

Monday, January 14, 2019

12:00-2:00pm

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

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 Philadelphia HIV Integrated Planning Group.

- **Call to Order/Moment of Silence**
Introductions
- **Approval of Agenda**
- **Approval of Minutes**
- **Report of Chair**
 - **Participation**
 - Acknowledgements**
- **Report of Staff**
-
- **Discussion Items:**
 - **Meaningful Involvement of PLWH**
 - **Newsletter**
- **Old Business**
- **New Business**
- **Announcements**
- **Adjournment**



AGENDA

POSITIVE COMMITTEE

PLEASE TURN ALL CELL PHONES AND PAGERS TO SILENT OR VIBRATE.

The next meeting of the Positive Committee is February 11, 2019 from 12:00-2:00PM at 340 N. 12th Street, Suite 320, Philadelphia, PA 19107. Please refer to the Office of HIV Planning calendar of events for committee meetings & updates (www.hivphilly.org). If you require any special assistance, please contact the office at least 5 days in advance.

Philadelphia EMA HIV Integrated Planning Council
Positive Committee
Meeting Minutes of
Monday, December 10, 2018
12:00-2:00p.m.

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

Present: 11 (PH), 2 (PA), 2 (NJ)

Guest: Amy Hueber (AACO)

Staff: Nicole Johns, Briana Morgan

Call to Order/Moment of Silence/Introductions: M. White called the meeting to order at 12:10 p.m. and read the mission statement. Those present then introduced themselves.

Approval of Agenda: M. White presented the agenda for approval. **Motion: R. L. moved, J. Whitfield seconded to approve the agenda. Motion passed: All in favor.**

Approval of Minutes (November 5, 2018): M. White presented the minutes for approval. **Motion: S.T. moved, J. Whitfield seconded to approve the November 5, 2018 minutes. Motion passed: All in favor.**

Report of Co-Chair:
None.

Report of Staff:

N. Johns noted that the Prevention Committee, the Nominations Committee, and the Planning Council would not meet this month. She stated that the only other meeting remaining in December would be the Comprehensive Planning Committee meeting on Thursday, December 20.

Special Presentation:

HIV/HCV Focus Groups – Amy Hueber, AIDS Activities Coordinating Office (AACO)

A. Hueber stated that she coordinated Hepatitis C outreach at AACO. She stated that RAND Corporation would be holding a focus group on Hepatitis C for 6 – 8 people with HIV on Thursday, January 10. She noted that focus group participants would receive \$50 CVS gift cards. She stated that enrollment for the focus groups would begin once they received Institutional Review Board (IRB) approval. She noted that the focus groups would be held at Health Federation’s new offices at 123 S. Broad Street, Suite 650. She asked the group to select a time for a focus group: 10 - 11:30 a.m., 12:00 p.m. - 1:30 p.m., or 2 – 3:30 p.m. The group chose 12:00 p.m.

A. Hueber added that the Pennsylvania Department of Health was hosting a free naloxone event at four Philadelphia library branches on Thursday, December 13.

Discussion Item:

- **Meaningful Involvement of People with HIV**

N. Johns stated that this discussion was a carryover from the previous month's agenda. She noted that this conversation was related to a discussion in Comprehensive Planning Committee about the meaningful engagement of people living with HIV (PLWH) in planning. She stated that the quality management team at AACO was also reviewing similar concepts.

N. Johns stated that she had included a tool designed to help groups assess the meaningful involvement of PLWH in their organizations (*see – attached handout*). She noted that, for the purposes of the current conversation, the "organization" would be the HIV Integrated Planning Council.

M. White stated that they did not have an ethnically diverse group in the room today, and that the group was almost entirely African-American. He stated that people from other racial/ethnic groups were not currently participating in the process. He noted that there were previously Hispanic participants, but that the group they had been affiliated with was no longer attending Positive Committee meetings. N. Johns added that the group also had opportunities to include more geographic diversity.

N. Johns asked the group to begin working through the tool. She first asked the group if the Planning Council advocates for PLWH to participate in decision-making or policy-making bodies, and if they felt that input from PLWH is equally valued. Most of the group agreed that their input was valued, but that there was room for improvement. M. White noted that they could use more voices from youth.

N. Johns asked if the Planning Council advocates for PLWH to be recognized as important providers of information, knowledge, and skills. M. Coleman stated that there should be more people talking about substance use among PLWH and the LGBTQ community.

N. Johns asked if the Planning Council advocates for people with HIV to carry out real and meaningful roles in HIV interventions. Three people said that this needed improvement. J. Murdock stated that they needed improvement among outreach workers and peer educators. N. Johns noted that South Jersey had a successful community health worker program. J. Horan noted that she was a community outreach worker. M. Coleman stated that the PA counties needed more training on Narcan in ambulatory care settings.

N. Johns asked if the Planning Council advocates for a broad range of PLWH, including all genders, young people, men who have sex with men, sex workers, drug users, formerly incarcerated individuals, people experiencing homelessness, transgender individuals, and other marginalized people, to be meaningfully involved in the design, implementation, and evaluation of HIV services. The group agreed that this needed to be improved, and N. Johns asked if there was anything in particular that needed improvement. K.M. replied that they needed to include everyone, and that

they also needed help with language translation. She stated that they also needed to have open-minded people opening bridges of communication. N. Johns asked if there were specific things that the Planning Council or Positive Committee could do to make any of these groups feel more included. M. White stated that they needed to go to support groups and community advisory boards. R.W. stated that it was difficult to reach Asian communities. K.M. stated that it was important to reach out to other communities of people who were HIV-positive. N. Johns stated that there were unique cultural issues to consider in different groups, and that learning more about those differences could provide an opportunity to make people feel more comfortable.

N. Johns asked if PLWH participate at the same level as professionals in the design, implementation, and evaluation of HIV services. M. White replied that he did not think that people with HIV were involved in the design, even though they were involved in the implementation. J.M. stated that they were not longer just talking about PLWH, but that they were also talking about PLWH who are homeless and PLWH with opioid use disorder. He stated that these people were not at the table, and that this system was not set up to have input from people who were actually most affected. He stated that there was nothing to address the long-term effects on PLWH, and that they were going to have to be really clear about the questions they were asking. He then stated that the Broke In Philly article series¹ was drawing attention to poverty in Philadelphia, added that they were examining how poverty was now beginning to affect white people. He went on to say that this would affect how people in general saw poverty, although poverty had not been addressed when it did not affect white people. N. Johns stated that it sounded as though the answer to the question was “no,” and asked how they could address these issues that J.M. raised. K.M. replied that they needed to start with talking, and that they needed to address racism. R.W. stated that some communities of PLWH were less likely to advocate for themselves and for PLWH.

J.M. stated that the turnout at the current meeting was disappointing, and that the room should be packed based on the continuation of the survey that they were discussing. He went on to say that a lot of the people who were not in the room today would show up for social events. He expressed concern that, one day there may not be any funding left, and there would be no one there to fight for it.

N. Johns next asked if the voices of people of all genders are heard at the decision-making tables. The group agreed that they were not. M. Coleman stated there was a problem with trans folks getting equitable services, citing a specific example. N. Johns replied that she would speak with M. Coleman about that specific example after the meeting, and encouraged those present to direct complaints to the health information helpline at 215-985-2437. B. Morgan noted that it was extremely important to call when there are issues with services, because AACO would not know about any issues if they were not told about them.

¹ <https://brokeinphilly.org/>

M. White asked what had happened with the Positive Committee newsletter. N. Johns explained that OHP staff were happy to compile and format the newsletter, but that the Positive Committee needed to contribute to the content in the newsletter. She asked the group if they'd like to contribute to a newsletter, and a number of meeting attendees raised their hands.

N. Johns asked if the HIPC advocates for PLWH to be active spokespersons in campaigns to change behaviors and be meaningfully involved in sharing their views at meetings and conferences. K.M. replied that they needed improvement, and that they needed more people, especially those from marginalized groups. N. Johns noted that OHP would be launching a series of lunchtime programs about different topics and skills in 2019, such as public speaking and learning about issues with equity around race, LGBTQ issues, and gender. She stated that Mari Ross-Russell (OHP) had been developing this in partnership with Adam Thompson (AETC). K.M. stated that she would like to attend those and be part of those conversations. N. Johns noted that they would also take suggestions for speakers.

N. Johns asked if the Planning Council advocates for PWLH to be actively involved in the development of HIV information, education, and communication resources. The group agreed that this was a "yes."

N. Johns asked if the Planning Council advocated for the meaningful inclusion of voices of PWLH who are marginalized because of gender, sexuality, age, or other factors in the HIV response. The group agreed that this needed improvement.

N. Johns asked if PLWH decide who represents them on decision-making committees. M. White replied that the Planning Council had been becoming increasingly provider-heavy, and that they needed more voices from PLWH. K.M. asked what qualified a person to be at the table. N. Johns replied that HIPC members needed to attend the meetings on second Thursdays from 2 – 4 p.m., and that they also needed to come to a committee meeting. She noted that the Positive Committee counted as a committee meeting. She added that the HIPC application was now available online.²

The group agreed to table the second half of the survey until the next month's meeting. N. Johns stated that they would then bring recommendations and ideas to the Planning Council about how they can improve. She went on to say that, to J.M.'s point, they had been discussing a number of these issues for a long time. She concluded that it was time to begin addressing them. She added that the newsletter could be one of those improvements. J. Murdock stated that they could also use the newsletter to invite people to Planning Council and Positive Committee meetings. She asked those present to invite people at support groups to meetings to come out. She stated that that they needed more people to come out to the meetings. K.M. stated that they needed more doctors' offices and organizations to come into these meetings. She asked how many doctors' offices in the area served people with HIV. N. Johns

² <https://www.hivphilly.org/planning-council/apply/>

replied that there were dozens. J. Murdock stated that they could put newsletters in the doctors' offices.

K.M. asked if they could do webinars. N. Johns replied that they had not done them in the past, although OHP did just add the capability for people to call in to meetings. She noted the Planning Council had requirements around voting and public meetings, which made some of these issues more complicated.

Old Business:

None.

New Business:

None.

Announcements:

M. Coleman announced that City Council passed a minimum wage increase for city workers, contractors, and subcontractors. He stated that they had also passed a Fair Workweek bill.

J. Horan stated that Family and Community Services of Delaware County was having a monthly support group meeting with keynote speakers in Media.

S.T. stated that there was no longer any support for transportation to support groups in New Jersey. N. Johns stated that it was important to talk about this when transportation came up in the Planning Council meetings. She noted that this change was made because New Jersey had overspent its transportation funding early in the year, and that they had to ensure that PLWH were able to get to their doctors' offices.

J. Murdock stated that open enrollment through healthcare.gov would end on December 15.

Adjournment: The meeting was adjourned by general consensus at 1:44p.m.

Respectfully submitted by,

Briana L. Morgan, OHP Staff

Handouts distributed at the meeting:

- Meeting Agenda
- Meeting Minutes from November 5, 2018
- Meaningful Involvement of People Living with HIV Assessment Tool
- OHP Calendar

Advocating for the meaningful involvement of PLWH and affected communities in all aspects of the HIV response.

To ensure that PLWH and affected communities are meaningfully involved in all aspects of the HIV response it is essential that we all work together to advocate for and with PLWH. Effective advocacy requires that:

The voice of PLWH of all genders, ages, and races/ethnicities is heard

The interests of all PLWH are represented

PLWH can exercise their rights and

PLWH can access necessary services and support, regardless of their gender, age, sexual orientation, ability/disability, and or racial/ethnic identity.

Does your organization advocate for PLWH to participate in decision-making or policy-making bodies and ensure their input is equally valued?

Y N NI

Does your organization advocate for PLWH to be recognized as important providers of information, knowledge, and skills?

Y N NI

Does your organization advocate for PLWH to carry out real and meaningful roles in HIV interventions such as counselors, peer educators, and/or outreach workers?

Y N NI

Does your organization advocate for a broad range of PLWH, including all genders, young people, men who have sex with men, sex workers, drug users, formerly incarcerated individuals, people experiencing homelessness, transgender individuals, and other marginalized people, to be meaningfully involved in the design, implementation, and evaluation of HIV interventions?

Y N NI

Do PLWH participate at the same level as professionals in the design, implementation, and evaluation of HIV interventions?

Y N NI

Are the voices of people of all genders heard at the decision-making tables?

Y N NI

Does your organization advocate for PLWH to be active spokespersons in campaigns to change behaviors, and to be meaningfully involved in sharing their views at meetings and conferences?

Y N NI

Does your organization advocate for PLWH to be actively involved in the development of HIV information, education and communication resources?

Y N NI

Does your organization advocate for the meaningful inclusion in the HIV response of voices of PLWH who are marginalized because of gender, sexuality, age or other factors?

Y N NI

Do PLWH decide who represents them on decision-making committees?

Y N NI

Fostering the meaningful involvement of PLWH and affected communities in our work.

Promoting the active and meaningful involvement of PLWH and affected communities within our own organizations – in partnership with organizations and networks of PLWH and affected communities – is essential for implementing these principles.

This section will help you consider how well your organization promotes the meaningful involvement of PLWH and affected communities in your work.

Does your organizational environment foster non-discrimination and value the contributions of PLWH and affected communities?

Y N NI

Does your organization recognize and encourage the involvement of a diverse range of PLWH and members of affected communities in your work?

Y N NI

Does your organization ensure that PLWH and people from affected communities have a variety of roles at different levels within the organization?

Y N NI

Does your organization clearly define the roles and responsibilities of PLWH and members of affected communities?

Y N NI

Does your organization support the capacity of PLWH and members of affected communities to fulfill those roles, for example by providing the necessary organizational and financial support and mentoring?

Y N NI

Does your organization support capacity building within PLWH and affected community organizations and networks?

Y N NI