

VOICE-C Ethnographic Interview Guide

Instructions: Use this guide for each Group 1 participant randomized to ethnographic interviews. Ethnographic interviews should touch on the topics suggested below, but the interviews should be iterative. Interviewers should take field notes on separate sheets of paper. Below each research question are notes about when and how the question should be asked at each visit. In general, visit 1 will collect initial information about the participant which will then be reviewed, expanded and updated as Visits 2 and 3. Visit 4 will focus on assessing their overall experience of the trial and of the trial product.

ENGLISH:

READ: Hello, my name is _____ [NAME] and I work with the RHRU. Thank you for agreeing to take part in this [home] visit interview. I would like to spend the next 1-2 hours talking to you about your life and your experiences of participating on the VOICE trial. I am especially interested in talking about the different aspects of your life and how these may have influenced your use of the study **gel/tablets**. I will be asking questions but there are no right or wrong answers and you do not have to answer any question that you may feel uncomfortable with. You can also stop the discussion at any time, ask me questions. If you decide to stop the interview this will not impact on your participation in the VOICE trial. Please remember not to use real names.

SESOTHO:

BALA: Dumela, lebitso laka ke _____ [LEBITSO] hape ke sebetsa RHRU. Ke leboha ha o dumetse ho nka karolo mo puisanong ha re o etetse [mo lapeng]. Ke rata ho sebedisa 1-2 ya dihora ke buisana le wena ka bophelo jwa hao le boiphihlello ba hao ba ho nka karolo dipatlisisong tsa VOICE. Haholo ke thahasella ho buisana le wena ka dintho tse fapaneng ka ha bophelo ba hao hape le hore se se bile le susumetso jwang tshebedisong ya **jele/dipilisi** tsa dipatlisiso. Ke ile ho o botsa dipotso fela ha ho na dikarabo tsa nepahetseng kapa tse fosahetseng le hona ha o a qobellwa ho araba potso efe kapa efe eo o ikutlwang o sa lokolohe o e araba. Hape o ka emisa puisano ena nako efe kapa efe, wa mpotsa dipotso. Ha eba o nka qeto ya o emisa puisano seo se ka se ame hampe ho nka karolo ha hao dipatlisisong tsa VOICE. Hle hopola hore o se sebedise mabitso a nnete.

ISIZULU:

FUNDA: Sawubona, igama lam ngingu _____ [IGAMA], ngisebenzela iRHRU. Ngiyabonga ukuthi uvume sikuvakashela sizokhuluma nawe ekhaya. Ngingathanda ukuchitha isikhathi esiphakathi kwehora elilodwa ukuya kwamabili ngixoxa nawe, mayela nempilo yakho nezipiliyoni zakho zokubamba iqhaza kucwaningo lweVOICE. Nginomdlandla kakhulu ukukhuluma nawe mayela nezingxenywe ezehluka hlukeni ngempilo yakho, futhi nokuthi ingabe lezi zingxenywe zibe nomthelela onjani ekutheni usebenzise **ijel/amaphilisi** yocwaningo. Ngizo kubuza imibuzo, kodwa ke azikho impendulo ezilungile noma ezingalungile, futhi awuphoqelekile ukuthi uphendule imibuzo engakuphathi kahle. Ungahoxa kule zingxoxo noma kunini, ungangibuza imibuzo. Uma unquma ukumisa le nkulumiswano, lokho akungeke kubenomthelela ekubambeni kwakho iqhaza kucwaningo lweVOICE. Khumbula ukuthi ungasebenzisi igama lakho langempela.

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1. Biography

Visit 1: Yes

Visit 2-4: Record any changes in their personal circumstances

ENGLISH:

Please tell me about your life, from when you were growing up until now?

SESOTHO:

Hle, mpoelle ka ha bophelo ba hao, ho tlohela o sa hola ho fihla hona iwale?

ISIZULU:

Ngicela ungxoxele ngempilo yakho, sukela usakhula kuze kube manje?

Birth place (including where, if in Johannesburg)

- ... When did you arrive in Johannesburg?
- ...Why moved here/why stayed here (if born here)
- Note current residence: (physical aspect, location, type of residence)
- ...Length of time residing here?
- ...Why live here

Major life events (lifetime and recent):

- ...Births
- ...Deaths
- ...Movements
- ...Schooling
- ...Marriage
- ...Work /employment

2. Community

Visit 1: Yes

Visit 2-4: Record any changes in their personal circumstances

ENGLISH:

Please tell me what it is like to live in this area:

SESOTHO:

Hle, mpoelle hore o jwang ho phela mo tulong ena:

ISIZULU:

Ngicela ungxoxele kunjani ukuhlala kule ndawo:

-how do you like living here (why, why not)
-how safe is it to live here (for you, your family, your children)

Social ties and networks

- How is it to have friends/make friends here?
- How is the social life?
- Neighbours?
- How close-knit are relationships with people around you?

Level of isolation/involvement in the community

- ...what do you do around here socially?

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- How are you involved in local community groups?
- Other types of groups?

3. Sexual/ relationship history

Visit 1: Yes

Visit 2-4: Record any changes in their personal/ sexual circumstances

ENGLISH:

Please tell me about the relationships you have had, and about your current relationships?

SESOTHO:

Hle, mpoelle ka dikamano tsa thobalano tse o bileng le tsona le ka ha dikamano tsa hao hona jwale?

ISIZULU:

Ngicela ungixoxele ngobudlelwane oke wanabo,nabantu besilisa futhi nangomuntu onaye manje?

- Current partner
- Previous partners
- Concurrent partners
- First relationship
- First sexual experience

4. Previous experience with research studies/trials

Visit 1: Yes

Visit 2-4: No

ENGLISH:

Have you ever participated in a research study or a trial previously?

SESOTHO:

E kaba o kile wa nka karolo dipatlisiso nakong e fitileng?

ISIZULU:

Inqabe uke wabamba iqhaza kucwango esikhathini esidlulile?

- What kind of research study/trial was it? What did it involve? Please explain
- What was your experience with the research study (while you were in; after you completed your participation?)
- Rumours about medical research
- How do you feel about the CAPRISA 004 results?

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5. VOICE trial experience

Visit 1: Yes

Visit 2-4: *Record their most recent clinic visit and to probe about any changes in their experiences; for example whether they are experiencing better or worse service at the clinic; whether they are finding it more or less difficult to participate; whether they have heard new stories about VOICE*

ENGLISH:

What are your experiences of the VOICE study so far:

SESOTHO:

Boipihlelo ba hao ka dipatlisiso tsa VOICE ho fihla hona jwale ke afe?

ISIZULU:

Yini izipiliyoni zakho zokuba kucwaningo lweVOICE kuze kube manje?

- ...What do you like and dislike about VOICE study?
-How do you feel treated during your visits?
- ...Comments about the services at the VOICE study
- Comments about the adherence sessions: what helps and what doesn't help, initially at enrolment and later during each FU
- ...What are the benefits and the challenge you have experienced of participating?
- ...What have you heard about the VOICE study in the community/around you (rumours, stories)

6. Reasons for joining the VOICE trial

Visit 1: Yes

Visit 2-4: No

ENGLISH:

What were the main reasons for joining the VOICE study and how did this happen?

SESOTHO:

Ke mabaka afe a bohlokwa a entseng hore o kenele dipatlisiso tsa VOICE le hona se se etsahetse jwang?

ISIZULU:

Yini izizathu ezisemqoka zokuthi uzibandakanye nocwaningo lweVOICE, futhi kwenzeke kanjani lokhu?

- Why join this trial?
- How were you recruited, describe in detail

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7. Experience of using gel/tablet

Visit 1: Yes

Visit 2-4: Probe in a similar way but to focus on their recent experiences of using the tablet/gel and specific events. See below.

ENGLISH:

What is it like to be using the gel / tablet?

SESOTHO:

Ho jwang ho ba o sebedisa jele/dipilisi?

ISIZULU:

Kunjani ukusebenzisa ijel/amaphilisi?

How do you feel about the group you were assigned to [gel vs. tablet]

- likes/ dislikes
- bodily changes
- timing and method
- Feelings of protection/perceived mechanism of action (how does it work?)
- Sexual experience and/or sexual interference with [gel / tablets]

(Subsequent Visits) Specifically focus on describing a particular event:

- Where they had a problem/challenge using their assigned product (is this typical?)
- When someone in the household/ a partner helped or interfered with use of their assigned product (is this typical?)
- When it was easy to use their assigned product, and what did they do to help them remember (is this typical?)

8. Adherence

Visit 1: Yes

Visit 2-4: Subsequent visits are to probe in a similar way but to focus on their recent experiences of using the tablet/gel. For example: has anything changed that has influenced your adherence.

ENGLISH:

How is it for you to take this product daily as told to do by VOICE staff?

SESOTHO:

Ho jwang mo o wena ho sebedisa sehlahiswa se sa dipatlisiso letsatsi le letsatsi ho ya ka moo basebeletsi ba VOICE ba o jweditse ka hona?

ISIZULU:

Kunjani kuwena ukuthatha lo mkhigizo nsuku zonke ngendlela owatshelwa ngayo ngabasebenzi beVOICE?

- Self report ... good adherence / poor adherence / inconsistent
- Reasons for good, poor, inconsistent adherence
- What are the reasons the last time you missed a dose (details: when, circumstances)

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- What methods do you use to remember to take **gel/tablet** (does it work or not...could it work in real life, or only because you are in a trial? Have you tried different ways to help you remember? Which ones worked and which ones didn't work?)

9. Explore “boundary” of Adherence

Visit 1: Yes

Visit 2-3: No

Visit 4: *Asked later in the interview*

ENGLISH:

Outside of a trial, would it be possible for you to take such a product daily (why, why not?) how different would it be for gel vs. tablets?

SESOTHO:

Ka ntle ha dipatlisiso, o ka etsahala hore o sebedise sehlahiswa se jwalo letsatsi le letsatsi (hobaneng o le jwalo kapa o se jwalo) ho ka fapana jwang ha e le jele e bapetswa le dipilisi?

ISIZULU:

Ngaphandle kocwaningo, ungakwazi yini ukuthatha umkhigizo onje ngalo nsuku zonke (kungani, kungani ungeke ukwazi). Ingabe kunganomehluko uma uqhathanisa ijel nama maphilisi?

- What do you think would be feasible and/or “good enough” adherence (acceptable amounts of missing doses): in normal life, under special circumstances (travel, when not having sex, when partner is travelling, other circumstances)

10. Basic demographic and household member information (membership, authority, economic, educational).

Visit 1: Yes

Visit 2-4: *Record any changes in their personal circumstances*

ENGLISH:

Please describe the people you live with in your household [Household defined as people who share resources and sleep under the same roof.]

SESOTHO:

Hle, hlalosa batho ba o phelang le bona ka lapeng la heno? [Lelapa le hlaloswa e le botho bao ba arolelanang leruo hape ba robala ntlong e le nngwe]

ISIZULU:

Ngicela ungixoxele ngabantu ohlala nabo ekhaya? [Abomuziwonke yilabo balala kanye kanye endaweni, besebenzisa bonke iindlela oziphilisa ngayo umndeni]

[Interviewer: Please use the questions below to fill in the basic table below]

- Who do you live with?
- Age, sex
- What does each household member do?
- Who supports the household? What do they do? What is your relationship with them?

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- How is household consumption determined?
- Who attends school, university?

	Age	Sex	Occupation	Student?	Relationship	HH income	HH Head
Ego	-	-					
HH1							
HH2							
HH3							
HH4							
HH5							

11. Explore “boundary” of Adherence

Visit 1: *No (already asked above)*

Visit 2-3: *No*

Visit 4: *Yes*

ENGLISH:

Outside of a trial, would it be possible for you to take such a product daily (why, why not?)
how different would it be for gel vs. tablets?

SESOTHO:

Ka ntle ha dipatlisiso, o ka khonahala hore o sebedise sehlahiswa letsatsi le letsatsi
(hobaneng o ka khona hoba o sa khone) ho ka fapana jwang ha e le jele ha e bapetswa le
dipilisi?

ISIZULU:

Ngaphandle kocwaningo, ungakhona yini ukuthatha umkhiqizo onje ngalo nsuku zonke
(kungani, kungani ungeke ukhone). Ingabe kunganomehluko uma uqhathanisa ijel nama
maphilisi?

- What do you think would be feasible and/or “good enough” adherence (acceptable amounts of missing doses): in normal life, under special circumstances (travel, when not having sex, when partner is travelling, other circumstances)

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12. Willingness to participate and to use

Visit 1: No

Visit 2-3: No

Visit 4: Visit 4 ONLY

ENGLISH:

Would you be prepared to join another clinical trial such as this one in the future if you had the choice?

SESOTHO:

A o ka e itokisetsa o kenela dipatlisiso tse ding tse tshwanang le tse na nakong e tlang he haeba o na le khetho?

ISIZULU:

Ungakulungela ukuzibandakanya nolunye ucwaningo olufana nolu kwisikhathi esizayo uma ukhetha njalo?

- Do you feel that your experiences of participating in the trial has changed you in anyway, or changed your relationship with romantic/sexual partners?
- What was the worst thing that happened to you in the trial?
- What was the best thing that happened to you in the trial?
- If the tablets or gel were shown to be successful would you be prepared to use them?