

Experiences  
in HIV  
testing and  
health care  
in  
Philadelphia

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Young men who have  
sex with men

April 2015

## **Acknowledgements**

Special thanks to the Mazzoni Center, The Attic and Youth Health Empowerment Project for help with recruiting participants and for providing a location for the focus groups.

Extra special thanks to the alumni of the SWEAT Project for help developing the moderator's guide and designing this study.

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## Introduction

In recent years, reversing the incidence of HIV among young men who have sex with men (YMSM) ages 13-24 has become a priority of the Centers for Disease Control and Prevention (CDC) and local jurisdictions (Centers for Disease Control and Prevention, 2014). According to the CDC, the number of new infections among YMSM (aged 13-24) increased 22 percent, from 7,200 infections in 2008 to 8,800 in 2010 (Centers for Disease Control and Prevention, 2012). Stall, et al. (2009) estimate that HIV prevalence for 20 year old YMSM will be 25.4% by the time they reach the age of 30, 41.4% at age 40, and 54% at age 50. For African American YMSM, the model predictions are even more dire: 59.3% BMSM will be HIV-positive by age 40 (Stall, et al., 2009).

Black men who have sex with men (BMSM) bear a disproportionate burden of the HIV/AIDS epidemic in the U.S, particularly young BMSM. BMSM are the only group within the black community with increasing numbers of infections. Black gay men make up 0.2% of the U.S. population and make up approximately 25% of the new HIV infections each year (amfAR, 2015).

As of 2012, Philadelphia had an HIV incidence rate three times the national estimated average. The majority of new infections are among men, non-Hispanic blacks, persons aged 25-44, and MSM. Youth aged 13-24 accounted for one-third of estimated new infections in 2012. This is a 69% increase in the number of estimated new infections among youth between 2006 and 2012, largely due to the new infections in young, black MSM. Based on the estimated size of at-risk populations, MSM in Philadelphia are acquiring HIV at a disturbingly high rate; an estimated 1.2% of MSM in

Philadelphia acquired HIV in 2012. This increase is driven by new infections in 13-24 year old African American MSM. As of December 31, 2013 there were 367 living AIDS cases and 876 living HIV cases among youth aged 13 to 24. Compared to Latino YMSM (5.2%) and white YMSM (1.1%), black YMSM have a significantly greater HIV prevalence of 12.5% (Philadelphia Dept. of Public Health/AIDS Activities Coordinating Office HIV Incidence Surveillance Program and Philadelphia eHARS data, 2014).

In addition to high prevalence rates among young people, Philadelphia is experiencing high rates of sexual risk among youth. According to the 2013 Youth Risk Behavior Survey (YRBS), 22% of sexually active students had sexual intercourse with 4 or more people in their lifetime. Forty-two percent of sexually active students did not use a condom at the time of last sexual intercourse. Eighteen percent of students report never having been taught about HIV/AIDS in school. Almost one-quarter of sexually active students reported using drugs or alcohol before the last sexual intercourse (Centers for Disease Control and Prevention, 2013). However, there are some indications that risk trends are improving, as STD cases in adolescents and young adults decreased between 2010 and 2013 (PDPH, 2014).

Public health messages about HIV testing are reaching YMSM in Philadelphia. According to the 2011 National HIV Behavioral Surveillance (NHBS), 91% of the 18-24 year old MSM and 82% of 25-34 year old MSM were tested for HIV in the last 12 months. Testing for sexually transmitted infection (STI) was not as common, only 40% of the 18-24 year olds reported any STI screenings in the previous 12 months. However, 8% of the YMSM reported having had

an STI in the past 12 months (Philadelphia Department of Public Health/AIDS Activities Coordinating Office).

It is not because of risk behaviors alone that YMSM, particularly black YMSM, face high risk of acquiring HIV and other sexually transmitted infections. Rather, the high prevalence of HIV and other STIs within the YMSM, youth, black and MSM populations and structural barriers like low income and lack of health insurance increase the chance that YMSM will engage in risk behaviors and be exposed to HIV at the time of those risk behaviors (Dorell, et al., 2011, Millet, Flores, Peterson, & Bakeman, 2007). HIV incidence in the YMSM and MSM populations, especially in the black and Latino populations is due in a large part to the high prevalence of HIV within these populations. Having condom-less anal sex within the context of high HIV and STI prevalence means a greater risk of coming in contact with and acquiring HIV. In fact, black MSM report less substance use and fewer sex partners than white MSM (Millet, Flores, Peterson, & Bakeman, 2007). And yet an estimated 32% of black gay men are HIV-positive (amfAR, 2015). Black MSM are also more likely to report preventive behaviors than other MSM in the US. However, black MSM have two-fold greater odds of low income, previous incarceration, and other structural barriers that increase their HIV risk than other MSM (Millet, et al., 2012).

Dorell, et al. (2011) found that black YMSM were more likely to be HIV-positive if they lacked access to primary care, were uninsured, did not have counseling about HIV and sexually transmitted infections, and failed to disclose their sexuality to their healthcare provider. Of those factors, not having a primary care provider and not disclosing sexual identity to a

health care provider were independent risk factors for HIV infection for black MSM (Dorell, et al., 2011). Engaging YMSM in primary care, educating them about risk reduction strategies, and promoting good sexual health practices are important steps towards reducing HIV incidence.

In order to best serve the needs of YMSM, the HIV prevention system must address their complex social needs and their experiences as young black gay and bisexual men, and the intersection and interactions of those identities and the structural barriers that increase their HIV risk (Millet, et al., 2012, Mustanski, Newcomb, Du Bois, Garcia, & Grov, 2011, Malebranche, Peterson, Fullilove, & Stackhouse, 2004).

## Study Purpose

The Philadelphia HIV Prevention Planning Group (HPG) provides community feedback to the Philadelphia Department of Public Health's AIDS Activities Coordinating Office (AACO) HIV prevention policies and program/system planning. The HPG requested that the Office of HIV Planning conduct focus groups with YMSM (and other at-risk populations) in order to better target HIV testing and prevention services in culturally competent and accessible ways. Successful diagnosis and linkage to HIV

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*"...but at the end of the day you can always tell when somebody's trying to be ignorant or shady, for lack of a better word; just treating you the wrong way. I think that if they stop doing that more people would be willing to come to the doctor and go get their medicine...."*

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treatment requires meeting the medical, emotional, and social needs of individuals. The purpose of this study is to assess the individual-level, provider-level and system-level barriers experienced by YMSM in order to better understand how these barriers affect at-risk YMSM's use of healthcare and HIV testing and prevention services. The study findings will inform the Philadelphia Department of Public Health's planning and delivery of HIV prevention, testing, and treatment services.

## Methodology

The Office of HIV Planning (OHP) conducted three focus groups in June 2014 with young gay and bisexual men (and other men who have sex with men) at community-based organizations serving LGBTQ youth and young adults. OHP partnered with these organizations (Youth Health Empowerment Project, The Attic, and Mazzoni Center) to recruit participants for the focus groups to help facilitate trust between OHP and the young men. OHP worked with the CBOs to identify the best times to hold the focus groups on-site to maximize participation. Focus groups were held during drop-in sessions and other times in which young men participated in program activities. OHP staff recruited participants on-site at the time of the focus group with the assistance of CBO staff. Inclusion criteria were: residency in Philadelphia, identifying as a man who has sex with men, English proficiency, and age over 18. Minors will not be included in any of the focus groups within this study, because of the concerns with securing parental consent.

OHP staff developed the moderator's guide to focus on participants' experiences with health care in the last 12 months, knowledge of HIV testing sites, and vision of ideal health care

experiences. Questions about sexual behaviors, substance use, and other risk behaviors were purposely avoided. The investigators decided to focus on experiences in health care settings and with HIV testing, because the risk behaviors of YMSM are well documented and being explored through other local research. In addition, the purpose of this study is to inform the planning and provision of HIV testing and other prevention interventions for YMSM. Delivering these interventions where they will be most accessible and acceptable to YMSM is essential. The investigators designed the study to explore and identify the barriers and facilitators of health care access, in order to develop recommendations for the publicly funded HIV prevention system in Philadelphia.

OHP staff collaborated with the local investigators developing the National HIV Behavioral Surveillance pilot study of YMSM which was under development at the time of the design and implementation of this study. OHP staff worked with the NHBS investigators to include questions on access to care in those interviews; with the hope that further analysis and comparisons can be made upon the completion of both studies. YMSM under 18 were not included in this study because of concern of duplicating efforts with the NHBS pilot study, which targeted young men who have sex with men under 18.

All participants were asked to complete an 11 question anonymous survey at the conclusion of the discussions. The survey collected basic demographic data and HIV testing experience. Participants were free to refuse the survey.

During the focus groups, only first names or aliases were used. Digital audio recordings were made of the discussions and an outside

contractor produced verbatim transcripts. All names and personally-identifiable information were stripped from the transcripts. Transcripts were uploaded to and analyzed in NVIVO 10, qualitative data analysis software by OHP staff.

All study materials and protocols were submitted to and ruled to be exempt from full review by the Philadelphia Department of Public Health Institutional Review Board due to the nature of the study. All participants were given a \$20 CVS gift card, two SEPTA tokens, and a meal in appreciation of their participation.

## Characteristics and demographics of participants

All participants were asked to fill out an 11 question survey at the conclusion of the focus group discussion. All participants completed a survey, but everyone did not answer all the questions. In total, 27 men participated in the three focus groups, ranging in age from 18 to 33 years old. Twenty-three participants were between 18-25 years old. Four participants were over 25, but were considered part of the peer group of younger men. Twenty-two of the men identified as black/African American, four identified as bi- or multiracial and one as white. Three men were Hispanic. Educational attainment varied, with 10 participants finishing high school or acquiring a GED and another 10 completed some college courses. The other seven men had not completed high school (2), acquired a vocational or technical degree (2), or graduated college (3). One participant was staying at a shelter; all the others rented/owned their own apartment or house (16) or were staying with friends or family (8). The majority of participants (15) earned less

than \$10,000 a year. The rest earned between \$10,000 and \$39,999.

The participants represented a broad collection of zip codes, 17 zip codes in all. Most of the participants resided in high HIV prevalence zip codes. 19142 (3), 19144 (3), 19102 (2), 19132 (2), and 19147 (2) were the five most frequent zip codes.

The survey included a question about who the men were sexually and romantically attracted to. All respondents to this question reported attraction to males. Some others also reported attraction to females (4), transgender individuals (1) and gender queer individuals (2). Respondents could choose as many responses as appropriate.

Of the 27 participants, 25 reported ever being tested for HIV. Two respondents did not answer the question. The most popular answer for why they were tested for HIV was “Just to find out” (6). Other answers selected were “As a part of a routine medical checkup” (5), “No reason” (4), “I was at risk” (2), and “Partner suggested it” (2). Three respondents gave other answers which included getting tested because of the incentives offered and to acquire life insurance. Some of the participants disclosed their HIV-positive status within the discussions, but participants were not asked their HIV status by moderators or the survey.

## Theoretical Framework

The investigators developed this analysis based on the socio-ecological model in order to best highlight and consider the multi-level factors of influence on YMSM health care access. Human behavior has a social context. Young urban minority men who have sex with men must

negotiate a variety of barriers and influences/pressures when it comes to health care access and healthy sexual behaviors which include individual, interpersonal, community, institutional/health system, and structural factors. Any efforts to end the HIV epidemic must acknowledge and address the interaction and intersection of all of the levels of social, economic, political, interpersonal, and psychological factors impacting health behaviors of individuals (Kaufman, Cornish, Zimmerman, & Johnson, 2014). This study attempts to highlight some barriers and facilitators of healthcare access that YMSM experience in Philadelphia.

## Themes

Participants shared a range of experiences, points of view and opinions during the discussions. Even with all the variation in experience, several key themes emerged. Four of the six themes concern interactions with health care providers or access to services. Health insurance problems and lack of sexual health and HIV education reflect larger systemic barriers related to health literacy and access to appropriate information.

### Major themes:

- **Interaction with front office staff**
- **Accessibility of services**
- **Health insurance problems**
- **Lack of sexual health and HIV education**
- **Confidentiality**
- **Impact of Stigma on healthcare access**

### Interaction with Front Office Staff

Negative experiences with a front office staff member or a receptionist in a health care

setting were common. These included being ignored, shamed, and treated rudely. Three participants mentioned witnessing a receptionist or other staff member speak loudly about a patient's health status or insurance situation, including an incident at a community

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*"A lot of people don't have money for a co-pay in the way they expect for you to pay it upfront. Things like that. People don't have it. That's why people don't go to the doctor."*

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health center when a staff member chastised a young woman about her sexually transmitted infection in front of other patients. The young men did not think such behavior was respectful or professional. Almost universally, the young men shared that they had a good relationship with their doctor or nurse practitioner, based on mutual respect and trust. The vast majority of negative experiences of shame or rudeness occurred outside the exam room.

Waiting for long periods of time before seeing a doctor was mentioned frequently, for both "walk-in" appointments and scheduled appointments. The participants understood that there are valid reasons why doctors are late or they cannot be seen at their appointment time. Their complaints were with the ways the delays and waits were handled by office staff. Often they would not be told how long their wait would be or why the delay was occurring. Some of the men perceived that people with insurance or "good insurance" got seen before they did, even when they had arrived before the other patients.

The thread that ran through all the conversations about the front of office staff was

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*“You know how you get certain hospitals that are in the ghetto. And you got certain departments or representatives that are ghetto-like?”*

*“Yeah like, 'You're in the ghetto. You don't count'”.*

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the need for common courtesy and proactive communication in interactions with patients. The participants perceived discrimination and lack of courtesy in many of their interactions with medical institutions. Most of the other nuisances and inconveniences of accessing healthcare were considered understandable or

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*“The better your insurance, the better care you going to get”*

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bearable, but being treated disrespectfully was considered a barrier to care by all three focus groups. Participants also shared some positive experiences and suggestions of how they would like to be treated by office staff. Suggestions included welcoming patients as soon as possible and informing them on how long they are likely to wait before being seen.

### **Accessibility of services**

Among the concerns about accessibility were the distance traveled to health care providers, appointment times, appointment setting processes, and walk-in hours and procedures. Transportation and distance concerns were the most often mentioned problem with accessibility, with issues related to appointment times or operating hours closely following in frequency. Transportation concerns were most

often mentioned in the context of having to travel far to receive services. For instance, a participant shared his experience of having to travel out to the suburbs to visit a specialist and then having to return for multiple visits. His challenge was not only the travel expense, but also the time it took to take public transportation to appointments. Other participants also talked about the burden of the time it takes to use public transportation to get to appointments. Patients may spend the better part of a day going to an appointment between travel time and the wait to see the provider. Primary care access is affected by limited transportation, reflecting the need for clinic locations in places YMSM can access easily.

Other participants were reluctant to receive services in their own communities and preferred to travel from their neighborhoods to Center City where they perceived more anonymity. Reasons mentioned for wanting to travel outside their neighborhoods included fear of a breach of confidentiality and the perception that care in their neighborhood was not high quality, or that it was “ghetto”.

Participants made the distinction between “ghetto” providers (hospitals, clinics, etc.) and those that they felt had good reputations and offered quality care. The geographic location of the organization did not necessarily dictate if it was “ghetto”, but attitude and professionalism of the staff surely did (see examples above). “Ghetto” providers included prominent institutions (including teaching hospitals) and small community-based organizations. The young men did not want to be associated with “ghetto” institutions.

Participants shared experiences of trying to attain services, including HIV testing, and being

frustrated by the hours of operation or the process for making an appointment. These frustrations included having to arrive (or call) early in the morning to attain a walk in appointment. The frustration stemmed from the process of having to call or show up first thing in the morning, having to take off from school or work, and not having a promise of an appointment. Other frustrations included not having the current hours of operation listed on the organization's website. A participant shared an experience of being sick and getting up extra early to get to the health center first thing to secure a walk-in appointment, only to find out that the health center was closed mornings on that particular day. The current hours were not posted on the health center's website. When the participants were asked to brainstorm about their ideal health care provider, many included that the organization would have evening hours, even as late as midnight to accommodate people who don't work traditional 9-to-5 schedules.

### **Health Insurance Challenges**

Participants mentioned a variety of challenges in understanding and using their health insurance. Most, if not all of the men were insured, often through guardians or parents. There were many questions about what happens as they age: when do they need to have their own insurance, how to get insurance, what type of coverage do they need, how to afford the premiums and co-pays, etc. Co-pays were the most often mentioned barrier to accessing medications and health care. There was confusion about when co-pays apply and how much they would be.

Confusion about out of pocket costs and coverage may prevent a young man from accessing a needed service or medication. For

instance, a participant described his experience of needing specialist care that was not fully covered by his health insurance. He explained that if the doctor's office had informed him of his co-pays and cost-sharing when he called to make the appointment he could have made a more informed decision about his care. Medication co-pays were often cited as barriers to medication adherence, not only for the participants but friends and family members as well. Even "nominal" co-pays of \$2 or \$3 could be a barrier, especially if someone had to pay for several medications at one time.

These focus groups occurred in June 2014, after the implementation of the Patient Protection and Affordable Care Act (2010). Participants stated that "Obamacare" didn't work for them or their family. Participants shared experiences of friends and family members who had problems signing up for insurance on [healthcare.gov](http://healthcare.gov) and the confusion caused by the lack of information on plans and out of pocket costs. Participants also believed that Obamacare didn't address the needs of poor people who couldn't afford the premiums and cost-sharing. These conversations happened before Pennsylvania expanded Medicaid eligibility to low income adults.

### **Sexual Health Education**

Most of the participants talked about a lack of sexual health education in their high schools. The few who received sexual health education described what was presented as either misinformation or information that did not meet their needs. Some stated that the "sex ed" given was focused on pregnancy prevention, and had little useful information to offer young gay and bisexual men. Some participants had

positive experiences in school, usually because a school-based Gay Straight Alliance (GSA) invited speakers or the school hosted afterschool activities that offered the opportunity to learn about sexual health issues. One participant said that his Catholic high school offered comprehensive sexual health information, including information on prevention of sexually transmitted infections. The experiences varied, but the majority of participants were not satisfied with the information presented at school.

The participants agreed that the information and services they received from LGBTQ-serving

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*“I think one thing is particular to African American men in general....African American men are not encouraged to seek healthcare. I can understand it, because my family—I have traces to the Tuskegee experiments. So going to the doctor was very looked down upon....And on the flip side of it, unfortunately, is a lot of the healthcare providers don’t really attend to the needs of the particular experiences that African American men go through.”*

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organizations, especially youth-focused organizations, met their current health information needs. They trusted the information they received and the people who advised them. The men were most trusting of medical professionals for sexual health information, especially about HIV and STIs.

During the discussion in one focus group, misunderstandings about HIV transmission came up. A participant believed that HIV could be transmitted by mosquitos, after another participant was sharing his previous beliefs

about HIV transmission. The other participants were well informed and explained why that was

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*“They pulled a lot of programs out of schools; especially in Philadelphia....They cut the sex education programs and also health classes.*

*And the nurses, the real nurses in Philadelphia schools got cut as well. So that’s probably why a lot of teens don’t know about where to get healthcare or get tested because there is like no outlet for them to get that information. A lot of parents are kind of scared to let them know, or don’t want to tell them about sex education or where to get tested, because then they feel like that’s a pass to do these things; but it’s really making sure your child is aware of the situation. I believe teens will do it anyway, have sex anyway, but you just want to let them know that you can be protected while doing it. A lot of parents are scared to even have that conversation with their kids.”*

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not true. The moderator allowed the group to correct misinformation, and then shared relevant clarifying information. Another misunderstanding concerned the scope of the HIV epidemic in Philadelphia: a participant thought 25% of the population was infected. Once it was apparent the others were not sure of the statistics, the moderator clarified that about 1% of Philadelphians were HIV-positive. So even though these young men are connected to organizations with HIV prevention and health education programs, there is still some misunderstanding and confusion among them

about HIV transmission and their risk of infection.

Overall, the participants were well informed about how and where to get HIV testing and other sexual health information and services. The participants had either sought out this information or had received it through participation in a group or program. Some participants used Google to find information on sexual health and healthcare services. This highlights the need to make sure that relevant healthcare and social services information is easily accessible to YMSM (and others) who feel most comfortable going online to find information.

### **Impact of Stigma on Access to Care**

Participants stressed the importance of healthcare providers treating them with care, courtesy and respect. Most of the young men felt that they received respectful care from their primary care providers. The participants expect their doctors and nurse practitioners to treat them respectfully and professionally. When they are not treated respectfully, they are unwilling to return to that individual provider for care, and feel shamed and stigmatized. From comments made about these different experiences, it's clear that professional behavior is desired from all members of an organization's staff, but rudeness is more generally expected (and tolerated) from front office staff.

Participants did not share much about their particular experiences as minority gay and bi men. One participant shared an experience with a female doctor (at a city health center) who did not appear to be comfortable talking about his sexual behaviors or his sexuality in general. He did not feel that this doctor gave him high quality care or treated him respectfully,

because she could not comfortably address his concerns and questions.

Participants' racial and ethnic identities were only mentioned or referred to a few times. The issues of pride and denial were mentioned when the conversation turned to why others might not access healthcare. The community norms that teach men, particularly black and Muslim men, that seeking healthcare is undesired or not a masculine behavior were mentioned a few times. The comments about these norms indicated seeking healthcare isn't desirable because it may indicate a lack of strength or ability to take care of oneself, and because seeking healthcare often means going outside the trusted community, in terms of race/ethnicity, geography, and culture. The

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*"...nowadays, a lot of our peers are testing us. Somebody that I know tested me, and I'm like, 'What if I test positive and then he'll know, because he knows basically everyone that I chill with and talk to.' People can't keep quiet..."*

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participants were more likely to mention the healthcare experiences of their mothers, grandmothers and sisters than the male family members.

### **Confidentiality**

Participants often mentioned a lack of privacy or confidentiality when speaking about healthcare organizations that they found undesirable or unprofessional. Examples of front office staff speaking about individual patient's information too loudly or in public spaces were shared, but the participants did not share any personal experiences with breaches

in confidentiality or privacy. Even without personal experience, confidentiality concerns are central for YMSM thinking about HIV or STD testing and healthcare services. Some organizations have a reputation among Philadelphia YMSM as not respecting patients' personal information or protecting their

privacy. Some organizations were considered undesirable in all three groups because of the perceived lack of professionalism of the staff. Even in the age of HIPAA, which the young men demonstrated an understanding of; there is still enough fear of stigma and general embarrassment about sexually transmitted diseases that the young men didn't want to take any chance that their personal business would be public, either through their peer networks or through family or neighborhood channels.

Young men were concerned that having peers test them, or even just work at organizations where they received HIV testing and prevention services, could leave them vulnerable to having their HIV status or other health information get out into the community. This fear of having a peer tell their social network about their HIV status or health information was a strong theme whenever the discussion turned to unacceptable HIV testing providers or bad experiences in healthcare settings. The group discussions made it clear that the YMSM understood how HIV stigma worked within their

## Unacceptable Testing Site Characteristics

- Bad reputation
- I know people who work there
- Unprofessional staff
- Testing in public settings

## Acceptable Testing Site Characteristics

- Healthcare provider
- LGBTQ-friendly organization
- Incentives offered
- Sexual health or HIV provider

communities and that it acts as a barrier to testing and HIV care services for many people, including their peers. They understood the purpose of having other young gay and bi men provide HIV outreach, education, and testing services but did not trust their peers to follow the rules. Medical professionals, especially primary care doctors, were mentioned as trusted sources of HIV testing services, sexual health information and STD screening.

### HIV Testing

Moderators asked the participants to name all the places they could get an HIV test. In all three groups, the participants quickly named many options for places to go for a test, including hospitals, community-based organizations, mobile units, AIDS service organizations, emergency departments, LGBTQ organizations, home tests, and primary care providers. It should be noted that all of the young men had some affiliation with LGBTQ organizations in Philadelphia, attending support groups, receiving medical care or other services at these places (they were recruited from these

sites). They appeared to be comfortable talking about HIV testing in general, and about their specific experiences. No one shared negative experiences with HIV testing, but they offered negative opinions and perceptions about some HIV testing providers.

From the group discussions, getting tested regularly was a common occurrence and expectation for their peer group. It is impossible to know how often the young men were tested because the survey only asked if they had ever tested and why. Two of the 27 participants did not answer the survey question about whether they had ever received a HIV test.

After the groups listed HIV testing providers, they were asked where they would and would not go to get an HIV test. The groups were consistent about where they would and wouldn't go and why. The two most popular reasons for not wanting to go to a particular testing site were lack of professionalism and concern about confidentiality. Trusted HIV testing sites were LGBTQ organizations and/or healthcare providers (including hospitals, clinics and primary care providers).

Participants held differing views about whether peers doing the outreach and/or testing was a barrier. As mentioned previously, some participants worried that a peer would be tempted to tell others about the testing results or even just tell others that they had visited a testing site. Other participants did not share the fear of a breach of confidentiality, and explained why having peers work in outreach and testing was a successful strategy to get young men to test. When the moderator pressed for examples of any experiences of breached confidentiality, no one gave a personal example. However, several of the men expressed that they were unwilling to take the

chance that their testing experience would become fodder for gossip.

One of the groups discussed how incentives are seen positively, not necessarily because of the incentive's monetary value, but because the incentive offered a "cover" to those seeking HIV or STI testing. For example, one participant explained he would say he was going to the mobile testing site to get a slice of pizza, if questioned by a friend or neighbor.

## Ideal Healthcare Setting

The moderators asked participants to describe their ideal healthcare setting including who would work there, what it would look like, where it would be, etc. Many of the participants offered detailed descriptions and thoughtful reasons why their clinic would have certain features. The most frequently mentioned characteristics of the ideal healthcare setting were diversity of staff, highly-qualified providers, and a feeling of acceptance and inclusion.

Characteristics of an ideal healthcare setting mentioned more than once included:

- **Free food and snacks**
- **Highly-trained professional staff**
- **Help with transportation**
- **Diverse staff**
- **Evening and weekend hours**
- **On-site access to medications**
- **Accessible location**
- **Friendly and polite staff**
- **Multiple services in one location**

The YMSM were sure to include spaces for other members of the community in their ideal settings, including childcare centers so parents

and caregivers can receive healthcare services. Many of the young men also mentioned accompanying their grandparents to hospitals and clinics, and so also considered the needs of older people in the designs of their imaginary healthcare setting, like snacks and on-site access to medications. There was a general emphasis that any healthcare setting should be accommodating to everyone and serve all with respect and care.

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*“It would be a convenient location. It would be super clean. It’ll be a fast-paced environment and it’ll be diverse in sexual orientation and ethnicity. I also feel like, it’ll be very polite, because nowadays people need that, especially sick people. They just need someone to be polite to them.”*

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## Discussion

This study indicates that the barriers to care experienced by YMSM in Philadelphia vary from the systemic and structural to the interpersonal. YMSM, especially minority YMSM, face a society that discriminates against them because of their race, age, sexual orientation and/or gender identity. Perceived stigma due to one’s sexual orientation (or other characteristics) involves heightened sensitivity to rejection that is marked by expectation of being treated as unequal (Meyer, 2003). This phenomenon can be seen in some of the experiences and opinions shared by the participants, especially when considering their stories of disrespect from providers.

Black MSM experience stigma and discrimination on many levels due to social

prejudices against black people, especially black men, and their sexual minority status. Black and other minority YMSM must navigate the healthcare system with all the other barriers experienced by the general population: lack of insurance or being underinsured, health illiteracy, transportation challenges, competing needs, other responsibilities, and any number of other barriers (Cheung, Wiler, Lowe, & Ginde, 2012). Anticipated or perceived discrimination adds another layer of stress, which may also prevent the individual from seeking or accessing care (Meyer, 2003). The internalization of these negative experiences impedes engagement in healthcare, HIV testing, and treatment adherence (Irvin, et al., 2014, Malebranche, Peterson, Fullilove, & Stackhouse, 2004).

When providing services to YMSM and other minority populations, one should be sensitive to the previous experiences of stigma and actively work to make individuals feel accepted and welcome; to see the person beyond the labels society has stuck to them (Hussen, et al., 2013, Malebranche, Peterson, Fullilove, & Stackhouse, 2004). Experiencing stigma from healthcare providers is associated with longer time lapses for last examination for both HIV-negative and HIV-positive MSM. However, it may be possible that having a trusting relationship with an individual healthcare provider may negate the impact of prior negative experiences with health care (Eaton, et al., 2015). As mentioned by this study’s participants, individuals may perceive discrimination based on characteristics outside of sexuality, gender or race/ethnicity. Income and insurance type are other reasons individuals give for perceived discrimination, however perception of discrimination is unlikely to account for the observed disparities in healthcare access and receipt of preventive

health services (Irvin, et al., 2014, Trivedi & Ayanian, 2006).

YMSM who do not receive relevant sexual health information may have limited understanding of how anal sex and other sexual behaviors affect their risk of HIV or other STIs. In the absence of health education young men may rely on older partners, information gained from the internet, and pornography for information related to risk (Kubicek, Beyer, Weiss, Iverson, & Kipke, 2010). Young men who are exposed to HIV-related information are

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*“I can only imagine how a person would feel if you’re trying to open yourself up to be that vulnerable, and someone just blatantly disrespects everything that you are, and everything that you just came for them to talk about.”*

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more likely to have positive beliefs about HIV testing and the perceived behavioral control to get tested. Knowledge about HIV does not correlate to intentions to get an HIV test; however, exposure to HIV-related information is directly associated with testing intentions. YMSM who are exposed to HIV-related information, whether they are knowledgeable about HIV or not, are more likely to get an HIV test (Meadowbrooke, Velnot, Loveluck, Hickok, & Bauermeister, 2014).

Public health programs often view individuals as a member of a "target population", rather than an individual. As one young man described, some safer sex messages feel stigmatizing to YMSM because they see their heterosexual peers engaging in unprotected sex and other risk behaviors, but they don't receive the same

messages. YMSM may perceive that their healthcare providers expect certain behaviors from them, regardless of what the individual men actually do. These expectations may feel stigmatizing; even if the providers intend to be inclusive and accepting.

Providing a safe space for young men to discuss their sexuality and well-being is essential to providing effective HIV prevention services to YMSM. Healthcare providers must prepare to have these conversations with YMSM, to assess

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*“A lot of places....they have issues in customer service. Where individuals who attend those locations are made to feel less than. They’re not greeted professionally. It’s usually based upon attitude. Even if a consumer is coming to them with attitude, they should be a little bit professional – to treat them as a client or consumer, as opposed to a buddy.”*

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their true risk for HIV and other STIs and then provide comprehensive care to meet those medical and social needs (Hussen, et al., 2013, Mustanski, Newcomb, Du Bois, Garcia, & Grov, 2011). Exactly how to create those safe spaces will vary depending on the individual healthcare provider and the context in which care is provided. Some YMSM prefer to talk to peers, whether that is other YMSM or a healthcare provider of their racial/ethnic group, or a provider who identifies as gay or bisexual.

The atmosphere and culture of the clinic, hospital or practice impacts the comfort level of YMSM. As the participants shared, they will not go where they do not feel welcome. A welcoming healthcare experience may include: snacks, comfortable waiting areas, easy

procedures for setting appointments, expanded office hours in the evening or on weekends, and open communication between office staff and patients on expected wait times and other matters that affect the patient experience (Cheung, Wiler, Lowe, & Ginde, 2012, Anderson, Barbara, & Feldman, 2007). Anderson et al. found that having an outstanding office staff was one of the core domains of healthcare associated with patient's perception of high quality healthcare. Traits related to high quality office staff included professionalism, friendliness, and being helpful (Anderson, Barbara, & Feldman, 2007). These characteristics are in keeping with the concerns and preferences of many patients of primary care. A positive interaction (partnership-building, facilitating rather than directing, friendly) with a doctor often leads to high patient satisfaction. The more patient-centered the facility and provider are the more positive the patient experience (Williams & Williams, 1998).

Early diagnosis is essential to the goal of the National HIV/AIDS Strategy to reduce new HIV infections (U.S. Department of Health and Human Services, Dieffenbach & Fauci, 2009). According to recent research, undiagnosed individuals were responsible for 30.2% of the estimated 45,000 HIV transmissions in the U.S. in 2009 (Skarbinski, et al., 2015). Early diagnosis of men who have sex with men reduces the number of new HIV infections in two ways: diagnosed MSM are likely to reduce their sexual risk behaviors through condom use, sero-sorting, strategic positioning and other harm reduction methods (Crepaz, et al., 2009, Marks, Crepaz, Senterfitt, & Janssen, 2005) and diagnosed individuals can begin HAART and reduce their viral load to undetectable levels (if adherent). Transmission of HIV among MSM is

significantly associated with recent infection, sexually transmitted diseases, and higher viral load (Fisher, et al., 2010). Thus, with routine HIV and STI testing and efficient linkage to care of newly-diagnosed MSM, there is likely to be a reduction in new infections.

A study of black MSM's access to HIV testing and prevention services found that inadequate access to culturally competent services, stigma and discrimination, and limited services in the areas BMSM live acted as structural barriers to these services (Levy, et al., 2014). Structural interventions like locating services within minority communities and helping BMSM build the navigation skills necessary to access healthcare and social services would serve to mitigate these barriers.

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*“Yes, who pays attention to HIPAA all the time? They go to church and they share communion and stuff. [chuckles] Accidentally talking about me across the communion line.”*

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Individuals come to HIV testing with their own beliefs, perception, attitudes and experiences. There is no one “right” way to offer HIV testing, as demonstrated by the variety of preferences shared by participants. Some participants want to be tested by a doctor as a part of routine medical care. Others like to be able to walk in and receive a test in a community setting whenever they feel like it is necessary or desired. Hussen, et al. (2013) developed a typology of HIV testing behaviors of BMSM that provides context to this study's findings. In the typology there are four types of HIV testers: Maintenance, Risk-Based, Convenience, and Test Avoiders (Hussen, et al., 2013).

*"I personally have a problem with the expectation that people have, that people or LGB people are supposed to be doing more than straight people are doing. And it's very frustrating, because I think it's counterproductive....Because it makes people feel like they're singled out. It makes them feel like, 'I don't see this pregnant chick down at-- or this young mother, making all these kids-- Nobody's telling them why I go to Health Center, or something like that, is because they do their condoms use. They might be, they do multiple things. They test for smth'g, don't get the impression that they're being harassed about it. When when you go in. Whereas, when you go somewhere that might just do HIV testing, you could be missing a whole lot of things." But in regard to consequences for their actions.... But in regard to that environment, you could have experienced that directly. But other than that sensation that you're being harassed, you're not sure that you talk to your heterosexual patients the same way. It may not be explicitly said, but you give that impression maybe. I don't think you give them the same hassle. Even when they come in here with a STD or if they're coming here with-- if they're young and pregnant or whatever, I don't think you give them that same way."*

Hussen, et al. (2013) found that the younger men were more likely to be Maintenance Testers and Test Avoiders. Most of the participants in these focus groups fit the description of Maintenance Testers, with others falling under the other three types. Maintenance Testers see themselves as advocates for their health and HIV testing as a part of routine health care. These men regularly access care, are open about their sexuality, and have internalized public health messages about HIV testing (Hussen, et al., 2013). Test Avoiders are also openly gay or bisexual; however they cite more experiences of bullying than the Maintenance Testers. Avoiders have a high perception of HIV risk, however their fear of the results and HIV stigma impede their engagement with healthcare and HIV testing.

Stigma experienced by sexual minorities impacts the HIV testing access of the remaining two types Risk-Based Testers and Convenience Testers. Hussen, et al. (2013) observed that these types generally describe their appearances as masculine, and they tend to endorse more traditional masculinity social norms and beliefs. Risk-Based Testers and Convenience Testers advocated for prevention strategies that focused on black men, not black gay men, highlighting black brotherhood as central to their identity (Hussen, et al., 2013).

This typology offers a way to conceptualize the heterogeneity of the black MSM and YMSM populations' experiences with HIV testing and HIV prevention messaging. Some men view HIV testing as possibly "outing" their sexuality. Public health messages about HIV testing often focus on gay men. The targeting of these messages may reinforce perceptions that HIV testing is something only "gay" men do.

Participants supported this idea when discussing incentives for HIV testing; that incentives act as a “cover” for them so they can seek HIV testing while reporting to others that they were only going to receive the incentive. Relatedly, another participant explained he would pretend to be accompanying a female friend to Planned Parenthood in order to get services without risking exposing himself to possible ridicule or stigma. These beliefs about HIV testing and fear of stigma emphasize the importance of access to and engagement in primary care for YMSM.

According to the CDC’s revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings (2006), all MSM should be offered a HIV test at least annually. For these recommendations to be successful in routinizing HIV testing for MSM and all Americans, healthcare providers must offer HIV testing and discuss their patients’ sexual behaviors to recommend other appropriate screenings and interventions. This is especially important for MSM populations, considering the prevalence of HIV within MSM and YMSM communities. Healthcare providers cannot assume that men will always disclose their same-sex attraction or their sexual behaviors. For this reason, providers must be willing and able to have open dialogue with their patients about their sexual history and behaviors on an ongoing basis, in addition to offering annual HIV tests.

If YMSM are actively engaged in primary care and routine HIV and STD testing, they do not have to negotiate how stigma impacts how they seek HIV testing and prevention services. HIV prevention messages should promote HIV testing as a standard part of routine medical

care, in order to normalize HIV testing and destigmatize HIV testing as something only “gay” people do (Parent, Torrey, & Michaels, 2012). Disclosing same-sex attraction to a healthcare provider is a difficult act for some MSM because of fear of discrimination and internalized stigma. In a study of MSM in New York City, 39% of MSM did not disclose their same-sex attraction to their health care providers and none of the bisexual men disclosed (Bernstein, et al., 2008). An online survey of MSM found that, of the 4620 MSM who reported visiting a health care provider in the last year; only 30% were offered an HIV test. The men who disclosed sex with men were more likely to be offered a test (Wall, Khosropour, & Sullivan, 2010).

## Limitations

The analysis of these discussions cannot be generalized to reflect the experiences, needs or barriers of all YMSM. As mentioned previously, all the participants were recruited through LGBTQ and/or youth serving organizations with HIV prevention and testing programs. All of these young men had participated in at least one program or activity at these organizations. Due to this limitation, the results of these discussions cannot be applied generally to all YMSM in Philadelphia. YMSM who do not identify as gay or bisexual, or otherwise do not identify as part of the local “gay culture”, may have different opinions and experiences. The young men in this study also reported regular engagement with healthcare; this may not be true for their peers.

Participants were aware that the purpose of the study was to inform the planning of HIV prevention services in Philadelphia, and so they may have given responses in support of organizations they frequented in order to

protect the funding or reputations of those organizations. The participants also may have given socially acceptable answers in order to gain the respect and admiration of the moderators and/or their peers. The moderators were clear to emphasize that there were no correct answers or opinions.

Overall, caution should be exercised when applying the results of this study. This analysis is offered as insight into how YMSM view healthcare and the local HIV testing and prevention system, to be used alongside other data for policy and program planning.

## Recommendations

In order to address the healthcare and HIV prevention needs of Philadelphia's YMSM, a combination of strategies, policies and programs are necessary.

### **Increasing access to and engagement with primary care for YMSM is essential.**

Engagement in primary care is an especially important tool in the HIV prevention "toolbox" in this age of biomedical interventions like pre-exposure prophylaxis and "treatment as prevention". HIV-negative YMSM can be linked to appropriate interventions and have regular sexual health screenings. YMSM who are regularly tested and engaged in healthcare will have a better chance of being linked to HIV care and treatment, should they acquire HIV. Programs that engage YMSM in healthcare should address their complex needs, including mental health, substance use, chronic health conditions, and social needs, in developmentally appropriate ways.

### **A combination of routine testing in all primary care settings and targeted community-based testing is necessary.**

Risk-based testing alone may miss high-risk individuals who are reluctant to disclose same-sex attraction and/or their sexual behaviors or substance use.

### **Comprehensive evidence-based sexual health education, inclusive of all gender identities and sexual orientations, is needed in the Philadelphia school district.**

Young people need sexual health education that promotes not only their health but their well-being.

**HIV testing protocols should address concerns about confidentiality.** HIV testing programs ought to consider who provides the

counselling and testing, where testing occurs, and how to address concerns about confidentiality and privacy. It may be beneficial to include information about privacy protections and confidential testing protocols in outreach and marketing materials, in order to address those concerns before they can become barriers to testing.

**Special attention should be paid to creating welcoming and accepting organizational cultures.** Healthcare organizations need to prioritize the barriers, challenges and concerns of YMSM. YMSM want to go to providers who can relate to their experiences and accept them as they are.

**Relevant information about local services, sexual health, and HIV/STD testing should be online in the places YMSM are likely to find it.** Reliable online content will help many YMSM, especially those who are reluctant or unable to access services in the "gay" community. More local research is needed to better understand how Philadelphia's youth access online health information.

**Community level efforts are needed to address HIV stigma and discrimination of LGBTQ individuals,** which persist and act as a barrier to open communication about the sexual health needs of YMSM.

**Public health programs and healthcare organizations must be sensitive to the effects of stigma and discrimination on YMSM;** especially minority YMSM who face not only stigma because of their sexuality and/or gender expression, but also live in a society with pervasive structural racism.

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