often have you been aware of being gossiped about? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 5a.

4b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4

5a. In the last 12 months, how often have you been verbally insulted, harassed and/or threatened?

(Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 6a.

5b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4

6a. In the last 12 months, how often have you been physically harassed and/or threatened? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

If the answer is **NEVER**, please go to question 7a.

6b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
For (an)other reason(s)? 2
Both because of your HIV status and other reason(s)? 3
Not sure why 4
-



7a. In the last 12 months, how often have you been physically assaulted? (Tick one box only.)

- Never 1
 Once 2
 A few times 3
 Often 4

If the answer is **NEVER**, please go to question 8.

7b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
 For (an)other reason(s)? 2
 Both because of your HIV status and other reason(s)? 3
 Not sure why 4

7c. If so, who physically assaulted you? (Tick one box only.)

- My husband/wife/partner 1
 Another member of the household 2
 Person(s) outside the household who is/are known to me 3
 Unknown person(s) 4

8. In questions 1–7, if you experienced stigma and/or discrimination for reasons other than your HIV status, please choose one category that best explains why you felt you were stigmatized and/or discriminated against. (Tick one box only.)

- Sexual orientation (men who have sex with men, gay or lesbian, transgender) 1
 Sex worker 2
 Injecting drug user 3
 Refugee or asylum seeker 4
 Internally displaced person 5
 Member of an indigenous group 6
 Migrant worker 7
 Prisoner 8
 None of the above – it was because of an(other) reason(s) 9

If you chose **None of the above**, please explain why you think you were stigmatized or discriminated against.

9. In the last 12 months, how often have you been subjected to psychological pressure or manipulation by your husband/wife or partner in which your HIV-positive status was used against you? (Tick one box only.)

- Never 1
 Once 2
 A few times 3
 Often 4

10. In the last 12 months, how often have you experienced sexual rejection as a result of your HIV positive status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

11. In the last 12 months, how often have you been discriminated against by other people living with HIV? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

12. In the last 12 months, how often has your wife/husband or partner, or any members of your household experienced discrimination as a result of your HIV-positive status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

13. If you have experienced some form of HIV-related stigma and/or discrimination in the last 12 months, why do you think this is? (Tick more than one box if appropriate.)

- People are afraid of getting infected with HIV from me 1
People don't understand how HIV is transmitted and are afraid I will infect them with HIV through casual contact 2
People think that having HIV is shameful and they should not be associated with me 3
Religious beliefs or "moral" judgements 4
People disapprove of my lifestyle or behaviour 5
I look sick with symptoms associated with HIV 6
I don't know/I am not sure of the reason(s) 7
-



SECTION 2B YOUR ACCESS TO WORK AND HEALTH AND EDUCATION SERVICES

1a. In the last 12 months, how often have you been forced to change your place of residence or been unable to rent accommodation? (Tick one box only.)

- Never 1
 Once 2
 A few times 3
 Often 4

1b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
 For (an)other reason(s)? 2
 Both because of your HIV status and other reason(s)? 3
 Not sure why 4

If interviewee has **not** been earning an income (either through some form of formal employment or on a casual or part-time basis) or has not been self-employed during the last 12 months, go to question 5.

2a. In the last 12 months, how often have you lost a job (if employed) or another source of income (if self-employed or an informal/casual worker)? (Tick one box only.)

- Never 1
 Once 2
 A few times 3
 Often 4

2b. If so, was this...? (Tick one box only.)

- Because of your HIV status? 1
 For (an)other reason(s)? 2
 Both because of your HIV status and other reason(s)? 3
 Not sure why 4

2c. If because of HIV status (wholly or partly), did you lose your work/income...? (Tick one box only.)

- Because of discrimination by your employer or co-workers 1
 Because you felt obliged to stop working due to poor health 2
 Because of a combination of discrimination and poor health 3
 Because of another reason 4

3. In the last 12 months, have you been refused employment or a work opportunity because of your HIV status?

- Yes 1
 No 2

4a. In the last 12 months, how often has your job description or the nature of your work changed, or have you been refused promotion, as a result of your HIV status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4

4b. If so, did this happen...? (Tick one box only.)

- Because of discrimination by your employer or co-workers 1
Because poor health prevented you from doing certain things 2
Because of a combination of discrimination and poor health 3
Other reason 4

5. In the last 12 months, how often have you been dismissed, suspended or prevented from attending an educational institution because of your HIV status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4
Not applicable 5

6. In the last 12 months, how often has your child/children been dismissed, suspended or prevented from attending an educational institution because of your HIV status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4
Not applicable 5

7. In the last 12 months, how often have you been denied health services, including dental care, because of your HIV status? (Tick one box only.)

- Never 1
Once 2
A few times 3
Often 4
Not applicable 5

8. In the last 12 months, have you been denied family planning services because of your HIV status? (Tick one box only.)

- Yes 1
No 2
Not applicable 3

9. In the last 12 months, have you been denied sexual and reproductive health services because of your HIV status?

- Yes 1
No 2
-



SECTION 2C INTERNAL STIGMA (THE WAY YOU FEEL ABOUT YOURSELF) AND YOUR FEARS

1. In the last 12 months, have you experienced any of the following feelings because of your HIV status?

(Tick one box for each category.)

- | | | | | |
|-----------------------------|-----|----------------------------|----|----------------------------|
| I feel ashamed | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I feel guilty | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I blame myself | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I blame others | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I have low self-esteem | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I feel I should be punished | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I feel suicidal | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |

2. In the last 12 months, have you done any of the following things because of your HIV status?

(Tick one box for each category.)

- | | | | | |
|---|-----|----------------------------|----|----------------------------|
| I have chosen not to attend social gathering(s) | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I have isolated myself from my family and/or friends | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I took the decision to stop working | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I decided not to apply for a job/work or for a promotion | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I withdrew from education/training or did not take up an opportunity for education/training | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I decided not to get married | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I decided not to have sex | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I decided not to have (more) children | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I avoided going to a local clinic when I needed to | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| I avoided going to a hospital when I needed to | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |

3. In the last 12 months, have you been fearful of any of the following things happening to you – whether or not they actually have happened to you?

- | | | | | |
|---|-----|----------------------------|----|----------------------------|
| Being gossiped about | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| Being verbally insulted, harassed and/or threatened | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| Being physically harassed and/or threatened | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |
| Being physically assaulted | Yes | <input type="checkbox"/> 1 | No | <input type="checkbox"/> 2 |

4. In the last 12 months, have you been afraid that someone would not want to be sexually intimate with you because of your HIV-positive status?

- | | |
|-----|----------------------------|
| Yes | <input type="checkbox"/> 1 |
| No | <input type="checkbox"/> 2 |

SECTION 2D RIGHTS, LAWS AND POLICIES

1a. Have you heard of the *Declaration of Commitment on HIV/AIDS*, which protects the rights of people living with HIV?

Yes 1
No 2

1b. If yes, have you ever read or discussed the content of this Declaration?

Yes 1
No 2

2a. Have you heard of
[insert the best-known national law/policy or set of guidelines from your country – choose one only],
which protect(s) the rights of people living with HIV in this country?

Yes 1
No 2

2b. If yes, have you ever read or discussed the content of this
[select the appropriate term based on your choice – law/policy/set of guidelines]?

Yes 1
No 2

3. In the last 12 months, have any of the following things happened to you because of your HIV status?
(Tick more than one box if appropriate.)

- I was forced to submit to a medical or health procedure (including HIV testing) 1
- I was denied health insurance or life insurance because of my HIV status 2
- I was arrested or taken to court on a charge related to my HIV status 3
- I had to disclose my HIV status in order to enter another country 4
- I had to disclose my HIV status to apply for residence or nationality 5
- I was detained, quarantined, isolated or segregated 6
- None of these things happened to me 7

4a. In the last 12 months, have any of your rights as a person living with HIV been abused?

Yes 1
No 2
Not sure 3

If the answer is **NO**, please go to the next section (Section 2E: Effecting change).

4b. If yes, have you tried to get legal redress for any abuse of your rights as a person living with HIV?

Yes 1
No 2
Not sure 3

If the answer is **NO** or **NOT SURE**, please go to question 4e.

4c. Has this process begun in the last 12 months?

Yes 1
No 2



4d. What was the result?

- The matter has been dealt with 1
The matter is still in the process of being dealt with 2
Nothing happened/the matter was not dealt with 3

Please now go to question 5a.

4e. If the response to question 4b was NO or NOT SURE, what was the reason for not trying to get legal redress?

- Insufficient financial resources to take action 1
Process of addressing the problem appeared too bureaucratic 2
Felt intimidated or scared to take action 3
Advised against taking action by someone else 4
No/little confidence that the outcome would be successful 5
None of the above 6

5a. Have you tried to get a government employee(s) to take action against an abuse of your rights as a person living with HIV?

- Yes 1
No 2

If the answer is NO, please go to question 6a.

5b. Did this happen in the last 12 months?

- Yes 1
No 2

5c. What was the result?

- The matter has been dealt with 1
The matter is still in the process of being dealt with 2
Nothing happened/the matter was not dealt with 3

6a. Have you tried to get a local or national politician to take action against an abuse of your rights as a person living with HIV?

- Yes 1
No 2

If the answer is NO, please go to the next section (Section 2E: Effecting change).

6b. Did this happen in the last 12 months?

- Yes 1
No 2

6c. What was the result?

- The matter has been dealt with 1
The matter is still in the process of being dealt with 2
Nothing happened/the matter was not dealt with 3
-

SECTION 2E EFFECTING CHANGE

1. In the last 12 months, have you confronted, challenged or educated someone who was stigmatizing and/or discriminating against you?

Yes 1
No 2

2a. Do you know of any organizations or groups that you can go to for help if you experience stigma or discrimination?

Yes 1
No 2

If the answer is **NO**, please go to question 3.

2b. If yes, which kinds of organizations or groups do you know about?

(Tick more than one box if appropriate.)

- People living with HIV support group 1
 Network of people living with HIV 2
 Local non-governmental organization 3
 Faith-based organization 4
 A legal practice 5
 A human rights organization 6
 National non-governmental organization 7
 National AIDS council or committee 8
 International non-governmental organization 9
 UN organization 10
 Other 11

2c. If you ticked **OTHER** please describe the kind of organization or group you are referring to:

3. Have you sought help from any of the above organizations or groups to resolve an issue of stigma or discrimination?

Yes 1
No 2

4. If you have tried to resolve an issue of stigma and discrimination either on your own or with the assistance of others, briefly describe what the issue was about, who – if anyone – helped you, and how you and/or others tried to resolve the matter.

WHAT was the issue of stigma and discrimination about?



If others helped you resolve the matter – **WHO** helped you?

HOW did you (and, if appropriate, others) try to resolve the matter (i.e. what specifically did you and/or others do)?

5a. In the last 12 months, have you supported other people living with HIV?

- Yes 1
No 2

5b. If YES, what types of support did you provide? (Tick more than one box if appropriate.)

- Emotional support (e.g. counselling, sharing personal stories and experiences) 1
Physical support (e.g. providing money or food, doing an errand for them) 2
Referral to other services 3

6. Are you currently a member of a people living with HIV support group and/or network?

- Yes 1
No 2

7. In the last 12 months, have you been involved, either as a volunteer or as an employee, in any programme or project (either government or non-governmental) that provides assistance to people living with HIV?

- Yes 1
No 2

8. In the last 12 months have you been involved in any efforts to develop legislation, policies or guidelines related to HIV?

- Yes 1
No 2

9. Do you feel that you have the power to influence decisions in any of the following aspects...?

(Tick at least one box. You can tick more than one if appropriate.)

- Legal/rights matters affecting people living with HIV 1
Local government policies affecting people living with HIV 2
Local projects intended to benefit people living with HIV 3
National government policies affecting people living with HIV 4
National programmes/projects intended to benefit people living with HIV 5
International agreements/treaties 6
None of these things 7

10. There are a number of organizations of people living with HIV working against stigma and discrimination. If one of them asked you, "What is the most important thing we should be doing as an organization to address stigma and discrimination?" what would you recommend? (Tick one box only.)

- Advocating for the rights of all people living with HIV 1
- Providing support to people living with HIV by providing emotional, physical and referral support 2
- Advocating for the rights and/or providing support to particularly marginalized groups (men who have sex with men, injecting drug users, sex workers) 3
- Educating people living with HIV about living with HIV (including treatment literacy) 4
- Raising the awareness and knowledge of the public about AIDS 5

SECTION 3A TESTING/DIAGNOSIS

1. Why were you tested for HIV? (Tick one or more boxes as appropriate.)

- Employment 1
- Pregnancy 2
- To prepare for a marriage/sexual relationship 3
- Referred by a clinic for sexually transmitted infections 4
- Referred due to suspected HIV-related symptoms (e.g. tuberculosis) 5
- Husband/wife/partner/family member tested positive 6
- Illness or the death of husband/wife/partner/family member 7
- I just wanted to know 8
- Other 9

If you ticked **OTHER**, please describe the reason:

2. Was the decision to be tested for HIV up to you? (Tick one box only.)

- Yes, I took the decision myself to be tested (i.e. it was voluntary) 1
- I took the decision to be tested, but it was under pressure from others 2
- I was made to take an HIV test (coercion) 3
- I was tested without my knowledge – I only found out after the test had been done 4

3. Did you receive counselling when you were tested for HIV? (Tick one box only.)

- I received both pre- and post-HIV test counselling 1
- I only received pre-test HIV counselling 2
- I only received post-test HIV counselling 3
- I did not receive any counselling when I had an HIV test 4



SECTION 3B DISCLOSURE AND CONFIDENTIALITY

1. For each of the following people or groups of people, please describe how they were first told about your HIV status, if they have been told.

(Please tick your answers. Only tick more than one box in each line if the answer is different for different individuals.)

	I told them	Someone else told them, WITH my consent	Someone else told them, WITHOUT my consent	They don't know my HIV status	Not applicable
Your husband/wife/partner	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Other adult family members	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Children in your family	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your friends/neighbours	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Other people living with HIV	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
People who you work with (your co-workers)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your employer(s)/boss(es)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Your clients	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Injecting drug partners	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Religious leaders	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Community leaders	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Health care workers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Social workers/counsellors	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Teachers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Government officials	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
The media	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

- 2a. How often did you feel pressure from other individuals living with HIV or from groups/networks of people living with HIV to disclose your HIV status?

Often 1
 A few times 2
 Once 3
 Never 4

- 2b. How often did you feel pressure from other individuals **not** living with HIV (e.g. family members, social workers, non-governmental organization employees) to disclose your HIV status?

Often 1
 A few times 2
 Once 3
 Never 4

3. Has a health care professional (for example, a doctor, nurse, counsellor, laboratory technician) ever told other people about your HIV status without your consent?

Yes 1
 No 2
 Not sure 3

4. How confidential do you think the medical records relating to your HIV status are? (Tick one box only.)

I am sure that my medical records will be kept completely confidential 1
 I don't know if my medical records are confidential 2
 It is clear to me that my medical records are not being kept confidential 3

5. How would you describe the reactions of these people (in general) when they first knew about your HIV status? (Tick one box only for each category of people.)

(Tick **Not applicable** if these people do not know your HIV status or you don't know what their reaction was.)

	Very discriminatory	Discriminatory	No different	Supportive	Very supportive	Not applicable
Your husband/wife/ partner	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Other adult family members	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Children in your family	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Your friends/neighbours	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Other people living with HIV	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Your co-workers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Your employer(s)/boss(es)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Your clients	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Injecting drug partners	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Religious leaders	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Community leaders	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Health care workers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Social workers/counsellors	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Teachers	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
Government officials	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
The media	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

6. Did you find the disclosure of your HIV status an empowering experience?

(Tick **Not applicable** if you have not disclosed your HIV status.)

Yes 1
 No 2
 Not applicable 3



SECTION 3C TREATMENT

1. In general, how would you describe your health at the moment? (Tick one box only.)

- Excellent 1
Very good 2
Good 3
Fair 4
Poor 5

2a. Are you currently taking antiretroviral treatment? (Tick one box only.)

- Yes 1
No 2

2b. Do you have access* to antiretroviral treatment, even if you are not currently taking it?
(Tick one box only.)

- Yes 1
No 2
Don't know 3

* In this context access means that antiretroviral treatment is available and free or you can afford it.

3a. Are you currently taking any medication to prevent or to treat opportunistic infections?
(Tick one box only.)

- Yes 1
No 2

3b. Do you have access* to medication for opportunistic infections, even if you are not currently taking it?
(Tick one box only.)

- Yes 1
No 2
Don't know 3

* In this context access means that treatment is available and free or you can afford it.

4. In the last 12 months, have you had a constructive discussion with a health care professional(s)
on the subject of your HIV-related treatment options?

- Yes 1
No 2

5. In the last 12 months, have you had a constructive discussion with a health care professional(s)
on other subjects such as your sexual and reproductive health, sexual relationship(s),
emotional well-being, drug use, etc?

- Yes 1
No 2

SECTION 3D HAVING CHILDREN

Questions 1–5 can be completed by both male and female interviewees.

- 1a. Do you have a child/children? Yes 1
No 2
- 1b. If Yes, are any of these children known to be HIV-positive? Yes 1
No 2
2. Since being diagnosed as HIV-positive, have you ever received counselling about your reproductive options? Yes 1
No 2
Not applicable 3
3. Has a health care professional ever advised you not to have a child since you were diagnosed as HIV-positive? Yes 1
No 2
Not applicable 3
4. Has a health care professional ever coerced you into being sterilized since you were diagnosed as HIV-positive? Yes 1
No 2
Not applicable 3
5. Is your ability to obtain antiretroviral treatment conditional on the use of certain forms of contraception? Yes 1
No 2
Not applicable 3
Don't know 4

Questions 6 and 7 should be completed by female interviewees only.

6. In the last 12 months, have you been coerced by a health care professional in relation to any of the following because of your HIV status?
- | | Yes | No | Not applicable |
|-------------------------------------|----------------------------|----------------------------|----------------------------|
| Termination of pregnancy (abortion) | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| Method of giving birth | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
| Infant feeding practices | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 |
- 7a. Have you ever been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy? (Tick one box only.) Yes – I have received such treatment 1
No – I did not know that such treatment existed 2
No – I was refused such treatment 3
No – I did not have access to such treatment 4
No – I was not HIV-positive when pregnant 5
- 7b. If yes, were you also given information about healthy pregnancy and motherhood as part of the programme to prevent mother-to-child transmission of HIV? Yes 1
No 2



SECTION 3E PROBLEMS AND CHALLENGES

What do you see as the MAIN PROBLEMS and CHALLENGES in relation to:

1. Testing and diagnosis:

2. Disclosure and confidentiality about being HIV-positive:

3. Antiretroviral treatment:

4. Having children when you are HIV-positive:

This is the end of the interview. Before completing the quality check section with the interviewee, thank the interviewee for their time. Once you have completed the quality check, complete the referral and follow-up section at the beginning of the questionnaire and confirm any follow-up arrangements. Provide the interviewee with the honorarium and thank them again for their time.

After the interview, take some time alone reflecting on the interview that you have just conducted: review the notes that you took during the interview, make sure that you recorded all the details that you wanted to and add to your notes if necessary. Write down anything that you feel you need to discuss or need advice about from your team leader.

QUALITY CHECKS

This section is designed to help the interviewer and team leader to check the questionnaire to make sure that it has been properly and fully completed. However, you also need to use your own judgement to make sure that a good job has been done! The team leader will check the interviewer's responses on his/her return to base.

The interviewer should respond to the following points before the closure of the interview so that the interviewee is able to assist you to complete the responses to these questions.

1. Has the interviewee answered **every** question in Sections 1–3 of the questionnaire? Yes No

If **NO**, please specify which questions have not been answered and give reasons why:

2. Do the answers to question 7 in Section 1 and question 8 in Section 2A (groups the interviewee has belonged to or does belong to) appear consistent? Yes No

If **NO**, please explain:

3. Does the information given in Section 1 (questions 14 and 15) seem credible? (i.e. is the poverty level of the household roughly consistent with their experience of having insufficient money to buy food for the household – taking into account that some low-income households may grow their own food?) Yes No

If there are **differences**, have you checked the reasons with the interviewee and recorded why there are these differences below? Yes

4. Has the front page of the questionnaire been completed? Yes

The last quality check can be completed by the interviewer after the interviewee has left, but **before** the interviewer leaves the place of the interview:

5. Has the questionnaire code been written in the top right-hand corner of every page? Yes



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