Next Generation Research podcast

Episode 4: We have the tools to stop HIV: learning from girls and young women about the barriers they face

GILES: [00:00:00] HIV remains one of the world's most significant public health challenges, particularly in low and middle income countries. As a result of recent advances in access to medication called antiretroviral therapy or ART. HIV positive people can now live longer and healthier lives. Research has also confirmed this type of medication prevents onward transmission of HIV.Despite this medication, the virus is still a problem in many countries.

Valentina: At the moment, there are 38 million people living with HIV in the world, and over half of them are in Eastern and southern Africa. In Zimbabwe specifically, one in eight people are living with HIV. The number of new cases is substantially higher among young girls, for example, compared to young boys, and so that's why we really think [00:01:00] it's important to focus on them.

GILES: Welcome to Next Generation Research where we bring you to the heart of the most important and exciting research happening at the moment. I'm Professor Giles Yeo, a scientist at the University of Cambridge, and in each episode I have the pleasure of introducing you to one of the best researchers working in the UK right now.

GILES: All of them are part of the Future Leaders Fellowship, a scheme that supports their research. They are all working to solve problems and improve our [00:01:30] lives as we know them. Valentina Cambiano, who you just heard, is an associate professor in epidemiology at the Institute of Global Health at University College London.

GILES: She makes models of diseases to try and understand what is causing infection. Her current HIV research project is based in Harare, Zimbabwe. I'll let Valentina give you some context around the current situation with HIV in the country.

Valentina: So we have a quite good picture of what is the current [00:02:00] HIV epidemic in Zimbabwe, and the country's done extremely well in terms of response for HIV. The UNAIDS has set this target of 95% of. People living with HIV being diagnosed, 95% of those diagnosed being on treatment and 95% of those on treatment being suppressed.

GILES: To help Zimbabwe reach these targets, they need to focus on younger women who are currently at a much higher risk of contracting the virus.One of the key ways of reducing the risk [00:02:30] and therefore the number of people living with HIV is to take preventative medication. Valentina's project is to research and propose new ways to improve the uptake of this medication in adolescent girls and young women in Zimbabwe. The work combines an important mix of quantitative and qualitative research in order to make it as effective as possible.

GILES: Let's first think about the qualitative data. That's the firsthand evidence gathered through things like interviews and [00:03:00] questionnaires, which shows the sorts of problems people are experiencing in accessing or using the medication. Then Valentina and her research colleagues in Zimbabwe will use that information gathered in person to design a study, which then becomes quantitative analysis because it shows, in numbers, what the preferences of the young women would be.

GILES: Then finally, Valentina will model how a new healthcare program may improve uptake of medication and prevent new [00:03:30] infections, which she will then present to the Zimbabwean government. A lot of work

needs to be done to gather evidence if the government or external funders are going to pay for a new medical or educational intervention.

Valentina: In the past, I've been working mainly as a statistician, a mathematical modeler. I was working on cardiovascular disease before, and what I found exciting about HIV is the fact that [00:04:00] when research is done, especially if you manage to engage activists and people living with HIV, they then really push and make sure that those advances are translated into policy.

Valentina: Although it has been around now for over 30 years, there has been tremendous progress in terms of treatment for HIV because if you now you adhere to treatment, which means still taking pills every day, [00:04:30] you can have a normal life expectancy. And relatively small side effects, but you need to continue taking that pill every day because if you stop taking, your virus can start replicating again and you will have symptoms.

Valentina: So although there are this amount of progress, we don't have a cure. So you will need to take this treatment for life. And so averting new people becoming infected with HIV is really fundamental cause otherwise the number of people who are living with HIV will [00:05:00] increase as they live, luckily, for a longer time with HIV , so more people are actually able to infect unless they are suppressed on treatment.

Valentina: Stopping people becoming infected with HIV is fundamental if we want to have a fast decline in the number of new HIV infections and eventually this epidemic.

Gertrude Ncube: What I do mainly is to look at HIV prevention [00:05:30] activities, especially coordinating the HIV prevention interventions. My name is Gertrude Ncube. I'm the National HIV Prevention Coordinator within the Ministry of Health and Childcare.

GILES: Gertrude is a crucial person when it comes to designing the guidelines for HIV testing and prevention in Zimbabwe. She has a key role in deciding what gets implemented as well.

Gertrude Ncube: If we look at HIV and AIDS in [00:06:00] Zimbabwe, I can say as a country, we've actually done very well in the reduction of new infections in the reduction of HIV prevalence as well. We are coming from a prevalence of about 29 point something in the 1990s, and now our prevalence. If you look at our HIV estimates for 2022, we are at 11.8% looking at the prevalence of HIV. In 2020, [00:06:30] we conducted a population based survey looking at people who are living with HIV, who have been tested and know their status. We actually were at 86.6% on the people who have been tested and know their status, but we realised that we are not doing well when it comes to our young people, especially the adolescent girls and young people, and the [00:07:00] adolescent boys and young people.

Gertrude Ncube: On that, we are still far below the 1990 targets. The issues of access to services, the issues of consent to services as well, poverty as well within our communities where we find the adolescent girls maybe wanting better things and then that's why maybe they even get into intergenerational sex and with that [00:07:30] is actually where now we find our young people vulnerable to HIV.

Gertrude Ncube: Older men may be having sexual activities with young people. We call them Blessers or Sugar Daddies, who actually go around with the adolescent girls and young women.

GILES: These young women might not know about the available drugs or they might not be able to access them, Valentina and her colleagues are investigating why.

GILES: So what is [00:08:00] this all important drug? It is called PrEP or pre-exposure prophylaxis. It contains antiretroviral properties. This means it can stop the replication of the HIV virus. Prep has also been found to be very effective at preventing someone from contracting the virus as long as it's taken consistently.

GILES: Here's Gertrude again,

Gertrude Ncube: the pre-exposure prophylaxis, it's one of the latest interventions in our basket of interventions. [00:08:30] Mainly, it's actually for those who tested negative

Valentina: pre-exposure phylaxis has now been approved in the US since 2012. The first form of formulation that was approved was Oral Daily Prep, which was very effective.And now there are other formulations which are available, which are a vaginal ring and injectable formulation, which from our focus group discussions we are finding is quite attractive as it kind of [00:09:00] removed the issue of people being seen with pills. So I think we have this amazing innovation that really for the injectable one, it protects you kind of 99%. And despite all the effort that has been put to develop these tools and the fact that they work extremely well, the uptake, the proportion of women that they are using is extremely low. And for example, in the uk, just as a comparison, we have the opposite issue that people are demanding [00:09:30] prep and they're struggling to find appointments to access it.

Gertrude Ncube: Looking at the uptake of oral prep, this study was going to help us to better place these services, these choices to the adolescent girls. And they should be able to be given a lot of information and I'm looking at them to have a choice of whichever method they want to prevent them from creating HIV.[00:10:00]

GILES: As Gertrude says, their department needs to know what the preferred method of access would be for these young women before they try and scale up the services. Valentina and her colleagues went directly into communities in order to find out these preferences and learned about relevant experiences directly from the young women.

GILES: Here is Valentina again.

Valentina: We had talked about the fact that the first thing we would do was this focus group discussion with adolescent girls and young women [00:10:30] to understand their barriers and preferences, and then that we would look at those information, write a report, and use that information to inform our survey.

Valentina: I'm new to qualitative research and I think coming from a statistical background, in my first years of research, I was kind of a bit skeptical cause I was like, oh, you're gonna talk with a few people and then you think, what is the reason why they're not taking prep? But [00:11:00] what I really have appreciated by doing this discussion, you really get a wider insight.

Valentina: And they might come up, for example, for a reason why they're not taking prep that you haven't really thought of. So I think this qualitative research that we did really informed then what we're asking in a much larger survey. To run the focus group discussion. We needed a local person and anyway, I'm a statistician so I could not run a focus group discussion.

Valentina: [00:11:30] We've been very lucky in finding Kudzai as our project manager. She has been organizing the focus group discussion, talking with the different implementers and clinics lead to identify the girls. And then she actually been running the focus group discussion, supervised the translation of course, because they are offered in in the local language, in Shona, so transcribe that, translate it and then analyse them to really

extract from those discussions. What are the main themes that are coming out?[00:12:00]

Kudzai: My name is Kudzai Chidhanguro. I am a social scientist at CeSHHAR Zimbabwe, in Harare.

GILES: Kudzai is a key part of this research, and her work involves designing, organising, and running the all important-focus groups to make sure they are effective and maximise the precious time they have with these young women.

Kudzai: The name of our organisation, it's Center for Sexual Health, HIV, and AIDS Research, Zimbabwe CeSHHAR Zimbabwe.

GILES: in Zimbabwe, as [00:12:30] in many countries. This subject is especially sensitive and it requires careful planning.

Kudzai: We are actually working with organisations that are already working with adolescent girls and young women offering different sexual reproductive health programs so that we recruit them through those channels in terms of maintaining our confidentiality, because it'll be sort of unusual for us to be going in communities and say, we want to identify sexually active adolescent girls so that we can have a focus group discussions.

Kudzai: We'd have [00:13:00] breached their confidentiality that way, so you actually arrange for a group of different adolescent girls and young women with the same age range, so that they're comfortable together when they're now participating.

GILES: Rather than ask the girls to explain their personal circumstances, Kudzai uses role play to help the young women explain their thoughts on the topic.

GILES: She explains a scenario and they then act out how a young woman like [00:13:30] them might respond.

Kudzai: We will give each of them a different scenario from the others. Then we then ask them to actually do sort of a role play where they select maybe two members from that group. They go and try and act it out. Then we have got a situation maybe of an adolescent girl has been using prep for maybe two years.

Kudzai: But now they're thinking of stopping to use prep. So we want you maybe to help us to understand the [00:14:00] reasons behind why they would want to stop using the prep. So we are just trying to help them engage throughout that process so that we can actually be effective in working with young people because in some instances, young people sometimes do not really want to open up at first meetings.

Kudzai: We have tried to break the ice a bit and they're now a bit more comfortable with each other. So I think especially our topic is sexually active adolescent girls, and it's actually a sensitive [00:14:30] topic. So maybe if we do one-on-one, they might not really be comfortable if you actually maybe want to ask about their personal experiences.

Kudzai: But now if you're just asking about generally in their communities, how do sexually active girls and young women perceive prep, they can actually be contributing because it's a group setting, it's not directed to individuals.

GILES: When making this episode, we wanted to include the voices of young women who are part of this important research [00:15:00] here, Kudzai speaks to a young woman from one of the focus groups. We've recorded this especially so you are able to hear what one of these discussions sound like.

Kudzai: How did you find out about the prep medication? How did you get to know about prep?

Young woman: I get find about prep, uh, through a friend during my time at university. I have a friend who used to take them, so I get to know about it because I [00:15:30] asked her and she explained me about prep.

Kudzai: Can you just share what she told you what prep was?

Young woman: During the university, she have, uh, a blesser.

Young woman: A blesser is someone older than you who gives you money for sex. Mostly men, even old enough to be your uncle or your father. Just a relationship being there for money. The blesser had HIV, so [00:16:00] she said it's a medication that protects you from getting HIV.

Kudzai: Yeah. Okay. Did you take it? No, I Or have you taken it before?

Young woman: No, I have not taken any prep. If I'm offered to prep in the future, yes I can take it. Mm-hmm. Because I have seen her taking them and I haven't seen any problem with her taking them.

Kudzai: What would sort of be motivations for you to be taking the prep [00:16:30] medication?

Young woman: It's something that it doesn't have side effects.

Young woman: Also, there might be a scenario in which you are married. Maybe in some instances your husband gets HIV. Mm-hmm. Or maybe you can find someone you love with living with HIV. So you can just take prep. You can have kids while you're on prep and you, you cannot contract HIV.

Kudzai: Is there anything that worries you about taking prep?

Young woman: It's not that common. Yeah, [00:17:00] I think. A lot of people needs to be educated on that because nowadays people think if someone is HIV positive or you can find someone you love who is living with HIV, you can't be with that person because of fear of contracting HIV.

Kudzai: What do you think are the most important features that should be there in that prep program?

Young woman: Young women are the most typical who are in danger mm-hmm. Of, uh, contracting HIV, you feel, [00:17:30] and also young girls. Yes.

Young woman: The most important feature it has to reach most places, every places, rural areas. Okay. Mm-hmm. A lot of people are shy about confidentiality. I think even men they need to be educated on this program also, because there are, as we can see, even young girls, young boys.

Young woman: We see some marriages that break down because one person have got HIV. Maybe they [00:18:00] haven't been educated enough about this PrEP program. I think both sides should be there on the program.

GILES: When undertaking these studies, it's important to remember that these are the real life experiences of these young women, some of which you've just heard. These are the sort of important findings that this project is about. There were also surprises that emerged.

Kudzai: from the research that we've done so far. Some were not even [00:18:30] aware of what prep is. There's a group as well that do not even know that there are now some options that you can use to protect yourself against HIV. So it sort of took me by surprise cause I was just having this assumption in my head to say, I think now everyone knows that on top of

the condoms, there are other things that are now available that you can be using to protect yourself against HIV.

GILES: The young women also included privacy and confidentiality in their list of [00:19:00] important considerations

Kudzai: In our different communities people have got a perception to think that Prep, it's actually HIV treatment. The pills that are actually taken by people who are HIV positive.

GILES: they were concerned that people around them might mistake the prevention medication for a drug given to people already infected with HIV.

GILES: A similar concern was raised by young women already married or in partnerships. They felt that their partners might not be [00:19:30] aware of the medication and hence misunderstand its use. Another theme that came out was perhaps unexpectedly related to sound.

Kudzai: The other thing that was being highlighted was to say the oral prep, the pills. So they come in a small container, so they're saying that container, the pills, they make quite a noise, which is not really nice. So that noise draws attention, unnecessary attention, such that one might want to know more [00:20:00] information. What are these pills for? If anything, that can be done so that is packaged in a way that there's no noise that is coming out of wherever the pills are packed from.

GILES: the responses, from all the focus groups across Zimbabwe, were vital in designing the next stage of the research, the survey.

Valentina:If we hadn't done the focus group discussion, our list would be my ideas of what are, the possible reason. So really to make sure that it comes from the [00:20:30] girls and we do capture as much as we can, all

those reasons. The other way in which the focus group discussion informed the survey was we asked them actually in a role play to describe how an intervention distributing prep for adolescent girls and young women would work and to think about what matters to them. We then designed this discrete choice experiment where basically we identify what are their [00:21:00] characteristics of an intervention. So for example, venue, for example, we consider pharmacies a possible venue, a traditional clinic like the corresponding of a GP, and because there as well, like a community health worker, which is someone in the community that you can go and ask for a medication.

Valentina: We consider the formulation, whether injectable or pill or vaginal ring, as from the focus group discussion kind of emerged that they seem to prefer the injectable one. And the main reason for that was that [00:21:30] with an injectable, you go to the clinic, you get your injection, you go away. So you need to be careful not to be seen only when you go to the clinic.

Valentina: But once you're at home, no one knows that you have taken it so you don't need to discuss and justify your behaviour. And then another characteristic that came up was the attitude of the person distributing the prep. They thought that many of them, even if they go to a clinic asking for prep or asking for prevention or disclosing that they've been having [00:22:00] sex without a condom, they would be judged.

Valentina: And so that's a barrier clearly to access those services. And then a program for parents and partner to have a more positive attitudes toward prevention in a way to acknowledge that young women are having sex and so that the best thing they can do is protect themselves. Another characteristic that was mentioned was time spent at the clinic.

Valentina: So whether, clearly in a pharmacy, you could collect medication quite quickly. If you go [00:22:30] to a health clinic, you need to wait. How far is the location and there are many other characteristics that we included, and what we ask them to do is to choose between two intervention that are slightly different, maybe one is prep is collected in a pharmacy is half an hour away and is in a pill, and another one in which it is a traditional clinic is an injectable and it is an hour walk.

Valentina: And so, using this [00:23:00] method, which is called discreet choice experiment, you do understand what are the trade off and so what are really the characteristics that are more important to them and that drive the uptake of an intervention because we know that we are not gonna satisfy all of them. So we need to really try to make sure an intervention that maximizes how many of them are gonna access prep.

GILES: Getting enough people to participate in the survey is not so simple, [00:23:30] especially given the sensitivity of the subject. Valentina is using something called a respondent driven sampling survey where they asked the initial participants to recruit others, hopefully causing a snowball effect.

Valentina: Respondent driven sampling survey is mainly used to reach a hidden population, so to reach, for example, female sex workers or people who inject drugs so difficult to reach, for example, by using a national representative survey or by sampling a [00:24:00] postcode, for example.

Valentina: And we felt that in order to reach sexually active adolescent, gay young women, in a way, we didn't have any other strategies because we felt we couldn't go house to house and ask for that information to contain the risk of their family or, or their community knowing. That by taking part in this survey, they need to be sexually active.

GILES: The young women who consent to do the survey are compensated for their time and given two coupons to give to two [00:24:30] other young women, inviting them to come and participate as well.

Valentina:Once all of that has been collected and we need to do a lot of data cleaning and kind of data analysis, how many girls have used prep?

Valentina: What is their interest in prep? What comes out as their preferences, and then. We will use this information to co-developed with the Ministry of Health, the National AIDS Council, other local prep implementer, of [00:25:00] course, addressing girls and young women to co-develop an intervention.

GILES: After this long process, there is still more work to be done, and this is where Valentina's expertise comes in. She needs to model how effective these interventions might be. And what they could cost in order to offer value for money.

Valentina: If, for example, that intervention is delivery of pills in a pharmacy, or for example, if it is [00:25:30] an educational program, we will try to get an idea of how much that would cost. It would be an estimate, and then we'll try to estimate, given it attracts 10% of the women. And it could cost up to this amount, if it can attract 20% of these women who are sexually active and in need, it could cost this amount and so on. So we will not provide a single answer, but give them a kind of a range of scenarios and discuss with the Minister of [00:26:00] Health whether they think that is affordable and evaluate whether it is cost effective. As the epidemic progresses and really funding is kind of stalling, if not declining.

Valentina: We really need to make sure that the interventions that we develop to offer value for money are affordable. Otherwise, there is no point in developing intervention that the Minister of Health is not able to scale up. My hope for the future is to test whether the [00:26:30]

intervention that we will have co-developed with the stakeholders and the young women to test on the ground, whether actually that is able to attract more women.

Valentina: To those services so that they can be, if they wish, if they need, they will be using prep and being protected from becoming infected with HIV.

GILES: What was interesting to me about this particular project, [00:27:00] was it wasn't about the technology behind designing the drugs, the genetics, the biology. The drugs are there. It was literally about why people won't, can't, don't want to take the drug. And as a biologist like me, who spends time trying to find out new pathways, this is not part of science that I normally take part in.

GILES: It's so nice to hear from people who end up taking the drugs that are designed because I think at the end of the day, there is no point in designing all these [00:27:30] fancy shmancy drugs if you can't actually get people to take them. Thank you very much to Valentina and also to Gertrude, Kudzai and our young interviewee for their contribution to this episode.

GILES: If you wanna find out more about Valentina's work and the work of CeSHHAR Zimbabwe, you will find links to their websites in the episode description. In the next episode, we are going to be looking at how genetics research can help us learn about our reactions to life-threatening infections. [00:28:00]

Vanessa: Infectious disease can be due to a genetic defect, which most people don't notice. People think of genetic defects as developmental, big changes, but it can just alter your response to one pathogen.

GILES: Thank you for listening to this episode of Next Generation Research. Please share this episode with someone who might find it interesting and we'd love for you to give us a rating or review wherever you're listening to this.

GILES: This podcast is supported by the Future Leaders Fellows Development [00:28:30] Network. You can find out more about the Future Leaders Fellowship by following at LF Dev Network on Twitter, and we will link to their website and our episode description. I'm Giles Yeo, and you can follow me on Twitter and Instagram @GilesYeo

GILES: The producer is Hester Cant. The executive producer is Freya Hellier. The sound engineer is Morgan Roberts. And thanks to Oliver Mytton and Laura Carter for their additional support.[00:29:00]