



Crafting Policy and Funding Initiatives to Increase PrEP Uptake and Retention

A California HIV/AIDS Policy Research Centers Think Tank

On November 8 and 9, 2017, the California HIV/AIDS Policy Research Centers (CHPRC) convened two groups of public health department and community leaders to develop concrete strategies for increasing uptake and retention of pre-exposure prophylaxis (PrEP). PrEP is a highly effective HIV prevention strategy in which HIV-negative individuals take a daily medication to reduce their risk of acquiring HIV. Increasing PrEP use is a key goal of California's Laying a Foundation for Getting to Zero plan, but data indicate that uptake has been limited particularly among key populations. The California Department of Public Health (CDPH) estimates that there are 220,000 to 240,000 Californians with an indication for PrEP, but data suggest that only 9,000 people were taking PrEP in late 2016.¹ Although some local health jurisdictions have implemented programs to increase PrEP uptake, many parts of the state do not have sufficient support or resources to effectively reach all those who could benefit from this intervention. The overall purpose of these meetings was:

1. To identify the most significant barriers to increasing PrEP uptake and retention;
2. To identify promising strategies to increase PrEP uptake and retention; and
3. To reach consensus among public health department and community leaders on key policy and funding initiatives to accelerate PrEP uptake and retention in California.

Participants identified several key policy and funding initiatives that should be prioritized to increase PrEP uptake and retention. Each of these recommendations is described in further detail later in this report.

1. Create durable funding streams to support PrEP outreach, navigation and delivery.
2. Improve communication and coordination between clinical and non-clinical sites.
3. Develop statewide marketing and educational resources to increase awareness, knowledge and motivation to use PrEP, particularly among key populations.
4. Develop and disseminate best practices for PrEP delivery to medical providers, health departments, PrEP navigators and other stakeholders.
5. Improve PrEP access for youth by addressing medical confidentiality concerns and employment needs.

CHRPC is sharing the results of these proceedings with statewide advocates and policymakers to establish recommendations for future policy and funding proposals. CHRPC will also identify specific research opportunities raised during the meetings in order to be responsive to any future policymaking efforts.

¹ California Department of Public Health, Office of AIDS. (2016). *Laying a foundation for getting to zero: California's integrated HIV surveillance, prevention, and care plan*. Retrieved from https://archive.cdph.ca.gov/programs/aids/Documents/IP_2016_Final.pdf.

Background

The meetings began with an overview of key activities influencing PrEP uptake in California since Truvada® was first approved by the U.S. Food and Drug Administration (FDA) for use as PrEP. These activities include the launch of PleasePrEPMe.org, San Francisco's Getting to Zero initiative, the Los Angeles County Board of Supervisors' approval of a countywide PrEP program, statewide and local funding from the Centers for Disease Control and Prevention (CDC) for Project PrIDE, state funding for PrEP navigation services and the development of a statewide financial assistance program for uninsured and underinsured individuals. A summary of these activities is included at the end of this report.

Information was also presented regarding PrEP utilization among enrollees in Medi-Cal, California's Medicaid program. Data were presented on PrEP use from 2014 through 2016, when California expanded Medi-Cal coverage, and compared it to PrEP use in 2013, just prior to full implementation of the Affordable Care Act. These findings indicate that PrEP uptake has increased dramatically throughout the state and across most demographic groups, except those ages 65 and older and women, whose rates of uptake rose and then leveled from the second half of 2015 on. The data also reveal several areas of concern, namely in terms of lower rates of uptake among Blacks and Latinos. With regard to age, rates of uptake were much lower for the youngest age group, 13-24, than for those ages 25-34 or 35-44 years. Furthermore, despite large increases in PrEP uptake over time, the findings point to a large potential gap between Medi-Cal beneficiaries who have accessed PrEP and those with indications for this preventive measure. A complete overview of these findings will be available on CHPRC's website in early 2018.

Defining Success

Participants were first asked to define how they envision success in terms of PrEP uptake and retention in California. All participants agreed that there must be equitable access and uptake regardless of socioeconomic status, age, race, sexual orientation, gender identity, geographic region and documentation status. In order to accomplish this, participants envisioned a future where there was a common, non-stigmatized understanding of PrEP among providers, consumers, health departments and other stakeholders. Several participants cited birth control as a similar model, where PrEP is free from stigma and providers proactively discuss the intervention with their patients as part of routine sexual health counseling and family planning. In addition, several participants envisioned a future where providers take a person-centered approach to both retention and re-engagement and there were commonly used metrics to evaluate PrEP use. Finally, participants stressed the importance of adequate, stable funding for health departments, providers and community-based organizations to help ensure equitable access and uptake.

Barriers to Increasing PrEP Uptake and Retention

Participants were asked to identify the most significant barriers to increasing PrEP uptake and retention including individual, social and structural barriers. At the individual level, participants cited stigma, medical mistrust, poor health literacy, limited knowledge and understanding of PrEP, concerns about side effects, adherence challenges and limited

information about when it is appropriate to start and stop PrEP. Numerous other challenges that may interfere with a person's ability to adhere to PrEP were mentioned including mental health, competing needs, and substance use issues.

Several populations were highlighted for whom PrEP access and adherence may be particularly challenging. **Undocumented communities** may not access PrEP due to fears that accessing services may lead to their information being shared with federal authorities and result in deportation proceedings. PrEP knowledge and uptake among **women** has been especially low in part because PrEP education and outreach efforts have focused almost exclusively on gay and bisexual men. In addition, there is limited knowledge about those factors which increase women's HIV risk and no good guidance about how to prioritize PrEP for this population. **Homeless individuals** may have difficulty accessing and adhering to PrEP due to a confluence of social and structural barriers and outreach to this population has been limited. Many **people of color** do not feel comfortable at existing PrEP access points, lack proper knowledge about PrEP, assume it is inaccessible or distrust it. In addition, funding for PrEP education and navigation programs has not been consistently prioritized for impacted people of color and transgender communities. Some **transgender women** express concerns that PrEP will interfere with feminizing hormones or lead to weight gain. Finally, there was much discussion about the challenges faced by **youth** when attempting to access and adhere to PrEP including lack of privacy for those still covered under their parent's health insurance plans and limited competency among medical providers and navigators.

At the structural level, participants highlighted several significant barriers to PrEP uptake including the high cost of the medication and labs, lack of or poor insurance coverage, limited workforce readiness and complex paperwork and data entry requirements. Notably, participants cited the dearth of funding that is currently available for PrEP navigation, benefits counseling and medical services. Although some jurisdictions and organizations have been able to obtain government or philanthropic support for these activities, there is currently no dedicated funding stream to support PrEP-related activities statewide. Participants also cited confusion about how existing funding streams, including Family PACT, can be used to support PrEP access. In addition, participants noted the lack of county-level data about how many people are currently taking PrEP and how many would benefit from the intervention. Finally, there was much discussion about the limited competency among medical providers in dealing with sexual health.

Strategies to Increase PrEP Uptake and Retention

In an effort to identify effective and innovative approaches to increasing PrEP uptake and retention, participants engaged in a discussion about promising strategies to address the barriers identified previously. Many of the strategies focused on how to increase consumer awareness, knowledge and motivation to begin PrEP. Meeting attendees cited the need for both local and statewide marketing campaigns that focus not only on PrEP, but also on post-exposure prophylaxis (PEP) and overall sexual health. Several individuals suggested leveraging the social and sexual networks of current PrEP users to increase PrEP uptake. Targeted education campaigns, possibly including celebrities and social media influencers, also have potential to increase awareness and knowledge among the most vulnerable

communities including women, young men of color and transgender individuals. Several participants shared their desire that more funding be directed toward smaller organizations with a history of serving vulnerable communities, rather than larger organizations with the capacity to write strong grant applications. Smaller organizations may require some capacity-building assistance in order to obtain funding for PrEP-related activities. Similarly, participants cited the need to invest in the overall health and well-being of communities of color and transgender individuals including addressing medical mistrust and combining PrEP with economic empowerment programs.

Strategies were also directed at increasing medical provider knowledge and willingness to prescribe PrEP. These strategies include medical school courses on PrEP and PEP, standardized guidance from CDPH or another trusted medical source, requiring family planning providers to discuss PrEP and PEP with their patients, identifying PrEP provider champions at major health centers and carrying out provider detailing. Participants suggested directing the Department of Health Care Services (DHCS) to circulate an All Plan Letter (APL) to Medi-Cal providers directing that PrEP be provided to Medi-Cal recipients upon request, unless there is a medical contraindication. Finally, participants suggested encouraging providers to offer PrEP education and access during treatment for sexually transmitted infections (STIs), family planning and general health screenings particularly for women.

In addition to medical providers, participants discussed ways to train PrEP navigators and other frontline staff. For example, participants suggested creating a certification for PrEP navigators that includes best practices and in-depth information about PrEP, how to communicate with clients and evaluate risk, public and private insurance options, how to support adherence and retention and when it may be appropriate for clients to start and stop taking PrEP.

Participants offered several strategies to increase PrEP awareness and uptake among youth. Information about PrEP and PEP should be included in all school sexual health curricula in California. In addition, participants suggested creating guidance for providers on PrEP use among youth including off-label use for those less than 18 years old. Participants also cited the importance of online webinars, including continuing medical education (CME) credits, for pediatricians and adolescent providers. Finally, participants stated that the process for youth to keep their medical information confidential must be improved, citing instances in which established protections failed.

Several strategies were shared to help reduce structural barriers to PrEP access. Participants shared the importance of “same-day initiation of PrEP,” as a typical PrEP initiation can take 1-2 weeks from the screening visit to the medication initiation visit. The potential loss-to-care and risk of acquiring HIV for vulnerable clients could be high during those 1-2 weeks and delays could dissuade some individuals altogether. Some participants suggested offering starter packs at the first visit, including the ability to offer starter packs to clients who might be visiting from another jurisdiction. In addition, participants discussed increasing awareness and use of online PrEP access points like Nurx®. These companies allow PrEP users to avoid going to the doctor’s office and laboratory by using a mobile health platform and at-home testing kits. Participants also discussed the need to expand the availability of culturally

appropriate PrEP access points for uninsured and underinsured individuals. Finally, several participants expressed a need for standardized quality metrics (similar to HEDIS®) and clearer guidance about how Family PACT can be used to support PrEP access.

Key Policy and Funding Initiatives to Increase PrEP Uptake and Retention

Participants were asked to identify key policy and funding initiatives that should be prioritized. These included the following:

- 1. Create durable funding streams to support PrEP outreach, navigation and delivery.**

Participants emphasized the scarcity of adequate, reliable funding to support PrEP-related activities. Although some health departments and community-based organizations receive federal, state and/or philanthropic support, most parts of the state do not have sufficient resources to effectively reach even a majority of those who could benefit from PrEP. In Los Angeles, 14 “PrEP Centers of Excellence” provide PrEP-related medical services for uninsured and underinsured patients and offer health insurance navigation and enrollment for individuals eligible for Medi-Cal and Covered California. Los Angeles County residents can also initiate PrEP at multiple Public Health STI clinics. Similar streamlined, culturally appropriate access points should be funded and developed in other jurisdictions. California’s PrEP financial assistance program will be a major source of funding for PrEP delivery beginning in 2018. For insured individuals, the program will cover PrEP-related medical copays, coinsurance, deductibles, and drug costs not covered by the individual’s health insurance plan or Gilead’s copay assistance program. For uninsured individuals, the program will cover PrEP-related medical costs. CDPH will also reimburse participating sites for enrolling individuals in the program. Still, additional funding is needed to provide ongoing training for medical providers and support PrEP outreach and navigation activities.
- 2. Improve communication and coordination between clinical and non-clinical sites.**

Participants cited the need to improve communication and coordination between clinical and non-clinical sites. Non-clinical sites, particularly community-based organizations with a history of working with communities of color and other vulnerable populations, are critical to reaching many of those who could benefit from PrEP and connecting them with a culturally competent medical provider. Many of these sites also offer HIV testing, which is a natural entry point to PrEP services. One participant cited California’s “Hub and Spoke” model as an example, which teams Narcotic Treatment Programs (NTP) with medical providers to provide opioid addiction treatment services. NTP’s serve as “Hubs” and medical offices that are qualified to dispense medications serve as the “Spokes”. A similar model should be explored to connect clinical and non-clinical sites and improve PrEP uptake and retention among vulnerable populations.
- 3. Develop statewide marketing and educational resources to increase awareness, knowledge and motivation to use PrEP, particularly among key populations.**

Although multiple health departments and community-based organizations have developed their own education campaigns, many jurisdictions do not have the funding or resources necessary to create effective marketing materials. Participants believed that

statewide marketing materials should be developed, but still allow some flexibility for local health jurisdictions to tailor the materials to their individual communities (similar to the California HIV/AIDS Clearinghouse). In addition, the resources should include broader sexual health messaging including information regarding STI prevention and treatment, condoms and other prevention options such as treatment as prevention (i.e., Undetectable=Untransmittable). Ideally, the campaign would enlist the support of celebrities and social media influencers to reach vulnerable communities including young men of color, women and transgender individuals. Participants suggested conducting an inventory of existing marketing materials in California and across the country that might be leveraged for statewide marketing materials.

4. **Develop and disseminate best practices for PrEP delivery to medical providers, health departments, PrEP navigators and other stakeholders.** For medical providers, CDPH should partner with DHCS to develop standardized trainings and resources to improve provider knowledge and willingness to prescribe PrEP (particularly for youth). CDPH should also gather and disseminate best practices related to provider detailing and same-day PrEP. For PrEP navigators and other frontline staff, CDPH should develop a certification (similar to the HIV test counselor certification) that includes best practices for PrEP delivery and can be offered online. Participants also stressed the importance of creating a venue for health departments, medical providers and community-based organizations to share information, resources and best practices related to PrEP.
5. **Improve PrEP access for youth by addressing medical confidentiality concerns and employment needs.** It is extremely important to ensure affordable and confidential PrEP access for youth, particularly those still living with their families or accessing medical care through someone else's insurance. In 2013, California lawmakers enacted the Confidential Health Information Act to address privacy concerns of individuals insured as dependents on a parent's or partner's health plan. The law allows individuals to submit a "confidential communications request" to their health plan when seeking sensitive services such as PrEP under another person's policy. However, once a confidential communications request is submitted, it can take up to six weeks for the health plan to guarantee that sensitive information will not be shared with the main policy holder. The law also does not prevent the Explanation of Benefits (EOB) and other documents from showing a decreasing deductible which can raise the alarm for some policyholders. California's PrEP financial assistance program, set to launch in 2018, should provide free, streamlined access to PrEP and related medical services to youth and other individuals with confidentiality concerns. In addition, PrEP and sexual health promotion programs should seek to address structural barriers that may impede PrEP access for youth including unemployment. Participants suggested creating demonstration projects that combine PrEP delivery with economic empowerment programs. Such programs have the potential to address both community- and individual-level barriers to PrEP uptake. For example, Black and Latino communities are often suspicious of health campaigns that are tailored to them, and may be more concerned about the lack of quality educational and job opportunities than they are about HIV prevention. Furthermore, stress, poverty, lack of insurance and transportation due to unemployment is an individual-level barrier to health care.

Next Steps

The mission of the CHPRC is to work in partnership with consumers, advocates and policymakers to conduct policy-relevant research that strengthens local, state and national HIV prevention and care services for affected persons and populations. CHPRC will share the results of these proceedings with statewide advocates and policymakers to establish recommendations for future policy and funding proposals. CHPRC will also identify specific research opportunities raised during the meetings in order to be responsive to any future policymaking efforts. We thank all participants and presenters who dedicated their time and energy to these important meetings. We look forward to continue working together to implement practices that will increase uptake and retention of PrEP and ultimately end the spread of HIV in California.

Sincerely,

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Key Events Influencing PrEP Uptake in California

1. **California HIV/AIDS Research Program Demonstration Projects** – Through its initial demonstration project, CHRP grantees have initiated nearly 1,000 men who have sex with men (MSM) on PrEP, of whom nearly 60% are MSM of color. Grantees have developed various methods to work with study participants to increase adherence – from specialized adherence counseling to individualized text-message reminder systems. Grantees are also exploring outcomes such as risk compensation, STI prevalence, and sexual satisfaction. CHRP also launched the first PrEP demonstration project initiative in the United States to focus exclusively on women. Research teams in Los Angeles, San Diego and the San Francisco Bay Area will offer PrEP to an estimated 150 high-risk uninfected women. In 2016, CHRP funded three groups of grantees to initiate PrEP projects focused on transgender persons.
2. **Project PrIDE** – Nationally, the CDC funded 12 state and local health departments to facilitate and promote PrEP implementation. CDPH is partnering with 3 LHJs - San Diego, Orange, and Alameda Counties, as well as working with Desert AIDS Project in Riverside County. Los Angeles and San Francisco also received individual PrIDE awards.

San Diego County – San Diego County has subcontracted with the San Diego LGBTQ Center to provide PrEP Navigation services to the transgender community. A transgender person has been hired to provide PrEP navigation services to trans-clients and facilitates group and individual training for healthcare providers, group educational forums for consumers, and outreach to transgender women who are at high risk for HIV acquisition. Subcontractor Family Health Centers of San Diego has developed and implemented a social media and marketing campaign to raise awareness of PrEP's efficacy and availability to transgender women in San Diego County.

Orange County – Orange County's 17th Street Testing, Treatment and Care Clinic has developed protocols to provide PrEP to patients at high risk for HIV through one-on-one engagement. PrEP navigators have been hired and protocols for same day referral within the Orange County Clinic have been developed. For clients not appropriate for clinic services, individuals are referred to agencies to provide culturally appropriate PrEP-related services via the Orange County PrEP Coalition. The Coalition, which Orange County participates in, includes representatives from various HIV testing sites, medical facilities, and other providers and organizations who serve populations at high risk for HIV in Orange County.

County of Alameda – Alameda County has contracted with community-based organizations to provide PrEP navigation and related services to gay/MSM and transgender individuals. In addition, Alameda County has contracted with the Bay Area & North Coast AIDS Education Training Center to conduct outreach to providers and provide technical assistance and training to clinical sites in order to increase their internal capacity to deliver culturally appropriate PrEP clinical services.

Desert AIDS Project – To support PrEP navigation services developed under the funding from the PrEP Navigation Program, Desert AIDS Project developed PrEP outreach/

education to providers and a medical detailing program. The detailing program educates providers outside of Desert AIDS Project's network to increase the number of providers providing PrEP within the Riverside/Coachella Valley and San Bernardino region. In addition, Desert AIDS Project leveraged PrIDE funding to produce an extensive social media campaign utilizing digital and print media to increase awareness, knowledge about PrEP and access to PrEP for young gay/MSM and transgender women of color within the Palm Springs Coachella Valley area of Riverside County.

3. **Los Angeles** – In June 2015, the LA County Board of Supervisors passed a motion approving the implementation of a countywide PrEP program. The goals of LA County's PrEP program include increasing consumer awareness of PrEP, increasing medical provider awareness and use of PrEP, and increasing safety net access to PrEP. In order to increase consumer awareness of PrEP, the LA County Department of Public Health has developed a social marketing campaign called "The Protectors," created a website that includes a PrEP/PEP provider directory, and participated in numerous community events and forums. The Department of Public Health has also increased provider awareness through public health detailing and TA, the development of PrEP clinical tools, and other community provider trainings and activities. In 2016, LA County Board of Supervisors approved contracts to fund 14 PrEP Centers of Excellence that provide PrEP-related medical services for uninsured and underinsured patients and offer health insurance navigation and enrollment for individuals eligible for Medi-Cal and Covered California. LA County residents can also access PrEP services at multiple Public Health STD clinics.
4. **San Francisco** – San Francisco's Getting to Zero initiative has a PrEP committee that is taking a multi-pronged approach to increasing uptake focusing on users, providers and measurement. For users, the committee is working to expand the PrEP ambassador program with a particular focus on increasing diversity to ensure inclusion of African-American and Latino MSM, youth and women. They are also focused on launching a social media recruitment campaign using apps, expanding access among homeless populations, and launching a demo project for transgender women and men. For providers, the committee is focused on ensuring PrEP capacity in clinics that serve prioritized populations. In order to ensure broader access, there is work underway to establish a youth access program as well as a pharmacy delivered PrEP program in the Mission neighborhood. They are also focusing on establishing a protocol around PrEP users who seroconvert as well as a quarterly meeting of PrEP providers. The committee is also focused on measurement that includes establishing a PrEP cascade and evaluating reasons for poor retention, with updated metrics every 3 months. Another new initiative is a citywide PrEP navigator's group, which also includes PrEP navigators in the East Bay and South Bay.
5. **OA-Funded PrEP Navigator Programs** – Nine PrEP Navigator Projects have successfully developed PrEP navigation programs in the geographic areas they cover. Each navigator program is reaching the populations at most risk for acquiring HIV including gay/MSM, young gay/MSM of color, transgender women of color, and people who inject drugs. PrEP Navigators in all 9 projects successfully link individuals to insurance/benefits via the Gilead program, insurance and Medi-Cal where appropriate. PrEP navigators conduct readiness

assessments and referrals to PrEP providers, as well as provide PrEP education, adherence support, help identify and address barriers to PrEP access and adherence, linkage to adjunct services such as STD testing, and general follow-up. PrEP education campaigns have been developed for both clients and providers.

6. **Strategic HIV Prevention Projects (July 2017 to June 2019)**

AltaMed – Alta Med is expanding its reach, scope, and impact in both LA County and Orange County by partnering with APAIT to provide HIV Prevention services to the Asian Pacific Islander (API) community and is providing navigation and retention services for PrEP to the API community.

Los Angeles LGBT Center – LA LGBT Center is implementing a range of approaches designed to significantly reduce new HIV infections among gay/MSM of color, young gay/MSM of color, transgender women of color, and Spanish speaking gay/MSM. The Center is concentrating outreach to gay/MSM of color in South Los Angeles and a first-of-its-kind Transgender Wellness Center to operate in the Pico-Union district in Central Los Angeles. Core activities to date include outreach and social marketing, PrEP assessment/referral, development of protocols to provide rapid PrEP and PrEP retention and adherence support.

San Francisco AIDS Foundation – SFAF is collaborating with API Wellness and East Bay AIDS Center to reach high risk individuals for HIV/HCV testing, linkage to care and PrEP navigation as well as retention in PrEP for young MSM 18-24, MSM and trans women of color, and people who are homeless or marginally housed. SFAF uses existing infrastructure to expand services for the most impacted populations and increase community engagement. Outreach occurs with social media, peer-based outreach/social networking, strong relationships with community-based organizations, and targeted campaigns designed to engage priority communities.

County of San Diego - County of San Diego's HIV, STD and Hepatitis Branch (HSHB) is in the process of launching new health navigation services for newly diagnosed or out-of-care individuals, as well as PrEP navigation assistance services. HSHB is utilizing existing infrastructure to further enhance services for the most impacted populations through education and prevention, counseling and HIV testing, and care and treatment services. This project is a joint effort between HSHB and the following organizations: Family Health Centers of San Diego, San Ysidro Health Center, Vista Community Clinic, and San Diego LGBT Community Center.

7. **PleasePrEPMe.org** – Launched in 2015, PleasePrEPMe.org connects users interested in taking PrEP to willing providers with its unique searchable location-based capabilities. The website also offers resources for patients to learn more about PrEP and how to pay for it, as well as providers to increase their capacity to include PrEP in their practice. PleasePrEPMe.org was produced by HIVE with support from Gilead and is a collaboration between partners in the San Francisco Bay Area, Los Angeles and San Diego counties to unify the various regional lists of PrEP providers in the state. PleasePrEPMe.org is funded by the Office of AIDS under the Project PrIDE grant for the directory and online chat navigation services.

8. **PrEP Assistance Program** – CDPH is currently developing a statewide PrEP Assistance Program (PrEP-AP). For individuals with health insurance, the program will cover PrEP-related medical copays, coinsurance, deductibles, and drug costs not covered by the individual's health insurance plan or Gilead's copay assistance program. For uninsured individuals, the program will cover PrEP-related medical costs only (uninsured individuals can get free PrEP medication from Gilead's patient assistance program). The PrEP-AP will be implemented in two phases, with Phase 1 prioritizing the uninsured population and Phase 2 expanding to cover insured individuals. Phase 1 is projected to be implemented in early 2018, while Phase 2 will be implemented in the spring of 2018. CDPH plans on leveraging the existing ADAP enrollment site infrastructure to enroll individuals in the PrEP-AP by training existing ADAP enrollment workers to perform enrollment. Additionally, CDPH is working to establish a PrEP-AP Provider Network to provide clinical services to the uninsured population.