

*"AIDS is a problem in our community, in all ages, genres, and we need to do something about it. Us, not someone else. We need to help our own communities without someone else to reach out and help us."*

(Female, 30-49)

*"We knew that another of our friends had AIDS and we was all kind of looking at him like he was going to be gone in a minute. It's a lot of people who were standing in the circle who's gone before he even gotten ill."*

(Male, 18-29)

*"It was somebody else's problem. It's always somebody else's problem, then it finally hits you. There's very few people who are willing to stand up in the face of many issues."*

(Male, 30-49)

*"I think the strongest message is that we are the ones who are responsible for overcoming this issue as we have overcome all of the issues of our past, our history in this country. This is no different from slavery or civil rights issues or anything else. We have to take control of it."*

(Female, 30-49)

*"We are bigger than AIDS. It's a very, very powerful statement. It means we have control over it and somehow it's still taking control of us."*

(Female, 30-49)

To inform the Black AIDS Media Partnership's *Greater Than AIDS* campaign, the Kaiser Family Foundation and Black AIDS Institute held focus groups in Oakland, CA on December 2 and 3, 2009. These were the second set in a series held around the country. The previous focus groups were held in Chicago, IL in August 2009.

Michaels Opinion Research recruited and moderated the focus groups, which consisted of a total of 33 Black adults segmented into four groups by gender and age, 18-29 and 30-49. Participants were not screened for any specific association with HIV/AIDS and were not informed in advance about the focus of the research, other than that it would address health issues facing Black Americans.

The objective of the focus groups was to provide insight into how HIV/AIDS is viewed in the Black community. Additionally, public service ads and other outreach elements developed for the *Greater Than AIDS* campaign were shared to help inform future campaign messaging and development. (*Greater Than AIDS* public service ads began appearing in Oakland and elsewhere around the country in fall 2009. With the exception of the women in the younger group, some participants in each of the groups had seen the campaign.)

While the participants represented a random selection from the wider Bay area, with a focus on Oakland, the views of these individuals are not intended to represent the opinions of all Black Americans. Rather, the focus groups are seen as providing a useful means of hearing first-hand, in their own words, how some in the target population perceive the impact of HIV/AIDS in their lives and community, as well as response to the *Greater Than AIDS* campaign.

*"I think that we also as a community don't like to talk about [STDs]. It's very taboo so even in environments where we may individually be used to talking about it I think culturally it's not something that we like to talk about."*

(Female, 30-49)

*"It's become very manageable but it's still something you don't want to talk about because it's uncomfortable."*

(Female, 30-49)

*"To me it's like committing a crime if you get AIDS or something. That's what they be acting like. If you get AIDS, there's a lot of things you get cut out of. Not just you, your siblings and stuff too."*

(Male, 18-29)

*"A lot of the reason people don't go get tested is because nobody talks about it because nobody wants to bring it up and all that. If people would talk about it more, then maybe more people would go get tested."*

(Female, 18-29)

*"I think a lot of people are scared to find out, too. They would rather not know."*

(Female, 18-29)

*"I have first hand experience too, my little cousin had it. Everybody like – they just started teasing him and stuff, they just be like don't drink off our stuff."*

(Male, 18-29)

### HIV/AIDS AS AN ISSUE FACING BLACK AMERICANS

Both groups of men mentioned HIV and/or AIDS almost immediately as a top-of-mind health issue facing Black Americans, along with heart disease and diabetes. With the group of younger women, the moderator inadvertently referenced HIV/AIDS when asking participants to name major health issues facing Black Americans, so it is unclear as to whether it would have been mentioned otherwise. When probed, the younger women said the issue was on their mind. Of the four groups, only the one of women ages 30-49 did not initially mention HIV and/or AIDS as a health issue facing Black Americans. When asked why, they said that discussion of HIV/AIDS and STDs is "taboo" and that "we don't talk about that." A few mentioned that HIV/AIDS along with other STDs was not something that personally affected them, thus it had not come to mind; though most recognized it as an issue that was affecting Black Americans, women in particular.

In all groups, there was consensus that HIV/AIDS was a significant problem facing Black Americans with most perceiving the problem as worsening. Among the reasons cited for the higher rates among Black Americans were people not using condoms, not getting tested, and not talking about HIV/AIDS. A few mentioned high rates in prisons and also men on the "down low." Many participants mentioned a sense that attention to HIV had decreased in media and in the community, and as a result people were thinking less about it.

When asked who is at greatest risk for getting HIV/AIDS, participants said those who were promiscuous or drug users – one woman said "law breaking citizens" – yet there was acknowledgement in all groups that anyone could get HIV and most were well informed about how HIV is transmitted. Participants of all ages tended to talk about the problem of HIV in terms of youth – for parents the concern was specific to their children. Many said they thought younger generations were less sexually responsible.

Notably, in every group, a number of participants brought up a personal connection to HIV/AIDS. For several it was an immediate family member living with HIV or AIDS and one of the older men identified himself as living with HIV. Many of those with personal experience described witnessing instances of discrimination or stigma. These experiences seemed to shape at least some of participant's views about the challenges that face people living with HIV/AIDS. At the same time, participants described their own interactions with people living with HIV/AIDS as very normalized.

*"I think we heard about the H1N1 more than we heard about AIDS this year. I think it started with the flu, when they should be worried about something that much more can kill you than the flu. It's been in the media all day. When is the last time you heard about AIDS being in the media?"*  
(Male, 30-49)

*"I think we don't talk about it because in my peer group we don't think that we'll get it. We talk about death and dying and middle age and all the other stuff...we don't talk about AIDS because I don't think we think we're in a group of people that could get it."*  
(Female, 30-49)

*"If you gave me a list of 10 things this year that I would have talked about, say 100, [HIV/AIDS] wouldn't have been 101. That's the problem. It's still there, but it's so far back on everybody's media, paper, newspaper, internet....there's nothing at all."*  
(Male, 30-49)

*"Another thing, like you said, they have the walks, and they've got the AIDS ride, the bike ride that goes all the way from Eureka all the way down to LA. All the ads you see, they're all white people doing the stuff. Whether it's the lack of outreach to the Black community saying, "Hey, you guys need to get involved also," or a lack of giving a care from the Black community, there is a disconnect."*  
(Male, 30-49)

Many worried about access to care and treatment. There was significant discussion about the high cost of medications. A few mentioned the misconception that Magic Johnson was cured as a result of his "special" treatment. One participant commented "Why can't we have what he has?" Another responded "It's a big difference when you have money." Others mentioned that they thought managing treatment would be "really difficult." In the abstract, the groups perceived life with HIV as lonely, shameful, scary, and confusing; young women in particular worried about not having a relationship after HIV. One commented "I'm quite sure [a person living with HIV/AIDS] just don't have a partner, and they know they don't want to spread it to others, so I'm quite sure they keep it to themselves at all times."

### RESPONSE TO HIV/AIDS IN BLACK AMERICA

While there was a high level of awareness and concern about the impact of AIDS in the Black community, participants were almost unanimous in saying that the issue has moved off the public agenda, citing lack of attention in the media, less visible community outreach efforts as compared to past years, and no apparent spokesperson.

Many noted that HIV/AIDS is still considered "taboo." One young man commented that "it brings up other things that people don't really want to talk about." Fear, shame, embarrassment, especially if one had a family member living with the disease, were among reasons given for not talking about HIV/AIDS. Several said that bringing up the topic of HIV/AIDS would raise questions about one's own status. Still a few participants in each group said they did talk about it with their close friends.

Participants commented on seeing less public service messages about HIV/AIDS as compared to other health issues. One notable exception was the *Rap It Up* campaign (undertaken by BET and the Kaiser Family Foundation) which was mentioned in every group, although some noted that there was less attention than in the past. *ESSENCE* magazine was mentioned, as well as earlier campaigns featuring the hip hop artist Common (produced by Kaiser with MTV and Viacom). Many commented on an association between less media attention to HIV/AIDS and decreased public concern or urgency.

Younger women mentioned Planned Parenthood, schools, and doctors' offices as sources of information for HIV/AIDS issues. Older participants named a handful of locally-based organizations. Overall participants struggled to think of individuals or organizations

*"I can't think of no leaders, period."*  
(Male, 18-29)

*"If someone comes forward with an AIDS project, you might look down upon them for whatever reason. Don't be the forefront of a lot of things, so you're going to wait till somebody else jumps forward, then jump with them."*  
(Male, 30-49)

*"The only face that constantly rings in my head is Magic. He has been a constant source in the Bay area and nationwide. He, honestly, is the face that kind of makes it not as taboo as it once was because you see him as healthy. He doesn't look sick. I mean from what we read and hear it's almost dormant in his system, almost nonexistent. Why can't we have what he has?"*  
(Female, 30-49)

*"We represent the segment of America that nobody want to talk about or talk to. We're basically; we've given away our rights and stuff like that. In these communities where so many convicted felons and stuff like that, they just wrote us off."*  
(Male, 18-29)

*"I think it's an empowering slogan. It feels like the community is greater than this problem."*  
(Female, 18-29)

visible on HIV/AIDS. Young men in particular were least likely to name a trusted source. World AIDS Day also was brought up, although it should be noted that the focus groups were held the two days following World AIDS Day. Still, it was notable that it was not mentioned too often considered the timing.

### LEADERSHIP ON HIV/AIDS IN BLACK AMERICA

There was a notable perceived leadership vacuum on AIDS in Black America. Few participants in Oakland were able to name any individuals in the Black community who have been strong voices speaking out about HIV/AIDS. There was strong agreement that HIV/AIDS should be a priority among leadership in Black America, while acknowledgment that was not the case today. Several participants noted that there are so many issues on the table, HIV gets lost in the shuffle or may be seen as too "controversial."

A consistent theme across the groups was a sense of "lack of caring." Participants cited lack of attention by Black leaders and the media as evidence, as well as general public apathy, especially among young people. They said HIV/AIDS did not have enough "status," or lacked sufficient funds to garner attention. This was particularly striking among the young men, for whom there was a general sense that leaders do not care about their demographic as a whole and that attitude translates to HIV. The young Black men worried about being seen as scapegoats for all issues that plague the U.S., or "what the world sees us as."

With the exception of an occasional name, participants generally were not able to identify a strong voice fighting against HIV/AIDS in the Black community. Magic Johnson is the only constant that surfaced in every group as an example of a HIV positive Black American who has worked to reduce stigma surrounding the disease. One young Black man said "I feel I'm a Black leader, I don't know about everybody else. I'm a Black leader, I be doing certain positive things out there. Trying to change a little bit of something, but I don't know what you mean by leader."

### REACTION TO THE GREATER THAN AIDS CAMPAIGN

While different elements resonated with different groups, overall, participants responded well to the campaign, understanding the message and relating to the images. Although not specifically identified as such, many participants saw the campaign as focusing on Black Americans. Most viewed this as a positive; though a few younger men worried it reinforced negative images about them

*“Also, it’s a reminder. “Hey, everybody, AIDS is still here. Let’s be aware.” I got that.”*

(Male, 30-49)

*“It just reminded me that, every time you go to the barbershops, there’s all sorts of dumbass conversations – seriously, stuff that we could do without talking about sometimes. But this is something that’s a big issue, even though it doesn’t get talked about.”*

(Male, 30-49)

*“That’s what it’s about; bring it to where you – bring the conversation to the community, which is pretty positive.”*

(Male, 18-29)

*“Yeah, the knowing is greater than doubt, that’s really about getting tested just so you know what your status. If you know, you can actually do something about it and not worry. I just think that talking is better than silence, because if we’re talking and we have some knowledge, some real knowledge to talk about, then things can change a lot quicker.”*

(Male, 30-49)

*“At the end when everybody was saying, “count me in, count me in,” I was like, “I want to be counted in.”*

(Female, 18-29)

among white Americans. All groups commented that the diversity of individuals represented across the campaign was a good thing. The older groups appreciated in particular that it was not only “young people.” Many saw someone who was “relatable,” a few of younger men saw some images as “a little stereotypical.”

As compared to other HIV/AIDS campaigns participants had seen, *Greater Than AIDS* was distinguished as focusing on “the community.” Participants noted that the campaign reaches more people, and in doing so, commented “more people can spread that word.” The take away was seen as the community getting together to overcome the problem, which participants responded to. Participants also interpreted more personal calls to action from the campaign, most notably “to get tested” and “protect yourself,” and also to become “more educated” and more vocal in discussing HIV/AIDS with family and friends because “it all starts with conversation.” A few participants, most notably in the older male group, expressed a sense of “guilt” and “embarrassment” about not doing more about HIV/AIDS after seeing the campaign, which they said motivated them to want to do more.

The younger male group was the most cynical about being able to do something about HIV/AIDS, but even among the more critical segment there were those that appreciated the intent of the campaign to “bring the conversation to the community.” Others noted that they saw AIDS as part of a “larger problem” – including “healthcare, mass incarceration” – that needed to be addressed first. Even among this group participants commented that the campaign made them feel “motivated,” “curious,” and to want to “educate myself more.”

Several participants commented that what first caught their attention was the hand sign, which they interpreted as a “peace sign,” and upon closer read the message was clear: “We are bigger than AIDS. It’s a very powerful statement. It means we have control over it.” For some, the imagery suggested “living in peace” with HIV, “[not] having to suffer through it.”

Participants commented that the campaign took a different approach to what they have seen in the past and that the message will make people more aware that HIV/AIDS is still out there. One woman in the 30-49 group remarked “Now I’m rethinking, ‘Wow, is AIDS that big of a problem? In our community? That’s what I was thinking.’” Participants expressed a renewed feeling that they are the ones who are responsible for overcoming this problem.

## About the Black AIDS Media Partnership

The **Black AIDS Media Partnership (BAMP)** is a sustained commitment among major U.S. media companies to work together to address the AIDS crisis facing Black Americans. Organized as part of **Act Against AIDS**, a multi-year effort by the **U.S. Centers for Disease Control and Prevention (CDC)** to help refocus national attention on the HIV/AIDS crisis in the United States, the Partnership is undertaking a coordinated campaign presented under a common brand – **Greater Than AIDS** – to reach Black Americans with life-saving information about HIV/AIDS and to confront the stigma surrounding the disease.

The **Kaiser Family Foundation** – a leader in health policy and communications – is providing strategic direction and day-to-day management for BAMP, as well as overseeing campaign production and helping to support member company commitments. **The Black AIDS Institute** is also providing strategic leadership, guidance, and technical assistance to BAMP. Other AIDS service organizations as well as the CDC's Act Against AIDS Leadership Initiative, a collaborative of fourteen highly respected and influential organizations serving African American communities, are providing additional counsel and support for community mobilization efforts.

*The Kaiser Family Foundation is a non-profit private operating foundation, based in Menlo Park, California, dedicated to producing and communicating the best possible analysis and information on health issues. For more information, visit [www.kff.org](http://www.kff.org).*

*The Black AIDS Institute is the first Black HIV/AIDS policy center dedicated to reducing HIV/AIDS health disparities by mobilizing Black institutions and individuals in efforts to confront the epidemic in their communities. Their motto describes a commitment to self-preservation: "Our People, Our Problem, Our Solution." For more information, visit [www.blackaids.org](http://www.blackaids.org).*