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# Out of Care Study

*Summary of Study Design and Findings*



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## Background

The Out of Care Study grew out of the 2000 Ryan White Comprehensive AIDS Resources Emergency (CARE) Act requirements that Title I and Title II grantees<sup>1</sup> and HIV services planning bodies should determine the number of HIV-positive people aware of their status but experiencing unmet needs.<sup>1</sup> For the purposes of this study, the term “Unmet Need” has been defined as: Neither a CD4 test nor a viral load test within a 12-month period, which is consistent with Health Resources and Services Administration (HRSA) definitions. Estimates of Unmet Need for Oregon were similar to national and regional estimates,<sup>2,3</sup> but Ryan White management and community members were interested in what factors might lead to a person living with HIV/AIDS (PLWH/A) having unmet needs for medical care.

Ryan White Title II management in Oregon hired Program Design and Evaluation Services (PDES) to work with HIV/STD/TB (HST) staff on the initial Unmet Need Estimate<sup>4</sup> and to conduct follow-up studies on this estimate. PDES is an interdisciplinary, inter-agency evaluation and research work group, jointly established by the Multnomah County Health Department and the Oregon Department of Human Services (DHS) Health Services. PDES has a staff of over 20 persons, including psychologists, health service researchers, and epidemiologists, along with research analysts and support staff.

**Purpose of the Study.** The Out of Care Study is an exploratory study to examine the Unmet Need Estimate from multiple perspectives. The study was designed in three phases using both quantitative and qualitative methods, with each phase designed to reach a different population of interest.

- 1) Explore whether PLWH/A identified as having unmet needs for health services according to the HRSA definition (no CD4 and/or viral load tests in past 12 months) are in fact out of care.
- 2) Explore whether PLWH/A are experiencing unmet medical care needs besides regular lab testing.
- 3) Fill in the gaps in our current knowledge of out-of-care PLWH/A in Oregon.

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<sup>1</sup> Ryan White CARE Act Program is now structured as Parts A and B, but at the time of the work, the Program was organized by Titles I and II, so those terms will be used throughout this report.

- 4) Explore reasons for not getting CD4 or viral load tests performed annually.
- 5) Examine the trajectory of medical care for people who left or were dropped from the CAREAssist (ADAP) program.

### Phase One: Provider Interviews

Qualitative telephone interviews were conducted with 19 HIV service providers between August and October 2005: eight medical doctors (four from EMA, four from non-EMA), eight case managers (two from EMA, six from non-EMA), and three complementary & alternative medical (CAM) providers (all in the EMA). Interviews focused on medical care for PLWH/A, specifically looking at issues related to CD4 and viral load lab tests, as well as how providers see their professional roles.

**Results.** *The Department of Health and Human Services (DHHS) HIV Treatment Guidelines<sup>5, 6</sup> clearly influenced the types of lab work and the frequency of lab work that providers recommended to PLWH/A as critical aspects of their medical care.*

*Overall, service providers interviewed appeared to be consistent with DHHS guidelines regarding CD4 and viral load tests, performing or recommending these tests every three to six months at a minimum.*

*Providers did, however, identify barriers to meeting the standards of care with some PLWH/A. Client-level psychosocial barriers primarily related to untreated mental illness and substance abuse were first identified. Upon questioning, other barriers emerged including structural barriers (lab hours, location of lab, etc), “feeling healthy,” financial barriers, and the system failure commonly described as “falling through the cracks.”*

*No single facilitator was identified; rather, a combination of factors at different levels – client, provider, agency, and system – appeared to help keep PLWH/A engaged in care and getting annual lab tests done.*

*Beliefs regarding professional roles depended on the type of provider:*

*Physicians roles varied widely from persistently and systematically keeping their patients in care, to relinquishing any responsibility for tracking patient. Notably, a number of physicians interviewed helped patients overcome financial barriers and insurance problems.*

*Case managers most consistently viewed their primary role as “getting someone into medical care and keeping them engaged in their care” even though drawing boundaries with clients and other service systems could obfuscate that role.*

*CAM providers saw their role as focusing on patient's "quality of life and living with chronic illness" by integrating their care with standard medical treatments and complying with national standards for HIV treatment.*

**Conclusions.** Oregon HIV service providers interviewed appeared to perform or recommend CD4 and VL tests every 3-6 months at a minimum for their clients. Provider-identified barriers to PLWH/A receiving the CD4 and VL tests as often as recommended included: untreated mental illness and substance abuse, lack of client finances, structural barriers such as lab hours and location, clients feeling healthy and the system failure commonly identified as "falling through the cracks." Beliefs regarding professional role and responsibility around this issue varied according to provider type.

## Phase Two: CAREAssist Client Follow-Up Interviews

In 2002 and 2003, the CAREAssist program (Oregon's Ryan White AIDS Drug Assistance Program or ADAP) instituted a number of cost-saving strategies that resulted in a number of clients losing program services. No systematic follow-up had been done with these clients to see if they were able to access healthcare coverage through other systems or if they had fallen out of care. A simple random sample of 125 clients was drawn from a list of 297 clients who lost CAREAssist coverage between 1/1/03 and 6/30/05 and were 18 and older, living in Oregon and not currently receiving CAREAssist services.

PDES staff contacted former clients by letter and phone between January and March 2006 to describe the study and obtain informed consent. Interviewers reached 50 (40%) former clients; five (4%) refused to participate and 12 (10%) were ineligible due to a variety of reasons. Thirty-three clients completed the 30-minute structured telephone interview for an overall response rate of 26%. Respondent characteristics were similar to those of non-respondents, except in regards to gender: women were more likely than men to complete the interview.

**Results.** *All but one of the 33 (97%) respondents were stably housed in the year before the interview. Thirty two respondents (97%) had graduated high school or received a GED, and 21 respondents (64%) had some college education or more. Fifteen participants (46%) had a paying job at the time of the interview. The average income level was \$2432 (standard deviation (SD)=\$2017); 17 of the respondents (51%) reported a monthly household income less than \$2000.*

*Five respondents (15%) were uninsured at the time of the interview. Fifteen respondents (46%) had private insurance, ten (30%) were on OHP/Medicaid, and nine (27%) had Medicare as primary or secondary insurance. This breakdown is similar to national estimates of coverage.<sup>7</sup>*

*All respondents believed they should see a healthcare provider at least every year. But two respondents (6%) had not seen a provider and had not had CD4 or viral load labs done in the last 12 months; two additional respondents (6%) had only one healthcare visit in the last year. Eight (24%) respondents had gone six months or longer without seeing an HIV healthcare provider.*

*Eight (24%) reported a time in the last year when they needed to see a healthcare provider but could not because of cost; interestingly, five of these respondents were currently insured.*

*Twenty-five respondents (76%) were taking HIV medications at the time of the interview. In the last 12 months, nine (27%) respondents reported skipping doses or taking less of an HIV medication in order to save money; eight of these nine respondents were currently insured, and five had a paying job.*

*Fifteen respondents (45%) reported some level of medical debt owed to a doctor, clinic or hospital. The mean level of medical debt for those 15 respondents was \$1533 (SD=\$2233). Notably, 12 (80%) of the respondents with medical debt were currently insured, and 11 (73%) were currently taking HIV medication.*

*Twenty respondents (61%) did not have a case manager in the last year. When asked who other than HIV case managers help them find services they need, 14 (42%) said “Nobody” and 9 (27%) said their doctor.*

*At the end of the interview, respondents were asked an open-ended question about how losing CAREAssist affected their health. Nearly half of the respondents reported that losing CAREAssist services affected them financially, mentally or physically. In fact, seven (21%) stated that losing CAREAssist resulted in their health deteriorating, often due to financial barriers.*

**Conclusions.** We interviewed primarily stably housed, relatively well-educated, employed PLWH/A. Of the 33 former CareAssist clients who completed the interview, 15% were uninsured. Two respondents (6%) met our definition of “out of care” in that they had not had a CD4 or viral load tests in the past 12 months. However, even patients who did not meet the “out of care” definition reported other unmet needs around HIV care:

- **One in four respondents had gone 6 months or longer without seeing an HIV care provider.**
- **Eight (24%) reported a time in the last year when they needed to see a healthcare provider but could not because of cost.**
- **Nine (27%) reported skipping doses of HIV medications to save money.**
- **Just under half (45%) reported some level of medical debt.**

**While the loss of CAREAssist services did not result in negative health outcomes for all the former clients interviewed, one in five believed that losing CAREAssist caused their health to deteriorate. The financial assistance from this program was important for these participants, a finding summarized by one former CAREAssist client who stated, “I don’t get the HIV care I need now because I can’t afford it.”**

### **Phase Three: Out of Care Client Interviews**

The third phase was designed to gather data from 60 current CAREAssist (ADAP) and Ryan White Title II Case Management clients who met the Oregon definition of having unmet medical needs (no CD4 or viral load in the last 12 months). A 45-minute mixed methods interview guide was developed to gather qualitative data on barriers and facilitators to healthcare, specifically focusing on lab tests.

In July 2006, PDES staff worked with CAREAssist staff and Ryan White Title II management to identify current eligible clients from both programs. Of the 1344 current CAREAssist clients, 310 (23%) were identified as not having labs done in the prior year. Of the 609 Title II Case Management clients, 406 (67%) had no evidence of labs in RW CareWare 4.1.

After combining the clients from both programs and removing any clients with special contact restrictions identified by case managers (e.g., do not call, do not leave messages, no mailings), the final total client sampling frame was 602 clients (342 Title II Case Management, 217 CAREAssist, and 43 in both programs). Between December 2006 and February 2007, a random sample of 120 clients received letters about a survey related to “assistance programs” (HIV/AIDS and/or Ryan White Care Act programs were never mentioned in the letter) and received follow-up phone calls.

**Results.** *Of the 73 clients reached, two (2%) refused to participate. Only one (1%) of the 73 clients reached was eligible. However, this client was not interviewed due to difficulty in scheduling the interview. The 70 (58%) ineligible clients reached all reported having received CD4 or viral load tests in the past 12 months; however, a number of them mentioned other unmet needs related to insurance challenges, questions about program eligibility, and financial barriers to healthcare.*

*After two months of contacting clients, 46 (38%) of the 120 clients were deemed unreachable, and one was deceased. The main barriers to reaching clients were invalid phone numbers or addresses: 35 clients (28% of the overall sample) had bad addresses or invalid phone numbers. Case Managers were contacted for updated client contact information, but those clients were still either unreachable or ineligible.*

*To better understand the demographic characteristics of the unreachable clients, PDES staff compared the unreachable clients to those reached. Those unreachable clients were not significantly different from those who were reached with respect to race, ethnicity, gender and program type. Furthermore, HST Surveillance staff checked Trio, the electronic lab records database, to see if the unreachable clients had evidence of a lab or if the unreachable clients may have been out of care. Staff found that 41 of the 46 (89%) unreachable clients had evidence of at least one lab since 6/1/05, indicating they were not truly out of care.*

**Conclusions.** **Over a third of the clients were unable to be reached and only one of the clients reached reported experiencing unmet medical needs consistent with this study's definition. Notably, nearly all of the clients reached were supportive of the project, and a number of clients stated they feel unmet medical needs are an important issue for PLWH/A.**

**Although information contained in the RW CareWare 4.1 and CAREAssist databases could be key to identifying Ryan White clients for evaluation projects in the future, using client contact and lab data from the databases was not an effective way to identify and locate CAREAssist and Case Management clients with unmet medical needs. The lab data in both databases were incomplete or outdated. Given the data system and data quality issues, these databases should not be considered reliable data sources for estimating unmet need among the CareAssist or Title II HIV Case Management populations. Program management should consider investing resources in data cleaning with both databases.**

## Summary

The Out of Care study used three phases, numerous data sources and multiple perspectives to examine the issue of PLWH/A not receiving viral load and CD4 lab tests according to the standard of care. HIV care service providers in Phase One offered insight into numerous structural and systemic factors that might be associated with PLWH/A not receiving CD4 and viral load tests annually. However, we encountered challenges in reaching PLWH/A without CD4 or viral load test in the last 12 months who were engaged in Ryan White Care programs.

Although the Unmet Need Estimate indicated that a substantial proportion of PLWH/A might not be getting CD4 and viral load tests done yearly,<sup>4</sup> our results suggest that almost all current and former CAREAssist and Title II Case Management clients are getting their CD4 or viral load tests at least annually. These findings are consistent with those from the Ryan White Case Management Needs Assessment.<sup>8</sup> Nevertheless, information shared in the Phase Two interviews and the Phase Three eligibility screening suggest that some of these same clients need assistance and support around medication, financial and insurance issues.

Because so few “out of care” PLWH/A were located for this study, we were unable to increase our understanding from a client’s perspective around unmet medical needs and the reasons someone living with HIV/AIDS might not be receiving annual CD4 or viral load tests. In order to learn from a PLWH/A’s perspective what factors are associated with not getting these labs done, future studies could go outside the CAREAssist and Title II Case Management programs using multiple recruitment methods to locate these PLWH/A who are difficult to identify using traditional recruitment methods.

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