Enumeration FGD #2—survey participants that did not join the cohort study

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Interview date: 21 Nov 2017
Interview language: English & isiXhosa
Duration: 94:96

Interview text:

LM: We want to find out what young women think about this new method, this new method of preventing. We want to find out, are young women going to be interested or not in this thing, because we went to the houses of 650 girls in [this community]. We went to so many girls' houses, and a few of them were interested and they have come and they have joined, but most of them haven't. I am just curious, I wanted to meet you guys today, because I wanted to know what you thought when we came knocking on the door, what your impressions were, what was going on for you. So, that's kind of what I want to talk to you about. If you want to learn more about the study after, we can share that with you and you can come another day, and we can tell you more about that. Any other questions from anybody? I will just close the door, so we have privacy. Anybody? [Silence] This is a small group, so it shouldn't take long, maybe an hour, to an hour and a half. So, if we can go around, introduce yourself, maybe tell us, you can say your name if you want to, we won't type it up, or just your number, can you tell me, how old you are, maybe what section you stay in, in [this community]? Yes, maybe let's just start with introductions first. Maybe if you wouldn't mind, also share if you are in a relationship now, or not, and if you are, maybe a little something about your partner, like how old he is or something? Number one, can you start?

F1: I stay in N* and I'm in a relationship.

LM: How old are you?

F1: 19.

LM: Maybe also, are you in school, or if you're not in school, are you home, are you working, a little bit about what you are doing. Are you studying?

F1: I'm doing grade 12.

LM: Maybe tell us a little bit about your partner too, like how old is he, and how long have you been seeing him?

F1: I think he is 25, and it's been two years.

LM: Okay, and does he also stay in [this community]?

F1: Yes.

LM: Fantastic, thank you for that. Number two?

F2: I am staying in N* Road. I am not in a relationship.

LM: Are you studying now?

F2: No, I'm not studying.

LM: Okay, so you're home. Number three?

F3: My name is N*, my surname is X*, I am 17 years old. I live in the [informal settlement], on the E section. I am in a relationship with a 25 year old guy. We have been seeing each other for two years. And ja, I am at school, I am doing grade 11.

F4: I am A*. I stay in S* Road. I am 20 years old. Last year I did grade 12, now I'm taking a gap year. I'm in a relationship with a guy, 25 years, and we have been dating for six years now.

LM: Six years?

F4: Ja.

NM: 25? Maybe you are dating the same guy [laughter].

LM: Ja, we don't want to discover that and have any dramas today. Okay and you are number four, so when you speak, you can just say your number each time so we can tell the different voices apart later on, because when you just listen to the audio, it's harder than when you see the faces. Okay, fantastic, so I know that each of you guys like got a home visit from someone on our team. I'm not even sure when, but I'd love to hear from each of you if you can tell me the story of what happened, and what you remember about that day. So, I'm curious, like how long ago was it? I should also say, throughout this conversation, you know, each of you will have your own experience and your own, you know, views and opinions, and I want to hear from everyone. So, somebody might have liked something, like maybe you loved this video that you saw, and somebody else maybe hated it, and both are okay. I want to hear from the one who loved and the one who wasn't so sure. Like you, it sounds like maybe you're interested in these pills, you, you might not be, and that's fine. So, what I really want today, if it's okay, to hear from everybody about your own opinions, and if somebody has an opinion that is different from you, don't be shy about sharing yours. So, I just want to hear from everyone. So yes, I want to know what you remember about the day they came to visit you at home. How long ago was it? What were you doing at the time? What did they say? Like, what did you think as you answered the questions? I just want to know what you remember about that day, and how did you feel at the time? [Knock on door] Yebo? Hello. Fantastic, excellent, welcome, welcome, come on in. Maybe let's even pause this for a moment. Excellent, hi guys, how are you?

F5: Good thanks, and you?

LM: Excellent, thank you for coming. We will just carry on with introductions, but if you can sign the consent, after you've had a look. Okay, so I was asking for someone to tell me what you remember about that day when they came knocking at your door. Who can start? Number three, oh, and you will be number five.

F3: I remember she came in.

LM: Who? Who came, do you remember, or no?

F3: I don't remember, but it was a short lady. Then, she told us her name, I forgot, and she told us about the triple, and the explained what it does, that it prevents HIV, and then she gave us those questions to answer, and then we answered the questions. Then she said that she was going to call us the following week, I think. But I think it was a month or two months back, I'm not sure.

LM: When they came to your house, like a while ago?

F3: And then she said that she was going to call us the following week, but if she didn't call us, then we can come and join, ja.

LM: Ja, okay, and did she also show you the video?

F3: She did show the video. It was interesting, more especially because I knew some of the people who were in the video. So I was more interested that there are some other people that I know who are in the study, and they are doing just fine. So, I was interested in learning more and maybe joining the study.

LM: Hmm, exactly. So, after that, so then she left?

F3: She left, yes.

LM: What did you do or what did you think?

F3: [Chuckles] I thought it was interesting, but then when I talked about it to other people, um, they said that the pill did this and this to you.

LM: Like what? Can you remember what other people said?

F3: Yes. They said that it make you dizzy, sometimes. Sometimes it makes um, your stomach hard, you lose appetite, and ja, that's all I can remember.

LM: Hmm, so then you thought...?

F3: Ja, then I lost a little bit of interest.

LM: Ja, and you never came to learn more, right?

F3: No, I never came.

LM: That's fine. Okay, fantastic, thank you, number three. Who else remembers what happens, what happened the day they visited?

NM: Number four?

LM: Ja, I want to hear from number four too [laughs]. First of all, how long ago was it that they came to your house? Was it a long time ago?

F4: It was a long time ago.

LM: Do you remember how long?

F4: No.

LM: Okay, what do you remember about that day?

F4: What I know about that day, she explained everything about the study, and she said that if I want to join, I can join. Then if I don't, if I'm uncomfortable with that, I cannot join.

LM: Hmm mm, and had you heard about this pill before, before they came to your house?

F4: Ja, I heard, and one of my sisters joined the study.

LM: Joined this study?

F4: Ja.

LM: Okay, one of your sisters did?

F4: Ja.

LM: Like at your home? Do you stay with her?

F4: No, we're not staying at the same house.

NM: When was that?

F4: She joined last month.

NM: Oh, last month. I thought she was referring to the 3P pill.

LM: Okay, and so when she came, did she also show you the video as well?

F4: Ja, she showed me the video.

LM: Okay, and then you answered the questions. What did you think, like you know, when she told you about this pill and how it works, were you surprised at this thing, that you could take a pill? Like what was your opinion? Did you believe her or not? Like how did you think?

F4: Ja, I do believe her, but I said to her, I'm not going to join this, not interested.

LM: And why not? It's totally fine, I'm just curious like what your reasons were?

F4: [Laughs] because sometimes I will forget to take the pill, that's why.

LM: Ja, thinking that it will be difficult to remember to do every day. Did you have any other concerns?

F4: No.

LM: Okay, fantastic, and did anyone phone you afterwards?

F4: No.

LM: Like you never heard from us again? Got you. Were you a bit interested to learn more about the study, or did you think this isn't for me?

F4: Ja, I can just listen but I am not interested.

NM: Oh, okay, she was not interested. Just only to come and do the session.

LM: Excellent, and thanks for agreeing to come today. I appreciate that. Who else remembers what happened when they visited your house? Number one, how long ago was it that they came?

F1: I think it was, I'm not sure.

LM: Okay, I know it was a while ago, it was like quite a few months ago, but what do you remember about that day?

F1: I think it was Y*, she came to our house. We were watching TV. Then she told us about the study, but I already knew about it because my cousin is taking the pills, and my friend.

NM: So you were with your cousin that day?

F1: Hmm mm.

LM: Okay, so they had already joined early, like a long time ago. Okay, what else do you remember from that day? Do you remember what you thought of it as you watched it?

F1: Uh-uh, no.

LM: Okay, cool, and did anyone phone you later?

F1: No.

LM: So, no one called. We didn't do a good job of these calls, I don't think [laughs]. Okay, and ja, were you interested to learn more about this pill or not? Why, or why not?

F1: Hmm, I am interested.

LM: Like you were a bit interested, but not so much. You came on your own, but you were like, put it in the back of your mind, kind of?

F1: Ja.

LM: Did you think about it much after that day?

F1: No.

LM: You kind of forgot?

F1: Ja.

LM: Ja, okay, cool. Did you speak to anyone about it afterwards, like what you learnt?

F1: Uh-uh.

LM: Okay, cool, interesting. Super, thanks for that. Okay, you guys, what do you remember?

F5: I think she came to our house like two times, and then I wasn't there, and then she came again, and my dad was a bit uncomfortable. I don't know why, and then she didn't really, for me personally, she didn't explain it properly, because I didn't, everyone was talking about a video, I didn't watch a video, I wasn't quite sure why.

LM: Yes, so some of the girls didn't see the video. So that wasn't an accident, that was on purpose, because we were wondering, will having a video like this make people more interested, versus if they never see the video, will they be less interested. So, that wasn't an accident.

F5: Oh, okay.

LM: But okay, so they never showed you the video?

F5: No.

LM: Got you, I'll show it to you just now. What else do you remember from that day?

F5: She asked whether I was, before I did the survey, she asked when last did I have like my HIV test, and it was quite recent, because like I had it on my birthday. Then she asked my age, and then ja, she asked whether I'm interested to do the survey first, like, and I said okay. The questions were really irrelevant for me at that stage, so ja.

LM: Ja, you think it just didn't apply to you or your situation.

F5: Ja, it didn't apply to me at the time.

LM: Ja, so we're moving around and introducing ourselves. Can you also just let me know how old you are, and what you are doing at the moment, if you are studying or not, and if you are in a relationship or not.

F5: I'm 19. I'm studying.

LM: You're at high school?

F5: No, I'm at a college. I don't know, I don't know what to call my relationship status at the moment, complicated.

LM: Complicated. There is someone, but ja. I know a lot of relationships go?

F5: I don't have many, but like it's just, I don't know what it is. That's it.

LM: Ja, for sure, I understand. Okay, so do you remember anything else about the questions that they asked?

F5: No, I just rushed it, that's it.

LM: Ja, you wanted to get this over, and you said that your dad was a bit uncomfortable with it?

F5: Ja, I don't know why, but I told him that I go to the centre, so you shouldn't be... because the thing is, my dad is like, no, you guys make money out of us, so I'm like it's really not like as it looks like to you. I think maybe you should have like, I don't know, and she didn't explain it properly to my dad. Once my dad heard HIV and AIDS, I think he was a bit like lost it, so ja.

LM: Interesting, I see, yes. Hello there. [New person arrives] So, what we need, because these guys aren't in the study, they were just enumerated. We just need like a page for them to sign. If you don't have one, I can open up my computer and send you one, probably, but we just need like five vouchers, and just like a sheet. Even though I'm in the middle of this discussion, I will try [laughs].

FS: But they don't have PIDs?

LM: Ja, they don't, because they're not...

FS: We will just need to do something, scribble something.

LM: That's fine, I've got from... I will send you something, you can just change the columns as you like. But basically, put a name, phone number and amount received.

FS: Okay.

LM: Okay, I will do this at the same time. Okay, so that's interesting, so your dad was like a little unsure?

F5: Ja, what's my relationship between all of this? Nothing.

LM: Yes, so it was a bit awkward?

F5: Ja.

LM: Did anyone else find that as well, was it a little difficult in your household when they came to speak to you? Okay, and had you heard about this pill before?

F5: Ja, like my friend is on the pill.

LM: Okay, and now at the moment in this study?

F5: Ja.

LM: Because we did another study last year.

F5: Ja.

LM: Okay, so it wasn't a surprise to you?

F5: No. She also told me about the health benefits, about the check-ups and stuff like that.

LM: Okay, and so what did you think of all this?

F5: I think it's pretty cool for someone that is probably in like multiple relationships, the pill, ja. So, if you're not quite sure of the other person's status, it's quite a, like a surety for you personally if there

was no protection used in that situation, or in case if there is a rape or something, ja. So, it's pretty cool.

LM: Were you interested in finding out more, or not so much?

F5: Um, not really, I wasn't really interested.

LM: Can you say like why not for you?

F5: Well, at the time I wasn't interested, now I'm not quite, like I'm a bit like maybe.

LM: Ja, and at the time, if you think back to that day, what did you think?

F5: Well, firstly I'm not sexually active, and secondly, how is it really going to help me because I'm fine, like my status is fine. So, ja.

LM: Like you're not concerned, like HIV isn't a problem for you now?

F5: Ja.

LM: I get you, that's fine. Okay cool, and did anyone phone you afterwards?

F5: No.

LM: No, okay, and you obviously didn't hear more. Okay, that just leaves number two then, right? Can you tell us what you remember from that day?

F2: She came, but I don't remember when. She showed me the video, she told me if I am interested to join the study, but that time I was not interested.

LM: Ja, and that's fine. I'm just curious, why? Why not? Like what were you thinking at the time? You can tell Ntombi as well, that's fine.

F2: I don't know why, but I was not interested.

NM: You were just not interested? [Chuckles]

LM: What concerns did you have about it, if any? Why were you not interested?

NM: She had no concerns.

LM: Okay, but just not interested?

NM: Hmm.

LM: Alright, we will see, just give me one second. [Typing email] Sorry about that guys, my apologies. Okay, I am curious, those of you who have heard about this pill and know people who are on it, is there anybody who could just explain to me a little bit about what it is and your understanding of how it works so that we are all on the same page about what PrEP is? Like what have you heard? What do you understand?

F3: It's a pill that you have to drink every day, and it prevents you from getting HIV.

LM: Fantastic, and does anyone have any idea how it does that? Like, how do you imagine it working in your body and being able to prevent this virus? Do you have any idea, number one, [laughter]? You say you have no idea, is that right?

F1: Hmm.

LM: Okay, cool. Others, does anyone have an idea like how it's able to do that?

FS: No.

LM: What do you think?

FS: I think it works like the family planning pills, even though I'm not sure how it works in the body. But I think it pretty much does the same job.

LM: So who knows how, but it's similar to like a birth control in a sense. Ja, fair enough. Is there anyone here who struggles to believe that you could take a pill that would prevent HIV? Like when you hear this, you think really?

FS: Ja, because I know like for example like with my biology background, you can treat a bacteria, but a virus, it's kind of like a different story. So I'm also a bit like...

LM: Like how can this be?

FS: Ja.

LM: So you've got questions, right?

FS: Ja.

LM: Anybody else have questions as to whether this would really work, or not?

FS2: I'm also not sure, even though I want to try it out. Not try it out, as in see if it's going to work [laughter], like test it on me, but I want to try it, yes.

LM: Like if it does work, hey, like you know.

FS2: Ja, but then I couldn't take the risk, but ja, I'm also not sure.

LM: Ja, and okay, was it new information for any of you? It seems like most of you knew in the study already. Was there anybody who hadn't heard of the pill when they came to visit you? Okay, well then otherwise, can you think back to the first time you heard about the pill, like if you did have a friend who told you about it, I'm curious what you thought, what your impression was when you heard that there was a pill that can prevent. What did you think?

FS: It's pretty cool, because it's like your own ARVs, in a way, but even though you are not diagnosed with HIV or AIDS. So ja, it's like a prevention method for the other party, if your partner is infected.

LM: Okay, others, what did you think when you heard about it? Or how did you feel when you discovered there was this new way of preventing? Like did it sound, you know, were you curious, excited, not really that interested or not that bothered about HIV anyway? Like what was your reaction that you heard there was something you could do besides condoms, I guess? [Silence] Maybe for others, if they do know someone who is taking PrEP, what have they been saying about it? What kinds of things have you heard other people saying?

NM: Like your cousin, what is she saying about it?

LM: Hmm, and I'm curious, like is it going well for her? Is she having problems with it? Like you know, it could be, ja, like what has she said so far?

FS: I don't ask her. It's just that she lost weight.

LM: Oh right, ja, and she thinks it's because of the pill, not something else? Okay, interesting. Number three, what have you heard people saying?

F3: I haven't heard any good comments about it.

LM: What are the bad comments about it?

F3: Like I've said before, they say that it makes them feel dizzy, or it makes them lose appetite. Some people even think of stopping the study, because they are saying there is no positive impact from the pills.

LM: Interesting, and those people, what are they complaining about the most? Is it dizziness, or do they have another problem with it?

F3: No, it's just the dizziness, and the appetite losing.

LM: Hmm, interesting. Others, what have you heard people saying?

F4: My sister complained that the pill is too much for her.

LM: It's what?

F4: It's too much. It's probably big.

LM: Like the size of it, or just taking it every day?

F4: Yes.

LM: Like it's hard to remember every day. Okay, and when you hear about it, or if for a moment when you sit there and think do I want to do this myself, if you sit there and ask yourself that question, how

do you feel about the idea of taking a pill every day? What is your reaction to that, like if you imagine doing that yourself? How do you feel about that?

F5: Like already I forget my multivitamins, and I don't take them every day. So when I remember, I'm like oh, my pill. So like taking it every day, I will probably forget, and it probably won't be as active as it's supposed to be than if I was taking it every day. Yet again, it's kind of useless me taking it and I'm not sexually active.

LM: Others what do you think about the idea of a pill you'd have to take that often?

F3: I also think it's a difficult thing to do. More especially, I'd prefer medicines instead of pills. So I'd forget even more, more especially I don't like pills. So it would also be a difficult thing for me.

NM: You don't like them because you have difficulty in swallowing, or you just don't like pills?

F3: I don't like pills, and the fact that other pills are big, and they get stuck in your mouth [chuckles].

LM: For sure [chuckles]. Anyone else? Have you heard any other people talking about these pills? Like maybe they aren't in the study, but have you heard anyone just around [this community] talking about these things?

FS: I've heard it on, what's that show? It's the one that used to play, Shuga.

LM: Shuga, the TV show?

FS: Ja, but it was like a teenage show, and then this guy from Nigeria, he was infected but he didn't want to infect his girlfriend. So, I heard it on the TV show, so I was like oh, this is like that.

LM: Okay, like when you saw that, did you think this not just some special [this community] thing?

FS: Yes, I thought it was a Desmond Tutu thing, and then when I heard it on TV, I had like affirmation now. Oh, okay, it's a legit thing. I wasn't quite sure, because I was like oh, maybe we're guinea pigs.

LM: Did anybody else what that episode of Shuga? You saw it? Okay, and did anyone else think like it's weird that you are not hearing about it in the newspapers or outside? Like anyone else thinking it's just some Desmond Tutu thing [laughter]? I like how you put that. Number four, did you think it was just like a Desmond Tutu thing, but not real?

F4: Ja.

LM: Because that's one of the challenges with a brand new thing, is like how do you get the word out about something when people haven't heard of it before. I think a lot of participants are finding that when they tell their parents or whatever, they're like what?! There is no such thing as a pill, you know. Anyone else hear other people talking about it, or saying anything negative about the pill? Okay, so you have heard friends complaining about side effects. Do all the people that you know that are in the study, have they all been complaining?

FS: Yes.

LM: Or just some of them? Really, like a lot?

FS: Not a lot. About three or four people that I know.

LM: Interesting.

NM: But you still wanted to try it?

FS: Yes [chuckles].

LM: What makes you interested in it? Like what is your feeling?

FS: I don't want to be infected one day, so I'm just looking out for myself. I just want to protect myself, because you never know, even if you're in a relationship for how many years, you never know what your partner might do when you're not around, or what your partner does when you're not around. Sometimes they don't even mean it, maybe it's just a once-off thing, but then it could affect your life. It's a life changing thing.

LM: For sure, for sure. Tell me, now I realise you guys are not experts, you guys had kind of a short meeting with one of these community workers, right? So they gave you some information and maybe

you read about it as well. But I'm curious, what concerns do you have about these pills? Are there any other concerns, like reasons why you think maybe I wouldn't want to put this in my body and so forth?

FS: What are the like proper side effects?

LM: I'm not going to answer now, but I'm happy to answer at the end. But that's a question you have, is like will it affect my body in a negative way, right? Others, what other concerns or questions did you have about it, or reasons why like you didn't want to come and learn more?

NM: What are your reasons, number two? [Silence]

F3: I am also concerned about what it might do to my body, because when I started the family planning, I started gaining weight, a lot of weight. So I'm also concerned what it will do to my body.

LM: Definitely, definitely. Did any of you guys think of coming to an education session? Why, or why not, like to learn more?

NM: Were you told about education sessions?

LM: Ja, actually, were you told? [No] like they didn't tell you when to come? Okay.

NM: Didn't they leave like something like a card with contact numbers?

F3: They did for me. It was a small card. I can't remember, actually, I didn't read what was written on it. I just put it away, and I didn't come because I was waiting for a call.

LM: Ja, and they told you they were going to.

F3: They did.

LM: So then they never did. Did anybody else get that card? Because I think sometimes they gave them, sometimes they didn't. You didn't get one, number five, you also didn't.

F5: No.

LM: Did you guys get a card?

FS: I did get a card.

LM: You did, with a bit of information, okay cool, and did you think of coming through? Why not?

FS: I was lazy to.

LM: Exactly. Here's the thing, there are different reasons. I want to say a few reasons that you might have had for not coming, and there could be more than one. If what I say, if you agree with it, like that was true for you, can you raise your hand? So let's say like okay, I'm open to it, but actually I was lazy to come. I didn't actually care enough to come all the way through. If you were feeling lazy about coming, can you raise your hand? Like, you were open, but lazy. So, two of you. Was that a yes or no?

FS: No.

LM: How many feel like you know, I'm really not concerned about getting HIV. It's not like a big concern on my mind. Like preventing this thing is not high on my list. Is anybody not really that concerned? None of you? Okay, how about the idea of taking a pill every day, *hayibo* [laughter], like that just seems like too much hassle. Okay, that's four people. This is what I am interested in, is how does it come off to young women like you, because I'm actually concerned about all the young women in this country, not just you guys. But you guys are like typical, right? You guys represent others. Is the hassle, like the idea of taking this pill, is it such a pain? Does it seem like such a hassle that it's more difficult than the possible benefits of being able to prevent this virus? Like how does the hassle, the daily hassle of having to take pills all the time, does that seem worse than like the concerns about prevention? Does that make sense, what I am trying to say?

FS: Yes.

LM: Like how do you weigh up the two in your mind, can anyone say?

NM: Let me say it in Xhosa. Will you say taking the pill to prevent HIV, would you say the responsibility of taking it outweigh the benefits of taking it? So it outweighs something, taking a pill, they're not sick.

LM: It just sounds more difficult.

NM: Ja.

LM: Is that part of it what Ntombi said, but I'm not feeling sick?

FS: Yes.

LM: Is that part of the problem? [Yes] Like I feel well, I'm fine, why am I going to take a pill when I'm not sick? [Yes] Okay, so how many of you feel, let's raise your hands, like why take pills when I'm fine. I'm healthy, I'm young. All of you, okay. Then as a result, does the risk of HIV seem like far away?

FS: No.

LM: No? It's still around?

FS: It's such a contradicting thing because you want to take the pill, but at the same time, there is nothing wrong with you, but at the same time the risk of getting HIV and AIDS are high. Especially I think also being young, you are naïve enough to think no man, I don't think I will be infected at such an early stage.

LM: A lot of people think that, yes. Anyone else want to add on this topic about this question? [Silence] okay, I'm going to go back to my poll then. How many of you were really just waiting for us to reach out and maybe if we had phoned up and made the effort to really say number one, we want you to come here, come here this day, this is how it's going to work, that maybe you would have come, but actually no one called, and then you kind of forgot about it. So, three of you would have been open if we actually like showed some, like made the effort. How many of you would say it's quite important to you that there are lots of people around you who know about this pill or are taking this pill? If more people in your life were aware of it and talking about it or maybe taking it themselves, would that make a difference, if it's like your friends or family maybe? Okay, three people for that. Okay, that's good. Can you think of any other reasons? How many of you who do have someone who you have sex with, however serious they are or not, like for me, my whole reason for taking PrEP, I would need to have some questions about that person, some concerns about them, right? But if I have zero concerns about that person brining me HIV, then I'd be less motivated to take this pill. So how many of you would say I don't have questions about a partner? Like I feel like perfectly safe, so I have no chance of the person I have sex with, if I have sex with someone, is going to bring me this virus. He is a pure angel [laughter]. He never has sex with anyone. Now, you are not active, which is cool, but you guys have concerns about what people get up to when they're not with you. Okay, so that's not it. So maybe just lastly on that HIV stuff, I'm a little bit curious about whether, you know, HIV is something we hear about all the time. It goes on and on and on, TV, at school, life skills, what-what. Can I hear from a few of you, how do you feel about this whole HIV thing? Like how much do you think about it? If you do, what's happened that makes you concerned about it? If it's really not something you think about much, can you say a bit more about why not? Is it something you are concerned about, or actually like you hear, but don't really give much thought to? Where does this HIV thing stand in your mind?

F5: I think primary wise, like we have all those LO [life orientation] lessons and we are taught what it is. Then high school, I think it changes a bit because people maybe are into sexual relationships and get infected without knowing, unless say for example the whole school knows about it. So, there is information, but at the same time there is lack of information. It's not like that person is going to give me HIV and AIDS if they are sitting next to me. So there is lack of information with that. Then when it comes to me personally, I feel like the same way we learn about HIV, I think PrEP should be like established somehow within that. Like we know about it, because now I am going to share with you, what is HIV, when your antibodies are affected, your side effects are so and so. It would be so cool if PrEP could be put into, like we could know about it at an earlier age. Then when we get to it, oh, I know what PrEP is, and stuff like that.

LM: Very good point. So this is like a new thing that you didn't hear about when you were younger, so it's like you've got questions because it's not part of your education you have been getting your whole life, right?

F5: Ja.

LM: I totally get that, and I think in the future it will be, because now it's starting to be a thing, and so still it's hard to get PrEP. People can buy it from a pharmacy, but otherwise it's easy, in this community you come to us, but otherwise it will be like in a couple of years everybody can get it from the clinic. But right now, it's like only special people this area [laughs] and like if you join a study. Okay, anybody else got comments on this HIV thing? Is it something you think about much, not so much?

NM: Is it something you discuss amongst your friends?

LM: Ja, that's good, is it something that you talk to your friends about?

F3: We do talk about HIV, and for me, it is not that much of a concern, but every now and then it comes to mind, what would I do if I would actually be infected with this. I think, ja, I don't think it really is a concern to me. For example, I have heard about this PrEP for quite a while now, but I didn't do a move about it. So, I am concerned a little bit, but in between.

LM: Exactly, I get that. That makes sense. Is that true for others too? Maybe? No? Maybe that's it, because most people are in that boat. Like oh, okay, it sounds a bit interesting, but I'm not so interested to take action. I'm not going to walk down to this place, I'm not going to find out more. It's like I don't care enough, and I'm curious, can you think for yourself, can you put words to what kept you from finding out more? Like you heard about it, you knew there was this thing, but it didn't move you enough to take action. Condom you say why not?

FS: People's comments, first, and then secondly, my relationship was in a – I don't know what to call it – a very good stage maybe, that it didn't concern me that maybe I could be infected.

LM: Ja, that's huge. That plays a big role, like how much you are concerned about the person you are with, if you are with someone. I'm curious if, for you guys who are seeing people now, if you're willing to share. I'm curious, like have you had conversations about prevention with your partners? Is it something that you discuss, or is it something that doesn't really get discussed? That can be quite different for each person, but is it something that you talk about with people you get involved with, and if so, how do you guys manage that?

F3: I do. I once spoke to him about this PrEP after I heard about it, and then he just thought it was like a lie, and there is no such thing.

LM: Did that make you a little discouraged about it, when he was like against it?

F3: Ja, [laughs].

LM: Interesting. Others, did anyone else tell people that you are involved with or seeing about these pills, and if so, what did they say? Number one? Did you not tell your partner? Were you concerned about it? Like why didn't you?

F1: No, I don't know.

LM: Like what did you think he would be say? [Laughter] don't be shy.

FS: She didn't know.

LM: Number four, what about you, did you tell your partner?

F4: No, I didn't.

LM: And just out of curiosity, why not?

F4: Sorry?

LM: Why didn't you mention it to him? Do you guys talk about prevention? Is that something you have talked about with him?

F4: Ja, we did talk about prevention. We go together, get tested for HIV and AIDS.

LM: Ja, so you have, and do you do that somewhat regularly, like more than once?

F4: More than once.

LM: Okay, so that's like... and was your testing with him one of the reasons why you weren't so interested in the pills because you knew his status?

F4: Because I trust him.

LM: Have you guys also tested with partners, or no? Have you ever discussed it with your partner? Is he not keen?

FS: Sorry?

LM: Is he willing to go?

FS: He does sometimes, but he goes alone.

LM: Ja, he doesn't want to go with you. Does he show you his results, or does he tell you his results?

FS: [Laughs] he shows me.

LM: He shows you, so you know. What about you guys, have you talked about your status with your partner and vice versa? [Silence]

NM: Number three, when he shows you his results, do you also do the same, or you just tell him.

F3: I tell him.

NM: You don't show him?

F3: I don't show him, because I always get tested here, and then there is no written something that you take home with you. You just see and then you write it down.

NM: So you don't ask for proof?

F3: No.

LM: Okay, I think that's kind of good. Let me maybe move to another section. So I want to talk about the video in particular, and I'm going to play it in a moment, because I'm not expecting anyone to remember it with much detail. Like, it was a while ago. But I am curious for those of you, and I know you haven't seen it, but for the four of you, like what do you remember about it? Do you remember anything that happened in it or the message? Was there anything about the video that stood out to you that you can still recall now?

F3: I remember, I think it's [actor's name] Ja, she said something about I'm looking after myself and I want to make sure that my future is something, something. So, if you also take triple, you can be like me, and ja. She said something like that. So it kind of motivated.

LM: You know her as well?

F4: Yes, I know her.

LM: Interesting, and what was it like? Do others of you guys know some of the people who were in the video? Did you recognise?

FS: Ja. Well, I know there was a pamphlet. Ja, it's the one that was now or never.

LM: Yes, okay, exactly. Others, did you know the people in the video? No? Yes? What was that like, you know, seeing people you know, in your neighbourhood, a good thing or a bad thing?

FS: A good thing.

LM: What did you think? Did it make it easier to relate to what you see, like they're more like me?

FS: Ja, I related more.

LM: What was it like for you, like recognising some of the places and the people?

FS: No, I can't remember.

LM: Do you remember how you felt when you watched the video? Like did it make it seem more real?

F4: Yes, it did for me, and at that time I got even more excited when I was watching the video. I got really excited, within, ja. I didn't follow up, but I was excited at the moment, that I actually really want to do this.

LM: So in that moment it made you interested?

FS: Yes.

LM: Okay, others, what do you remember from that moment? Did it have an effect on your interest, or not? Number four, what was it like for you?

F4: I thought it was just for fun.

LM: Okay, number one and two, you guys?

FS: I don't think I was interested at that time.

LM: Why not? What was your concern at the time? Like what about it didn't appeal to you? It's okay, I'm just curious. It's no problem. Like I really want to know what you thought when you watched this thing, when they talked about this thing. Like what did you feel inside? Do you remember? [Silence] Did any of you talk about the video with anyone else? Did you discuss it?

FS: I did with my cousin, because both of us were there. We just talked about it briefly. We were just talking about the people that we saw in the video, and not much about what was being said.

LM: Sure, cool. Anyone else? Okay, I think let me just play it, to refresh our minds. It will be easier than discussing. I'll just turn the lights off so you can see. Okay, so it's a minute and a half, and you haven't seen this, right, this is new? But you guys recognise this a little bit. Okay, so I'm just going to play it. Oh, wait a minute, I have a little quick, very short survey I would love you to fill out after you've watched it. So let's just see the questions beforehand so you have that in the back of your mind. So if you can come up with a word or two to describe the video, like what kind of feeling does it give what-what kind of video is it? How would you describe this video in a word or two? How did you feel when you were watching the video? Whatever you felt was fine, and what-what did you like the most about the video, or what stood out to you, and what did you not like about it, or how could it be improved? Maybe you can just answer those before we talk, that would be great. Are you guys ready? Oh no, now we've got sound issues. [Play video 00:58:37] Okay, was that fine? We got it? Shall I play it a second time, or you got it? That's fine, okay great. So answer those questions for a second. So I'm just kind of curious, so what did you guys think of the video? With all this you can be critical, whatever you think is fine. In fact, let's start with how would you describe it in one or two words? Like what sort of video is this?

F5: It was informative.

LM: Thank you, others, how would you describe the video?

F2: Educational.

F4: Always healthy

NM: It encourages you to stay healthy. Number two?

F2: Controlling your life.

NM: You are in control of your life. Number one?

F1: Exciting.

LM: Cool, and you know, there are different moments in the video. What stood out to you while you were watching it? Were there any moments that got your attention? Like of everything that happened, what stood out? Was it like a message or a scene, or a moment that got your attention?

F5: What stood out for me was when the guys were, like how guys can also take part. It's not only the girls. It was quite nice, seeing the dynamics.

LM: Like guys can also take part.

F5: Yes.

LM: Excellent, thanks for that number five. Others, what stood out to you about that? These aren't hard questions. Come on guys [laughs]. Are they? Like what did you think of it? What was your opinion?

NM: Do you want to say something, number three?

F3: Uh-uh [laughs]. What is your opinion of the video? If you liked it, what did you like about it? If you don't like it, what didn't you like about it? I'd love to actually, like you are being very, I'd love to hear from one of you guys if possible, and then I'll come to you. Thanks for being willing to answer. What did you think of it, number four? Let's have some opinion of the video. [Silence]

NM: What is it that you like about the video, or you don't like about the video?

F4: Me, what I like about the video, they are showing that it is simple to take the pill. There are no complications with the pill.

NM: What is it that you don't like about the video?

FS: There is nothing that I don't like.

NM: What about the setting, the video being played in [this community]?

FS: Ja, I do like it.

NM: Okay, number two, what did you like about the video?

F2: I am not afraid.

NM: You are not afraid of what?

F2: Of what is happening.

NM: Okay, they are proud to present themselves. They are not afraid. So, what did you not like about the video? You liked everything about the video?

F2: Hmm.

NM: Okay, number one, what did you like about the video?

F1: I liked the part where that girl took the pill. It shows that it's not hard to take the pill every day.

NM: And you?

FS: A*.

LM: Really? There must be stuff about the video that you didn't like so much guys? I've got a few things I can share that I don't like about it [laughs]. Were there any parts where you thought...?

FS: We didn't like?

LM: Ja, or how could it be improved? Any ideas about how we can make this video more interesting?

FS: If there was like a proper dialogue I feel. Like how are you on the pill, like how long have you been on the pill? Obviously like you can't say is it working, because it's going to make it seem a bit dodge. So, like a dialogue, like just to, an interaction would have been nice.

LM: Ja, like you are listening to some characters have a real conversation. It might pull you in a bit more?

FS: Ja.

LM: Or somebody sharing their story.

FS: Ja, their experience.

LM: Of why they take PrEP. I totally agree. I think that can make it, instead it's just kind of like people are talking, saying words to you.

FS: And like scripted.

LM: But not to each other, right? Other ideas like how it can be improved? [Silence] Okay, like how did you feel when you were watching it? When you watched this thing and you heard them talking about PrEP, how did you feel inside?

FS: I was interested.

LM: Did it make you more interested?

FS: Ja.

LM: Others? How did you feel while you were watching it? Is there anyone else who felt, like watching it a second time now, is there anybody else who felt a little bit more interested than they were before? Maybe the answer is no. Number one, did it make you any more interested to see it again?

F1: It did.

LM: A little [laughs], excellent, and what part of it got your attention? Like what about it made you a little more open?

NM: Yes, number three?

F3: I liked the part that they used the people that we know, the people that we see every day. So it gave more reality to what they are saying.

LM: Number five, you didn't see this video when they came to your house. If you had seen this video when they came to your house, do you think it would have changed?

F5: Ja, for me it would have been irrelevant, but for my friends, I would have probably had more information for them, knowing what situation they are in. Like, I could give better advice. Like I didn't watch it obviously, but I didn't tell them about the pill, because I didn't know any better. So, if I had watched it, I feel like I would have probably told more people. Like more people would have been aware. The word would have gone out.

LM: Okay, fantastic. How well could you identify with the people in the video, and the characters, what they were saying? Like if you could relate to them, like why? What was it about them, or if you didn't, why not?

FS: I could relate, because they are youngsters. They are solely just looking out for themselves, so ja.

LM: Others? Is there anything else that you would change that would make it more appealing to young women? You know, like if we were going to, say we want to put this on TV to get the word out about PrEP and to make young women interested enough to go and take action to go to their clinic, or go to the centre here, what could we do to the video to make it more like attention grabbing and appealing to people like you?

FS: I think maybe if it was shot in more public places, like maybe the youth centre, or maybe the library, or the soccer field where most people are and where most things happen.

LM: Ja, if it shows like a big group as well?

FS: Yes, like it's cool to see each person's reaction sometimes.

LM: Is it clear? Was there anything that you didn't understand or found confusing in what was said? [No] Like it made sense. Were there any lines of dialogue that didn't sound like the way young people around here speak?

FS: Ja, the guys for example, like it's a shock to see that there are guys like that, but at the same time guys aren't really like that. Like generally you wouldn't associate guys, like I'm not saying, like I'm not generalising.

LM: Like they don't talk that way?

FS: Ja, it's rare to find guys who talk like that. But I guess it's cool to show them on a different platform.

LM: Like it's possible, but they don't seem realistic.

FS: It's so given that girls care more and guys care less. But like guys do care, but it's rare to find guys that care, if that makes sense.

LM: Ja, and he's like, I'm looking out for my future.

FS: Ja.

LM: Is that not like how guys speak a lot?

FS: No.

LM: Excellent. Were there any other lines that struck you like people don't talk that way? [Laughs] I mean, I think like probably a lot of the lines didn't speak, sound like the person was speaking for themselves, but reading a script. Did it feeling that way?

FS: Well, there was a point where one girl spoke in a native language, that I felt people could relate more.

LM: Did you like that there was a little bit of mixing, rather than all in English?

FS: Ja.

LM: Do you think it would have been better if the whole thing was in in Xhosa?

FS: Ja, and yet again, it's kind of a disadvantage for other people who are not Xhosa.

LM: Okay, and what would you guys say is the message of the video? What is it trying to get across to people? Number one, what do you think is the message that it's trying to say? Number three?

F3: I think they are sending out the message that we should really, really now, it's about time that we all change the way we think and the way we see things. They are really encouraging us to take this pill, because they are even saying that we're going to be the generation that's going to end HIV. That should just, if everybody has that thing that I also want to be part of this group that's going to change the generation.

LM: Brilliant, and can I ask about those lines in particular? Like when talk about like on the logo it says be the generation to end HIV, how do you feel when you hear those words? What is your reaction to that line?

FS: I think for me personally, it's quite like a change, a revolution I guess, because AIDS has destroyed so many lives that we don't have to repeat history again. We can change. We can change something about the way things are going. So it's like up to you. It's your choice, at the same time, making your choice, you are helping so many people. So like our children's children, they won't have to go through this. It won't like carry on.

LM: Excellent. Others, how did you feel when you heard that phrase, be the generation?

NM: Does it make sense, the phrase itself?

FS: Ja.

LM: Do you believe in the phrase?

NM: That it can happen?

FS: I believe if the pill really can prevent HIV, then really, we can be the generation that's going to change, that's going to end HIV.

LM: Does that possibility, does it land? Like does it feel like an invite, like an invitation to you to be part of it? Does it like call you forth, like I want to be part of that, or does it not so much? Like maybe it doesn't speak to you? For you it does?

FS: It does for me.

LM: Like that sounds good [chuckles]. What do other people think? Does it feel like something you want to be part of right now?

FS: Personally, I would like to, like when I get to varsity, for example, I know like they say the scene changes there a little bit. Like people go clubbing and have unprotected sex. It just would be great if it could be, I don't know, like advertised or people would know more about it, because I feel like that's where, I don't know, like most people get infected at that stage. So it would be so great if it were to be taught to varsity students also, if that makes sense.

LM: Anybody else, what do you think is the message? What is it trying to get across? What is the message? [Silence]

NM: What do you think is the message, number two? What do you think the video is trying to say?

F2: Trying to say people must protect themselves.

LM: What do you think of the style of the video, like the look, the music, you know, like the production values?

FS: It's pretty good.

LM: Can I actually ask you to put your phones away for 15 minutes while we finished, because it's just really hard to have any discussion when everybody's attention is elsewhere. We are nearly done, but is that okay guys? Because it's like you are just staring down, and I feel like, you know, if that's okay? Okay, so what did you think of the look of the video?

FS: It's vibrant, it's young, it's bright. It's more realistic.

LM: What about the music? Did you like the music, or not like the music? [Silence] Any opinions on the music? These are easy questions, come on. And was it too long?

NM: Or too short?

FS: It's too short.

LM: Do you think it should have more information in it?

FS: Ja.

LM: Like it doesn't say much? It was only very brief, hey?

FS2: I think it was fine, because the message is straightforward. So you don't get too tired watching, you don't get bored. You just get the message straightaway and then it's done.

LM: Like it's not too informational?

FS2: No.

LM: Ja, I think that was part of the idea. Like let's do a little video that makes people interested to find out more, and then come with more information later, was kind of the idea. Do you think it worked like that?

FS: I think it did.

LM: I mean, for you guys maybe not so much, because you didn't come through, but that's fine [chuckles]. You know, but if you had been more interested in the thing itself then you would have, you know. Okay, do you think, how do you think other young women would react to this video if they saw it?

F5: I think personally it depends on the person. For me at this stage it's relevant, but if you'd shown me like in June, it would have been irrelevant.

LM: Exactly, it will also depend on your need for something like this. Others, how do you think other young women would react if they saw this video? Would it make them more interested to see, find out more, or not so much? Do you think it's persuasive? Is it convincing, or not?

FS: I think they would be interested.

LM: What do you think would happen if more people in [this community] saw this video?

FS: It would be great.

FS2: Maybe more people would start to think about protecting themselves.

LM: Ja, because one of the challenges is it's sort of this unknown thing, this new way, but if more people saw it, maybe it would be a little bit easier to get people to try it, hey? Did any of you guys see anything about PrEP on social media ever, and have you guys seen this video on Facebook?

NM: Are you on [the community's] Facebook [group]?

FS: Ja.

FS2: I am.

NM: Did you see this?

F5: I never saw it, maybe..

LM: None of you guys saw any of this. It's just been out for the last couple of weeks, it hasn't been long, and nobody has heard about the competition.

FS: No.

LM: Okay, you must look on the [community] page, but if you like the Desmond Tutu Foundation, then you will see the video. There is another post with the posters, and if you share it with hashtag HIV free [name of community], you can win R500 voucher. So have a look and share, but there haven't been a lot of people sharing, but a lot of people have been watching. I wonder, what do you guys think? How many of you would be willing to share that post to earn the R500? You'd be willing to?

F5: Ja.

LM: You wouldn't feel like oh, I don't want to share this thing that's about HIV, because you know, of stigma? Because I mean, it's about prevention, right?

F5: Ja.

LM: But I've been wondering if we haven't had that many shares because people don't want to say anything about HIV to their friends, but they're watching it. Like thousands of people are watching it, but only a few people are sharing it [laughs], which I think is interesting. What else is interesting, at first we said that you have to live in [this community] to win the voucher, because obviously I don't care if you are in Joburg, I'm not going to like help you out, right? But we weren't clear originally that you have to be in [this community] to get the pill. We had people from Khayelitsha, from Eastern Cape, emailing T* saying I want to come get this pill, I'll move to [this community] [laughter]. So there are people who want it far away, who are willing to move to your township. Like what do you think when you hear that? Here you guys are like it's available, you can do it, but most people don't have access, which is interesting, hey? Well, I want to know, I think we still have a couple more days of the competition. Are there other groups, like Facebook groups, that you guys are on or your friends are on, that if we share this post to that group it might reach more young women? Any tips about what pages to try and reach? Are you guys on Facebook?

FS: Ja.

LM: Are there groups that you and your friends are on, that people follow? [Silence] Okay, can I also ask, I'm curious, and we are almost done. She's waiting.

FS: She said she is leaving now.

LM: Okay, cool, I like that one. So I think it should be fine if you have two pieces each. We've got the spicy chicken, and the barbeque bacon. Help yourself in the meantime. My last questions were, oh, and I'm wondering, have any of you guys seen the posters around [this community]? We've been hanging some posters around?

FS: I have seen them at the * Clinic.

LM: Anyone else, have you seen posters around? You haven't really? You haven't? Not so much, okay, cool. What did you think of the posters that you saw?

FS: I think, and it's like someone I know, so I'm more interested.

LM: Okay, cool. Obviously we want to get the word out, we are still looking for more young women to join, where would be a good place to put some posters around [this community] to kind of get people's attention?

F2: At C*.

F5: Ja.

LM: What's that?

F5: It's like a popular tavern where like everyone goes.

LM: Perfect, did you get that?

FS: We never saw them

LM: Maybe we should check if it's still there.

NM: Maybe they removed it.

LM: Ja. Other places, where do you think it would be good? Like where would you go, that if you saw it? Okay, and how many of you guys got one of these posters when they came to your house, I mean, brochures?

FS: I did.

LM: You were given one of these?

FS: Ja.

LM: Were you? No? No? No? Yes, and did you read it? You didn't even read it? Really? I'm so curious, and why? What was the reason? Did it seem like there were just too many words?

FS2: Ja, it was just like... I did read, like skim read it, but like I didn't read it because I don't know.

LM: Because you weren't that interested in the pills, is that why?

FS2: Ja.

LM: Did you read it? Not at all? Huh. Okay, and did you give it to anyone to read? Did you share it with anybody at your house?

FS: No.

LM: Who did you share it with? What did they think of it? [Silence]

NM: Did they read it? [Silence]

LM: Okay. Okay, so to improve it, you think it was a little too wordy.

FS: Ja.

LM: Like it should be less information?

FS: Like I know one page will sound pretty stupid.

LM: Have you seen, guys, have a piece of pizza, we are almost done here, but you might as well eat so we can leave more quickly. We also have posters like this, just five or six facts about PrEP, so it's a little bit shorter. Do you like that more?

FS: Ja, I've seen that.

LM: It's a little simpler. Like, it has the key messages, a little bit easier to read than the longer one. Has anybody else seen this before? No? Okay. Okay, and I think that's kind of almost it. So I guess like ultimately, do you guys have any, like if you were to imagine that you worked for an ad agency and it was your job to make a campaign about PrEP, like what if I said you guys are like a media team, a creative team, I want to hire you to make some materials, maybe some billboards, maybe some videos, a few different things, to spread the word about this new pill. How would you do it? How would you... oh, did I not give you? Oh, shame man. We were short of cups. I looked around, and then I saw that everyone had, and I was like oh. I apologise. What would you guys do if you were going to make your own media? What would work? How would you do it if you were going to make it? Like what would you do that would get people interested?

FS: I would go to school assemblies. Obviously if there's like a community meeting, and also it would be good to inform like our parents, because sometimes when we have to explain something to them, like for example I am always stuck in that situation, they are very sceptical about it. Like just be careful what you get yourself into, because maybe I'm not giving them proper information about it, because I'm still trying to get used to it. But if maybe they heard about it and they understood it better than I do, they would be more than willing.

LM: Ja, like in a sense you need to tell more than just young women about this thing.

FS: Jal.

LM: You need to tell everyone in the community about it, is that what you are saying? Do you guys agree, is that important?

FS2: I agree.

LM: Would it make it easier for you yourself?

FS2: Ja.

LM: Exactly. That is one of the reasons why we do the brochures, is that if you do join the study, you can take this home and the people in your house can also read. It's not just up to you to explain what it is to people who have never heard of it before. Any other ideas guys?

End of sound file [01:29:16]