



## Expanding PrEP Access for Immigrant Latino Men Who have Sex with Men (MSM) in California

### EXECUTIVE SUMMARY

HIV rates among Latino men who have sex with men (MSM) are not decreasing at the same rate as they are decreasing among white MSM. This is a matter of concern as Latinx people are the largest racial/ethnic minority group affected by HIV in California. Currently, the California Department of Public Health in partnership with county health departments, community health centers, healthcare providers and non-profit service providers are collaborating to expand pre-exposure prophylaxis (PrEP) access throughout California to help curb HIV disease transmission. The state-funded payment assistance program for PrEP-related costs (PrEP-AP) has been a key development in facilitating PrEP uptake. In this study, we sought to document existing barriers and facilitators to expanding PrEP access for immigrant Latino MSM (ILMSM) in California, including un-/under-documented individuals.

### THEMES

The main themes across provider interviews included concerns with programmatic barriers that operate as additional “costs” to PrEP uptake, the need to dismantle PrEP as a “siloed” intervention and design culturally tailored services that account for multiple forms of stigma faced by ILMSM.

### Policy Recommendations

#### Offer Coverage for PrEP Case Management

PrEP programs require resources to offer ongoing case management support, including psychoeducation, to help build clients’ capacity to navigate systems of care while also working to reduce barriers on their clients’ behalf.

#### Destigmatize Data Collection

PrEP programs must identify and incorporate best practices for engaging clients around documentation requirements where immigration status is directly or indirectly implicated.

#### Decrease Documentation Requirements

PrEP programs at the federal, state, local and agency level, including privately funded PrEP assistance programs, must work to decrease documentation requirements for accessing services.

#### Restructure PrEP Service Access

PrEP service delivery designed to offer evening and weekend clinic and lab hours of operation, transportation services, and easy access to other health services are needed to better meet the holistic health needs of ILMSM.

#### Center PrEP Messaging on Wellness

PrEP programs must consider culturally tailored messaging that capitalizes on commonly accepted frameworks of wellness within Latinx communities.

#### Broaden Community Engagement

PrEP messaging must transcend the issue of disclosure related to same-sex behavior and/or sexual minority status to help decrease multiple forms of stigma, including PrEP-related stigma.

## Introduction

Recent statewide data in California indicates that HIV rates among Latino men who have sex with men (MSM) are not decreasing at the same rate as they are decreasing among white MSM. This is a matter of serious concern as Latinx people are the largest racial/ethnic minority affected by HIV in California (California Department of Public Health, 2020a). Furthermore, research has documented that Latinos, especially those who are immigrants, are diagnosed with HIV (i.e., tested) at a later disease stage, leading to delays in treatment (Dang et al., 2012; Keesee et al., 2012). Currently, the California Department of Public Health in partnership with county health departments, community health centers, healthcare providers and non-profit service providers are collaborating to expand pre-exposure prophylaxis (PrEP) access throughout California to help curb HIV transmission. The state-funded payment assistance program for PrEP-related costs (PrEP-AP) has been a key development in facilitating PrEP uptake. As of April 30, 2021, there are 192 PrEP-AP enrollment sites and 156 clinics that currently make up the PrEP-AP Provider network and 50% of PrEP-AP clients are Latinx (California Department of Public Health, 2021). This work includes efforts to increase partnership with private telehealth companies offering PrEP (PleasePrEPMe.org, 2018) and the recent passage of legislation permitting pharmacists to dispense post-exposure prophylaxis (PEP) and PrEP without a prescription (California HIV/AIDS Policy Research Centers, 2020a).

## Methods

The study's goal was to document existing barriers and facilitators in PrEP access among immigrant Latino MSM (ILMSM), including un-/under-documented individuals in the context of the robust efforts to increase PrEP uptake in California. The specific aims of the study were to:

1. Understand PrEP-AP service providers' current strategies for increasing awareness and uptake of PrEP among ILMSM;
2. Identify barriers and facilitators to increasing PrEP awareness and uptake among ILMSM; and
3. Examine common resources and strategies used for increasing PrEP uptake among ILMSM.

## Participants and procedures

In 2019, the study team identified all PrEP-AP service providers throughout California and targeted providers that represented diverse geographic locations and organizational sizes. To be eligible for the study, respondents were required to identify as (1) being age 18 and over; (2) currently working at a state-funded PrEP-AP enrollment site; (3) serving in the capacity of a PrEP enroller, a medical provider of PrEP services, or administrator of the PrEP program within their respective agency; and (4) providing PrEP-related services to ILMSM, including un-/under-documented individuals. In total, twelve (12) individuals were screened and deemed eligible and ten (10) completed the interview. Of these, five (6) respondents were from Southern California, two (2) were from Northern California, and two (2) were from Central California. Participants were offered a \$50 e-gift card for their participation. Of those interviewed, all participants were engaged in delivering PrEP-related direct services to clients.<sup>1</sup>

Eligible respondents who provided informed consent completed a study interview through an online platform, Zoom. Each interview was conducted by research staff and a content matter expert

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Participants delivering PrEP-related services include non-clinical staff as well as clinical staff. For this reason, reference to "clients" will be inclusive of patients served by clinical staff.

from *Bienestar Human Services*, a community-based health care and social services organization in the Greater Los Angeles area. *Bienestar's* expertise is in identifying and addressing emerging health issues faced by the Latino and LGBTQ populations, making them well suited to collaborate on this research study. Interview topics covered participants' experiences with delivering PrEP-related services to ILMSM.

## Data Collection and Analysis

The study team audio-recorded all interviews and summarized them according to a common template containing relevant provider information and conceptual domains derived from the interview guide. The summary template included key domains of inquiry including participants' role and organization; barriers and facilitators to PrEP for Latino MSM, with a sub-domain relating to un-/under-documented immigrants; and an overall summary of the interview. Based on a model of rapid qualitative analysis in health services research (Hamilton & Finley, 2019)(Hamilton, 2019), the summary data were combined into a single comprehensive matrix for analysis. The team conducted matrix analysis, using a set of reduced data tables jointly with subject matter experts from *Bienestar Human Services* and arrived at a consensus about the findings described below.

## Results

Three primary themes emerged related to PrEP awareness, PrEP uptake and PrEP service delivery. The first theme focused on how multiple forms of stigma and lived experiences of ILMSM contribute to a continued knowledge gap about PrEP and lower uptake of PrEP among this population. The second theme focused on the way programmatic barriers exact a "cost" on ILMSM accessing PrEP assistance programs. Participants described how ILMSM must overcome programmatic barriers that can make them feel more vulnerable to immigration-related consequences underscoring the misperception that PrEP is "free" or "no-cost." The third theme was a call from participants to break PrEP out of its "silo". Participants described the types of services that must be funded to increase PrEP uptake and facilitate access to comprehensive healthcare. Participants shared how addressing barriers to PrEP requires addressing barriers to whole-person health care. Participants offered insight into PrEP delivery models that can successfully address ILMSM with greatest need.

### Theme 1—Multiple Forms of Stigma and Lived Experiences of ILMSM

Participants pointed to multiple forms of stigma, including those related to race/ethnicity, sexual orientation, gender identity, as well as documentation status among ILMSM, as contributing to persistent knowledge gaps about PrEP. "*PrEP [adds] another layer of stigma in addition to the stigma related to sexual behavior*". Overall, PrEP-related stigma was cited frequently as driving misperceptions about PrEP. Participants explained that for some people, living with HIV and accessing PrEP/PEP is synonymous. Living with HIV and requesting PrEP were seen as "*inter-changeable*" and "*equal*" in that they carry a sense of being "*dirty*" or "*promiscuous*".

Participants illustrated challenges they have faced in broad dissemination of information about PrEP to ILMSM in California. Despite participants best efforts to educate clients about the utility of PrEP, participants acknowledged that there remains a significant gap in knowledge about PrEP among ILMSM. This is especially true when it comes to reaching individuals that do not feel comfortable disclosing their sexual minority status or same-sex sexual behaviors to others.

***It is still a common experience that Latinx MSM are afraid of coming out. These experiences and disclosure issues are unique... within Latino communities forcing many to live 'double lives.'***

Another participant shared that because of the absence of sexual health conversations within Latino families, likely due to the “taboo” nature of such conversations, *“white folks are leading the conversations without tapping into Latinx and African American communities”*. One participant described this as problematic as these conversations must take into account the cultural context of people’s experiences.

Participants state that issues of gay-related stigma and PrEP stigma serve as a backdrop to other lived experiences of ILMSM. *“Job security, finances and housing security make it difficult for farm workers to seek or access health services. Employers will fire staff if they take the day off to see the doctor or access services”*. Providers serving seasonal farm workers have difficulty with retention being that clients move frequently or “disappear”. One participant shared, *“they don’t have enough money for basic needs, they need to save money to send back to their families in Mexico, which adds to their stress/anxiety, diabetes and other uncontrollable primary care issues.”* These realities make accessing PrEP a lesser priority.

How PrEP providers engage ILMSM matters as well, especially in light of these multiple forms of stigma and lived experiences. Some participants described most of their clients as men who identify as heterosexual, but have sex with men. *“It is difficult to work with them when they are not willing to be open and share their sexual experiences due to the cultural stigma. We can’t help them if we don’t know what’s going on with them.”* Another stated that for clients, *“taking prescriptions is not their priority, they don’t get their labs done...so I won’t refill their prescription.”*

This approach or perspective differs significantly from that of other participants who shared ways that their clients actively harness resilience-based skills older generations have used, such as to speaking in “code”. One participant shared that for individuals that are not comfortable disclosing their same-sex sexual behavior and/or sexual minority status, the client frames taking PrEP medication as taking “vitamins.” The participant shared that their client, when asked about why he is visiting an agency offering PrEP services, shares with others that he is “participating in an “internship.”

### ***Theme 2—Programmatic Barriers Illustrate Other “Costs” to PrEP Uptake***

Despite the availability of structural supports such as PrEP-AP, access remains impeded. This is because the cost of PrEP for ILMSM cannot be captured merely by documenting the cost of the medication, doctor’s visits and lab work. Participants shared a broader perspective of other “costs” their clients must “pay” to access PrEP. For example, clients’ prior experiences with accessing publicly funded health services may influence their current experience. For immigrants, particularly, a denial of coverage in one context can drive the natural assumption to *“expect that this service, too, may not be covered.”*

Participants shared how *“the political climate greatly affects how people conceptualize health.”* Clients fear they cannot access services due to lack of documentation. *“That fear factor is a big problem because...people are afraid to even ask for assistance. It’s sometimes like they’re stepping on eggshells... they don’t know what they can do or how that could affect them in their future, especially if they are planning on doing something about their immigration status.”* Some of this manifests in the fact that *“[p]eople are just terrified to sign any document that’s government-related.”* Another participant explained that clients want to know who will have access to their medical records.

Regardless of whether these fears are material, ILMSM feel they must weigh their own safety and security from negative immigration-related repercussions against the required disclosures and documentation requirements related to accessing PrEP services and programs. When asked about how their respective programs request sensitive information about immigrant status, participants stated that their standard intake process from the outset requires asking whether the client has a Social Security number or holds U.S. citizenship. One provider stated explicitly that they do not ask about immigration status but focus, rather, on health coverage status as a proxy for U.S. citizenship. Another described an intricate process of determining immigrant status through reviewing various types of documentation, rather than asking the client directly. This included asking clients to gather documentation necessary to access such programs like proof of income that might give insight into documentation status as well.

Participants shared how PrEP services must be designed to decrease other programmatic barriers that may serve as a deterrent to PrEP access. Participants stated that this could be done through developing solutions tailored to meet the needs of the most vulnerable ILMSM, including:

- Funding ongoing case management support, including psychoeducation, to help build clients' capacity to navigate systems of care while also advocating to reduce barriers on clients' behalf
- Offering evening and weekend clinic and lab hours of operation
- Providing transportation services or resources (e.g., taxi vouchers, Uber/Lyft)
- Bundling PrEP services with easy access to other health services that can address other primary care needs
- Developing "...a one-stop... do it all at once..." approach by including other on-site services such as food banks, notary public, linkages to legal assistance, transportation/travel arrangements

### **Theme 3—Breaking Free the PrEP Silo**

PrEP uptake has been launched, in some instances, as a siloed health intervention; an approach that is often insufficient to meet the multi-dimensional needs of ILMSM. Despite having coverage for PrEP, participants shared about their need to care for clients' socioemotional health and provide ongoing psychoeducation. Participants highlighted the need for more comprehensive healthcare services and continuously expressed frustration with services that failed to meet clients' needs. Specifically, participants identified the need for client-centered services that are holistic and/or comprehensive, which includes reliable and accessible primary healthcare to address other health conditions (e.g., diabetes, high cholesterol) as well as behavioral health needs.

Although many clinics employ PrEP navigators who offer support and case management, participants shared that there exists an information and service gap between PrEP navigators and clinicians. These gaps serve as barriers that can unintentionally harm a client. One participant talked about the psychoeducation that must occur for clients to successfully access PrEP services and navigate service delivery. For example, the process does not end when a client receives a PrEP prescription from a physician. "[W]hen clients have no familiarity with picking up medication at a pharmacy... [I] coach them... tell them they may have to show an ID and [how to] pick it up themselves." Service gaps are particularly harmful when a client misses a day of work to meet with a PrEP navigator but their clinician

might not be able to meet the client for a same-day visit. A participant explained, *“It’s frustrating for them and especially for us as staff”* because clients can see a PrEP navigator on the same day but not the clinician, which happens more frequently than not. Another participant described the extra measures their program takes. *“We try to make it easy/accessible for clients to get care/labs and follow-ups so they don’t have to take time off from work.”* This is important as clients often do not receive sick time from employers and many work multiple jobs with little to no employment protections.

Participants talked about how addressing clients’ overall health needs requires a whole-person approach that designs services that consider overall health. Maintaining PrEP as a siloed health service does not help to achieve this goal. Additionally, participants spoke at length about the ways that PrEP services should be designed to meet the needs of ILSM who have the least amount of resources. This would include services that allow clients to do *“everything at a one-stop, lab and medication [PrEP] in one place,”* offering linguistically competent services to monolingual Spanish-speakers, designing programs for those with significant restrictions in terms of time, offering transportation and other supports needed to avoid delivery of “fragmented services.”

## Discussion

### Current Literature on PrEP Disparities

Evidence indicates that whether others will approve of PrEP uptake and ideas a person may have about who might be the right candidate to take PrEP depends on the particular cultural milieu (Schnarrs et al., 2018). Current literature on PrEP among Latinx populations documents the following types of concerns described by Latino MSM: (1) fear of negative side effects and toxicity of the medication; (2) doubts surrounding the effectiveness of PrEP; (3) burden of daily dosing; (4) feeling that their individual risks do not warrant use of PrEP; (5) Gay-related stigma; (6) PrEP-related stigma; and (7) fear of immigration-related consequences (Brooks, Landrian, et al., 2019; Brooks, Nieto, et al., 2019; García & Harris, 2017; Hess et al., 2019; Page et al., 2017; Schnarrs et al., 2018).

### Immigration Policy Landscape

Public support for increasing healthcare coverage options for individuals who are un-/under-documented holds steady in California (Cha, 2019). Californians broadly support a tolerant attitude toward immigrants: 72 percent believe immigrants are a benefit to the state, while 58 percent support the state taking separate action to protect un-/under-documented immigrants (Johnson & Sanchez, 2019). Immigration status has long played a critical role in determining health coverage and access to health services. Individuals who are un-/under-documented are ineligible for most forms of federally subsidized non-emergency healthcare coverage (e.g. Medicaid) and private health coverage, with limited exceptions. States like California may opt to expand access to Medicaid (referred to as Medi-Cal in California), as it did recently to offer health coverage to any eligible Californian under 26 years old, regardless of their documentation status (“SB 104,” 2019). County-funded programs are left to meet the needs of its residents that are otherwise unable to access other health coverage options.

Regardless of health coverage options, when it comes to matters related to immigration law, federal law and policy reigns supreme (*Chae Chan Ping v. United States*, 1889). In August 2019, the Trump administration issued a final rule related to Public Charge that upended established policy with regard to accessing public benefits, including publicly funded healthcare coverage (California HIV/AIDS Policy Research Centers, 2020b). While this rule has limited application, primarily targeting those seeking to adjust their legal status (e.g. get a “green card”) and those seeking to be admitted into

the U.S., it has had a considerable “chilling effect.” By design, the public charge rule has caused immigrants across the board, regardless of whether the Public Charge rule applies, from utilizing publicly funded services (Yoshikawa et al., 2019).

In April 2021, Presidential Executive Order 14012 facilitated a reversal in federal agency policy whereby the U.S. Citizenship and Immigration Services of the Department of Homeland Security notified all federal agencies to cease implementing the 2019 public charge rule (U.S. Department of Homeland Security, 2021). As noted in the agency letter, work to communicate this change in policy remains. It will take significant efforts to notify and educate communities and the broader public about this recent shift in policy. The deleterious effects resulting from such policies decreased rates of healthcare utilization for fear that accessing public benefit programs could make immigrant families vulnerable to removal from the U.S. (Tolbert et al., 2019). In California, one in six adults in immigrant families reported avoiding public benefits as a result (Bernstein et al., 2020).

Study interviews were conducted in a context where immigration enforcement efforts in California became highly publicized (Aleaziz, 2018) and continued even after California’s sanctuary laws were upheld as law (Miroff, 2020). Despite organized efforts by advocates to stay on message with regard to the Public Charge rule, sharing tested, accurate and streamlined messages (Vision Strategy and Insights, 2020), participants in this research described concrete instances where the “chilling effect” impacted healthcare utilization by immigrant Latinx communities. One cited recent presence of Immigration and Customs Enforcement in their geographic area as having a direct impact on client numbers at both of their locations. While providers are coming to understand that programs funded solely by the State of California do not fall within the purview of the law, they face challenges in trying to communicate such nuances to their client population. The damage done to public confidence in immigration as it relates to publicly funded health and public health systems will likely remain an issue.

### ***Policy Interventions to Address PrEP Disparities in California***

The state of California has made significant investments to increase PrEP uptake by removing barriers related to access and cost, making PrEP medication and PrEP-related services available at no cost to income-eligible individuals regardless of immigration status (California HIV/AIDS Policy Research Centers, 2020a). PrEP costs not covered by an insurance plan can be covered by accessing financial assistance programs offered through drug manufacturers, private foundations, and the state-funded California PrEP Assistance Program (PrEP-AP) (California Department of Public Health, 2020b). California’s PrEP-AP covers PrEP-related medical and drug costs not covered by an insurance plan or manufacturer assistance program. The program is available to both insured and uninsured California residents earning less than 500% of the federal poverty level (approximately \$64,400) regardless of immigration status. Gilead Sciences (Gilead Sciences Inc, 2020) has programs to help cover the cost of PrEP medication for both insured and uninsured individuals. The U.S. Department of Health and Human Services in their “Ready, Set, PrEP” program (U.S. Department of Health and Human Services, n.d.) also provides free PrEP medication to uninsured individuals and does not currently have an income limit. In addition, as a result of the U.S. Preventive Services Task Force (USPSTF) Grade A recommendation for PrEP, most private health insurance plans in California are now required to cover both PrEP drugs and related medical services without cost sharing.

## Policy Implications

Prior studies on HIV and the role of cultural and social norms among Latinx populations has been, at times, conflicting. For example, studies have produced mixed findings about whether cultural values such as “collectivism” and “familism” encourage or discourage sexual risk behavior (Watkins-Hayes, 2014). These data offer some insight into ongoing questions of cultural and social norms and their role in mediating individual-level decision-making about PrEP uptake among ILSM (e.g. micro-level). However, participants’ perspectives are most useful in offering insight at the mezzo- and macro-level, identifying practical implications and policy recommendations for addressing some of the noted barriers to expanding PrEP access to Latinx communities in California.

When it comes to building PrEP awareness, PrEP programs must consider culturally tailored messaging that capitalizes on commonly accepted frameworks of wellness within Latinx communities (Barreras et al., 2019; García & Harris, 2017; Martinez et al., 2016). Participants shared ways clients address this vulnerability such as to speaking in “code”. PrEP programs can continue supporting resilience-based skills older generations have used, especially given that messaging must address the fact that these communities are heterogeneous. Messaging must transcend the issue of disclosure and reach people who are not out about their same-sex behavior or sexual minority status. Because HIV and PrEP are seen as “inter-changeable” and equal terms that carry a sense of promiscuity, messaging can address this issue head-on through framing PrEP as a wellness intervention. Information dissemination can include not only online content in the Spanish language but be delivered by trusted members of communities, including peers that can serve as ambassadors for PrEP. This is particularly critical to reach individuals who do not identify as sexual minorities and those who may be living in provider deserts.

Clients’ racial/ethnic identity, same-sex behavior, sexual minority status, and immigration status can contribute to an increased fear of accessing services. No participant indicated receiving training on how to address questions related to nativity and immigration status nor could they cite agency-wide policy on how to address these sensitive questions. This indicates an area for potential growth. Programs must explore opportunities to decrease documentation requirements for PrEP programs at the state, local and agency level (e.g. enrollment forms, supporting documentation). Programs at the agency level can work proactively to identify and incorporate best practices for engaging clients around documentation requirements whether immigration status is directly or indirectly implicated.

Our study provides additional support for efforts to expand access to PrEP case management and support services to help build clients’ capacity to navigate systems of care while also working to reduce barriers on their clients’ behalf. These services may include support for PrEP initiation (e.g., providing information on accessing health insurance and financial assistance programs, answering questions about PrEP) as well as ongoing care coordination and adherence support. The California legislature is currently considering a proposal from HIV community stakeholders to increase funding for PrEP navigation and support services. Specifically, this proposal would build upon the state’s existing PrEP-AP by funding PrEP navigation and retention coordinators at local health departments and community-based organizations that are contracted with the Office of AIDS to provide PrEP-AP enrollment and/or clinical services. Funding could also be used to cover the cost of educational materials and transportation for clients.

Finally, the immigration policy landscape, subject to winds of political change, will likely continue to be a cause for concern in the context of PrEP service delivery to ILSM. For the many reasons noted

above, destigmatizing data collection in everyday administrative processes by taking a critical look at routine intake protocols and client-facing documents, for example, could go a long way in assuring clients they have a right to access such services and are legally entitled to confidentiality of their health records. Educating clients of recent changes in federal policy as it relates to public charge could help to increase confidence in our health and public health systems.

### **Limitations**

Despite having a range of PrEP-AP service providers throughout California participate in our study, we acknowledge that this is not a representative sample of the provider network. We successfully gathered data from providers from Southern, Northern, and Central California serving ILMSM. We did not transcribe the recorded interviews verbatim. Using rapid qualitative research techniques and analytic methods, we created summary memos that included direct quotes from participant interviews.

### **Conclusions**

Research remains underway to develop and support strategic framing of PrEP messaging through mass media (Calabrese, 2016) and to targeted populations (Rouffiac, 2020). The next generation of PrEP modalities (e.g., long acting injectable PrEP) will soon emerge on the market, which may help reduce some concerns with PrEP medication adherence and reducing barriers to access based on ease of use (Holloway et al., 2020). These innovations will fail to reach ILMSM without increased efforts to develop culturally appropriate services designed to tackle existing barriers to access. Efforts to destigmatize HIV, PrEP, and decriminalize immigrant Latinx communities must shape continued efforts to reach ILMSM.

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