

00:18:09 JD Davids: Good morning! JD Davids, co-director of Long COVID Justice and Strategies for High Impact in Brooklyn, US  
00:18:25 Krishen Samuel: Morning! Krishen Samuel (he/him) from aidsmap here.  
00:18:27 Samsung SM-A226BR: Good morning  
00:18:29 Steven Vargas: Steven Vargas, Texas D-CFAR Community Advisory Board  
00:18:32 Barbara Friedland: Replying to "Good morning. Udom L..."



00:18:34 Jeff Taylor: Good morning all. Jeff Taylor with theHIV+Aging Research Project-Palm Springs 42 year HIV survivor and Community Scholar mentor  
00:19:24 Charles Innocent Chinguwo: Hi, I'm an AI assistant helping Charles innocent Chinguwo take notes for this meeting. Follow along the transcript here: [https://otter.ai/u/FcZcEEIX4p8ReduWnNG4m8958oE?utm\\_source=va\\_chat\\_link\\_1](https://otter.ai/u/FcZcEEIX4p8ReduWnNG4m8958oE?utm_source=va_chat_link_1)

You'll also be able to see screenshots of key moments, add highlights, comments, or action items to anything being said, and get an automatic summary after the meeting.

00:19:40 Juan Michael Porter II: Good morning, all. Juan Michael Porter II, (he/him). Senior editor TheBody and TheBodyPro.  
00:19:43 Aisuluu Bolotbaeva: Hi all, Aisuluu Bolotbaeva from Kyrgyzstan. Happy to join the meeting  
00:20:09 Danielle Campbell: Danielle M. Campbell, Advocate, Los Angeles, CA.  
00:20:09 Kevin Herwig: Good morning everyone, Kevin Herwig, HIV+Hepatitis Policy Institute, he/him, Washington DC USA  
00:20:25 Larry Bryant (he, him) Reunion Project: Replying to "Good morning! Larry ..."

[www.reunionproject.net](http://www.reunionproject.net)

00:21:01 Jeff Berry: It should have been at the beginning of the program  
00:21:07 Jeff Taylor: Thank you for highlighting Frank's talk at the opening plenary. The community needs to respond to this blatant disrespect. This is what stigma looks like  
00:21:08 Daisy Ouya: Thank you Jim P  
00:21:23 IRIEBI Gboh: Hi all. Iriebi Gboh, ICHANGE, Côte d'Ivoire.  
00:21:28 Richard Jefferys: Hi all, Richard Jefferys from Treatment Action Group in New York USA  
00:21:28 Jeff Taylor: Replying to "It should have been ..."



00:21:35 David Palm: Good day to everyone...David Palm from Research Triangle Park NC...citizen-scientist and research advocate...

ERASE HIV COLAB, UNC, ACTG, AMC

00:21:42 axel vanderperre: good morning ...from Brussels - Axel UTOPIA-BXL Founder President - EATG member and iCOPE HIV International Coalition of Older Persons living with HIV founder executive member

00:21:44 Rick Guasco: Greetings from Chicago. Rick Guasco, Positively Aware.

00:21:51 Daisy Ouya: Daisy Ouya - AVAC- Kenya

00:22:16 Barbara Friedland: Barbara Friedland, Population Council Center for Biomedical Research

00:22:17 George Kerr III: Greeting George from Washington DC

00:23:10 Arda Karapınar: Hello everyone from Denver.

Arda Karapınar (originaly from Istanbul, Türkiye)

I am the volunteer president of Red Ribbon Istanbul and a member of EATG.

00:23:29 Angel Hernandez: Angel Hernandez, Puerto Rico, ACTG & AMC community rep

00:24:53 Sia Edward: Hello I am Sia Edward from Tanzania Community Health Information and Support (TaCHIS) I work with Key and Vulnerable Populations and Sexual Minority Communities in Tanzania

00:24:53 Talkmore Mazorodze: Hi 🧑, Talkmore Mazorodze from Eswatini (Swaziland)

00:25:20 Cindra Feuer: Go Ann Arbor!

00:25:36 Julie Patterson: 😊 Yes, Go Blue!

00:26:05 Jim Pickett: Thank you all for being here!

00:26:06 Wawira Nyagah: Greetings - Wawira Nyagah, AVAC

00:26:28 Neetha Morar: Replying to "Thank you all for be..."



00:26:40 Harry Tembo: Is it only me! There is no sound!

00:26:46 Jim Pickett: Please join the conversation by commenting in the chat, asking a question in the chat, or raising your hand to speak on camera

00:26:56 Julie Patterson: Who were the hosts of the new investigators workshop yesterday? Was Sharron Hillier part of it?

00:27:16 Jim Pickett: Replying to "Is it only me! There..."

The sound is working for us Harry. Can you check your computer settings?

00:27:56 TOWERA MSISKA: GREETINGS..Towera Msiska from Pakachere IHDC Malawi

00:28:10 Danielle Campbell: Katie Bar and Serena Spudich hosted @Julie Patterson

00:28:26 Julie Patterson: Replying to "Katie Bar and Serena..."

Thank you!

00:28:49 Shekinah Rose: Greetings, Shekinah Rose, joining from Pittsburgh, PA USA Positively Trans & HUREED (Uganda)

00:29:09 JD Davids: "The whole HIV epidemic is in context"  
- YES!

00:29:32 Jim Pickett: Replying to ""The whole HIV epide..."

100

00:29:38 Newton Asonya: Am Newton Asonya HIV and AIDS Advocate from kesnya

00:30:45 Daisy Ouya: 100%!

00:31:01 Jim Pickett: without SBS 0 it is all for naught!

00:31:15 Julie Patterson: As advocates, we've been able to emphasize social & behavioral sciences SOMEWHAT in the research networks - but I am very worried that as studies move into pharma-sponsored this gets lost. We have to be in those spaces, as well

00:31:16 Shekinah Rose: With a multifaceted approach across the globe

00:31:18 Jim Pickett: YES LaRON!

00:31:18 Charles Innocent Chinguwo: Hi, I'm an AI assistant helping Charles innocent Chinguwo take notes for this meeting. Follow along the transcript here: [https://otter.ai/u/FcZcEEIX4p8ReduWnNG4m8958oE?utm\\_source=va\\_chat\\_link\\_2](https://otter.ai/u/FcZcEEIX4p8ReduWnNG4m8958oE?utm_source=va_chat_link_2)

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00:31:37 Krishen Samuel: Often 'equity' IS merely used as lip service. Equitable principles need to be implemented at all levels from trial design to implementation. It's about walking the talk, not merely using the word.

00:31:41 Daisy Ouya: Replying to "YES LaRON!"

100

00:31:53 Gastón Devisich: Gastón Devisich. Community Engagement (Fundación Huésped - Argentina).

IMO, it doesn't have to do solely with a lack of integration of S&BS but with the world of politics and decision making

00:32:01 Jamir Tuten (He/Him): The social behavior element is the barrier

00:32:15 Aisuluu Bolotbaeva: Absolutely, LaRon 🔥

00:32:22 Gastón Devisich: And many people become frustrated to not have their life long work translated into concrete changes for real people

00:32:39 JD Davids: This gathering is one of the best things CROI does for equity - thank you to Jim and everyone else who make it happen.

00:33:04 Julie Patterson: YES 🌶️🌶️🌶️  
00:33:24 Marc-André LeBlanc: Replying to "This gathering is on..."

🙄  
00:33:34 Julie Patterson: Replying to "This gathering is on..."

🙌  
00:33:47 Jeff Taylor: So good to finally see sociobehavioral researchers on the Program Committee!  
Long overdue...

00:34:12 Kenyon Farrow: I've long argued we need social and behavioral research that focuses on how decision makers (researchers, medical and non medical service providers, policymakers) to understand what motivates THEIR decisions as much as we need this research that focuses on "community."

00:34:14 Newton Asonya: Replying to "This gathering is on..."

I also thank you

00:34:17 Shekinah Rose: Agree Jeff!  
00:34:37 Jeff Taylor: Replying to "I've long argued we ..."

👍  
00:34:47 Mitchell Warren: Just want to thank LaRon and Sari for really influencing the CROI program – at last! And special shout-out to Judy Auerbach who led the charge for YEARS to push CROI to do better to integrate social and behavioral sciences.

00:34:50 George Kerr III: @Kenya in agreement

00:34:58 JD Davids: Replying to "I've long argued we ..."  
YES!!

00:35:16 Jeff Taylor: Replying to "Just want to thank L..."

👍  
00:35:23 Daisy Ouya: Replying to "I've long argued we ..."

⚡👍  
00:35:34 Neetha Morar: Replying to "I've long argued we ..."

👍  
00:35:51 Julie Patterson: Replying to "Just want to thank L..."

👍  
00:35:57 Krishen Samuel: Replying to "I've long argued we ..."

Yes!

00:36:04 Jim Pickett: There are some great comments in the chat ----- if anyone wants to use their voice to bring these comments forward, please raise your hands - this is YOUR conversation

00:36:23 axel vanderperre: PRO Person Reported Outcomes measurement should include not only physical but also social, mental and sexual/affective questions... In medicine still prevention and social, mental, affective .. aspects are not enough put forward and including in the consultation time as time is too restricted..

00:36:29 Anna Maria Zakowicz: Replying to "Just want to thank L..."



00:36:32 Sharon Kruger: we should be advocating for social behavioural studies at these meetings especially about acceptance and preference of cure treatments over and above social factors that impact adherence, care and services to people living with HIV

00:36:56 Jeff Taylor: Replying to "PRO Person Reported ..."



00:37:13 Anna Maria Zakowicz: Replying to "PRO Person Reported ..."



00:37:22 Jeff Taylor: Quality of life IS an endpoint

00:37:33 Richard Jefferys: There's important SBR work being done related to HIV cure research but we've heard that the abstracts are often rejected by CROI because the reviewers lack expertise and have misperceptions around issues such as sample sizes

00:37:39 Judy Auerbach: Replying to "Just want to thank L..."  
Thanks, Mitchell! The struggle continues!

00:37:49 Shekinah Rose: I'd like to for us to look at replacing the word transphobia with transmisa.

00:37:53 Jim Pickett: these comments are all so good - we will collect them and share them with the recordings

00:38:18 JD Davids: Poster sessions are particularly inaccessible for virtual attendees! There's no streaming, we're basically locked out of them.

00:38:34 JD Davids: Huge disparity in access to info and dialogue.

00:38:35 Jeff Taylor: Replying to "There's important SB..."

Sad but true...

00:38:49 Shekinah Rose: phobia is fear...misa is hatred

00:38:54 Jeff Taylor: Replying to "There's important SB..."

Karine Dubé has been doing some amazing work for years now

00:38:57 Julie Patterson: It would be great to see a listing of the SBR posters that we should seek out once the embargo is over...

00:39:01 Daisy Ouya: Stigma is a BEAST.  
00:39:04 Charles Innocent Chinguwo: How best can I get more involved with CROI ? It's Charles Chinguwo Malawi (NATIONAL ASSOCIATION FOR YOUNG PEOPLE LIVING WITH HIV) Y+ MALAWI  
00:39:05 Nina Martinez: Replying to "Often 'equity' IS me..."

Agreed too many say equity, and don't bother doing equity. Literally just say a campaign that said "equity for all" but can't have that when all are not impacted by inequity 🤔

00:39:05 Jim Pickett: Replying to "phobia is fear...mis..."



00:39:18 Judy Auerbach: Replying to "As advocates, we've ..."  
Agree, Julie.

00:39:24 Nina Martinez: Replying to "Often 'equity' IS me..."

saw\* a campaign

00:40:10 Barbara Friedland: Embargo is lifted already for posters as we all had to upload them (that is my understanding from what was said yesterday, as well).

00:40:43 Jeff Taylor: Replying to "As advocates, we've ..."

100

00:41:00 Krishen Samuel: Replying to "Often 'equity' IS me..."

Precisely.

00:41:07 Jim Pickett: this CBC includes ppl who are not registered for CROI - so we can't share certain info here

00:41:12 Jacque Wambui: Great ask on Community Science!!

00:41:16 Nina Martinez: Replying to "I've long argued we ..."

I could have done a whole study on what it took to make this happen (me, I am the Little Red Hen who made this happen) <https://nikemawilliams.house.gov/posts/congresswomen-nikema-williams-and-katie-porter-lead-effort-to-increase-access-to-lifesaving-organ-transplantation-for-people-with-hiv>

00:41:24 Sharon Kruger: 100% agree about community voice being heard

00:41:24 Richard Jefferys: Although the poster embargo is lifted there doesn't seem to be any way to access them electronically yet via the website/virtual access system

00:41:32 Jeff Taylor: Replying to "As advocates, we've ..."

While some of the networks have SBR, many—especially the ACTG—do not fund SBR. Researchers are expected to volunteer their time without remuneration. Totally unacceptable

00:42:07 Neetha Morar: Great points to the panel and colleagues comments on the chat. We may want to revise our language of terms like science, social science, community science as the

perception exists that clinical science is "real science" . Community engagement is a science and needs more integration in our work.

00:42:08 Jamir Tuten (He/Him): Very important statement.

00:42:16 Jeff Taylor: AND make sure that community engagement and SBR are real, and not just a box that gets ticked off

00:42:32 Julie Patterson: Replying to "Great points to the ..."



00:42:50 Gastón Devisich: We had a great moment yesterday during the case discussion session where the need of diversity of speakers and global south representation was highlighted. That panel had people from all regions of the world and were able to put forward their regional perspectives instead of just focusing on "a molecular model" that can only be implemented at the global north, whereas our struggles at the south diverge completely.

00:42:58 Newton Asonya: The best way to over come stigma is to face it

00:43:28 Neetha Morar: Replying to "AND make sure that c..."

Great comments Jeff. As advocates, we are responsible to call out tick box work globally.

00:43:43 Mitchell Warren: Picking up on what Neetha is saying about embedding SBR in clinical research, it was SO terrific to hear Jeanne Marrasso, the new head of NIAID, talk about these issues related to the VOICE study in her presentation to new investigators and scholars. I wonder if LaRon and Sari might comment on their thoughts about her comments and perhaps opportunities to influence her and future funding.

00:44:29 Jacque Wambui: That was me 😊

00:44:37 Jim Pickett: Replying to "That was me 😊"

LOVE

00:44:47 Julie Patterson: Replying to "That was me 😊"



00:45:12 Marc-André LeBlanc: Thank you for highlighting this, Neetha! The Microbicides conferences in their twilight years had really effectively bridged the divide between fields and disciplines by organizing sessions around themes, where experts from community, policy, implementation, socio-behavioural, clinical and basic science all discussed various inter-related facets of the same topics. We ALL benefited from learning across disciplines/fields and gained a much more holistic understanding of complex issues. Sadly, this model seems practically non-existent in current conferences.

00:45:25 Jeff Taylor: Replying to "Picking up on what N..."

A couple of us raised this with Dr Marrasso. She agreed, but didn't

commit to anything (not surprising as a bureaucrat)

00:45:30 Jim Pickett: Replying to "Thank you for highli..."



00:45:46 Krishen Samuel: From an intersectional perspective, it is also important to speak of commUNITIES, and recognise the multiple and intersecting complexities operating within different communities.

00:46:20 Judy Auerbach: Replying to "Thank you for highli..."

Yes, Marc-André!

00:47:09 Jim Pickett: STIR UP SOME TROUBLE

00:47:14 Deborah Baron: Replying to "Thank you for highli..."

Exactly- we need that model back, including having community and advocates speak first.

00:47:56 Jim Pickett: Jeanne Marrasso talked about taking risk in our research yesterday.....

00:48:10 Neetha Morar: MOSAIC study principles which is a step in the right direction

00:48:24 Jim Pickett: I LOVE MOSAIC

00:49:07 David Palm: Replying to "Quality of life IS a..."

Structuring those objectives and using validated instruments makes the "science" easier to justify...to LaRon's point, we as advocates need to apply pressure to the sponsors when the study investigators say "this takes too much time, it'll slow down the study, participants will complain" etc.

00:50:42 Sharon Kruger: our PAVE study in SA can attribute its success to community engagement. When we told parents and adolescents what our study was about, what to expect and asked them what would make them enrol in the study and what would prevent them from enrolling we were able to make changes to ensure a participant-centred approach.

00:53:07 Richard Jefferys: Request for Information (RFI) to inform development of the FY 2026-2030 NIH Strategic Plan for HIV and HIV-Related Research <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-24-060.html>

00:53:11 Jeff Taylor: People are messy, and therefore too hard to study

00:53:21 Jeff Taylor: Replying to "Request for Informat..."



00:53:25 Manju Chatani: Replying to "Thank you for highli..."

It took a while to get to that point but we got there

00:54:04 Jacque Wambui: Wow

00:54:27 Francis Luwole: During ICASA 2023, I was personally excited to learn about Multi-purpose prevention technologies (MPT) such as the Dual Prevention Pill (DPP). These innovations address a key challenge observed by advocates when advocating for new HIV prevention methods, especially among young people. Government officials and elders at the community level often challenge the focus



of these technologies solely on HIV, neglecting issues like early pregnancy and STIs. As part of behavioral science, I was hoping to learn about the progress on MPT at this year's CROI. However, I noticed there isn't a presentation on that. It's critical to expand choices within the community and reduce pill burden, especially considering the key challenges reported by AGYW on Oral PrEP in Tanzania.

00:54:30 JD Davids: This Fair Market for patient engagement calculator is pegged to US dollars/economy but shows how people should be compensated for their time and input. I never encountered it as an HIV advocate, though: <https://nationalhealthcouncil.org/fair-market-value-calculator/>

00:54:59 David Palm: @Barbara Friedland would you mind sharing your email address?

00:55:26 Barbara Friedland: My email is [bfriedland@popcouncil.org](mailto:bfriedland@popcouncil.org)

00:55:46 Jeff Taylor: Replying to "This Fair Market for..."



00:55:49 Deborah Baron: Are folks already advocating for more NIH funding for implementation science?

00:55:54 axel vanderperre: it is all about the research questions which should not only biomedical... efficacy etc

00:57:00 Charles Innocent Chinguwo: [phiriinnocentcharles@gmail.com](mailto:phiriinnocentcharles@gmail.com)

00:57:41 Ben Plumley: Thinking of the dapivirine ring trials. Not to be too simplistic, but the clinical trials poorly accounted for African women's experiences, leading to disappointing findings, which seem to be countered by real life experience.

00:57:48 Judy Auerbach: @Barbara Friedland – thank you for so clearly articulating a core and common problem in trying to integrate SBS and community into the clinical trial apparatuses. This has been a longstanding issue.

00:57:52 Charles Innocent Chinguwo: Replying to "Are folks already ad..."

Yap and am one of th...

00:58:34 Jim Pickett: I am so appreciating the enthusiasm and passion today in this session

00:59:10 Jim Pickett: Who would like to see us do this again? We clearly need more time!

00:59:35 Sharon Kruger: Barbara I would suggest an acceptability and preference study to determine preferences and acceptance of product

00:59:38 Judy Auerbach: Replying to "Who would like to se..." I would!

00:59:52 Jeff Taylor: Replying to "Who would like to se..."

How can we continue this important conversation after CROI?

01:00:07 Deborah Baron: Replying to "Who would like to se..."

Yes please

01:00:10 Barbara Friedland: Replying to "Who would like to se..."

Definitely!

01:00:11 Jim Pickett: Replying to "Who would like to se..."

I would like to bring this to The Choice Agenda

01:00:34 Jim Pickett: Replying to "Who would like to se..."

We do 90 minutes webinars and would love to bring this to that programming

01:00:54 Ben Plumley: Replying to "Who would like to se..."

Me too! Strikes me that it's in our biomedical colleagues' interests too. What will be the news story from the opening yesterday? What science to expect or how Frank – at this excruciatingly difficult time for African minorities – was disrespected

01:02:49 Judy Auerbach: Yes to Karine's comments about cure research.

01:02:52 David Palm: Well-said @Karine Dube

01:02:58 Newton Asonya: Replying to "Who would like to se..."

Yeah

01:03:01 Jeff Berry: Replying to "Who would like to se..."

Absolutely!

01:03:11 Jamir Tuten (He/Him): Replying to "Who would like to se..."

For sure

01:03:19 Jim Pickett: great points about the need for hybrid conferences to continue!

01:03:30 Yusuf Hassan Wada: Replying to "Who would like to se..."

Absolutely. Karine said it all

01:06:52 Jim Pickett: this conversation is just TOO GOOD

01:07:16 Jim Pickett: THANK YOU ALL for really bringing it today

01:07:17 Jeff Berry: As community advocates we need better understanding of exactly what social and behavioral science is, talking points, clear examples, because otherwise they get lumped in to "community" and easily dismissed

01:07:18 Barbara Friedland: Hi all -- I believe everyone who is registered (even virtually) has access to the CROI app. You can download/view the posters on the app. I just tried it. It's not the most straightforward way to get to the posters, but it is possible. If you registered and you have trouble, let CROI know. you paid to be at the conference and have access to ALL of the materials!

01:08:46 Sharon Kruger: thank you – these conversations are important – unfortunately I need to log off

01:08:59 Simon Collins (he, him) i-Base: Active community

involvement in research from the first stages can definitely lead to faster and better enrolment – and quicker answers to the study questions – essential 😊

01:09:22 Judy Auerbach: A big thanks to Sari and LaRon for agreeing to serve on the Scientific Planning Committee and for fighting the good fight for better integration of SBS in the conference. It's a lot of work and there still is a lot of resistance but we have to keep pushing. Thanks to Jim, to for highlighting this.

01:09:24 David Palm: Replying to "Active community inv..."



01:09:44 Richard Jefferys: Replying to "Hi all -- I believe ..."

Thank you Barbara!

01:10:10 Jeff Taylor: Replying to "Yes to Karine's comm..."



01:10:45 Jeff Taylor: Replying to "A big thanks to Sari..."

A huge thanks to you Judy for championing this for so many years, and finally making it happen

01:10:50 Jim Pickett: Over 200 registered!

01:11:11 Luciana Kamel: all great thoughts

01:11:28 Krishen Samuel: Fantastic insight–provoking discussion this morning!

01:11:35 Jeff Berry: Great conversation, I look forward to keeping it going!

01:11:47 Neetha Morar: Excellent session and maybe we could follow up with how to action on the valuable comments. Thank you to the panel and Jim for the efforts.

01:12:30 Barbara Friedland: Replying to "During ICASA 2023, I..."

AGREE! Not one word about MPTs here at CROI! :(

01:12:50 Richard Jefferys: Thank you all!

01:13:20 Yusuf Hassan Wada: Thank you all!

01:13:31 Grace Kumwenda: GREAT CONVERSATION! So much to take away and to think through ❤️

01:13:34 George Kerr III: Thank you

01:13:53 axel vanderperre: thank you... it was very constructive

01:13:54 Shekinah Rose: Thank you all!

01:13:56 Arda Karapınar: Thank you all for this amazing and so informative, so important session ❤️🙏

01:14:06 Jeff Taylor: Kudos to Jim for making this happen!

01:14:11 Udom Likhitwonnawut: Thank you everyone

01:14:12 LaRon Nelson: THANK YOU EVERYONE!!  
01:14:14 mario cascio: Thanks to all, great conversation  
01:14:22 Shekinah Rose: Thanks Jim !  
01:14:30 Talkmore Mazorodze: See you tomorrow, thank you  
all!  
01:14:34 Jamir Tuten (He/Him): Thank you everyone ! Jim  
you're so good 🤍🌸💡  
01:14:44 Sia Edward: Some of us we do not have the link for  
the tomorrow  
01:14:53 Steven Vargas: Thank you and see you tomorrow  
morning! Great session!  
01:14:57 Giorgio Barbareschi: See you tomorrow! Thank you  
for a very inspiring discussion and the great moderation!  
01:14:58 Stacey Hannah: Thank you! Great way to start the  
CBCs!!!  
01:15:02 Sia Edward: Kindly share the link for the tomorrow  
session  
01:15:08 Richard Jefferys: Lime scooters...  
01:15:24 Charles Innocent Chinguwo: See you tomorrow  
01:15:43 Sari Reisner (he | him): We love you, Jim!!  
01:16:03 Jim Pickett: Bye!  
01:16:16 ULANDA MTAMBA - MALAWI: Bye great conversations