



## PODCAST TRANSCRIPT

### Human-Centered Design and Prevention in the Real World

<https://www.avac.org/podcast/human-centered-design>

October 21, 2019

**Jeanne Baron:** You're listening to *Px Pulse*, a regular podcast bringing you fresh voices on critical issues facing HIV prevention research today.

[0:00:02]

[00:00:25] There's much talk of keeping young women at the center of efforts to develop and roll out strategies for HIV prevention. After all, 2019 figures from UNAIDS show four of five new infections among adolescents are in girls. But the task is daunting. While incidence is high among women in Sub Saharan Africa, stigma, gender-based violence and other forms of inequality persist as serious barriers to prevention.

[00:00:52] Later in this episode, we'll talk about research AVAC has been doing with partners in South Africa using human-centered design. This research is exploring strategies to overcome these barriers to prevention. As an approach, human-centered design (or HCD) is gaining traction as a way to get answers to difficult questions, and to use those answers to better connect adolescent girls and young women to highly effective prevention.

[00:01:17] To learn more about AVAC's research—called Breaking the Cycle of Transmission—we'll hear from AVAC'er Anabel Gomez, one of the leaders of this research project. As a complement to the advocacy at the heart of AVAC's mission, our research in South Africa is part of our broader work with product introduction to understand a product's users, analyze market data and share information so that effective prevention reaches those who need it most. We explore this big and important topic in-depth in AVAC Report 2018.

[00:01:49] Anthony Ambrose is someone paying close attention to this research and



how to make prevention a reality for adolescent girls and young women (AGYW for short). Anthony is a program specialist at South Africa's NACOSA, an organization supporting prevention programs across the country. I asked him, 'as an implementer of programs in South Africa, what's working for young women right now and what's not?'

**Anthony Ambrose:** So I would say what's working for South Africa at the moment, in terms of bringing the HIV/AIDS infection rate down, is that there are good prevention programs across the country—good prevention programs in communities that involve AGYW into their programs. What isn't working is that South Africa has done lots of prevention that was more of a top-down approach, and little was done taking into consideration the views of young people—how do they see their prevention journey with themselves? With Partners? We haven't come to the actual point of saying, 'what else is needed for AGYW'? And the big disconnect is that we've been focusing too much on sex, sex, sex without the whole holistic picture of what else matters in terms of their goals, relationships, their journeys, in terms of what do they aspire to, etc. So I think it's a very one-sided approach. Prevention programs have been very one-dimensional.

**Jeanne Baron:** And that dimension has been sex, as you say, which is really to say a focus on talking about risk as bad. Yeah?

**Anthony Ambrose:** Yeah, it's like saying, 'don't do this' and 'don't do that' and 'just do the right thing; just abstain from sex'—messages that are not positively focused. We have not done much in terms of having a multi-sectoral as well as a multi-disciplinary approach of having major integration in the programming.

**Jeanne Baron:** Let me ask you, what indicated that something was wrong? That there needed to be a change?

**Anthony Ambrose:** I think when you're looking at what was coming out from research, as well as clinical data, the increase of the number of teenage pregnancies across the country showed that something was happening. Why was prevention messages not getting through? We knew that teenagers are having sex

and they're not using good prevention, for example condom usage, in order to prevent pregnancy, to prevent HIV infections and STIs, etc. So, we would see that there were not many youth-friendly clinics in the local communities and therefore that didn't attract young people to go to these places. It's a lack of information as well as not knowing what to ask for in sexual and reproductive health. So those are contributing factors that one needs to take into account.

**Jeanne Baron:** In South Africa, there are some signs of progress. Some surveillance data has documented a double-digit decline in incidence among youth—26 percent for girls ages 15 to 24, and that was between 2012 and 2017. Of course, it's important to have momentum around a trend like that.

**Anthony Ambrose:** I think prevention infection rates may come down in certain areas, and I agree with that aspect, but not enough is being done in the majority of the country. So I think that's where we need to go, to places where there are no services, where there's lots of risk. So in terms of focusing for impact, you really want to pinpoint the hotspots and the high burden areas. You go to those areas and find out why there's no change in the infection rate coming down, or why there's no change in terms of services being directed there. And that's where we need to start.

**Jeanne Baron:** To help answer 'what's missing' and 'what's needed' so that adolescent girls and young women get the prevention products, programs and services that will protect them, AVAC's Anabel Gomez and partners launched a research project using human-centered design. I asked Anabel to first explain, what is human-centered design? What principles and techniques define it?

**Anabel Gomez:** One of the big things about human-centered design is it develops solutions from the human perspective, not from a systems perspective. So it looks at 'what does a human being desire?' versus 'what can the system do?'—that's the big difference. So where in the past some of the more traditional social behavioral research has done things like focused

on global health experts to get information, this is very much about talking to the people who are going to receive the service or the product, and then it tries to see if the system can actually deliver what the human being desires. And I think also just understanding that the whole premise behind human-centered design is that you get to prototype quickly. You learn quickly, you fail quickly and you move on.

**Jeanne Baron:** Before we get to the findings, there were phases to this research. Give me a sense of what it involved.

[00:07:11]

**Anabel Gomez:** So the research consisted of a qualitative section, which meant that we spoke to 240 adolescent girls and young women in two high-risk provinces, and we used a lot of ethnographic techniques to try and understand how adolescent girls and young women make decisions.

[00:07:17]

[00:07:35] We also spoke to what we called their influencers, which were matriarch —any older woman that was in a role that may influence—it could be your mother, your grandmother, your auntie, older sister. Whether they were good or bad decisions, we weren't passing judgment, but it was just somebody who actually influenced the way that their mind analyzed a product or prevention and may sway the end result—whether they take it up or not. We spoke to male partners, we spoke to nurses, because most of the girls that we speak to see a nurse, not a doctor. So we thought it was important to speak to them, and also to community health care workers. More than anything, community health care workers are very much an entry point for any new product or service.

[00:08:20] From that work we came up with three very discrete segments—so while you're in a relationship, one girl might be in a relationship for love, another girl might be in a relationship for material gain—and understood that they went through a journey and their motivation changed with each segment.

[00:08:36] We then devised a secondary questionnaire and did some quantitative work, and that consisted of speaking to two thousand adolescent girls and young women, trying to find out who these girls were. So what were the

characteristics of a high-risk young woman? How would we recognize them and how would we reach them? So that was sort of the next stage.

[00:08:56]

Following that, we did something called a discrete choice experiment, which is really aimed to understand what product characteristics an adolescent girl and young woman would like in a prevention product. Would they like an injection? What sort of injection? Would they like a pill? How big would the pill be?

[00:09:13]

Following that, we're about to do something called 'ideation stage' to bring all this research together and actually come up with actionable, insight driven interventions that programs can immediately use. So it's data driven interventions that come from this richness of insights that we have. That work starts in November and we're very keen to be doing some piloting in the field with that work to see how our work can all lead to impact.

**Jeanne Baron:**

[00:09:42]

So coming up, you'll be looking at what to do, what's been learned from listening closely to these young women. What were the major findings you'll be thinking about as you develop these strategies and prepare to pilot them?

**Anabel Gomez:**

[00:09:55]

If I was going to walk away with two key things, or three I guess, one is that women and adolescent girls go through a journey, and it's a journey to agency. Having a good relationship with a man is overriding, and anything that puts that relationship at risk or causes conflict is going to mean that, most likely, the prevention mechanism will lose, especially in the early parts of the journey.

[00:10:21]

In the latter parts of the journey where she's willing to actually stand her ground or at least be able to have a conversation with her partner about prevention, it's different. But we need to do all our programming for adolescent girls and young women around that relationship frame. And if we don't do that, we will start losing them, because that's what they think about—they think about their relationships.

[00:10:44]

You will get uptake of prevention; you're always going to get uptake because you're going to have early adopters regardless of what sort of project or product you've got out there. But to get that entrenched support, you really need to understand girls where they live, and what they're about and very much about their relationships. I think discussions about risk need to be very clearly framed in a way that's relatable to them, because as I said, most adolescent girls and young women don't speak about risk. So this whole focus on risk tools and making girls realize that they're at risk is not as easy as it sounds. And I think this is something that people need to take into account. Having providers that are skilled in being able to bridge the empathy gap, and I think also just understanding that adolescent girls and young women go through a journey and we have different segments out there and they all go through the journey differently.

**Jeanne Baron:**

[00:11:41]

Moving along that journey where a young woman starts to feel more agency, did the research suggest what supports that sense of agency? I guess that's part of what's different by different segments. Right?

**Anabel Gomez:**

[00:11:53]

Yeah. I mean, it's one of those situations that if we treat every 15- to 18 year-old girl the same because she lives in a rural population, we don't really actually understand what her individual drivers and motivators might be. We don't understand how to speak to her, whether they're seeking respect, or whether they're seeking affirmation, affection everybody is in those relationships for different reasons. And what will motivate them will be very different.

[00:12:19]

We need to really start understanding that they're not just a group of 15- to 19-year-olds; 15- to 18-year-olds are not all the same. Those nuances in terms of who we are as human beings has got to be drawn out. What causes that flip, if you like, from being externally focused to being more internally focused? It's really going through a number of experiences where women are sort of reframing their lives, reframing their view of the

world, reframing what they want and what is important to them. How many times they have to go through that reframing is different for each and every one of us. If we could bottle that secret sauce and then move them forward to advocacy, that would be the multi-million dollar question.

**Jeanne Baron:**

[00:13:06]

We have more details about this research on the Px Pulse landing page. The insights gained so far are just the beginning. The next phase is critical—piloting how to change or adapt products, services and programs for young women. Lesego Taule and Mpumi Mbethe were part of the team that spoke to hundreds of young women at sites across South Africa to learn more about their needs and their hopes and their challenges. I asked them what needs to happen to reach the girls and women they met. Lesego spoke first.

**Lesego Taule:**

[00:13:35]

For me, and I don't know if I'll be answering your question, maybe indirectly. But I remember when I was working on this project, I just felt like I think it's time we moved away from coming up with these campaign —HIV prevention, HIV prevention, HIV prevention. Because when you speak to these young girls and these young women and first of all, they are one hundred percent disempowered, they come from poverty, crime. Some of them, you speak to them, they live in this village, and this girl is 16 years old and they've never left that village. They've never been exposed, they've never been to even the nearest town. All they know is life in this small, tiny village. And I believe that, and from my personal experience, I also come from a background like that. I lived in a township that probably didn't even have five thousand people altogether. And we were far from Johannesburg, the city.

**Lesego Taule:**

[00:14:52]

My life changed at the age of fifteen, when my sister was in university in Johannesburg, and she decided to take me and my other sister to come and live with her. That was the first time I began to dream. That was the first time I could imagine myself being better, doing better. And there's a lot of other young women my age who are still in the township. When I go

back there, they have gone on to have five, six children. They have never worked. So for me, we can bring products and products and products. Until these girls are empowered, they are just in this cycle, and they don't know how to get out. If we bring opportunities or programs or campaigns, whatever you want to call it, that will ignite something in these young women, it does not have to have anything to do with HIV- opportunities for them to go out of their environment to something better, to something different- that will then bring them to a place where they can start thinking, 'I want these opportunities. I want a scholarship. Therefore, I will make sure that I don't get infected with HIV'. But to come and bring condoms and this and that. It's like, 'for what?' You know?

**Jeanne Baron:**

[00:16:13]

So what you're saying is making me think about the research itself and the process at the heart of human-centered design, which is so focused on listening and striving to understand. It seems like these are the very things one would think are the basic ingredients to developing self-esteem, and from there, agency. What do you think?

**Lesego Taule:**

[00:16:34]

So there were those who would at the end, be very grateful—thank you for listening to my story. I've been needing someone to offload, to talk to. You know what I mean?

**Mpumi Mbethe:**

[00:16:49]

Most definitely. You know, if you could inject self-esteem, because you see the most beautiful girls and you think of all the potential and the great possibility. And then knowing that this information is going to be valuable in terms of the products that are being developed to help them was comforting.

**Jeanne Baron:**

[00:17:08]

What message would you want to deliver to decision-makers after having conducted this research, from what you learned?

**Mpumi Mbethe:**

[00:17:14]

As much as we want to talk to young girls and women, empower them and everything, I feel that our boys need to be given attention, because we had

groups with boys—the partners to these young girls. And you can tell that boys know that in any relationship, even if it's with an older girl, they are in charge. And that is something that they grew up with. Our society, even from the time I was growing up, seeing other mothers and stuff, we knew that the man is in charge. And I think until that changes, we can empower girls all we want, but we need to get to the root of the problem—speak to the boys and mentor our boys to see women the way they should.

**Jeanne Baron:** Lesego and Mpumi's focus on opening eyes so young people see women as empowered is echoed, too, by NACOSA's Anthony Ambrose, who says the research conducted by Anabel and partners changed the way he thinks about risk.

[00:18:09]

**Anthony Ambrose:** Yeah, I mean, I've learned a lot from the research in terms of the whole understanding risk and why young people take risk often. As much as the youth voice that speaks about freedom and passion, etc., is youth associated with risky behavior? And my answer is no. It's that the lack of knowledge and the lack of awareness of what is risk compared to what is norm. So they may have associated risk with norm and think norm is risk, and that's where the problem identification lies. It's that 'I'm taking risk, I enjoy taking risks because I think it's normal to take risks'. It's normal for young people to take risks. And the saying 'what is life without risk?' I think that's where we needed to change the narrative. Because we may have preconceived ideas of how society sees risk, but how do youth see risk? Having more than one multiple partner at a young age, for them, it's not seen as a risk, it's seen as norm. The way I enjoyed the research was that it was groundbreaking in that it was taking it from a different social aspect] rather than being too biomedical and scientific.

[00:18:24]

**Jeanne Baron:** So how will you apply this to programs? What will it mean in those terms what programs look like?

[00:19:49]

**Anthony Ambrose:** So if we are able to start tracking young women in their journeys, how

[00:19:55]

would they be able to start to self identify their own risk, self identify their own goals and take control of their journey, take control of their destiny? And for me, that is powerful because you're looking at—how powerful is my dream, my hopes, my future and my life. But if I don't have control of it and if I don't understand my risk, I don't understand the behavior that I'm doing. Then my dreams, my hopes, my future, my life will be shattered. So the whole aspect of that research was to be able to say to us that we can get young people to understand themselves. They're shaped by their life chances and they're shaped by their communities, but they're also shaped by who influences them and their opinions. Those kind of themes that came up from the research will help us design products, which we are at the moment in the middle of—this whole journey plan—reframing the risk and the reward aspects. And I think that for me is very important.

**Jeanne Baron:**

[00:21:12]

You want this, as you describe it, to be able to work at scale, right? This takes a lot of investment. It takes buy-in from all the stakeholders. They have to support it. You have to fund it and staff it. It takes commitment and a shared vision. What do you need to have impact in your opinion? And are you getting it?

**Anthony Ambrose:**

[00:21:30]

Nothing about us without us. You've got to have the voices of AGYW from the start, from the offset, being part of the co-design of your program. So if you look at healthy sexual relationships for example, how are these relationships helping them with their goals in life? The big gap of this whole program at the moment is that we are targeting AGYW without adolescent boys and young men. So I think that needed to be taken into consideration. You need to bring ABYM (adolescent boys and young men) into the program. And the human-centered design is not only at the beginning of a project and at the end, but during the project at various points of the program say 'okay, what is it in the program that we're doing right? Where are we going wrong? Where can we improve?' And constantly being with them, or them being with us as part of the design, the implementation, as well as the monitoring aspect. So it becomes co

creative, co-design, human-centered, but youth-centered in taking them into consideration at all times, and leave out the tokenism.

**Jeanne Baron:**

[00:22:46]

This research is just part of a large body of similar work being done around the world. You can get a picture of this landscape from resources on our landing page for *Px Pulse*. The barriers that get in the way of HIV prevention for young women are not simple to overcome, but neither are they insurmountable. Young women must have agency, and tools to carve out a path to empowerment. While there's no one approach to understanding what women want and no single path for a young woman to follow, Anthony's call to co-create with young people the programs and products that work is surely the map to a future free from AIDS. Keep an eye out on [AVAC.org](http://AVAC.org) for the next phase in this research, and for resources from projects all over the world using human-centered design to improve sexual and reproductive health. You've been listening to *Px Pulse*, recorded in the Relic Room. Our theme music was composed by Alexie Stevens. Our engineer is Sam Bair.