



WE  **AIDS**
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AIDS **IN GAY AMERICA**
FINDINGS FROM FOCUS GROUPS
Winter 2012

INTRODUCTION

Since the beginning of the epidemic, gay and bisexual men have been disproportionately affected by HIV/AIDS. According to the U.S. Centers for Disease Control and Prevention (CDC), one in five (19%) men who have sex with men (MSM) — and an even greater proportion of Black MSM (28%) — in 21 major U.S. cities is HIV positive — and nearly half of those who are infected (44%) do not know it.

Between January and March 2012, the Kaiser Family Foundation and the Black AIDS Institute (BAI) conducted focus groups in three cities with men self-identifying as gay or bisexual to provide insight as to how HIV/AIDS is viewed in the gay community today and what actions are being taken to stem its spread. Additionally, different messaging strategies, including some used by *Greater Than AIDS Pride*, a national public information campaign developed by the Kaiser Family Foundation and BAI, were shared to help assess the response to different approaches.

A total of six focus groups, two each, were held in three cities: Philadelphia, PA (January 18, 2012); Los Angeles, CA (January 25, 2012); and Dallas, TX (March 1, 2012). In all three locations, one group was composed of men of different races/ethnicities, approximating the composition of the market (sometimes referred to as “mixed” race groups throughout the report), and another group was composed of only men who identified as Black and/or African American, reflecting the disproportionate impact on the community. Each focus group included between 7-10 self-identified gay or bisexual men between the ages of 25-45 for a total of 53 participants.

Community Marketing, Inc. (CMI), a San Francisco-based LGBT market research company, was contracted to recruit and moderate the focus groups. A Black gay male moderated the groups with Black gay men, and a white gay male moderated the groups of men of different races. The discussion guide was developed by the Kaiser Family Foundation and the Black AIDS Institute, with input from CMI.

Participants were chosen at random and intended to be representative of the mix of income levels, educational attainment and occupations among the gay male population in each city. The men also represented a mix of relationship statuses (i.e., single, dating, living with partner) and the degree to which they consider themselves to be “out” (i.e., completely out, somewhat out, not out to many). Throughout the report, “gay” is used to refer to the male participants though the term is intended to be more encompassing and include bisexual and other men who have sex with men.

Participants were not informed in advance about the focus of the research, other than it would address health issues facing gay and bisexual men, nor were they screened for any specific association with HIV/AIDS. Notably, throughout the groups, almost all participants revealed that they knew someone who is living with HIV, in many cases a close friend, and several men disclosed their HIV positive status. More men in the Black only groups disclosed their status than in the mixed race groups, however it is unknown if there were more men in all of the groups who were HIV positive and did not disclose, or if the men in the Black groups were more comfortable disclosing.

PARTICIPANTS PER FOCUS GROUP

	Philadelphia, PA January 18, 2012		Los Angeles, CA January 25, 2012		Dallas, TX March 1, 2012		TOTAL
	Mixed Group	Black Only Group	Mixed Group	Black Only Group	Mixed Group	Black Only Group	
Number of Participants	9	9	9	10	9	7	53
Number of Participants, by Race/Ethnicity							
White	4		3		5		12
Black	1	9	1	10	1	7	29
Latino/Hispanic	2		2		2		6
Asian/Pacific Islander	2		2		0		4
Mixed Ethnicity	0		1		1		2

EXECUTIVE SUMMARY

GENERAL KNOWLEDGE & ATTITUDES ABOUT HIV/AIDS

- When asked about the “big issues” facing the gay community today, HIV/AIDS was mentioned as a top of mind issue.
 - In the groups made up only of Black gay men, HIV/AIDS was the predominant issue of focus, whereas in the groups of men of different races, other issues, notably “equality” and “gay marriage” also came up frequently, along with HIV/AIDS.
- HIV/AIDS was again mentioned when asked about the “biggest health issues” facing gay men today.
- A “generational gap,” typically described in terms of those old enough to have known firsthand the ravages of HIV before treatment was available, as compared to those who have come of age in a time when effective treatment has been available, was mentioned in all groups and associated with a sense of personal risk.
- Many of the men commented that HIV is increasingly seen as a chronic, manageable disease.
- Complacency around protection also came up in discussion, and the sense that concern about HIV/AIDS generally has “died down” and “there’s not as much of a focus on it.”
- Notably, almost all participants knew someone who is living with HIV, and in many cases it was a close friend.
 - Throughout the groups, several men ended up disclosing their HIV positive status although generally not until later in the discussions.

EXPOSURE TO HIV MESSAGING

- In all groups, participants mentioned seeing HIV-related messages, both paid advertising, by pharmaceutical companies, as well as public service ads (PSAs), especially messages around HIV testing, in neighborhoods described as “gay.”
 - Some men commented there seems to be fewer PSAs over the years and “only during a certain time” or “during certain months.”
 - The men also discussed that unless they were directly affected, either themselves or having a close friend who is positive, they “don’t notice” the HIV messages.
- Although social media websites and applications like Grindr, Manhunt and Adam4Adam were mentioned as popular among the participants — many of whom acknowledged using the sites regularly — it was said there was little, if any, HIV messaging.

HIV TESTING

- When asked how frequently gay men should be tested for HIV, participants in all groups consistently said “every six months.”
- When asked how they knew this, many said it was “common knowledge,” adding that it had been “drilled in our heads” at health clinics and by their doctors. They were generally aware that free testing was available, noting that cost should not be a barrier to testing today. Many commented about testing being “quick and easy,” an apparent reference to rapid oral tests.
 - Several of the Black gay men, who said they lived in “less gay” areas, said testing was less accessible for them.
 - Participants mentioned that testing is easier for an “out” gay man living in a more “gay” neighborhood, than one who is less open about his status.
- When asked why some gay men do not test, the major reason expressed was “fear” of knowing; some also said that not identifying as gay, or being less comfortable with their sexual identity, kept men from getting tested.

TALKING ABOUT HIV

- In general, the men said that when HIV comes up in conversation it is typically either a conversation among their closest circle of friends, especially if there is concern, or with a new sexual partner.
- Even among close friends, however, it was commented that HIV is not necessarily a daily or common discussion.
 - Those who said they talked with friends about HIV said it was usually in the context of a specific event, such as a friend had an unsafe sexual encounter or a friend just found out he is HIV positive.

EXECUTIVE SUMMARY (continued)

DISCLOSURE

- For some men, asking a new partner whether they were HIV positive seemed more like “ticking off the box,” that is knowing it was the “right thing” to do but not necessarily expecting the response to be truthful. A few men described experiences where they found out afterwards a partner was positive though did not initially disclose.
- When asked about whose responsibility it was to disclose, there was a significant discussion about if it was solely the HIV positive person’s responsibility to disclose their status, or if it is also a HIV negative person’s responsibility to ask about the other’s status. Most said it was the responsibility of the HIV positive person even if safer sex was being practiced and that “he’ll tell me if he is [positive].” While others, though far fewer, felt that status did not need to be discussed as long as participants were practicing safer sex, and an assumption that a partner would disclose his status if he was positive.
- When asked why some men who are positive may not disclose to a new sexual partner, fear of rejection was most commonly mentioned.

STIGMA

- Most participants said that stigma around HIV/AIDS was not a major concern within the gay community; saying that it has “decreased” over the years and that there is “not as much as before.”
 - There was notable exception to this among Black gay men, who were more likely to say stigma persisted, sometimes from their own family or non-gay acquaintances.
- Yet, later in the discussion many of the men described not wanting to be in a relationship with someone who was positive and having “rejected” partners who disclosed they were living with HIV.
 - Even though many of the men said that they did not initially perceive these attitudes as stigmatizing, after further discussion some made the observation that in fact these types of behaviors and actions were a form of stigma.

PERCEPTIONS OF LIFE WITH HIV

- When asked about the major concerns for people living with HIV, those most commonly named were rejection from sexual partners — and among Black men, from family as well — and access to healthcare, specifically paying for treatment.
- The fear of “being alone” — of being rejected by sexual partners — was a major concern voiced about those who had identified as positive.
- Healthcare — both in terms of cost and access — was also a big worry.
 - Participants talked about those living with HIV not being able to get health insurance and the high cost of paying for treatment for the rest of their lives. There was also concern about the quality of HIV care for the poor or uninsured, or losing health insurance due to a preexisting condition.

REACTION TO CAMPAIGN MESSAGES

- Toward the close of the groups, participants were shown two different messaging directions and asked about the effectiveness of each in response to HIV/AIDS.
- Participants responded equally favorably to the two distinct messaging directions, in that one was more statistic-based and the other took a more personal approach, featuring real people living with or affected by HIV.
 - Both types of messaging directions were viewed as valid by participants. It was discussed that effective HIV prevention needs to use a combination of approaches to reach all types of people.
 - Some felt the more statistic-based approach was better used within the gay community, rather than in mainstream. There was mention that on its own these messages might raise fears, yet most men agreed it was important to know this information.
 - Upon seeing the message direction using personal testimonials, several men commented that they liked the inclusion of people who had relationships — as a partner, or mother — with someone who is HIV positive, feeling it helped to reduce stigma.

GENERAL KNOWLEDGE & ATTITUDES ABOUT HIV/AIDS

When asked about the “big issues” facing the gay community today, HIV/AIDS was mentioned as a top of mind issue. In the groups made up only of Black gay men, HIV/AIDS was the predominant issue of focus, whereas in the groups of men of different races, other issues, notably “equality” and “gay marriage” also came up frequently, along with HIV/AIDS.

HIV/AIDS was again mentioned when asked about the “biggest health issues” facing gay men today. Cancer and other sexually transmitted disease (STDs) were also named with some frequency, although less so than HIV. Mental health issues and substance use were noted as concerns sometimes associated with someone “coming out” (as gay), or with HIV/AIDS.

A “generational gap,” typically described in terms of those old enough to have known firsthand the ravages of HIV before treatment was available, as compared to those who have come of age in a time when effective treatment has been available, was mentioned in all groups and associated with a sense of personal risk. Some older men in the groups commented that the younger gay men “didn’t live through the ‘80s” and that “they weren’t around when people were dropping like flies,” and thus HIV/AIDS may not be as important or pressing for younger generations. It was also commented by some that there seems to be less of a “community” around HIV than there was in the early days of the epidemic. This was associated with less physically apparent consequences, as a result of improved HIV treatment, and also that HIV is “not as in your face as it was... 20 years ago.”

There was also discussion about how younger gay men are living in a time when being gay is more accepted, and that they have not had to face stigma about their orientation in the same way as older gay men. As a man in Philadelphia put it, “a lot of younger people don’t know the history of the gay rights movement.”

When discussed further, many of the men commented that HIV is increasingly seen as a chronic, manageable disease. Several commented that paid advertisements for HIV medications reinforce this message, while noting that some of the side effects of those treatments, as well as the economic and emotional impacts of living with the virus, are less often talked about.

Complacency around protection also came up in discussion, and the sense that concern about HIV/AIDS generally has “died down” and “there’s not as much of a focus on it.” Participants, both younger and older, expressed the view that younger gay men take more sexual risks, perhaps they thought because of less concern about HIV — thinking that even if they do contract it, they are able to take medication and live with HIV. Some in the groups commented that younger gay men are more likely to have unprotected sex and/or have sex with more partners and think they are “invincible,” potentially putting themselves at higher risk for HIV.

Some participants associated a lack of knowledge about HIV/AIDS, especially among younger men, as contributing to more risky behavior. Others thought that most men were aware of the risks, and made a choice whether or not they want to take those risks. Despite this view of others, the men participating in the focus groups, themselves, came across as generally informed about the risks for HIV and how it is transmitted.

“ I think HIV is still a big issue in the gay community. ”
(Philadelphia, Black Only Group)

“ Gay men, the first thing you think about is HIV and STDs. ”
(Philadelphia)

“ The first thing that comes to me is equality — marriage equality, employment equality, but just equality on the whole. ”
(Dallas)

“ We certainly all have health issues such as cancer and they all play a part. But I think the gay-specific definitely comes down to HIV. ”
(Philadelphia)

“ Like I think drugs are a big problem, excessive drinking is a big problem, and a lot of that’s to cover up that uncomfortable feeling of not being able to fit in. ”
(Dallas, Black Only Group)

“ We’ve lost the physical fear to HIV and AIDS, but what I don’t think people are prepared for is the emotional trauma that that causes, you know. ”
(Dallas)

“ I also think that people are desensitized a little bit. People are living a lot longer, more healthier, productive lives even as positive status. ”
(Philadelphia)

“ I personally came out in the late ‘80s. So it was much more of a bigger issue than now. It was much more in the news. It was much more on a gay man’s conscious than it is now. ”
(Philadelphia)

“ Twenty years ago it was a huge concern, but I think now people are really comfortable with thinking that even if you have it, you’re going to live forever, you know, so they’re not taking medication, they’re acting out sexually. ”
(Los Angeles, Black Only Group)

“ You know, two words — Ryan White. The older generation remembers when that kid was locked out of his school for a blood transfusion. ”

(Dallas)

“ I think that most people are aware. We all know what HIV and all these STDs and everyone is aware of them. But I think that a lot of people just don't care. ”

(Philadelphia, Black Only Group)

“ Like certainly in gay magazines you see a lot of advertisements for HIV and AIDS and all that stuff. But personally I don't see really that much in terms of advertising. ”

(Philadelphia, Black Only Group)

“ You know a lot of things that I see in the magazines are the ads from the drug companies. You know you've only got to take one pill or something like that, which I think is an issue across the board with the drug companies. ”

(Philadelphia)

“ I mean, I'll read an occasional article here and there, but not like in the past, where it was prevalent in the media. Nowadays, I'm lucky if I see anything about it. ”

(Los Angeles)

“ Actually, the advertising I think is a big thing where it says, you know, 20 years ago it was pretty much a death sentence. It is no longer a death sentence anymore. I don't really know what kind of message that sends, because to a younger person they're like, oh, they'll cure that eventually. ”

(Philadelphia)

GENERAL KNOWLEDGE & ATTITUDES ABOUT HIV/AIDS (continued)

Notably, almost all participants knew someone who is living with HIV, and in many cases it was a close friend. Throughout the groups, several men ended up disclosing their HIV positive status although generally not until later in the discussions. More men in the Black only groups disclosed their status than in the mixed race groups, however it is unknown if there were more men in all of the groups who were HIV positive and did not disclose, or if the men in the Black only groups were more comfortable disclosing. In the Los Angeles Black only group, nearly half of the men disclosed that they were living with HIV.

EXPOSURE TO HIV MESSAGING

In all groups, participants mentioned seeing HIV-related messages, both paid advertising, by pharmaceutical companies, and public service ads (PSAs), especially messages around HIV testing, in neighborhoods described as “gay.” Some men commented that there seems to be fewer PSAs over the years and “only during a certain time” or “during certain months.” As one participant commented, “it's huge on December 1 [World AIDS Day], and then the rest it's gone.” The men also discussed that unless they were directly affected, either themselves or having a close friend who is positive, they “don't notice” the HIV messages.

There was significant discussion about advertising for HIV medications. Many felt these ads downplay the reality of HIV and only show images of people who are “healthy;” however, others, including some who had revealed themselves as HIV positive, expressed that these ads help to reduce stigma facing people living with HIV.

Although social media websites and applications like Grindr, Manhunt and Adam4Adam were mentioned as popular among the participants — many of whom acknowledged using the sites regularly — it was said there was little, if any, HIV messaging. Some of those who used the sites described users talking about their own status or asking about others HIV status, but that disclosure of HIV status on the sites was a personal choice and that “half the people online lie about their status in the first place.”

HIV TESTING

When asked how frequently gay men should be tested for HIV, participants in all groups consistently said “every six months.” When asked how they knew this, many said it was “common knowledge,” adding that it had been “drilled in our heads” at health clinics and by their doctors. They were generally aware that free testing was available, noting that cost should not be a barrier to testing today. Many commented about testing being “quick and easy,” an apparent reference to rapid oral tests.

Several Black gay men, who said they lived in “less gay” areas, said testing was less accessible for them. Participants mentioned that testing is easier for an “out” gay man living in a more “gay” neighborhood, than one who is less open about his status. Some of the men noted that men who are less open about their status may have hesitations with entering into a “gay” neighborhood and publically using resources like free clinics or mobile testing vans.

Most of the men said they themselves were tested “regularly,” though when pressed for specifics some acknowledged that perhaps they were not testing as often as they knew they should. While the participants were aware of the six month standard, it was clear not all acted on the recommendation and there appeared to be a disconnect for some men between what they knew they should be doing and what they actually did.

When asked why some gay men do not test, the major reason was “fear” of knowing; some also said not identifying as gay, or being less comfortable with their sexual identity, kept men from getting tested. There was discussion that for some gay men finding out they are HIV positive may be too “scary” and so they would “rather not know.” One participant commented that “once you know about it,” then “you’d have to do something about it.”

A positive test result raised concerns about fear of dying, fear of telling partners and fear of not finding future partners who will accept them. Black men mentioned fear of telling their family if they were HIV positive, saying that having to come out as gay was difficult enough.

Several men said testing was something they did with friends; one described it as “like a field trip, almost.” A few described testing annually on their birthdays. Others noted that if HIV testing was part of a regular physical exam it would help to normalize testing.

“It’s like everything else. I mean, you’ve got to go to the dentist twice a year, you’ve got to go to the doctor twice a year, and you’ve got to get tested twice a year. That’s how — I don’t know how I got that information, but it’s just there.”

(Los Angeles)

“It’s really easy to get tested quickly and free without any like sweat out of your day, really.”

(Philadelphia)

“I guess if you’re more closeted, I guess you wouldn’t go to your primary doctor or your main doctor. You would probably go to another doctor’s office, but you definitely wouldn’t go to one of those RVs and get tested. So you’d probably go to maybe somewhere a little farther away, where people wouldn’t know you, and you would get tested.”

(Los Angeles)

“I have one friend who has never been tested, and I’ve tried every trick in the book to get him tested, but he would just rather not know.”

(Philadelphia)

“It’s like I think sometimes because when I was young it was such an event, it put so much more pressure on you, whereas if it’s just part of your normal routine, I think that that helps also take some of that stigma away, and a lot of pressure.”

(Dallas, Black Only Group)

“ I thought it helped me when my friends told me about it. That made me more like aware and, hey, this happened to my best friend and it could definitely happen to me. ”
(Philadelphia, Black Only Group)

“ I don't think it's a subject unless we have like crazy sex, like unprotected sex or you make a mistake or you know that you're at risk. ”
(Los Angeles)

“ And it drives a lot of the issues that are happening in the community, because I've found that if I just open up about the subject, then, you know, there's usually two or three other people who probably wanted to as well. ”
(Dallas, Black Only Group)

“ I guess they really don't want to know about it or talk about it or know somebody who has it, so they never bring it up. ”
(Los Angeles, Black Only Group)

“ I think a lot of people like their first question whether you meet somebody online or in person is like, 'Are you positive or negative?' ”
(Los Angeles)

“ Even now when you ask somebody, 'Hey, are you HIV positive?' and they tell you yes or no, I mean, are you really going to believe that? ”
(Los Angeles)

“ I don't think you need to disclose to everyone except your sexual partners. ”
(Philadelphia, Black Only Group)

“ If you're going to have a relationship with someone where you can infect them with HIV, then you need to have that conversation with that. Other than that, it ain't any of your damn business. ”
(Dallas)

TALKING ABOUT HIV

In general, the men said that when HIV comes up in conversation it is typically either a conversation among their closest circle of friends, especially if there is concern, or with a new sexual partner. Even among close friends, however, it was commented that HIV is not necessarily a daily or common discussion. Those who revealed they were positive talked about needing to trust someone before disclosing their status, as that it is a very personal piece of their lives. Others mentioned that if you talk about HIV or bring it up in a conversation, people might assume that you are HIV positive. Several men also said that once you get the conversation going, then people actually do want to talk about HIV/AIDS.

Those who said they talked with friends about HIV said it was usually in the context of a specific event, such as a friend had an unsafe sexual encounter or a friend just found out he is HIV positive. A couple of the men who had identified as positive mentioned that they talk to their friends just in case something happens, for example if they got sick then their friends would know what was wrong and how to help.

Participants mentioned that gay men have a unique experience around HIV, which is part of their shared culture. While they do not necessarily talk about it often, it comes up in unusual ways, such as special sections on gay dating sites, talking with friends about testing, increased attention in LGBT media or public health campaigns. Some participants wondered if straight people talk about HIV before sexual interactions, if at all. There was discussion that heterosexuals are probably concerned with pregnancy the way gay men are concerned with HIV status.

DISCLOSURE

For some men, asking a new partner whether they were HIV positive seemed more like “ticking off the box,” that is knowing it was the “right thing” to do but not necessarily expecting the response to be truthful. Most said that the conversation with sexual partners about status comes up just before sex — if you ask and they say that they are negative, then that is the end of the conversation. A few men described experiences where they found out afterwards a partner was positive though did not initially disclose.

Many of the participants felt that men who are HIV positive should tell their sexual partners “first and foremost.” “That's the only person they have to disclose it to,” “otherwise it's personal.” It was also noted that close friends could offer a support system if they knew. The men agreed that you do not necessarily need to disclose to parents or extended family. Black men, in particular, said disclosure to family would be difficult.

There was considerable debate over whether or not someone needs to disclose if both partners are using protection. Most of the men said there is an imperative that if you are positive, then you should reveal your status, while some others said that it was not necessary to disclose if protection was used. When asked about whose responsibility it was to disclose, there was a significant discussion about if it was solely the HIV positive person's responsibility to disclose their status, or if it is also a HIV negative person's responsibility to ask about the other's status. Most said it was the responsibility of the HIV positive person even if safer sex was being practiced and that “he'll tell me if he is [positive].” While others, though far fewer, felt that status did not need to be discussed as long as participants were practicing safer sex, and an assumption that a partner would disclose his status if he was positive.

Still, it was acknowledged that some men may lie about their HIV status. It was commented that if there was concern that a potential partner might no longer be interested if an HIV positive person did disclosure, then why would they tell them the truth?

When asked why some men who are positive may not disclose to a new sexual partner, fear of rejection was most commonly mentioned. By telling other men they are HIV positive they could be rejected for sexual activity (even if it is safe) or be rejected for the potential of a relationship.

While not a big topic of discussion, serosorting — limiting one's sexual partners to those with same HIV status — was mentioned a few times. Some men who identified as positive mentioned that it is easier for them to date other HIV positive men, while other men said they are only interested in HIV negative partners. As the participants were not screened or selected for their HIV status, and information was only available from those who chose to disclose their status during the groups, the conversations about sexual practices on this subject may have been less forthcoming.

STIGMA

Most participants said that stigma around HIV/AIDS was not a major concern within the gay community; saying that it has “decreased” over the years and that there is “not as much as before.” Many mentioned having friends with HIV, and they do not feel that people with HIV are widely discriminated against within the gay community and that HIV status does not negatively affect their friendships. There was notable exception to this among Black gay men, who were more likely to say stigma persisted, sometimes from their own family or non-gay acquaintances.

Yet, later in the discussion many of the men described not wanting to be in a relationship with someone who was positive and having “rejected” partners who disclosed they were living with HIV. Those participants who had disclosed that they were HIV positive said fear of rejection was a major concern in sharing their HIV status with new partners, and that they would not want the responsibility of potentially infecting someone else. Even though many of the men said that they did not initially perceive these attitudes as stigmatizing, after further discussion some made the observation that in fact these types of behaviors and actions were a form of stigma. A few of the men acknowledged the disconnect between saying that there is no stigma around HIV, and these realities.

“You have to tell — it's your responsibility to say, ‘By the way, I'm HIV positive,’ and then it's up to that person, the other person, to decide whether or not they want to or can deal with that.”
(Dallas)

“What's surprising to me is how some people don't even ask. Like they're willing to have sex with you and that's not even a conversation, that's not even something they would bring up in the conversation.”
(Philadelphia)

“I do think all of it has kind of decreased because I know I have heard of people being shunned completely and that seems weird to me now. I wouldn't expect that to really happen among the people that I know.”
(Philadelphia)

“There is not really a stigma, but there is a stigma.”
(Dallas)

“And so I think for a lot of people personally, if they do end up positive, that ruins their chances of possibly a good long-term relationship.”
(Los Angeles)

“There's a stigma with it. I'm sorry; I think it's just a stigma with it.”
(Philadelphia, Black Only Group)

“I mean, I consider myself a good-looking guy, but once I tell some people that I'm positive, then forget it. It's like all those qualities, all those physical characteristics that that person's attracted to you for, that goes out the window.”
(Los Angeles, Black Only Group)

“I came in contact with a lot of people who were positive, and instantly I was like, ‘Okay, then we can't date.’ And that was me, and I was rejecting some really good guys just because in my own mind I was like I can't.”
(Los Angeles)

“People think that because, okay, I’m dirty, I won’t get to spend my life with somebody that I will fall in love with, nobody will accept me for what I have, not who I am. So it’s the fear of being alone. They won’t have a relationship, they won’t have someone to call their partner, they won’t have somebody to call their husband or their boyfriend. ”

(Dallas)

“I’m positive. I just found out last year, and my biggest issue is I’m getting to the age where I want to have a family and I want to do the whole — I want to enjoy my gay life and be me and do me, but I also want to have a family and raise some kids and do all that too, and that’s very difficult to do when you’re positive. ”

(Los Angeles, Black Only Group)

“It’s not so much that it would ruin their lives. It’s just the fact that, ‘Oh, my God, I don’t even have medical insurance right now. How could I even afford that? How can I access it?’ My life’s going to be shortened because I can’t access the medication. ”

(Los Angeles)

PERCEPTIONS OF LIFE WITH HIV

When asked about the major concerns for people living with HIV, those most commonly named were rejection from sexual partners — and among Black men, from family as well — and access to healthcare, specifically paying for treatment. The fear of “being alone” — of being rejected by sexual partners — was a major concern voiced about those who had identified as positive.

A related concern expressed was acceptance of oneself as an HIV positive person and the changes that may mean for their lives. Black participants agreed with all these concerns, but their concerns seemed amplified, especially in relation to stigma. The men talked about how all of the rejection and concern can affect a person’s self-esteem, potentially creating difficulty with self-acceptance and internalized stigma.

Healthcare — both in terms of cost and access — was also a big worry. Participants talked about those living with HIV not being able to get health insurance and the high cost of paying for treatment for the rest of their lives. There was also concern about the quality of HIV care for the poor or uninsured, or losing health insurance due to a preexisting condition. The Black men were especially concerned about “cost of the medicine” and access to healthcare.

RACE & HIV

Significant differences surfaced between the focus groups composed of men of different races and ethnicities, and the groups composed of only Black men. When discussing HIV, participants in the Black only groups often talked about health concerns in relation to the stigma that they perceive around their sexual orientation, especially in the larger Black community. There was discussion about the challenges of what it means to be Black and gay. The men talked about fears of rejection from family, isolation and an inability for Black gay men to express their true sexual orientations.

Some commented that it is hard enough being a Black American in general, and that the stigma is not only about being Black and gay within the context of the Black community, but also dealing with the stigma of being Black, gay and then for some living with HIV. Participants indicated that there was a layering of stigma coming from multiple places.

Many of the men in the Black only groups said they do not discuss HIV with their families, and that there was often an underlying perception that being gay would lead to HIV infection. The men mentioned that it is difficult enough to discuss their sexual orientation with their families, if they had, and it was simply too much to bear to add HIV to the mix. Some said they would be ostracized if they told their family they are both gay and HIV positive.

When discussing the perceptions of stigma, there seemed to be a difference between the mixed ethnicity groups and Black groups. The Black groups mentioned HIV-related stigma prior to it being asked by the moderator and almost all said it was a concern not only in the larger Black community but also in the gay community. This was expressed differently in the mixed groups as many initially said that HIV-related stigma has diminished or been eradicated in the gay community (although later came to acknowledge that stigma may still exist). In addition to the Black groups being able to better identify or accept the existence of stigma, stigma also might be more of an issue for the men who are both Black and gay, and concerned about HIV.

Compared to the mixed groups, the Black groups appeared to be more forthcoming about their views, which might have driven more emotional or deeper discussion. Since HIV is such a personal issue, perhaps talking in groups with less diversity helped drive more in-depth discussions. Yet some acknowledged that it can still be difficult to talk about HIV within the Black community, and one man in the Black only group in Los Angeles said that “I can tell some of my Caucasian friends something and they will be a lot more open-minded to it or want to know more about it than if I tell an African American.”

“ Sometimes you can’t be Black and gay and masculine at the same time. Just doesn’t fit. ”

(Philadelphia, Black Only Group)

“ I just feel like it’s stereotypes within the gay community. People just put down one another instead of uniting as one or however you want to put it. ”

(Los Angeles, Black Only Group)

“ In the Black community, in general, being gay is a bad thing, something that’s wrong. When I was growing up a lot of my Black friends, the family, if you were gay they would shun you. One of my friends actually was kicked out by his own family because he was gay. So a lot of the time you have sex, be it unprotected, but you don’t talk about it. You don’t talk about it with your family. ”

(Philadelphia, Black Only Group)

“ If you’re gay, you get judged negatively. If you’re HIV positive, you get judged negatively. If you’re Black, gay and HIV positive... ”

(Los Angeles, Black Only Group)

“ There was this life where I worked hard and paid my bills and raised my younger siblings and raised a family, and then there was this life where I was gay, but I couldn’t let nobody know because it was a weakness, and if anybody found out — you know, if anybody in the church found out, you might as well forget it. You was out the door... ”

(Dallas, Black Only Group)

“ The stigma, you’ll know it — you’ll know what the stigma will be based upon what your parents’ reaction was when you came out. If their first thing was, ‘You’re going to catch a disease,’ then that’s going to be a wrap for you. ”

(Los Angeles, Black Only Group)

“ I feel like it's a variety of things because you're not going to hit anybody with one certain campaign. There has to be a whole bunch of different campaigns. ”

(Philadelphia, Black Only Group)

“ I think they both have a place. That one I would think would have more impact if it was in a magazine, like if you were sitting there and you read it, I mean, just because it stands out, it's quick, it's to the point, it makes you think about yourself and maybe other people. ”

(Los Angeles)

“ I mean, personally, I believe they both have a place and they're both effective, but there are certain personality types that would lean more towards the numbers and the hard facts and the stats than somebody's sappy story. ”

(Los Angeles, Black Only Group)

“ I would think like in a gay bar or gay setting that would be great. But as far as like on the bus or something like that, that would create more of a phobia for everybody else that's reading it. ”

(Philadelphia, Black Only Group)

“ There's something you can do whether you're positive or negative or straight or if it's your kids or your partner or you work in a hospital, doesn't really matter what you're doing. You can make a difference. ”

(Philadelphia)

REACTION TO CAMPAIGN MESSAGES

Toward the close of the groups, participants were shown two different messaging directions and asked about the effectiveness of each in response to HIV/AIDS. The first was a statistical, fact-based approach that used a graphic (“1 in 5 gay men in major U.S. cities is living with HIV... nearly half don't know it”), and the second was a set of personal testimonials from real people living with or affected by HIV/AIDS (both in print and video form). Both message directions have been used by the *Greater Than AIDS Pride* campaign. Participants were asked to provide their reactions to each set of messages individually, and then compare the two types of ads and share their thoughts on which direction would be more effective at reaching gay men.

Participants responded equally favorably to the two distinct messaging directions, in that one was more statistic-based and the other took a more personal approach, featuring real people living with or affected by HIV. Both types of messaging directions were viewed as valid by participants. While some of the men said they thought the statistic-driven approach was more compelling, others expressed preference for the personal stories approach. It was discussed that effective HIV prevention needs to use a combination of approaches to reach all types of people.

Some felt the more statistic-based approach was better used within the gay community, rather than in mainstream. There was mention that on its own these messages might raise fears, yet most men agreed it was important to know this information. It was suggested that some type of follow up — about what to do or where to go — should be included.



Upon seeing the message direction using personal testimonials, several men commented that they liked the inclusion of people who had relationships — as a partner, or mother — with someone who is HIV positive, feeling it helped to reduce stigma. They also felt the “stories” were compelling, that it “grabs you personally.”

DECIDING MOMENT:
“ASKING FOR HELP WHEN I NEEDED IT.”
 -JASON

After a year of dating, Jason decided to ask for help when he needed it. He was the one who needed it. He was the one who asked for help. He was the one who asked for help when he needed it. He was the one who asked for help when he needed it.

I AM JASON AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT adobe.com/greaterthan WE **AIDS**

DECIDING MOMENT:
“LOVING MY SON AND HELPING HIM LIVE WITH HIV.”
 -TERESA

My son Matthew never even got the test. When he told me he was the parent, I promised that I would be there for him no matter what. He has no one else to turn to but me. In his words, “I love you and I support you.”

I AM TERESA AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT adobe.com/greaterthan WE **AIDS**

DECIDING MOMENT:
“KNOWING I CAN MAKE A DIFFERENCE.”
 Dennis

As a nurse and a gay man, I am confronted by the reality of HIV/AIDS every day. That's why I made sure my patients are educated about how they can best protect their own health. It's not only about the community to help who the spread of HIV. There is a positive what I know. We all have a responsibility to the fight.

I AM DENNIS AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT greaterthan.org/pride WE **AIDS**

DECIDING MOMENT:
“REALIZING IT COULD HAVE BEEN ME.”
 -CHRIS

I had my moments for AIDS. We were really close and shared a lot in common. My death would be another death. I had my moments for AIDS. I realized I could have been me. I had my moments for AIDS. I realized I could have been me.

I AM CHRIS AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT adobe.com/greaterthan WE **AIDS**

DECIDING MOMENT:
“BEING OPEN AND HONEST ABOUT MY HIV STATUS.”
 Duane

I am a photographer, a director and an activist. After finding out I was HIV positive, I realized to be honest with myself and the people I love. Even though disclosure isn't always easy, it's important for me to talk honestly about HIV/AIDS.

I AM DUANE AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT greaterthan.org/pride WE **AIDS**

DECIDING MOMENT:
“LOVING MY HIV POSITIVE PARTNER.”
 Larry

I believe that if you love someone, you should be there. When my partner of 17 years was hospitalized with pneumonia as a consequence of his HIV, I was there by his side every day until he got better. Even though we are no longer together, he lives for him, he loves himself.

I AM LARRY AND I AM GREATER THAN AIDS.

SHARE YOUR DECIDING MOMENT AT greaterthan.org/pride WE **AIDS**

“The part that really got me was the mother accepting her son, seeing that he’s HIV positive and gay. That was like a home run for me right there.”
 (Dallas)

“There was more diversity than in a lot of ads I’ve seen.”
 (Dallas, Black Only Group)

APPENDIX

DISCUSSION GUIDE

I. Introduction

- > Moderator:
 - Purpose of session – to discuss perceptions on health issues
 - No right or wrong answers
 - Audio-taping
 - Presence of observers
- > Participants:
 - What part of the city do you live in?
 - Where are you originally from?
[Note: Probe on age and race similarities and differences throughout the discussion where appropriate.]

II. General Knowledge & Attitudes About HIV/AIDS

- > What do you think are the big issues in the gay community today?
- > What do you think are the biggest health issues for gay men today?
[Probe: If HIV or STDs are not mentioned, then ask about STDs, followed by HIV.
For Black men only – What about for Black gay men?]
- > Thinking about HIV specifically, how big of a concern is HIV/AIDS in the U.S., and here in [city]?
 - For gay men?
 - For any other groups?
- > Who do you think is at most risk of getting HIV today?
[Probe: If gay men are not mentioned, then ask about gay men]
 - What puts people at risk?
[Probe: What is putting gay men at risk for HIV these days?
For Black men only – Are the risks any different for Black gay men?]
- > Is stigma around HIV an issue within the gay community?
[Probe: For Black men only – What about stigma in the Black community? In the Black gay male community?]

III. Personal Experiences

- > Do you feel like you are hearing or reading much about HIV/AIDS in the U.S.?
[Probe: Where are you hearing or reading about it? Who is speaking out about this issue? Who is talking about it?]
 - What about AIDS in the gay community – are you hearing or reading much about it?
[Probe: Are there any companies you can think of that are supporting the issue? What about public information campaigns or public service ads? Are you seeing any of those?]
- > Thinking about you and your peer group, are gay men talking much about HIV/AIDS?
 - If no, why do you think that is? What holds people back from discussing what's going on with HIV/AIDS today?
 - If yes, what are they saying? What prompts those discussions? Who is talking about it?
- > What about HIV testing? Is that something that is talking about? Is it something that people you know are doing? Do they talk about testing or going to get tested?
 - What might keep someone from getting tested? What are the reasons?
- > Does anyone know what the recommendations about HIV testing are?
 - Are the recommendations any different for gay men?
 - Would it surprise you if I told you that the CDC recommends testing for HIV once a year? And that sexually active gay men might benefit from more frequent testing (that is, every 3 to 6 months)?
- > If someone has HIV, do they need to disclose it?
 - Who do they need to disclose their status to?
 - When might someone reveal that they are HIV positive?
- > Thinking about HIV today, what is life like for someone who has HIV/AIDS?
[Probe: What are some of the issues they might face? What are their relationships like?]

IV. Review of Campaign Messages

- > Now I would like you to give me your reactions to some materials that are under development about HIV.

PASS OUT COPIES OF “1 IN 5” AD.

- Does this statement surprise you?
- Did you know this? Have you seen this statistic before?
- Do you think it is true?

- > Now I am going to show you some ads that would appear on a billboard, at a bus stop or in a magazine.

PASS OUT COPIES OF “DECIDING MOMENTS” ADS AND HAND PAPER TO PARTICIPANTS.
SIMULTANEOUSLY PLAY VIDEO.

- > Please write down your initial reactions to these images, and then we can discuss as a group.
Please write down:

- What are your general reactions to these ads?
- What do you think the message is?

- > Now let's discuss as a group:

- What are your general reactions to these ads? What is the first thing that comes to mind?
- What do you think the message is?
- Has anyone ever seen these images before? Do these look familiar to you?
- Please tell me what you take away from these ads.
- Do you like this campaign overall? Why or why not?
- Do you think this message is effective?
- Do you think this message is inspiring?

- > Can you compare the two types of ads we saw – the 1 in 5 and the images of people? Which do you think would be more effective at reaching gay men? Does it depend on the situation or location?



ABOUT GREATER THAN AIDS

Greater Than AIDS is an unprecedented collaboration among a coalition of public and private sector partners — including media and business leaders, Federal, state and local health agencies, AIDS service and other community organizations, among others — united in response to the domestic epidemic. Through targeted media campaigns and community outreach, Greater Than AIDS works to increase knowledge and understanding of HIV/AIDS and confront the stigma surrounding the disease, while promoting actions to reduce its spread.

The Kaiser Family Foundation — a leader in health policy and communications — provides strategic direction and day-to-day management, as well as oversee the production of the media campaign. The Black AIDS Institute — a think tank exclusively focused on AIDS in Black America — provides leadership and expert guidance and directs community engagement. Additional financial and substantive support is provided by the Elton John AIDS Foundation, Ford Foundation and MAC AIDS Fund, among others.