

AZDHS

# **African American HIV Research**

## Final Report

Research: April-September 2018

Report: September 2018

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# 1

## Research overview

Goals, tactics and methodology

# Research Goals

1. Gain a greater understanding of attitudes toward, and awareness of, HIV and safe sex among members of the African American community in Arizona
2. Identify differences between the Arizona and national audiences
3. Determine which insights are most compelling for behavior change.

# Research Tactics



## National Web Survey

275 total participants

186 AA adults, ages 16-45 (186  
MSM, 89 females)

Partnered with YouGov and  
Nielsen

## National Online Bulletin Board

19 select participants from web  
survey

AA adults, 17-43

8 MSM, 11 females (lesbian - 3,  
bisexual - 4, heterosexual - 4)

Private online forum in which  
users share information, ideas,  
opinions

## Arizona Combined Study

112 total participants

AA adults, ages 15-45 living in  
Arizona

27 males, 83 females (lesbian /  
bisexual - 50, heterosexual - 33),  
2 trans individuals

Web survey using panel partner

## Arizona 1 on 1 Interviews

21 total participants

African American, LGBTQ+  
and hetero adults, 20-56

Arizona residents

Interviews conducted in  
person and over the phone

# 2

## Web-based Research

Insights from national web survey, bulletin board and AZ-based web survey

## Insights:

# National Web Survey and Bulletin Board

- This audience knows the basics but there are still inroads to be made
- Stigma plays a huge role in the conversation
- This community faces several barriers to testing
- Great insecurity about the support from family, friends in the event of a positive result
- Low awareness of community programs and resources
- Growing sense of complacency amongst AA MSM



# This audience knows **the basics**

- Majority confirmed understanding of HIV / AIDS - how HIV is contracted, benefits of knowing your status, early detection, treatment efficacy and risk factors
- Uncertainty around the meaning of a negative test result
- Some confusion around the effects of being HIV positive on life expectancy and affordability of treatment

**Takeaway:** This community still believes myths about HIV.

*“I know it's a badass virus that mucks up your immune system, making you vulnerable to other diseases. It is transmitted through exchange of blood, semen, vaginal fluid, and other bodily fluids. **It usually results in death, unless you can afford expensive anti-retroviral treatment like Magic Johnson is able to afford.**”*

# Stigma plays a huge role

- Participants express that the AA community is impacted by “stigma, fear, discrimination and homophobia” due to:
  - Church-centric culture where homosexuality is forbidden
  - Cultural mores that suggest that black men must be strong in every way, and that being gay is weak
- The majority of respondents of both genders said they would be ashamed if they received a positive test result
- More than 50% of women said they’d be uncomfortable dating someone who is HIV positive

**Takeaway:** Stigma is barrier to proactive testing and treatment.

*“Homosexuality is negatively regarded as **abnormal behavior and strictly unacceptable** in the African American community. Living an openly gay lifestyle can cause your family to disown you and your community to shun you. **Your treating (sic) is similar to that of someone with a deadly disease.**”*

## Support is Questioned

- Significantly more MSM than women feel they would have the support of their spouse / family if they were to test positive for HIV
- 52% of men strongly agree compared to 36% of LGBT women and 30% of heterosexual women

**Takeaway:** Fear of losing support could be a huge barrier to getting tested or sharing status.

*“Being homosexual in the African American community is forbidden. The fear of being openly gay in the African American LGBTQ community **can cause you to lose everything from friends to jobs.** The stigma of being gay will also keep you blackballed from certain areas in your family and the African American community.”*

## Unaware of **community resources**

- Fewer than 4 in 10 of those surveyed are aware of local programs or activities aimed at preventing the spread of HIV
- 1 in 7 have accessed these programs (and, by association, information and education about HIV / AIDS)
- Face-to-face is the most preferred means of receiving information about HIV/AIDS

**Takeaway:** Lack of awareness of local resources creates feelings of isolation and contributes to lack of proactive testing and action.

## Growing sense of complacency

- Majority agreed with the statement “studies find there is a growing sense of complacency among AA MSM.” Causes cited include:
  - Feeling of entitlement to engage in risky sexual activity such as unprotected sex, or “stealthiness”
  - Feeling of being protected now that there are preventative treatments such as PrEP
  - AIDS no longer being a “death sentence” (those who are younger in the LGBTQ community never witnessed firsthand the devastating effects of the disease.

**Takeaway:** Campaign must account for these obstacles that likely prevent a proactive approach to prevention, testing or treatment.



*“Black men **don't think it's as big a deal anymore** because HIV/AIDS isn't regarded as the epidemic it once was. I can count on my fingers and toes all the times I've heard, “But Magic Johnson's had it forever and he's good.” **They see this unique example as the face of HIV in the black community and don't see the reality of the disease.**”*

*“Some of them are **looking for HIV infected men to give them HIV.**”*

*“...they feel like they **can now have risky sex and not worry about dying** if they get AIDS.”*

*“I think this could be true to some degree and maybe this **applies more to the younger African American male population as the older generation has seen the devastating effects** of what this disease can do.”*

# Advice from participants is to **combat stigma, promote education**

*“Erase the shame & stigma.”*

*“I would say that testing is protecting yourself and others.”*

*“The key message is there's power in knowledge and no one should be ashamed for wanting to know more about sex. Normalize it.”*

*“Let's separate fantasy from reality or ‘This is the truth’ or ‘Let me show you what happens’ or ‘Here are the statistics’.”*

*“Knowledge is the start - get tested!”*

*I would say ‘testing is caring.’”*

# 3

## Arizona vs National

Major insights from AZ-based web study

# Arizona web study at a glance

<b>Consistencies with National Study</b>	<b>AZ- Specific Findings</b>
<ul style="list-style-type: none"><li>- This audience is knowledgeable, but in need of further education</li><li>- Stigma is rampant</li><li>- Complacency related to “no longer being a death sentence”</li><li>- Testing habits are reactive instead of proactive</li></ul>	<ul style="list-style-type: none"><li>- Significantly less likely to see benefits of early detection and treatment</li><li>- More likely to connect being HIV positive with promiscuity</li><li>- AA MSM much less likely to feel they would receive support if they tested HIV positive</li><li>- More stigma associated with detecting someone’s status by outward appearances</li></ul>

# Opportunity to **advance knowledge**

- Consistent with national studies, Arizona LGBTQ and AA heterosexual women seem to have a base of knowledge about HIV and testing
- However, fewer AA Arizonans:
  - Disagree with the statement “you can tell by looking at someone if he / she is HIV positive” – 58% in AZ disagree and 76% nationally disagree
    - Males less likely to strongly disagree with this statement than females (37% and 65%, respectively)
  - Disagree with the statement that HIV positive people are promiscuous than nationally – 23% and 36%

**Takeaway:** There is still progress to be made in getting accurate information to the population, debunking myths, and removing stigma.

## Benefits of early detection **less clear**

- While 7 in 10 see the benefit in early detection and treatment, strong agreement with this statement is significantly less among Arizonans than it is nationally - 38% compared to 58% - indicating that the benefits are less understood
- 1 in 4 AA LGBT confess to not having been tested
  - Those not tested say they're not likely to have HIV / STDs
  - Consistent with national data

**Takeaway:** The benefits of early detection must be articulated and publicized in order to encourage regular testing.

## Knowledge differs **by gender**

- Males are more likely to strongly agree that if a person receives a negative HIV test result, they never need to be tested again – 15% of males, compared to 1% of females
- Men are more likely than women to strongly disagree that people who are HIV positive are promiscuous – 4% and 30%, respectively
- 6 in 10 males strongly agree that early and consistent treatment can lead to live a normal life span (30% of females strongly agree)

**Takeaway:** The benefits of early detection must be articulated and publicized in order to encourage regular testing.

# Barriers to getting tested in Arizona

- Issues with accessibility and affordability of healthcare
- Embarrassment and fear of both testing and a positive result
  - Several emotions associated with testing and HIV including guilt, denial, anxiety, and the fear of being judged
- Lack of education / knowledge
- Key messages that participants feel would increase testing:
  - Focusing on not being afraid / knowledge is power
  - Confidentiality
  - Benefits of early detection / statistics on incidence

**Takeaway:** Messaging must take into account that additional actual and perceived barriers need to be overcome to encourage testing.



## Low awareness of local resources

- Just one-quarter (27%) of Arizona AA LGBTQ are aware of local programs or activities that aim to prevent the spread of HIV
- Fewer than half of those aware (40%) have accessed these resources
  - Some of the organizations named include: Planned Parenthood, local health departments, and Gay Pride events

**Takeaway:** Making this community more aware of the resources available to them can play a significant role in combating fear, barriers to testing.

## Summary: AZ vs National

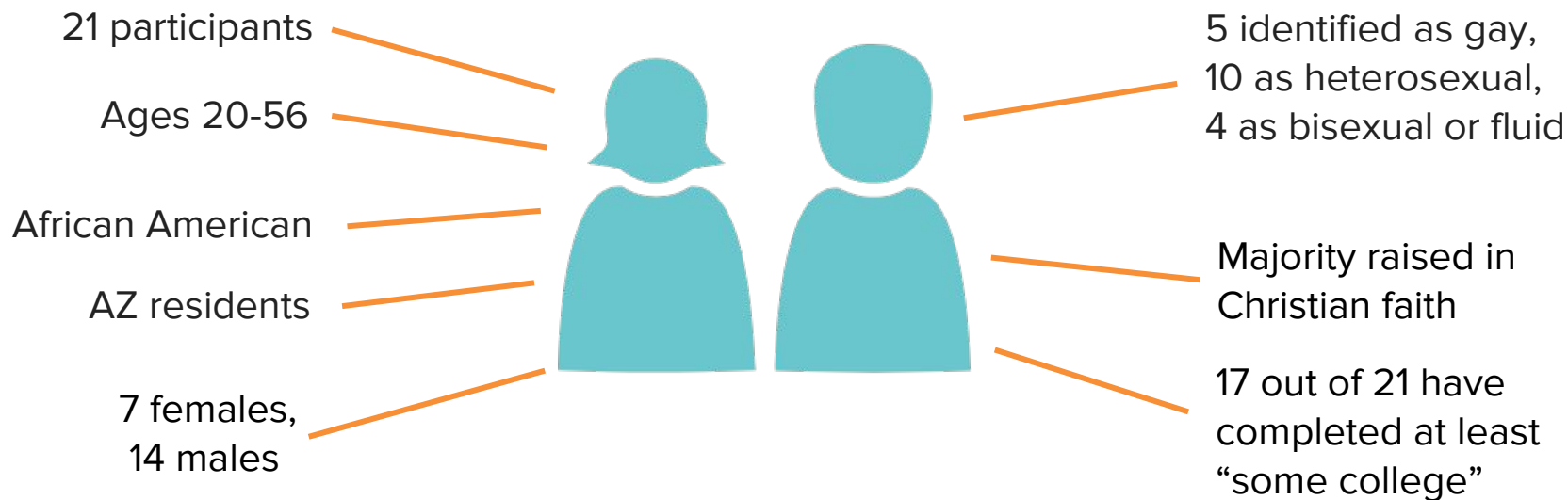
- The findings from the Arizona and national studies are very similar with a few exceptions:
  - Data indicates the AA LGBTQ community in Arizona is slightly less knowledgeable about the topic and perhaps feel more discrimination because they are black in a state with an AA population of less than 4%
  - Arizona AA MSM are significantly less likely to feel they would have the support from their spouse/partner/family
  - This, combined with the embarrassment and fear of both testing and a positive result, contribute to one in four who admit to not being tested

# 4

## One-on-One Interviews

Insights from the local African American community

# Participants at a Glance



## Not aware of HIV's impact on the African American community

- Most participants exhibited a “basic understanding” of HIV / AIDS (definition, transmission methods, etc.)
- Awareness of the incidence in the African American community was only indicated in 3 responses
  - *“It is killing us (more) rapidly than any disease in the world”*
  - *“I know that our people meaning African-American people mainly and even some Hispanic, Latin, races are probably the highest rated.”*

**Takeaway:** Opportunity to highlight impact on this community and energize around personal impact.

## Religion plays a huge role in both healthcare and stigma around HIV

- Friends and family knew sexual preferences in every case of MSM
  - *“I have an aunt that's accepting, but I have an aunt that's very religious that doesn't...When it comes to my sexuality and her religious beliefs, my aunt believes that I... should be disowned.”*
- All but 2 respondents agreed that faith influences their conversations about health care within their families

**Takeaway:** It cannot be understated how big a role religion plays in the African American community.

*“If you do this outside of marriage **you're going to go to hell**. The people who were out having sex out of wedlock and doing this and doing that, they are already done. **If they caught AIDS, that was God punishing them basically.**”*

*“Some of my family members are kind of in denial (about their health) so they don't want to go and see about their health, they'll just say, "I'm okay. **We're Christians so God will take care of me.**" stuff like that.”*

*“I think sometimes our families tend to be like, **'I'm just going to pray. I'm not going to the doctor.'**”*

## Low awareness of **community resources**

- Confusion around “who the authority on HIV” really is
- Only 6 of the participants could name a local community program or partner
  - Ex: McDowell Clinic, Area Agency on Aging, Aunt Rita’s, CDC

**Takeaway:** Drawing attention for local resources should be a primary focus to distributing information and providing prevention and care.



## Limited understanding of prevention methods

- When asked about prevention methods, most respondents named abstinence, condoms, or not having multiple partners
  - Only 5 participants said PrEP by name
- Some confusion around transmission
  - *“I know it's very hard if someone's positive or you're doing oral, more than likely you're not going to get HIV from that, it's very rare.”*
  - *“I would say be careful who you kiss since I was told it can be transmitted through saliva. Even be careful when using public bathrooms and having contact with blood.”*

**Takeaway:** There is a lot misinformation (or missing information). It is critical that an authority is established to spread knowledge.

## Testing is usually prompted by worry

- Almost all participants reported being tested as a cautionary reaction after an event or instance that caused them to “be worried”
  - Only 1 participant mentioned testing as part of a regular healthcare routine
- Over 50% of respondents reported being tested more than 12 months ago

**Takeaway:** By normalizing testing, encourage community to make it part of a routine health check up.

## Mixed feelings about complacency

- Over 4 in 10 are unsure whether there is a growing sense of complacency in AZ around HIV among African American MSM
- Those who agreed attribute the complacency to:
  - The belief that Arizona does not support the gay community in general, so people are afraid to come out
  - People feel like they are invincible, so do not use protection
  - HIV “does not equate to death”

**Takeaway:** While not as prevalent as in the national study, it’s important to get “ahead” of complacency before it becomes the norm in Arizona.

## Preferred communication: **social, in-person**

- Active on social media:
  - Facebook: 76%
  - Instagram: 52%
  - Snapchat: 28%
- Best ways to reach AA community with info on HIV:
  - Besides social media, events were mentioned most often as the best platform for reaching the community

**Takeaway:** As with most audiences, social should be a key piece of any campaign media mix. Partnering with local orgs for events also presents a big opportunity.

## Interview anecdotes **worth noting**

- It's possible that men are less likely to go to the doctor than women as a function of masculinity:
  - *“My mom and my sisters are more open about their health, my health, my brothers, they all talk about their health a lot. My dad is one of the **traditional black men who doesn't like to go to the doctors.** [laughs] He feels like he's fine as long as he wakes up feeling fine then he's fine.”*
- Drug use was mentioned in several responses about how participants learned about HIV (i.e. “I know people that used drugs and contracted HIV.”)

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## Takeaways

Insights from looking at the full body of research

# Major Concepts

## Fact vs. Fiction



This audience has a basic understanding of what HIV is, but lacks factual knowledge on contraction, prevention and treatment.

## Prevention Education



Need to promote the benefits of early detection, accessibility, confidentiality and methods of prevention like PrEP.

## Stigma + Religion



Shame, fear and feelings of “going against God” create unique and significant barriers to taking positive action.

## Gender Differences



Men and women have attitudes that differ, specifically around causes of HIV, the need to get tested and stigma.

## No Authority



Low awareness of community resources and confusion around where to get treated, education, etc.

## Combat Complacency



Need to ensure that empowering messages about the power of treatment don't water down the importance of prevention.

# 6

## Appendix



# Executive Summary: Nat'l Web Survey

African American adults (ages 16 to 45) are most likely to learn about HIV and AIDS at school, online and at health centers. Two-thirds of those interviewed have learned about the virus and condition through school, with slightly fewer learning through online sources and at health centers / doctors' offices. Men are more likely than women to learn about HIV and AIDS online, through their spouse/partner, on dating apps or from sexual partners. Facebook and Google are the most frequently mentioned online sources.

Other popular sources among both genders include TV, friends, community organizations and magazines / newspapers.

This audience knows “the basics” about HIV. A strong majority (three-quarters or more) of all participants strongly agreed that there is personal benefit in knowing your HIV status.

There is widespread understanding among all participants that early detection and treatment can result in a long, healthy life and that having more sexual partners increases the risks of becoming HIV positive. More than half strongly agreed and more than eight in ten agreed in total (strongly + somewhat) with these statements.

Additionally, participants widely disagreed with the statement regarding a negative HIV test result means that person never needs to be tested again.

# Executive Summary: Nat'l Web Survey

However, there is some uncertainty over the statement “despite a negative test result, a person could still be HIV positive.” Approximately one third of survey respondents had no opinion or actually disagreed with this statement. More education on the specifics of what a negative test means may be warranted.

The genders disagree on statements related to support and judgment. Significantly more African American LGBT men than women:

- are comfortable dating someone who is HIV positive (50% of men agreed vs. 22% of women, and just 9% of heterosexual women).
- feel they would have the support of their spouse / family if they were to test positive for HIV (52% of men strongly agree vs. 36% of women, and 30% of heterosexual females).
- disagree that they'd feel ashamed if they tested positive for HIV (19% of men strongly disagreed vs. 9% of women, and 6% of heterosexual women).

However, it's important to note that the flip side of these statements also carry insight:

- While 50% of African American LGBT men are comfortable dating someone who is HIV positive
- 27% are not comfortable with this.
- While men are less likely than women to feel ashamed if they tested positive for HIV – still 55% of AA LGBT men would feel ashamed.

## Executive Summary: Bulletin Board

Participants feel that African Americans may be impacted by “stigma, fear, discrimination and homophobia” to a greater extent than other ethnic groups for several reasons, including: 1) the perception that discrimination against African Americans is more pronounced than for other races, 2) the church-centric culture, which has taught that homosexuality is forbidden, and, 3) the African American mores that suggest that black men must be strong in every way, and that being gay is weak.

For the most part, participants agree there is a growing sense of complacency around HIV among African American men who have sex with men. Reasons for this include the belief that being HIV positive and / or having AIDS is no longer a death sentence, the lack of awareness of the devastating effects of AIDs, or the feeling of being protected now that there are preventative treatments such as PrEP. A few suggested some gay African American men feel ‘entitled’ to having unprotected sex with each other.

Participants feel that African American women and men who have sex with men have been hit hard by HIV because men (more than women) are engaging in risky behavior and not communicating with their partners due to their unwillingness to show their true selves. At the root of this, many feel is the lack of education due to lower socio-economic status and distrust of medical institutions. In addition, a couple of female participants offered that some AA women are afraid to confront their male partners for fear of losing them.

# Executive Summary: **Bulletin Board**

A lack of resources and emotional backlash were cited as the top barriers to getting tested. Privacy is also a concern to this community, likely due to the severe stigma and fear surrounding homosexuality in the African American community.

While schools and parents were suggested most often, many feel educating the AA community about HIV and AIDS needs to come from multiple sources, including health clinics, the media, the government, and even churches.

Participants are most likely to start with online resources to learn about treatment and prevention options, but they trust in-person healthcare sources most.

Suggestions for encouraging testing included: making it a part of regular medical check-ups before entering high school, providing home testing to mitigate the privacy concerns, and having testing events at various locations. A few suggested offering incentives for testing, such as gift cards or drawings.

Messages that participants feel are key to impart in a campaign to increase testing include focusing on benefits, facts, protecting the community, and reducing stigma.

Those participants who are African American and a part of the LGBTQ community, largely, do not wish to separate the two identities. “They intersect with each other.”

## Executive Summary: AZ Web Study

African American adults (ages 15 to 45) are most likely to learn about HIV and AIDS at school, at health centers and online. Over seven in ten reported learning about the condition / disease through each of these methods. Men are more likely than women to learn about HIV and AIDS online, on TV, through friends and on a dating app, while women are more likely than men to have learned about the condition in school and through family members.

Consistent with the national study, this audience knows “the basics” about HIV. A strong majority of study respondents agree there is personal benefit in knowing your HIV status and that having more sexual partners increases the risk of becoming HIV positive. Additionally, participants widely disagreed with the statement a negative HIV test result means that person never needs to be tested again.

While seven in ten see a strong benefit in early detection and treatment, which they understand can result in the individual living a near normal lifespan, strong agreement with this statement is significantly less among Arizonans than it is nationally - 38% compared to 58%.

## Executive Summary: AZ Web Study

There are two other notable differences when comparing Arizona and national data: Fewer Arizona African Americans disagree with the statement people who are HIV positive are promiscuous than nationally – 23% of Arizona respondents disagree compared to 36% of respondents nationally. (Though this suggests that Arizonan LGBTQ are more likely to agree people who are HIV positive are promiscuous, the agreement data are not statistically significant. Strongly agree + agree: national = 12%, Arizona =19%).

Similarly, fewer Arizonans disagree that you can tell by looking at someone if he / she is HIV positive than the national audience – 58% and 76%, respectively. Again, though this suggests Arizona African American LGBTQ are more likely to agree with the statement, the data do not show statistically significant differences in agreement, only disagreement. (Strongly agree + agree: national = 9%, Arizona =13%).

# Executive Summary: AZ Web Study

The genders disagree on statements related to support and perceptions.

- Heterosexual females were most likely to strongly agree they would have support from their spouse / family if they were to test positive for HIV (52%) with lesbian / bisexual females following (38%).
- Males were least likely to strongly agree their spouse / family would support them if they tested positive (22%).
- This is in contrast to the national study in which males were more likely to feel they would have support than women (52% of males strongly agree).
- Males are significantly more likely than females to strongly agree that if a person receives a negative HIV test result, that person does not ever need to be tested again – 15% of males strongly agree, compared to 1% of females.
- Men are significantly more likely than women to strongly disagree that people who are HIV positive are promiscuous – 4% and 30%, respectively.
- Six in ten males (59%) strongly agree that people living with HIV who start treatment early and remain on treatment, can expect to live a near normal life span. This is significantly higher than the 30% of females who strongly agree.

# Executive Summary: AZ Web Study

Three-quarters of respondents have been tested for HIV and / or other STDs. Among those who have been tested, most feel it is good practice and make it a part of their annual routine.

One in four African American LGBT in Arizona confess to not having been tested. Those who have not gotten tested say they're not likely to have HIV / STDs. This is consistent with national data.

The #1 practice to keep from getting HIV among African American LGBT men is to use condoms with all partners. Among women it's monogamy and using condoms with all partners.

One-quarter of the Arizona AA LGBTQ community are aware of local programs or activities aimed at preventing the spread of HIV. Four in ten of those aware have accessed a program. This means, in total, about 10% of those responding to the survey have accessed a program.

Among African Americans in Arizona, email is the preferred means of receiving information about HIV / AIDs (31%) followed by face-to-face (29%). This is different than what we saw in the national study, in which there was a strong preference for face-to-face communication. (Face-to-face=43%, email=21%).