



Life on antiretroviral therapy

Adaptive coping and adjustment to living with HIV as a chronic condition in Wakiso District, Uganda

Survey questionnaire for 160 people living with HIV

CONTROL GROUP

Date this questionnaire was verified by supervisor

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DVER

Signature of supervisor

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Section A: Identification

A1 Name of interviewer _____

A2 Interviewer code: **INT**

A3 Respondent identity number **IDNO**

A4 Date of interview (date, month, year) **DINT**

A5 Time interview begins: **TINTBEG**

A6 Place of interview: **PLINT**
 Home ☐ (1) Health facility ☐ (2) Elsewhere ☐ (3) *Specify place.....*

A7 Does the respondent live in an urban, semi-urban or rural setting? **LOC**
 Urban ☐ (1) Semi-urban ☐ (2) Rural ☐ (3)

A8 Where does the respondent live?
 Village: Ekyalo _____ **RESVILL**
 Parish: Muluka _____ **RESPAR**
 Sub-county: Gombolola _____ **RESSUB**
 District: _____ **RESDIS**

A9 What relationship does the respondent have to the head of this household **RELHH**

Nannyini mu omuyita otya?

1 = head of household

2 = spouse/partner

3 = parent

4 = brother /sister

5 = child

6 = grandchild

7 = other *specify* _____

8 = no relationship

Section B: Socio-demographic characteristics of the participant (CONTROL GROUP ALSO)

- B1 **Wazaalibwa ddi ?** Date of birth day month year **DOB**
 99 = Don't Know if don't know, estimate age in B2
- B2 **Gerageranya emyaka gyo** Estimation of Age **AGE**
- B3 Sex 1 = male, 2= female **SEX**
- B4 **Olina buyigirize ki?** What level of education did you reach?
 00 = nil 20 = pre-primary 01 = P1-P3 02 = P4-P7 03 = J1-J3 04 = S1-S3 05 = S4-S6
 06 = further/higher 99 = Don't Know **EDU**

Religion

- B5 **Oli wa ddini ki?** What is your religion? **RLG**
- 01 = Christian, Catholic 02 = Christian, Protestant
 03 = Christian, Born Again 04 = Christian, SDA
 05 = Christian, Jehova's Witness 06 = Muslim
 07 = Hindu 08 = *other specify* _____
 09 = no religion

Marital status

Kati ngenda kukubuuza ku bikwata ku mbeera y'ebyo bufumbo. I am going to ask about your marital status

- B6 Do you live with a partner in this house? **PARTNER**
Obeera n'omwagalwa/omubeezi mu nnyumba eno?
 1 = Yes **If Yes, go to B7**
 2 = No **If No, go to B8**
- B7 Do you regard this person to be your husband/wife Yes = 1, No = 2 **HUSWIFE**
Ono omutwala nga mwami/mukyala wo?

- B8 Do you have a partner who lives elsewhere? **PARTElse**
Olina omwagalwa/omubeezi abeera awalala?
- 01 = Yes ☐ **If Yes, go to B9 + to B10**
 02 = No ☐ **If No, go to B11 + to B12**
- B9 Do you regard this person to be your husband/wife ☐ Yes = 01, No = 02 **HUSWIFEELSE**
Ono omutwala ng'omwami/mukyala wo?
- B10 For how many years have you been together or married? **Mubadde mwena kumala bbanga ki?**
- Partner - Home: months years **PARTDURHO**
 Partner – Elsewhere: months years **PARTDUREL**
- B11 So do you regard yourself as single? ☐ Yes = 01, No = 02 **SINGLE**
Wetwala nga atalina mubeezi/mwagalwa?
- B12 Are you a widow/widower? ☐ Yes = 01, No = 02 **WIDOW**
Oli Namwandu/ Ssemwandu?

If a woman:

- B13 Does your husband / partner have other wives / partners?
Omwami/omwagalwa wo alina abakyala/abagalwa abalala?

☐ Yes = 01, No = 02, Don't Know 99 **POLYGF**

GO TO B15

If a man:

- B14 Do you have more than one wife / partner? **Olina omukyala /omwagalwa asukka ku omu?**

☐ Yes = 01, No = 02 **POLYGM**

GO TO B15

- B15** Do you have children? ☐ Yes = 01, No = 02 **CHHOME**
Olina Abaana?

- B16 Number of your own children who live with you **CHHOME1**
Abaana bo bameka ababeera nawe?

- B17 Number of your children who live elsewhere **CHNOHOME**
Abaana bo bameka ababeera awalala?

B18 Do you have other children who live with you ☐ Yes = 1, No = 2 **OTHCHILD**
Abaana abalala ababeera nawe

B19 If yes, how many? **CHHOME2**
Oba Yee, bali bameka?

Household composition

I would like you to think about **all** the people who are part of your household. **How many** people live in, OR share, this household?

Nsaba olowooze ku bantu bonna abomumakaago.

B20 Total number of people living in this household **HHTOT**
Omuwendo gw'abantu bonna ababeera mu maaka gano. Abantu bameka ababeera mu maka gano?

OF THESE, HOW MANY ARE: Bameka ku bantu bomumaka go nga:

B21 Children under 10 years of age **HH10**
Baana abali wansi w'emyaka ekkumi

B22 Children aged 11-17 years **HH17**
Baana abalina emyaka okuva ku kkumi nagumu okutuuka ku kumi namusanvu

B23 Adults aged 18-35 years **HH35**
Bantu bakulu okuva ku myaka kkumi na munaana okutuuka kwasatu mw'etaano

B24 Adults aged 36-49 years **HH49**
Abantu bakulu okuva ku myaka asatu mu mukagga okutuuka ku ana mu mwenda

B25 Adults aged 50-59 years **HH59**
Bantu bakulu okuva ku myaka ataano okutuuka ku ataano mu mwenda

B26 Adults aged 60 years and older **HH60**
Bantu bakulu okuva ku myaka nkaaga n'okusoba

Definition of household: Two of the following: - Share same food

Living in same residence for the past month, or return regularly from migratory work

Contribute to the household economy and activities (includes lodgers)

Section F: **Quality of Life:** WHO Qual Bref **(CONTROL GROUP ALSO)**

Instructions:

(Interviewer needs to take note and should read the statement to the patient)

This assessment asks how you feel about your quality of life, **health**, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life

in the last four weeks!!!!

Bino bibuza ku ngeri gy'owuliramu ku mutindo gw'obulamu bwo oba ebintu ebirala mu bulamu bwo. Tukasaba oddemu ebibuuzo byonna. Bwoba tewekakasa kya kuddamu, tukusaba olonde ekisinga okwefananyiriza embeera yo. Kino kitera okuba ekisooka okugira mu ndowooza. Tukasaba oleme kwerabira omutindo, byosuubira, ebikunyumira n'ebikweralikiriza. Tukasaba olowooze ku bulamu bwo mu banga lya wiki nnya eziyise.

To the interviewer:

Please read each question, assess feelings of respondent, and circle the relevant number on the scale for each question that gives the best answer

		Very poor <i>Bubi ddala</i>	Poor <i>Bubi</i>	Neither poor nor good <i>Mpaawo wengwa</i>	Good <i>Bulungi</i>	Very good <i>Bulungi ddala</i>
F 1	How would you rate your quality of life? Omutindo gwo bulamu bwo ogugerageranya otya?	1	2	3	4	5

		Very dissatisfied <i>Siri mumativu nakamu</i>	Dissatisfied <i>Siri mumativu</i>	Neither Satisfied nor dissatisfied <i>Mpaawo wengwa</i>	Satisfied <i>Mumativu</i>	Very satisfied <i>Mumativu ddala</i>
F 2	How satisfied are you with your health? Oli mu mativu kwenkanawa nembeera y'obulamu bwo?	1	2	3	4	5

The following questions ask about **how much you experienced** certain things **in the last four weeks**. [*Ebibuzo bino wamanga byekusa kungeri gyobade owuliramu ebintu ebimu mu wiki ennya eziyise*]

		Not at all <i>Wadde nakamu</i>	A little <i>Katono</i>	A moderate amount <i>Katono katono</i>	Very much <i>Nnyo</i>	An extreme amount <i>Nnyo ddala</i>
F 3	To what extent do you feel that physical pain prevents you from doing what you need to do? Owulira nga Obulumi obwomubiri bukuziyiza kwenkanawa okukola byewetaaga okukola?	1	2	3	4	5
F 4	How much do you need any medical treatment to function in your daily life? Obujjanjabi obwekika kyonna obwetaaga kwenkanawa okutambuza obulamu obwa bulijjo?	1	2	3	4	5
F 5	How much do you enjoy life? Obulamu bukunyumira kwenkanawa?	1	2	3	4	5
F 6	To what extent do you feel your life to be meaningful? Owulira nga obulamubwo bwamugaso kwenkanawa?	1	2	3	4	5
F 7	How well are you able to concentrate? Osobola bulungi okusa essira kubyokola?	1	2	3	4	5
F 8	How safe do you feel in your daily life? Olowooza nti olina obukuumi ku bulamu bwo obwa bulijjo?	1	2	3	4	5
F 9	How healthy is your physical environment? Embeera y'ebbulamu kwebyo ebikwetolode eri etya?	1	2	3	4	5

The following questions ask about **how completely** you **experience**
or were able to do certain things **in the last four weeks.**

Ebibuuzo bino wamanga bikwata kw'ebyo b'yoyitamu oba by'okoze mu wiki nnya eziyise

		Not at all <i>Wadde nakamu</i>	A little <i>Katono</i>	Moderately <i>Katono katono</i>	Mostly <i>Nnyo</i>	Completely <i>Ddala ddala</i>
F 10	Do you have enough energy for everyday life? Olina amaanyi agamala okukola ebintu byo ebyabulijjo?	1	2	3	4	5
F 11	Are you able to accept your bodily appearance? Osobola okukkiriza embeera gyofananamu?	1	2	3	4	5
F 12	Do you have enough money to meet your needs? Olina sente ezimala okwetusaako byewetaaga?	1	2	3	4	5
F 13	How available to you is the information that you need in your day-to-day life? Osobola okufuna amawulire ge wetaaga mu bulamu bwo obwa bulijjo?	1	2	3	4	5
F 14	To what extent do you have the opportunity for leisure activities? Ofuna ebiseera ebye ddembe ebyokwewumuzamu?	1	2	3	4	5

		Very poor <i>Bubi ddala</i>	Poor <i>Bubi</i>	Neither poor nor good <i>Mpaawo wengwa</i>	Good <i>Bulungi</i>	Very good <i>Bulungi ddala</i>
F 15	How well are you able to get around (move around)? Osobola bulungi okutambulatambula?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you feel about various aspects of your life **over the last four weeks**. [*Ebibuuzo bino wamanga bibuuzza kubumativu bwolina mubintu ebimu mubulamubwomu wiki ennya eziyise*]

		Very dissatisfied <i>Siri mumativu nakamu</i>	Dissatisfied <i>Siri mumativu</i>	Neither Satisfied nor dissatisfied <i>Mpaawo wengwa</i>	Satisfied <i>Mumativu</i>	Very satisfied <i>Mumativu ddala</i>
F 16	How satisfied are you with your sleep? Olimumativu notulo twofuna?	1	2	3	4	5
F 17	How satisfied are you with your ability to perform your daily living activities? Olimumativu kwenkanawa ku ngeri gy'okakalabyamu emirimu'gyo egyabulijjo?	1	2	3	4	5
F 18	How satisfied are you with your capacity for work? Olimumativu kwenkanawa ku busobozi bw'olina okukola emirimu?	1	2	3	4	5
F 19	How satisfied are you with yourself? Olimumativu kwenkanawa nengeri gyewetwalamu?	1	2	3	4	5
F 20	How satisfied are you with your personal relationships? Olimumativu kwenkanawa nenkolaganayo n'abantu mubulamubwo?	1	2	3	4	5
F 21	How satisfied are you with the intimate or long term relationship in your life? Olimumativu kwenkanawa ku nsonga y'ebyomukwano mu bulamu bwo?	1 DO NOT ASK	2 THIS QUESTION	3 IN SENSITIVE	4 CASES e.g. widowed or divorced	5 or single or in later years of life

		Very dissatisfied <i>Siri mumativu nakamu</i>	Dissatisfied <i>Siri mumativu</i>	Neither Satisfied nor dissatisfied <i>Mpaawo wengwa</i>	Satisfied <i>Mumativu</i>	Very satisfied <i>Mumativu ddala</i>
F 22	How satisfied are you with the support you get from your friends? Olimumativu kwenkanawa nobuyambi bw’ofuna okuva eri mikwano gyo?	1	2	3	4	5
F 23	How satisfied are you with the conditions of your living place? Olimumativu kwenkanawa nekifo wobeera ?	1	2	3	4	5
F 24	How satisfied are you with your access to health services? Olimumativu kwenkanawa n’engeri gyofunamu empeereza ku byobulamu?	1	2	3	4	5
F 25	How satisfied are you with your transport? Olimumativu kwenkanawa n’ebyentambula?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the last four weeks**. [*Ekibuuzo kino wamanga bikwata kungeri gyobadde owuliramu ebintu ebimu muwiiki ennya eziyise*]

		Never <i>Tekibangawo</i>	Seldom <i>Obwolumu</i>	Quite Often <i>Kitera okubaawo</i>	Very often <i>Wekiri ddala</i>	Always <i>Wekiri oluberera</i>
F 26	How often do you have negative feelings such as blue mood, despair, anxiety, depression? Otera okuwulira nga toli musanyufu, nga welalikirila, omutima teguteredde wamu, oba nga wenyamira?]	1	2	3	4	5

Do you have any comments about the assessment?

Section G: Depression Hopkins symptom list **(CONTROL GROUP ALSO)**

Instructions: Olukalala luno wansi bw'ebubonero oba obuzibu abantu abamu bw'ebatera okubera nabwo. Lusomere oyo abuzibwa n'obwegendereza osse obubonero mulunziriri olulagga bw'abadde yeewulira mu mwezi oguwedde nga mwotwalidde n'olwaleero.

Listed below are symptoms or problems that people sometimes have. Please read each one of them carefully to the respondent and write in the appropriate column the score that best describes how he or she has been feeling **in the last one month including today**.

	Depression symptoms Obubonero bw'obulwadde bw'okweraliikirira	Not at all Nedda	A little Katonotono	Quite a bit Nnyo	Extremely Nnyo nnyo	Not applicable Tekigendera ku mbeera eriwo
		1	2	3	4	0
G1	Okuwulira obunafu, no'buyongobevu mumubiri Feeling low in energy, slowed down					
G2	Okwesalira omusango ku bibaddewo Blaming yourself for things					
G3	Okukaaba amangu Crying easily					
G4	Obutayagala kulya Poor appetite					
G5	Okubulwa otulo Difficulty falling asleep or staying asleep					
G6	Okubulwa essuubi Feeling hopeless about the future					
G7	Okunakuwala Feeling sad					
G8	Okufuna ekiwuubaalo Feeling lonely					
G9	Okwagala okwetta Thoughts of ending your life					

		Not at all Nedda	A little Katonotono	Quite a bit Nnyo	Extremely Nnyo nnyo	Not applicable Tekigendera ku mbeera eriwo
		1	2	3	4	0
G10	Okuwuulira nga onyigiriziddwa Feeling of being trapped or caught					
G11	Okweraliikirira ennyo ebintu Worry too much about things					
G12	Obutanyumirwa buli kintu Feeling no interest in things					
G13	Okwekaka okukola ebintu Feeling everything is an effort					
G14	Okuwuuliranga tolina mugaso Feeling of worthlessness					
G15	Obutayagala oba obutanyumirwa kwetaba munsonga z'obufumbo Loss of sexual interest or pleasure	DO NOT ASK	IN SENSITIVE CASES	e.g. widowed or divorced	or single or in the later years of life	

Total score = |__|__|__| DEPScore (If total score is 31 or more, offer the participant counselling and referral)

Section I: Socio-economic characteristics of the participant (CONTROL GROUP ALSO)

Livelihood activities

I 1 What are the main activities that produce food and earn money for **this household?**

Mirimu ki emikulu egireeta eby'okulya n'okufuna ssente mu maka muno?

	<u>CODES</u> (see below)			
ACTIVITY 1	<input type="text"/> <input type="text"/>	ACT1		
		Self employed	<input type="checkbox"/> Yes= 1; No =2	ACT1SE
		Regular Income	<input type="checkbox"/> Yes= 1; No =2	ACT1RI
ACTIVITY 2	<input type="text"/> <input type="text"/>	ACT2		
		Self employed	<input type="checkbox"/> Yes= 1; No =2	ACT2SE
		Regular Income	<input type="checkbox"/> Yes= 1; No =2	ACT2RI
ACTIVITY 3	<input type="text"/> <input type="text"/>	ACT3		
		Self employed	<input type="checkbox"/> Yes= 1; No =2	ACT3SE
		Regular Income	<input type="checkbox"/> Yes= 1; No =2	ACT3RI
ACTIVITY 4	<input type="text"/> <input type="text"/>	ACT4		
		Self employed	<input type="checkbox"/> Yes= 1; No =2	ACT4SE
		Regular Income	<input type="checkbox"/> Yes= 1; No =2	ACT4RI
ACTIVITY 5	<input type="text"/> <input type="text"/>	Specify _____		ACT5
		Self employed	<input type="checkbox"/> Yes= 1; No =2	ACT5SE
		Regular Income	<input type="checkbox"/> Yes= 1; No =2	ACT5RI

CODES:

- | | |
|---|---|
| 1 = Manual labour – unskilled | 2 = Farming – mainly subsistence |
| 3 = Fishing – small scale | 4 = Informal micro-enterprise |
| 5 = Manual labour - skilled artisan | 6 = Formal enterprise / service sector / professional |
| 7 = Other <i>please specify</i> _____ | |
| 8 = No activity that “produces food / earns money” for the household. The Household is therefore dependent on support from friends / relatives | |

I 2 What is **your** main activity?
Mulimu ki omukulu gw'okola?

RESPACT

Interviewer: for questions I3 and I4, please assess the roof; only ask if you are not sure of the answer from your observations.

I 3 **Yaseresa ki?** Type of roof

1 = thatch 2 = tile 3 = iron sheets 4 = plastic sheeting 5 = mixed iron/thatch

6 = mixed iron/tile 7 = other *specify* _____

☐

ROOFTYPE

I 4 **Omutindo /Embeera yakasolya eri etya?** Quality/state of the roof

Poor = ☐ 1

Average/fair/ok = ☐ 2

Good = ☐ 3

ROOFQUAL

I 5 **Enyumba eno yammwe ku bwamwe?**

Is the house owned by the household members living here?

1 = yes GO TO I 7 2 = no GO TO I 6

3 = don't know

☐

OWNER

I 6 Are you renting this accommodation? **Wano opangisaawo?**

1 = yes

2 = no

☐

RENTER

I 7 **Amazzi osinga kugajja wa?** What is your main water source?

1 = river

2 = well

3 = protected spring

4 = borehole

5 = rain catchment

6 = water tap in house

7 = trench

8 = tap-stand

9 = other please *specify* _____

☐

WATSOURCE

I 8 **Olina Kabuyonjo?** Do you have a toilet?

☐

1 = yes; 2 = no

TOILET

I 9 **Oba yee, kabuyonjo ya kika ki?** If yes, what type?

1 = pit latrine

2 = ventilated pit latrine

3 = flush

4 = pit

5 = other please *specify* _____

☐

TOILTYPE

I 10 **Musinga kukozeza ttaala yangeri ki munju muno okufuna ekitangala mubudde obwekiro?**

What is the predominant form of lighting for the house at night?

1 = electricity (HEP, generator, solar), 2 = paraffin lantern, 3 = wax candle,

4 = paraffin candle, 5 = other please specify

☐

LIGHT

Food (in) security and coping index

- I 11 **In the last 30 days**, have you been able to eat enough meals **EACH day** so as not to go hungry?

Mu nakku asatu eziyise, musobodde okulya emmere emala buli lunaku obutalumwa njala?

☐

Yes = 1, No = 2

MEALS

IF YES, GO TO I 13

- I 12 How often in the last month have you had to do any of the following?
Mirundi emeka mu mwezi oguyise gyewesanze ng'okoze bino wammanga?

(Circle a response to each question)

		Tekibangawo	Omulundi gumu oba ebiri mu wiiki	Emirundi egyisinga mu wiiki	Buli lunaku
A	Rely on less preferred & less expensive food? Okubeerawo ku mmere gyemutayagala nnyo n'etali yabbeeyi	Never	1x - 2x per week	3x - 6x per week	Every day
B	Rely on gifts / help from relative or friend outside the household? Okubeerawo ku birabo/buyambi okuva mu benganda oba abemikwano nga tebali mumaka muno.	Never	1x - 2x per week	3x - 6x per week	Every day
C	Borrow food, or borrow money to buy food from relatives or friends from outside the household? Okwewola emmere, oba ssente ezigula emmere okuva mu benganda oba emikwano nga tebali mu maka muno.	Never	1x - 2x per week	3x - 6x per week	Every day
D	Borrow money from a moneylender to buy food Okwewola ssente okuva mu bawola ensimbi okugula emmere	Never	1x - 2x per week	3x - 6x per week	Every day

E	Purchase food on credit? Okufuna emmere ku bbanja	Never	1x - 2x per week	3x - 6x per week	Every day
F	Eat wild foods Okulya emmere y'omunsiko	Never	1x - 2x per week	3x - 6x per week	Every day
G	Limit portions at meal times? Okukekkereza emmere eriibwa	Never	1x - 2x per week	3x - 6x per week	Every day
H	Reduce spending on other essential items? Okukendeeza ensasaanya kubyetagisa ebirala.	Never	1x - 2x per week	3x - 6x per week	Every day
I	Limit your own intake to ensure that your child / children get enough? Okukekkereza ku by'olya abaana bo basobole okufuna ebimala.	Never	1x - 2x per week	3x - 6x per week	Every day
J	Reduce number of meals eaten each day? Okukendeeza ku mmere gy'olya buli lunaku.	Never	1x - 2x per week	3x - 6x per week	Every day
K	Skip whole days without eating? Okumala olunaku nga tolidde.	Never	1x - 2x per week	3x - 6x per week	Every day

End of Interview

I 13

Time interview ends:

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Hours Minutes

TIMEND