

**Ryan White Planning Council of the Philadelphia Part A EMA
Positive Committee
Meeting Minutes
November 9, 2015
12:00-2:00p.m.**

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

Present: PH (10), PA (2)

Staff: Nicole Johns, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: K. Carter called the meeting to order at 12:15p.m. He read the mission statement.¹ A moment of silence followed. Those present then introduced themselves.

Approval of Agenda: K. Carter presented the agenda for approval. **Motion:** L. Way moved, D. Gana seconded to approve the agenda. Motion passed: All in favor.

Approval of Minutes (*October 19, 2015*): K. Carter presented the minutes for approval. **Motion:** M. White moved, L. Way seconded to approve the minutes. Motion passed: All in favor.

Report of Chair:

- **Participation Acknowledgments**

K. Carter recognized participants who were attending their first Positive Committee meeting.

K. Carter noted that N. Santiago had been elected Co-Chair but was unable to attend today's meeting.

Report of Staff: N. Johns reported that the group filled out a transportation survey at their last meeting. She said the survey was designed to gather information about transportation challenges. She explained that a similar survey would be distributed to providers, including case managers. She stated that the survey would be designed to gather information about barriers to medical transportation. She said the provider survey would be distributed in the next few weeks.

N. Johns noted that 23 people had filled out the transportation survey at last month's Positive Committee meeting. She said 1/3 of the survey results were in Spanish. She reported that many participants came from zip codes with high percentages of PLWHA. She said many people (41%) got their medical care in Center City. She explained that others got their medical care in North Philadelphia, UPenn, or other areas. She stated that 1/4 of respondents got medical care in their own zip codes.

N. Johns reported that participants were asked how they got to their medical care, and they could choose more than one option. She said most people (17) took public transportation, and the second largest number of people walked (5). Other modes of transportation included riding a bike (2), driving their cars (2), getting a ride (2), Medicaid/Medicare transportation (4), rides from provider (1), and taxi (1). She said that 35% of respondents said they had challenges with transportation to

¹ 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.

HIV medical care. Of these, 50% were money related, 38% were caused by lateness with Medicaid/Medicare pickup, and 12% were related to scheduling. In contrast, 43% of respondents had no challenges (61% did not answer the question), and 4% reported personal challenges.

N. Johns reported that 45% of people said they had missed appointments because they did not have a way to get to the doctor, whereas 55% said they had not missed appointments because of transportation. She said that 50% of participants said they did not get help for transportation to medical appointments, while 50% did. 50% of this latter group got help from case managers, 30% from friends and family, and 20% received tokens or SEPTA assistance. Of participants who chose to share additional comments on transportation, 5 made remarks related to money (2 needed \$1 for the bus), 4 commented on scheduling and pick-up time, 1 had difficulty securing transportation, 1 had issues related to a disability, and another person needed more tokens.

N. Johns explained that the Planning Council would continue investigating issues people were having with transportation. She said if issues were mainly concentrated around Logisticare/MATP transportation, the Planning Council could share that information with the state.

N. Johns reminded the group to RSVP in advance for each month's meeting so she could order the right amount of lunches.

M. Coleman asked if any focus groups would be held soon. N. Johns said no additional focus groups were being held for the time being. She said she hoped to have her report on the high-risk heterosexual focus groups completed by the end of the year.

Discussion Item:

- **Retention in care discussion**

N. Johns stated that she'd be asking the group a series of questions. She said answers would be tabulated using clickers. She explained to the group how to use the clickers.

N. Johns asked the group how they identified. 30% identified as female and 70% identified as male. She next asked participants to select their age group. 33% selected 41-50, 50% chose 51-60, 8% selected 61-70, and 8% chose 80+. N. Johns asked respondents if they had missed a doctor's appointment in the last year because they didn't have a way to get there. 18% said yes, and 82% said no. She asked for feedback from those who had missed an appointment. E. Campbell said he missed an appointment because transportation did not come, and he didn't have tokens. N. Johns asked if participants felt it was easy to make it to doctor appointments. 42% strongly agreed that it was, 33% agreed, and 25% were neutral. She asked the group for feedback. M. Coleman said his appointments were sometimes too early. K. Carter suggested scheduling appointments at a more convenient time. J.W. said she was sometimes able to reschedule appointments. She added that her case manager helped her get day passes to travel to appointments when she could not get tokens.

N. Johns asked the group if they got tired of going to the doctor all the time. 100% of participants said they did not. She asked for feedback from the group. E. Campbell said he liked going to the doctor to learn about his health and to confirm he was still undetectable. J.W. explained that doctors sometimes delivered bad news, but she made herself go anyway because she knew it was important to be proactive about her health. D. McGee said doctors' appointments allowed her to find out information about her health that she did not know. She said this information had allowed her to manage her health conditions. E. Campbell noted that some people did not want to go to the doctor to

get tested for HIV. N. Johns explained that it was important that everyone get tested to curb new HIV infections.

N. Johns asked the group if their HIV doctor/nurse was easy to get along with. 82% said true and 18% said false. She asked the group to elaborate. J.W. said she could not always say what she wanted to her doctor. Other participants encouraged J.W. to be upfront with her doctor. K. Carter encouraged her to choose a doctor she felt comfortable with. M. Coleman stated that he was able to go to his doctor for advice about health as well as personal matters. K. Carter said other types of doctors could provide support for mental health and other outside issues. D. McGee remarked that patients could ask questions about medication. She said the doctor-patient relationship was a two-way street, and patients had choices about their treatment. E. Campbell asserted that withholding information from doctors could be harmful. He said that increased openness with his doctor had improved his health. J.W. agreed that her viral load had improved while she was in medical care.

N. Johns asked the group to agree or disagree with the statement “My HIV doctor/nurse practitioner cares about me.” 100% responded that the statement was true. E. Campbell said that it was doctors’ job to care for patients. He added that it was clear when medical providers genuinely cared about their patients. He said he felt his providers cared about him. J.W. stated that she had been very close with a previous provider. She said when the provider had retired, they kept in touch.

N. Johns asked the group to agree or disagree with the statement “I get high quality HIV care.” 100% answered true. N. Johns pointed out that the last several questions were related. She said the Philadelphia area offered excellent HIV care.

N. Johns asked the group to agree or disagree with the statement “I feel like I have all the social support I need.” 91% answered true and 9% answered false. E. Campbell said that he could always use more social support. J.W. said she received social support from her family and support groups. She said this support helped her to take her medications and stay healthy. D. McGee said she did not have the support of everyone she would like (e.g. family members). However, she said she had worked to gather the support she needed from members of the community.

N. Johns asked the group to agree or disagree with the statement “sometimes I can’t take care of myself because I’m taking care of someone else.” 9% answered true and 91% said false. D. McGee said that people had to take care of themselves before they could take care of others. J.W. said she had a natural tendency to place others first. She said she needed to remember to take care of herself as well.

N. Johns asked the group to agree or disagree with the statement “it takes too long to get to my HIV care.” She said the question referred to travel time. 30% said true, and 70% said false. A community member encouraged the group to manage their time effectively. J.W. asserted that people needed to prioritize their appointments and cancel when they could not make it on time.

N. Johns asked participants to rate their agreement with the statement “my case manager is a big help to me.” 55% strongly agreed, 27% were neutral, 9% disagreed, and 9% strongly disagreed. She asked if anyone who disagreed with the statement would like to share. K. Carter said he got transportation through his case manager from his house to doctors’ appointments. He said his case manager was supposed to take him to an appointment and had not showed up. D. McGee stated that she had answered neutral because many case managers had large caseloads and did not have the information they needed. She said she was proactive about her health and sometimes shared information with

case managers that they didn't know. She said her case manager tried hard but did not have enough resources available to her. E. Campbell said he was very satisfied with his case manager. He said she accompanied him to appointments and checked in with him about his life.

N. Johns asked the group to rate their agreement with the statement "I think the HIV service system is easy to understand and navigate." 60% strongly agreed, 30% agreed, and 10% disagreed. M. White pointed out that many services required a large amount of paperwork. D. Gana said he disagreed because of his experiences helping out newly-diagnosed individuals. He said many people were confused about services after they were first diagnosed. E. Campbell said he had gathered as much information as possible following his initial diagnosis.

N. Johns asked the group to rate their agreement with the statement "Information about HIV services is easy to find." E. Campbell said some people did not want to ask questions because of stigma and fear. 30% said they strongly agreed with the statement, 40% agreed, 20% were neutral, and 10% strongly disagreed. A participant said it was difficult for people who were new to the city to understand the service system. E. Campbell said he worked with a CAB (community advisory board). He said some members of the group were afraid to ask questions. K. Carter pointed out that privacy laws protected confidentiality.

N. Johns asked the group if they knew where to go to get all their questions about HIV answered. 82% said they did, and 19% said they did not. M. White said it was difficult to get all questions answered in one place. D. McGee said sometimes people had to go to multiple sources to get information. M. White said he wanted to access information in a timely manner.

N. Johns asked participants if they had told most of the people in their life about their HIV status. 45% said true, and 55% said false. A community member said he didn't feel it was necessary to share his HIV status with everyone. Y.D. stated that it was important to share HIV status with sexual partners.

N. Johns asked the group if they understood their health insurance and what it covered. 73% responded true, and 27% responded false. A participant said he had responded false. He explained that he'd picked up more information about his insurance coverage over time. However, he stated that he still felt he didn't have all the information that he wanted. D. Gana agreed.

N. Johns asked the group to rate their agreement with the statement "I can afford my copays." 18% answered all of the time, 18% said some of the time, 45% said never, and 18% said they did not have any copays. E. Campbell pointed out that over the counter drugs were not covered by insurance. M. White said Ryan White and other programs could sometimes be used to pay additional costs not covered by private insurance. E. Campbell said co-pays were expensive but he was willing to pay them to protect his health. J.W. said she did not pay for co-pays for most of her medications. She noted that she received her medication through a home delivery service. M. Coleman said some people had been cut off cost assistance programs. N. Johns pointed out that ADAP provided assistance with co-pays. K. Carter explained that he'd received some bills for lab work. He said his labs were not covered 100% under his insurance plan.

N. Johns asked participants if they were treated well by the front desk staff at their doctors. 100% said they were. N. Johns asked the group if they felt like their privacy was protected by their doctor and staff. 100% said they did. She asked respondents if they had felt disrespected by someone at the doctor's office in the last year. 17% said they had, and 83% said they had not. J.W. said she had felt

disrespected on one occasion. She said a staff member had not allowed her to enter the office when she arrived early for an appointment. She added that the staff member had apologized.

N. Johns asked participants if they thought free clinics provided excellent care. 55% said they did, and 45% said they did not. She asked for feedback. A participant stated that the care at free clinics did not meet his expectations. He said he felt judged in the clinic setting. He explained that he felt respected by providers, but he felt put off by the behavior of staff and other patients in the waiting room. A community member said his doctor at a free clinic was not professional. M. Coleman asserted that free clinics provided excellent service. He stated that free clinics provided outside referrals to services they could not provide in-house. However, he noted that clinics sometimes had long waits for medications. He said the waiting area for medications was not accessible for seniors.

N. Johns opened the floor for discussion on what made it hard to get to their HIV care appointments and remain in care. A community member said he had insomnia. Therefore, it could be difficult to get to appointments, especially early in the morning. E. Campbell said he preferred to schedule his appointments early in the day. He pointed out that transportation and physical disabilities or illnesses sometimes acted as barriers. He added that lack of childcare could prevent people from getting to appointments.

N. Johns asked what made it easier for people to get to appointments. M. Coleman stated that he managed his time effectively to make sure he got to appointments on time. K. Carter said he had a friend who helped him attend his appointments. He said he and his friend scheduled their appointments at similar times so they could travel together. J.W. said she prepared herself well the night before and prearranged for childcare. D. McGee said she had gotten used to attending her appointments. She explained that getting to medical appointments had become part of her routine. K. Carter pointed out that some people had reasons that it was difficult for them to get to appointments. D. McGee said that being diagnosed with HIV had changed her life in a positive way. She explained that it had caused her to care more for her health. J.W. said she still had some difficulties in her life. However, she said she did what she needed to take care of herself anyway. K. Carter said he had negative experiences in HIV care and HIV medications in the past. He said these experiences had made him wary of HIV care for many years.

N. Johns asked the group why they thought people fell out of HIV care. M. Coleman replied that depression and other mental illnesses could keep people out of care. D. McGee said people grew tired of taking their medications. She pointed out that some people had other medical conditions aside from HIV and took many medications. She added that a lack of support and encouragement could take people out of care. She pointed out that relationships and sex could be difficult to navigate for PLWHA. She added that this could lead to isolation. She stated that some people thought it was not important for them to see a doctor, particularly if things were going well in other areas of their life. A community member explained that some PLWHA had trouble accepting their status. D. Gana remarked that some people gave up on being in care.

Old Business: None.

New Business: None.

Announcements: M. Coleman said it was Bone Marrow Awareness Month.

K. Carter stated that December 1st was World AIDS Day.

M. Coleman said there were holiday volunteer opportunities at Philabundance and MANNA, along with Philly AIDS Thrift and community churches.

D. Gana stated that FACT (in Bucks County) would be holding their Gay Bingo event on December 9th from 6-10:30p.m.

Adjournment: The meeting was adjourned by general consensus at 1:53p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- October 19, 2015 Meeting Minutes
- OHP Calendar

Monday, November 9, 2015

12:00-2:00pm

Office of HIV Planning 340 N. 12th Street Suite 203
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 Ryan White Part A Planning Council and the HIV Prevention Planning Group.

○ Call to Order/Moment of Silence
Introductions

○ Approval of Agenda
○ Approval of Minutes

○ Report of Chair
• Participation
Acknowledgements

○ Report of Staff

○ Discussion Item
• Retention in care discussion

○ 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
December 14, 2015 from 12:00-2:00PM at 340 N. 12th Street, Suite 203,
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.*

**Ryan White Planning Council of the Philadelphia Part A EMA
Positive Committee
Meeting Minutes
October 19, 2015
12:00-2:00p.m.
Office of HIV Planning, 340 N. 12th Street, Philadelphia, PA 19107**

Present: PH (19), PA (2), NJ (1)

Staff: Nicole Johns, Antonio Boone, Jennifer Hayes

Call to Order/Moment of Silence/Introductions: D. Gana called the meeting to order at 12:25p.m. He read the mission statement.¹ A moment of silence followed. Those present then introduced themselves.

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

Approval of Minutes (September 14, 2015): D. Gana presented the minutes for approval. **Motion:** M. White moved, L. Way seconded to approve the minutes. **Motion passed: All in favor.**

Report of Chair:

None.

Report of Staff:

N. Johns introduced Antonio Boone, the newest OHP staff member. She stated that Antonio would be working as a Health Planner focused on HIV prevention.

Action Item:

- **Co-Chair Election**

N. Johns announced that 4 members had been nominated for Positive Committee Co-Chair. She said these included G.T., C.S., R.M., and N. Santiago. 3 of these individuals were present at the meeting. Additionally, J.M. and D. Gana were nominated for the position.

N. Johns said the vote would be conducted by a secret ballot. D. Gana stated that all nominees would give a speech about themselves and their qualifications for the position. All nominees present gave brief speeches.

After the votes were tabulated by N. Johns, Nancy Santiago was announced as the new Positive Committee Co-Chair.

Discussion Items:

- **Retention in care discussion**

Postponed until next meeting.

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- **Brainstorm future topics**

N. Johns stated that the Positive Committee often invited speakers or discussed topics of general interest at their meetings. She asked the group to brainstorm topics they'd be interested in discussing at future meetings. M. White suggested inviting Penn Dental to the group. D. Gana said the group had discussing inviting Heshie Zinman of the LGBTEI to future meetings to discuss HIV and Aging. G.T. suggested inviting a yoga instructor to meetings, and K. Carter added that the group might discuss stress reduction. D. Wingate suggested discussing ways that people who were ineligible for food stamps could obtain food vouchers.

J.G. asked the group to discuss a Medicaid card to help consumers pay for transportation. N. Santiago reported that clients needed a dollar to use Medicaid transportation. N. Johns noted that transportation had been a frequently-discussed topic in recent months. She said she'd be distributing a transportation survey at the end of the meeting today. She noted that the Planning Council did not have any authority over the Medicaid transportation program, but was investigating how Ryan White might be used to fill gaps in transportation.

K. Carter stated that an MATP representative had recently spoken to the Planning Council. He noted that she had encouraged consumers with feedback to collect detailed information before calling the state MATP program with feedback. He said MATP representatives might attend more RWPC meetings in the future. He added that consumers who had issues with Medicaid transportation could file a grievance with their case managers.

G.T. stated that she worked in Home Health Care. She explained that Home Health Care clients had to make appointments for Logisticare a week in advance. She added that clients and staff members often had to remind Logisticare providers to pick up patients.

M. Coleman suggested discussing LGBTQ youth who were homeless. He recommended the group invite YHEP to give a presentation.

N. John said anyone who wanted to make a suggestion for future topics could email or call her at any time.

M.T. suggested the office host professional development courses to help educate individuals in the community about finding jobs, furthering their careers, and re-entering the workforce after time off work. She requested that the Positive Committee invite groups to speak who helped community members stay healthy physically and mentally. She noted that patients at Esperanza Health Center participated in a course on caring for their health.

M. White stated that housing was a pressing issue for PLWHA. He suggested the group focus future discussions on housing and homelessness.

Old Business: None.

New Business:

- **Transportation survey**

N. Johns distributed a brief survey on transportation to the group. She collected the surveys after they were completed, and she said she would report back on the results in the future.

Announcements: M. White stated that a rally would be held in Harrisburg. He said transportation and food would be provided at the event.

M. Coleman stated that Philabundance needed volunteers for meal distribution during the holiday season.

K. Carter stated that a Pumpkin Ball event would be held in New Hope, PA, at the Bucks County Firehouse, on October 24th.

Adjournment: The meeting was adjourned by general consensus at 1:30p.m.

Respectfully submitted by,

Jennifer Hayes, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- August 10, 2015 Meeting Minutes
- Transportation Survey
- OHP Calendar

DRAFT