

Impressions of HIV/AIDS in America:

A report on conversations with people throughout the country

Building public support for workable solutions to end the epidemic



Prepared for the National AIDS Strategy Coordinating Committee

With support from the **MAC AIDS FUND**

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by Jonathan Rochkind, Samantha DuPont and Amber Ott

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SUMMARY OF FINDINGS

Introduction		5
Finding One	HIV/AIDS in the United States Is Off the Radar for Most People Experts say, and survey research indicates, that concern over HIV in America has lost salience with the public. Our groups showed this to be true, though African-Americans and New Yorkers were more aware of the issue.	12
Finding Two	Empathy Toward Those with HIV Though knowledge about HIV is low, people expressed great sympathy for what they thought it may be like living with HIV/AIDS. They envisioned a life of loneliness and isolation for those who are HIV-positive. Their own frustration with the U.S. health care system also provided a starting point for the discussion. Experts also maintain that addressing problems in the health care system is essential to addressing HIV/AIDS and recommend systemic changes to the system, including increased access to treatment and the elimination of general health disparities.	14
Finding Three	Fear About HIV Transmission Persists Experts say the stigma around HIV/AIDS stems primarily from two sources, the first being fear of transmission. We found that while most people do understand how HIV is most likely transmitted, they clearly overstate some risks and question whether enough is known about the virus. Not being certain about the possibility of indirect transmission, many adopt a “better safe than sorry” attitude. These uncertainties may also explain the anxiety many say they would feel around individuals with HIV.	16
Finding Four	A General Focus on Individual Behavior Another source of stigma stems from people’s views on how HIV is commonly transmitted. They maintain that, unlike heart disease or cancer, HIV is an infection that mostly affects people who are taking risks or engaging in behaviors that people don’t approve of. Experts tend not to focus on individual behavior when thinking about HIV risk. Instead, they maintain that stigma around how HIV is transmitted, and who gets HIV, is a major barrier to solving problems within the epidemic.	18
Finding Five	Education Is Favored by All Both the public and experts support education as the best way to address HIV/AIDS, though they frame it quite differently. In our groups, people talked primarily about broad-based awareness campaigns targeted to the general population, giving general information about the disease. Experts focused on targeting at-risk populations with particular information about being tested and treated.	21

SUMMARY OF FINDINGS

Finding Six	A Vaccine Is Right Around the Corner?	23
	Putting more money into a vaccine received strong support from people, perhaps because vaccines have historically been a key component in strategies for eradicating disease. Some even believed that finding a vaccine should take precedence over increased education, either because they felt that current education efforts are sufficient or because they had tremendous faith in the scientific community to have a breakthrough. Experts also supported funding for a vaccine but were quick to point out the need for prevention efforts as well.	
Finding Seven	Primed for Engagement	25
	The experts we spoke with weighed in on a variety of policy proposals, including condom distribution, testing and partner notification. While the public has not thought about or even generally heard about these or other specific proposals, we find that they are willing to discuss these issues and consider trade-offs, showing opportunity for further engagement.	
Community Profile	Birmingham, Alabama	28
Community Profile	Des Moines, Iowa	30
Community Profile	Los Angeles, California	32
Community Profile	New York, New York	34
Community Profile	Tarrytown, New York (Westchester County)	36
Community Profile	African-Americans Nationwide	38
Acknowledgments		40
About Public Agenda		41

INTRODUCTION

Current statistics reveal that HIV/AIDS remains a major public health problem in America. In 2005, AIDS was the sixth-leading cause of death among people aged 25–44, and AIDS was the third-leading cause of death for African-American women aged 25–44. In addition, growing numbers of people disabled by the disease increasingly burden some communities. There are more than 56,300 new HIV infections every year and a total of 1.1 million people living with HIV/AIDS. Of those infected with HIV, 21 percent don't know their status.¹ And while treatment advances have substantially reduced AIDS-related morbidity and mortality, not all who need treatment have access to it, and treatment is not a cure.² Half of those living with HIV are not receiving care and treatment.

But as the AIDS epidemic in America has matured, there has been growing public perception that the issue is under control. In 1995, just under half of the public (44 percent) named HIV/AIDS as the most urgent health problem facing the nation—since then, that figure has dropped to 6 percent.³ This may be fueled in part because policymakers had, in the past decade, shifted their attention to the epidemic overseas. The expansion of global initiatives, such as the President's Emergency Plan for AIDS Relief (PEPFAR), underscores this reallocation of resources and attention toward crises in the developing world.⁴

A recent national survey conducted by the Kaiser Family Foundation shows decreased HIV/AIDS awareness among Americans as compared with a similar survey five years ago. In 2004, 34 percent of adult Americans surveyed stated they had heard “a

lot” about the problem of AIDS. In 2009, that percentage dropped to 14 percent. The findings also uncovered decreased awareness among African-Americans—62 percent knew “a lot” about AIDS in 2004 compared with 33 percent in 2009.⁵

Policymakers are now reengaging on the issue of HIV/AIDS in the United States. The Obama administration recently pledged \$45 million for a five-year communications campaign—Act Against AIDS—to “put the HIV crisis back on the national radar screen.” It is targeted both to populations most affected by the virus and to organizations and media outlets striving to raise awareness.⁶ Funding efforts such as this often need public support in order to gain momentum. Some questions that officials should be asking include the following:

- + Does the public think HIV/AIDS in the United States is a serious issue?
- + Do they have an understanding not only of how HIV is transmitted, but also of the obstacles and barriers that infected people face?
- + How do the public's views on strategies to curb HIV transmission differ from solutions experts and policymakers are considering?
- + What proposed solutions are people ready to support now, and what proposals do they need more background on?
- + What beliefs and values do the public consider when they voice their support or their opposition?

¹ “Fact Sheet: The HIV/AIDS Epidemic in the United States.” Kaiser Family Foundation, February 2009.

² Teshale, E.H., et al. “Estimated Number of HIV-Infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States.” Abstract #167, 12th Conference on Retroviruses and Opportunistic Infections, February 2005.

³ “2009 Survey of Americans on HIV/AIDS,” Kaiser Family Foundation, April 2009.

⁴ In FY 2008, 25 percent of federal funding to combat HIV was directed toward the international epidemic. “Fact Sheet: The HIV/AIDS Epidemic in the United States.” Kaiser Family Foundation, February 2009.

⁵ “2009 Survey of Americans on HIV/AIDS,” Kaiser Family Foundation, April 2009.

⁶ <http://www.nytimes.com/2009/04/20/opinion/20mon3.html>

INTRODUCTION, continued

The disease cannot be sidelined in policy and discussion, and it is not a problem that can be addressed without engaging the public. Policymakers not only need public support for their initiatives, they also need to raise awareness. This is particularly important within communities most at risk for HIV to reduce the rate of new infections. Unless leaders can build public support for their ideas, they probably won't realize their goals.

About the Research

With the counsel of the National AIDS Strategy Coordinating Committee and support from the M-A-C AIDS Fund, Public Agenda—a nonprofit, non-partisan research organization that studies public issues—conducted five focus groups around the country, talking with a wide range of demographically distinct individuals in New York City; Westchester, New York; Los Angeles, California; Des Moines, Iowa; and Birmingham, Alabama, to explore whether people are aware of the incidence of HIV/AIDS domestically, as well as the composition of those living with HIV/AIDS and the challenges they face. We also wanted to uncover the values underlying people's perceptions of the disease to see how those views affect their attitudes toward their policy priorities and initiatives. In addition, 13 telephone interviews were conducted with people who work on various HIV/AIDS issues—including scientists, advocates and policymakers—to get a deeper sense of how their knowledge about HIV/AIDS informs their thinking.

Executive Summary

A SYSTEMIC APPROACH

In-depth interviews with policymakers, researchers and activists from within the HIV/AIDS community found perspectives that are often divergent from public attitudes. Experts, who are well versed in the issues, their underlying causes and various cultural currents, tended to approach HIV/AIDS systemically and favored structural solutions that addressed these problems. For example, experts commonly offered two reasons why HIV/AIDS in the United States has fallen from the cultural radar. First, the public believes treatment is available to anyone who needs it—in other words, HIV has been successfully “managed” and is no longer a problem; and second, many people think HIV still happens only to “those people,” suggesting that the public links HIV/AIDS to specific behaviors, having little understanding of heightened risks and barriers in specific communities or social contributors to the epidemic.

Experts commonly referred to the United States health care system as a contributor to a variety of problems with HIV. Lack of access to care, experts said, prevents people from getting the medicines and treatments they need to stay healthy; and fostering trusting relationships between health care providers and patients is necessary for people to get and maintain appropriate care. Experts also implicated other socioeconomic and structural problems as primary factors contributing to the spread and devastation of the epidemic, with many showing how HIV disproportionately affects disadvantaged or marginalized groups. For example, some said those who do not have the adequate tools to negotiate sex within their relationships are more at risk. Other experts talked about how less educated and low-income individuals are more at risk because they have little hope in their lives and consequently engage in riskier behavior.

INTRODUCTION, continued

When talking about solutions, experts focused on education, but they pointed out that there is much more to be done to make education effective. Experts pointed to social marketing and additional research on human sexuality and risk behavior as ways to improve education. They strongly believed that targeted messages to high-risk demographics would be most effective. While most experts supported funding for vaccine research, many emphasized that it may take some time before one is ready for use, and consequently, more funding needs to be directed toward prevention, care and treatment.

Experts also discussed how HIV stigma not only has contributed to widespread discrimination of those with HIV/AIDS, but also has been a driver of the epidemic. For example, some of our experts working in the African-American community shared that many African-Americans still believe that HIV is a “gay disease” and do not feel that they are at risk. Additionally, experts said that existing beliefs and prejudices held by policymakers—homophobia, racism, disapproval of drug users and non-monogamous people, and perceptions about transmission risk—have resulted in policies that are counter-productive to solving the epidemic. As such, some experts talked about condom distribution, needle exchange and honest discussions about sex as examples of prevention strategies that must be used going forward.

Experts also pointed out that providing care and services to people with HIV is an important prevention strategy. Some said that providing people who are HIV-positive with antiretroviral medication can lower the amount of HIV in their blood, thereby reducing the risk of transmission. Others said that providing housing and drug treatment for those with HIV is crucial in reducing risky behavior and improving adherence to treatment and drug regimens.

LOW SALIENCE, SUPPORT FOR FUNDING

Focus groups confirmed and elaborated what surveys have shown—for most Americans, the issue of HIV/AIDS in the United States is off the radar—but it is worth noting that this is not universal. In every city we studied, African-Americans had a greater awareness of HIV/AIDS and often knew someone touched by the disease. Young people, particularly in New York City, were well versed in the ways in which HIV is transmitted and the difficulties facing HIV-positive individuals. And nearly all participants, regardless of their age, knowledge level or experience, expressed sympathy for those who have HIV. In trying to imagine the life of someone who has the illness, people spoke emotionally about the isolation and financial hardships they must face, sometimes using their own experiences with health care in the United States as a basis for how HIV patients may feel.

In addition, most people strongly supported funding and initiatives for education campaigns to raise awareness. The public's ideas about how this would work were not the same as those expressed by the experts with respect to finding ways to combat stigma or target populations at risk; rather, they took the form of broad-based awareness campaigns to fill the holes in their own knowledge about the disease.

INTRODUCTION, continued

OBSTACLES AND BARRIERS

The stigma that still surrounds the disease is clearly a barrier that needs to be overcome in order to combat HIV/AIDS. Our research uncovered two distinct strands of thinking that lead the public to look at this disease differently from others and may lead to the stigmatization of individuals who are HIV-positive.

First, there is widespread apprehension about how HIV is, and is not, transmitted. Across the country, and even among otherwise knowledgeable participants, perceived risks of infection were often overinflated. Though some participants rejected certain scenarios as unlikely to transmit HIV and were quick to rattle off the ways that HIV is most commonly spread, they were often still concerned about the risk, however small. This sense of concern was compounded when participants considered the possibility of an HIV-positive person being around their children or other vulnerable persons. Thus, we found many people would be uncomfortable if they or their loved ones were around someone with HIV.

Second, most people believed HIV results from a person's individual actions—namely, from “risky behavior.” Some feared that their children or another loved one might have to pay a terrible price for “making a bad decision.” Consequently, they assumed that the only way to address the problem is to educate people on ways to reduce risky behaviors or eliminate the risks entailed in them, as with the creation of a vaccine. The general public's lack of understanding about and familiarity with a whole range of public health solutions—measures that could make a significant dent in the number of Americans acquiring and transmitting HIV—was apparent. Even among participants who understood that certain demographic groups were at a higher

risk—low-income, urban, minority, young and gay—most still focused on individual behavior and risk taking, not immediately understanding how public health and other structural remedies that address social determinants of health might be helpful.

RECOMMENDATIONS FOR ENGAGEMENT

■ Help people to understand that the problem has not been “solved.”

HIV/AIDS in America has clearly lost some urgency with the general population. Many people haven't thought about the issue in years. As a result, some of their knowledge about the disease has faded, become out-of-date or is just plain false. Raising awareness of how serious HIV/AIDS still is here in the United States—and that it disproportionately affects particularly vulnerable populations—is necessary for building support to fund projects to effectively target and combat the disease.

An avenue into raising awareness is making sure that HIV/AIDS is included in the national health care debate. The rising cost of health care is an issue that Americans are very aware of. In surveys, people most frequently say they worry about the cost of health care more than any other concern—even more than the quality of education, saving for retirement and crime.⁷ Many of the participants we spoke with assumed that life would be difficult and costly with HIV/AIDS because navigating the health care system is a difficult endeavor, regardless of the illness. In addition, participants expressed sympathy for the economic and social difficulties of those who are HIV-positive. Making sure that HIV/AIDS treatments are included in the health care debate may be an effective strategy and something the public may be ready to support.

⁷ Survey by NBC News, Wall Street Journal. Conducted November 1–November 5, 2007. Question wording: Let me read you several things that people worry about in their own lives. Please tell me the one or two, if any, that you worry about in your own life: access to affordable health care, quality of education, saving enough for retirement, the cost of gasoline, crime and violence, job security and the cost of housing and mortgages.

INTRODUCTION, continued

■ Give people a more accurate sense of how HIV is transmitted.

Leaders must contend with the fact that overall fear of HIV transmission still exists. Even among the more knowledgeable focus group participants, there was misunderstanding and apprehension about whether HIV can be contracted through casual contact. Concerns at this level make it difficult to combat stigmatization of people who have HIV/AIDS and may cause many people to avoid the subject entirely.

Participants themselves suggested an avenue to address this issue, as nearly all were aware of their lack of knowledge and expressed strong support for education efforts, both in public schools for their children and in general awareness campaigns for everyone. This support can be used not only to talk about prevention efforts and the necessity for testing, but to explore the realities of how HIV can and cannot be transmitted and the real consequences of stigmatization for those who are HIV-positive.

■ Help people understand the benefits of public health solutions.

Finally, an obstacle that still needs to be overcome is the public's framing of HIV/AIDS as something different from other diseases, in that HIV is transmitted through "risky behavior." We heard this in every group, and it does mean that the participants consider HIV/AIDS uniquely when compared with other health issues. It also means that the solutions the public gravitates toward involve education or other measures that could change the choices individuals make. And while experts certainly agree that prevention efforts are important, this is an area where the public's mindset and starting point is markedly different from those of experts. These experts favor a plethora of public health interventions, and there is a fairly steep learning curve involved in understanding public health solutions and how they work.

However, when considering various expert proposals, people start to think about the pros and cons and weigh competing values, such as concerns over privacy competing with the need to prevent new HIV infections. Even during fairly brief discussions in a focus group setting, we saw considerable reassessment and working through solutions.

Raising awareness and education about all facets of the disease and ways to address them can go a long way toward refining the view that HIV, because of how it is transmitted, is in a different category from that of other life-threatening illnesses.

METHODOLOGY

This preliminary report is based on five focus groups conducted with the general public in order to gauge their views on HIV/AIDS in America today. The focus groups allowed for an in-depth, qualitative exploration of the dynamics underlying the public's attitudes toward complex issues. Actual quotes were drawn from the focus groups in order to give voice to these attitudes. The groups were conducted as follows:

- + New York, NY: Young adults under the age of 30;
- + Westchester, NY: Parents of children under the age of 25;
- + Los Angeles, CA: General public;
- + Des Moines, IA: General public; and
- + Birmingham, AL: General public.

INTRODUCTION, continued

In addition, a total of 13 interviews were conducted between October 2008 and February 2009 with experts specializing on the issue of HIV in a variety of ways. Again, actual quotes were drawn from the interviews. For this project we interviewed:

- + The executive director of an HIV community advocacy and activism organization that focuses on community organization;
- + The executive director of an HIV law and policy organization that works primarily with marginalized community members;
- + The president of a national AIDS grant-making organization;
- + An HIV program officer for an international women's organization;
- + The executive director of a national public health organization who focuses on community-based health programs;
- + A city public health commissioner working in the HIV division of the department;
- + The head of research and development for an international vaccine research organization;
- + A state legislator championing HIV legislation;
- + A member of a U.S. government advisory board on HIV/AIDS policy;
- + A vice president within an international organization enlisting businesses in the fight against HIV;
- + A civil rights attorney specializing in HIV discrimination within an LGBT organization;
- + The founder of an organization working with African-American churches in the United States and Africa to fight HIV; and
- + A medical historian who authored a book on the history of the AIDS epidemic.

These findings offer insight into public perception of this issue; however, this work is qualitative in nature, so the findings are suggestive and cannot be generalized to the public overall. Nevertheless, a number of clear, characteristic patterns of thinking emerged from these discussions, illustrating the need for further research.

FINDING ONE: HIV/AIDS in the United States Is Off the Radar for Most People

Experts say, and survey research indicates, that concern over HIV in America has lost salience with the public. Our groups showed this to be true, though African-Americans and New Yorkers were more aware of the issue.

Experts viewed the AIDS epidemic in the United States as an urgent problem. They believe, and rightly so, that the American public has become increasingly less concerned with HIV/AIDS. Having dedicated many years of their lives to studying and fighting the AIDS epidemic, they consider HIV/AIDS in the United States to be as urgent a problem as ever. Many experts lamented the lack of a single coordinated national effort geared toward educating the public and preventing the spread of the virus. A director from a national public health organization said, "I think that we have a communication problem in public health around prevention. We talk to ourselves, we listen to ourselves and we answer ourselves. We have not engaged the American people effectively in this prevention message. And this is not just for HIV/AIDS, it's for every disease." This was echoed by a program officer for a women's organization who stated, "There are many people who've been saying, 'Gosh, we've been thinking about this since the early 1980s, and there has never been a strategic, collective effort around [combating HIV/AIDS]...' The public perception is that AIDS is

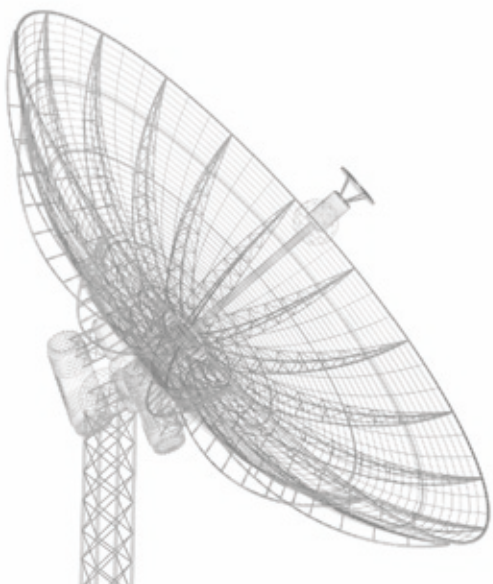
still a problem, but that there are things that have been fixed, so that everything is okay. There's still not a cure, but things are okay."

For many experts, there has never been a serious effort to combat the disease, and they believe that the problem is only exacerbated by the public's complacency with the epidemic in the United States. As observed by an activist who works primarily with African-American churches, "One of the biggest challenges [in HIV/AIDS] is the lack of reality that AIDS is a major problem in America. I think Americans of all races, creeds and color have no idea that this epidemic is so bad here in the U.S." One public health official we spoke with put it more bluntly: "HIV is not a major problem just for Africa; it's a major problem in the United States. That's what I would like for people to understand. When you talk about HIV, people are always looking to Africa or someplace else, not the U.S. They think the problem is over, essentially, in the U.S." And another health official, the director of a national public health organization, concurred: "There are folks that think we've cured it, that say, 'We've handled that problem; it's not an issue anymore. But it's an issue overseas.' We have people who think it's an overseas problem and not a U.S. problem anymore."

Research with the public shows that while a vast majority of Americans consider HIV/AIDS in Africa to be a very serious problem,⁸ less than half of the public has heard even "some" about HIV/AIDS in America today, and just 14 percent say that they have heard "a lot" about it.⁹ Our focus groups clearly corroborated that finding. While at least two people in each focus group identified HIV/AIDS as the biggest health problem facing the world today, only in Los Angeles did anyone cite HIV/AIDS as the biggest health problem facing the nation. Additionally, the majority of participants noted that since they had not heard much about HIV in the

⁸ A Gallup poll in December 2006 found that 96 percent of Americans said that HIV/AIDS in Africa is a very serious problem.

⁹ "2009 Survey of Americans on HIV/AIDS," Kaiser Family Foundation, April 2009.



FINDING ONE, continued

United States for years, they assumed it was no longer a serious issue. Many participants mentioned Earvin “Magic” Johnson, the high-profile professional basketball player who announced he was HIV-positive on November 7, 1991, about 17 years ago, as the last time they really heard about HIV/AIDS.

Surveys show that African-Americans have a higher awareness of the disease,¹⁰ and our research suggests this as well; people are also aware that the disease strikes more frequently in minority populations. We heard from an African-American in Birmingham: “Most reports I’ve been listening [to] on the radio recently [are] saying it’s African-Americans.” In Los Angeles, an African-American said, “In certain communities, the rate is much higher, such as in the African-American community, much higher,” and an African-American woman in Westchester correctly knew that “minorities, Spanish and African—they probably have a greater risk...”

To one African-American male in New York, the issue hit close to home: “It’s just a problem that I see increasing more and more. I know more people, I meet people every day that they either lost somebody close to them or somebody they know died from AIDS.”

We also found that HIV/AIDS messages clearly had reached the young adults in New York, including awareness of where to be tested. One male was very specific, saying, “You could get [testing for] free. They have parties now in Brooklyn [where you get]

free food and get tested.” Another man in New York spoke more generally: “I’m aware that they have like the health clinics that you go to, like to go get tested... [If] it’s HIV, there’s people there who are willing to help you... It’s free.”

Focus group respondents from other regions showed less awareness of the problem. Residents in Los Angeles spoke of the disease as practically absent from social consciousness, with one male saying, “To be quite honest with you, I haven’t done any research or really talked about it with anybody in years. It’s a nonsubject,” and one woman confessed that “it’s like an underground disease. I just think that people think it’s somehow gone away or it’s not important.”

This lack of recognition was replicated in other regions as people noted there is little or no continuing dialogue concerning AIDS, leaving some to conclude that the rates of infection are less of a problem. In Westchester County—a suburb of New York City, a city that has one of the highest HIV rates in the country—a woman said, “I don’t even hear anything talked about it. You don’t see anything in the papers; up here you’re not seeing it in the papers. I don’t see anything about it out there anymore.”

This was echoed hundreds of miles away by a woman in Des Moines, Iowa who said, “You don’t hear about [HIV/AIDS] as much anymore, so maybe the [rate of infection] is staying the same.”

“It’s like an underground disease. I just think that people think it’s somehow gone away or it’s not important.” — Woman, Los Angeles

¹⁰ “2009 Survey of Americans on HIV/AIDS,” Kaiser Family Foundation, April 2009.

FINDING TWO: Empathy Toward Those with HIV

Though knowledge about HIV is low, people expressed great sympathy for what they thought it may be like living with HIV/AIDS. They envisioned a life of loneliness and isolation for those who are HIV-positive. Their own frustration with the U.S. health care system also provided a starting point for the discussion. Experts also maintain that addressing problems in the health care system is essential to addressing HIV/AIDS and recommend systemic changes to the system, including increased access to treatment and the elimination of general health disparities.

Most focus group participants imagined the hardships that those affected with HIV face in terms of personal relationships and mental well-being. One woman in New York wondered what if “you find out you have it, and then your family turns around and says, ‘Look, I don’t want no part of that.’ Now you found out you have AIDS or HIV and now you’re alone. That just makes you feel awful.” A man in Los Angeles voiced similar concerns: “A person with AIDS, even if it’s a loved one or friend or whatever, you’re going to distance yourself, because you don’t know if you might get contact with it or it may spread.”

A woman in Birmingham thought about personal relationships more generally, saying, “People [would be] drawing away from you. They don’t want to have anything to do with someone who’s infected... I think that socially, it would just cut them off.” And a woman in Des Moines summarized what she thought it would be like by saying that “they sometimes will ostracize people that have [HIV/AIDS] because the fear is just like, ‘I don’t want to be around you because I don’t know how to deal with you because you have HIV.’”

The public also understood that most people who have HIV/AIDS face financial hardships as well, with one man in New York focusing on workplace issues: “If you have a manager, they can just make up reasons [to fire you] and then back it up.”

Participants often grappled with the disease by using their general views of health care as a starting point for discussion. We heard many people talk about their difficulties in dealing with their own health issues and imagined them to be as bad (or worse) for those with HIV. In Birmingham, a woman summarized her thoughts as, “I don’t think [it’s possible to afford medications]. I don’t have medical insurance, so I know how hard it is to try to find help to get anything.” And a male there said, “[African-Americans and Latinos] are not able to go to the doctor and have health care and stuff like people with money do.”

Participants also used Magic Johnson as a reference when describing how quality of health care is linked to a person’s income. A woman in Los Angeles said, “I think it’s manageable and treatable for the people that could afford it. I think it also has to do with social classes. Someone like Magic Johnson could afford to have those cocktails or whatnot. People that are in the lower brackets of income, they probably wouldn’t be able to afford those treatments.”

This was echoed by a woman in Birmingham: “Take Magic Johnson, for instance. He was able to live this long and he is as healthy as he is because of the amount of money he has... I would think maybe his wealth acquired him better medicines than maybe the poor people. You might get some medicine, but it might not be as good as what he has.”

Many experts agreed that not everyone in the United States who has HIV can get medication. As one activist told us, “[I]n this country [it is] estimated that half the people who know that they are HIV-positive and who fit the clinical definition to be on treatment can’t consistently get that treatment.” In 2003, a study showed that only 55 percent of people aged 15–49 who were eligible for antiretroviral medication actually received it.¹¹

¹¹ Teshale, E.H., et al. “Estimated Number of HIV-Infected Persons Eligible for and Receiving HIV Antiretroviral Therapy, 2003—United States.” Abstract #167, 12th Conference on Retroviruses and Opportunistic Infections, February 2005.

FINDING TWO, continued

But experts tended to underestimate the public's awareness of the gaps in HIV treatment. As our director of a national public health organization said, "I think there's still a general perspective that [treatment is] available and everybody's got it. I don't think people understand that there are still populations that don't have access to appropriate therapy. People believe that if you're poor in America, Medicaid takes care of you, but it doesn't."

The president of an AIDS grant-making organization lamented, "In this country people believe that we have good treatments, people believe that people who need them have them, and there is a general lack of coordinated communication about the realities of this epidemic... There are far too many people who do know their status and don't have access to care: They don't have transportation, they don't have child care. And then there are people who don't know their status who obviously aren't going to be in care." A survey in 2006 showed that 70 percent thought most people in the United States who need medication for HIV do not get it.¹² The outpouring of concerns we heard in our focus groups about the cost of treatment for HIV, and health care generally, shows that people are aware of the difficulties in securing adequate health care.

"I think it's manageable and treatable for the people that could afford it. I think it also has to do with social classes. Someone like Magic Johnson could afford to have those cocktails or whatnot. People that are in the lower brackets of income, they probably wouldn't be able to afford those treatments." — Woman, Los Angeles

¹² "2006 Survey of Americans on HIV/AIDS," Kaiser Family Foundation, May 2006.

FINDING THREE: Fear About HIV Transmission Persists

Experts say the stigma around HIV/AIDS stems primarily from two sources, the first being fear of transmission. We found that while most people do understand how HIV is most likely transmitted, they clearly overstate some risks and question whether enough is known about the virus. Not being certain about the possibility of indirect transmission, many adopt a “better safe than sorry” attitude. These uncertainties may also explain the anxiety many say they would feel around individuals with HIV.

Many of our experts maintained that the public is still not clear on how exactly HIV is and is not transmitted, saying that this misinformation leads to widespread HIV stigma. A civil rights attorney thought that “the biggest challenge in the U.S. is that there’s still a lot of stigma and discrimination against people with HIV, and that challenge relates to an incredible amount of ignorance on the part of the general public about HIV and how it is and is not transmitted.” They also point out that there is a great deal of fear of transmission. A medical historian put it this way: “I think an awful lot of people out there have at some point read or been exposed to the fact that you can’t get HIV by someone coughing on you, or sharing a toilet seat, or even by kissing. Whether or not people actually believe it is different.”

Some experts pointed to existing policies that draw on outdated notions about HIV transmission and lead to further discrimination. Experts gave examples of how agencies discriminate based on outdated laws and guidelines. The director of an HIV law and policy organization told us, “[A]gencies exclude people with HIV from serving in the military, have special rules for flying an airplane...and just about every state in the country has some specific law or interpretation of the law that excludes people with HIV from doing everything from being hair-dressers or massage therapists to being nurses and

physicians.” A civil rights attorney offers another example: “The FDA won’t let any man who’s had sex with another man anytime since 1977 donate blood. That’s sending out a false message about how dangerous men who have sex with men are and how likely it is they will have HIV.”

Overall, the public generally has an understanding of the relative risks of HIV. When asked how HIV was transmitted, people identified the most direct routes of transmission—unprotected sex, needle sharing and blood transfusions—and did not volunteer any other possibilities. Yet when presented with possible scenarios—such as getting HIV through casual contact, mouth sores or open cuts on the skin—almost everyone said it was less of a risk, but many clearly overstated the actual danger for these activities. In a recent survey, 1 in 5 Americans were found to believe that a person can become infected with HIV just from sharing a drinking glass.¹³ Some participants in Los Angeles even thought that HIV could be transmitted through sweat.

In every group, participants demonstrated anxiety about the possibility of transmission through contact with HIV-positive individuals in certain occupations, such as medicine, dentistry, sports, food service, child care or teaching. In medicine, dentistry and sports, the fear was that there would be high potential for both the HIV-positive person and the person interacting with him or her to get cuts and exchange blood. And while some were more skeptical that HIV could be transmitted this way, they often refused to rule it out. In addition, some admitted to their own fear of being around people they knew who were HIV-positive. In New York, a woman thought that athletes should have to disclose their status to their coach, although not the whole school. They recognized that their attitudes were perhaps “selfish” and might be unfair, but they were uncomfortable with not knowing the HIV status of their doctors and dentists.

¹³ “2009 Survey of Americans on HIV/AIDS,” Kaiser Family Foundation, April 2009.

FINDING THREE, continued

For some, it was more about not taking any risks when it comes to the safety of their children. One man in Los Angeles explained: “[Y]our child is your number one priority. That should come first... If you know a person has AIDS, or you find out a person has AIDS...you might feel sorry for them, et cetera, but you wouldn’t want them around your child.” Another man in Westchester feared for the well-being of his family when discussing why he felt his employees should disclose their HIV status: “[I]f I’m working with you, and you have AIDS, and I have a family of four kids, you’re going to get me with AIDS, and I’m going to be gone in two years, but you should be able to at least let the employer know, and I know that you have AIDS, and I’ll be careful around you, or you’ll be careful around me, so he’s giving me the respect that I don’t have it.”

Another possible source of participants’ fears and misconceptions about HIV transmission may stem from their reliance on messages they had heard years before, which made it difficult for them to separate rumors from fact. One man from Westchester was confused about the transmission risks for kissing, saying, “A lot of these questions... I don’t know, I’m only going back to like the late 1980s, mid- to late 1980s, and I remember at that time they had said that they weren’t sure, so I really don’t know. I would say...it’s probably a possibility [to get HIV from kissing].” Another woman in Des Moines said, “I know like when AIDS first hit in the ’80s, people started hearing about it, and there was all these rumors how you can get it and how you can’t. I don’t think anyone ever heard the answers. It kind of went away, and people started saying, ‘No, you can’t get it that way,’ and then like I said, no one

really knows.” A man in Birmingham pointed out that there may be a generation gap, saying, “People that are mostly my age, some of our ages, that everybody was so scared when it first came out. They even thought like mosquitoes might be able to carry the germ. It just put so much fear in everybody’s mind that it’s hard to get that out.” A man in Los Angeles remained skeptical that everything is known about HIV transmission, saying, “[F]irst it was just everybody thought you couldn’t touch anybody that had it. Then they come to find out, well, no, you have to have blood. Then it come to be intercourse, then they thought it was gays. Then they thought it was this and that. There’s a whole lot of rumors, and scientists are still studying and finding out every day.”

Nevertheless, participants did seem to recognize the unique stigma that stems from fear about HIV’s communicability. Some participants directly addressed how ignorance can lead to HIV discrimination; as one man in Des Moines put it, “I’d probably really find out all the facts I could about becoming HIV-positive so I wouldn’t be crucifying somebody from lack of knowledge or from stupidity. That’s outrageous to condemn somebody without even knowing the facts. A lot of humans do that. That’s a human frailty.” A man in Westchester talked about how the perception of transmission leads to fear, saying, “The perception of being able to transmit, even across the table, is like, ‘I don’t want to be here,’ like, ‘I don’t want to take that chance.’ That, I think, is the difference, and that goes back to educating people on really how the disease is transmitted, because I think that you could eliminate a—not all the fear, but a heck of a lot of the fear.”

“[F]irst it was just everybody thought you couldn’t touch anybody that had it. Then they come to find out, well, no, you have to have blood. Then it come to be intercourse, then they thought it was gays. Then they thought it was this and that. There’s a whole lot of rumors, and scientists are still studying and finding out every day.” — Man, Los Angeles

FINDING FOUR: A General Focus on Individual Behavior

Another source of stigma stems from people's views on how HIV is commonly transmitted. They maintain that, unlike heart disease or cancer, HIV is an infection that mostly affects people who are taking risks or engaging in behaviors that people don't approve of. Experts tend not to focus on individual behavior when thinking about HIV risk. Instead, they maintain that stigma around how HIV is transmitted, and who gets HIV, is a major barrier to solving problems within the epidemic.

Some of the people in the groups we spoke with talked about the unique stigma attached to HIV/AIDS. Participants said, for example, that while cancer has little to do with personal choices and more to do with bad luck or genetics, HIV/AIDS is usually acquired because of bad choices. One woman in Los Angeles said, "Socially, if I have cancer, it's not my fault. It happened to me. If I tell you I have HIV, I have a stigma on me, because you'll say, 'What kind of a person are you?'" A woman in Des Moines said something similar: "A lot of people think that AIDS is you did that to yourself. It's your own fault. You weren't careful, and so that's what happens. With cancer, that's like, 'Oh, I feel so bad for you. You didn't do anything to get it, and it's not your fault.'"

Focus group participants went on to say that some people acquire HIV/AIDS through no fault of their own, and they showed greater sympathy for these individuals. In Birmingham a woman said, "What about those that are born with it? They're born with it. They can't help that." Some also suggested that education should emphasize these more sympathetic individuals. For instance, a woman in Westchester suggested this for a public education campaign: "You can show like an old man that had a blood transfusion that has full-blown AIDS, and show the public, 'Look. I have AIDS. You're going to discriminate against me? I got it through a blood transfusion while I was in the hospital for a kidney

transplant.'" These focus groups comments show that, unlike other diseases, there is still a stigma attached to becoming HIV-positive, and perceptions of the patient being at fault vary depending on how the virus was contracted.

The public did realize that some groups of people are more at risk for HIV, but they had a hard time conceptualizing how structural issues could influence who is most likely to acquire the disease. Because they framed the issue in terms of their own lives and behavior, they continued to see the issue as one of personal responsibility. If a demographic group has a higher incidence of HIV, participants generally said it was because that group behaves differently from other populations. For example, a woman in Los Angeles thought her gay friends had particularly risky lifestyles. She said, "I have a lot of gay friends. For the most part, they have a different lifestyle, shall we say. They're a lot more promiscuous. It's just like a different party lifestyle. The disease is very prevalent in that society." They also thought urban areas were havens for riskier lifestyles. We heard from a man in Des Moines that "some big cities...would have a little bit higher percentages due to the larger numbers of certain lifestyles that you don't see, as opposed to one of our real small towns where if you got an IV drug user in the town, everybody knows it."

Although some participants maintained that HIV/AIDS is different from other diseases (in their eyes, it is a disease caused solely by choices a person makes), a few did agree that life choices also factored into other diseases, such as heart disease and cancer. A man in Des Moines said, "There are things you can do to combat heart disease; with exercise you can strengthen your heart," and we also heard in Los Angeles that if you get "too fat, [heart problems]...are your own fault."

FINDING FOUR, continued

Many experts had a different take. They talked about the existing prejudices that contribute to problems with HIV/AIDS. They framed it not as the public did—that is, not in terms of personal responsibility or “people making bad decisions”—but as currents of homophobia, racism and negative attitudes toward drug users and those not practicing monogamy. To many of them, this not only contributes to HIV stigma, but is a major barrier to fighting the epidemic in the communities that are most at risk—perhaps, as some of the experts we spoke with said, because some policymakers also hold these views. In the words of the director of an HIV law and policy organization, some experts think that “if there was one single thing [that could most help fight HIV], it would be focus[ing] on eliminating all of the homophobic, gender-based, civil rights problems that feed the belief that people are getting what they deserve.”

Some experts contend that the disease is seen as a problem of “other people.” A state legislator put it, “[Policymakers] are hesitant to do anything. It’s not affecting, in their view, the larger society.” And policymakers may not be as aware of the problem, because HIV/AIDS is not a disease that affects them personally. A medical historian pointed out that “we disproportionately fund diseases that affect our life or the lives of those who are similar to us, which is one of the reasons why breast cancer and prostate cancer get such good funding.” But other experts saw the bias as more deliberate—accusing policymakers of pursuing socially conservative policy positions that exacerbate AIDS issues. In the words of one activist, “We have public dollars that are being used to fund HIV stigma... ‘Abstinence only until marriage’ is federally funded stigma promotion.”

Two of the experts, both heavily involved in helping African-American churches take the lead in educating their communities about HIV, pointed to misinformation within the at-risk communities. They said that there is a misconception among African-Americans that HIV affects only the homosexual population. One thought that “the biggest stigma attached to HIV/AIDS is homosexuality. Folks still don’t get it that homosexuality does not cause AIDS.” And some experts pointed out that any kind of stigma associated with HIV may prevent people from being tested for fear that they will be discriminated against. One director of an HIV law and policy organization thought that “the perception of social risk associated with HIV testing is extraordinarily high and based in reality.”

Experts also view the AIDS epidemic in broader terms than the public does. They see it as driven by socioeconomic factors, with some explaining how social marginalization and its associated hopelessness can lead to increased risk for HIV. Overall, many see HIV/AIDS as “truly an epidemic of poverty, race, class and gender.” This women’s health organization’s program officer went on to say, “All of the societal factors are just as [important as], if not even more important than, the traditional notions of what makes someone at risk or vulnerable to acquiring HIV.” Some go so far as to say that without these structural problems, the epidemic would not be so severe. One public health official said, “If we had started 20 years ago dealing with the real underlying issues—like lack of education, therefore lack of hope, lack of getting a good job, not caring what happens with you tomorrow because nobody cares about you, you feel marginalized, stigmatized—we’d be in a different place in the epidemic right now.”

FINDING FOUR, continued

Since experts mostly considered structural or socio-economic factors as contributing to the spread of the disease, they made efforts to avoid placing blame on individuals for engaging in risky behavior. Those who did talk about individual behavior framed it in terms of empowerment, in one case, according to the director of a national public health organization, of “women becoming empowered to protect themselves so it becomes the norm to carry a condom.” Another AIDS activist dismissed using individuals’ behavior as a sufficient model of assessing risk, saying that “risk behavior does not adequately describe vulnerability to HIV or STDs... Average sexual behaviors of a standard person puts them in harm’s way if they have higher rates of HIV in their community. And so measures to help people reduce their risk may not help reduce their vulnerability enough to HIV.”

“A lot of people think that AIDS is you did that to yourself. It’s your own fault. You weren’t careful, and so that’s what happens. With cancer, that’s like, ‘Oh, I feel so bad for you. You didn’t do anything to get it, and it’s not your fault.’”

— Woman, Des Moines

FINDING FIVE: Education Is Favored by All

Both the public and experts support education as the best way to address HIV/AIDS, though they frame it quite differently. In our groups, people talked primarily about broad-based awareness campaigns targeted to the general population, giving general information about the disease. Experts focused on targeting at-risk populations with particular information about being tested and treated.

By far, the most favored way to address the issue of HIV/AIDS in America for the public was more education, particularly in the form of public awareness announcements. In the words of a Des Moines woman, public service announcements would “go a long way” because “people pay attention, and when they are captivated by something, they are learning and taking it in.” A man in Los Angeles thought that if celebrities were open about their status, “the talk will start coming about more...and then you get more enlightened, and you want to know more.”

Older participants largely wanted these public service announcements to be directed to their own cohort, saying that the younger generation knows much about HIV/AIDS already, suggesting perhaps that they are interested in knowing more. One woman in Des Moines said that “[kids] talk about it in health class, so I think they’re probably more educated than we are, at least I am.”

Perhaps because they had had more education about HIV/AIDS in school, the New York young adult group was very skeptical that education would be particularly helpful to people who are naturally going to take risks or those under the influence of drugs and alcohol. One young man thought that “if you’re doing drugs and drinking on a regular basis, then your decision making is going to be reckless.” They also knew of infected people who were not cautious

about their own behaviors, putting others at risk. One man explained that his “[friend with HIV] doesn’t care who he sleeps with. Doesn’t care where he goes. Doesn’t use condoms still. He just doesn’t care. He’s like, ‘You know, I’m dying anyway. Take the rest of them with me. I don’t care.’ Then I have other friends who are like, ‘You know, I don’t want to spread this.’ They want to get educated more about it. Tell people. They go and do seminars and things like that. They’re actually trying to become more active with it, but it depends on the person.”

Experts also spoke of education, but, in the words of the president of an AIDS grant-making organization, it should be education that is “targeted and culturally relevant and appropriate” to different demographic groups. Some talked about how more research funding is needed to uncover ways to craft the most effective educational messages. A state legislator pointed out that “there is no single method for disseminating information, particularly in minority communities. You really need to understand the structure of those communities and how people communicate within them, and tailor your communication efforts to that structure.” Unfortunately, some experts think that those within the AIDS community have not done a particularly good job at targeting education, or else they think that the education hasn’t resonated with those they need to reach. The director of a national public health organization said that “we have spent almost no money trying to understand how to educate people and change their behavior. The marketing people tell us, ‘If you want to get people to buy stuff—look at the pharmaceutical industry, they have figured out how to drive demand for medications—even stuff that has side effects—they have figured out how to do that.’ We haven’t done it because we either haven’t figured it out or for other sociological reasons we’ve decided we don’t want to do it.”

FINDING FIVE, continued

Similarly, many experts talked about the need to not cast a wide net with funding HIV programs overall, but to make sure they are targeted to the demographic groups that need it the most. A civil rights attorney explained that “from a practical standpoint...targeting more vulnerable populations is likely to be a more productive use of resources.” The president of an AIDS grant-making organization elaborated on this point, explaining, “[I]f you look at the epidemiology [of the disease], the fact of the matter is that most people simply are not at risk for HIV... In a world where we have limited resources and obvious data that show significant impact among MSM [men who have sex with men], African-Americans, Latinos, to not direct those resources to those most impacted populations or underserved areas is simply irresponsible.”

“[I]f you’re doing drugs and drinking on a regular basis, then your decision making is going to be reckless.”
— Man, Des Moines

FINDING SIX: A Vaccine Is Right Around the Corner?

Putting more money into a vaccine received strong support from people, perhaps because vaccines have historically been a key component in strategies for eradicating disease. Some even believed that finding a vaccine should take precedence over increased education, either because they felt that current education efforts are sufficient or because they had tremendous faith in the scientific community to have a breakthrough. Experts also supported funding for a vaccine but were quick to point out the need for prevention efforts as well.

One man in Birmingham summed up what many people were thinking by saying, “My goodness, we’ve been educating for 20, 30 years, and I believe in continuing education, but maybe you need to stray from that... Continue education, but I’d say put more of the dollars into research and the vaccine, just like cancer. Let’s cure it one day.” A man from Westchester saw advances in science overall as evidence that progress on a vaccine could and should be made. His point was that “if you look at our science, and how far we[’ve] come from quantum theory, quantum physics and everything we’re doing...I believe we should [educate] as well, but it sounds like we’re settling...I think we should never stop working till there’s a vaccine to eradicate something like we beat the plague.”

And some were certain that the wherewithal to create a vaccine already existed but that pharmaceutical companies were directly responsible for delays in progress. In New York, people focused on the profitability of current anti-retroviral drugs. One man thought that “if they find a cure, then there’s no money coming into those pharmaceutical companies that are making the AZTs, making all those drugs for people that have AIDS.” He went on to say that “they’re getting money as long as there’s still AIDS in the world, so why—what’s the advantage of finding a cure for AIDS?”

We should note that although there was widespread support for a vaccine, a few participants took steps to say that it is not a good idea to put all of your faith in it. Money should still go toward other ways to address the issue. Some recognized that research takes time. In Des Moines, a man pointed out that “research can be 20, 30, 40 years. We don’t know,” so he thought that “initially, maybe you need to take a greater sum or greater percentage of that money available and pump it into education, knowing that that may carry you a lot farther than research might.”

FINDING SIX, continued

While experts supported research in vaccine development, they ultimately emphasized the need for prevention strategies. In the words of one leader of a national public health organization, “[W]e have to reenergize the prevention focus. If you don’t have a cure—just like every other ‘chronic’ disease—the best way to get your hands around the chronic disease is to prevent the disease, whether it’s diabetes, hypertension, cardiovascular disease or HIV/AIDS.” This sentiment was echoed by a state legislator who thought that “if you can prevent people from ever getting a disease, finding a cure becomes less of an issue.”

Unlike the public, experts also made a clear distinction between a vaccine and a cure. One government HIV advisory board member thought that “vaccines are a good way of [dealing with the epidemic]—it’s not a cure, but it’s the next best thing.”

The experts also pointed out the technical challenges involved in developing a vaccine. One expert working in vaccine research told us that a vaccine is not going to be available in the near future. He explains that “HIV is a challenging target. To begin with, it hasn’t been [around] that long... Generally, if you look at the development of vaccines over time, it takes a long time. It’s not a surprise really that we don’t have a vaccine yet.”

“[I]f they find a cure, then there’s no money coming into those pharmaceutical companies that are making the AZTs, making all those drugs for people that have AIDS. They’re getting money as long as there’s still AIDS in the world, so why—what’s the advantage of finding a cure for AIDS?” — Man, New York

FINDING SEVEN: Primed for Engagement

The experts we spoke with weighed in on a variety of policy proposals, including condom distribution, testing and partner notification. While the public has not thought about or even generally heard about these or other specific proposals, we find that they are willing to discuss these issues and consider trade-offs, showing opportunity for further engagement.

In addition to talking about reducing stigma and providing targeted education as important in solving the AIDS epidemic, experts provided a wealth of alternative strategies to prevent the spread of HIV, and they did not always agree. For example, experts were divided on the issue of consent for HIV testing. Some saw consent forms as a barrier to getting tested, but others saw them as not only crucial for keeping one's HIV status confidential, but also important in maintaining a trusting relationship between health care providers and patients, which may be compromised if people are tested without consent. One expert working in a women's organization advocated reduced barriers to testing, saying, "[A]ny time you have an extra 'thing' to go through, it can be overwhelming, it can discourage people from feeling comfortable going through the process. And when you look at HIV and how it disproportionately affects low-income, no-income, people of color—communities that have been disenfranchised in many ways—there's also a disproportionate level of illiteracy. All that put together, it makes it even tougher, putting up all these different little barriers."

Another public health official also thought that written consent leads to fewer people being tested and more people spreading the disease unknowingly. She sees a problem in the fact that many people who are diagnosed with full-blown AIDS have "been in contact with the health care system repeatedly and they haven't been tested, because people don't want to have to find another piece of paper and get somebody to come in and talk to you about it." Others believed that consent is a civil rights issue. One government advisory board member did allow that "it could be informed consent" because

he feels that "there should be an opportunity for the patient to opt out, for them to be given information about HIV/AIDS, how it's spread, et cetera" However, the director of an HIV law and policy organization disagreed and emphasized the need for written consent, saying, "If [consent is] not documented, you might as well say you can test [without consent], because if there isn't an actual legal requirement for documentation, there is no question that people will be tested without their knowledge."

Similarly, some of our experts disagreed on the issue of partner notification by doctors. One tried to put herself in the shoes of her organization's grantees—women living with HIV—saying that partner notification would be "crucial" for them, but she recognized the inherent tension with that approach. She says, "It's a slippery slope for me, personally...but if I were to relay the message of [my grantees] across the country affected by HIV, I think they would say that partner notification is absolutely crucial." Another expert said that partner notification must be voluntary and encouraged—but not required—by health care professionals, for a reason similar to the need to keep written consent in HIV testing—that it is better for an HIV-positive individual, and others, to have a trusting relationship with their health care providers so that they will stay in care. This civil rights attorney pointed out that "this is an area doctors need to be careful about because there's a huge downside to a doctor breaching their patient's confidentiality, not just because it's an issue of 'Are they legally allowed to do that?'—which they might not be—but also there's consequences, because if a person doesn't trust their health care provider, they are much less likely to get into care or stay in care."

The idea that HIV-positive individuals should have trusting relationships with their medical providers so that they stay in care touches on a general approach to HIV prevention. This approach focuses on taking care of people with HIV in order to prevent transmission of the virus. The CDC has coined this the "serostatus approach" to preventing HIV, and it can include providing HIV medicine, treatment of other illnesses, mental health care, drug treatment,

FINDING SEVEN, continued

sterile syringes and housing for those who are HIV-positive.¹⁴ Some of these approaches—such as providing sterile syringes to drug users—could also be used to prevent HIV in those who are HIV-negative. As mentioned previously, some experts said that providing HIV medication to people with HIV is an important prevention strategy, as it can lower a person's viral load and can reduce that person's risk of transmitting it to others. A public health official we spoke with also advocated this multifaceted approach by saying, “[W]e need to also deal with other underlying issues that are more immediate, which is the fact that many people use drugs, and if we don't do drug treatment, trying to tell them about HIV when they're trying to go get high is not going to work.” The Institute of Medicine has stated, “For injection drug users who cannot or will not stop injecting drugs, the once-only use of sterile needles and syringes remains the safest, most effective approach for limiting HIV transmission.” And the director of an HIV law and policy organization maintained that “[h]ousing is one of the most important prevention initiatives that one can take.”

Some experts also talked about the need to talk about sexuality more openly, not only in the form of more comprehensive sex education for the public, but also in educating health care professionals involved in HIV testing to be more comfortable addressing sex. One activist talked about society's aversion to talking about sex. She said that “there's a chill effect in talking honestly about sexuality in this country. There's been hardly any research on sexuality. We don't know much about how people have sex in this country, so you end up with AIDS organizations internalizing the stigma about sexuality period, saying stuff like, ‘If you are going to have sex, use a condom,’ as if it's an abnormal thing to do. Ninety percent of people have premarital sex. How much of that is known by the public and AIDS service and health providers? We don't invest in strategies that support healthy sexuality.” Another expert talked about the problem in terms of health care providers more

specifically. The director of an HIV law and policy organization pointed to a survey of physicians, showing that “two of the primary reasons [physicians don't offer HIV tests were] because they didn't feel like they understood, they didn't feel comfortable... asking questions...or they didn't know what to do with people once they tested positive.”

With a low awareness of HIV/AIDS in the United States, it makes sense that the public gravitated toward solutions that they can easily grasp, such as raising awareness through education and medical breakthroughs in the form of a vaccine. Yet when we brought up a few specific proposals, people often had an opinion. Unlike the experts, they based their opinions not on any evidence or experience, but on the values and beliefs that were most important to them. We believe that this demonstrates that the public may be ready for a discussion and perhaps even willing to consider funding for some HIV/AIDS specific proposals.

For example, on the issue of testing, some participants really saw mandatory testing as a matter of practicality, saying it made sense to treat testing like anything else in health care, and it would be better for people's health just to find out. A woman in Birmingham said, “I think it's ridiculous to have to sign a consent form. If you're sick, you're sick. If you go in for a sinus infection, do you sign a waiver to be treated for it?” Another participant in New York said, “The sooner you catch it, the better off you'll be.” They thought that at the very least, doctors should always offer the test. One woman in Des Moines talked about placing the initiative on the doctor rather than on the patient. She said, “I think if someone's asked, they'll say yes more likely than if they have to ask the doctor themselves. Maybe they're embarrassed about it and they don't want to ask, but if someone asks straight out, then maybe they'll have more courage to say yes if that's something they want to do.”

¹⁴ Janssen, R.S., et al. “The Serostatus Approach to Fighting the HIV Epidemic: Prevention Strategies for Infected Individuals.” Atlanta: Division of HIV/AIDS Prevention, Centers for Disease Control and Prevention, 2001.

FINDING SEVEN, continued

Others were more concerned about privacy, maintaining that there was a benefit to extra barriers to testing. Some participants were very thoughtful about the emotional difference between knowing one's status without fully understanding what is happening as opposed to being an active partner in agreeing to be tested. One woman in Des Moines said, "I think [testing] should be something you have to agree to... You don't feel comfortable letting that information out there where anyone might get it." A woman in Westchester put it this way: "I think that as an adult, you should be able to consent to the different tests that you're having... I wouldn't want to just get a random phone call."

A similar tension played out on how much follow-up should be practiced with HIV/AIDS patients to ensure that they are following their drug regimen and are doing well overall. Some participants stressed autonomy for HIV/AIDS patients, suggesting they need to be self-reliant at some point. One woman in Birmingham saw forcing people to follow treatment as futile. She said that "if [HIV/AIDS patients] don't want the help, you'd just hope that the majority decides to take the help. The ones that don't want the help, well, you're not going to be able to help them if they do."

Others stressed compassion over responsibility, acknowledging that some HIV/AIDS patients are people in difficult situations. Support groups were very popular in the New York group. One woman thought support groups "should be an option if you want to go do it," and a man in the same group said that "you'll need support, like for anything in any situation you got to have support." Participants in Westchester even discussed how there should be more locations for support groups so that people don't have to risk being seen by their neighbors and face discrimination. One participant in Westchester suggested that counseling "should be more private—like one-on-one counseling with a doctor and patient. That's something that don't get tax dollars."

When it came to the role schools should play in addressing the issue, particularly concerning condom distribution, there were again mixed views. Participants largely supported sexual education in schools, though many emphasized that parents need to take an active role in educating their children about HIV. Some parents supported messages of abstinence along with education about safe sex. In Des Moines, a woman said, "We got to teach them to have protected sex. Abstinence is a great thing if you can convince them to be abstinent... [But] make some of the things [condoms] available to them [in schools so] that they can protect themselves." But another Westchester parent thought that "no one's going to do as good a job [at education about sex] as my wife and I will."

Some drew the line in handing out condoms in school, because it might suggest that schools condone sex. A man in Birmingham elaborated this thought when he said, "I do think you can supply them with the information, maybe. To give out condoms, to me, is in a way...saying that 'we suggest you don't do it, but just in case you want to, here it is.'" Some participants in New York maintained that kids are too embarrassed to ask for condoms in school anyway. One man said, "You can get a condom, but the question is are you actually going to look at your girlfriend and be like, 'Yeah, you know, why don't we walk over to the nurse and get a condom, let them know we're going to have sex.' There's a lot of kids just don't want to do that." When asked about distributing free condoms outside of school, participants were almost unanimously supportive. In Des Moines, one woman mused, "I don't see why [condoms] shouldn't just be available [outside of school], go to the pharmacy counter anywhere and walk in any clinic and a big bowl of them or whatever."

**"[I]f [HIV/AIDS patients] don't want the help, you'd just hope that the majority decides to take the help. The ones that don't want the help, well, you're not going to be able to help them if they do."
— Woman, Birmingham**



Community Characteristics

Population: 242,820¹⁵

State population: 4,447,100

Median age: 34

Race/ethnicity:

25% white, 74% black, 2% Hispanic, 1% Asian¹⁶

Annual HIV cases reported (Alabama):

529¹⁷

Persons living with AIDS (Alabama): 4,046

Federal funding for HIV/AIDS (Alabama):

\$33,896,136

¹⁵ Unless otherwise noted, figures refer to the city where the focus group was conducted.

¹⁶ Sources: U.S. Census Bureau, 2005–2007 American Community Survey or U.S. Census Bureau, Census 2000. Also note that race and ethnicity figures may add up to more than 100 percent, because people identify with more than one category.

¹⁷ *HIV/AIDS Surveillance Report: Cases of HIV Infection and AIDS in the United States, 2007*, Centers for Disease Control and Prevention, Department of Health and Human Services, 2009.

The Birmingham group was quite outspoken in its views, with one participant introducing himself as “married 31 years to my high school sweetheart” and another who announced his concern that the government is “kind of sacrificing free market principles” in trying to fix the economy.

Yet even with these conservative viewpoints, the group overall was supportive of the government providing services to those with HIV, such as inexpensive medications, mental health services and free testing to those who request it. Though there was some opposition to allowing condoms in schools, there was agreement that sex education in at least some form should be taught in the schools. When it came to needle exchange programs, though, the majority rejected spending government funds for such a program.

Participants generally understood that HIV can lead to AIDS and that the condition is manageable with the right medication. They also understood that unprotected sex and needle sharing can lead to contracting HIV, but a few said that using a condom did not significantly reduce the risk, or as one put it, “I’m old school—even with protection nowadays, I think you’re taking a risk if you don’t know who you’re with.” And though they understood how HIV is transmitted, there was concern about allowing HIV-positive teachers or dentists to interact with the focus group participants or their children. Some even believed that there is a law in Alabama requiring teachers to inform authorities if they are HIV-positive.

Perceptions were mixed on whether African-Americans have a higher incidence of HIV/AIDS, with the African-American participants and some whites saying this is true and others echoing one person who said, “[Y]ears ago, maybe...but I think nowadays [HIV/AIDS is] like cancer. It doesn’t have any particular color or anything it goes after.” Interestingly, many thought that Hispanics would have a lower incidence, with one participant saying, “You just don’t hear of a lot of Hispanics with HIV,” and another saying it is because “[m]ost Hispanics are Catholic.” One group that participants all agreed had a higher risk was young people. Many agreed with one participant who said young people these days are more likely to engage in risky behavior because “[t]hey now think there’s medicines to cure everything...all you need to do is take a couple pills and they’ll be fine... They take more risks now because they know that there are people checking into cures for it...”

Five people, including all three African-Americans in the group, knew someone who is HIV-positive or has died from AIDS.

Discussions about health care dominated much of the conversation in the Birmingham group. At the outset, two participants wrote down HIV/AIDS as the most important health problem facing the country today. One participant talked in particular about his cancer, drawing a connection between his difficulty in dealing with insurance for medications and the challenges that those who are HIV-positive must face.



Community Characteristics



Population: 198,682

State population: 2,926,324

Median age: 34

Race/ethnicity:
84% white, 9% black, 7% Hispanic, 4% Asian

Annual HIV cases reported (Iowa):
93

Persons living with AIDS (Iowa): 917

Federal funding for HIV/AIDS (Iowa):
\$6,842,895

Knowledge about HIV/AIDS seemed lower in Des Moines than in the other groups, with several people unsure about the difference between HIV and AIDS. Some were aware that people with AIDS could benefit from medication,, but many were not aware that medications could be used to manage HIV and prevent the onset of AIDS. One participant maintained that the chance of someone dying of AIDS is connected to how the virus is transmitted, implying that getting it through risky behavior means a greater chance of death. Yet all agreed that condoms prevent the transmission, and as one participant put it, “It’s not like the flu. If one of us walked in here with the flu, it’s [likely] every one of us is going to walk out of here with it. If one of us walked in here with AIDS, even if we did have a

wild party, it would still be a very unlikely chance that very many of us would walk out of here with it.” But overall, as in other groups, they were clearly uncomfortable with the idea of having a teacher or doctor with HIV work with them or their children.

The one African-American in the group said she heard that African-American women are more likely to get the disease, and while a few others thought that was true, most said it had to be young people of any race, because “younger people would have a wilder lifestyle.” Interestingly, some participants asserted that the incidence of HIV/AIDS cases in Des Moines is equal to that in urban areas like New York City, because “the chances of having sex with someone with AIDS is pretty much the same.”

Not surprisingly, as overall their awareness of the issue was less than in the other groups, they leaned strongly toward general education as a good solution for dealing with HIV/AIDS, but they disapproved of campaigns that would use emotional appeals or condone certain lifestyles, instead favoring education where they could “get the facts” and make their own decisions.

There was also concern that a vaccine might lead to more risky behavior, or as one participant put it, “If we got a vaccine for it, how many kids are going to say, ‘Well, I have nothing to worry about now. You can’t get AIDS now.’ She might go get pregnant...”

On more specific proposals, participants tried to straddle a line between privacy and moral obligation, stressing that the government generally should not intrude but people themselves should come forward, or as one person put it, “I think we should just be more moral.”





Los Angeles, California

Community Characteristics

Population: 3,694,820

State population: 33,871,648

Median age: 32

Race/ethnicity:

51% white, 12% black, 47% Hispanic, 11% Asian

Annual HIV cases reported (California):

17,588

Persons living with AIDS (California): 65,582

Federal funding (California):

\$362,987,483

Los Angeles was the only group where HIV/AIDS came up as the most important health problem facing the country today, and more people in the Los Angeles group knew someone with HIV/AIDS than any other group. Despite their apparent awareness about HIV/AIDS, many participants displayed some glaring misconceptions about HIV: Nearly half the group thought there was at least some possibility that one could get HIV through sweat, over half reported that one could get HIV from kissing and, not surprisingly, most of the group thought that scientists are still learning how HIV is transmitted. “People don’t really know how you get AIDS,” said one man. “They thought it was this and that. There are a whole lot of rumors, and scientists are still studying and finding out every day.”

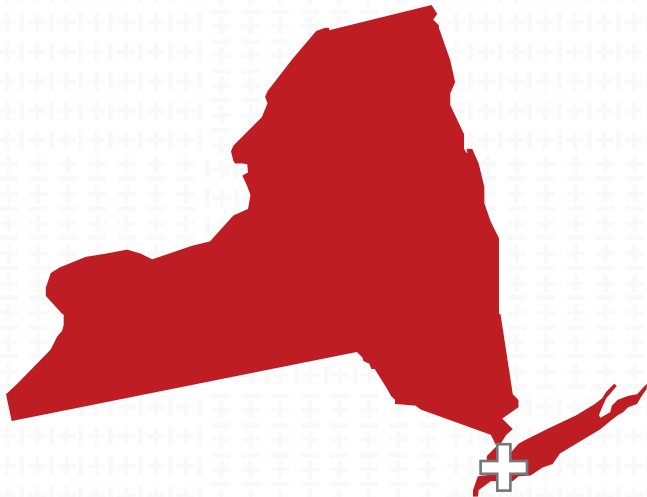
Participants in Los Angeles were more inclined to say that people get HIV because of factors outside of one’s control. They were more likely than those in the other groups to talk about socioeconomic factors and fear of testing. One participant pointed out that “we got a lot of people under economic pressure, which basically has a trickle-down effect on people. Some people will get a little wilder than others because of it... If you go into a more well-off economically suburb or white neighborhood as opposed to there, there’s going to be a difference.” Another woman said that more people would be inclined to get tested if there were more support for people with the disease: “I think that if people feel that they can be taken care of, they would go and get tested—because there wouldn’t be so much fear, like, ‘What would I do if I do have it?’ If you have support groups, then those people don’t feel isolated. I think it would really, really help.”

Participants were very supportive of proposals to provide medication and mental health services for those with HIV, and some participants actually went out of their way to criticize the government's handling of the AIDS epidemic. One man said we don't have more HIV testing going on because "the government don't want to pay nothing out of their pockets," and another woman agreed, saying, "[T]hat's why there hasn't been any education for the last eight years." And later in the group, one woman said that HIV won't get more funding because

"the old boys' group in Washington are sitting there making the decisions for the population. These are guys that can get heart attacks, so let's see, is the money going to go to heart disease or is it going to AIDS?... They're prejudice[d]." Conversely, there was one participant who was very much against government intervention because he's "opposed to the idea that we can turn to the government for all the medical things." Political statements like these rarely surfaced in other groups.



Community Characteristics



New York, New York

Population: 8,274,527

State population: 18,976,457

Median age: 36

Race/ethnicity:

44% white, 25% black, 27% Hispanic, 12% Asian

Annual HIV cases reported (New York State):

5,197

Persons living with AIDS (New York State): 75,253

Federal funding (New York State):

\$493,058,849

This group of young people in New York City was more knowledgeable than other groups. While most participants admitted that they knew some facts about AIDS, a few said they knew “a lot,” getting information from grade school, news and television. One participant cited her HIV-positive friend as a source of information. New York participants generally understood the difference between HIV and AIDS and correctly identified the vectors of transmission such as blood, semen and sharing needles. They were generally aware that HIV was not transmitted through casual contact, but still voiced concern about being around people with HIV/AIDS.

Participants said that condoms can be used to prevent contracting the disease and said that abstinence, monogamy and not sharing drug needles also prevented the disease. The group understood that some groups have a higher risk of contracting HIV, such as uneducated people, Latinos, homosexuals and low-income individuals. The group did not emphasize personal responsibility as much as other groups when considering why people are at risk for HIV. Rather, they said that a combination of bad luck, poor choices made

under the influence of drugs and alcohol and individual behavior contributed to HIV risk. However, when it came to solutions to preventing HIV, many participants were skeptical that prevention initiatives, such as education and condom distribution, would be effective in reducing risk because people will always take risks.

All participants understood that there is no vaccine for HIV. They were aware that treatment and medicine for the disease can be expensive. The group was distrustful of private pharmaceutical companies creating a cure for AIDS; as one individual put it, “[I]t’s more profitable to have AIDS than to not have AIDS.”

Participants discussed the stigma associated with HIV/AIDS and unlike the other groups did not stress the idea of risky behavior as much. As one participant said, “I mean, it could be a bad choice. You just choose the wrong person and you make a bad choice to be with that person. It’s bad luck that you met the person. It’s a bad choice to be with that person.” And through discussion, participants revealed that they contribute to this stigma to some degree. For example,

most thought that people with HIV shouldn't be allowed to work in the food service industry, with one man saying, "I just feel like it's a greater risk if you're involved with chopping and anything else, and just anything that could potentially do bodily harm to you." They also believed that dentists who are HIV-positive should disclose their status.

The group mentioned that HIV-positive individuals would have a hard time getting a job, even though they say it's illegal to discriminate on these grounds. They also admitted that HIV-positive individuals have a hard time with romantic relationships and that it may strain family relations. As one woman said, "[N]ot everybody has that support from their family. Not everybody can go and get tested and have AIDS and go home and say, 'Look, I got tested and I have AIDS, and you're my family and I want you to stand by me.'"

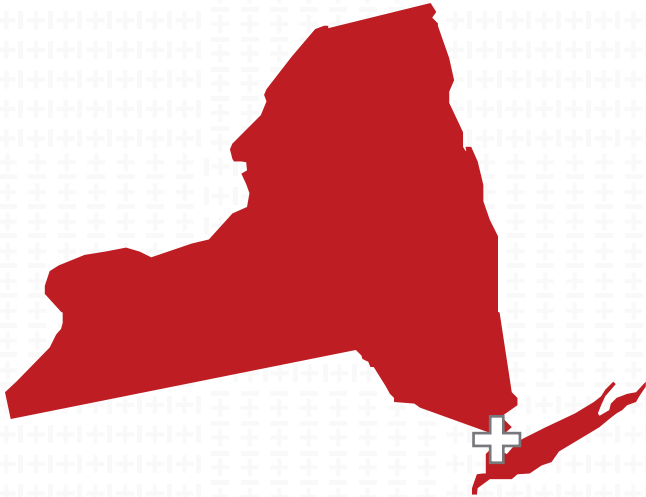
Furthermore, they discussed how it is hard to care for children, and some claimed that HIV-positive people must avoid contact with other sick people to avoid becoming very sick themselves. As one woman put it, "If I have a cold, I can't go hang out with my girlfriend, because she can get sick and it'll hurt her more than it hurts me. You have to maintain a distance between people that are sick."

Widespread condom distribution was mentioned as a solution to the problem, along with education. Participants mentioned that condom use could be problematic, though, because not everyone uses them or they are sometimes embarrassed to ask for them. The efficacy of education is undermined by young people not taking the education seriously and the fact that sexual activity is becoming prevalent among younger and younger age groups, so education may be too late. When it comes to education, the group dismissed TV campaigns as ineffective because it is too easy to ignore them and DVR devices make advertising less effective. As one man said, "You'll [still] probably hook up with someone who, 'All right, this person looks healthy, I'm not going to wear a condom.'"

Participants said that social services such as free testing and free medicine should be available for those who need it. Ultimately, however, some in the group saw treatment as a personal responsibility, believing that there are some who can't be helped. There was some ambivalence over whether or not the ultimate blame for the disease falls on individuals. Some definitely felt this way, while others put the blame on poor availability of condoms and ineffective education.



Community Characteristics



Tarrytown, New York

Population: 11,090

State population: 18,976,457

Median age: 37

Race/ethnicity:

77% white, 8% black, 16% Hispanic, 7% Asian

Annual HIV cases reported (New York State): 5,197

Persons living with AIDS (New York State): 75,253

Federal funding (New York State):

\$493,058,849

Despite being the most highly educated group included in this project, these participants—all parents of children college age or younger in Westchester County, a suburb of New York City—demonstrated a very mixed knowledge of HIV. Some people were fairly educated and vocal about what they knew, but others were clearly guessing as to how HIV is transmitted and treated. A few participants said that their age and lack of contact with the disease meant that they were drawing on their knowledge from the 1980s. “I graduated in ‘89,” said one man, “so I’m 37, and at that time no one really knew exactly what it really was yet, so because of that, I don’t have the knowledge.” At the end of the focus group, many participants actually admitted that they did not know as much about HIV/AIDS as they had originally thought and expressed a strong desire to better educate themselves and their children. “It goes back

to really letting people know how you can and how you cannot get the disease,” said one participant. “I think it’s a pretty educated group here, just because of where we all live, and yet we couldn’t all agree on just about every question.”

As with other groups, participants in Westchester displayed anxiety about the transmission of HIV, with one man saying that an HIV-positive employee would need to “give me the respect to tell me you are positive,” suggesting that if the employee gets AIDS and dies, he’d be leaving behind his family. Another participant, who is an elementary school physical education teacher, felt conflicted about giving CPR to one of his students who is HIV-positive should she need it. “What am I supposed to do?” he wondered. “This girl has done nothing wrong...she got HIV from her

parents.” Despite expressing their own fears about people with HIV, all participants thought that people with HIV are discriminated against, and they had a lengthy discussion on how to best serve the mental health needs of those with HIV. “I think there should be lots more locations [of support groups],” said one woman. She advocated for more choices as to where patients could get help after other participants pointed out that people with HIV may face discrimination if their neighbors “catch” them attending local support groups.

Like the participants in other groups, participants in Westchester County favored education and vaccine research as primary strategies for combating HIV/AIDS. Unlike the other participants, however, they were actually able to resolve a tension that came up during a discussion about education. One participant said that educating children about HIV was not sufficient, because poor self-worth, especially in young girls of color, inhibits decision making in sexual relationships, and she insisted that parents need to foster better self-esteem in their children. However, another participant pointed out that poor self-esteem works in a vicious cycle, where a parent feels no self-worth and passes on that feeling to his or her children. This problem was settled toward the end of the forum, with one participant saying that any role model in a child’s life—a coach, a teacher, a minister—could provide this emotional support for children and break the cycle of feeling worthless.



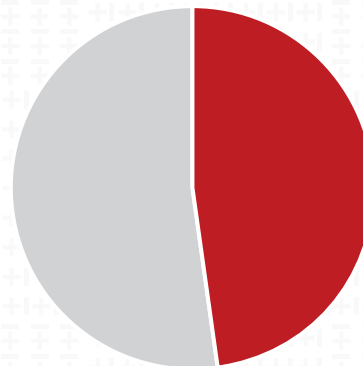
African-Americans participated in each of our focus groups. Regardless of location, virtually all of the African-Americans we spoke with had a heightened awareness of HIV compared with the other participants. In most of the groups, the African-Americans were among the most active participants and generally volunteered their thoughts early in the discussion. Every African-American except for one identified HIV/AIDS as the most important health problem facing the world, and they reported seeing advertisements about HIV when others in the group thought media attention had all but disappeared. A participant from Los Angeles said, "I still see advertisements. You guys might not see them. I see them. They might not be as prevalent as they used to be 10, 5 years ago, but they still have them." Additionally, any time we asked about the rate of HIV increasing or decreasing, most of the African-Americans believed that the rate was increasing.

Their heightened awareness of HIV was emphasized by the fact that they were aware of the increased incidence of HIV within their own group. Every African-American except for one knew someone either with HIV or who had died of AIDS, and in almost every group, they were able to identify African-Americans as a group at higher risk for HIV. As a male in the New York City group put it, "I meet people every day that they either lost somebody close to them or somebody they know died from AIDS." And a woman in Des Moines said, "I know that in African-American females, that number has raised significantly in the last couple years... It is going up in that population exponentially."

Interestingly, while the participants we spoke with were more aware of the increased incidence of HIV in their community, there were more statements from the African-Americans that indicate HIV is still seen as a gay disease. A woman in Westchester put it this way: "[F]or men [on finding out someone is HIV-positive], the first question is, 'Is he gay?'... You know—he doesn't have to be gay."

Community Characteristics

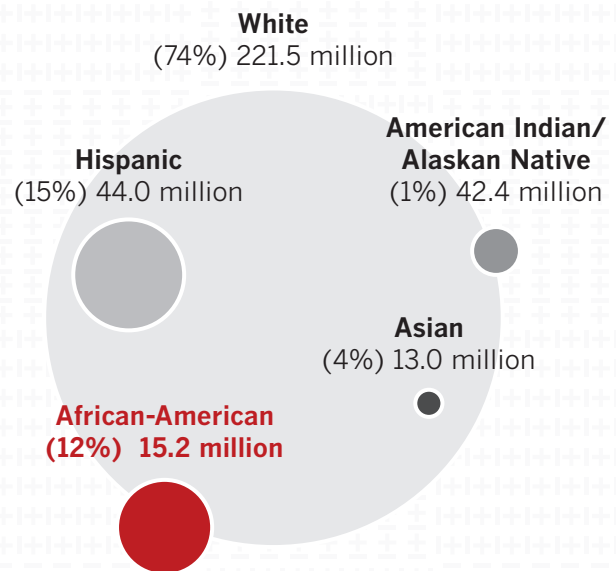
In 2005 37,331 people were diagnosed with HIV/AIDS



49% of those diagnosed with HIV/AIDS were African-American

Source: "Fact Sheet: HIV/AIDS Among African Americans," Centers for Disease Control, revised August 2008.

Total U.S. population 298.8 million



African-Americans comprise only 12 percent of the U.S. population

Source: U.S. Census Bureau, 2005-2007 American Community Survey.

While the African-Americans in each group offered more information about HIV/AIDS and often were the first to answer our questions—such as those asking about the difference between HIV and AIDS or details about HIV medication—like other participants, they sometimes overstated risks about HIV and had other misconceptions of the disease. In the Los Angeles group, both African-Americans said that we still “have a lot to learn” about how HIV is transmitted. Both thought one could get HIV from kissing, and one thought that HIV could be transmitted through sweat. Two African-Americans in the New York group were opposed to the idea of HIV-positive people working in food service.

The African-Americans we spoke with had similar views as the others in the focus groups on how to address HIV/AIDS. Like most other participants, they favored education and research toward a vaccine. And as with others we spoke with, there was no consensus on other proposals, with many participants thinking of these ideas for what seemed to be the first time.



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