

D. NEEDS ASSESSMENT

1. CONSUMER SURVEY, 2001-02 (selected results)¹

The consumer survey examined service access and use by people living with HIV/AIDS, barriers to services, and characteristics of those with unmet needs. While it was primarily done for the Ryan White Title I Planning Council, it also had items that were relevant for prevention. The survey encompassed the nine counties of the metropolitan area. That included Philadelphia County; the four New Jersey counties of Burlington, Camden, Gloucester, and Salem; and the four Pennsylvania suburban counties of Bucks, Chester, Delaware, and Montgomery. The services included medical and dental care, and other HIV-related services. To better understand service access and use, logistic regression models were developed. They examined factors associated with having been tested later in disease stage, having entered medical care late, having had dental care, and having case management. All results discussed here were statistically significant ($p < .05$), unless otherwise noted. Statistical tests were done as part of the logistic regression models, and the odds ratios were given. In addition, chi-square tests were done with categorical variables.

Survey participants were mainly reached through providers, due to confidentiality of mailing lists. The Office of HIV Planning sent batches of survey packets to 40 agencies serving people living with HIV/AIDS (PLWHA) in the nine-county area. Enough surveys were sent for a systematic sample of 20% of clients, or every fifth person on the agencies' mailing lists. Such sampling decreased the likelihood of multiple mailings to people who received services from more than one agency. Providers were asked to include those who had lapsed from care as well. Providers were HIV/AIDS service organizations, medical services, case management and other social services, and substance abuse treatment. Confidentiality information was included with survey instructions for the participants, and the packets each contained a small 'thank you' gift. The surveys were anonymous, so there was no follow-up mailing for non-responders. The return envelopes for respondents were addressed to the Office and were postage-paid.

In addition, several agencies were interested in reaching those who might not respond to a mail survey. They were sent additional copies of surveys, and the agencies administered them personally to people in clinics, agencies, or drop-in centers. Nearly 3,400 surveys were sent from the Office. That included 2,600 mailed in packets and 750 provided to those who wanted to individually administer them. About 280 were in Spanish, and the others were in English. There were no requests for translation into other languages.

Descriptive information. Demographics were run by region. These included gender, ethnicity, age group, and language, along with socioeconomic variables such as education and housing. Other HIV and care data were run by region for descriptive and planning purposes.

Logistic regression models. Two models examined factors related to HIV care that were relevant for prevention. They looked at those who were tested late in their disease stage and those who entered HIV care later. The first model looked at the "late testers," who were 26% of the respondents. They found out they had AIDS at the same time they learned they had HIV. They

¹ Section developed from work done by Laureen Lopez and Aneez Agha of the OHP.

were compared to those who learned they had AIDS at a later time, or who were not yet diagnosed with AIDS. Those who did not remember were not included.

The second model examined the factors related to getting medical care right after diagnosis. Two-thirds of respondents had gotten care right after diagnosis. They were compared with those who got HIV care later in their disease stage. Later care included 6-12 months after diagnosis, having waited until they were sick to get care, or not yet having care. This section also looked at those who were diagnosed more recently (1997-2001). They were compared with those diagnosed in 1996 or earlier. That was to explore why time of diagnosis was significant in several models.

The models looked at the factors related to the outcomes of interest. They included age as a continuous variable (18 years and older). The factors that had multiple categories were recoded into two-category variables (with a value of 0 or 1). They were as follows: Gender (male vs. female and transgender), education (high school diploma/GED or college vs. no high school diploma), HIV diagnosis time (1997 or later vs. 1996 or earlier), IDU exposure or not, heterosexual exposure or not, ethnicity (African American vs. all others), housing (own/rent vs. all other), region (Philadelphia vs. NJ4 and PA4). Some of the groups were too small to analyze separately, and combining them with other groups seemed a better solution than leaving them out of the analysis. That was the case for transgender people, as well as some ethnic groups. They were still looked at individually, when that factor was important in the model. Any differences were noted in the text.

Respondents

There were 724 responses to the survey. By region, the respondents reflected the proportions of the epidemic (Figure 1). There were 69% from Philadelphia, 14% from the four southern New Jersey counties, and 17% from the four Pennsylvania suburban counties.

There were 711 responses to county of residence. The responses from Philadelphia are shown in Figure 2 by Health District. The districts were estimated from Zip Codes. About 21% of those from Philadelphia did not provide a Zip Code, so they were not included here. The largest groups of responses were from North Philadelphia (HD 5 and HD 6), the Frankford/Richmond area (HD 7), and South Philadelphia (HD 2).

Figure 1. Survey responses by region

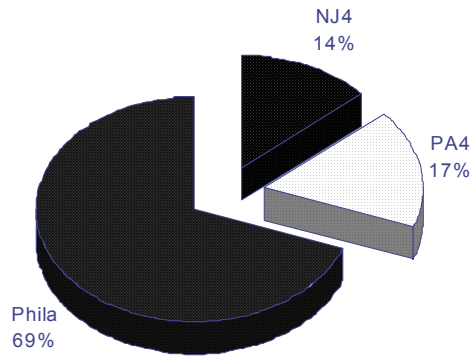
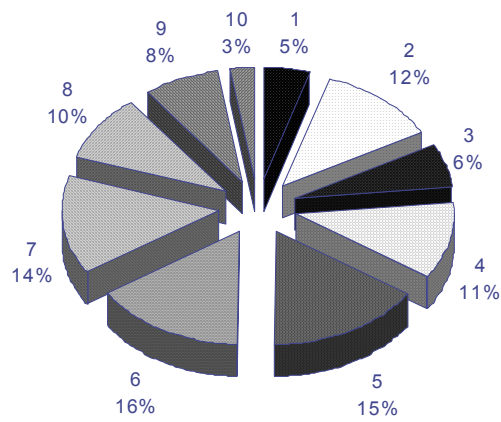


Figure 2. Responses for Philadelphia by Health District (est. from Zip Codes)



Late testers

Many people delay testing, and therefore care, for months or years after infection. This logistic regression model examined the characteristics of those who were tested later in disease stage (26%). That is, they learned they had AIDS at the same time as they were diagnosed with HIV. They were compared to those who did not have an AIDS diagnosis (42%) or who learned they had AIDS later (29%). Those who did not recall their status at time of diagnosis were excluded from this analysis (n=20).

The results for this and other regression models show the final models. They have the factors that were significantly related to the outcome of interest. That includes the odds ratio (OR) for that factor and its 95% confidence interval (CI) or range. A probability (p value) of .05 was used as the cutoff for statistical significance. That means there was only a 5% chance that it was a random result rather than a real difference. In some cases, results that were nearly significant were noted, if they were important (p<.10). Aside from the regression models, other significant results were from chi-square tests of categorical (group) variables.

The odds ratio (OR) indicated that males were nearly 1.7 times more likely to be late testers than females and transgender people (Table 1). Those with at least a high school diploma were less likely to be late testers, as the odds ratio was less than one (OR = 0.62). Those who were diagnosed in 1997-2001 were nearly 1.6 times more likely to be late testers than those who were diagnosed earlier. The latter was also before the widespread availability of highly active antiretroviral therapy (HAART).

Table 1. Final model for “late testers”

(n = 648) Factors	p value	Estimated odds ratio	95% CI for odds ratio
Gender (male vs. female and transgender)	.009	1.67	(1.14, 2.43)
Education (high school grad/GED or college vs. no high school diploma)	.014	0.62	(0.42, 0.91)
HIV diagnosis time (1997-2001 vs. before 1997)	.018	1.56	(1.08, 2.24)

Table 2 shows the percentages for each group compared in the model for late testers. These were straight percentages, while the models tested for differences after adjusting for the previous variables. However, the percentages can help identify the differences for planning purposes. The table shows that more of the males were late testers (29.5%) compared to females and transgender people (23%). Of the 10 transgender people, 4 had been late testers.

Table 2. Comparisons of factors for “late testers”

Factors in final model	Not late tester	Late tester
Gender		
Female and transgender	77.0%	23.0%
Male	70.5%	29.5%
Education		
Less than HS grad	68%	32%
High school or more	75%	25%
HIV diagnoses		
1996 or earlier	76%	24%
1997-2001	68%	32%

Fewer of those who were high school graduates were late testers (25%), compared to those without a high school diploma (32%). Within the latter group, there were somewhat more late testers among those with an eighth grade education or less (37%) than among those with some high school (31%). There was no difference in late testers between those with a high school diploma and those with some college or more (25% each). Those diagnosed with HIV in 1997-2001 were more likely to be late testers (32%) than those diagnosed before 1997 (24%). Those diagnosed in 1997-2001 are examined further below.

The model was examined for Philadelphia alone, as there was interest for prevention planning. The relationship held for education ($p < .05$), but not for the other variables in the model. That can happen when the sample size decreases. However, the percentages were similar and they are shown below (Table 3). Fewer of those with a high school diploma or GED were late testers (24%) than those who did not finish high school (34%).

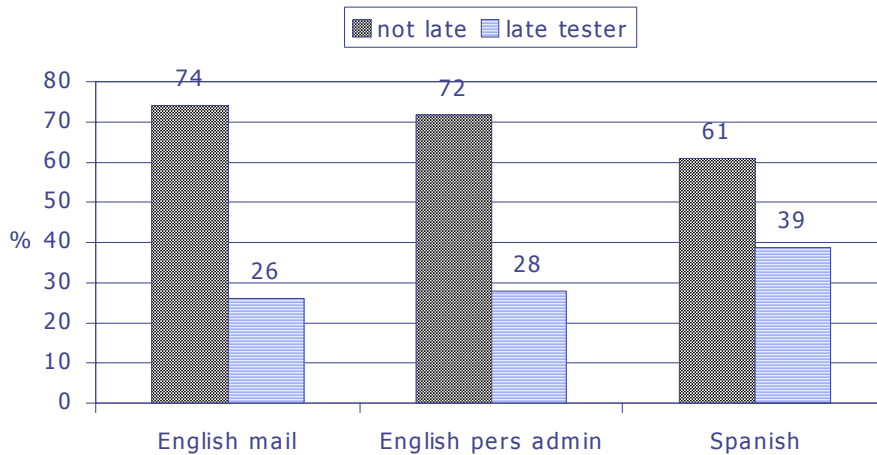
Table 3. Factor for late testers in Philadelphia

Factor	Not late tester	Late tester
Education*		
Less than HS grad	66%	34%
High school or more	77%	24%

* $p < .05$

More of those who completed a Spanish-language survey ($n=39$) were late testers (Figure 3). That is, 39% learned they had AIDS at the same time they learned their HIV status. Their results can be compared to the results for those who completed an English-language survey that was mailed (26%) or personally administered (28%). Those groups were much larger, however.

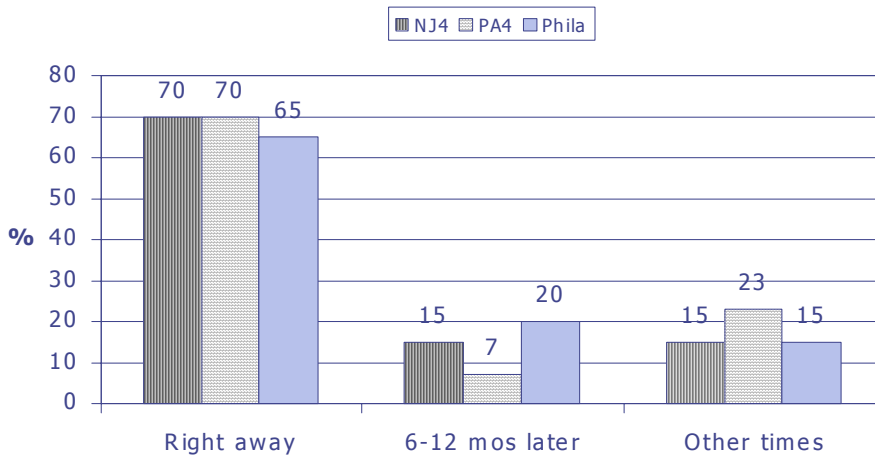
Figure 3. Survey format by late tester or not (%)



Care right after diagnosis

The logistic regression model examined those who reportedly got medical care right after being diagnosed (67%). They were compared with the 33% who said they got care six or twelve months later (17%) and other times (16%). The latter included those who got care when they became sick, got care some other time, and those who had not had care yet. Among those who had checked 'other,' 14 listed times from 2 to 6 years, and 6 people said 10 years or more. Figure 4 shows some differences in when people got care.

Figure 4. Time of getting care by region



There were also some differences by survey format. Those who completed a mailed survey in English were less likely to have gotten care right away (64%) than those who completed a personally administered survey (73%) or one in Spanish (74%), most of which were personally administered.

Model for getting care right away

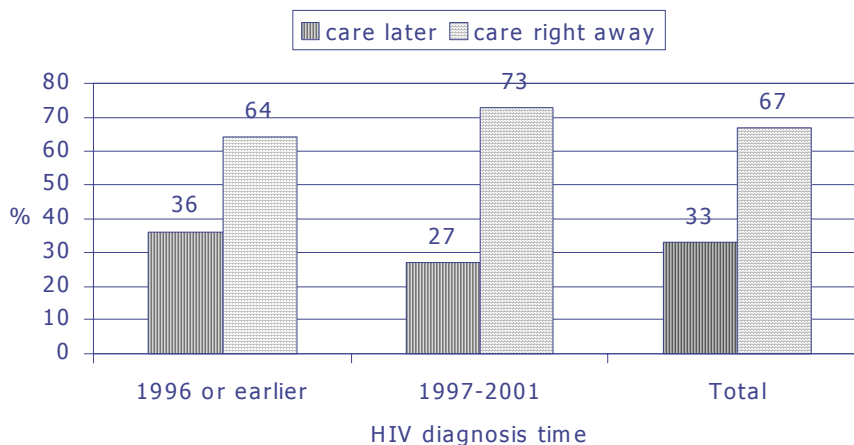
The only factor that was significant in the logistic model was time of HIV diagnosis (Table 4). Those who were diagnosed with HIV in 1997-2001 were about 1.5 times more likely to have gotten care right after diagnosis. The cutoff year of 1997 was chosen due to the wider availability of HAART by that time.

Table 4. Final model for “care right away”

(n = 682) Factors	p value	Estimated odds ratio	95% CI for odds ratio
HIV diagnosis in 1997 – 2001 (vs. diagnosed before 1997)	.018	1.52	(1.07, 2.15)

To help in interpreting the model, Figure 5 shows the percentages for each category. Overall, 33% got care later. That was consistent with national estimates for people living with HIV/AIDS who were out of care. Of those diagnosed in 1997-2001, 73% had gotten care right away, compared to 64% of those diagnosed before 1997. This group was examined separately, and the results are shown later. They were more likely to have been diagnosed with AIDS at the same time they learned they had HIV. They may have been tested when they went for care.

Figure 5. HIV diagnosis time by care right away or not (%)



This model was also examined for Philadelphia alone, as there was interest for prevention planning. The concern was about linking prevention with care. The relationship was not significant with the smaller numbers for Philadelphia alone. However, the percentages were similar, and they are shown in Table 5.

Table 5. Philadelphia: HIV diagnosis time by care right away

HIV diagnoses	Care later	Care right away
1996 or earlier	37%	63%
1997-2001	30%	71%
Total	34.5%	65.5%

HIV diagnosis time

This section was intended to explore why those diagnosed more recently (34%) were important in several models. They included those who learned they were HIV positive in 1997-2001 (8% in 2001 and 26% in 1997-2000). HAART was widely available by 1997. They were compared with those who learned before 1997 (33% in 1992-1996 and 31% in 1991).

This logistic regression model was exploratory, since it was done after the other models (Table 6). Those diagnosed more recently were more likely to be African American (OR = 1.62), but less likely to be male (OR = 0.66). Those diagnosed in 1997-2001 were less likely to live in Philadelphia than in the surrounding New Jersey and Pennsylvania counties (OR = 0.68). The model for medical insurance, shown earlier, indicated that those diagnosed in 1997-2001 were more than twice as likely to be uninsured (OR = 2.36). Having dental insurance was not related to HIV diagnosis time.

Table 6. Final model for “HIV diagnosis time”

(n = 676) Factors	p value	Estimated odds ratio	95% CI for odds ratio
Ethnicity (African American vs. all others)	.005	1.62	(1.16, 2.27)
Gender (male vs. female and transgender)	.014	0.66	(0.48, 0.92)
Region (Phila vs. NJ4 and PA4)	.029	0.68	(0.48, 0.96)

The percentages help illustrate the model (Table 7). More of those diagnosed in 1997-2001 were African American (39%) than all others (29%). Within the “all other group,” there was little difference, for those diagnosed 1997-2001 were 30% of Caucasians, 30% of Latinos, and 24% of the remaining group (Asian and Pacific Islander, American Indian, and Other).

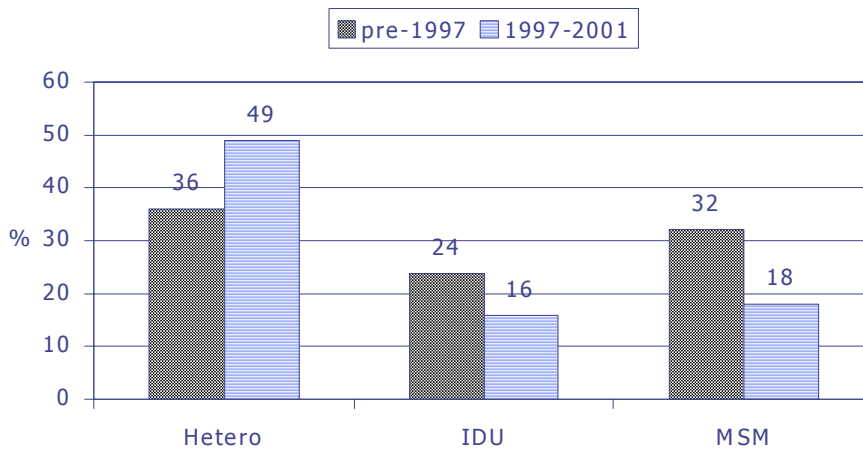
Table 7. Comparisons of factors in model for “HIV diagnosis time”

Factors in final model	Diagnosed 1996 or earlier	Diagnosed 1997-2001
Ethnicity		
All other groups	71%	29%
African American	61%	39%
Gender		
Female and transgender	60%	40%
Male	69%	31%
Region		
NJ4 and PA4	61%	39%
Philadelphia	67%	33%

Fewer of those diagnosed in 1997-2001 were males (31%) than females and transgender people (40%). Of the 11 transgender people in this analysis, 9 were reportedly diagnosed in the earlier time period (before 1997). Those diagnosed in the later period were less likely to live in Philadelphia (33%) than in the surrounding counties (39%). There was no difference between the NJ4 and the PA4 in the percentages of those diagnosed 1997-2001 vs. before 1997.

For descriptive purposes, exposure groups were examined by HIV diagnosis time (Figure 6). There were more respondents with heterosexual contact who were diagnosed in 1997-2001 (49%) than diagnosed in 1996 or earlier (36%). There were fewer MSM in the later group (18%) than in the earlier one (32%). There were also fewer IDU in the later period (16%) compared with the earlier one (24%).

Figure 6. Exposure group by HIV diagnosis time



There were some differences by survey format as well. Of those who completed an English survey by mail, two-thirds were diagnosed before 1997. That compares to 55% of those who did a personally administered survey in English, and 82% of those with a Spanish-language survey.

Sources of care information

There was interest in knowing where people got most of their information about HIV care. That can help with planning. People were asked to check up to three items. They were listed in order of most frequently mentioned (Table 8). The most common source was medical care provider (64%). Case manager was next (39%), and it differed by region. More of those in the PA4 said case manager (55%) than those in Philadelphia (38%) or the NJ4 (25%). Next were newspapers or magazines (18%) and brochures (17%). Many checked ‘other’ sources, including noted HIV/AIDS service organizations (n=19), drug and alcohol treatment programs and/or support groups (n=12), and clinics or doctors’ offices (n=5).

Table 8. Where you get most information about HIV care

Sources (% who checked the item)		NJ4 (n=96)	PA4 (n=116)	Phila (n=499)	Total (n=711)
Medical care provider (doctor or nurse practitioner)	N %	64 67%	69 60%	319 64%	452 64%
Case manager	N %	24 25%	64 55%	190 38%	278 39%
Newspapers or magazines	N %	19 20%	23 20%	89 18%	131 18%
Brochures	N %	20 21%	17 15%	83 17%	120 17%
Family or friends	N %	18 19%	18 16%	53 11%	89 13%
Health department staff (other than doctor or nurse)	N %	9 9%	11 10%	66 13%	86 12%
Outreach worker	N %	12 13%	7 6%	56 11%	75 11%
Radio or television	N %	8 8%	10 9%	41 8%	59 8%
Internet	N %	17 18%	12 10%	30 6%	59 8%
Other source	N %	12 13%	16 14%	61 12%	89 12%

By survey format, there were differences. Fewer of those who completed Spanish surveys got HIV information from medical care providers (54%) than the other groups (62% - 64%). Far more got information from their case managers (64%), compared to the others (34% - 39%). More also used radio or television (26%), compared to the others (7% - 8%).

Compared to those who did English surveys by mail, more of the others said other health department staff (15% - 22%). Fewer of those who were personally administered in English used newspapers or magazines as a source (13%), compared to the other groups (20% - 28%).

2. CARE OUTREACH SURVEY (selected results)²

Care outreach workers were surveyed for information to complement the consumer survey. The intent was to see what barriers they perceived in trying to help people get HIV care. Factors related to getting care may also be similar to those for getting tested, and hence, can be relevant for prevention. That was evident in the focus group on linking prevention and care, which is discussed later in this section.

Mailings were sent to 23 agencies identified as having care outreach in the nine-county metropolitan area. Each outreach coordinator was sent surveys, with a request to distribute them to their outreach workers. The surveys each had a cover letter, an explanation of the purpose and confidentiality issues, and a postage-paid self-addressed return envelope. The surveys were anonymous. There were 36 responses out of an estimated 80-85 care outreach workers in the area. Many survey items were multiple response questions, so the percentages totaled more than 100%.

More than half of the respondents (61%) had been working in outreach for a year or more, while the others had been doing this work for less than a year. Most were involved in targeted street outreach (72%) as well as loss to medical care (69%). Many were also involved with links from testing (39%).

Respondents worked in the various regions of the EMA, according to the counties they checked. Of the eight from the NJ4, all worked in Camden County, but two were in other counties as well. Issues in Camden are relevant for Philadelphia, due to similarities in the populations and the epidemic. From the PA4, there were four who worked in either Delaware or Montgomery County. Twenty worked in Philadelphia, and they were asked to identify the Zip Codes in which they did most of their work. The listed Zip Codes were compared with the Health Districts (HD) to provide some context. There were several mentions each of Zip Codes in North Philadelphia, Olney Oak area, Frankford/Richmond area, and Germantown. There was one mention of a Zip Code in South Philadelphia and one in West Philadelphia.

Care issues for PLWH

Participants were asked for reasons they thought PLWH were not getting care. This included questions about PLWH in general, questions focused on the population(s) they knew best, when they thought people should begin HIV care, reasons for not completing referrals, and where they felt PLWH generally got information about HIV care.

General reasons people were not in HIV care

Most (83%) felt that people were generally not in HIV care due to active substance use (Table 1). That is not surprising, given that two-thirds reported that drug/substance abusers were a population of focus for them. The majority also felt people were not in care because they could not afford it or did not have insurance (53%). That suggested that more and better information about Ryan White CARE funding could help such people get care. Another major reason was not trusting agencies or providers (50%).

² Section developed from work done by Laureen Lopez and Aneeza Agha of the OHP.

Many responded that potential clients did not want to get care (44%), felt they did not need care (39%), did not get care due to depression (39%), or did not know where to find care (25%). Some of these responses also suggested that more and better information could facilitate getting people into care.

Table 1. General reasons PLWH may not get regular HIV care

Reasons checked by care outreach workers	Number	Percent
Active substance use	30	83%
Can't afford it or don't have insurance	19	53%
Don't trust many agency people or providers	18	50%
Don't want to get care	16	44%
Don't think they need care	14	39%
They are depressed	14	39%
Don't know where to find care	9	25%
Can't find a provider who speaks their language	5	14%
Other	7	29%

Percentages for types of outreach add to more than 100% due to multiple responses.

Group Outreach workers knew best

Most (72%) felt that the reasons for not being in care differed across groups. They were asked which group they felt they knew best, which could have been the group of focus they mentioned previously. The fill-in answers were grouped for analyses (Figure 1). The groups included drug or substance users (39%), African Americans (14%), Hispanics/Latinos (14%), African Americans with another characteristic such as substance use (14%), and other groups (21%). 'Other' included responses of multiple groups or additional groups such as minority teens and young adults or people with mental illness.

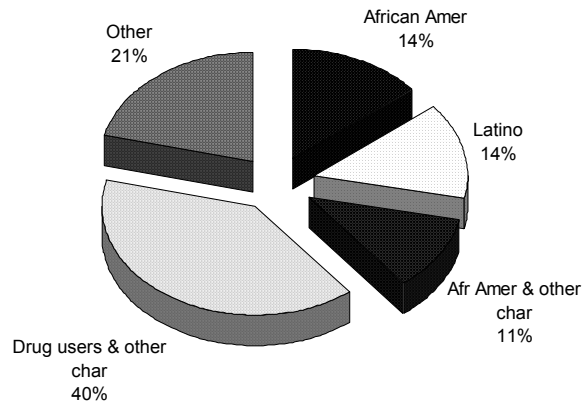
The proposed reasons for a certain group not being in care (Table 2) were similar to those given in general. Nearly all mentioned active substance use (93%), followed by lack of trust in agencies and providers (69%). Others said depression (48%), can't afford it or don't have insurance (45%), don't think they need care (38%), or don't want to get care (35%). Other issues included apathy, denial, culture (care only for emergencies), and too many barriers.

Table 2. Why group you know best is not in regular care

Perceived reasons	Number	Percent
Active substance use	27	93%
Don't trust many agency people or providers	20	69%
Can't afford it or don't have insurance	13	45%
They are depressed	14	48%
Don't think they need care	11	38%
Don't want to get care	10	35%
Don't know where to get care	6	21%
Other	5	17%

Percentages for types of outreach add to more than 100% due to multiple responses.

Figure 1. Group you know best (n=28)

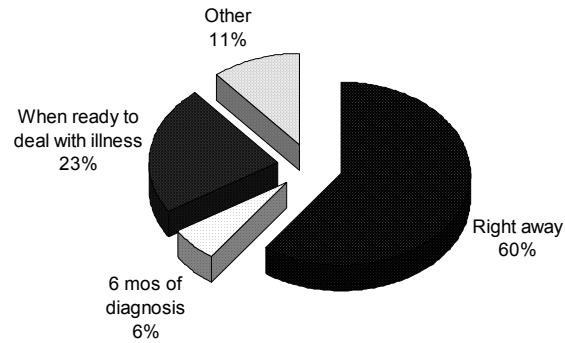


It appeared that care outreach workers were often trying to reach people from varying backgrounds. They may have been working with two or more ethnic groups and genders. The lifestyle issues that affect care were many and complex. They included drug use, homelessness, and mental illness. Many were concerned that they needed more time and resources to help clients with multiple problems and issues. Those data are shown later.

When people should get care

The outreach workers were asked when they thought people who were HIV-positive should get HIV care (Figure 2). This was similar to an item on the consumer survey. Of the 35 who responded, 60% felt they should get care right away. The other 40% felt they should get care later (within six months of diagnosis, when ready to deal with illness, or other). Some checked more than one response, so they were included in 'other.' They were 'right away or within six months' and 'right away or when they feel ready to deal with their illness.' The percentages for responses varied a little by length of service. However, the difference was not significant even with a 2 x 2 table for analysis (right away vs. later, and less than a year vs. a year or more).

Figure 2. When you think PLWH should get HIV care (n=35)



Where PLWH get most information about HIV

Responses varied for where they thought PLWH got most of their information about HIV care (Table 3). The question was also asked on the consumer survey. The most responses were for medical care provider (58%), followed by outreach worker (53%). Additional responses included case manager (44%), health or social service agency (42%), health department staff (other than doctor or nurse) (31%), or family and friends (31%).

Table 3. Where most PLWH get information about HIV care

Perceived sources of information	Number	Percent
Medical care provider (doctor or nurse practitioner)	21	58%
Outreach worker	19	53%
Case manager	16	44%
Written material at health or social service agency	15	42%
Health department staff (not doctor or nurse practitioner)	11	31%
Family or friends	11	31%
Radio or television	5	14%
Newspapers or magazines	3	8%
Other source	2	6%

Percentages for types of outreach add to more than 100% due to multiple responses.

Factors that could help care outreach

The respondents checked multiple items that could help them with helping people get HIV care (Table 4). The leading item was more time to handle multiple needs of clients (46%), followed by different hours (24%) and locations (21%) for outreach. Additional responses were less staff turnover (18%), more bilingual staff or interpreters (15%), and shorter times to appointments (12%).

Table 4. Changes that could help with helping PLWH get into care

What could help	Number	Percent
More time to handle many needs of clients	15	46%
Different hours for outreach	8	24%
Different location for outreach	7	21%
Less staff turnover	6	18%
More bilingual staff or interpreters	5	15%
Shorter time to care appointments	4	12%
Other	11	33%

Percentages for types of outreach add to more than 100% due to multiple responses.

They were asked what skills or knowledge would help them help people get care (Table 5). The most common response was better ways to locate people who need help (47%), followed by greater knowledge of HIV/AIDS services in the area (33%). The next items were more cultural sensitivity or understanding and ways to talk with people to get them into care (28% each). Greater knowledge of HIV/AIDS care was also mentioned by 17%.

Table 5. Skills or knowledge to help PLWH get into care

Skills or knowledge	Number	Percent
Better ways to locate people who need help	17	47%
Greater knowledge of HIV/AIDS services in area	12	33%
More cultural sensitivity or understanding of client culture	10	28%
Better ways to talk with people to help them get care	10	28%
Greater knowledge of HIV/AIDS care	6	17%
Other skill or knowledge	7	19%

Percentages for types of outreach add to more than 100% due to multiple responses.

3. ISSUES IN LINKING PREVENTION AND CARE (focus group summary)³

The Positive Committee planned the focus group, with the assistance of the Office of HIV Planning (OHP) and Community Planning Group members. It was intended to help inform planning for prevention and care services. Participants included members of the Positive Committee, as well as people living with HIV whom they recruited. It was held in March 2002.

Participants were asked questions about what helped them get tested for HIV, barriers to being tested in their communities, what interventions they thought would be most helpful in their communities and where interventions should be provided. There were also questions about when they got medical care after learning they were HIV-positive, barriers to care in their communities, and what might help prevent transmission.

Testing issues

Most participants were tested as part of another process. They had not planned to get tested for HIV, nor did they respond to an intervention or message. Some were prompted because others had gotten sick, or they wanted a partner to get tested. Several had been tested many times, but did not expect to become infected, even though they knew they were at high risk. Most did not recall any particular prevention interventions that seemed relevant to them. Many felt that young people thought they were invincible and would not get infected.

There were many reasons in their communities for not being tested. They included denial of being at risk, fear of finding out they had HIV and the stigma of having it, and fear of losing their job or insurance. Also, people don't get tested because there are no signs of the disease. You can't tell you have it.

Prevention interventions

People generally talked about the ones in which they participated. They included giving information and condoms to sex workers on the street. However, several people mentioned the need for more and better programs to reach young people, including those in school. One said seeing a hip-hop star get tested might help. Another thought billboards in the community might lead people to being tested eventually.

When asked about the best locations for programs, they felt that people went to places other than where they lived for high-risk activities. They also felt it was helpful to provide HIV information at concerts. It was suggested that giving information at nightclubs was more useful than handing it out in the streets. People would stop and ask questions in the clubs, more than they would on the streets. Some felt that handouts were not useful, since many people threw them away. Others thought it was worthwhile if a few read them.

Medical care issues

Participants varied regarding when they got medical care after learning they were positive. One went right away, because there was a system in place. Another said four months, while others mentioned years. Many said people did not get care because they were in denial. They may not

³ Section developed by Lauren Lopez from work that included Mari Ross-Russell, the Positive Committee and CPG members.

go until they get sick. If it doesn't hurt yet, they don't go. Others had relocated to another state and got much better access to care.

Preventing transmission

This was considered a difficult issue, since it was easy to blame the person with the disease. It was also felt you could help people take better care of themselves and help them prevent transmission to others. There was a need to include PLWH in prevention messages. However, participants felt some people did not want to address having the disease themselves. Several thought their providers had given them good information about preventing transmission.

In a separate discussion, participants talked about how people might feel fine knowing they had the disease their partner had, and choose not to have safe sex. Others felt that some people did not care if they got infected since they felt they had little to lose, while others suggested that some people wanted others to get infected.

Participants

Of the nine participants, there were six males, and the others identified as female or transgender. Their average age was 41 years, and ranged from 26 to 55 years old. There were six African Americans, and the others were Caucasian/White or American Indian. All reportedly had a high school diploma or GED, and six had some college or a degree. For housing, six rented or owned their homes. The others were in housing for PLWHA, staying with family or friends, or in transitional housing.

Six were from Philadelphia and the others were from Burlington and Camden Counties. Five were diagnosed before 1997, including several before 1991. They were generally not "late testers." That is, hardly anyone was diagnosed with AIDS at the same time they learned they had HIV. They generally learned that later or had not been diagnosed with AIDS. For HIV exposure, five noted they were men who had sex with men, while the others noted heterosexual contact, transfusion, or did not know.

4. TOWN HALL MEETINGS (summary)⁴

The Positive Committee of the Philadelphia EMA Ryan White Title I Planning Council and Philadelphia Prevention Community Planning Group (CPG) set as one of its goals the development and implementation of town hall meetings as a way to increase community participation and involvement. In the Fall 2001, meetings were held in Philadelphia and Camden to hear from consumers. A meeting in the Pennsylvania suburbs was cancelled. The Committee wanted the voices of those living with HIV/AIDS in the community to be heard, and their needs given full consideration in the decision-making processes and needs assessments of the Planning Council and the CPG.

There were many issues mentioned at the meetings, since they were open to any comments about HIV services or interventions. About 24 people spoke at the two meetings. Major issues included developing more services that were appropriate for youth, both for prevention and care; having more consumer involvement in planning and speaking out; getting more information to those who needed it for prevention, testing, and care; and improving coordination and communication across agencies. Several people mentioned case management. Some wanted to see improvements in case management services, while others wanted to see consumers taking more responsibility for their own care.

There were several mentions each of the continuing needs for substance abuse treatment, mental health services, transportation, housing, and medications. A few people said there was a need to focus on specific populations, such as African Americans, Latinos, or women. Other issues had single mentions, and they included dental outreach and training for hospice workers.

There was a voluntary information card for attendees. Of those who used the form in Philadelphia, about 75% were African American, 13% were Asian and Pacific Islander, and 13% were Hispanic/Latino. In New Jersey, 50% were African American, 33% were Caucasian, and 17% recorded Other ethnic groups. In Philadelphia, males were 50%, females 40%, and transgender 10%. In New Jersey, 33% were male and 67% were female.

⁴ Section developed by Lauren Lopez from work done by Ericka Harden-Dews (OHP) and the Positive Committee.

