

# Financial Assistance for PrEP

## Best Practices & Recommendations for the California State Office of AIDS' PrEP Assistance Program



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## Executive Summary

We conducted a rapid assessment study of the enrollment structure of California's AIDS Drug Assistance Program (ADAP) to identify best practices that could be incorporated into the design and implementation of a new PrEP financial assistance program. In addition, we assessed the feasibility and acceptability of having ADAP enrollment staff and/or PrEP navigators serve as enrollment workers for such a program.

From June to July, 2017, we conducted 15 key informant interviews across 5 California counties: Alameda, Fresno, Los Angeles, San Diego, and San Francisco. We selected participants who had familiarity and experience with the ADAP enrollment system or who had experience with PrEP navigation duties in a variety of clinical and community-based settings.

Informants expressed enthusiasm about the potential for a PrEP financial assistance program modeled after the ADAP. Informants reported that it would be useful for those who were currently accessing PrEP as well as those not yet accessing PrEP. The value of such a program was perceived to be especially high among clients with either no insurance or those with a high-deductible insurance plan. Modeling the program after ADAP was generally perceived as a good idea. Informants who interact with the ADAP system find the portal easy to use. ADAP enrollment workers in certain settings and PrEP navigators may be well situated to do benefits enrollment work for qualified prospective or current PrEP users. The ideal staffing plan for this program, however, will depend on the setting, the size and characteristics of the patient/client population, and the capacity of the existing staff at each agency where enrollments may take place.

In this report, we highlight best practices of the current ADAP enrollment system, attitudes about the PrEP benefits assistance program, and perceived concerns about implementing the new program. We then provide recommendations to consider regarding the staffing and structural aspects of the program.

## Background

Currently, Truvada® is the only drug approved by the US Food and Drug Administration and widely available to be used as an HIV pre-exposure prophylaxis.<sup>1</sup> The Centers for Disease Control recommend Truvada® be taken daily and that patients using PrEP undergo clinical follow-up and monitoring every three months. The monitoring requires consistent laboratory testing including HIV testing every 3 months and creatinine testing every 6 months and STI and pregnancy testing, as needed. Without insurance, PrEP costs approximately

\$1,250 a month or \$15,000 a year.<sup>2</sup> Most Californians cannot afford the market rate cost.

Truvada® is covered by most private insurance plans and by Medi-Cal. However, for people who are uninsured or who have high co-pays or deductibles, PrEP may be out of reach. Gilead, the manufacturer of Truvada®, offers a co-pay card that covers up to \$3,600 of medication costs annually.<sup>3</sup> Most Covered California plans in conjunction with the Gilead co-pay card reduce a person's out-of-pocket spending for Truvada® to zero.<sup>2,4</sup> For people insured through the bronze-level Covered California plan, the out-of-pocket cost for

Truvada® is \$6,000 a year, with the Gilead co-pay card lowering that cost to \$2,400 a year. Note, these out of pocket cost estimates do not include the necessary follow-up clinical visits and laboratory testing.

There is an urgent need for a state-level assistance program to help current and potential PrEP users access care. In 2016, the Office of AIDS, a division of the California Department of Public Health, was authorized to develop a PrEP benefits assistance program that will be modeled after ADAP. For PrEP users with annual incomes below 500% of the federal poverty level, the program will cover: 1) PrEP-related medical costs for uninsured clients; and 2) PrEP-related medical co-pays, co-insurance, deductibles, and drug costs not covered by a client's health insurance plan or the manufacturer's co-payment assistance program for insured clients. Uninsured clients who meet the drug manufacturer's income criteria can get free drugs from the manufacturer's Patient Assistance Program until they can be navigated to more comprehensive health care coverage. The Office of AIDS expects to begin implementing this program in January 2018.

By implementing this new program, California will join Massachusetts, New York, Colorado, and Washington as the fifth state in the nation offering state-level PrEP benefits assistance.<sup>5-8</sup> We conducted a study to understand experiences of frontline healthcare workers to generate recommendations for the new program.

## Methods & Analysis

We purposively sampled participants either having familiarity and experience with the ADAP enrollment system or experience with PrEP navigation duties. Our sample included 5 counties (Alameda, Fresno, Los Angeles, San Diego, and San Francisco) and a range of workplace settings (i.e., community health centers, STI clinics, HIV clinics and community based settings, and health departments).

We leveraged our research team's formal knowledge of and relationship with a number of key informants in these counties. Beginning in May 2017, we approached 26 potential informants of which 19 agreed to be interviewed, 4 declined and 3 did not respond to our request for an interview. Those who declined to be interviewed did so because they were either new to the position or leaving soon, and two others reported being too busy to take time away from client services. Of the

19 willing to be interviewed, we conducted telephone interviews with 15 key informants. Two people were willing to participate, but felt that others would be better informants, and were not scheduled for interviews. Two more people were scheduled, but were unable to join the call due to scheduling conflicts.

Interviews lasted between 45-90 minutes (1 hour on average), were audio recorded, and were transcribed. We conducted a thematic analysis of the data.

## Findings

Of the 15 people interviewed, 8 were ADAP enrollment workers and 7 were PrEP navigators. In one case, an ADAP enrollment worker informally served as a PrEP navigator as well. See Table 1 for a description of the key informants and their respective settings.

Informants were enthusiastic about the idea of a PrEP benefits assistance program. Concerns about the program centered around the capacity of staff members to take on new work, and questions around who would be eligible for the program and what exact costs would be covered. Many participants, however, especially PrEP navigators, were not concerned about additional work load, and often envisioned the new program as a natural extension of their existing duties. We describe these themes and more in the sections below.

## Experiences with the AIDS Drug Assistance Program (ADAP)

Based on preliminary discussions among leadership and staff at that Office of AIDS, the forthcoming PrEP benefits program will mirror many aspects of the AIDS Drug Assistance Program including, specific eligibility criteria and documentation requirements as well as an electronic platform (an online enrollment portal) to facilitate enrollment. The ADAP portal has been easier to use and navigate since the California Department of Public Health (CDPH) took over its administration from an external contractor in early 2017. Previously, there were serious and widespread problems with the management of the program resulting in the termination of the contract with the external contractor. Frontline users appreciated the increased communication and collaboration with the Office of AIDS (OA) regarding the design of the new portal. A new

enrollment currently takes on average 20 minutes if the client has the necessary paperwork and up to an hour or more if the client does not have the necessary documents. Informants noted that presenting income verification and residency paperwork were the most common barriers to rapid enrollment.

### **Helpful portal features**

- Universal search tool to look up client by first name, last name, date of birth, or social security number
- Dashboard feature indicating time left to complete application or renewal
- Scanning feature to upload supporting documentation

### **Helpful process features**

- 30-day grace period to submit paperwork
- Assigned ADAP advisor at the state
- Monthly conference call between the Office of AIDS (OA) and frontline users

Despite the improved functioning of the portal since CDPH intervention, there were still significant challenges with ADAP. Two types of issues emerged: proximal and longer-term.

### **Proximal issues**

- ADAP enrollment workers do not always get confirmation that CDPH received an application or document. The portal does not allow for either the tracking of out-of-pocket cost claims or supporting documents related to ADAP enrollment eligibility.
- Maintaining paper copies, while necessary for audit purposes, can be a nuisance.
- ADAP enrollment workers must file an explanation if a client needs a 30-day grace period. Previously, there was an automatic grace period.
- Re-certification letters sent by mail to clients are sometimes mistakenly discarded, not received or lost.
- Some clients were confused about documents required for annual re-enrollment versus bi-annual re-certification due to frequent changes in program guidance.

### **Longer-term issues**

- Social workers performing ADAP enrollment work distracts from performing other services on behalf of clients.
- Clients with chaotic lives have trouble providing paperwork and require a lot of tracking to fully complete enrollment.

## **Response to PrEP Benefits Program**

Both ADAP enrollment workers and PrEP navigators perceived a need for and were enthusiastic about a PrEP benefits program. PrEP navigators were more likely than ADAP enrollment workers to have heard about the possibility of a state-level PrEP benefits program.

### **Perceived advantages**

Informants believed that a PrEP benefits program would decrease disparities between those with and without PrEP access. In particular, uninsured clients (including those without established US residency) or those with a high deductible insurance plans are two groups that stand to benefit in particular. The Gilead patient assistance program, with its annual cap on spending, is limited and potentially leaves people without continuous access to medications. Informants felt that this new program could help people sustain PrEP use and expand access to people unable to initiate PrEP due to financial burden.

PrEP navigators explained that, in some cases, the new program may make benefits counseling easier by expanding access to PrEP. Several ADAP enrollment workers perceived PrEP users as more educated and younger than the average ADAP client living with HIV, thus assumed that enrollment for PrEP benefits assistance would be quicker than those for ADAP.

### **Perceived concerns**

Informants raised concerns that it may be challenging to implement a PrEP benefits program because HIV care and prevention often occur in different settings. ADAP enrollment workers may have difficulty incorporating prevention into their jobs, since they are often situated in HIV clinics. Additionally, current and potential PrEP users may not receive services in places where ADAP enrollment workers are placed.

There was a perception that PrEP users tend to be young and therefore may move or change jobs

frequently. This patient population may experience more frequent changes in health insurance status than older patients. Thus, informants expressed that PrEP clients may induce additional documentation updates than ADAP clients, depending upon the paperwork requirements for the PrEP benefits program.

## Who handles PrEP benefits enrollment?

Attitudes about who was best suited to enroll clients into a state-run PrEP benefits program varied according to the informant's role and workplace setting. PrEP navigators generally felt that they would be well suited for this work. Yet some expressed concerns that it would take away time that they could be spending on health education and counseling.

The capacity to increase caseloads of existing staff was often seen as a challenge, particularly at sites anticipating large numbers of PrEP seekers, in addition to large numbers of HIV-positive clients needing ADAP. Two of the interviewed ADAP enrollment workers were based in settings with a high volume of PrEP users. They recommended hiring a new person specifically for PrEP benefits assistance. They felt that they had already reached their maximum caseloads and could not reasonably foresee serving PrEP patients in addition to serving patients accessing ADAP.

Informants also expressed different interpretations of the role of benefits and enrollment work in building client relationships, which shaped their attitudes about who should take on enrollment work. For instance, some saw enrollment work as a discrete task that could be performed by a PrEP navigator, an ADAP enrollment worker or a benefits counselor. Whereas some PrEP navigators perceived benefits counseling as an integral part of a longer-term relationship. In general, most participants expressed a desire to reduce the number of hand-offs if at all possible to build rapport with potential PrEP users.

ADAP enrollment workers in settings without any other benefits counselors or PrEP navigators were generally willing to take on PrEP benefits enrollment in the future, if such clients were to be seen at their agencies, provided those conducting new enrollments would receive sufficient training.

Informants with either a background in benefits counseling or health navigation or among those with

extensive experience working with systems such as Medi-Cal, Medicare, and Covered California were well equipped to handle benefits navigation for the most complicated PrEP seekers i.e., those with a high-deductible. This points to the need for comprehensive training on multiple health benefits systems. One benefits counselor made this point while expressing concerns that ADAP enrollment workers may not receive enough comprehensive training. From her perspective, handling ADAP often required a deeper knowledge of other systems, such as Medi-Cal, Medicare, and Covered California. Meanwhile, PrEP navigators report frequent prevention counseling and risk assessment with PrEP users that often involves discussions about sexual practices and were concerned about the ability of those without expertise in sexual health counseling to serve PrEP clients. Some ADAP enrollment workers expressed the concern that they lack sufficient training to competently navigate these sensitive topics.

## Conclusions

Frontline workers embraced the idea of a state-funded program for PrEP financial assistance, though some agencies may need to hire additional staff to effectively implement this new program.

In summary, our staffing recommendations are as follows:

- ADAP enrollment workers or PrEP navigators could be well suited to do this work. We recommend flexibility in staffing so that organizations can incorporate the new program in a way that best fits their setting. We provide specific recommendations for staffing depending on the structure of the agency/clinic. (See Figure 1)
- In settings where PrEP services have yet to be rolled out, the ADAP enrollment worker may be the only person on-site that could absorb the work, thus they must become proficient in both care and prevention benefits assistance. For clinic sites that only offer PrEP and not HIV care, PrEP navigators are an obvious choice to fill this role. They may also need to be equipped to handle ADAP enrollment should a case arise.

See the next page for further recommendations.

## Summary of Recommendations for PrEP Financial Assistance Program

### Enrollment Staffing

- In settings with a high volume of PrEP users, use existing PrEP navigator(s) or hire a new person(s) to take on PrEP benefits enrollment. ADAP enrollment workers in this type of setting lack the capacity to take on a greatly expanded caseload.
- In settings with a low volume of PrEP users, ADAP enrollment workers are likely able to take on some PrEP benefits enrollment.
- In settings with PrEP navigators and ADAP enrollment workers, allow staff to decide who ought to enroll PrEP users into the benefits program based on clinic workflows.
- In settings without a benefits counselor or ADAP enrollment worker, a newly hired or existing PrEP navigator may be best positioned to take on PrEP benefits enrollment.

### Eligibility and Portal Features

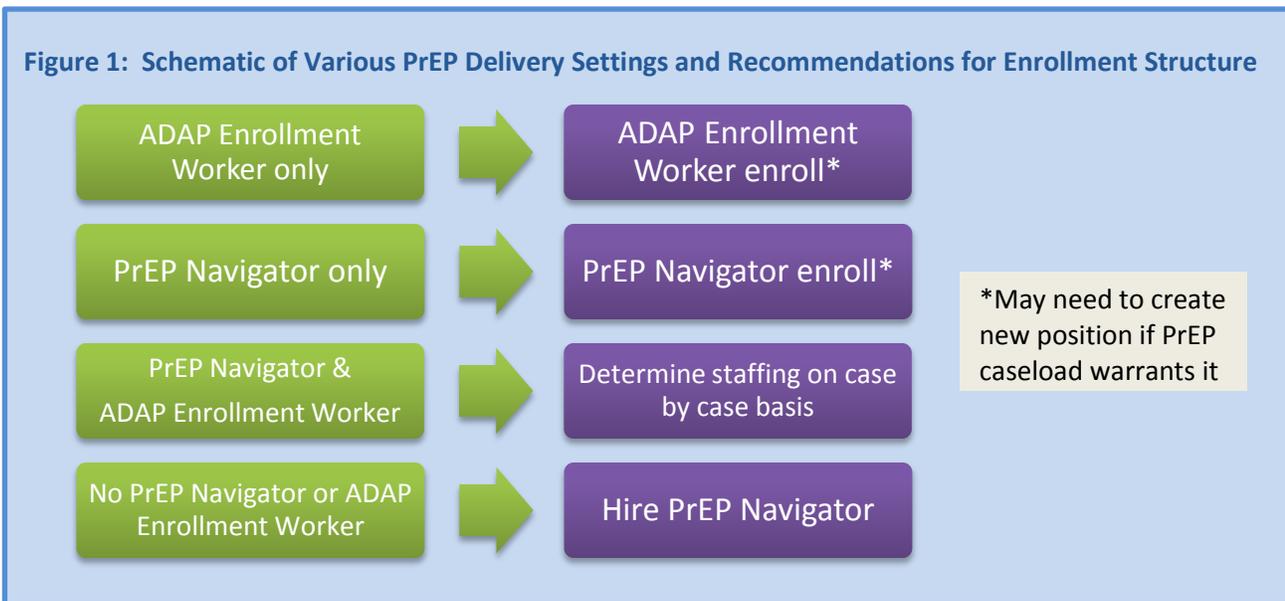
- Make the application process simple, with a quick turnaround time. Otherwise, people can become discouraged and not initiate PrEP. The existing medical out-of-pocket costs program for ADAP is time consuming and complicated. Ensure a way to electronically track submission of the medical out-of-pocket cost claims.
- Include an automatic 30-day grace period for enrollments so that clients can start PrEP immediately while gathering any necessary supporting documents.
- Consider offering clients the option to complete electronic applications on their own.
- Minimize the number of changes to required paperwork and documentation, as this can cause confusion for both enrollment workers and clients.

### Program Structure and Implementation

- If ADAP enrollment workers are going to do the enrollment, they may need training on counseling related to PrEP and prevention.
- Consider implementing an Enrollment Worker Advisory Committee similar to the one used with ADAP to facilitate collaboration between the State and enrollment workers.
- Have a follow-up system in place to monitor beneficiaries over time.

**Table 1: Key Informants and Setting Descriptions**

County	N=	Role	HIV/PrEP Services?
Alameda	N=2	PrEP Navigator ADAP Enrollment Worker (Benefits Counselor)	HIV & PrEP Services HIV & PrEP Services
Fresno	N=1	ADAP Enrollment Worker	Non-medical services for HIV & PrEP
Los Angeles	N=3	PrEP Navigator ADAP Enrollment Worker PrEP Navigator	HIV testing & PrEP Services Non-medical services for HIV & PrEP HIV & PrEP services
San Diego	N=5	ADAP Enrollment Worker ADAP Enrollment Worker ADAP Enrollment Worker PrEP Navigator PrEP Navigator	HIV Services (PrEP coming soon) HIV Services (PrEP coming soon) HIV Services (refer out PrEP) Non-medical services for HIV & PrEP HIV & PrEP Services
San Francisco	N=4	ADAP Enrollment Worker ADAP Enrollment Worker (Benefits Counselor) PrEP Navigator PrEP Navigator	HIV & PrEP Services HIV & PrEP services HIV & PrEP services PrEP services only



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