

COMMUNITY FOCUS GROUP INTERVIEWS/ MIMBHURISANO NA MINTLAWA YA NJHEKANJHEKISANO EMUGANGENI

HIV AND CHANGES IN COMMUNITY OVER TIME/HIV NA KU CINCA LOKU VEKE KONA EMUGANGENI HI KU FAMBA KA NKARHI

(For interviewer only: This topic is an icebreaker. We want to know how community experiences of HIV and AIDS were in the past and what they are like now. Specifically, we want to know about changes brought about by the introduction of ART. We also want to know how people think that HIV is perceived in the community).

*(For interviewer only: **Nhloko-mhaka leyi I yunyanyuri. Hi tsakela ku tiva ndlela leyi mintokoto ya muganga hi HIV/AIDS a yi ri xiswona eka nkarhi lowu nga hundza na leswi yi nga xiswona sweswi. Hi ku kongoma, hi tsakela ku tiva mayelana na ku cinca loku tisiweke hi ku tivisiwa ku va kona ka ART. Hi tlhela hi tsakela ku tiva ndlela leyi vanhu va hleketaka leswaku HIV yi tekisiwa xiswona la mugangeni).***

For people living with HIV in this community, how is life different than it was 15 years ago, let's say in 2003?

Eka vanhu lava hanyaka na HIV emugangeni, xana vutomi byi hambane hi ndlela yihi ni leswi a byi ri xiswona eka khume-ntlhanu wa malembe lama nga hundza, a hi nge hi 2003?

What are some of the most important changes related to HIV that have happened in this community over the past 15 years? What about the last 5 years? [**Probe:** Has the introduction of ART changed things? If so, how?]

Xana hi kwihi ku cinca ka nkoka swinene loku fambelanaka na HIV loku humeleleke emugangeni lowu eka malembe ya khume-ntlhanu lawa ya nga hundza? A swi ri njhani eka malembe ya ntlhanu lawa ya nga hundza? [Vutisisa:** Xana ku tivisiwa ka vukona bya ART swi ngava swi cincile swilo? Loko swi ri tano, hi ndlela yihi?]**

How are people living with HIV treated in the community? (**Probe:** positive experiences, negative experiences? Stigma? Family experiences?)

Xana vanhu lava hanyaka na HIV laha mugangeni va khomiwa hi ndlela yihi? (Vutisisa:** ntokoto wa kahle, ntokoto wo ka wu nga ri kahle? Ku hlawuriwa? Ntokoto wa ndyangu?)**

Has this changed over time? If so, how, why?

Xana leswi swi ngava swi cincile hi ku famba ka nkarhi? Loko swi ri tano, hi ndlela yihi, hikwalaho ka yini?

What would make things better (if not good now)?

Xana I yini lexi nga endlaka swilo swi antswa (loko swi nga ri kahle sweswi)?

HIV TESTING MOTIVATIONS AND EXPERIENCES MINHLOHLETELO NA NTOKOTO WO KAMBELA HIV

(For interviewer only: In this topic we want to know about the HIV testing motivations and experiences of older people. We want to know what they know about HIV testing services, motivations for going to test, and experiences before and after testing. We are also interested in how much testing features into how older couples manage their relationships).

(For interviewer only: Eka nhloko-mhaka leyi hi tsakela ku tiva mayelana na minhlohletelo na ntokoto wo kambela HIV eka vanhu lavakulu. Hi tsakela ku tiva leswi va swi tivaka mayelana na vukorhokeri byo kambela HIV, minhlohletelo yo ya kambela, na ntokoto loko va nga si kambela na loko se va kamberile. Hi tlhela hi va na ku tsakela eka ndlela leyi vatekani lava kuleke va lawulaka ha yona swilo leswi vaka kona eka ku kambela).

Baba Lazarus just retired from working in JHB. While he was away from his village home, he had some affairs/girlfriends at his place of work. He is now reunited with his wife and children after over 15 years of separation and only short visits during month's end and the festive season.

Baba Lazarus wa ha ku huma mpeceni ku suka Ejhb laha a tirha kona. Loko a ha ri le kule na muganga wa yena, u vile na vugangu/swinhwanyetana leswi a hanya na swona laha a tirha kona. Sweswi u hlenganile na nsati wa yena na vana endzhaku ka khume-ntlhanu wa malembe va nga tshami swin'we naswona ku ri tendzo ta xinkarhana hi ku hela ka n'hweti na hi nkarhi wa makhisimusi.

What will the reunion of Baba Lazarus with his wife look like? (*Probe*: in terms of household matters, living together under the same roof, their relationship, talking about sex, etc.)

Xana ku vuyelelana nakambe ka Baba Lazarus na nsati wa yena ku ta va hi ndlela yini? (Vutisisa: loko swi ta eka timhaka ta ndyangu, ku tshama swin'we eka ndzhawu yin'we, vuxaka bya vona, ku vulavula hi timhaka ta masangu, etc.)

(*Probe*, if necessary): Might HIV testing be part of their discussion? If so, how might the topic be raised? Who might encourage Baba Lazarus – or his wife – to be tested?

(Vutisisa, loko swi fanerile): Swi fanerile ku va nkambelo wa HIV ku va leswi va bulaka ha swona? Loko swi ri tano, xana nhloko-mhaka leyi yi fanele yi sunguriwa njhani? I mani loyi a faneleke ku hlohletela Baba Lazarus – kumbe nsati wa yena – ku va va kamberwa?)

What if Baba Lazarus used condoms with his girlfriends--is testing still necessary? What about for his wife?

Xana swi ngava swa ha fanerile ku kambela – loko ku ri hiku Baba Lazarus a tirhisa tikhodomu na varingani va yena? Xana ku nga endleka yini hi nsati wa yena?

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Are there any HIV testing services in this community? Where would he go? Are there testing places he would not go? Why?

Xana ku ngava ku ri na vukorhokeri byo kambela HIV laha mugangeni lowu? Xana a nga ya kwihi? Xana ku na tindzhawu to karhi to kambela laha a faneleke ku ka a nga yi? Hikwalaho ka yini?

Testing at the Clinic/ Ku kambela eklilini:

If you were explaining to Baba Lazarus what will happen when he goes to the clinic, what advice would you give him? What would you tell him to expect? (e.g., how long would it take, how would he be treated, what exactly would happen? etc)?_

Loko a mi ri ku hlamuseleni ka Baba Lazarus leswi swi nga ta humelela loko a ya eklilini, hi xihhi xitsundzuxo lexi a mi ta n'wi nyika xona? Xana a mi ta n'wi byela leswaku a langutela yini/ (e.g., nkarhi lowu swi nga ta teka wona, ndlela leyi a nga ta khomiwa hi yona, leswi swi nga ta humelela hi xiviri? Etc.)

As a man, what would his experiences be at the clinic? (*Probe*: positive experiences, negative experiences). What about if it was a woman? Or someone younger?

Tani hi vavanuna, xana mi khomiwa njhani eklilini? (Vutisisa: ntokoto wa kahle, ntokoto wo ka wu nga ri kahle). Xana a swi ta va njhani loko a ri wansati? Kumbe a ri ntsongo?

How might his experiences be improved?

Xana ntokoto wa yena wu fanele wu antswisiwa hi ndlela yihi?

Would he be treated differently if he was HIV positive? HIV negative?

Xana a ta khomiwa hi ndlela yo hambana loko a ri na xitsongwatsongwana xa HIV? A ri hava xitsongwatsongwana xa HIV?

What would happen at the end of his visit ?

Xana a nga langutela leswaku rendzo ra yena ri ta hela njhani?

What do you think he would do or feel after he left the clinic? (*Probe*, disclosure, feelings, etc.) How would this be different if he found out he was HIV negative?

Xana mi ehleketa leswaku a nga endla yini, a titwa njhani endzhaku ko suka eklilini? (Vutisisa, ku humesela ehandle xiyimo xa yena, vutitwi bya yena, etc.) Xana leswi a swi ta va swi hambanile hi ndlela yihi loko a kumile leswaku u hava xitsongwatsongwana xa HIV?

In general, who helps or encourages people to get tested in this community? What makes it hard to get tested?

Hi ku angarhela, I mani loyi a pfunaka, kumbe ku hlohletela vanhu leswaku va kamberiwa laha mugangeni lowu? Xana I yini lexi endlaka swi tika ku kambela?

What do you think about home based testing? What about mobile testing? What about couples testing? What are some of positive things about it? Any negatives? Would more people test? Would more people go on treatment? What advice would you give to people expanding this service in the community?

Xana mi hleketa yini hi nkambelo lowu endleriwaka emakaya? Vukamberi lebyi taka emugangeni? Hi nkambelo wa varingani? Xana hi swihi swa kahle hi swilo leswi? Ku ngava ku ri na leswi nga riki kahle? Xana vanhu vo tala va nga kambela? Xana vanhu vo tala va nga teka vutshunguri? Xana hi xihi xitsundzuxo lexi u nga xi nyikaka vanhu ku kurisa vukorhokeri lebyi laha mugangeni?

ANTI-RETROVIRAL TREATMENT/ VUTSHUNGURI BYA ANTI-RETROVIRAL

(For interviewer only: In this topic we want to know about people's perceptions of, and clinic and life experiences on, ART. In particular, what is the clinic experience of starting/taking ART like? Who supports people with taking their meds? What is daily and romantic life like on ART? And in general, what are the positive and negative perceptions of ART in the community as a whole? (ie, how has ART not just affected those who are HIV positive?).

(For interviewer only: Eka nhloko-mhaka leyi hi tsakela ku tiva mayelana na mavonelo ya vanhu hi, na kliliniki na ntokoto wa vutomi eka vutshunguri bya ART. Ngopfu-ngopfu, xana hi wihi ntokoto wa klilini wo sungula/teka vutshunguri bya ART, I mani loyi a seketelaka vanhu ku teka vutshunguri bya vona, xana vutomi bya siku rin'wana na rin'wana xikan'we na vutomi bya swa rirhandzu byi njhani, naswona hi ku angarhela, xana hi wahi mavonelo ya kahle na lawa ya nga riki kahle hi vutshunguri bya ART emugangeni hi ku angarhela (ie. Hikwalaho ka yini vutshunguri bya ART byi nga khumbangi lava nga na xitsongwatsongwana xa HIV).

Makhi Thandi is recently widowed; her husband died from AIDS. She went to the clinic and the doctors found her to be positive for HIV and started her on treatment.

Mhaki Thandi I noni eka nkarhi wa sweswi; nuna wa yena u lovile hikwalaho ka AIDS. U yile ekliniki naswona vadokodela va kumile leswaku u na xitsongwatsongwana xa HIV na ku tlhela va n'wi nyika vutshunguri.

What was the process she went through to be put on treatment? (What exactly happened?)

Xana hi swihi swigava leswi a swi fambeke ku fikela loko a ta nyikiwa vutshunguri? (Xana ku ngava ku endlekile yini, kahle-kahle?).

What would make it easy for her to take treatment? What would make it hard?

Xana I yini leswi nga ta endla leswaku swi n'wi olovela ku teka vutshunguri? Xana I yini leswi nga endlaka swi tika?

Are there reasons why someone would not agree to be on ART? (*Probe*, worried people will find out? Financial reasons?)

Xana ku ngava ku ri na swivangelo swa leswaku un'wana a nga pfumeli ku teka vutshunguri bya ART? (*Vutisisa*, a vilela leswaku vanhu va ta swi tiva? Swivangelo swa swatimali?)

Is she likely to tell people that she is on treatment? If so, who?

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Xana swi nga endleka leswaku a byela vanhu leswaku u teka vutshunguri? Loko swi ri tano, I vamani?

What is her life going to be like on treatment? What would her daily routine look like?

Xana vutomi bya yena byi ta va hi ndlela yihi loko a ri ku tekeni ka vutshunguri?

Xana mintirho ya yena ya siku na siku yi ta va njhani?

Who/what is most likely to assist her in taking her treatment (e.g., going to appointments, reminding her to take her meds, etc.) (*Probe*: what if she doesn't have children, or her children are away – studying or working, in JHB, etc?)

I mani/I yini leswi nga n'wi pfunaka eku tekeni ka yena vutshunguri (e.g., ku ya eku tekeni nakambe, ku n'wi tsundzuxa ku teka vutshunguri bya yena, etc.) (Vutisisa: kutani loko a nga ri na vana, kumbe vanava yena va ri kule – eku dyondzeni kumbe eku tirheni, e JHB, .?)

In general, who helps or supports people on ART in this community? How?

Hi ku angarhela, I mani loyi a pfunaka kumbe ku seketela vanhu lava va tekaka vutshunguri bya ART laha mugangeni lowu? Njhani?

Will Makhi Thandi be able to date or marry again? Where can she meet a partner? What will their relationship be like? What if Makhi Thandi were a man? Would it be the same or different? In general, what is the romantic life like for HIV positive older people who do not (no longer) have a spouse?

Xana Mhaki Thandi a nga swi kota ku va na muringani kumbe ku tekiwa nakambe? Xana a nga n'wi kuma kwihhi muringani? Xana vuxaka bya vona byi ta va hi ndlela yihi? Xana loko Mhaki Thandi a ri wanuna? A swi ta va swi fana kumbe ku hambana? Hi ku angarhela, xana vutomi bya swa rirhandzu bya vanhu lavakulu lava va nga na xitsongwatsongwana xa HIV lava nga riki (va nga ha riki) na varingani va vona byi njhani?

In general, how has the availability of ART affected this community? (*Probe*, positive ways, negative ways, for HIV negatives not just for HIV positives)? Can you tell anymore if people are HIV positive?)

Hi ku angarhela, xana ku va kona ka vutshunguri bya ART swi khumbile muganga lowu hi ndlela yihi? (Vutisisa, tindlela ta kahle, tindlela to ka ti nga ri kahle, eka vanhu lava nga riki na xitsongwatsongwana xa HIV ku nga ri lava va nga na xitsongwatsongwana xa HIV)? Mi nga ndzi byela swo tala loko vanhu va ri na xitsongwatsongwana xa HIV?)

CHRONIC DISEASES/ MAVABYI LAWVA YA NGA TSHUNGULEKIKI

(For interviewer only: In this vignette we are trying to understand the motivations and experience of being tested for NCDs (e.g. diabetes/sugar, hypertension) and if HIV testing is also part of care for chronic conditions. We are also interested in the experience of living with NCDs.)

(For interviewer only: Eka xiyenge lexi hi ringeta ku twisisa minhlohletelo na ntokoto wo va mi kamberiwile NCD ni loko nkambelo wa HIV wu wi xiphemu xa mpfuno eka swiyimo leswi nga tshungulekiki. Hi tlhela hi va na ku tsakela eka ntokoto wo hanya na mavabyi lawva ya nga tshungulekiki (NCDs)).

Makhi Mpumi is 45/55/65 [adjust age given age of FGI participants] years old and has been feeling unwell for sometime. She went to the clinic to consult and found out she has high blood pressure (or hypertension or diabetes).

Mhaki Mpumi u na 45/55/65 [lulamisa malembe hi ku ya hi lawa ya nyikiweke hi vangheneleri va FGI] wa malembe naswona u vile a nga titwi kahle swa nkarhinyana. U yile ekliliniki ku ya pfuniwa naswona u kumile leswaku u na high blood (kumbe hypertension kumbe vuvabyi bya chukele).

What was she feeling that made her go to the clinic? Why might she not go to the clinic?
Xana a twa yini leswi nga endla leswaku a ya ekliliniki? Hikokwalaho ka yini a fanele ku ka a nga yi ekliliniki?

What is her experience like at the clinic? (What happened? What advice was she given? How was treatment/interaction with the nurse?) Would her experience had been different if she were a man? Would he have been as likely to consult? What would his experience have been?

Xana u khomeke njhani ekliliniki? (ku humelele yini? Xana u nyikiwile switsundzuxo swihi? Xana u khomiwile njhani hi muongori?) Xana ntokoto wa yena a wu ta va wu hambanile loko a ri wanuna? Xana a ta va a yile ku ya kuma mpfuno? Xana a tava a khomiwe njhani loko ari wanuna?

What is it like to manage high blood pressure/hypertension/diabetes in this community? What are the challenges? What makes it easy? How often does she need to visit the clinic to manage treatment for high blood pressure/hypertension/diabetes?

Xana swi va njhani ku lawula high blood/hypertension/vuvabyi bya chukele emugangeni lowu? Xana hi kwihi ku tikeriwa? Xana I yini leswi endlaka swi olova? Xana u fanele ku ya kangani ekliliniki ku kota ku lawula vutshunguri bya high blood/hypertension/vuvabyi bya chukele?

Would the health worker suggest that she also test for HIV while she was at the clinic? How would that happen?

Xana mutirhi wa swarihanyu ata n'wi tsundzuxa leswaku a kamberiwa HIV loko a ha ri ekliliniki? Xana a swi ta endleka hi ndlela yihi?

What is it like to have more than one illness to manage in this community?

Xana swi va njhani ku lawula ku tlula mavabyi man'we laha mugangeni lowu?

Is the experience of living with NCDs different or similar to dealing with HIV?

Xana ntokoto wo hanya na mavabyi lawa ya nga tshungulekiki no vulavula hi wona (NCDs) wu hambanile kumbe wu fana njhani eka ku langutisana na HIV?

**CLINIC EXPERIENCES AS PEOPLE AGE / NTOKOTO WA TIKLILINIKI
LOKO VANHU VA YA VA KULA**

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What are the different reasons people will be going to the clinic as they age? Are there differences by gender?

Xana hi swihi swivangelo swo hambana leswi nga endlaka leswaku vanhu va ya eklililiki loko va kula? Xana ku ngava ku ri na ku hambana ku ya hi rimbewu?

How often do older people go to the clinic to seek care?

Xana vanhu lavakulu va ya kangani eklililiki ku ya kuma mpfuno?

Are there times that older people feel unwell but choose not to go the clinic? Why? Are there differences by gender?

Xana yi ngava yi ri kona minkarhi leyi vanhu lavakulu va titwaka va nga pfukanga kambe va nga yi eklililiki? Hikwalaho ka yini? Xana ku ngava ku ri na ku hambana ku ya hi rimbewu?

Are there groups of people who get the best service at the clinic? The worst service at the clinic? (*Probe:* gender, illness status, rich/poor, patronage/knowning clinic staff, etc.)

Xana ku na ntlawa wa vanhu vo karhi lava kumaka vukorhokeri byo antswa etiklililiki? Vukorhokeri byo ka byi nga ri kahle nakantsongo etiklililiki? (Vutisisa: rimbewu, xiyimo xa mavabyi, ku fuma/vusiwana, ku vaxaka/ku tiva mutirhi wa le klililiki, etc.)

GENERAL/ HI KU ANGARHELA

What are the most important challenges/issues facing this community? Are they different from the issues from 10 years ago? 5 years ago? What do you think might change in the future?

Xana hi kwihi ku tikeriwa lokukulu lo kulangutaneke na muganga lowu? Xana ti ngava ti hambanile eka timhaka leti a ti ri kona eka malembe ya khume lawa ya nga hundza? Malembe ya ntlhanu lawa ya nga hundza? Xana mi ehleketa leswaku ku ngacinca yini eka nkarhi lowu taka?

What are the most important health issues in this community? (We have talked about HIV, but are there health issues that are more important? That have been ignored?) What are the biggest health concerns for older persons?

Xana hi tihi timhaka ta nkoka ta swarihanyu emugangeni lowu? (Hi vulavurile hi HIV, kambe ku ngava ku ri timhaka tin'wana ta swa rihanyu leti nga ta nkoka ngopfu? Leti ti nga tekeriwangiki enhlokweni?) Xana hi swihi swivilelo-nkulu swa rihanyu swa vanhu lavakulu?

Which health issues in the community do you think have been dealt with well? (*probe:* e.g give examples of good interventions they have already been exposed to)?

Xana hi tihi timhaka ta rihanyu laha mugangeni leti mi hleketaka leswaku ti lulamisiwile kahle swinene? (Nyika swikombiso swa kahle leswi endlilweke swa rihanyu?)