

**Ryan White Planning Council (RWPC) of the Philadelphia Part A EMA
Needs Assessment Committee**
Meeting Minutes of
Monday, November 14, 2011
2:00 p.m. – 4:00 p.m.
Office of HIV Planning, 340 N. 12th Street, Suite 203, Philadelphia, PA 19107

Present: Christine Ambrose, Naseem Bazargan (Co-Chair), Dawna Edwards-Watson (Co-Chair), Kevin Huang, Gerry Keys, Kevin Smith

Excused: Amy Eusebio

Staff: Debbie Law, Briana Morgan, Nishika Vidanage

Call to Order/Introductions:

D. Edwards-Watson called the meeting to order at 2:20 p.m. All those present introduced themselves.

Approval of Agenda:

D. Edwards-Watson presented the agenda for approval. **Motion:** C. Ambrose moved, K. Smith seconded to approve the agenda. **Motion passed:** All in favor.

Approval of Minutes (October 17, 2011):

D. Edwards-Watson presented the October 17, 2011 minutes for approval. **Motion:** C. Ambrose moved, D. Edwards-Watson seconded to approve the October 2011 minutes. **Motion passed:** All in favor.

Report of Co-Chair:

D. Edwards-Watson stated that the co-chair position for the Needs Assessment Committee was still vacant, and asked anyone interested in the position to speak with D. Law.

Report of Staff:

None.

Discussion Item:

• **Plan for the 2012 Consumer Survey**

D. Law noted that the committee calendar was included in the meeting packet (*see – attached handout*). She stated that Office of HIV Planning staff had spoken with the other organizations that they had discussed partnering with, and that they had found that the other organizations were on a shorter timeline than the OHP. She went on to say that staff had also brainstormed some ideas for outreach. D. Edwards-Watson stated that she had many contacts at recovery houses and shelters so it would be easy for her to reach out to them in order to promote the survey.

D. Law next stated that the wording in the survey had been simplified, although some questions could not be simplified to a third-grade reading level. She noted that they did include a suggestion in the introduction for those taking the survey to ask their case managers for assistance if need. D. Edwards-Watson agreed that it would be impossible to reduce the survey to a third-grade reading level. She noted that the typical standard for documents was a sixth-grade reading level to an eighth-grade reading level.

D. Law then stated that they had been asked to include a question on whether the respondent had translation available at his or her doctor's office, but that a similar question was asked elsewhere. She went on to say that they had also been asked to include a question on whether respondents had been asked to participate in clinical trials, but the group agreed that this question was not relevant to the RWPC's work. She added that the survey could be test-piloted with the Positive Committee at their December 12 meeting.

D. Law next stated that the survey packet would be placed in a 6 x 9" manila envelope, and would include a cover letter from the agency to its clients, a return envelope, the survey itself, a flat pocket first aid kit, an AACO hotline card and condom instructions. She noted that they had discussed including condoms, but that this had not been approved. D. Edwards-Watson stated that they might not want condoms to go through the mail because they could be damaged. C. Ambrose then suggested asking providers to give condoms to clients that completed the survey. D. Edwards-Watson next asked if the condom instruction card included instructions for both male and female condoms. D. Law replied that she had not yet seen the card. She noted that they may include a flier for the spring social in the mailing if they had details available. C. Ambrose suggested including palm cards with the Office's social media sites in the packet as well.

D. Law noted that the Needs Assessment Committee would be taking time at its next meeting to formulate questions for Evelyn Torres' (AACO) presentation at the Comprehensive Planning Committee's January meeting.

D. Edwards-Watson suggested emailing RWPC members to see when they would be available to stuff survey packet envelopes. D. Law replied that they would try to find a time for everyone to meet that would not conflict with other meetings. She noted that they would also like to make packets for those that could distribute surveys at group meetings. She then stated that they had also previously asked providers to leave drop boxes for surveys in their waiting areas. She went on to explain that they would follow up with providers in March, and begin initial analysis in April. C. Ambrose noted that a script for phone calls to providers would be available.

D. Law then distributed draft copies of the consumer survey (*see – attached handout*). C. Ambrose stated that it would be important to add the names of each of the nine counties to the cover letter. She then stated that she thought that question #35 was oddly placed. D. Law replied that those that were HIV-negative would skip to question #35, but that #35 could be moved to #23. D. Edwards-Watson then suggested clarifying #35 so it read, "Medicare (for people who are disabled and/or 65 years and older)." C. Ambrose

suggested putting “welfare” next to Medicaid. D. Law replied that they had previously considered this, but chose not to use the term “welfare” due to a negative connotation. The group then agreed to leave #35 at its current position in the survey.

D. Law noted that question #46 was supposed to read, “In your opinion, why are people not in HIV care?”

D. Edwards-Watson next stated that she had an easy time taking the survey as a test. K. Smith agreed that taking the survey had gone well, though he found some questions confusing. He then stated that some consumers had Medicaid or Medicare in addition to third-party insurance. K. Huang stated that he had a hard time reading the survey due to the lack of contrast in colors. He then stated that the question on race did not ask for specific responses for someone identified as biracial/multiracial. N. Bazargan suggested asking those that considered themselves biracial/multiracial to “check all that apply.” D. Law explained that this would cause them to count some respondents twice, and noted that the list of races was based on a list from the CDC. She then noted that biracial consumers represented approximately 2% of PLWHA. N. Bazargan asked how those that wrote their race in the survey would be counted. D. Law replied that they had previously been individually listed, adding that they had not had many biracial respondents in the last round of the survey.

K. Huang stated that many HIV-positive Asians would not be able to complete the survey if they were monolingual. D. Law replied that they were asking providers to help clients to fill out the surveys. She went on to say that they would ask providers to do this while making their initial phone calls.

D. Law next stated that she had formatted the survey including many different shades of gray so the group would be able to determine which shades provided the best contrast. K. Huang asked if it was necessary to have some of the text on a gray background, rather than using a white background alone. He explained that it would be more difficult for some people to read black text on a gray background. D. Law replied that they had followed the format from the census. She explained that they had found that an all-white background was visually confusing, and those taking the survey had a difficult time following it.

Action Item:

- **Co-Chair Position**

C. Ambrose stated that N. Bazargan had accepted the nomination for the position of Needs Assessment Committee co-chair. **Motion passed: 4 in favor, 0 opposed, and 0 abstentions.**

Next Steps:

D. Edwards-Watson stated that there would be a joint meeting for committee co-chairs on Thursday, December 8 from 1 p.m. – 2 p.m. She added that the next Needs Assessment Committee meeting would be on Monday, December 12.

Old Business:

None.

New Business:

None.

Announcements:

N. Bazargan stated that she would be instructing TEACH Outside classes at Philadelphia FIGHT beginning in January.

K. Huang announced that ASIAC would be holding a preliminary presentation on its needs assessment for Asians and Pacific Islanders on December 20.

Adjournment:

Motion: K. Smith moved, N. Bazargan seconded to adjourn the meeting at 3:22 p.m.

Motion passed: All in favor.

Respectfully Submitted by,

Briana L. Morgan, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- Meeting Minutes from October 17, 2011
- Needs Assessment Committee Calendar 2011 – 2012
- OHP Calendar

RYAN WHITE PLANNING COUNCIL (RWPC)

Needs Assessment Committee

Meeting Agenda

Monday, November 14, 2011

2:00p.m.-4:00 p.m.

Office of HIV Planning 340 N. 12th St. Suite 203, Philadelphia PA, 19107

Call to Order/Introductions

- The Needs Assessment Committee reviews and recommends needs assessment, epidemiological data, research, and other informational activities and other activities as assigned by the Planning Council.

Approval of Agenda

Approval of Minutes (*October 17, 2011*)

Report of Co-Chairs

Report of Staff

Action Item

- Co-chair Position

Discussion Item

- Plan for the 2012 Consumer Survey

Next Steps

- Joint Co-chair Meeting 12/8
- Next Meeting 12/12

Old Business

New Business

Announcements

Adjournment

Please turn Phone to Silent or Vibrate

The next meeting date and time of the Needs Assessment Committee will be December 12, 2011 from 2 pm-4pm. at the Office of HIV Planning, 340 N. 12th St. Suite 203, Philadelphia PA 19107

Please refer to the Office of HIV Planning's attached Calendar of Events or its website, www.hivphilly.org, for updated committee meeting information.

If you require any special assistance, please contact the office at least 5 days in advance.

Needs Assessment Committee

2011-2012*

<p>September <i>Begin developing list of activities to address for the upcoming year based on priority setting decisions</i></p> <p>Self Assessment Module</p>	<p>October <i>Finalize developing list of activities to address</i></p> <p>Develop timeline for upcoming year</p> <p>Finalize Self Assessment Module</p>	<p>November <i>Finalize plan for needs assessment activities for following year</i></p> <p><i>Begin plan for needs assessment activities for following year</i></p> <p>Finalize Consumer Survey questions</p>	<p>December . 12 <i>Begin process of implementing needs assessment activities</i></p> <p>Questions for CSU?</p> <p>Start assembling CS packets</p> <p>Test pilot survey 12/12</p>
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<p>January . 9 <i>Finalize implementation and begin needs assessment activities for year</i> <i>-Start Town Hall recruitment</i></p> <p>Joint mtg w/ CPC on CSU by E. Torres</p> <p>Contact providers for CS mailing</p> <p>Finalize CS packets & start distribution</p>	<p>February . 13 <i>Finalize implementation and begin needs assessment activities for year</i></p> <p>2nd phase of CS distribution</p>	<p>March .12 <i>Ongoing needs assessment activities</i> <i>- Regional Town Halls</i></p> <p>Follow-up w/providers on CS</p>	<p>April <i>Ongoing needs assessment activities</i> <i>- Regional Town Halls</i></p> <p>CS 1st cut-off analysis</p> <p><i>Ongoing analysis of data</i></p>
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<p>May <i>Results from Town Hall</i> <i>Results from Epi</i></p> <p>2nd phase of CS promotion</p> <p>Prepare for Priority Setting - Review summarized data results?</p>	<p>June <i>Review 1st level CS analysis</i></p> <p>continue CS promotion</p>	<p>July <i>Evaluate process for past year</i> <i>Debrief planning year</i></p>	<p>August <i>Evaluate process for past year</i> <i>Start SAMS</i></p> <p>Plan Activities for next Cycle</p>
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Parking Lot: Postive women who want to have babies

**Ryan White Planning Council (RWPC) of the Philadelphia Part A EMA
Needs Assessment Committee
Meeting Minutes of
Monday, October 17, 2011
2:00 p.m. – 4:00 p.m.
Office of HIV Planning, 340 N. 12th Street, Suite 203, Philadelphia, PA 19107**

Present: Christine Ambrose (Co-Chair), Henry Bennett, Dawna Edwards-Watson (Co-Chair), Amy Eusebio, Pamela Gorman, Kevin Huang, Gerry Keys, Kevin Smith

Excused: Naseem Bazargan

Guests: Sharee Heaven, Gary Tumolo, Robert A. Woodhouse

Staff: Debbie Law, Briana Morgan, Nishika Vidanage

Call to Order/Introductions:

C. Ambrose called the meeting to order at 2:20 p.m. All those present introduced themselves.

Approval of Agenda:

C. Ambrose presented the agenda for approval. **Motion:** G. Keys moved, A. Eusebio seconded to approve the agenda. Motion passed: All in favor.

Approval of Minutes (September 12, 2011):

C. Ambrose presented the September 12, 2011 minutes for approval, reminding those present that they had worked on the SAMS and discussed the survey during their September meeting. She noted that they had lost some staff at the Office due to budget cuts, so they would need to make special considerations with the survey. She added that they would also need to develop a new Comprehensive Plan, which would affect how they conducted the survey with limited staff and limited resources. **Motion:** K. Smith moved, G. Keys seconded to approve the September 2011 minutes. Motion passed: All in favor.

Report of Co-Chair:

None.

Report of Staff:

D. Law reported that the regularly scheduled joint co-chair meeting hosted by the Nominations Committee would be held from 1 p.m. – 2 p.m. on November 10. She noted that this would be the same day as the happy hour, which would be an informal social event from 4 p.m. – 6:30 p.m.

B. Morgan reported that the Office had sent out its first email newsletter at the beginning of the month, and that anyone interested in being added to the email list could give her their email addresses.

Discussion Items:

- **Co-Chair Position**

C. Ambrose stated that she would have to step down as co-chair of the Needs Assessment Committee after being elected as the co-chair of the RWPC. She noted that her schedule had also changed, so she would no longer be able to stay until the end of Needs Assessment Committee meetings. D. Law then stated that any nominees for co-chair of the Needs Assessment Committee would have to be an RWPC member in good standing for at least a year. C. Ambrose suggested N. Bazargan as a possible new co-chair, although she was not at the present meeting. D. Law replied that she would contact N. Bazargan to see if she would accept the nomination. She added that the committee would be able to vote on this at the next meeting if N. Bazargan accepted the nomination.

- **Plan for the 2012 Consumer Survey**

D. Law stated that the Office had been informed that certain agencies would be conducting community assessments on the general population. She explained that Office staff had spoken with some of these agencies about collaborating on the consumer survey, even though the target population was different. She further explained that they could have respondents skip HIV-related questions if they were not positive. She went on to say that they planned to collaborate with Action AIDS and Mazzoni, and that the collaboration had been approved by AACO. She also stated that this would allow them to send the survey to a broader audience while cutting costs, citing a cost of \$25,000 for the mailing alone of the last survey.

C. Ambrose asked for more information about the agencies receiving these grants. B. Morgan replied that these two agencies had received grants to establish community health centers. C. Ambrose then replied that she was concerned that they may not have a diverse group of respondents through only working with two agencies. D. Law explained that the surveys would be distributed to all Ryan White providers as before, but that they would also be collaborating with two providers to reach an even broader audience.

G. Keys stated that the committee had brainstormed on ways to cut costs at their previous meeting, and asked how this idea had come about. D. Law replied that the idea of collaborating had arisen at a meeting at AACO. C. Ambrose then suggested inviting these organizations to a future committee meeting. D. Law explained that they had wanted to conduct a web-based survey in addition to a paper survey, and that these two providers could help with advertisement and staff support as well as mailing costs. D. Edwards-Watson asked how aggressive they planned to be in getting the surveys back. D. Law replied that this would be up to the committee.

D. Law then began to review the survey timeline (*see – attached handout*). She went on to say that they had had a list of 122 providers for the last survey, and that they were able to contact 110 of these. She noted that 66 of the agencies that they had been able to contact were willing to participate in the survey. She then stated that the Office was looking into first aid kits and Philadelphia Freedom condoms as possible incentives for the survey. She also stated that surveys would be color-coded based on area and method of distribution.

C. Ambrose stated that the committee had previously discussed contacting executive directors to follow up on the surveys, and went on to say that they would be more successful if they contacted the head of case management at each agency. P. Gorman suggested emailing executive directors to ask for point persons at each agency.

K. Huang next stated that it would not always be best to try to reach clients by mail, since many clients did not want to receive mail at home. He noted that high rates of illiteracy would also make it difficult to get responses. C. Ambrose replied that her agency had staff that helped clients to fill out surveys while they were in the office. She noted that they had previously assigned this task to a social work intern so the person taking the survey would not feel influenced. A. Eusebio agreed that she had similar concerns, since her agency saw many Spanish-dominant speakers. She noted that her agency would have a staff person available to help clients complete the survey. P. Gorman stated that she was also concerned since 45 – 47% of Camden residents were Hispanic. She went on to say that staff at her agency would help clients to complete surveys in person, but that they would not be able to provide this support with mailed surveys. G. Tumolo stated that they had heard that outreach to homeless people, both on the street and in shelters, was very important. He noted that these people may not be in care. He went on to say that they had also heard that it would be important to provide support for those that speak Spanish and Asian languages, as well as for the deaf and hard-of-hearing. K. Huang stated that he was working on a cultural competency toolkit, and added that translation would not be inexpensive. He then asked how long the survey would be. D. Law replied that the survey would be approximately eight pages. K. Huang replied that it may be worth the cost to translate the survey into Spanish. D. Law added that they would need to utilize bilingual volunteers.

C. Ambrose then stated that committee members could stuff envelopes for the mailing during its meetings. She also suggested joining with the Positive Committee to have a mailing party. She explained that they could be creative in helping staff and reducing the cost of the survey.

D. Law next reviewed a draft copy of the survey with the group. She noted that they had tried to reduce the number of pages in the survey so it would weigh less for mailing. K. Huang stated that high contrast was very important for those with visual disabilities, and added that the minimum font size should be 12-point. He added that he could forward information on accessibility guidelines. D. Law replied that they had followed the census format. P. Gorman then stated that she could see literacy challenges with these forms. She went on to say that she was not sure if it would be advisable to mail these surveys. C. Ambrose stated that they would need to find the easiest way possible to ask the survey questions. P. Gorman also stated that the survey was written at a high reading level. K. Huang noted that many non-English speakers could read at a third-grade reading level. D. Edwards-Watson stated that individual agencies could choose to help its clients complete surveys in person. She then noted that the recommendation for Philadelphia was a sixth-grade reading level.

D. Law continued reviewing the survey, pointing out that the new ranking question included choices of “not important,” “somewhat important,” “very important,” and “not sure.” K. Huang suggested providing bigger spaces for questions #49 and 50, as respondents would provide more information in a larger space. P. Gorman asked for more information about the responses from the last survey. D. Law replied that they had a response rate that was over 10%, and that they found that respondents were less likely to answer open-ended questions. She added that respondents from the previous survey did not know what ambulatory care was, so they changed this to “medical care/doctor’s visit.” P. Gorman clarified that there would be a letter to providers explaining why the survey was important, and D. Law agreed.

P. Gorman stated that she did not see any questions about research, and asked if they would like to ask such a question. She explained that Ryan White required providers to collaborate with research agencies and provide access to clinical trials. D. Edwards-Watson suggested adding a question such as, "Have you ever participated in a clinical trial at your agency."

- **Complete Self-Assessment Module Survey (SAMs)**

D. Law explained that the Needs Assessment Committee completes an annual four-part survey to analyze how effective the needs assessments were and how they could improve. She went on to say that they would be discussing the success of the analysis. The answers to the questions were as follows:

26. 3pts

27. 3pts

28. 3pts

29. 3pts D. Law explained that Office staff reported what worked and did not work to the Needs Assessment Committee. She went on to say that they would discuss areas they did not reach. She then stated that they looked at how they had conducted a town hall in Delaware County but not the other three PA Counties, so they had missed some groups. P. Gorman then asked where the New Jersey town hall was held. D. Law replied that it was in Camden. P. Gorman asked what they thought was an adequate sample size. D. Law replied that they did not have a minimum sample size, but that they had seen burnout amongst consumers. D. Edwards-Watson noted that they did notify providers of upcoming events.

30. Yes, yes

No, no D. Edwards-Watson stated that they had had a hard time reaching this population, and G. Keys agreed.

Yes, yes

Yes, yes

Yes, yes

Yes, yes

No, no D. Edwards-Watson stated that it was harder to reach sex workers as well.

No, no D. Edwards-Watson stated that this was another population that had been hard to reach. P. Gorman suggested targeting federally qualified health centers (FQHCs) that focused on homeless persons, and also suggested contacting Project HOPE. R. Woodhouse stated that homeless persons had health needs that needed to be addressed.

Yes, yes

No, no K. Smith noted that this was a hard-to-reach population.

No, no

Yes, yes R. Woodhouse stated that some people found out that they were positive in prison.

D. Law stated that they had been successful in reaching this population.

Yes, yes

30a. 3pts P. Gorman asked how this was addressed. D. Law explained that they reviewed surveillance data and intake data from AACO.

30b. 3pts K. Huang stated that these questions provided an opportunity to find out whether consumers' doctors provided interpretation services. P. Gorman stated that medical case management agencies should provide interpretation as well.

30c. G. Keys suggested adding pregnant women, sex workers, homeless persons, and runaway/street youth to their list. P. Gorman suggested focusing on perinatal groups

receiving federal funding in order to reach pregnant women. K. Huang stated that many women used midwifing services, and asked if there were agencies that govern those services. P. Gorman replied that pregnant women had to be tested at the 36th week of their pregnancy, and if they had not been tested at delivery, they were required to test then. G. Keys clarified that they were only required to offer the test. The group then agreed to try to reach homeless populations through FQHCs.

31. 3pts

32. 3pts

33a. 3pts

33b. 3pts

33c. 3pts

34. 3pts

35. 3pts

35a. 3pts

36. D. Law stated that the only population that they targeted but did not reach was the adolescent population.

37. 3pts

37a. 3pts

38. 3pts

38a. 3pts

39. 3pts

40. 3pts

41. 3pts

Yes

Yes

Yes

Yes

Yes

Yes

Worked well: D. Law stated that surveillance data worked, and G. Keys stated that literature reviews had worked.

Room for improvement: P. Gorman stated that they could expand the scope beyond HIV providers.

42. 3pts

43. 3pts

44. 3pts

45. 3pts

46. 3pts

3pts

47. 3pts

Worked well: A. Eusebio stated that it was good to use these in the Comprehensive Plan and Priority Setting process.

Room for improvement: P. Gorman suggested working outside of HIV and including prevention agencies as well. R. Woodhouse added that anything could be improved.

Old Business:

None.

New Business:

K. Huang stated that ASIAC would be conducting a needs assessment for Asian/Pacific Islanders, and that he was seeking support from the RWPC. He explained that they had already conducted an extensive literature review on Asians/Pacific Islanders and HIV, as well as other health-related issues. D. Law replied that it would be helpful if K. Huang were able to provide updates at the Needs Assessment Committee meetings. She went on to say that they could also discuss results and methodology. K. Huang stated that he could compare his survey with the RWPC's consumer survey in order to develop similar questions. He explained that this would enable them to compare results. He went on to say that they were currently conducting policy review and epidemiological research, and would then hold community forums. D. Law asked if K. Huang would be able to conduct a presentation on their progress. K. Huang and D. Law then suggested working toward having such a presentation at the December meeting.

Announcements:

None.

Adjournment:

Motion: G. Keys moved, K. Smith seconded to adjourn the meeting at 3:57 p.m. **Motion passed:** All in favor.

Respectfully Submitted by,

Briana L. Morgan, Staff

Handouts distributed at the meeting:

- Meeting Agenda
- Meeting Minutes from September 12, 2011
- 2012 Consumer Survey Timeline
- Needs Assessment – Self-Assessment Module (SAMS)
- OHP Calendar

CONSUMER SURVEY, 2012

Ryan White Part A Planning Council
and the Office of HIV Planning
Philadelphia EMA

DRAFT

INSTRUCTIONS AND CONFIDENTIALITY

If you have already filled out and returned this survey, please ignore this mailing. Various agencies are sending the surveys, and you may receive services from more than one.

Thank you in advance for helping with this survey. We are trying to understand the service needs of people living with HIV/AIDS. Your input is very important. The survey was sent to you by one of your service providers. That agency is noted on the enclosed cover letter.

The attached survey asks about HIV-related services. It includes items about your HIV history, service use, and factors affecting services. It also asks for some personal information, such as age and ethnic group. However, your personal information will not be connected with your responses. Your responses will be grouped with those of others. The information is for the Ryan White Part A Planning Council. The Council helps plan HIV/AIDS services in Philadelphia, as well as four counties in South Jersey and four in suburban Pennsylvania. Your local service provider is working with the Office of HIV Planning to do this survey for the Council.

It is your choice to take part in the survey or not. Your decision will not affect whether you get services from any agency. There are no right or wrong answers. It is important that you answer as honestly as you can. If you are not comfortable with a question, you can skip it and go to the next one. However, it is important that you answer as many as you can.

Contacts

- For help in completing the survey, please contact your case manager, or the service agency listed on the cover letter.
- If you need HIV-related care or services, please call the agency listed on the cover letter.
- If you have any questions about this survey, please contact the Office of HIV Planning (215) 574-6760.

If you choose to do the survey, please return it to the Office of HIV Planning in the enclosed envelope within two weeks of receiving it. A small incentive is enclosed as tokens of appreciation for your time.

Thank you for your help.

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
- 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)

- 8th 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)

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 #
- 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 #33
- Another description not listed above (please specify) _____

Questions 17 through 22 only apply for those who are HIV positive. If you're are NOT HIV positive skip to question #35 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 _____

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

34. 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)

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 and older)
- 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 #37

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 #39

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 HIV 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 get 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. 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)

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 Educations/Risk Reduction
- Health Insurance Premium/Cost Sharing Assistance
- Home & Community Based Health Services
- Home Health Care
- Hospices 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

52. Rate the following services categories by the level of importance to you (choose one response for each service category)				
	<i>Not Important</i>	<i>Somewhat Important</i>	<i>Very Important</i>	<i>Not Sure</i>
AIDS Pharmaceutical Assistance (Emergency Medications)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Child Care Services	<input type="checkbox"/>	<input checked="" 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 checked="" 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 checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health Educations/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"/>
Hospices Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing Assistance Services	<input checked="" 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.