

Out of Care Study: Phase Two

CAREAssist Client Follow-Up Study

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Out of Care Study: Phase Two

Background

Estimate of Unmet Need

In 2000, the Ryan White CARE Act implemented requirements that Title I and Title II grantees and planning bodies should determine the number of HIV-positive people aware of their status but not receiving primary medical care. HRSA defines a person as having an Unmet Need for primary medical care when “there is no evidence that s/he received any of the following three components of HIV primary medical care during a defined 12-month time frame: (1) viral load (VL) testing, (2) CD4 count, or (3) provision of anti-retroviral therapy (ART).”

In 2003, PDES worked with Title I and II grantees and HST surveillance staff to estimate unmet need for primary medical care. For the purposes of this project, the term “Unmet Need” has been defined as: Neither a CD4 test nor a VL test within a 12-month period to be as consistent as possible with HRSA’s definition. Using existing surveillance data, this project estimated that half of PLWH-non AIDS (aware) and one-third of PLWA (aware) did not receive CD4 or viral load testing in 2003. While these estimates are similar to national estimates and those produced by the state of Washington, there were limitations in the calculation of these estimates. Indeed, numerous community members question the accuracy of these data and why a person might not receive annual CD4 or viral load tests.

Around the same time, the CAREAssist program instituted a number of cost-saving strategies including a cost-share mechanism, at which time some clients lost CAREAssist services. While some of these clients have re-enrolled in CAREAssist, there has been no systematic follow-up to determine what happened to the other CAREAssist clients. Because many of these clients may be uninsured and not receiving adequate medical care, this group might have high levels of unmet medical needs. Therefore, the Ryan White Title II Program Manager, Victor Fox, asked PDES to develop an exploratory qualitative project to better understand the Unmet Needs estimate and gather information regarding current insurance coverage and medical needs of former CAREAssist clients.

CAREAssist Program Changes

To better understand and document the policy and cost-saving changes to the CAREAssist program over the last five years, PDES staff interviewed various CAREAssist stakeholders and staff members. The following timeline of key program changes and historical events was generated as a result of those interviews.

Early 2002: Eligibility criteria were 'one size fits all' with overall program restrictions identical for all program respondents. Federal Poverty Level (FPL) was set at 325% or lower with no asset checks (i.e. clients were eligible for program services regardless of countable assets such as liquid assets, additional cars, boats and other properties of value). Client family members were covered, regardless of their HIV serostatus. CAREAssist paid insurance premiums, deductibles and copays for nearly all ancillary and medical services, such as dental visits, lab work and x-rays. Program covered the entire cost of medical, dental or ancillary services rendered; clients did not need to pay any part of the cost. The formulary was unrestricted so all prescription medications were covered. The program began to look for cost-containment strategies.

May 2002: "The Wake-Up Call" - a waiting list was implemented and the formulary was restricted.

July 31, 2002: Program support was eliminated for HIV-negative family members.

August 2002: Letters went out to CAREAssist members summarizing recent cost containment strategies and informing them of upcoming changes to the program. Dental premiums, dental co-pays and dental deductibles were no longer supported through the program. Coverage was eliminated for insurance plans that did not have a prescription drug benefit of at least 50% of drug costs, which included Medicare supplemental insurance policies.

Fall 2002: Financial limits were set on non-drug medical co-pays and deductibles like x-rays and lab visits. A minimum amount was also set on copays and deductibles so that only charges of \$15 or more were processed. Finally, the three tiers were implemented, which added restrictions to client eligibility criteria and created distinct target populations served by the program. Group One, known as Oregon's ADAP, had income eligibility lowered to 200% FPL for new clients, providing payments for insurance premiums or access to prescription drugs if a client didn't qualify for insurance coverage. Group Two was created to provide

supplemental support to those with federally funded coverage (such as OHP or Veteran's Administration). Currently covered clients were "grandfathered" into the program as Group Three, as long as they were continuously enrolled in the program.

December 2002: The first cost share letters and payment invoices were sent to CAREAssist clients. By collecting financial contributions from clients to offset program costs, the cost share meant each client was required to pay a monthly fee based on a sliding scale (2%, 5%, 7%) according to income level.

January 2003: Spend-down program was eliminated.

March 2003: Oregon Health Plan (OHP) Standard was eliminated. CAREAssist waiting list reached a high of approximately 250 people.

April 2003: OHP Standard was reinstated. Over the next few months, CAREAssist started staging people off the waiting list by cycling people back onto the program in groups of five.

June 2003: Program started to see cost-savings strategies working.

July 2003: Asset test implemented, allowing up to \$10,000 per client/family in assets such as cash, savings, convertible stocks and bonds, or other saleable items such as cars and real estate. Excluded items were one house, personal possessions such as furniture, one vehicle, and tax deferred retirement accounts (such as IRAs, 401K Plan, or any IRS/federally recognized retirement account). Asset determination was self-reported and not verified by program staff.

August 2003: Waiting list was eliminated.

July 2004: Cost share rate went to a flat 2% for all clients.

September 2004: Bridge program was implemented as a stopgap measure for uninsured PLWH/A needing emergency access to HIV medication.

October 2005: Implemented "Restricted Status" for clients who have missed cost-share payments or have not returned recertification paperwork and are at risk of being terminated from CAREAssist.

January 2006: Medicare Part D was implemented, offering medication coverage for some PLWH/A who previously had assistance with medication only from CAREAssist.

Brief Literature Review: Healthcare Coverage for PLWH/A

While non-financial barriers to care such as cultural, structural or psychosocial issues must be acknowledged, examined and addressed, the importance of the role of insurance and healthcare coverage in helping PLWH/A access primary HIV care cannot be overlooked. Therefore, this brief literature review summarizes key findings from recent articles related to insurance coverage and the role of Ryan White services in reducing barriers to healthcare for people living with HIV/AIDS.

Public Financing for HIV/AIDS

Of those living with HIV/AIDS who are receiving medical care and are insured, most people are covered by publicly funded programs such as Medicaid and Medicare. Additionally, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and other community health centers, public hospitals and private clinics act as an important safety net for uninsured or underinsured PLWH/A. Basic needs, however, are competing with healthcare needs for most of those who are accessing services through the public safety net (Diamant et al., 2004). In fact, a recent Institute of Medicine report (Institute of Medicine, 2005) found that the system of coverage and care for people with HIV is challenging to access and navigate for those it intends to serve. Indeed, this coverage has been deemed “a quilt with many holes” (Kates, 2004) that results in some being left entirely without care or coverage and others with significant financial barriers.

A recent review on healthcare utilization (Uphold & Mkanta, 2005) found that insurance status was one of the most significant factors associated with patterns of utilization for HIV-related care. Yet this review also found that having insurance did not eliminate barriers to healthcare services, particularly in vulnerable subgroups like injection drug users and those with unstable housing. Social factors such as living with family or friends and being in a committed relationship were considered enabling factors as well as insurance status. After reviewing the literature, authors postulated that social and financial supports coming from these enabling social factors might provide PLWH/A with tangible and intangible resources for maintaining regular and appropriate medical care.

Goldman et al. (2003) used data from the HIV Cost and Services Utilization Study (HCSUS) to examine the insurance status of PLWH/A in the last decade, a period of effective but expensive treatment options. Using these nationally representative data, the authors found that 50% of people receiving medical care for their HIV had publicly funded insurance. Interestingly, many of those with public insurance had considerable work experience and earning capacity, but were not currently working. Findings indicated that public insurance increasingly financed the medical care as the disease burden got higher, meaning that some people living with HIV had coverage from publicly funded insurance only when they experienced clinical deterioration.

Looking specifically at employment issues for PLWH/A in an urban setting, Brooks and colleagues (2004) found that a majority of their respondents were contemplating returning to work. Yet one of the main barriers cited by two-thirds of the respondents (67%) was the loss of their publicly funded health insurance if they returned to work. Both of these studies (Brooks, Martin, Ortiz, & Veniegas, 2004; Goldman et al., 2003) suggest that public financing of coverage for PLWH/A should be reformed to allow healthier people to return to work while maintaining their healthcare coverage.

A recent study (Goldstein et al., 2005) examined the role of insurance, health status and clinical care received by PLWH/A in clinics and social agencies in four different large cities. Medicaid was the most common insurance type, though authors combined insurance types for analysis. Findings showed that 78% – 90% of the respondents had seen a healthcare provider at some point in the previous 3 months, regardless of insurance type. Few differences in clinical care existed between publicly and privately insured respondents; however, uninsured respondents were less likely to see a healthcare provider in the previous 3 months and less likely to receive antiretrovirals. Authors concluded that being uninsured was associated with significant barriers to care; however, the differences between private and public insurance were relatively small in regards to clinical care.

Public versus private insurance coverage has been examined in a number of studies on healthcare quality, access and utilization without inconsistent findings. While Goldstein et al. (2005) did not find a significant difference in care for those publicly or privately insured, other studies indicate that publicly insured PLWH/A may have higher rates of mortality (Bhattacharya, Goldman, & Sood, 2003), lower quality of care (Kilbourne et al., 2002; McNaughton, Gallagher, & K.M., 2003), or higher unmet needs (Bonuck et al., 1996).

The Role of Ryan White Programs

Ashman and colleagues (2000) analyzed existing data sets from HRSA and CDC to better understand how well Ryan White funding was reaching vulnerable PLWH/A. The study looked at the extent to which Ryan White funded providers were reaching the populations they were intended to serve, namely the uninsured, women, minorities and those with significant co-morbidities. Authors found that providers funded through the CARE Act were effectively reaching and serving their intended populations. The only group that appeared to be underserved at half of the study sites was injection drug users (IDUs), a population that is often poorly connected to healthcare and treatment facilities.

Marx et al. (2001) examined barriers to HIV-related care for clients served through Ryan White-funded agencies in northern California. Findings indicated that 70% of the clients had needs for physical health services that were not being met; however, there were no statistically significant differences in insurance status, socioeconomic or demographic characteristics between those clients with and without unmet health needs. Clients with unstable living situations and who had lower perceptions of health were more likely to need services that were not being met. Based on these data, authors concluded that Ryan White funding is succeeding in reducing the barriers typically associated with accessing healthcare for HIV, though needs remain high for physical health services.

Methods

Purpose of the Study

The HST Program at the Oregon Department of Human Services, State Public Health, contracted with PDES in 2005 to conduct the Out of Care Study, an analysis of PLWH/A who may not have received a CD4 count or a viral load test in the past 12 months. This mixed methods study uses three phases to explore the following aspects of Unmet Need for primary medical care for PLWH/A in Oregon:

- Are the PLWH/A included in the 2003 Estimate of Unmet Need in fact “out of care” (i.e., not engaged in medical care)?
- Do PLWH/A experience other unmet medical care needs besides regular lab testing?
- What are the gaps in our current knowledge of Oregon PLWH/A who are “out of care”?

- What are the reasons for not receiving annual CD4 or viral load tests?
- What is the trajectory of medical care for PLWH/A who left or were dropped from the CAREAssist program?

Overall Study Design

The Out of Care Study is a multiphase exploratory study to better understand the salient factors related to the evaluation questions from multiple perspectives.

Phase One, the Provider Study, was based on interviews of HIV service providers, including included interviews of service providers, including medical doctors,¹ complementary and alternative medicine (CAM) providers,² and HIV case managers.³ PDES staff used a semi-structured interview guide to conduct 15- to 45-minute audio taped interviews over the phone with 19 service providers. Service providers were located throughout the state, with equal numbers coming from the Title I and Title II areas.

Phase Two, the CAREAssist Client Follow-Up Study and the phase described in this report, examines CAREAssist system changes and reasons that some PLWH/A in Oregon may not have had annual CD4 or viral load tests done. PDES staff has followed up with clients who were terminated from CAREAssist to better understand what happened to them since losing CAREAssist services, and identify former clients who have not had CD4 and viral load testing in the past 12 months.

Phase Three, the final phase of the Out of Care Study, will focus on PLWH/A in Oregon who have had neither a CD4 count nor a viral load test in the past 12 months (and were not interviewed as part of Phase Two). While still in the planning stages, this phase anticipates using varied recruitment methods based in extant service system datasets and social networks to identify eligible respondents.

Phase Two methods

Phase Two, the CAREAssist Client Follow-Up Study, consisted of structured phone interviews with former CAREAssist program clients.

¹ Participating medical doctors include Doctors of Medicine (MD) and Doctors of Osteopathy (OD).

² Participating CAM providers include licensed naturopaths (ND), licensed acupuncturists (LAc), and providers of psychosocial services in CAM settings.

³ Participating case managers include HIV-related case managers and case management supervisors funded by Ryan White and other sources.

PDES staff worked with HIV/STD/TB analysts to generate a list of clients who lost CAREAssist coverage between 1/1/03 and 6/30/05 for inclusion in this phase of the study. HST analysts checked the list of 345 clients against the HARS database to verify that none of the clients listed were known to be deceased, which removed 23 people from the list. (For additional analysis on these 23 people, see Appendix.) Inclusion criteria further restricted the list to former clients who were 18 and older, living in Oregon and not currently receiving CAREAssist services. From the list of 297 clients meeting those criteria based on the data set, a sample of 125 potential respondents (42%) were randomly selected. To refine processes and procedures with contacting clients, a pilot group of 25 clients was chosen from the sample for initial contact. After a week, the remaining 100 clients were contacted.

PDES staff attempted to contact former CAREAssist clients by letter and then by phone between 1/13/06 and 3/7/06. Telephone calls were distributed over the data collection period with a minimum of eight telephone contacts initiated to phone numbers that were operational⁴ and valid.⁵ Public information sources⁶ were used to update client contact information when necessary. To maximize the likelihood of reaching former clients, calls were made over at least two weeks on different days of the week, and at varying times of the day (i.e. in the mornings, afternoons, and evenings). The former clients received at least one call on a Saturday or Sunday.

Interested and eligible⁷ former clients gave informed consent over the phone to participate in a 20- to 30-minute telephone interview, called the Part A Interview. Structured interviews focused on these four key evaluation questions:

- 1) What was the main reason that respondents stopped receiving CAREAssist services?
- 2) What kind of medical care, including laboratory tests, have former clients received since leaving CAREAssist?
- 3) What kind of insurance or healthcare coverage have respondents had since leaving CAREAssist?
- 4) How did the loss of CAREAssist affect the health of former clients?

Two interviewers used a structured interview guide with questions having pre-coded response categories and two open-ended questions.

⁴ Not disconnected or out of service

⁵ Not otherwise known to be a number where the respondent could not be reached

⁶ DEX Online, Google, Cole's Directory and Oregon Inmate Search Online

⁷ Additional inclusion criteria: able to complete interview in English, able to recall participation in CAREAssist program, and not currently in prison or correctional facility.

Systematic pretesting with five experts in the field of HIV ensured that questions were clear and could gather valid data when asked as worded. Data were then entered into an SPSS database for analysis. Responses to open-ended questions were pulled into a table and coded thematically.

The Part A interview also acted as a screener to identify PLWH/A who had not received CD4 or viral load testing in the preceding 12 months for inclusion in Part B of the interview, a semi-structured interview lasting 45-60 minutes. That interview guide is similar to the guide that will be used as part of Phase Three of the Out of Care Study. Because only two former clients fit eligibility criteria for the Part B interview, these data are not included in this report.

Phase One Results

CAREAssist Sample

Even with the systematic calling protocol,⁸ 75 former clients (60%) were considered unreachable at the end of the seven-week data collection period (see Table 1).⁹ The majority of these clients had no valid phone number (disconnected or reassigned), or no valid phone number and an address known to be invalid (letters were returned with no forwarding address). Eleven of them (9%) did not respond to the messages left or the letters sent and were deemed unreachable by the end of the data collection period.

Of the 125 former clients in the sample, interviewers reached 50 (40%). Five former clients (4%) refused to participate and 12 (10%) were ineligible due to a variety of reasons (see Table 1). It is notable that so few of the clients who were reached refused to do an interview, and that only one client reached was angry that we were used former contact information to locate that client, a concern prior to starting this study phase. Thirty-three clients gave informed consent and completed an interview for an overall response rate of 26% (33 out of 125).

Basic demographic characteristics, including gender, race/ethnicity and family size were available from the CAREAssist database on all 125 clients in the sample. Data on income and educational level were not available, nor were clinical characteristics such as AIDS status and time since HIV diagnosis. We examined the characteristics of the respondent group against the non-respondent group to look for any statistical

⁸ One former client was out of town during the data collection period, so did not receive all eight phone calls.

⁹ All Tables can be found at the end of this document.

differences using a Pearson chi-square test, with continuity correction (see Table 2).

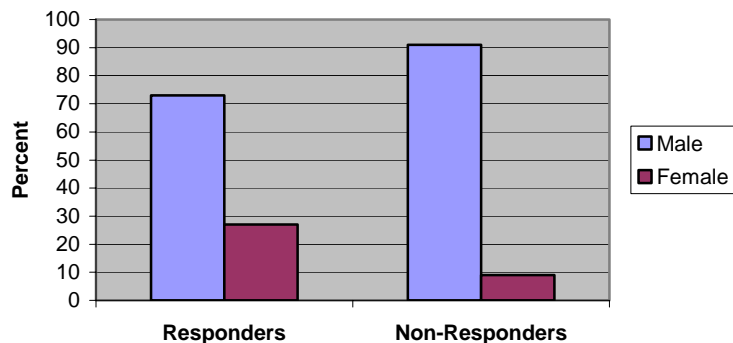
Race and ethnicity data from the CAREAssist database used a single variable for ethnicity and a single variable for race, which included a “multi-racial” category. The sample of former clients was mainly Caucasian/white (n=101, 81%), with Non-White clients distributed among the other six categories, which included Other and Unknown categories.

Family size, defined according to HRSA definitions, ranged from one to six people with 82% (n=102) of the group having a family size of one. Eight people (6%) had a family size of four or more.

Two data elements specifically related to CAREAssist were examined: Region and Days since termination from CAREAssist. Regions were consistent with HRSA definitions and broken down into eligible metropolitan area (EMA)¹⁰ and non-EMA. Sixty percent (n=73) of the sample was from the EMA. The sample was further categorized by how long it had been since they lost CAREAssist services (i.e., Days since termination). Half of the sample (n=62) had lost coverage two years ago or longer.

Overall, respondent characteristics were similar to those of non-respondents. Respondents and non-respondents did not differ significantly with respect to region or days since termination. The key difference between these groups was gender, with significantly more women completing the interview than men ($\chi^2=5.640$, $p=0.018$; see Figure 1). Though not a significant difference, more respondents than non-respondents had a family size of two or more (27% vs. 15%).

Figure 1. Respondents by Gender



¹⁰ For this study, the EMA consists of Clackamas, Columbia, Multnomah, Washington and Yamhill counties, excluding Clark County, since only Oregon residents were eligible to participate.

Respondent Results: Part A Interview

Respondent Characteristics

The Part A interview guide collected both ethnicity and race data, but asked two separate race questions – one allowing respondents to choose multiple race categories and one asking respondents to identify the race that best described them. Self-reported race and ethnicity data from the Part A interview were inconsistent with data in the CAREAssist database. Due to these two issues, race and ethnicity data presented previously in the CAREAssist sample were different from data gathered from respondents during the interview.

Race and ethnicity data were gathered using three distinct questions, with respondents first asked if they considered themselves Latino/a or Hispanic and then asked two questions about race (see Interview Guide in Appendix). No respondents considered themselves Latino/Hispanic, though one respondent identified as “Other: Mexican” for race. Thirty respondents (90%) identified as Caucasian/White. Five respondents considered themselves to be partially Native American or Alaskan Native, but none of them considered that to be the race that best represents them.

Sixteen respondents (49%) were in their forties and 24 (73%) identified as male (see Table 3). Fifteen of the men (63%) were from the EMA, while four of the women (44%) were from the EMA. Twelve (75%) of the gay identified respondents were from the EMA. All of the nine women identified themselves as straight or heterosexual.

All but one of the respondents were stably housed in the year before the interview.

Nineteen of the respondents (58%) were living with a spouse or girlfriend/boyfriend at the time of the interview and all but one were living in their own home or apartment. One respondent was unstably housed in the last 12 months, having moved three times, lived on the streets and had periods with no permanent place to stay. One additional respondent had been in jail or a correctional facility in the last year. Six respondents (18%) were primary caregivers for someone else who lives with them (e.g. a child, elderly person or someone living with a disability). One primary caregiver was male and five were females.

All but one respondent (97%) had graduated high school or received a GED. Twenty-one respondents (64%) had some college education or more. Fifteen (46%) had a paying job at the time of the interview; of those with a paying job, ten (67%) were from the EMA.

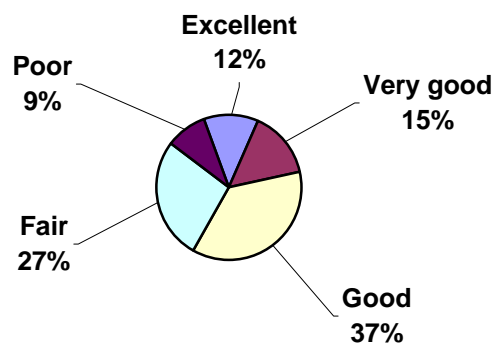
Income data were gathered two ways, first, by asking about monthly household income and then, by asking about all income sources. Seventeen of the respondents (51%) reported a monthly household income less than \$2000, eight of whom had income less than \$1000. The average income level was \$2432 (standard deviation=\$2017), with a higher average income reported in the EMA (\$2830 vs. \$1891). Wages and salaries were the most frequently cited source of household income (n=20 respondents), followed by Social Security Disability Insurance (n=12) and then food stamps (n=10).

Health History

Over half of the respondents (55%, n=18) have been told by a healthcare provider that they have AIDS. Respondents first tested positive for HIV across a wide range of dates, from 1985 to 2003. Nearly half of the respondents (49%, n=16) tested positive ten or more years ago; six of these respondents have not been given an AIDS diagnosis.

Respondents answered a single-item measure for people living with HIV (Crane et al., 2006) to assess their health-related quality-of-life (see Figure 2). Twelve respondents (37%) stated their health was “good” while nine (27%) said “poor.”

Figure 2. Health Status of Respondents, n=33



All 33 respondents believed they should see a healthcare provider at least every year.

The interview asked respondents how often they think they should see a healthcare provider for their HIV. Because respondents were allowed to give a range as a response (e.g. “Every 3-6 months”), we recoded responses into non-exclusive categories (e.g. “Every 3-6 months” and “Every 6-12 months”). Eighteen respondents (55%) thought they should see a healthcare provider every 3-6 months, while nine (27%) said

every 6-12 months. All respondents believed they should see a healthcare provider at least yearly.

Healthcare Experiences

Interviews gathered information on whether former clients have a place they usually go for HIV care and a regular healthcare provider.¹¹ Three respondents (9%) did not have a place they usually went for care and did not have a regular healthcare provider. Of the 30 respondents with a regular place for HIV care, 13 (39%) went to a private doctor's office or clinic and 13 (39%) went to a hospital-based clinic.

Twenty-five respondents (76%) were taking HIV medications at the time of the interview. Of the eight respondents not on HIV medication, three (38%) were women, three (38%) were 50 or older, and four (50%) currently had a paying job. All three respondents without a regular healthcare provider were not taking HIV medications. One respondent not taking HIV medication had seen a healthcare provider 20 or more times in the past year, and two (25%) have been given an AIDS diagnosis. Half of the respondents (n=4) not taking HIV medication rated their health as "fair" or "poor." Five respondents not on medication (63%) reported monthly incomes of \$2000 or higher and the other three reported monthly incomes of less than \$1000; nobody reported incomes of \$1000-\$1999.

Two respondents (6%) had not had CD4 or viral load tests done in the last year.

Interviews also gathered information specifically about respondents' healthcare experiences in the last 12 months. Two respondents (6%) had not had CD4 or viral load labs done in the last 12 months; correspondingly, these same respondents had no visits to a healthcare provider for HIV care. Two additional respondents (6%) had only one visit to a healthcare provider in the last year, while 19 (58%) had 2-4 visits. Four respondents (12%) saw a healthcare provider for HIV care 20 or more times. Five respondents (15%) had been to the emergency room for HIV care at least once in the last year, with one respondent reporting ten HIV-related ER visits. Of the 31 respondents receiving CD4 or viral load tests in the last 12 months, three (10%) reported that their healthcare provider did not discuss the lab results with them.

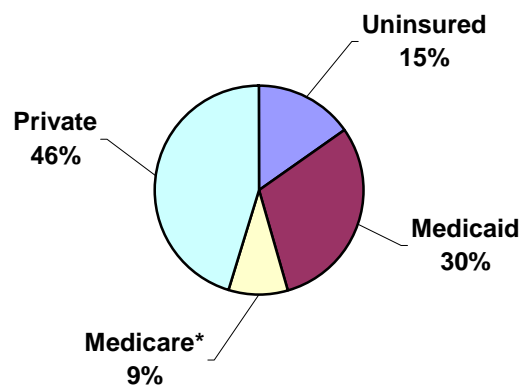
¹¹ Regular provider was defined for respondents as "one health care provider that you think of as your HIV provider who checks how you are doing, who talks with you about your CD4 counts, viral load, and treatment, and who helps you with referrals to other doctors if you need to see a specialist."

Insurance and Healthcare Coverage

To explore what other systems former CAREAssist clients accessed after they lost CAREAssist coverage, interviewers asked about respondents' insurance and healthcare coverage. Findings show that many former CAREAssist clients were served through other healthcare coverage systems after they left the program.

Of those 28 respondents with current healthcare coverage, fifteen respondents (46%) had private insurance, nine (27%) had Medicare as primary or secondary insurance, and seven (21%) were on OHP/Medicaid. Three clients (9%) said they had "Other" coverage: one said "OMAP," another said "OMIP" and the third said "Title XIX" covered him/her (these respondents were counted as "Medicaid" in Figure 3 on next page). Of those nine respondents with Medicare, three (9%) were solely covered by Medicare with no additional insurance.

Figure 3. Insurance Coverage of Respondents, n=33



* Includes respondents solely covered by Medicare; 2 with private insurance and 4 with Medicaid also have Medicare

In Table 4, we present health-related characteristics of respondents by whether they were currently insured or not. Lack of insurance coverage

Five respondents (15%) were uninsured at the time of the interview.

appears to be a barrier to healthcare for former CAREAssist clients (see Table 4). Those two respondents that might be considered at risk or "out of care" (i.e. no regular healthcare provider, no CD4 or viral load tests done, and no visits to a healthcare provider in the last year) were both uninsured. Since leaving CAREAssist, two of the five uninsured respondents had not had any insurance and four had gone six months or longer without seeing a healthcare provider. Of those currently uninsured, one lost CAREAssist

services because s/he could not afford the cost-share, one because of a paperwork problem, one was ineligible due to income increase and two got other healthcare coverage.

Interviewers gathered data from the former client's perspective on why they left the CAREAssist program. The majority of the respondents stated they lost CAREAssist because they were no longer eligible due to the following reasons: sixteen (49%) got other healthcare coverage, five (15%) had an increase in their income level and one (3%) moved out of the state. Two respondents (6%) each gave the following reasons:

- "I could not afford the cost-share."
- "It was not worth it financially with my cost-share."
- "There were paperwork or payment problems."
- "There were cuts and changes to the CAREAssist program."

Three respondents (9%) stated they did not know why they lost CAREAssist. None of these responses were compared to the reason codes in the CAREAssist database, primarily due to the fact that clients often had multiple reason codes assigned.¹²

30 respondents (91%) had not reapplied for CAREAssist services.

Three respondents (9%) reported they had reapplied for CAREAssist coverage since they lost program services, though they were not reinstated in the program. Interviewers asked the remaining 30 respondents why they have not reapplied for CAREAssist. Ten themes were identified from the open-ended responses (see Table 5). As seen with the insurance data, many former clients got healthcare coverage through another system; consequently, the most frequently mentioned response by 12 respondents (40%) was "I didn't reapply because I have other coverage." Another nine respondents (30%) said they did not reapply because they "Assumed or were told they're not eligible" for CAREAssist. Amongst other responses, three people (10%) said they "Can't afford it" and two (7%) said, "Other people need it more." Of the five uninsured respondents, three "Assumed or were told they're not eligible," one said s/he "Can't afford it," and one had other coverage but just lost it and intends to reapply.

¹² In addition, program staff said reason codes might not be consistently applied to clients.

Gaps in Care

Eight (24%) respondents had a gap of six months or longer without seeing an HIV healthcare provider.

Interviews gathered data on gaps in insurance and healthcare-related services for two time periods: since losing CAREAssist coverage and over the last 12 months. Interviewers asked respondents if they had any times when they needed medical care but did not get it since their CAREAssist termination date. Six respondents (18%) confirmed that they had at least one time when they did not get the medical care they needed. Since losing CAREAssist coverage, eight respondents (24%) had experienced a gap of six months or longer without seeing a healthcare provider for their HIV. (This did not include emergency visits or hospital admissions.) Of those eight respondents, two had been given an AIDS diagnosis by a healthcare provider.

Six respondents (18%) had gaps of three months or longer without health insurance since losing CAREAssist, and two respondents (6%) have not had any health insurance in the last 12 months. Notably, five of the six respondents with a three-month gap in insurance had also gone six months or longer without seeing a healthcare provider for their HIV.

Healthcare Costs

Interviewers gathered data on costs related to healthcare, in order to better understand the financial lives of former CAREAssist clients. Fifteen respondents (45%) reported some level of medical debt owed to a doctor, clinic or hospital. The average amount of medical debt for those 15 respondents was \$1533 (SD=\$2233), while the median amount was \$800. Notably, 12 (80%) of the respondents with medical debt were currently insured, 11 (73%) were taking HIV medications, and six (40%) had gone six months or longer without seeing a healthcare provider since losing their CAREAssist coverage.

The remaining cost-related items focused on healthcare experiences from the last 12 months. Two of the respondents (6%) had borrowed money from friends or family to pay medical bills. Eight (24%) reported a time when they needed to see a healthcare provider but could not because of cost; interestingly, five of these respondents were currently insured. Six respondents (18%) had a time in the last 12 months when they needed HIV medication but could not afford it.

Nine (27%) respondents skipped doses or took less of an HIV medication to save money.

In the last 12 months, nine (27%) respondents reported skipping doses or taking less of an HIV medication in order to save money (see Table 6). Of those nine respondents skipping doses of their HIV medication, six had been given an AIDS diagnosis and none of them reported Excellent or Very Good health. Although eight of these nine respondents were currently insured and five had a paying job, five of them had medical debt of \$500 or more.

Case Management

To gather information on how former CAREAssist clients are finding services they might need, interviewers asked respondents about case management and other support and services they might receive. Thirteen respondents (39%) had an HIV case manager¹³ in the last 12 months, while 17 (52%) did not have a case manager and three (9%) did not know if they did or not. Eight of those respondents (62%) with a case manager reported 12 or more contacts (phone or face-to-face) over the last year.

In the last 12 months, 17 (52%) respondents did not have a case manager and 3 (9%) did not know.

Because a relatively high number of respondents did not have case management in the last year, we ran subgroup analyses with this group of former clients by combining the No and Don't Know respondents. Of those 20 respondents without active case management in the last year, nine have been diagnosed with AIDS, and four were uninsured. Seven (35%) lived in the Title II/non-EMA region of the state. All three respondents lacking a regular healthcare provider or facility, and both respondents lacking CD4 or viral loads in the last year, did not have HIV case management. Of those eight respondents who went six months without seeing a healthcare provider, seven (88%) did not have case management in the last year. Finally, five of the nine (56%) respondents skipping doses did not have case management.

Respondents were also asked, other than HIV case managers, who else might help them find services they need - friends, family, or service agency staff.¹⁴ Fourteen of the respondents (42%) said "Nobody" helps them find

¹³ Because case management is difficult to define and understood differently by many people living with HIV/AIDS, we used a definition consistent with the 2005 Ryan White Case Management Satisfaction Survey: "By HIV case manager, we mean a person who helps you figure out what services you need, helps you sign up for the services and may help you get insurance or medical care services."

¹⁴ Each respondent could give multiple answers so percentages add up to more than 100%.

services, nine (27%) said a social service agency or caseworker helps them, and nine (27%) said their doctor helps them find services they need.

Impact of Losing CAREAssist

At the end of the interview, respondents were asked an open-ended question about how losing CAREAssist affected their health. These responses were thematically coded and categorized into six categories. Respondents may have had multiple themes present in their response so the total number will be greater than the number of respondents.

"[When I lost CAREAssist], I already had one foot in the grave and the other on a banana peel."

Seventeen respondents said that losing CAREAssist did not affect their health, though eight of these respondents clarified that their health was not affected because they managed to get other coverage. As one respondent stated, *"I went on my employer's insurance, but had I not had CAREAssist [before that], things would have been really bad. I would have had only 6 months before I went downhill without my meds."* One person specified that it did not affect his health because his health was already so deteriorated. As he put it, he already had *"one foot in the grave and the other on a banana peel"* when he lost CAREAssist services.

Nine respondents said that losing CAREAssist caused them stress or specified that their health was affected by the resulting anxiety and stress. This response was often mentioned as they talked about financial stresses or the anxiety around gaps in coverage and maintaining their health while uninsured. One uninsured respondent was not sure how losing CAREAssist affected her health, but said that *"it really freaks me out"* to go without insurance. Another respondent stated, *"I felt abandoned. I really appreciated what CAREAssist did for me and it was hard to have it just be gone."*

Seven people discussed the financial burdens they incurred when they lost CAREAssist, specifying that *"it didn't affect my health, but it affected my finances."* As one respondent described, *"I have to pay for it all myself now. Having CAREAssist was a great help. I know it sounds like I make a lot of money, but I'm just barely scraping by."* Privately insured respondents and those with monthly household incomes above \$1000 talked more about the financial burden and anxiety of losing CAREAssist.

"I don't get the HIV care I need now because I can't afford it."

Losing CAREAssist resulted in deterioration of health and unmet medical needs for seven respondents, three of whom were currently uninsured. Financial barriers were cited as a key factor related to these negative health outcomes

and unmet medical needs. *"I don't get the HIV care I need now because I can't afford it [without CAREAssist]."* Five of the seven talked about losing access to their HIV medication or not being able to afford their medications. *"I stopped going to the doctor and stopped taking [HIV] medication...now I'm starting to deteriorate."* Another respondent said that it *"Probably saved my life having CAREAssist - losing it made my T-cells drop and made me get sick. It's terrible."*

Limitations

Because no follow-up had been conducted with this population prior to this study, we were not sure how feasible it would be to reach this population. And although we reached 40% of the total sample, the response rate for this phase of the study was 26% overall (10% were not eligible to participate and 4% refused). Due to the relatively low response rate, non-response bias must be considered. Basic demographic characteristics of respondents and non-respondents were compared and no statistical differences were found other than gender, but the variables available from the CAREAssist data set were limited. Therefore, there might be key differences between the respondents and non-respondents that would alter the findings. For example, non-respondents might be more likely than respondents to be unstably housed, have lower income levels, and have an AIDS diagnosis, but without those data for the entire CAREAssist sample, we cannot know if those differences existed.

There are a number of limitations to the Phase Two CAREAssist client follow-up study. While the number of respondents was higher than anticipated during the planning phase of the study, the sample size is still quite small. We did not run any statistical analyses beyond basic descriptive or bivariate analyses. Due to the small sample size, estimates for key characteristics are not very precise. For example, 15% of study respondents were uninsured at the time of the interview. The margin of error for this estimate was +/- 13%, so we are 95% confident that the true estimate of uninsured former CAREAssist clients is within 13 percentage points of 15% (i.e., 2% to 28%). The margin of error for all of our estimates did not exceed +/- 17%.

Discussion and Recommendations

Question 1) What was the main reason that respondents stopped receiving CAREAssist services?

Two-thirds of the respondents said they lost CAREAssist because they were no longer eligible for the program, mainly because they got other healthcare coverage through another system or were no longer eligible due to program restrictions around income level. When asked why they had not reapplied for CAREAssist services, a number of respondents used the terms “too confusing” and “too difficult” and that it “wasn’t worth it” to reapply.

A number of former clients lost coverage at a time of significant programmatic changes, when cost-share amounts were set at varying levels and when the program was implementing new cost-saving strategies that may have been misinterpreted. One respondent said these “programs morphed into one another” and that “it was too difficult to figure out what was what.” Many of the respondents used terms like “I assumed” and “they said” and “I was told” different things about eligibility and program changes. In fact, one respondent said, “*I thought they [CAREAssist] didn't exist anymore because it was defunded and taken over by another program.*”

Recommendation: The number of changes to the program and the confusion around program specifics and eligibility criteria may indicate a need for greater public awareness and education about the CAREAssist program. CAREAssist management might consider a public awareness campaign and targeted outreach to potentially eligible clients through systems PLWH/A are already accessing, such as case management, physicians, pharmacists and social service agencies.

Recommendation: CAREAssist management could implement other cost-share payment options for CAREAssist clients; specifically, the program could add a 6-month pre-payment option similar to the structure that many auto insurance companies use for their payment options. This may reduce the number of clients who lose program services due to missed cost-share payments.

Question 2) What kind of medical care, including laboratory tests, have former clients received since leaving CAREAssist?

One positive finding from the study was the relatively high number of people receiving medical care according to national standards of care (Aberg et al., 2004), which includes getting CD4 and viral load tests done at least yearly. However, that finding was not true for all the respondents we interviewed. While all the respondents believed they should see a healthcare provider for HIV care at least once a year, there were two respondents unable to reach that goal.

And beyond those two respondents considered “out of care” (no labs and no healthcare provider visits in the last year) from this sample, there were a number of respondents who might be considered *at risk* of falling out of care. These respondents had identified unmet healthcare needs around provider visits or HIV medications, had experienced gaps in their insurance coverage, or were dealing with significant amounts of medical debt.

One of the most troubling findings was around the issue of skipping doses or taking less of an HIV medication in order to save money. Because medication adherence and full compliance with most HIV prescription medication is critical to the success of these medications, it is notable that over one-quarter of the respondents reported this practice in the last 12 months alone. The characteristics of this group are striking: none report “Very Good” or “Excellent” health, all but one are insured, over half have a paying job, and over half have medical debt of \$500 or more.

Factors related to adherence and retention in primary HIV care have been examined in the literature around case management and ancillary services (Katz et al., 2001; Conover & Whetten-Goldstein, 2002; Conviser & Pounds, 2002). People “at risk” for falling out of care or those skipping doses might benefit greatly from case management and other Ryan White funded services. However, many of the former CAREAssist clients in these two risk groups were not receiving case management.

Recommendation: Conduct outreach through clinicians and other social service agencies to identify and engage “at risk” PLWH/A who are not currently served through case management services.

Recommendation: Develop a systematic self-assessment for low acuity clients currently served by Title II case management. Clients could complete this assessment every six months to help identify which clients might need

additional financial and psychosocial support around medication adherence or medical appointments. This self-assessment would serve two additional purposes: 1) help build a client's self-management skills and abilities, and 2) increase the amount of contact between case managers and clients.

Question 3) What kind of insurance or healthcare coverage have respondents had since leaving CAREAssist?

Overall, findings indicate that a majority of clients terminated from CAREAssist found healthcare coverage through another system. While the number of uninsured respondents was relatively small at 5 people, the proportion (15%) is sobering. This proportion of uninsured former clients is similar to national estimates of PLWH/A (Goldman et al., 2003). Since lack of insurance is a critical barrier to receiving HIV care (Diamant et al., 2004), this finding indicates that losing CAREAssist program services may play an indirect role in PLWH/A having unmet medical needs, particularly for those with gaps in their insurance coverage.

Additionally, having insurance and/or having a paying job did not appear to alleviate the financial burdens faced by many respondents. While few respondents had borrowed money from friends or family to pay medical bills, nearly half of the respondents had some level of medical debt and most of these clients were insured. Although insurance coverage might lower the total amount of medical debt accumulated for some people, having coverage did not appear to eliminate cost-related issues for many respondents. In fact, one former CAREAssist client who had insurance had over \$3000 in medical debt and had gone without both medication and medical care due to cost.

Question 4) How did the loss of CAREAssist affect the health of former clients?

While many of the former CAREAssist clients did not have direct negative health affects due to the loss of CAREAssist services, many of them talked about the stress, anxiety and financial burdens they experienced after losing CAREAssist. Furthermore, a number of respondents who did not experience any negative outcomes related to the program changes talked about how grateful they were for the help they had received and felt it played a valuable role for PLWH/A.

However, the program changes appeared to have a direct negative affect on the health and well being of a subgroup of respondents. These former clients talked about clinical changes in their health and negative mental health outcomes around managing their disease without the program's

assistance. While the cost-saving strategies were effective at keeping this valuable program afloat, a number of people who relied on those services have had to “make do without” CAREAssist, sometimes at the expense of their physical health.

Findings call into question the role and purpose of Ryan White funding. While the program is intended to be a “payer of last resort” to fill gaps in care not covered by other resources, a number of former clients were ineligible to receive Ryan White services through CAREAssist, even though they were experiencing gaps in their care not covered by insurance or other resources. Possibly, some of the clients who believed they were ineligible for services might be currently eligible for CAREAssist. However, for those insured PLWH/A with mounting medical debt who are skipping HIV medications to save on cost or those not seeing a healthcare provider because they are uninsured, the safety net appears to have large holes.

Recommendation: CAREAssist managers might consider programmatic changes based on the following recommendations:

- *Examine the current process and procedures around termination from the program, adding more referrals and information to resources clients might need.*
- *Consider adding an ‘exit interview’ and systematic follow-up with clients 1-month post-termination.*
- *Restructure the resources currently available to the program; explore the role of the Statewide Benefits Counselor and consider changing the current Scope of Work.*
- *Explore current procedures around “restricted status” clients and consider working with case managers to provide intensive case management for those clients.*

Summary

While these data address our four evaluation questions for this study phase and provide valuable information on the lives of former CAREAssist clients, many questions still remain regarding the Estimate of Unmet Need. Because only two of the respondents had unmet medical needs that corresponded with the Oregon definition, additional exploration is warranted to better understand those PLWH/A who have fallen out of care and are not served by the current service sectors. Phase Three of the Out of Care Study will address those issues, gathering qualitative data from PLWH/A on barriers to care, unmet medication needs and systems that serve PLWH/A.

Table 1. Final Disposition Status of Clients in Sample

Final Disposition Status	Respondents	
	%	(n)
Completed Interview	26	(33)
Refused	4	(5)
Deceased	0	(0)
Ineligible		
Out of state	5	(6)
Language	1.5	(2)
Can't remember program	1.5	(2)
Unsure of benefit status	1	(1)
Prison	1	(1)
Unreachable		
No valid phone or address	27	(34)
No valid phone	24	(30)
No response to phone or mail	9	(11)
Total	100%	125

Table 2: Characteristics of Former CAREAssist Clients in Total Sample

Characteristic	Total Sample		Respondents		Non-Respondents	
	%	(n)	%	(n)	%	(n)
Total		(125)	26	(33)	74	(92)
<i>Demographic characteristics</i>						
Age group						
39 and under	32	(40)	33	(11)	32	(29)
40 - 49	50	(63)	49	(16)	51	(47)
50 and above	18	(22)	18	(6)	17	(16)
Gender**						
Male	86	(108)	73	(24)	91	(84)
Female	14	(17)	27	(9)	9	(8)
Family size						
One	82	(102)	73	(24)	85	(78)
Two or more	18	(23)	27	(9)	15	(14)
Ethnicity						
Hispanic	10	(12)	6	(2)	11	(10)
Race						
African-American/Black	6	(8)	6	(2)	7	(6)
Asian/Pacific Islander	2	(3)	0	(0)	3	(3)
Caucasian/White	81	(101)	85	(28)	80	(73)
Multi-Racial	4	(5)	6	(2)	3	(3)
Native American/Alaska Native	2	(2)	3	(1)	1	(1)
Other	2	(2)	0	(0)	2	(2)
Unknown	3	(4)	0	(0)	4	(4)
<i>CAREAssist characteristics</i>						
Region						
EMA [‡]	59	(73)	58	(19)	59	(54)
Days since termination						
365 days or less	16	(20)	18	(6)	15	(14)
366 – 730 days	34	(43)	39	(13)	33	(30)
731 days or more	50	(62)	42	(14)	52	(48)

[‡] Includes the following counties: Clackamas, Columbia, Multnomah, Washington and Yamhill

** Statistically significant difference between responders and non-responders ($p < 0.05$)

Table 3: Characteristics of Phase Two Respondents

Characteristic	Respondents	
	%	(n)
<i>Demographic characteristics</i>		
Age group		
39 and under	33	(11)
40 - 49	49	(16)
50 and above	18	(6)
Gender		
Male	73	(24)
Female	27	(9)
Race		
Caucasian/White	91	(30)
African-American/Black	6	(2)
Other*	3	(1)
Sexual orientation [†]		
Heterosexual/Straight	44	(14)
Homosexual/Gay or Lesbian	49	(16)
Bisexual	6	(2)
Living with Spouse/Partner		
Yes	52	(17)
Region		
EMA [‡]	58	(19)
<i>Socioeconomic characteristics</i>		
Educational level		
Grades 9 - 11	3	(1)
Grade 12 or GED	33	(11)
1-3 years of college	43	(14)
4 years of college or more	21	(7)
Household size		
One	33	(11)
Two	49	(16)
Three or more	18	(6)
Household income level (monthly)		
\$0 - \$999	24	(8)
\$1000 - \$1999	27	(9)
\$2000 and higher	49	(16)
Has paying job		
Yes	46	(15)

* One respondent described his race as “Mexican”

[†] One respondent refused to answer

[‡] Includes the following counties: Clackamas, Columbia, Multnomah, Washington and Yamhill

Table 4: Health-Related Characteristics of Respondents, by Currently Insured

Characteristic	Currently Uninsured*		Currently Insured	
	%	(n)	%	(n)
Total	15	(5)	85	(28)
<i>Health characteristics</i>				
Health status				
Excellent or Very good	40	(2)	25	(7)
Good	0	(0)	43	(12)
Fair or Poor	60	(3)	32	(9)
AIDS status				
Given AIDS diagnosis	40	(2)	57	(16)
<i>Current healthcare</i>				
Has regular healthcare provider (HCP)				
Yes	40	(2)	100	(28)
Taking HIV medication				
Yes	40	(2)	82	(23)
Medical debt				
\$500 or more	60	(3)	30	(8)
<i>Healthcare since leaving CAREAssist</i>				
Had <u>any</u> insurance coverage				
No	40	(2)	0	(0)
Gone 6 months without seeing HCP				
Yes	80	(4)	14	(4)
<i>Healthcare in last 12 months</i>				
Had CD4 or viral load done				
No	40	(2)	0	(0)
Number of visits to HCP				
Zero visits	40	(2)	0	(0)
1-4 visits	40	(2)	68	(19)
5 or more visits	20	(1)	32	(9)

*Percentages are provided for descriptive purposes only and should not be used for comparison across subgroup categories due to small numbers of uninsured respondents.

Table 5. Themes Identified for Why Respondents Have Not Reapplied for CAREAssist*

Response Theme	%	(n)
Has other coverage	40	12
Assumed or told they're not eligible	30	9
Intend to reapply soon	17	5
Hasn't needed it	13	4
Can't afford it	10	3
CAREAssist was "too difficult to deal with"	10	3
Other people need it more	7	2
Haven't thought about reapplying	7	2
Thought CAREAssist no longer existed	3	1

** Each respondent may have more than one theme identified in response given; percentages will add up to more than 100% of respondents.*

Table 6: Characteristics of Former CAREAssist Respondents, by Ever Skipped Doses

Characteristic	Ever skipped doses of HIV medication to save money?			
	Yes		No	
	%	(n)	%	(n)
Total	27	(9)	73	(24)
<i>Health characteristics</i>				
Health status				
Excellent or Very good	0	(0)	38	(9)
Good	56	(5)	29	(7)
Fair or Poor	44	(4)	33	(8)
AIDS status				
Given AIDS diagnosis	67	(6)	50	(12)
<i>Current healthcare</i>				
Insurance status				
Currently insured	89	(8)	83	(20)
Medical debt*				
\$500 or more	63	(5)	25	(6)
<i>Socioeconomic characteristics</i>				
Has paying job				
Yes	56	(5)	42	(10)

**One respondent did not know amount of medical debt*

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