Ryan White Part A Planning Council of the Philadelphia EMA Positive Committee Meeting Minutes February 13, 2017 12:00-2:00p.m.

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

Present: PH (15), PA (1), NJ (1)

Guests: David Griffith (LGBT Elder Initiative)

Staff: Antonio Boone, Nicole Johns, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: A. Boone called the meeting to order at 12:13p.m. He read the mission statement. A moment of silence followed. Those present then introduced themselves.

Approval of Agenda: A. Boone presented the agenda for approval. <u>Motion: D.G. moved, L.W. seconded to approve the agenda. <u>Motion passed</u>: All in favor.</u>

Approval of Minutes (*January 9, 2016*): A. Boone presented the minutes for approval. <u>Motion:</u> D.G. moved, J.M. seconded to approve the minutes. **Motion passed**: All in favor.

Report of Chair: No report.

Report of Staff: N. Johns said that the Planning Council was currently recruiting members. She stated that she could help anyone who was interested to fill out an application today. She noted that a tax compliance form had to be filled out online in addition to the application, due to requirements instated during Mayor Nutter's administration. She added that there was a computer available in the office, and staff could help fill out the form online.

N. Johns stated that the Consumer Survey had been going out into the community. She thanked the Positive Committee for helping review the survey before it went out. She said that 2855 copies of the survey were sent out so far, and 307 had been received back. She stated that an online version of the survey was also being conducted, and flyers for it were available on the side table. She noted that there would also be an online ad for the survey on the Philadelphia Gay News (PGN) website, which would run for about 8 weeks.

A. Boone asked members to spread the word about the survey and encourage others to apply for the Planning Council.

Special Presentation:

• Update on Local HIV Data

Mission statement: The Positive Committee supports and enhances the role of people living with HIV/AIDS to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the HIV Prevention Planning Group.

N. Johns noted that K. Brady, who was the medical director and chief epidemiologist at the AIDS Activities Coordinating Office at the health department, had presented data on the HIV epidemic in Philadelphia at the last RWPC meeting. N. Johns said she'd be presenting some of K. Brady's slides at today's meeting.

N. Johns began by reviewing the HIV care continuum. She said the care continuum classified PLWHA from unaware of their HIV infection from fully engaged in HIV care. She stated that people who were fully engaged in HIV care tended to be taking their medications, going to the doctor, and feeling healthy.

N. Johns reviewed a bar graph of people 13 and older who were both infected with HIV and diagnosed. She said that the totals of people who didn't know their status were estimates. She said that 13% of people in the United States who had HIV were estimated to be unaware of their status. She noted that some people who didn't know their status inadvertently passed along HIV infection. She pointed out more people became aware of their HIV status as they got older, because they tended to go to the doctor more.

N. Johns reviewed data from Philadelphia of people who didn't know about their HIV status by sex, race/ethnicity, and mode of transmission. She said that men were more likely to be unaware of their HIV status. She noted that men were sometimes less likely to seek medical care. She added that women were tested during pregnancy for HIV. She stated that people who were Black had a higher likelihood of being unaware of their status than White and Hispanic people. R.W. said stigma was one reason that Black people were less likely to be tested. N. Johns added that lack of insurance and discrimination were other reasons Black people were less likely to be diagnosed. She noted that percentages of people who didn't know their status among heterosexual people and MSM were similar. She asked participants why people who inject drugs (PWID) were more likely to know their status. She explained that PWID were more likely to be engaged in programs that did HIV testing. She pointed out that the unaware percentages were specifically for Philadelphia.

N. Johns moved forward to a bar graph demonstrating linkage to care within 1 month after HIV diagnosis by transmission category. She stated that MSM who also inject drugs were least likely to be linked to care after 1 month.

N. Johns noted that the guidelines used to require that people diagnosed with HIV be linked to care within 90 days. She stated that the new guideline was 30 days. She noted that linkage to care had been improving over the past 5 years. She said that in 2015, 81% of people were linked to care within 1 month, and 91% were linked within 3 months.

N. Johns reviewed a bar graph concerning retention to care. She said that retention in care was measured as 2 doctor visits in a year. She said that the red bar represented retention in care, and the blue represented viral suppression. She noted that, among men who have sex with men, more people were virally suppressed than were retained in care. D.G. explained that someone who had been undetectable for a long time might not visit the doctor more than once a year. N. Johns stated that around 10% of people served by the Ryan White program only needed to visit the doctor once a year.

N. Johns reviewed the bar graph for retention in care specific to Philadelphia. She noted that, in 2015, 53% of people were retained in care and 56% were virally suppressed. She explained that people counted in the bar graph were all people living with HIV in Philadelphia and not just the Ryan

White system. She noted that people in the Ryan White system had higher percentages of retention in care and viral suppression.

N. Johns said that prevalence meant how many people were living in HIV in an area regardless of whether or not they knew their status. She stated that around 93% of people living with HIV in Philadelphia knew their status. She added that 91% were linked to care, 49% were in care, and 52% had undetectable viral loads in 2015. She stated that one reason that many Philadelphians knew their status was targeted testing. R.W. noted that some people with HIV moved out of Philadelphia after their diagnosis, which made them hard to track. N. Johns said that there were a significant number of people with HIV that left Philadelphia. She stated that there were ways to attempt to track these people, though they were not always effective.

N. Johns compared rates of engagement in care of people living with HIV in the US and Philadelphia, out of 100 people. She stated that, in the US, 87 of these were diagnosed, 75 were linked to care, 49 stayed in care, and 48 had undetectable viral loads. She noted that, in Philadelphia, 93 were diagnosed, 91 were linked to care, 49 stayed in HIV care, and 52 had undetectable viral loads. She stated that diagnosis and linkage to care were both meeting national standards, but retention and viral suppression needed work.

N. Johns read a list of points of comparison of HIV prevalence in the US and Philadelphia. She noted that Philadelphia had 26,807 people living with HIV as of December 2015. She said that a majority of people living with HIV were Black, male, and greater than or equal to age 50. She stated that there was roughly an equal percentage of the epidemic who were MSM and heterosexual, though numbers of MSM in Philadelphia were much lower. D.R. asked how these factors were measured. N. Johns said that data was tracked from the health department and different organizations to establish surveillance numbers. She continued that, in the US, there were almost 1 million people living with HIV as of December 2014. She noted that a majority were black, male, greater than or equal to 50, and MSM. She said that the highest rates of HIV were in the Northeastern US. She pointed out that there were fewer women with HIV being reported each year. She noted that Philadelphia had a higher rate of HIV in people with heterosexual contact than the rest of the US.

N. Johns stated that the next graph demonstrated the proportion of Philadelphia EMA residents diagnosed with and living with HIV by race/ethnicity and sex in 2015. She noted that there was the highest percentage of Black males with HIV in Philadelphia. She added that the next highest were Hispanic men and Black women.

N. Johns moved on to a pie chart of people newly diagnosed with HIV in Philadelphia. She said there were 538 newly diagnosed cases, including 78% male (at birth), 72.4% Black, 14.1% Hispanic, and 10.4% white. She said that 25% of new diagnoses were among 13-24 year olds. She stated that most of these were probably 17-24 year olds. She added that this included a greater percentage of MSM than heterosexual people.

N. Johns said that the rate of MSM newly diagnosed with HIV in Philadelphia in 2011-2015 was rising. D.R. asked when the rates of PLWHA for 2016 would be available. N. Johns replied that they would likely to be available in the summer.

H.B. asked if there was data available for how many people got HIV tests each year. N. Johns responded that the city knew how many people were HIV positive and how many publicly funded tests were given, though many other tests could not be tracked. However, negative tests were not

reported to the health department. H.B. asked if there were statistics for how many people were tested versus how many people were positive. N. Johns stated that there was research on this. She explained that low rates of positive tests may imply that testing was poorly targeted. N. Johns said that doctors needed to test everyone, instead of relying on assumptions about who needed to get tested. D.R. suggested that peer counselors help people get tested. M.C. stated that some people who called themselves HIV negative on dating and social media sites when they were actually positive, but undetectable.

Discussion Items:

• Newsletter Update

A. Boone said that, in preparing for the newsletter, he had sought feedback from journalists who worked with and wrote about people with HIV. He said explained that he'd sent out a list of questions² for them to answer. He stated that D.G. had brought a newsletter he'd help to make in the past as a model. He said he'd distribute the newsletters to the group.

A. Boone reported that one journalist, Matthew Rodriguez, from Mic, had responded to his email. He stated that the newsletter could potentially be a forum for sharing about policy updates. He noted that Rodriguez's articles could be found online, and that he covered many current issues.

A. Boone read some of M. Rodriguez's responses to his questions. M. Rodriguez had noted the complex relationship between HIV and other forms of oppression. He had added that activism could take many forms, including sharing personal stories. A. Boone noted that some people in government and the community have never had conversations with people with HIV. He said this was one of the reasons why people with HIV needed to share their stories.

M. Rodriguez wrote that it was important for people who engaged in HIV activism to have as much information and connections to the community as possible. He added that veteran activists were still important to the movement, but needed to make sure they adapted with the times. A. Boone said there were many sources of information shared to Positive Committee and RWPC meetings. He stated that Jose Bauermeister would be presenting in a few months. He added that Kathleen Brady's epidemiological report also helped spread information to the community.

M. Rodriguez wrote that HIV activists were facing potentially hostile political changes, and would have many challenges to face. A. Boone stated that the newsletter could be a forum to write about their feelings about the new national policies.

M. Rodriguez had noted that it was important for audiences to hear stories that challenged them and expanded their worldview.

3. What inspires you to continue writing about HIV?

 $^{^{2}\,}$ 1. How is covering HIV different from other health topics that you've covered?

^{2.} What does HIV activism mean to you?

^{4.} How important are the personal stories of PLWHA when fighting HIV stigma?

^{5.} What are the three things every activist/journalist needs to know before advocating for a cause?

^{6.} What can veteran activists do to reach a larger audience in the 21st century?

^{7.} What challenges and triumphs do you expect HIV activists to face in the near future?

^{8.} What kind of stories do people respond to?

^{9.} As a writer and activist I would like to see a newsletter that....

M. Rodriguez had concluded that he'd like to see a newsletter that compiled information related to HIV in one place, as well as contacts for sources. A. Boone said this would include information sharing, particularly on legal and national issues like HIV criminalization laws, which varied from state to state. He noted that HIV services even varied across the city.

A. Boone stated that he'd format the presentation slides so they were easier to read. He added that he'd share information from other journalists if they responded to his questions in the future. He asked anyone with ideas for the newsletter to call or email him.

Old Business: None.

New Business: None.

Announcements: D. Griffith said he worked for the LGBT Elder Initiative (LGBTEI). He stated that the organization had 2 upcoming programs, including one on February 25th on Grief, Loss, and Possibility. He said the program would be held at Saint Luke's Church. He noted that tokens and lunch would be given out at the event. He added that RSVPs would be taken by phone, email, and inperson sign-up sheet. He passed out flyers with more information about the event. He added that the LGBTEI would attend the Positive Committee meeting in March to discuss legal and financial planning. He said that a lawyer and a financial planner would attend the meeting.

D.G. said that the presentation in March was a precursor for a legal clinic that the LGBTEI would be having shortly afterwards. He said the presentation would prime attendees about what documents they needed to bring to the clinic on April 8th. D.G. noted that all the events were free.

Adjournment: The meeting was adjourned by general consensus at 1:31p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- January 9, 2017 Meeting Minutes
- HIV in Philadelphia Epidemiological Presentation (Excerpt)
- OHP Calendar