

**HIV Integrated Planning Council
Prevention Committee
September 25 2019
2:30 PM – 4:30 PM**

Office of HIV Planning 340 N. 12th Street, Suite 320, Philadelphia, PA 19107

Present: Keith Carter, Mark Coleman, Dave Gana, Gus Grannan, Loretta Matus, Nhakia Outland, Lupe Diaz

Excused: Katelyn Baron, Janice Horan, Clint Steib

Absent: Erica Rand, Joseph Roderick

Staff: Briana Morgan, Nicole Johns, Sofia Moletteri

Call to Order:

L. Matus called the meeting to order at 2:40 PM.

Welcome/Introductions:

L. Matus skipped introductions since everyone in the group was familiar with each other.

Approval of Agenda:

L. Matus called for a motion to approve the September 25, 2019 Agenda. **Motion: G. Grannan moved.**

K. Carter seconded to approve the September 2019 agenda. Motion passed: general consensus.

Approval of Minutes (August 28, 2019):

L. Matus noted that on page 6, first paragraph and second sentence of the August 2019 minutes, there was the acronym EtE (Ending the HIV Epidemic) which was not defined before use. She proposed an amendment to the meeting minutes, dictating that EtE be defined before use. **Motion: K. Carter moved, G. Grannan seconded to approve the August 2019 minutes. Motion passed: general consensus.**

Report of Co-Chairs:

L. Matus had no report. She only reminded the committee that the November and December 2019 Prevention Committee meetings would not follow the regular schedule. In lieu of the two meetings, there would just be the one on December 4th. The meetings would return to the normal schedule in January 2020.

Report of Staff:

B. Morgan reported on the updates to the Service Directory page on the OHP (Office of HIV Planning) website. There were improvements made regarding navigability as well as mobile accessibility. From the homepage of the OHP website, go to the “find services” tab to get to the service directory page. She reminded everybody that there was a search bar to search zip code, language, service, etc. To get more information about a service, click on the name of the service.

She mentioned that people who work for or are engaged with an organization should check the directory for any misinformation and report it to info@hivphilly.org.

She also reported on a relaunch of the website blog. Thus far, there was a post about health equity and a profile on Dr. K. Moore who presented at the September 2019 Positive Committee meeting. She added that there would be a couple of posts about housing as well. Within a few weeks, the office would also distribute a revamped newsletter.

Last Thursday, September 19th, B. Morgan reported that she attended the HIV New Jersey Planning meeting. They discussed the change to the Public Charge rule and how it is affecting the way people access services. She said the committee would talk more about public charge later in the meeting.

Discussion Items:

—MSM Youth Healthcare—

Due to the recent topic of youth engagement, N. Johns decided to share the results and recommendations from 2014 focus groups OHP conducted with YMSM (young men who have sex with men).

To offer context, N. Johns mentioned the Lifetime Risk article from 2009. She noted that this article identified a risk projection that half of black MSM would have HIV by the age of 35. Because of this projected statistic, there was a rise in urgency.

The purpose of the study was to look with the PPG (prevention planning group) at some high-risk populations and to better understand engagement with and opinions on healthcare and HIV testing. Three service providers offered to host the focus groups, working with younger people mostly between 18 and 25. There was nobody under 18 years old, and there were about 10 people in each of the three focus groups.

OHP staff interviewed and held discussions with the groups, using prewritten transcripts for assistance and direction. N. Johns acknowledged that a limitation of the study was that focus groups are not generalizable to general population because of sample size. Most of the participating individuals graduated high school, some went to college, and all—except for one—were either Black, Hispanic, or both.

N. Johns said that socio-ecological factors of the structural, institutional/health system, community, interpersonal/network, and individual all effect healthcare and HIV risk and choices.

N. Johns listed themes that surfaced throughout the study: stigma, lack of comprehensive sexual health education, confidentiality and privacy concerns, distrust of the healthcare system and organizations, and cultural norms/gender norms. The themes came about by asking the group questions regarding emergency care, regular care, and appointment frequency. There were open ended questions as well as prompts that involved brainstorming. There was also a portion where participants rated services and explained the ratings. They describe what their ideal healthcare situation looked like. The ideal healthcare portion especially highlighted the issue around the courtesy and care from those in the front office.

N. Johns read a quote from a participant regarding why people do not get healthcare:

“...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.”

The previous quote, N. Johns explained, was specific to those with HIV and experiencing stigma. Some of the men who participated disclosed that they were HIV positive though they were not specifically asked. She said there are perceived layers of quality of care depending on a lot of different socio-ecological factors and identities/presentation. This often showed in the vast amounts of rude customer service. She mentioned two stories that participants shared wherein healthcare office staff publicly chastised individuals for being on Medicaid or getting an STI again.

N. Johns read three other quotes from participants that addressed why individuals may not link to healthcare:

“Why they got to have a reason,” “Sometimes it’s a time management issue – when someone’s working or going to school. So making sure their schedule is like ours,” and “I felt like a huge road block with accessing health care is stigma, pride.”

The acknowledgment of pride in the last quote referred to the cultural norm of men not accessing healthcare. Many participants mentioned that they helped other family members get healthcare even if they didn’t themselves. The fear of stigma is a powerful barrier.

Participants were also asked about HIV testing locations. Luckily, everyone in the group knew a lot of places that offered testing. N. Johns said participants were asked to describe an acceptable testing site. One participant responded, “[t]o be honest with [the question], [they] would most likely go to [their] primary doctor, and/or the ER because of confidential reasons and judgment. [They] wouldn’t feel comfortable with a heterosexual doctor asking [them] questions and/or just trying to get deep into [their] business. But [they] will actually go to a place that’s very comfortable and open to everybody that comes.”

The idea of inclusivity and affirming ideas was important to all of the participants. Going to regular care doctor for testing was preferable to going elsewhere because of the positive rapport and trust built up with a general practitioner.

K. Carter pointed out that there was a lot of assumption that all the doctors were straight. N. Johns said that if a provider is queer, that may be extremely beneficial; openness about queer identity could create a positive experience for the client. N. Johns mentioned how places that were serving LGBTQ+ individuals needed to be affirming and welcoming—for example, participants felt uncomfortable being labeled as “high risk.”

Along with the unacceptable quote, N. Johns explained how there was also a question asking about unacceptable HIV testing. One participant’s response was as follows:

“A lot of the places that were not selected, 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 some attitude, they should be a little bit more professional – to treat them as a client or consumer, as opposed to a buddy.”

The themes of kind customer service and confidentiality were apparent in responses. N. Johns reported that addressing people by their names, explaining wait times and keeping clients in the loop, respecting privacy, professionalism, comfortable waiting rooms, and answering the phone were all important to participants.

N. Johns listed unacceptable and acceptable testing site characteristics reported from the focus groups. Unacceptable included bad reputation, knowing people who worked there, unprofessional staff, and public testing settings. Acceptable testing sites included healthcare providers, LGBTQ-friendly organization, incentives offered, and a sexual health or HIV provider. She said that the incentives worked because they act as a “cover” for people. People could say that they’re going to get tested for the incentive so they don’t have to disclose that they might be at risk. L. Matus asked what a public setting might include. N. Johns said any pop-up public space would be considered a public testing site. B. Morgan said that it tied into the idea of being seen by people you know.

Confidentiality, as N. Johns noted previously, was a reoccurring issue within HIV care. One patient described the issue: “I know 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 or talk to.’ People can’t keep quiet.” N. Johns explained how having peers do the work was positive for some, but not all. No one could give an example of a peer breaking confidentiality, but participants were still afraid of the potential breach of confidentiality.

N. Johns moved onto the recommendations portion of the study. She said that the recommendations came from participants in the focus groups, but, based on other studies, reoccurring themes for the focus groups seemed to be the same for similar populations.

The recommendations were as follows:

1) *Increasing access to and engagement with primary care for YMSM is essential.* N. Johns commented on how everyone experiences barriers to healthcare, but YMSM have to deal with many layers of stigma and more barriers than usual. B. Morgan mentioned how lack of experience navigating healthcare was also a barrier. N. Johns said that the participants had a lot of concern around healthcare navigation, because the focus group research took place during rollout of Obamacare. She said that the relationship with a good and considerate doctor was vital to increased engagement.

2) *A combination of routine testing in all primary care settings and targeted community-based testing is necessary.* N. Johns said that there was research in Atlanta that identified four types of testing behaviors in Black MSM. One group gets testing regularly, some only get tested under risk-based circumstances, others only get tested when it is convenient to them, and others are avoidant and do not get tested. The reasons for the avoidant group are many: e.g. fear of homophobia, stigma, being seen by others, etc. N. Johns explained that targeted testing helps people who aren’t already engaged in healthcare begin the process.

3) *Comprehensive evidence-based sexual health education, inclusive of all gender identities and sexual orientations, is needed in the Philadelphia school district.* N. Johns noted that only one person felt like they had adequate sexual education. Many did not receive relevant or accurate health information. The focus groups reported that a lot of education was focused on avoiding pregnancy and was hetero-centric. K. Carter mentioned the Youth Behavior Survey and inquired about YMSM of color infection rates. B. Morgan said that infection rates were stable but still way higher than they should be. K. Carter asked where PA ranks in regards to sex education compared to other states.

N. Johns said it depends on the school—changing it would be a legislative push. Schools can individually teach more comprehensive sex education, but it is not required, so most do not. She did,

however, mention how participants received good and relevant information from some separate entities that came to the school for afterschool programs.

4) *HIV testing protocols should address concerns about confidentiality.* N. Johns said that being open and honest about confidentiality would put patients at ease.

5) *Special attention should be paid to creating welcoming and accepting organizational cultures.* She explained how diversity and inclusiveness was a top priority for all focus groups. Diverse and intergenerational care was valued in regards to services and employees alike. N. Outland asked if any of the people in the focus groups were fathers. For her organization, N. Outland mentioned how she was redoing intake form, and she noticed that a lot of men have kids. The reason this was such an important thing to note was because people generally assume that MSM do not have children. Therefore, childcare can be a barrier since they are not recognized to need related services. N. Johns agreed, saying that expanding the idea of who the caregivers are is important.

6) *Relevant information about local services, sexual health, and HIV/STD testing should be online in the places YMSM are likely to find it.* N. Johns noted that some places have the wrong address on their website. B. Morgan said that most businesses are listed on Google Maps, but organizations do not think to change it on there. This was problematic, because people often refer to Google Map for directions. N. Johns noted that people do not read brochures. Instead, people utilize online resources more. Accurate online information helps young people access healthcare and HIV resources. Online information can help to counter the lack in educational settings.

M. Coleman asked if people from Caribbean/African cultures have different issues with transmission or testing. N. Johns said that this focus group was YMSM who grew up in the EMA and especially Philadelphia. G. Grannan said that would be great information to research, especially since there is a healthy stream of immigration in Philadelphia. N. Outland mentioned M. Martinez and how she could be an excellent resource for such information.

7) *Community level efforts are needed to address HIV stigma and discrimination of LGBTQ individuals.* N. Johns explained that this specific recommendation was related to changing social norms, especially those existent within the African American community.

8) *Public health programs and healthcare organizations must be sensitive to the effects of stigma and discrimination on YMSM.* N. Johns explained how this final recommendation was often a topic of conversation, yet there are no policies or programs designed around this idea. She said that organizations need to find ways to incorporate it into their practices.

N. Johns emphasized the need for cultural competency. Cultural competency includes environments that are inclusive, respectful (use of eye contact, name), valuing privacy/confidentiality (and recognizing the difference between the two), sex positive (no shaming), treating patients as individuals, not as “risk populations (there is an existing partnership between patients and providers). She said that people should be making decisions together—a dialogue is needed. Trust leads to better healthcare.

N. Johns discussed the conclusions from the focus group. The first conclusion was that linkage to a supportive and informative provider is key to engagement in care. In other words, having an invested and caring provider helped, and it was important to have as few people as possible interacting with the patient’s confidential information. The second conclusion was that young men care about their

health, but often have significant individual, social and provider-level barriers to overcome. The third conclusion recognized that simple changes to how clients/patients are treated could impact retention in care. In other words, respect was a key factor in the care continuum.

—*Ending the HIV Epidemic*—

B. Morgan reported a small update to the local EtE (Ending the HIV Epidemic) Plan update in which the CDC announced the starter grant of funding. She said there was a handout in the meeting packet, so that the group could check the amfAR resource out more extensively later. She also noted that the acronym has been changed from EtE to EHE.

The amfAR website had information for the 48 counties and 7 states participating in EHE. B. Morgan noted that there is also data listed for other jurisdictions as well. She said the website included a lot of interesting information—deportation processes by ICE, criminalization/incarceration, and other data sets that might be more common. The website also offered information like location of syringe service programs and distance to nearest substance use provider offering MAT (Medication Assisted Treatment).

Though the most recent data was 2015, B. Morgan said it was all still very applicable. N. Johns asked if the data is only measured by state. B. Morgan said no, it depends on what you are looking to individually measure. For example, for RWHAP, providers can be broken down by county.

B. Morgan suggested everyone poke around the website to get a better understanding of where the EMA fits in a national context. She said that within the coming months, they will be looking at different jurisdictions EHE's plans. Therefore, referring to this website would be helpful.

—*Public Charge*—

B. Morgan noted that Public Charge was a significant topic at the recent HIV New Jersey Planning meeting. The NJ Planning Council saw Public Charge change a lot for providers and clients in NJ, specifically Newark. When the government evaluates immigrants for either green cards or visas, they assess whether the individual would be a “public charge” and cost the state money.

B. Morgan said that the public charge rule did not initially target those using essential health and nutrition programs—it only considered those who were “primarily dependent” on certain long-term benefits. However, the new rule would target those using Medicaid, SNAP (Supplemental Nutritional Assistance Program), food stamps, Public Housing and Section 8, and cash assistance. The drastic change in the rule has impacted the way immigrants are accessing healthcare. It is especially harming people who are living with disability, since Medicaid is the only way that many people can access disability programs.

She explained that Newark already noticed a decrease in those accessing healthcare, because people are afraid of not getting permanent status or losing their legal status and being deported. She said that when people are reviewed for immigration-related things, they are determined about how much they are a public charge. B. Morgan said that the problem is that there have been additions to the public charge rule. B. Morgan said the rule isn't supposed to be enforced in a way that impacts someone's family, but that will be possible.

N. Outland said that the “systems don't talk” in Philadelphia, so if people can access these services and nobody would know. N. Johns explained that the federal government has jurisdiction and can ask

for the information. G. Grannan agreed and said a lot of the programs are federal, so there aren't any privacy levels.

N. Outland asked about the timing for Public Charge. B. Morgan responded that it is very new, and N. Johns said it would be implemented on October 15, 2019. N. Johns said that RWHAP would not be considered in Public Charge, but facts may not matter since fear is driving people away from any sort of contact with healthcare. They do not want to take any chances. G. Grannan commented that RWHAP is a payer of last resort, so clients first have to go through Medicaid to get to RWHAP.

M. Coleman asked about immigrants' rights in the city of Philadelphia and confidentiality of information. N. Johns said that the city does not have to share information. L. Diaz agreed, saying that the city might not be complicit with this, but the other counties in the EMA are not in a sanctuary area and are going to be at risk.

G. Grannan said that he has done work with an immigration rights organization, and his organization had to do an astonishing amount of work to get even one database unplugged from the federal system. N. Johns said PA is not a sanctuary state, so anyone accessing a state funded program would not be "safe." B. Morgan agreed and said that anybody who costs the federal government money will have an issue finding any sort of service at all.

N. Outland said that even children who are natural born with an immigrant parent will be affected. N. Johns said that people are so driven by fear right now, and are afraid to take any risk because the consequences are so great. G. Grannan expressed concern around disease outbreaks in immigration communities and how they would not be addressed.

B. Morgan asked everybody to report back to the office if they hear anything from the communities impacted, providers, etc. She said that accessing information from impacted communities would be difficult, because there would not be a feedback loop—people would just be dropping out of the system.

N. Outland asked if there was any concise, informational handout that could be dispersed to the community. B. Morgan said that the office would look into it.

Old Business:

None.

New Business:

G. Grannan said that a second county in West Virginia had functionally gotten rid of their syringe exchange program. It was initially run out of the county Health Department in Clarksburg. He said there was an HIV outbreak in Huntington, WV as well as in the southern part of state. L. Matus asked if West Virginia was part of the EHE epidemic. G. Grannan said that Ohio and Kentucky were, but he was unsure about West Virginia. He said people should be aware and that there are only two pharmacies in the state that sell syringes without prescription. Still, he was not sure if even that was still true.

G. Grannan said that it is not a statewide policy, so in theory each county can choose their own legislation. However, it was unlikely that the legislation would change at all, since every county seems overall against the syringe exchange.

B. Morgan said that she was currently looking into information for people with a disability as well as HIV. She specified that this was not disability due to HIV. G. Grannan asked if she was only looking

into ADA (Americans with Disabilities Act) or disabilities in general. B. Morgan said any disability. N. Outland said there is a LGBTQ group for people with disability in Philadelphia that B. Morgan should look into.

Announcements:

K. Carter announced that he was leaving voting registration forms out on conference room table—he said that the deadline was October 5th, 2019.

L. Matus announced that this Friday, September 7th, would be National Gay Men’s HIV Awareness Day.

N. Johns announced that the Comprehension Planning Committee meeting in October 2019 would hold a conversation around housing and Housing First / its feasibility in RWHAP. She said they will be looking at especially vulnerable populations. The committee would also look at HIV positive women who are pregnant or postpartum. She said the population that is small in size but particularly vulnerable. They would also look into other vulnerable populations such as people reentering the community after incarceration or other institutions. If anyone is interested or has important resources/information, N. Johns asked people to email her and come to the Comprehensive Planning meeting.

N. Outland announced that Outfest would be October 13th, 2019.

L. Matus announced that October 15th would be National Latino AIDS Awareness Day and October 20th would be AIDS Walk.

N. Outland announced that she would be teaching a course on October 19th about adopting sex positive approaches in LGBTQ sexual health. The course would be at Temple University. To register, go to the Temple website and then noncredit courses.

M. Coleman announced that absentee ballots should be online until October 31st.

Adjournment:

Meeting adjourned at 4:12 PM by general consensus.

Respectfully Submitted,

Sofia M. Moletteri, staff

Handouts distributed at the meeting:

- September 2019 Prevention Committee Meeting Agenda
- August 28, 2019 Prevention Committee Meeting Minutes
- Experiences in HIV Testing and Health Care in Philadelphia for YMSM
- Ending the HIV Epidemic Database
- Public Charge: A Threat to Immigrant Families