

RYAN WHITE PLANNING COUNCIL (RWPC)

**Positive Committee**  
**Meeting Agenda**  
**Monday, December 12, 2011**  
**12:00p.m.-2:00 p.m.**

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Mission Statement- The Positive Committee supports and enhances the role of people with the HIV infection to empower their participation in the decision-making process of the Ryan White Part A Planning Council and the Community Planning Group.

**Call to Order/Moment of Silence**

**Introductions**

**Member Check In** (*voluntary*)

**Approval of Agenda**

**Approval of Minutes**

**Report of Chair**

**Participation Acknowledgements**

**Report of Staff**

**Guest Speaker: A Conversation with Dr. Karam Mounzer**

**Needs Assessment Activity: Consumer Survey Pilot**

**Old Business**

**New Business**

**Announcements**

**Member Check Out** (*voluntary*)

**Adjournment**

*Please turn Phone to Silent or Vibrate*

**Don't forget to sign in by 12:30pm if you need tokens. Thanks!**

Please RSVP at 215.574.6760 to ensure that there are enough lunches.

***Please contact the office at least 5 days in advance if you require any special assistance.***

*The next meeting date and time of the Positive Committee is January 9th at noon to 2pm at the Office of HIV Planning, 340 N. 12<sup>th</sup> Street, Suite 203 Philadelphia PA 19107.*

**Ryan White Planning Council (RWPC) of the Philadelphia Part A EMA  
Positive Committee Meeting Minutes  
Monday, November 14, 2011  
12 p.m. - 2 p.m.  
Office of HIV Planning, 340 N. 12<sup>th</sup> Street, Suite 203 Philadelphia, PA 19107**

**Present:** 13(PH), 2(PA), 3(NJ)

**Staff:** Nicole Johns, Briana Morgan, Nishika Vidanage

**Call to Order/Moment of Silence/Introductions:**

M. White called the meeting to order at 12:15 p.m. A moment of silence, reading of the mission statement, and introductions of those present followed.

**Approval of Agenda:**

M. White presented the agenda for approval. **Motion:** K. Smith moved, L. Way seconded to approve the agenda. **Motion passed:** All in favor.

**Approval of Minutes (17 October 2011):**

M. White presented the October 17, 2011 minutes for approval. **Motion:** K. Smith moved, L. Way seconded to approve the minutes from the October 2011 meeting.

**Motion passed:** All in favor.

**Report of Co-Chairs:**

None.

**Report of Staff:**

N. Johns stated that ten Positive Committee members had been invited to participate in a luncheon, as they were present at a minimum of six meetings from September 2010 to August 2011. She noted that they would be attending this sponsored luncheon on the following Wednesday.

J.M. thanked the staff of the Office of HIV Planning for a wonderful presentation at St. Luke's Church. He noted that this was the third community empowerment workshop that he had attended, and that they got better each time. He also thanked OHP staff for planning the event, and encouraged those present to attend future workshops.

**Special Presentation:**

- **Managing Health Concerns Through Nutrition** – *Nicole Laverty, MANNA*

N. Laverty stated that she was a registered dietician at MANNA, a non-profit organization providing nutrition services including home-delivered meals, one-on-one counseling, and group education sessions (*see – attached slides*). She went on to say that they would be discussing heart disease and diabetes in the current meeting. She reviewed risk factors for heart disease, types of cholesterol, and triglycerides. She also discussed ideal measurements for waist size, blood pressure, triglycerides, and

cholesterol. She then reviewed food guidelines for fat, fiber, protein, and sodium, noting that fried foods should be eaten only occasionally.

N. Lavery next discussed the nature and types of diabetes. She then reviewed how and why to count carbohydrates. She finally recommended that those present eat healthfully to manage illness, and follow all guidelines from doctors and dieticians. A community member then asked how a person developed diabetes later in life. N. Lavery replied that this was sometimes hereditary, but that it was typically related to poor diet and being overweight.

### **Skills Building:**

- **Health Reform and Ryan White Clients**

N. Johns began her presentation with a brief overview of universal coverage (*see – attached handout*). She noted that the RWPC had already received a similar presentation. She then summarized the Patient Protection and Affordable Care Act (ACA), noting that all health plans would be required to provide an essential benefits package. M. White asked if transgender persons would be able to receive care under the ACA, and N. Johns agreed. She also reviewed the individual mandate, and noted that each state would have a health benefit exchange. She then discussed cost-sharing subsidies, noting that the tax credits were advanceable so the government could write a check directly to the insurer at the beginning of the year. She next stated that there would not be much of a difference for those with employer-offered health plans. She went on to say that expanded Medicaid eligibility would help to remove barriers to many who were eligible. She then discussed the idea of “no wrong door,” which would help someone to get insurance at any point of enrollment and would include one form for all types of insurance.

N. Johns moved on to review insurance type and income for the general population before reviewing insurance status and income level for Ryan White clients. She pointed out that 78% of Ryan White clients were below the poverty line. She then stated that the Comprehensive Planning Committee would be reviewing gaps between Medicaid and Medicare and the standards for HIV care. She next provided income estimates for PLWHA in the Philadelphia EMA, and concluded the presentation by providing her resources.

### **Discussion Items:**

- **Outreach Activities for 2012**

R.P. asked what outreach activities the Positive Committee had done in the past. W. Walters replied that they had gone to MANNA on several occasions. She then suggested volunteering at SHARE, a program that provides food at significantly reduced cost. She explained that clients could receive an entire Thanksgiving dinner for \$7, or a box of steaks for only \$14. H. Bennett then suggested reaching out to men’s group at the Care Clinic. He also suggested reaching out to the Partnership and the Lax Center. N. Johns replied that this could be a good start to 2012, explaining that the Positive Committee could begin by reaching out to groups at medical providers before expanding.

**Old Business:**

None.

**New Business:**

None.

**Announcements:**

W. Walters announced that New Voices would be hosting a World AIDS Day celebration at Community Hospital on Friday, December 2. H. Bennett asked for more information about New Voices. W. Walters replied that this was a group that aimed to raise awareness of HIV in Delaware County.

N. Johns announced that there would be an event on housing with Jim McDermott on Friday, November 18 at the University of Pennsylvania. N. Vidanage noted that an RSVP was required.

**Adjournment:**

The meeting was adjourned at 2:03 p.m. by general consensus.

Respectfully Submitted by,

Briana L. Morgan, Staff

**Handouts distributed at the meeting:**

- Meeting Agenda
- Meeting Minutes for October 17, 2011
- Nutrition Matters Slides
- Affordable Care Act and Ryan White Program Slides
- OHP Calendar

**Please tell us about the HIV-related services you receive.**

23. Is there one place you usually go for your HIV medical care (such as physical exams, CD4 tests and medications)? (check one)

- Yes
- No → skip to #28
- Don't know → skip to #28

24. How long has this been your main source of HIV medical care? (fill in one)

\_\_\_\_\_ months or  
\_\_\_\_\_ years

25. In the past 12 months, how many times did you see a doctor or nurse practitioner for HIV care? (check one)

- One
- Two
- Three or more times
- Did not see anyone or get any care

26. If you need to see your HIV medical provider for an illness, how long do you usually have to wait to get an appointment? (fill in one)

\_\_\_\_\_ days or  
\_\_\_\_\_ weeks

27. In the past six months, did you ever need HIV medical care but could not get it? (check one)

- Yes
- No

28. If you don't have a main source of medical care for HIV treatment, what is the reason? (check all that apply)

- I do have a regular place for care
- Can't afford it
- Don't know where to find it
- Could not get regular appointments anywhere
- Don't think it is needed
- Didn't try to get care, though it seemed necessary
- Didn't want to get care
- Don't know where to find someone who speaks my language
- Another reason not listed above

29. Do you have an HIV/AIDS case manager? (check one)  
(Case manager can be a social worker, nurse, staff member of a service organization, or someone else who is assigned to help you get and coordinate your HIV care.)

- Yes
- No → skip to #31
- Don't know
- Not applicable

30. If you have an HIV/AIDS case manager did they do the following? (check all that apply)

- Help you to determine the services you needed
- Help you find the services you needed
- Follow up to see that you got the needed services
- Provide a referral for the needed services

31. Are you currently taking any antiretroviral medicines to treat your HIV?

- Yes → skip to #33
- No

32. What are the reasons you aren't currently taking any antiretroviral medicines? (check all that apply)

- Doctor told me to delay treatment
- Just started medical care
- Haven't had time
- CD4 (T-cell) count and/or viral load are good
- Feel good, don't need them
- Worried about side effects
- Drinking or using drugs
- Didn't want to think about being HIV positive
- No money
- No insurance
- Kept forgetting to take my medications
- I am currently homeless
- Taking alternative/complementary medications
- Another reason not listed above

33. Is there anything else you want to say about trying to get HIV-related services? (if you need more space please use the back side of this page)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

→ The skip from question # from question #34

34. In your opinion what would help people to get into HIV care? (Please explain):

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Please tell us about your medical history**

35. What medical/health insurance do you have now? (check all that apply)

- None
- Health insurance through work, school or union (Private)
- Health insurance bought directly and paid in total by yourself or your family (self insured)
- Medicare (for people who are 65+ years old or disabled)
- Medicaid or Medical Assistance (MA), Health Choices or Access Card
- Champus, TRICARE or CHAMP-Veterans Administration (VA)
- AIDS Drug Assistance Program (ADAP)
- Another insurance type not listed above

36. Is there a place you usually go for a regular medical visit, like a doctor's office or clinic? (check one)

- Yes
- No → skip to #38

37. In the last 12 months, how many times did you see a doctor or nurse practitioner?  
\_\_\_\_\_ number of times in the last 12 months

38. Do you have dental insurance now? (check one)

- Yes
- No

39. Is there a place you usually go for dental care, like a dentist's office or clinic? (check one)

- Yes
- No → skip to #41

40. In the last 12 months, how many times did you get dental care?  
\_\_\_\_\_ number of times in the last 12 months

41. The last time you needed medical care but did not get it, what was the main reason? (check all that apply)

- Couldn't afford it
- Didn't know where to get care
- Couldn't get an appointment
- Didn't try to get care, though it seemed necessary
- Had too many other things to worry about
- Didn't know where they spoke my language
- Didn't like my medical provider
- Was depressed
- Was actively using a substance
- Did not have transportation
- Couldn't get off work
- Was too sick to go
- Had to take care of someone else or needed child care
- Another reason not listed above

42. (For women): Do you get gynecological (GYN) care, where you go for most of your medical care? (GYN care includes PAP smears and pelvic exams.) (check one)

- Yes
- No
- Not applicable

43. (For women): When was the last time you received GYN care? (check one)

- Within 12 months
- Between one and two years ago
- More than two years ago

44. Did you need and get mental health care or counseling services in the last 12 months? (check one)

- I needed and got mental health care or counseling services in the last 12 months
- I needed but did not get mental health care or counseling services in the last 12 months
- I did not need mental health care or counseling services in the last 12 months

45. Did you need and get drug or alcohol treatment services in the last 12 months? (check one)

- I needed and got drug or alcohol treatment services in the last 12 months
- I needed but did not drug or alcohol treatment services in the last 12 months
- I did not need drug or alcohol treatment services in the last 12 months

46. In your opinion, why are people not in HIV care? (check all that apply)

- They don't qualify for the services
- They don't know about the service or where to go for help
- They don't try to get the service
- They have no way to get there
- They have too many other things going on
- They have to care for someone else
- They are not ready to get into HIV care
- They are actively using drugs
- They don't have insurance
- They lack information on available resources
- They are depressed
- They are homeless
- They are in denial
- Because side effects to the medications
- Because of the fear of being out/confidentiality concerns/disclosure concerns
- Another reason not listed above

47. Have you been offered any of the following HIV prevention services (check all that apply)
- STD testing at your HIV medical care provider
  - Condoms or safe sex kits
  - Safer injection/bleach kits
  - Information on needle exchange programs
  - Information on HIV counseling for pregnant women
  - Street outreach (a person gives you info. about STDs on the street)
  - Partner notification (assistance contacting previous sex partners after positive diagnosis)
  - Information on substance use treatment programs
  - Information on how to tell someone about your HIV status (disclosure)
  - None of the above
  - Another prevention service not listed above (please specify) \_\_\_\_\_

48. Have you talked to a Doctor within the past 5 years about birth control, family planning or having a baby?
- Yes
  - No
  - Don't know

49. Are there other services you felt you needed in the last 12 months but did not get? Please write them in the box below.

Service needed but did not get	Reason did not get service

50. Is there anything else you want to say? (if you need more space please use the back side of this page)

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51. Please check off all the services that you are using or have used in the past year:

- AIDS Pharmaceutical Assistance (Emergency Medications)
- Child Care Services
- Dental Care
- Direct Emergency Financial Assistance (DEFA)
- Early Intervention Services (HIV testing & follow-up care for those newly diagnosed)
- Food Bank/Home Delivered Meals
- Health Education/Risk Reduction
- Health Insurance Premium/Cost Sharing Assistance
- Home & Community Based Health Services
- Home Health Care
- Hospice Services
- Housing Assistance Services
- Legal Services
- Medical Care (i.e. Doctor's visit)
- Medical Case Management
- Medical Nutritional Services
- Medical Transportation Services
- Mental Health Therapy/ Counseling
- Outreach Services
- Psychosocial Support Services
- Rehabilitation Care
- Respite Care
- Substance Abuse Treatment/Counseling
- Translation & Interpretation/Linguistic
- Treatment Adherence
- I have not used any of the services in the past year

13. How would you best describe your sexual orientation? (check one)

- A man who has sex only with women (heterosexual male)
- A man who has sex only with other men (homosexual male)
- A man who has sex with both men and women (bisexual male)
- A woman who has sex only with men (heterosexual female)
- A woman who has sex only with women (lesbian)
- A woman who has sex with both men and women (bisexual female)
- A transgender/transsexual who has sex only with women
- A transgender/transsexual who has sex only with men
- A transgender/transsexual who has sex with both men and women
- A transgender/transsexual who has sex with other transgender/transsexual
- Unsure/questioning my sexual preference
- Another description not listed above \_\_\_\_\_

14. Have you ever gotten tested for HIV?

- Yes
- No → skip to #16
- Don't know

15. What was the main reason you got tested for HIV? (check one)

- I was at risk for HIV
- Partner suggested I get tested
- Doctor suggested I get tested
- Possible exposure through work
- Just to find out if I was infected with HIV
- As a part of a routine medical check up
- Because I felt sick
- Because of pregnancy
- For life or health insurance
- For military purposes
- For immigration purposes
- No reason
- Unsure
- Another reason not listed above \_\_\_\_\_

16. I am responding to the questions on this survey as: (check one)

- an individual who is HIV positive
- a community representative/service provider who is HIV positive
- an individual who is NOT HIV positive → skip to #34
- unknown status → skip to #34
- Another description not listed above (please specify) \_\_\_\_\_

Questions 17 through 33 only apply for those who are HIV positive. If you're NOT HIV positive skip to question #34

Please tell us about your HIV history.

17. When did you learn you were HIV-positive? (check one)

- During 2011
- 2006-2010
- 2001-2005
- 1997-2000
- 1992-1996
- 1991 or earlier
- Don't know

18. Did you learn you had AIDS at the same time that you were diagnosed with HIV? (AIDS is defined as a HIV positive individual who has a CD4 (T-cell) count less than 200 and/or an opportunistic infection) (check one)

- Yes
- No, that was later
- No, I have not been diagnosed with AIDS
- Don't know

19. How do you believe you got HIV/AIDS? (check one or two)

- I had unprotected vaginal sex with someone who had HIV
- I had unprotected anal sex with someone who had HIV
- I had unprotected oral sex with someone who had HIV
- By sharing needles or syringes (including those used for steroids) with someone who had HIV
- Infection during pregnancy, childbirth, or breast feeding
- Another way not listed above \_\_\_\_\_

20. What is your most recent CD4 (T-cell) count? (check one)

- Less than 200
- 200-500
- Over 500
- Never received a CD4 (T-cell) count
- Don't know

21. What is your most recent viral load? (check one)

- Undetectable
- Detectable but less than 5,000 viral copies/ml
- 5,000 to 100,000 viral copies/ml
- Greater than 100,000 viral copies/ml
- Never received a viral load test
- Don't know

22. After you learned you had HIV or AIDS, how soon did you seek HIV-related medical care? (check one)

- Have not had care yet
- Right away
- Within 6 months of learning my diagnosis
- Within a year of learning my diagnosis
- More than one year
- When I got sick
- Another time frame not listed above, please specify \_\_\_\_\_

CONSUMER SURVEY 2012

1. How did you get this survey? (check one)

An agency mailed it to me

An agency person gave it to me

Online/web

Another source not listed above

A friend or relative gave it to me → skip to #3

2. If you got the survey through an agency, please tell us the type of agency. (check one)

Clinic/Health Center or hospital

Case manager

Outreach worker

Drug and Alcohol treatment provider

Mental health service provider

HIV/AIDS service agency

Community agency (not an HIV/AIDS service provider)

Another agency type not listed above

**Please tell us about yourself. This will help with understanding service needs.**

3. I am (check one)

Female

Male

Transgender/Transsexual/ Intersexed

Another answer not listed above (please specify)

4. What is your age? \_\_\_\_\_

5. What is your ethnicity? (check one)

Hispanic/Latino (a)

Non-Hispanic/Non-Latino (a)

6. What is your race? (check one)

Asian

African American/Black

Caucasian/ White

Native American/Alaskan Native

Native Hawaiian/Pacific Islander

Biracial/Multiracial (please specify)

Another race not listed above (please specify)

7. What language do you speak most of the time? (check one)

English

Spanish

Asian Languages (i.e. Chinese, Korean, Vietnamese, etc.)

Another language not listed above (please specify)

8. What is the highest education level you completed? (check one)

8<sup>th</sup> grade or less

Some high school, but did not graduate

High school graduate or GED

Some college, but did not graduate

Vocational/Technical certification

College graduate (2 or more years degree)

Another answer not listed above (please specify)

9. What kind of housing do you have now? (check one)

Rent or own house or apartment (non subsidized)

Housing for people living with HIV/AIDS (HOPWA)

Staying with family or friends

Transitional (i.e. Halfway houses or drug treatment program)

Shelter (homeless or other)

Section 8/Assistant Housing

On the street – no home

Another type of housing not listed above (please specify)

10. What is your annual income? (check one)

Less than \$10,000

\$10,000 - 19,999

\$20,000 – 29,999

\$30,000 – 39,999

\$40,000 – 49,999

\$50,000 or more

11. What is your Zip Code? \_\_\_\_\_

12. What county do you live in now? (check one)

Burlington County, New Jersey

Camden County, New Jersey

Gloucester County, New Jersey

Salem County, New Jersey

Bucks County, Pennsylvania

Chester County, Pennsylvania

Delaware County, Pennsylvania

Montgomery County, Pennsylvania

Philadelphia County, Pennsylvania

Another county not listed above (please specify)

52. Rate the following services categories by the level or importance to you (choose one response for each service category)

	Not Important	Somewhat Important	Very Important	Not Sure
AIDS Pharmaceutical Assistance (Emergency Medications)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child Care Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Direct Emergency Financial Assistance (DEFA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Early Intervention Services (HIV testing & follow-up care for those newly diagnosed)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food Bank/Home Delivered Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Education/Risk Reduction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Insurance Premium/Cost Sharing Assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home & Community Based Health Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home Health Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospice Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing Assistance Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Care (i.e. Doctor's visit)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Case Management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Nutritional Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical Transportation Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental Health Therapy/ Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outreach Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychosocial Support Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respite Care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Substance Abuse Treatment/Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment Adherence Counseling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing this survey.

Please place this survey in the postage paid envelope provided and mail as soon as you can.