

WEBVTT

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00:00:04.720 --> 00:00:11.340

Jim Pickett: I'll let you know that these recordings will be available on Thursday. Everyone who's registered we will send out

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00:00:11.540 --> 00:00:17.910

Jim Pickett: an email with a link to these recordings, so you can look for those on Thursday.

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00:00:18.800 --> 00:00:26.700

Jim Pickett: and before we I turn it over to Nicoletta from Eatg, who will be moderating this session

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00:00:26.770 --> 00:00:37.430

Jim Pickett: with our wonderful speakers. Laurant, and sorry I wanted to just say a few quick words about the opening plenary at Croy last night.

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00:00:37.620 --> 00:00:55.160

Jim Pickett: So Croy kicked off last night, and as with opening plenaries at Croy, there is a special presentation named after Martin Delaney. So there's a Martin Delaney presentation that highlights, community voices and community concerns

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Jim Pickett: our Martin Delaney, speaker. This year is the world renowned global activist, human rights activist, Lgbtq, activist Frank Mugisha

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00:01:05.209 --> 00:01:19.429

Jim Pickett: from Uganda, who was speaking about the terrible laws against gay people in Uganda and Ghana, and the rest of the world, the homophobia that is creeping up and intensifying

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00:01:19.520 --> 00:01:23.279

Jim Pickett: really in every corner of the globe, including in no small part

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00:01:23.420 --> 00:01:26.940

Juan Michael Porter II: in the United States. And

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00:01:28.340 --> 00:01:34.600

Jim Pickett: There was sort of an appalling thing happened. When Frank was introduced and was beginning to speak.

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00:01:34.870 --> 00:01:40.869

Jim Pickett: Many, many, many. maybe hundreds, of researchers, left

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00:01:41.230 --> 00:01:44.980

Jim Pickett: the plenary session. Frank was the last speaker.

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00:01:45.030 --> 00:01:48.809

Jim Pickett: but they started to file out when he was beginning to speak.

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00:01:49.110 --> 00:02:15.679

Jim Pickett: and that is both appalling and completely unacceptable that scientists at an HIV conference could not sit around for another 20 min to listen to one of the most important activists ever talking about some of the most important issues of our time issues that directly impact many, many people who are impacted by HIV and Aids. So this is

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00:02:15.870 --> 00:02:20.340

Jim Pickett: a thousand percent are unacceptable. It's completely appalling.

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00:02:20.440 --> 00:02:27.619

Jim Pickett: And the community educator scholars. And I will be working on a statement that will be released.

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00:02:27.750 --> 00:02:42.070

Jim Pickett: Coming soon. So we are not taking this sitting down. This lack of respect for community. This lack of respect for an important speaker who risks his life every day to do the work he's doing on behalf of

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00:02:42.160 --> 00:02:46.789

Jim Pickett: queer people all over the world, and and really intersectional with

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00:02:46.940 --> 00:02:59.510

Jim Pickett: the rights of women and other people who are often oppressed. This is completely. It was really disconcerting and upsetting. So we're not letting that

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00:02:59.830 --> 00:03:09.199

Jim Pickett: be unnoticed. So with that said, I'm going to get off my little soapbox here. It's not a little one. It's a big one, and we're gonna keep the soapbox going. So stay tuned.

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00:03:09.360 --> 00:03:27.409

Jim Pickett: But I'm gonna now shift our attention. Today. We're gonna be talking about social behavioral sciences what we can expect to see in this category of science at Croy. And we're gonna have a really exciting conversation. I'm gonna now turn it over to Nicoletta

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00:03:27.420 --> 00:03:41.460

Jim Pickett: from EATG. European Aids Treatment Group, who's moderating and she will get us going. Thank you so much. Everyone for being here and thank you, Nicoletta, for working with us on this session today. Go ahead over to you.

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00:03:43.010 --> 00:03:52.389

Nicoletta Policek: Thank you, Jim, and thank you for sharing with us what happened yesterday. I think it's very important that as a community we make a stand.

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00:03:52.860 --> 00:04:03.750

Nicoletta Policek: My name is Dr. Nicolas Polychcek. I'm a social scientist. I'm a member of the European a treatment group. I am a woman who's been living with HIV for 42 years.

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00:04:04.230 --> 00:04:20.420

Nicoletta Policek: and that's how I want to start my very brief introduction by saying that it's very important that we contextualize HIV within society within the space which is not just a a scientific medical space.

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00:04:20.860 --> 00:04:27.669

Nicoletta Policek: I think it's very important as well that we take not for granted that as social beings

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00:04:29.140 --> 00:04:35.849

Nicoletta Policek: we are intersexual social beings, and there are so many determinants that make us who we are.

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00:04:35.970 --> 00:04:55.210

Nicoletta Policek: and specifically, when we leave with HIV the social determinants are much more powerful, or rather, it's much more difficult for us, because enough of me. And I think that, I'm looking very much forward to here from our 2 speakers today. Who are going to introduce themselves in a second. So

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00:04:55.600 --> 00:05:01.290

Nicoletta Policek: what they can share about the social behavior science that they've been tracking across.

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00:05:01.310 --> 00:05:04.490

Nicoletta Policek: I need to to say

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00:05:04.870 --> 00:05:20.380

Nicoletta Policek: although it's a firm, especially in a way that if you have a question or you want to make a comments, you can either use the chat, and I'll be monitoring the chat all the time, but also, if you want to raise your hands and make a contribution.

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00:05:20.380 --> 00:05:38.180

Nicoletta Policek: make sure that you unmute yourself. By the same token, while our speakers are talking, it would be very kind if we all unmute ourselves so we can vote full attention to them. I'm gonna start by giving the floor to later on, first to introduce themselves and then sorry. Thank you.

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00:05:38.940 --> 00:05:44.100

LaRon Nelson: Okay, thank you. Nicoletta. Good morning. I am Lauren Nelson.

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00:05:44.130 --> 00:05:53.959

LaRon Nelson: I'm a professor of nursing at Yale University. And my research area is focused on for the most part finding ways to implement

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00:05:54.170 --> 00:06:01.250

LaRon Nelson: the science that produces some of the strategies and products that have been used to treat and prevent. HIV.

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00:06:01.350 --> 00:06:13.979

LaRon Nelson: I've been a social behavioral science for probably 20 years, and I'm on a pro program committee on in the implementation track. I look forward to our conversation this morning. Thank you.

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00:06:19.230 --> 00:06:23.789

Sari Reisner (he | him): Hey, everybody! My name is Sari Reisner. My pronouns are he and him.

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00:06:23.870 --> 00:06:35.309

Sari Reisner (he | him): I am trained as a social and psychiatric epidemiologist. My sort of roots in terms of science kind of come from a community-based setting

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00:06:35.310 --> 00:06:58.220

Sari Reisner (he | him): largely operating in Lgbtq Health Center spaces through Fenway health which deeply informed my my science and sort of integration of of how research happens in a clinical context. But also kind of like in a broader societal context. So I was in Boston for many years in in the Us. And recently moved to Ann arbor, the University of Michigan in epidemiology.

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00:06:58.220 --> 00:07:09.700

Sari Reisner (he | him): I'm also on that program. Committee. And yeah, just really looking forward to this conversation. And wanna thank you. Jim, for for calling that out about yesterday's about yesterday's speaker. Thank you.

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00:07:16.180 --> 00:07:20.629

Thank you. So can we start by opening the conversation and

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00:07:20.940 --> 00:07:22.840

Nicoletta Policek: start, maybe

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00:07:23.070 --> 00:07:32.620

Nicoletta Policek: sharing. What is the impact of social and behavioral sciences on the understanding of HIV.

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00:07:39.940 --> 00:07:43.470

LaRon Nelson: Sure. Is that a question for us? I can. I can start.

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00:07:43.670 --> 00:08:06.480

LaRon Nelson: you know. So you know, I had a a chance to do this. They have this opening workshop for new investigators, and they part of what it is is to takes sort of give a preview or explanation of the Croyde program for people who haven't been to court before folks who just want to get some orientation to it. And I think across each one of the

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00:08:06.670 --> 00:08:11.980

LaRon Nelson: the focus areas cure molecular pediatric prevention

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00:08:11.990 --> 00:08:14.289

LaRon Nelson: that the the role

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00:08:14.430 --> 00:08:34.349

LaRon Nelson: or the need for more sort of social behavioral science and community integration was sort of spoken about. I don't think most people sort could articulate exactly what how it might work, except that some of

the designs of maybe some of the the trials that they've done. I think there was something that maybe they could have been better.

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00:08:34.350 --> 00:08:51.000

LaRon Nelson: you know, better designed and perhaps better outcomes if they had been more informed or driven by what we know from social behavior science. Certainly the impact that for some of these has been a lot less extraordinary, and we had all hoped.

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00:08:51.090 --> 00:09:17.529

LaRon Nelson: The the the thought is that social behavioral science could have contributed a lot to bringing out ways to make this stuff worked away. It should be working in terms of its impact on the community. Long acting, injectable sort of the the poster child, if you will, of something that should be doing a lot more than it has, and it just hasn't taken advantage of what we know from social behavior science standpoint. So I think, from the design element to how we actually can.

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00:09:17.530 --> 00:09:23.780

LaRon Nelson: I mean how you design these strategies, products, devices, whatever, how you actually conduct trials.

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00:09:23.810 --> 00:09:39.950

LaRon Nelson: you know what products are are relevant or interesting to communities. And actually, how we translate that into real impact. I think that's the role a role for social behavior science across every element that we're talking about at Croy. And I'm saying that particularly because I think it's

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00:09:39.980 --> 00:09:42.789

LaRon Nelson: it's easier for us to think about it in prevention.

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00:09:43.330 --> 00:09:52.040

LaRon Nelson: But I think it's not just in prevention that we should be thinking about figuring out ways to incorporate this. And I think there's some some

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00:09:52.200 --> 00:09:55.830

LaRon Nelson: more appetite for it, maybe among the newer

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00:09:56.010 --> 00:10:15.479

LaRon Nelson: there, I say, younger folks than the folks who sort of, you know, been in, you know, at the forefront so far. But there's definitely a role for it. I think those are some of the ways. And II think, as as we get different sort of people with different energies into it. I think we'll find that there'll be more demand for not just from the outside in.

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00:10:15.950 --> 00:10:19.120

LaRon Nelson: not like, not just from the

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00:10:19.510 --> 00:10:29.760

LaRon Nelson: the folks who usually find themselves on the fringes of Croy. But I think from folks who who are usually centered, we'll we'll wake up and realize we're we're we're

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00:10:29.990 --> 00:10:36.550

LaRon Nelson: we're missing out because we're not collaborating and integrating social behavior, science. And what we're doing. That's my initial thoughts on it.

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00:10:38.490 --> 00:11:02.470

Sari Reisner (he | him): Yeah, I would. I would echo. What? Lauren said. You know, I mean the HIV epidemic. The entire sort of epidemic in is in context, right? It's it's not devoid of context. And then in the social world. It's in all of the social and structural factors that sort of shape, the epidemic it, you know. So so not only kind of individuals, but but also the way that the science is done.

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00:11:02.470 --> 00:11:21.029

Sari Reisner (he | him): you know. And I think there's still this like sense of like, what is, there's that need to be sort of objective, and there is right, but are in terms of the science. But no, nothing is truly objective. Even the questions that are asked the way that they're asked. This sort of designs that are utilized there are already sort of theoretical and

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00:11:21.030 --> 00:11:41.399

Sari Reisner (he | him): viewpoints about the world being implemented by that like, for example, even if, like, I choose an individual randomized design right? That's like a a one orientation that I think would work at an individual level versus something like at the cluster level, right where, I'm thinking, and I'm not. I'm not prising one over the other. I'm saying that sort of it's just important to kind of articulate the assumptions, and I think there really is.

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00:11:41.400 --> 00:11:52.829

Sari Reisner (he | him): My sense is from some of yesterday's plenaries, you know. There the word equity was mentioned. You know it was. It was mentioned around vaccine equity. My sense is that there's a sort of lack

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00:11:52.830 --> 00:12:18.330

Sari Reisner (he | him): of or a need for us to kind of really come together in the social behavioral sciences, to to say, how do we actually do that? A. And what is equity? It's not just lip service. Right? So you know, I think that there really is an ongoing recognition of, without really understanding and addressing the multi level determinants that are at play, the dynamics, the pandemics that are driving the HIV epidemic.

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00:12:18.330 --> 00:12:39.550

Sari Reisner (he | him): We're not Gonna even be able to implement the technologies around cure and around prevention and around testing right? So that's the piece that's missing. We can develop many, many. There are incredible technologies. And I'm very confident and excited about you know the buy, the, the the biomedical pieces, you know. I think we need all the different pieces. But without the social behavioral

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00:12:39.550 --> 00:12:52.230

Sari Reisner (he | him): implementing those, you know is the challenge, right? So I think there's a growing recognition that that partnership really needs to be happening. So yeah, I was very so so yeah, I'll leave. I'll leave it there. Yeah.

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00:12:52.560 --> 00:13:00.730

LaRon Nelson: I mean, even if you look at at you know how we started. And you know, Jim, the acknowledgement of what happened yesterday at Frank's talk.

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00:13:01.070 --> 00:13:02.520

LaRon Nelson: I mean, the

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00:13:02.620 --> 00:13:19.700

LaRon Nelson: Croy is a social context, right? I mean, we're talking about. This is what you doing at your site in your lab. But you could look at what happened yesterday as sort of some evidence of whether or not scientists can be bothered with the topic right. Whether this, whether they think this it

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00:13:19.700 --> 00:13:32.690

LaRon Nelson: this is relevant to what they do. A lot of people didn't think it was relevant enough to stay to listen to the talk. I mean, that is, that's not a study. That's the real life. Scientific context of the people who are in charge to

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00:13:32.690 --> 00:13:59.149

LaRon Nelson: buy solutions to this epidemic. This is how they. This is how they think about this and and us, and some of us. And so I'm I don't know how we study that. But I think, the social behavioral element, just service point. Everything is in context. But even how we do the work and



how we talk about the work and how we organize ourselves around what our priorities is also in context. And I think that was just sort of a real life example of

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00:13:59.290 --> 00:14:16.180

LaRon Nelson: what we and I'm saying, we, as the scientific community, really think about the role of humans who aren't sort of in our labs. Whether or not we think this has any real relevance, serious, important relevance to what we're doing. That's and that's that is,

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00:14:17.090 --> 00:14:32.740

LaRon Nelson: I don't know. I feel like I want to say, because I think we talk about social baby size and studies, and I think we should sort of reflect on the way in which we actually show we don't give a shit about something about the things that matter that should matter most.

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00:14:35.070 --> 00:14:35.860

Sari Reisner (he | him): Yep.

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00:14:38.420 --> 00:14:50.049

Sari Reisner (he | him): Jim said. We could talk like with chat with friends.

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00:14:50.050 --> 00:15:14.959

Sari Reisner (he | him): and I think that you know one of the great things Lauren is, you know, you and I think you you were both new program committee members this year. You know. So I think that is sort of demonstrating a, you know, desire to really integrate this more and bring that in. And I think that you know from from my perspective, looking at the program this year, there is more content, you know, and there is content that I'm excited about you know that. I think that, you know, hopefully.

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00:15:14.960 --> 00:15:18.399

Sari Reisner (he | him): we've we've sort of helped bring to the to the forefront.

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00:15:18.400 --> 00:15:33.349

Sari Reisner (he | him): you know. So maybe we could talk a bit about that. So there, there is content around stigma and one of the things that struck me is, you know that there's content around. You know the the need to not just understand HIV stigma, which is like a major piece, and there's

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00:15:33.350 --> 00:15:56.780

Sari Reisner (he | him): and there's great content around that including some work. Looking at HIV stigma and Beirut lemon. So really like thinking about, how can we look at these stigmas in different contexts, because, of course, they don't operate across all places the same way. Right? so things like that. There's a piece around for me that I'm I'm thinking of, or at one is around a sort of novel risk

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00:15:56.780 --> 00:16:17.639

Sari Reisner (he | him): calculator looking at sort of how to look at suboptimal OP sub optima outcomes in a Kenyan setting. And I, you know they included stigma as part of that sort of measure. You know. So thinking about like, are there strategies that we can utilize? That would sort of predict outcomes that are not sort of your usual cast of characters, you know, if you will.

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00:16:17.640 --> 00:16:30.230

Sari Reisner (he | him): There's some some content on drug use stigma. So you know, for me. You know, my background is in social and psychiatric epi. And I'm very interested in how mental health substance use

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00:16:30.230 --> 00:16:55.069

Sari Reisner (he | him): and and and sort of violence, and those pandemics are driving sort of the epidemic, and that includes sort of the structural factors and drug use. Stigma is a major factor. Right? We know that. You know, substance use does impact. HIV, I can tell you. You know, I know we have an embargo policy, so I'll just talk, you know a lot of majors in transgender health and

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00:16:55.170 --> 00:17:08.369

Sari Reisner (he | him): I've been conducting a study with colleagues at Johns Hopkins, with Andrea works and colleagues at Johns Hopkins called the Light Study. It's a study in the US. Of transgender women. And we enrolled more than 1,500 transgender women, and we looked at Sera. Conversion

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00:17:08.589 --> 00:17:32.119

Sari Reisner (he | him): in a cohort. This is an a NH. And cohort and you know, and we did find that you know, substance use was a major predictor particularly, you know, stimulant use of HIV incidence, you know. So thinking about what? What is the what do we need to address? Sort of like stigma associated with substance? Use and actually, really like, bring that conversation which I think can be a hard one into the forefront.

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00:17:32.120 --> 00:17:57.109

Sari Reisner (he | him): yeah, I think there's also content on gender, healthcare, stigma as well as like thinking through sex work I've met who has sex with men and sex work stigma, and how that impacts. I think you know, just in terms of even thinking about like the stigma that's

operative homophobia, transphobia racism. You know. What? How does that? How does that manifest. So I think for me, that's an exciting thing that to see. And I was, like, you know, going through the program. I was doing my job

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00:17:57.110 --> 00:18:22.570

Sari Reisner (he | him): thing where I'm like Lauren, I'm like searching my keywords. You know what I mean. I'm like. Let me find I'm gonna see how many times the word stigma appears in the program, you know, like doing my thing. And and you know it was. It was more than I thought it was going to be so. I was very pleasantly like surprised about that. So I'm gonna be quiet. But one like framing for me around this is like II like to talk about is like like the situated vulnerabilities in which people live. They're also like the the

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00:18:22.640 --> 00:18:35.089

Sari Reisner (he | him): all promoting factors to right like it's not all negative. And we're not all Debbie Downers here, but but like thinking about those situated vulnerabilities. And for me, stigma is such a key driver, a a a of much of it. Truly. Key populations.

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00:18:36.410 --> 00:18:40.420

LaRon Nelson: Yeah, thank you. Sorry. I'll say, too,

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00:18:40.430 --> 00:18:56.060

LaRon Nelson: I appreciate it, seeing more behavioral interventions and even more so structural interventions. I think I was also surprised to the degree at which there were a number of at least posters focused on talking about

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00:18:56.070 --> 00:19:16.189

LaRon Nelson: understanding way that structures marginalize people and make it difficult for them to be a prep or stay in treatment, and that there was some work presented on ways that folks in the communities are looking at, addressing some of these structures and in some ways using multi level strategies, so structural and behavioral. So I was. I was happy to see that I think the

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00:19:16.220 --> 00:19:18.550

LaRon Nelson: you know where we could probably do better.

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00:19:19.510 --> 00:19:33.180

LaRon Nelson: Is making some more. I guess I will call the air time for some of it, because a lot of the things that were so interesting are in the poster sessions. And I think sometimes people, you know, they don't take poster sessions is.

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00:19:33.300 --> 00:19:59.599

LaRon Nelson: give them as much capital as the oral sessions, and they should. And I actually made a comment about that yesterday is, don't cheat yourself like a lot of what you wanna see is in these posters, but maybe making some more, finding some ways to get some of this really to be talked about in sort of a platform scenario. But one of the things that is in at least in one, maybe 2 oral sessions is focus on

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00:19:59.710 --> 00:20:14.539

LaRon Nelson: displaced people and refugees. And what impact that has and what those experience on what they do for the ability to stay engaged in treatment, and how people are navigating that. So that was definitely new. I remember, you know.

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00:20:14.740 --> 00:20:41.949

LaRon Nelson: the program committee really trying to think about ways to signal that. And I think that is UN. It sounds like it was sort of unusual, but they really wanted to sort of make some space to talk about what's happening, because there's so much displacement happening. Climate related, you know, conflict related policy related but it does have an impact. And it's something that they really wanted to make some room for. So I was really happy to see that, too.

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00:20:43.340 --> 00:20:51.260

Sari Reisner (he | him): Yeah, I was as well. And the whole idea of what displacement is like, it's such a rich like thinking about that as a concept.

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00:20:51.260 --> 00:21:14.889

Sari Reisner (he | him): It's such a rich concept. I think it's one that we could really like unpack and really do a lot of work in you know it. There's a lot of I was recently, we're working on a study in the Peruvian context. And we enrolled a sample of young trans women. And one of the things that we were seeing was really a lot of migration. And not just intrac, you know, intra country within country

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00:21:14.890 --> 00:21:22.090

Sari Reisner (he | him): for example, from ikitos and the jungle areas to Lima. Right? So a lot of young women

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00:21:22.090 --> 00:21:48.650

Sari Reisner (he | him): seeking opportunities. You know, having rejection from, say, families wanting to pursue their, you know, sort of gender true selves and authentic selves moving within the country, but then also, of course, within countries, and particularly from the Venezuela. So the Venezuela Diaspora into Peru. So II also, Lauren, have

been very interested in thinking about. Like, are there periods of sort of sensitive or critical periods in migration.

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00:21:48.700 --> 00:21:57.450

Sari Reisner (he | him): you know, that are kind of a particular ones that we need to address. And and how do we get services to those communities that are really that are really in need? So thanks for lifting that up

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00:22:03.940 --> 00:22:11.159

Nicoletta Policek: any any questions. So far. I know you've been very busy on the chat

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00:22:12.870 --> 00:22:23.090

Nicoletta Policek: specific question. Yeah, I just wanted to jump in and encourage people. There's a lot of really great comments here, and we see a hand raised.

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00:22:23.190 --> 00:22:25.629

Jim Pickett: Thank you, Anita, for bricking the ice.

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00:22:26.260 --> 00:22:42.749

Neetha Morar: Hi! So great conversations. I'm writing on the check. But I wanted to make 3 critical comments. The one is that we need to evolve ourselves as scientists because our language of science team seems to indicate clinical medical. I'm in clinical trials for a long time in South Africa.

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00:22:43.080 --> 00:22:55.389

Neetha Morar: and the second is, I don't like the fact that we all, including myself, we kind of compartmentalize our language. So it's social behavioral science. And then what about community science? Because that's key right? And

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00:22:55.390 --> 00:23:16.840

Neetha Morar: social science needs to integrate with biomedical and and community size, because communities is assigned. And we're not letting that voice come through in in the publications, because that's what's measured. And and the third is that you know the prep fact trial recently, although the result of the efficacy was negative, but because the African led consortium's trial

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00:23:16.930 --> 00:23:36.940

Neetha Morar: had a biomedical study linked to behavioral work and community science which had cab members speak out at at the Avac Led

Journal. Session, and they spoke about how they felt about transparency and advocacy. And so I feel we need to begin to topple our heads

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00:23:36.940 --> 00:23:52.599

Neetha Morar: really and challenge grants, challenge big funders and indicate upfront that if this protocol doesn't have community and social science, we're not gonna do this in the communities. And how do we engage our cab. So those are my brave comments. Thank you.

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00:23:54.200 --> 00:23:57.940

Nicoletta Policek: Thank you. Of course, someone else who raised their hands.

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00:23:58.730 --> 00:24:02.549

Nicoletta Policek: So please do go ahead. I can

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00:24:02.780 --> 00:24:11.140

Wakefield S.: Wakefield. Sure. Thank you all for for this conversation. Let me suggest that one way

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00:24:11.250 --> 00:24:29.080

Wakefield S.: we may try it amongst ourselves first to think about it, and then carry it back, and so I will put it on around and and sorry to to think about bringing it up in the closing meetings for Corey. It's a committee that for years has done everything it can to give lip service to community engagement.

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00:24:29.100 --> 00:24:33.720

Wakefield S.: But, Lauren, when you gave your talk yesterday, towards the end

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00:24:33.960 --> 00:24:42.510

Wakefield S.: you had. You had a slide where you showed both the model that you're using to do your work and summarize the rest of

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00:24:42.560 --> 00:24:46.349

Wakefield S.: of of your talk in terms of bringing a

116

00:24:46.960 --> 00:24:57.689

Wakefield S.: translational science, and and some of the questions that were asked afterwards, if you could share a little bit of that with us. I don't know if you even have access to that slide to share with the group.

117

00:24:57.820 --> 00:24:58.890

Wakefield S.: because

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00:24:59.050 --> 00:25:08.460

Wakefield S.: what I heard in that was that there's an ethos, or even an ethical responsibility to do this work in a way that integrates

119

00:25:08.540 --> 00:25:16.330

Wakefield S.: the social and translational sciences. It's no longer acceptable to think that we're going to get a biomedical

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00:25:16.380 --> 00:25:17.510

Wakefield S.: answer

121

00:25:17.890 --> 00:25:27.930

Wakefield S.: and use communities to do that and not incorporate community science. So I'd like you to say a little bit more about what you said yesterday, and

122

00:25:28.090 --> 00:25:33.999

Wakefield S.: share that with those of us that are here this morning didn't have a chance to hear you yesterday.

123

00:25:35.740 --> 00:25:44.789

LaRon Nelson: Thank you. Let me, I'll I'll share what I can remember from it. But first, let me say to the first comment, I think it was neat to that.

124

00:25:44.830 --> 00:25:48.439

LaRon Nelson: I agree. I think the the language

125

00:25:48.680 --> 00:26:00.619

LaRon Nelson: of community science needs to be more intentional. I mean even those of us who, to think a lot about it. II will admit that language doesn't come out. I think there's some in some, some

126

00:26:00.620 --> 00:26:21.930

LaRon Nelson: appliedness about it, but I just assumed it is, but I think it can be silencing in a way. And actually, in my talk yesterday somebody actually mentioned that, did you mentioned all these other different groups. But you didn't say community. And I think we have to be clear about about calling that out particularly so that it doesn't get lost. And it's important is is reinforced.

127

00:26:22.020 --> 00:26:36.980

LaRon Nelson: Wakefield. I think what I was saying yesterday. II think I mentioned the Httm study that I'm leading. Maybe that's what you're talking about, and saying that as much as we found ways and are trying to find ways to

128

00:26:37.730 --> 00:26:39.290

LaRon Nelson: discover new.

129

00:26:39.510 --> 00:26:54.149

LaRon Nelson: you know, devices or products to prevent or treat HIV, that they need to actually have impact. And a lot of the focus has been on efficacy and not on impact. And a way to make it have impact. And I think I use long acting. And Jack, but as sort of again

130

00:26:54.220 --> 00:27:15.949

LaRon Nelson: the the example, because it's such a stark example of something that just has not worked in the in real life as well as it could or should be working in this, because we've not paid attention to a lot of these complexities that make it very difficult to do what this could seem to be done easily in the clinical trial, and that, at least in

131

00:27:15.950 --> 00:27:32.019

LaRon Nelson: you know, the the the basis of that work is community driven the the ideas that we're advancing community coalitions, making sort of accessible peer support to everybody, using social media to influence social norms around stigma reduction

132

00:27:32.020 --> 00:27:48.820

LaRon Nelson: making health care clinics, the target of intervention and not black, gay men. Because we're saying what they're not. The problem. The problem is the context in which they're trying to get care. So that's a very complex study. And I'm not sure we could have done it if we didn't have well, I can say this truthfully.

133

00:27:49.040 --> 00:28:10.510

LaRon Nelson: I think it wouldn't have gotten funded through the normal Nih channels. I think the fact that we're doing it in the context of the Hptn HIV prevention trials network is sort of one way, something that complex could be done. But we said, Why, why would we tinker around with this? The community has told us what the needs are. So either we're gonna do it

134

00:28:10.510 --> 00:28:27.339

LaRon Nelson: to to have the impact, or we're just gonna do another study that's gonna be fundable. But it's not gonna do anything for anybody the the. So that that is an example. I think of it. And and even that study. Maybe I said this in another meeting like this, you know that



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00:28:28.310 --> 00:28:41.439

LaRon Nelson: that study got funded because of community activism that we had to write. A protocol had to had to pass scientific, you know, muster. But there was a lot of

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00:28:41.450 --> 00:28:59.389

LaRon Nelson: points along the way where the structures thought, this is too complicated. It's too messy. What is this racism thing? How you gonna address racism, what it stigma? Lgb, they just they didn't buy it. And it wasn't until community members made some phone calls and stirred up some trouble

137

00:28:59.390 --> 00:29:24.249

LaRon Nelson: that they said, Okay, we should give this a shot. It's it's risky. It is a risky study. They have not done anything like this before, but if if we did, if we don't try this, it didn't try this, I think we'll still be in the same situation. And so I was suggesting that we haven't figured out how we're gonna work together. Politics, political people, social scientists, culture folks community. But we gotta figure it out. And at least in this example is, I was trying to figure out how

138

00:29:24.250 --> 00:29:36.389

LaRon Nelson: gonna work together to solve this problem. I think that could be a model for future research. But then it has to be sponsored. And I think, the community effort is gonna what's going is gonna be what pushes

139

00:29:36.950 --> 00:30:06.799

LaRon Nelson: government funders or private funders to respond to this type of thing. It won't just be the science cause. If it was just us, I can tell you we wouldn't be doing the study. We don't see we don't. People's jobs don't depend on what we say. But when folks are worried about elections and budgets, you know, then we get responses. So I think that'll be available online for folks to see who didn't see it yesterday. And it'll probably be more more coherent to what I just tried to offer you. But that's sort of my summary. Thank you for asking me to say that. Wakefield.

140

00:30:08.430 --> 00:30:33.380

Sari Reisner (he | him): Yeah, II just wanna chime in and say, the community sciences piece it is something you know I feel like I take it for granted. Of course, our work is community engage from my in my, you know, space, but that is such a critical ingredient, and I'll you know, lift up again the need for like communities to be just present and with us, and that also, like those of us who are part of communities, you know. Like, for example, like myself, I'm part of the trick

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00:30:33.380 --> 00:30:57.500

Sari Reisner (he | him): transgender community like we are doing this work, too, right? So like trying to break down those silos, you know, around like who is community and how that functions. But I'll say also for the HIV prevention Trials network for HPTN. 09, one, which is the first protocol specifically for transgender women. That's co-locating gender affirming care including hormones for those who would like it with prep delivery.

142

00:30:57.500 --> 00:31:26.270

Sari Reisner (he | him): You know that that was so heavily informed by Community Tony Petite and I. He's the protocol Co. Chair. We went around to the 5 different sites, and we beforehand got feedback, and we advocated to change the design, you know, and that issue was, you know, we had a delayed condition. I think one question is always like, Who's our control condition, and what's the ethics of that? So we had a delayed condition. People immediately. And then 6 months later, and when we originally went to community, it was gonna be 9 or 12 months because we had gotten feedback.

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00:31:26.270 --> 00:31:51.710

Sari Reisner (he | him): You know that that we needed a longer period, and the community said, no way like, I don't know what's happening in a year in my life, right like too far out. So you know, just really like and hearing, not just soliciting and getting the impact and being there and showing up for it, but integrating it. And that does take advocacy. It takes advocacy within the science community as well, right? And the funding community and so forth. So yeah, it's just such a great point.

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00:31:52.160 --> 00:31:57.260

Sari Reisner (he | him): it should be. Community sciences should be elevated as any other kind of science. It should be part of that.

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00:31:58.410 --> 00:31:59.250

Nicoletta Policek: Yeah.

146

00:31:59.860 --> 00:32:04.390

Nicoletta Policek: I agree. Thank you. Thank you, Jeff, for waiting patiently.

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00:32:04.560 --> 00:32:22.859

Jeff Taylor: No worries, thank you. You know. I think the scientific community is forgotten that it was community engagement, specifically, community activism that got this whole ball rolling. We would not be where we are without that, and it's been forgotten over the years. And even though they've kind of made community engagement part of the the research networks that we fund.

148

00:32:22.860 --> 00:32:40.329

Jeff Taylor: It's become window dressing. They don't invest in it, you know. Early on, people are literally dying to get on these committees and get their input. Now, we have successful therapy therapy. People lives out jobs. They can't invest the incredible amount of time it takes to set up protocol teams. You know. Go to these meetings.

149

00:32:40.330 --> 00:33:02.439

Jeff Taylor: and do I do all this work without any remuneration with whatsoever. The Acg is the largest clinical trials group in the world. They do not pay their their global cab members, or even the Css members and they don't invest in in educating them and bringing people up to speed with the sciences. Things have changed, and it's the same thing sadly with socio research they just recently

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00:33:02.510 --> 00:33:11.209

Jeff Taylor: incorporated that into the Acg. And most of those researchers are expected to do so voluntarily unlike the biomedical researchers, and that is shameful one needs to change.

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00:33:11.480 --> 00:33:13.419

Jeff Taylor: Thanks. I'll get off my soapbox.

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00:33:15.090 --> 00:33:17.970

Nicoletta Policek: Thank you. That's a very good point, Barbara.

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00:33:22.060 --> 00:33:28.280

Barbara Friedland: Sorry, thank you very much. So 2 things to need to comment

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00:33:28.370 --> 00:33:46.480

Barbara Friedland: a while back. And I think people talking about how to change, how things are done. And I know you know Jeannie Marathso was sort of tentative about what she was saying. But, on the other hand, there is an Ni aid request for, input so I think we should probably all

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00:33:46.720 --> 00:33:52.589

Barbara Friedland: give input. But one of the things that I wanted to raise that was like very specific

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00:33:52.970 --> 00:33:55.160

Barbara Friedland: while Hptn, I think, is

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00:33:55.620 --> 00:34:04.919

Barbara Friedland: great in a lot of ways. We are actually getting ready to do a study of the dual prevention pill, which is a single pill that combines

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00:34:06.360 --> 00:34:08.440

Barbara Friedland: prep and oral contraception.

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00:34:08.840 --> 00:34:18.909

Barbara Friedland: And when we propose this study to Hptn, because no phase 3 trial is required. So really, what we're trying to see is how to get this out there

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00:34:19.150 --> 00:34:24.220

Barbara Friedland: to the people who need it and would use it. So we wanted to include

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00:34:24.350 --> 00:34:37.499

Barbara Friedland: a counseling module so that we could test, like how women in a family planning clinic would go in and be told about different methods, and could then choose if they thought this method was right for them.

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00:34:37.590 --> 00:34:48.119

Barbara Friedland: We also want to include a part about providers and getting providers on board and seeing how providers felt about counseling about the different options. Anyway.

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00:34:48.300 --> 00:35:08.699

Barbara Friedland: of course, we were told, this is way too complicated. Let's just focus on this randomized, controlled trial where crossover study, where people are going to use the dual prevention pill for 6 months, and they're going to use 2 separate pills prepping, or all contraceptive for 6 months, and then they get to choose. And let's see how adherence is.

164

00:35:08.700 --> 00:35:20.089

Barbara Friedland: And it's like, Okay, but you're missing the whole point here, because how do you know that the women who are enrolling in your study are gonna wanna use a pill and be okay about using a pill in the first place.

165

00:35:20.430 --> 00:35:30.659

Barbara Friedland: So I don't. I love input and help. I mean, I am like a tiny little person on this study. It's like, you know, way bigger than I am. But I just.

166

00:35:30.700 --> 00:35:45.070

Barbara Friedland: I'm concerned that we're going to do this big study adherence is still going to be an issue, because we aren't making sure that the women who are in the study are making a choice that they want to take a pill every day

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00:35:45.080 --> 00:36:01.600

Barbara Friedland: or 2 pills every day versus use a ring or long-acting cab, or whatever or use injectable contraception and prep, I mean, it's just it just seems like extremely short-sighted. We're gonna spend a lot of money.

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00:36:01.740 --> 00:36:08.779

Barbara Friedland: not get the answers we want and throw the dual prevention pill out with the bath water. So

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00:36:09.510 --> 00:36:13.300

Barbara Friedland: any input would be greatly appreciated. Thank you.

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00:36:15.600 --> 00:36:16.700

Nicoletta Policek: Thank you.

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00:36:17.200 --> 00:36:22.169

Jim Pickett: And sorry. Can you, can you help Barbara.

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00:36:23.970 --> 00:36:35.739

LaRon Nelson: Yeah, we. So I will say, you know, Hb, certainly is not immune to some of the issues that we're talking about, even though it offers more possibilities than some is definitely not a perfect

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00:36:36.010 --> 00:36:42.470

LaRon Nelson: for some of the work we want to do. I mean, I I've seen that. And I've experienced that in

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00:36:43.150 --> 00:37:02.910

LaRon Nelson: what I would say, and we can talk more. You know, offline to Barbara is a lot of the way this Httm works is through this this committee system. And so, although they invite, you know, anybody in anywhere in the world can submit something to it. It really has sort of a very elaborate

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00:37:03.220 --> 00:37:08.530

LaRon Nelson: administrative structure. And that's sort of kind of the ways to get.

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00:37:09.300 --> 00:37:15.150

LaRon Nelson: Maybe it's political, but I think it is kinda who you can get to sort of be a champion and sort of

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00:37:15.420 --> 00:37:44.269

LaRon Nelson: to have advanced the idea because it it has to make sense to the people who get to to Greenlight the study and that sort of been our challenge is that it makes a lot of sense to me, and it makes a lot of sense necessary. But we are the decision makers on that that piece, and there's some folks that you can get to say. This is why we need to do it. Who can really help influence the folks to get to decide whether they do it? The way that you propose, which is the way that's gonna make the most difference. So that's that's tough.

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00:37:44.270 --> 00:37:52.899

LaRon Nelson: And it can take years. And so, even as as you know, when Wakefield mentioned the study, I'm doing and sorry we talked about his

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00:37:52.900 --> 00:38:21.360

LaRon Nelson: the I mean it's it's not like you go to Nih. You write a grant, and they review it. And then, you know, you answer like this has been years in the making since the idea even came up. And so it's a if you can get it, it can be great, but it's a long haul process, and I think, being able to sort of articulate the issues like you just described, and the connect with folks who can help with strategizing how you make the most of that structure because they can work well if you can get it, if you can pull the right levers, but

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00:38:21.360 --> 00:38:27.030

LaRon Nelson: that that's been my experience, and I've done.

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00:38:27.100 --> 00:38:33.419

Barbara Friedland: But they're not doing it. How we suggested they're doing it. They're they're just focused on

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00:38:33.900 --> 00:38:43.390

Barbara Friedland: comparing adherence between women who take this single dual prevention pill or 2 separate pills.

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00:38:44.260 --> 00:38:55.969

Barbara Friedland: It's HP, yeah. And so anyway, I have a poster which I would love people to come by and chat about.

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00:38:56.050 --> 00:38:59.009

Barbara Friedland: So we did a small pilot study.

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00:38:59.140 --> 00:39:05.260

Barbara Friedland: using an over encapsulated dual prevention pill in Zimbabwe with 30 women and

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00:39:05.760 --> 00:39:14.049

Barbara Friedland: very short small study with 3 months on each regiment. There was no difference in adherence between the 2 regiments. So my fear

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00:39:14.410 --> 00:39:16.690

Barbara Friedland: is like

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00:39:16.820 --> 00:39:20.149

Barbara Friedland: we're gonna get the same. So results. And yeah.

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00:39:20.510 --> 00:39:35.470

Nicoletta Policek: we should top up line. Can I? Just sorry. It's very interesting. And I'm particularly interested in this topic. But I'm mindful that there are a lot of people still wanted to to say something, and also because I'm mindful of time, so shall I move to. She can roll, please.

190

00:39:36.370 --> 00:39:38.540

Shekinah Rose: Thank you. Nicoletta.

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00:39:38.760 --> 00:40:00.880

Shekinah Rose: Shakina rose here. I'm a trans woman living, surviving, and thriving now with HIV Aids for 39 years. I am really inspired by our conversations this morning. For the past 2 years I've been actively engaged with a lot of different people around the country. Whether it would be the 3 rust Far Bill.

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00:40:01.260 --> 00:40:05.009

Shekinah Rose: Rust! The rust belt sea bars! I'm involved in

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00:40:05.060 --> 00:40:14.040

Shekinah Rose: 2 State planning councils, a variety of coalitions as well as community advisory boards.

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00:40:14.200 --> 00:40:16.090

Shekinah Rose: this is

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00:40:16.200 --> 00:40:23.030

Shekinah Rose: what will. This is what's driving all of us to like. Create the picture, to bring it all together.

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00:40:23.110 --> 00:40:29.870

Shekinah Rose: It's taken a long time for my voice. Other voices to be heard.

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00:40:30.000 --> 00:40:36.900

Shekinah Rose: and the one component that we haven't added that I want to like bring into this space is trauma.

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00:40:37.150 --> 00:40:40.280

Shekinah Rose: you know, as advocates, we do a lot of work.

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00:40:40.430 --> 00:40:52.490

Shekinah Rose: We've all experienced trauma in some way, and so trauma is a component into all of the work that we're doing. And it's multifaceted because, like stigma.

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00:40:52.520 --> 00:40:59.520

Shekinah Rose: it has many variations, and the the experiences that people have are varied and important.

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00:40:59.790 --> 00:41:08.540

Shekinah Rose: not only to acknowledge and recognize, but to actually see. And it's often gone amiss in our communities, I find.

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00:41:08.720 --> 00:41:18.059

Shekinah Rose: and so moving on to another like observation. I'm currently involved in advocacy work both

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00:41:18.140 --> 00:41:27.269

Shekinah Rose: in HIV and human rights in East Africa, South Sudan, Kenya, Uganda, Tanzania

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00:41:27.370 --> 00:41:37.569

Shekinah Rose: a little bit in Rwanda. And what I'm saying is that language? Yes, I mean, we're uplifting in a way right now, that is good for

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00:41:37.670 --> 00:41:51.639



Shekinah Rose: the global North. But for other, the global style. Language is actually yeah, people are are hearing and not traumatized by language. But it's equating to violence.

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00:41:52.380 --> 00:42:10.559

Shekinah Rose: And so we need as a Lebron and Sara. II would like for us to all kind of consider. How do we move past just language, and deal with the violence part because it could like spread like the rest of like what we're experiencing in terms of

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00:42:11.260 --> 00:42:14.620

homophobia and transmissia

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00:42:14.700 --> 00:42:16.190

Shekinah Rose: it, too.

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00:42:16.230 --> 00:42:24.829

Shekinah Rose: eventually could come into our like consciousness that just addressing language in itself is great. But

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00:42:24.930 --> 00:42:33.689

Shekinah Rose: there may be a new avenue of what we need to look at to. How do you wanna like define it yet, cause it's too fresh.

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00:42:35.070 --> 00:42:36.849

Sari Reisner (he | him): Yeah, thank you very much.

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00:42:37.090 --> 00:42:51.089

Nicoletta Policek: Sorry. Ask to bring the other 3 people were patiently waiting. And then, if Verona. Sorry. Can Kate this? These are very important points. Thank you for raising them. She can. So I'm gonna ask Karen.

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00:42:52.320 --> 00:42:54.039

Karine Dube: Yes, thank you.

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00:42:54.070 --> 00:43:05.400

Karine Dube: Thank you for everything that's been said so far, and thank you, Lauren, for giving us a roadmap yesterday. But I think we also need to be thinking about the science that we're not hearing at Koi.

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00:43:05.440 --> 00:43:12.509

Karine Dube: There's a lot of biomedical research on HIV. Cure or HPV. But we're not hearing the social sciences aspects of it.

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00:43:12.520 --> 00:43:24.770

Karine Dube: A farmer Coy gave a talk yesterday on HIV. Cure research and social sciences was not mentioned as part of the roadmap and the strategy. So I think we have to be thinking about

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00:43:24.840 --> 00:43:32.560

Karine Dube: the sociable aspects of HIV. Cure research, particularly as treatment interruption trials are about to be scaled up in Africa.

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00:43:32.600 --> 00:43:51.520

Karine Dube: and the fact that there's incredibly limited formative research on this is very concerning. And as HIV. Cure trialists. We also need to be bridging with HIV. Prevention around partner protections, and, as Shikina mentioned, broken any trauma informed in healing centred designs and back to what Jeff Taylor was saying in terms of community engagement.

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00:43:51.520 --> 00:44:07.319

Karine Dube: The community engagement is not happening at the central level in the Ectg. But the the basic science collaborator's. The Martini laboratories are mandated to have community engagement. So we need to bring community engagement into the networks as well. Thank you.

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00:44:09.530 --> 00:44:16.219

Nicoletta Policek: Thank you. Can I ask Anna JD. And Kenzie to be brief in their comments.

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00:44:16.240 --> 00:44:24.520

Nicoletta Policek: and so questions. So then the Laron and Sari can have enough space and time to to get back to us to

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00:44:25.020 --> 00:44:27.320

thank you. So Jd has.

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00:44:28.000 --> 00:44:46.510

JD Davids: Hi, I'm Jd. Davidson. I long ago was a member of the community liaison Subcommittee of Croy, and so glad to see how much it has sort of expanded its impact, and that we can use these kinds of technologies. II also wanna put a word in for people to urge Croyd to stay hybrid, because so many

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00:44:46.510 --> 00:44:58.169

JD Davids: conferences and gatherings have gone back to in person, which not only excludes many of us who are disabled, or who have travel restrictions or are subject to travel violence because of our identities.

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00:44:58.170 --> 00:45:22.469

JD Davids: but also subjects people to risk of ongoing Covid transmission and I don't haven't seen the data yet. That's gonna be presented here and maybe locked out of a lot of it, because it's on posters. And the posters aren't really being discussed with online participants. But we know that there's some evidence that Long Covid is 4 times as likely, and people living with HIV. And that means ongoing or permanent

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00:45:22.470 --> 00:45:44.669

JD Davids: chronic illness and disability from Sars Cov. 2. So anybody wants to talk about that. That's what I'm working on at long Covid justice. And the second thing is, looking at sort of what's happening at other places in nih we see in the recover study, which is a a large observational study about long covid that's starting to do some limited, not great

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00:45:44.920 --> 00:46:09.279

JD Davids: treatment research. They pay people to be representatives. And I put in the chat this fair market calculator. I don't know that that's what they use it recover, but II never saw that in in over 30 years of HIV advocacy where there's there's recommendations and rates that people should be paid. But, on the other hand, people don't have as much of a voice or say in the in the research and there's not as much of a

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00:46:09.510 --> 00:46:33.680

JD Davids: opportunity for people to. There's not an emphasis on people being their own body of community representatives. They're more isolated from one another. So I think it's also helpful to look at what's happening in other places as far as input into research into be in solidarity with one another about what the best practices should be overall. Drawing. What we've seen is possible across different kinds of areas of study and networks.

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00:46:36.240 --> 00:46:38.539

Nicoletta Policek: Thank you, Kennedy, please.

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00:46:39.520 --> 00:46:44.179

Kennedy Mupeli: Oh, thank you so much mine is just. Perhaps a comment

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00:46:44.300 --> 00:46:55.700

Kennedy Mupeli: from observations, from studies that are taking place. And also like, I wanted to take an example of the voice study.

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00:46:55.740 --> 00:47:10.250

Kennedy Mupeli: Most most of the things that we omit to take into consideration that we design these clinical trials. Is that we? There's one aspect what is called the Masroh hierarchy of needs. You know, we need to incorporate this

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00:47:10.250 --> 00:47:35.610

Kennedy Mupeli: into the design of clinical trials and studies. I think this approach can enhance participation. And recruitment and retention, and ensure that studies are sensitive to the diverse circumstances and motivations of participants. I think it can also lead to a more engaged and cooperative cooperative participants. Result in a higher quality of data. And and if

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00:47:35.890 --> 00:48:05.399

Kennedy Mupeli: beginning moving forward from now we begin to incorporate the Maslow hierarchy of needs. As we design these studies, I think, especially in Africa, because we will take a study to a population which you, you take a product, a a study product, and that community actually there, the needs of that community is is not that pure, perhaps another need. And that's the reason why perhaps we end up with a poor data at the end of the studies. Thank you.

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00:48:06.950 --> 00:48:08.849

Nicoletta Policek: Thank you. Now, is

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00:48:08.880 --> 00:48:17.680

Nicoletta Policek: for little and sorry to to give us some sort of final comments or summary what we have said, and then I need to.

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00:48:17.920 --> 00:48:22.440

Nicoletta Policek: I need you to be short and sharp, so need a couple of minutes.

238

00:48:23.030 --> 00:48:29.080

Nicoletta Policek: Well, I can take a minute from the 9 min remaining. Thank you.

239

00:48:31.000 --> 00:48:33.429

Solar on first. Oh, sorry.

240

00:48:34.220 --> 00:48:51.669

LaRon Nelson: Okay, I'll say a few comments then. You know II I think you'll find at least those of you can access the content here and then

posters more social behavior, science content than in the past. And we hope that we'll we'll

241

00:48:51.710 --> 00:49:06.459

LaRon Nelson: increase that number and increase the diversity and ways in which social behavior science is presented at Croy. I think you know some of what you're saying. I know, sari, and I will definitely take this back in our discussions with program committee. And I think that you know part of

242

00:49:06.770 --> 00:49:09.709

LaRon Nelson: what I think social behavior science can offer

243

00:49:09.910 --> 00:49:13.969

LaRon Nelson: us. And that's based on some of what I'm hearing you say this morning

244

00:49:14.690 --> 00:49:26.110

LaRon Nelson: is, there's social behavior. Science can help us understand what's happening in real time as things are going along. And I think there's some ways that we could figure out that this trial is gonna fail.

245

00:49:26.200 --> 00:49:50.210

LaRon Nelson: I mean, I think that was Barbara's concern, like you could already kind of tell that there are certain things going on that if we don't do this, the chances of efficacy is going to be limited, and it could be maximized. And I think that's the kind of language, hey? This sort of say that way that they can understand that. If we if we stick to this current model where you design a trial, and you stick that way, even if

246

00:49:50.210 --> 00:50:08.259

LaRon Nelson: the both can tell you is failing, and you can wait 3 years for it to fail, or you can do something now based on what we know about the what's happening in the community or people's interest in this. And so I think that could change one. How research is done if scientists from Croy, all of us, you know, community scientists

247

00:50:08.260 --> 00:50:31.790

LaRon Nelson: and everyone champion it and if we can see more examples of that in future meetings. But I've been excited to have this discussion. I didn't get a chance to read the comments, because I've been trying to pay attention to the the discussion. But I hope you get a chance to read through some of that, too, and anything I can do to be useful to helpful. You could definitely reach out to me as a program committee member. So. Thank you.

248

00:50:33.040 --> 00:50:40.109

Nicoletta Policek: Thank you. Sorry. Yeah. So this has been such an amazing process. And everyone's comments are, are just

249

00:50:40.110 --> 00:51:04.100

Sari Reisner (he | him): it just so inspiring and also thought provoking. So thank you for creating this space together. You know, I was reminded, as we're talking about, I'm gonna lift up that piece about the community sciences again, and sort of I'm treating that as a science and like bringing that forward. I think that's such an important piece. And also this idea, somebody commented on a a on on trauma and you know the need to take into trauma informed

250

00:51:04.100 --> 00:51:29.660

Sari Reisner (he | him): approach. You know this is this is critical, and it's a larger aspect of of the context. You know, in which HIV is happening. The epidemic is happening. Excuse me, you know, and one that we really do need to pay very close attention to. You know the ultimately for me, when I think about sort of how this scientific enterprise works like, we enroll people in research. Right? Like, so is community

251

00:51:29.660 --> 00:51:49.589

Sari Reisner (he | him): without community. There is no research. I mean, that doesn't happen, you know. So you know, just like as people are saying, I know I don't need to tell this audience. But but for me, sort of the community, science is part of the social behavioral sciences. So I just feel like that's such an important piece. You know, Lauren, you mentioned this sort of idea of sort of failed trials, you know, and

252

00:51:49.710 --> 00:52:03.490

Sari Reisner (he | him): I think in some ways putting things in in language that people can hear. You know, I also think that, like you know, in some cases there's so many lessons that we can learn even in quote, unquote failed trials. Right? You know. And I think that piece of like

253

00:52:03.490 --> 00:52:27.979

Sari Reisner (he | him): understanding what works as well as what doesn't work is gonna be really key and you know, understanding like when there is, for example, slow uptake of long acting injectables like, why, right, you know, and sort of like, really kind of coming up innovating creative solutions together. So you know, from from my perspective. I, Laurana. II hope I think you are, too, from the program committee. I'm you know, excited to be part of this process, and I hope that we can.

254

00:52:28.010 --> 00:52:44.690

Sari Reisner (he | him): you know, continue to move the needle and add content, and work with with with you all, and know that we have a community here we have 130 people, or whatever on here who are interested in this in this area, and want to lift this up. So so I'll I'll leave it at that for now.

255

00:52:46.840 --> 00:52:59.260

Nicoletta Policek: Thank you. And I have 5 min left, and I'm going to take a couple of minutes just to thank everyone for being part of this interesting and

256

00:52:59.360 --> 00:53:22.730

Nicoletta Policek: provoking conversation we are leaving today thinking that again, the importance of social behavioral sciences in in mapping, what is the experience of HIV, but also in terms of thinking about how. You know, we spoke about trauma vulnerability. We spoke about violence. We spoke of the necessity of remaining.

257

00:53:22.730 --> 00:53:36.680

Nicoletta Policek: and in culturally sensitive, but also contested irrelevance. We want, and we need, as communities to engage diverse population with us, and in order for us to

258

00:53:36.880 --> 00:53:51.049

Nicoletta Policek: to make sure that as a long term behavioral changes, we all have to work together because we are community irrespectively of who we are in in a paradigm. We are community, and we can all work together.

259

00:53:51.600 --> 00:54:19.899

Nicoletta Policek: Before Jim gets really cross with me. I'm gonna say again, a big thank you to everyone and I didn't have a chance to read the all the comments, but some of the comments I read are really very positive and encouraging. So let's use this opportunity as a step install as a starting point to really, as I said, make sure that we are community, and we continue to be community from now on. Thank you, everyone. And now the floor is to Jim.

260

00:54:21.110 --> 00:54:32.170

Jim Pickett: Thank you, Nicoletta. Well, first of all, there's no way I could be cross with you. You did a beautiful job moderating this very robust and raucous discussion. I can't.

261

00:54:32.240 --> 00:54:41.149

Jim Pickett: I'm emotional because this is better than anything I could II wanted that. I dreamt of something like this, and this blows it all away.

262

00:54:41.310 --> 00:55:03.069

Jim Pickett: So thank you to you, Nicoleta. Thank you to you, Lauren to you, siri, to everyone who has made comments to this chat that is blowing up. I can't keep track of it, and that's been my job today, and I can't do it. We will be saving this all. We will share it in in conjunction with the recording. So people can go back and read through all this.

263

00:55:03.260 --> 00:55:18.920

Jim Pickett: I did, put in the chat at 1 point like a million messages ago, that it seems like we might need to keep this conversation going, and so I would love II run for Avac, A, a. A platform called the Choice Agenda. We do webinars.

264

00:55:18.940 --> 00:55:31.720

Jim Pickett: Once or twice a month. We have a very active listserv. I would love to bring this to a 90 min webinar, which we typically do with the choice agenda. So I'm going to be reaching out to folks to lure you into that web.

265

00:55:31.740 --> 00:55:48.129

Jim Pickett: Clearly, we need to keep this conversation going. And you know, maybe this is something we do on the regular until we really well, as long as it takes right, until as long as it takes, because silence is not an option here. And so I'm just really really excited

266

00:55:48.250 --> 00:56:06.320

Jim Pickett: for how this first community breakfast club kicked off today. Thank you all for making it so amazing. We will be back tomorrow morning. We're going to be talking about living with HIV for a lifetime, whether you're a long-term survivor or you're someone born with it

267

00:56:06.340 --> 00:56:10.430

Jim Pickett: super interesting conversation. We really hope you will be there.

268

00:56:10.470 --> 00:56:36.300

Jim Pickett: And then on Wednesday we have a panel of folks, both sort of seasoned and fresher takes on the science at Croy. People will be talking about what's really move them, what's important, what they're gonna be following up on. And so I hope you will come for all these days again all the recordings will be available on Thursday, including things like this. Amazing comments.

269

00:56:36.350 --> 00:56:46.990



Jim Pickett: It is now 1 min 2, and for folks who are here in Denver it's time to put on your roller skates and head over to the convention center the big blue bear

270

00:56:47.010 --> 00:57:06.920

Jim Pickett: and get your seat and start with the plenary. I'll see you all hopefully in the hall. And finally I'll say, look for the con. The statement from the community educator scholars regarding the appalling behavior of hundreds of scientists last night who walked out on Frank Mugish talk

271

00:57:07.020 --> 00:57:15.980

Jim Pickett: for the Martin Delaney presentation. We will not let that go unnoticed or unchecked, so pay attention for that. Lots going on.

272

00:57:16.040 --> 00:57:21.900

Jim Pickett: The the time is now clicking over to the top of the hour. So I'm going to officially say.

273

00:57:21.960 --> 00:57:28.439

Jim Pickett: see you later and see you all in the halls and and everyone online. Hopefully, we'll see you back.

274

00:57:28.470 --> 00:57:42.680

Jim Pickett: At the same place same time. Tomorrow I open the room a little early and have a playlist going, cause I'm a Dj. In my other life, so please come, bring tips for the Dj. And we'll see you all really soon, Chow.

275

00:57:43.760 --> 00:57:45.710

Nicoletta Policek: Okay, bye-bye, bye.

276

00:57:45.720 --> 00:57:47.520

mario cascio: I've

277

00:57:47.790 --> 00:57:48.850

Nicoletta Policek: bye.

278

00:57:54.690 --> 00:57:57.130

Gloria Noluthando Moche: Thank you. Bye.

279

00:57:57.490 --> 00:57:58.660

Harry Tembo: bye.