

Why do we need prevention research advocacy?

This activist and researcher panel will engage participants in a dialogue on critical perspectives on HIV prevention research, using current issues to provide context for important advocacy questions that must be answered.

Panelists:

Greg Millett, Centers for Disease Control and Prevention
Waheedah Shabazz-EI, Community HIV/AIDS Mobilization Project
Emily Bass, AIDS Vaccine Advocacy Coalition
Walt Senterfitt, Community HIV/AIDS Mobilization Project

Moderator: Mark McLaurin (NYS Black Gay Network)

Initial questions from the panelists:

Walt: From your perspective, what do you think are the most important “unknowns” for you and your work and your community?

Emily: What tools and conversations do we need so people can get more involved in prevention research? maybe adding one hour of prevention advocacy to their week

Greg: Why do we see disproportionately high rates of HIV in Black MSM compared to white MSM? You'd think it would relate to risk behavior, but it's not. Structural and environmental factors put people at higher risk. What types of factors do you think what the CDC should be looking at?

Waheeda: I'm on the working group, the only community person, trying to develop the women at risk concept. They are trying to find places where they can go to find women to do these studies. I've said bingo halls are good places to do outreach, they're loaded with women in my neighborhood. Where should we tell researchers to look for women to enroll for these trials.

Mark: What is aftermath of Merck vaccine trial? What do you think it means for community involvement in vaccine research?

Emily: who has seen fallout from the study in their work?

5 people raised hands.

Comment from Audience – people have more mistrust, like it ignites their fear about people being used as guinea pigs.

Comment – people ask, does this mean vaccines give people HIV? That is the message from the media people are understanding. Someone asked, OK, so first they give you HIV, right? I want to develop studies for African Americans, and these communities are most vulnerable already and were exploited in the Tuskegee trial and others.

Mark – I've been involved in vaccine research. If I tried to invent a way to get Black folks to stay out of vaccine trials, I couldn't think of a better way than VAXGEN and this. VAXGEN made it seem like it might work for Black folks. Activists said, no, this isn't

going to work. But the community said, OK so it only works for Black folks and that means you don't care about it. Now we're just getting over that fallout and here comes the STEP trial. Everyone understands failure. But to not have an answer to whether or not it increased risk of HIV, I can't imagine a worse scenario. I have questions about whether we'll ever be able to repair this damage. There are a lot of Black folks who don't know about Tuskegee. In Baltimore, people think that Johns Hopkins is taking people off the streets and experimenting on them. The resistance is bigger than Tuskegee.

Comment from Melanie Thompson -- There's a ripple effect, the legacy of Tuskegee even if people don't know about it. Katrina is the same thing, communities that have a good reason to distrust the establishment.

Roy -- I was in the SMART study. It came out with some useful data. Trials are needed for prevention, but sometimes they are stopped, maybe for money. We need trials to keep people from getting HIV. It's saving people's lives.

Emily -- AVAC doesn't just do vaccines. Related to the Step study, there was one HIV infection in 1,100 women. That is not because the vaccine worked in women. The women were enrolled according to risk population. We need to fund studies to define risk better, and this is a way to argue for it. The vaccine field has money, and we can use the need of vaccine trials for basic information as an argument to support the research to find out what the women's risks are.

Waheedah -- the study was stopped early. It's not like it dragged on for 5 years. We have to understand that the ethics were pretty good.

Walt -- we shouldn't be too defensive or sugar-coat it. That breeds distrust. This is a setback. Let's look at the barriers to implementing what we know already works, like condoms and needle exchange.

Melanie -- when this issue is resolved about whether the vaccine increases risk, if it doesn't, it's going to be in the back of the newspaper. They picked up on something that was sensational but not proven. We need to take charge of presenting the message when the data comes out.

Comment -- media message is different from what the info really is.

Comment -- as a trial participant, hearing the news has a powerful impact. We have to think about how the message is delivered. It's important for me to do this, so it's important to speak to my community about why I did this and it needs to go on. Old notion of building a cathedral, a lot of them knew they wouldn't live to see them finished -- that's how I frame my role in this. People we trust need to deliver the message, not a retraction in a newspaper. AIDS is taking a measure of us as a human species, and vaccines are one way to help deal with it.

Julie -- most prevention research was done on gay white men, what do you think can be adapted or shifted over for gay black men, and where do you think we need new research?

Greg -- in many of the studies we have, there are so few people of color in those trials, so you don't know what the risk factors are. I did a meta-analysis a couple months ago.

We need the same meta-analysis for Latino MSM and Native MSM. People assume what's true in white MSM is true in Black MSM. Like people talk about meth, but Black MSM are much less likely to use meth or any drugs related to HIV infection based on many studies, over and over again. We need studies only enrolling Black MSM, only enrolling Latino MSM, only Asian and Pacific Islander, etc. to look at risk factors specifically for these populations.

Mark – Discussions about crystal meth from researchers, they say that Black MSM are using it as much as white MSM, but it's based on 30 Black MSM in a trial in Chelsea, a white gay neighborhood.

Comment – People of color and distrust with medical community? What processes are put in place to deal with that. My 10 years working in HIV, it would make sense to train people of color to recruit for trials. POC aren't going to be receptive to medical community without that.

Comment from CDC researcher in audience – the Legacy project wants to create a new legacy that's different from Tuskegee.

Walt – every researcher meeting is very white, even today.

Waheedah – I went to an African-American MSM leadership conference, and a lot of people identified themselves as researchers.

Mark – not all of them were researchers, though.

Comment from CDC researcher – AIDS is only one thing that is of concern in our community. But CDC and NIH take that very seriously.

Jose de Marco – We have to not forget about the Latino community. It always seems to be an afterthought. Like materials in Spanish, medical interpretation, cultural outreach. We're all oppressed people. We need to speak in solidarity with people who aren't in the room.

Emily – STEP did enroll a much bigger group of African Americans than other trials in the past, and that's because of the outreach work you're talking about. So some of that is in place. But the funding for that kind of work is often the first to go, or the least amount. Community outreach and education is under-funded and under threat. AVAC tries to push for a bigger piece of the pie to community outreach and education.

Anna Forbes – Need to advocate for meaningful funding in Black MSM trial and women's trial (ISIS). The idea is there's not a large enough group in the US of women that are at high risk but not through injection drugs, in order to do a microbicide trial in the US. We don't know if that's true because the research into risk groups haven't been done. So we need that for Microbicides as well.

James Learned – Clinical trial sites and nonprofits don't pay much, but pharma does. We can't blame people for taking those pharma jobs. People who are experienced and knowledgeable go to pharma and it really benefits the pharma companies but drains the resources from the communities.

Thank You.