



National HIV and PrEP Navigation Landscape Assessment

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Prepared by NMAC Capacity Building Division

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EXECUTIVE SUMMARY

The purpose of the **National PrEP and HIV Navigation Landscape Assessment** is to provide a current understanding of how navigators are providing—or can provide—vital services to consumers at each stage of the HIV care continuum. This report provides input from people living with HIV, administrators of PrEP and HIV direct service programs, consumers, and PrEP and HIV navigators across the United States.

The following methods were used to collect, validate, and triangulate data with direct consumer and provider involvement:

- I. A **Navigator Needs & Resources Assessment** completed by over 678 attendees of the National HIV PrEP Summit (NHPS) held December 3–4, 2016, in San Francisco, CA;
- II. A **Literature Review** on PrEP and HIV navigation methods and guidelines (e.g., promising practices, evidence-based practices);
- III. A **National Landscape Survey** completed by 745 respondents working for community based organizations or other professional entities providing PrEP and HIV navigation services;
- IV. **Site Visits** to conduct 10 in-depth observational studies of current practices, opportunities, and contexts for PrEP and HIV navigation; and
- V. **Key Informant Interviews** with over 20 PrEP and HIV service providers.

Specific sections of this report provide details on the background, methodology, findings, discussion, and recommendations regarding PrEP and HIV navigation. The appendices provide copies of the data collection instruments, recommended resources, and references cited. The intended audience for this report includes funders and administrators of PrEP and HIV service programs, PrEP and HIV navigator personnel, and others who are interested in the evolution and growth of PrEP and HIV navigation along the HIV care continuum.

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ACKNOWLEDGEMENTS

We thank the PrEP and HIV navigators, coordinators, and other direct service personnel who generously gave their time and energy to provide interviews, conduct facility walk-throughs, send examples of materials and resources, and provide follow-up information to validate the accuracy and reliability of the summarized and detailed findings.

We also thank the NMAC Review Committee and administrators for providing input into the design and scope of the project, data collection instrument questions, how to best connect with organizations and experts, and for spreading the word about the purpose and intent of the project.

BACKGROUND & INTRODUCTION

Pre-exposure prophylaxis (PrEP) is defined by the Centers for Disease Control and Prevention (CDC) (CDC, 2017) as a “way for people who do not have HIV but who are at substantial risk of getting it to prevent HIV infection by taking a pill every day.” In 2010, the iPrEX clinical trial demonstrated the effectiveness of PrEP with the finding that HIV transmission was reduced by 44% among the men who have sex with men (MSM) who took part in this study. In July, 2012, PrEP was approved by the U.S. Food and Drug Administration (FDA).

PrEP is a prevention choice within a package or combination of HIV prevention approaches, including the use of medication and “HIV testing, counseling, male and female condoms, lubricants, antiretroviral treatment for partners with HIV infection, voluntary medical male circumcision, and harm reduction interventions for people who use drugs” (WHO, 2015, p. 1).

PrEP also represents a powerful opportunity to prevent and reduce the incidence of HIV across the United States. This opportunity, however, is unevenly distributed across state, county, and city lines by race, ethnicity, age, gender, and lesbian, gay, bisexual, and transgender (LGBT) identity. For example, recent estimates point to approximately 150,000 people who are using PrEP among thousands of individuals who are significantly at risk for HIV (CDC, 2016; Villarosa, 2017). Outreach to and uptake among minority and underserved communities to engage with PrEP is a specific disparity for allies to continually find common ground (Ryan, 2017).

The major reasons for this disparity are social/behavioral, infrastructural, and financial, which mirror many of the same overall health inequities that result from unequal treatment toward minority and underserved communities. These well-documented disparities have increasingly led to calls for cultural and linguistic competence/appropriateness/responsiveness and large-scale structural reforms to the health and human services sector to address social determinants of health (Gamache & Lazear, 2015; HHS, 2017; Smedley, Stith, & Nelson, 2003).

In tandem with structural reforms (e.g., to improve access and quality, reduce costs) at the public health infrastructure level, PrEP and HIV advocates are advocating for community-defined interventions by peers who reflect the communities they serve, qualified culturally and linguistically competent providers who are knowledgeable about stigma and integrated care, and the empowerment of marginalized groups among the nearly 1.1 million people living with HIV/AIDS in the United States who experience major gaps across the HIV care continuum from diagnosis to viral suppression (CDC, 2017; Gardner & Young, 2014; Mugavero, Amico, Horn, & Thompson, 2013).

Within this national contextual background in the United States, PrEP and HIV navigators who are charged with the vital responsibility of improving people’s lives are increasingly expected to achieve the following:

- (1) **Keep up to date** on the latest PrEP and HIV science through evidence-based trainings and other professional resources;
- (2) **Professionalize** their work duties and responsibilities by standardizing job descriptions, minimum/preferred qualifications, developing guides and toolkits, and moving toward specialized certifications; and
- (3) Continually **adhere** to shifting policies, regulations, standards, and guidelines while remaining **flexible** to changing local organization and community-based norms and expectations.

PrEP and HIV Navigation

PrEP and HIV navigators are an integral part of the HIV care continuum along each of the following stages:

- HIV Testing and Diagnosis;
- Getting and Staying in Medical Care;
- Getting on Antiretroviral Therapy; and
- Achieving Viral Suppression.

Navigators hold many different titles, including case manager, care coordinator, community health worker, patient navigator, health system navigator, and promotora, and include others who primarily identify as licensed clinical social workers and public health practitioners. Some navigators are required to demonstrate experience through a health or other human services degree (e.g., vocational nursing) or must have experience working with individuals living with HIV (e.g., 2 to 5 years prior experience as a minimum requirement). For example, a job announcement from the San Francisco AIDS Foundation included a requirement for a bachelor's degree in a health field or similar field or an associate's degree in health education.

The work settings of PrEP and HIV navigators range from street outreach to “shooting galleries” (locations where intravenous drug users can rent or borrow needles and syringes), first-responder and acute care facilities, and long-term care facilities. The University of California, San Francisco, has an informative video that provides an excellent overview of what a PrEP navigator in an area of high prevalence of HIV/AIDS does in their day-to-day activities. Common PrEP navigator job requirements (per job listings for navigators in California, Texas, and New York) include the following: (1) experience with high-risk populations in community settings; (2) culturally and linguistically competent client engagement skills based on the area and cultural demographics of client needs; and (3) familiarity with linkage to medical and other social support services. Navigator-specific funding is sourced from a blend of public and private sources, such as government cooperative agreements, pharmaceutical medical education programming, private foundations, and other funders. Federal funding nationally, through the Ryan White initiative, funds many HIV services across the country including PrEP.

The following clinical practice guidelines for PrEP from the U.S. Public Health Service [USPHS] and CDC (2014) include the following population(s) of focus that PrEP and HIV navigators work closely with:

- PrEP is recommended as one prevention option for sexually-active adult MSM (men who have sex with men) at substantial risk of HIV acquisition.
- PrEP is recommended as one prevention option for adult heterosexually active men and women who are at substantial risk of HIV acquisition.
- PrEP is recommended as one prevention option for adult injection drug users (IDU) at substantial risk of HIV acquisition.
- PrEP should be discussed with heterosexually-active women and men whose partners are known to have HIV infection (i.e., HIV-discordant couples) as one of several options to protect the uninfected partner during conception and pregnancy so that an informed decision can be made in awareness of what is known and unknown about benefits and risks of PrEP for mother and fetus.

Given the diversity of these populations of focus that overlap with underserved communities, navigator roles and responsibilities align with the need to use the enhanced National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (The National CLAS Standards). The CLAS Standards are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations. The principal standard of CLAS is to “provide effective, equitable, understandable and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs” (OMH, 2013, p. 1).

It is important to note that the World Health Organization (2014) focused its recommendation for offering PrEP on MSM, which was further updated and expanded in 2015 to “include all people at substantial risk of HIV infection as part of [a] combination [of] HIV prevention approaches” (WHO, 2015, p. 1).

The USPHS/CDC 2014 clinical guidelines also stipulate that HIV testing and symptom history information needs to rule out acute or chronic HIV infection before PrEP can be prescribed. This illustrates how navigator roles and responsibilities align with the first stage of the HIV care continuum (*HIV Testing and Diagnosis*).

The USPHS/CDC clinical guidelines further stipulate that repeat HIV testing should be assessed at least every three months and renal function should be assessed every six months while consumers are taking PrEP (USPHS/CDC, 2014). This illustrates how navigator roles and responsibilities align with the second stage of the HIV care continuum (*Getting and Staying in Medical Care*).

For consumers who are prescribed PrEP, the research and professional literature illustrates that navigators have an important role in supporting medication adherence. This includes a range of techniques and strategies, including reminders, verifications, and other supports (which further aligns with the HIV care continuum stage *Getting on Antiretroviral Therapy*).

Since the clinical guidelines also include active encouragement, referrals, and direct supports for PrEP providers to link consumers to “other effective prevention methods” and “proven effective risk-reduction services,” navigators are clearly aligned with the intent of the fourth stage of the HIV care continuum (*Achieving Viral Suppression*) so that consumers on PrEP continually remain HIV negative.

National HIV PrEP Summit

The National HIV PrEP Summit (NHPS) was held December 3–4, 2016, in San Francisco, CA. This event represented a collaboration between NMAC and community-based organizations, health departments, researchers, activists, and federal agencies. The primary objectives of NHPS were to come together to discuss implementation and how to bring the promise of biomedical HIV prevention to all communities highly impacted by HIV. The 2016 Summit was divided into seven tracks: Research, Public Policy, Priority Populations, Training Programs, Educational Campaigns, Healthcare Providers, and Program Implementation. Most of the workshops centered on interactive training sessions, while some were designed to elicit conversations to form a foundation for policy recommendations for the new administration.



Invitations to attend NHPS were sent in a number of ways to over 13,000 potential participants. The NMAC newsletter distributed announcements with a weblink to register, and announcements were sent from pharmaceutical companies to their employees, and from different divisions to others. The roster that was created from the registered participants was then sorted by organization, and NMAC staff, Federal agency staff (CDC, HHS), and funding organizations were removed from the list.

NHPS Navigator Needs & Resources Survey

The purpose of the Navigator Needs & Resources Survey was to collect information about organizations offering PrEP and HIV navigation services to consumers across the country. NHPS registrants were selected as the prime target for this high-level survey because of their programmatic experience and expertise in the field. This group offered a unique blend of program personnel from diverse areas of the country.

An email invitation containing a link to the online Navigator Needs & Resources Survey was sent to the narrowed down NHPS registration list (since not all participants were eligible) on Thursday, November 17, 2016, with a request to complete the survey within two weeks. A follow-up invitation was sent to those who had not previously completed the survey on November 28, 2016, and a \$5 gift card was provided in appreciation of the participants' time.

NHPS was attended by 696 participants, including 18 staff. At the NHPS registration desk, attendees were asked whether they had completed their survey. Hard-copies were available on-site, in addition to WiFi-connected tablet computers for direct entry. On site, NMAC staff interacted with approximately 100 persons, including about 31 participants who completed the hard copy version of the survey. The hard-copy and online datasets were then merged for analysis and reporting.

NHPS participants were asked to complete two main sections of the Navigator Survey. The first section asked a set of organizational capacity questions, including the organization name, whether the organization is minority-led, the types of HIV-related services that are offered, the population of focus (target population) by race and ethnicity, the total number of staff, and the estimated number of consumers on HIV antiretroviral therapy (ART) and PrEP.

The second set of questions asked whether their organization employs an HIV navigator who helps to recruit, link, and retain consumers in HIV treatment, care and HIV biomedical interventions, a PrEP navigator who helps to connect consumers to PrEP counseling, treatment, or other supports, or another type of navigator who helps to connect consumers to services. If the respondent indicated Yes to any of these questions, a follow-up question asked how many of each of these types of navigators are employed. A final question asked whether the respondent or a member of their staff could be contacted for more information, which links to subsequent phases of the project.

Literature Review

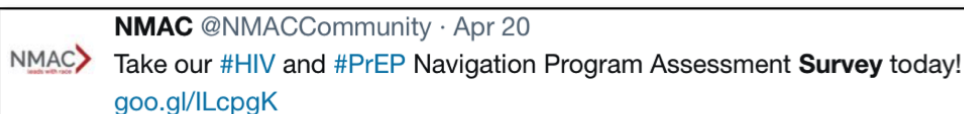
The scope of the literature review included a search of the research and professional literature, agency guidance/guidelines (e.g., HIV care continuum and National HIV/AIDS Strategy goals alignment), technical assistance/capacity building resources, and program requirements (if applicable) to provide a current understanding of the barriers, challenges, opportunities, and best/promising practices for using HIV and PrEP navigators.

The specific methods for the analysis of professional and research literature included a search of the published and grey literature (e.g., presentations, webinars, curricula, reports) specific to PrEP or as a component of HIV/AIDS literature regarding prevention, outreach/recruitment, testing, linkage, treatment, and retention. Examples include resources from the National Registry of Evidence-Based Programs and Practices, national clearinghouses, and numerous state agencies and independent organizations (e.g., AIDS Education and Training Centers [AETCs], CDC's Capacity Building Assistance [CDC CBA], the Health Resources and Services Administration [HRSA], funders, and other providers). Numerous additional types of resources were also scanned and evaluated such as webinar presentations, tools, and guidelines provided by Ryan White Minority AIDS Initiative (MAI)-funded providers. We focused our review on recent literature over the past 10 years and included some seminal materials from earlier years.

National PrEP and HIV Landscape Survey

The NMAC National PrEP and HIV Landscape Survey draft was reviewed by the NMAC Review Committee to ensure that the questions and item responses aligned with the needs of the PrEP and HIV navigation field. Following a round of pre-testing to ensure optimal format and question sequencing, the survey was conducted online from April 20, 2017, through May 12, 2017, with invitations to participate sent to community-based organizations, primary care organizations, government agencies (e.g., federal and state bureaus of HIV/AIDS), academic research centers, pharmaceutical divisions, and over 13,000 potential participants that included NHPS participants. In addition, NMAC distributed the survey through its social media accounts (e.g., Twitter, Facebook), which reached tens of thousands of interlinked followers, subscribers, and other interactive users.

All site visit interview participants described further in the following section were also encouraged to participate.



Site Visits & Key Informant Interviews

In-person site visits were held from April to early May 2017. The following cities were selected based on their HIV/AIDS incidence and prevalence, geographic diversity, organizational diversity, and diverse populations served. The following cities were visited to conduct observational studies and key informant interviews to understand the local context of PrEP and HIV, populations successfully served and underserved/in need, promising/evidence-based practices, electronic health record (EHR) integration and utilization, education and information needs of PrEP and HIV navigators, challenges, and opportunities to overcome challenges:

Sites

1. Baton Rouge, Louisiana
2. Washington, DC
3. Baltimore, Maryland
4. New York City, New York
5. Jackson, Mississippi
6. Houston, Texas
7. Chicago, Illinois
8. Ft. Lauderdale/Miami, Florida
9. Los Angeles, California
10. San Francisco, California

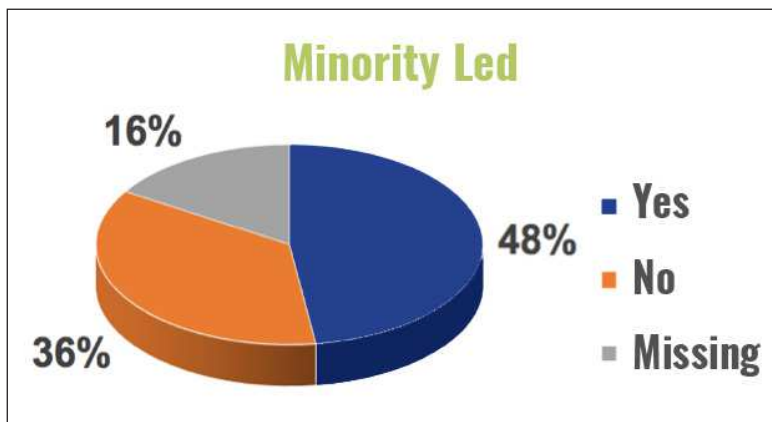
Invitations to participate were sent in advance, and a confirmed appointment initiated travel logistics to visit a clinical or office facility where space was reserved as needed. There were no cancellations, all questions were answered completely, and all participants agreed to provide follow-up via email or phone if this was requested. For example, several participants provided detailed workflow descriptions and examples of how they promote PrEP and HIV services (e.g., videos, flyers, weblinks, social media, materials). A special note of appreciation is extended to a clinical facility in Jackson, Mississippi that called in staff and their physician to come into the office during unscheduled hours to meet and provide PrEP and HIV information. All participants were generous with their time and energy.

FINDINGS

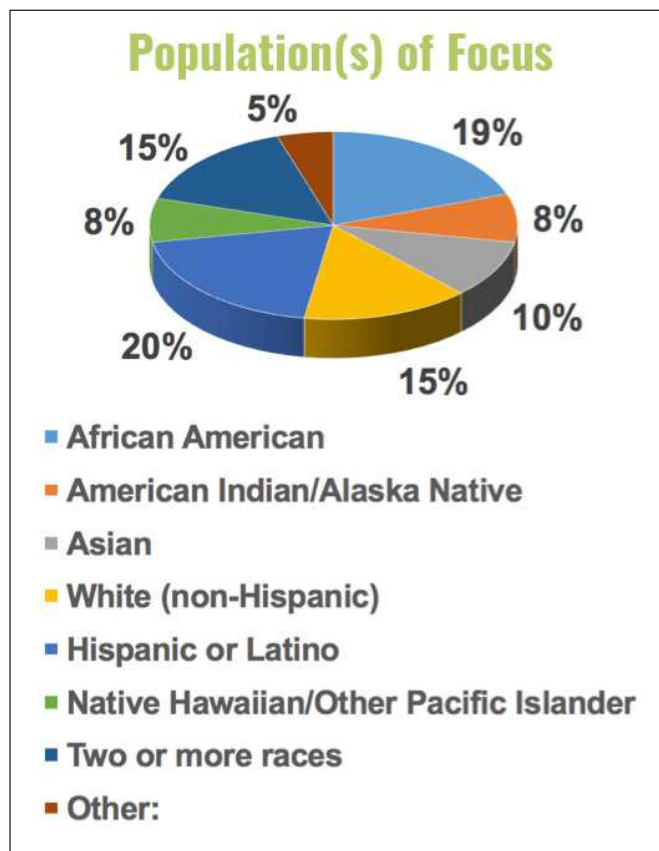
NHPS Navigator Needs & Resources Survey

Organization Summaries

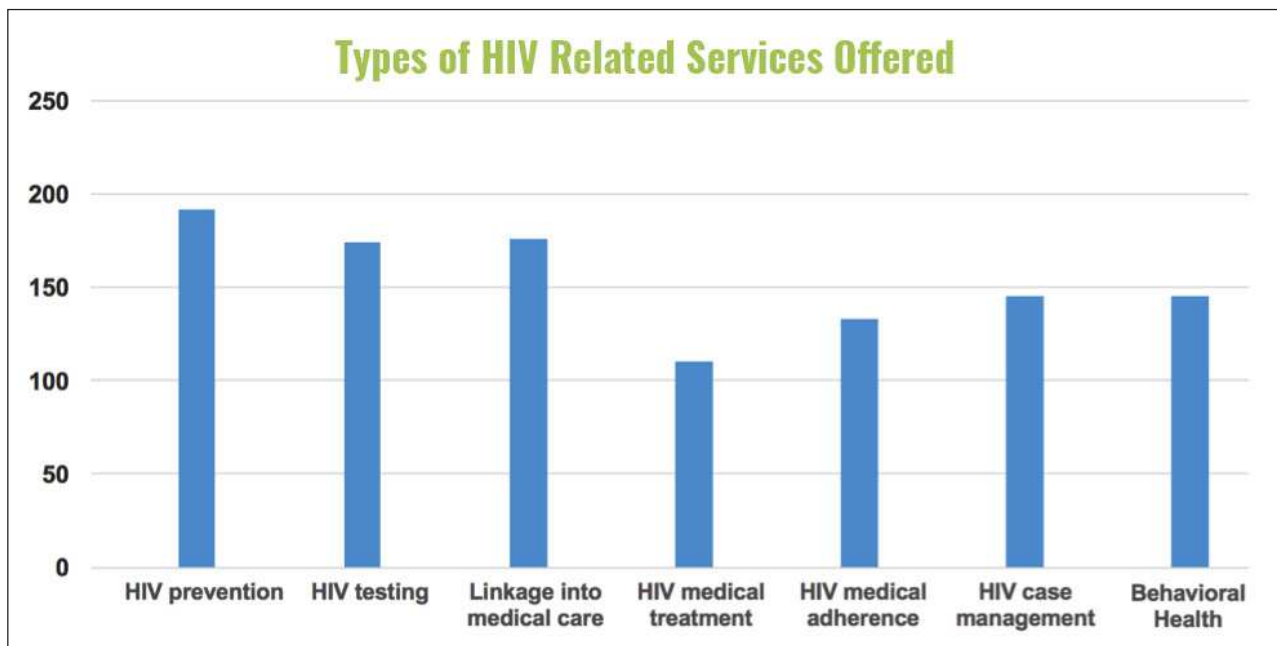
Among the 205 survey respondents, nearly half (48%) indicated that their organization is minority led. Over a third (36%) indicated that their organization is not minority led, and the remainder (16%) skipped the question.



When asked about the **population(s) of focus (target populations)** that their organization serves, respondents provided a range of diverse responses: the largest proportion (20%) indicated *Hispanic or Latino*, followed by 19% who indicated *African American*, 15% indicated *White*, 15% indicated *Two or more races*, 10% indicated *Asian*, 8% indicated *Native Hawaiian/Other Pacific Islander*, 8% indicated *American Indian/Alaska Native*, and 5% indicated *Other*.



When asked about the types of HIV-related services that their organization offers, the largest proportions of respondents indicated *HIV Prevention* (94%), *Linkage into Medical Care* (86%), and *HIV Testing* (85%). Additional responses included *Behavioral Health* (71%), *HIV Case Management* (71%), *HIV Medical Adherence* (65%), and *HIV Medical Treatment* (54%). The distribution of frequency counts are illustrated in the following chart:



Participants also indicated that their organizations offer *HIV Biomedical Intervention* (49%) as well as *Support Services* (74%).

When asked about their **total number of staff**, respondents provided a wide range of responses from 7 to 2,500. The majority of these responses were less than 100.

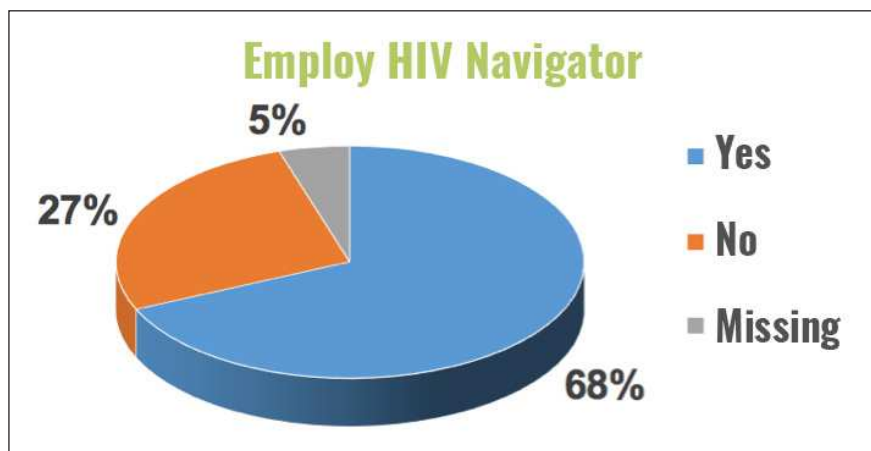
When asked about the number of **consumers that their organizations serve who are on ART**, respondents similarly provided a wide range of responses from as few as 3 to as many as 8,000. Those with the highest responses were from large health systems, health departments, or university medical centers. The majority of the responses were less than 300.

When asked about the **number of consumers that their organizations serve who are on PrEP**, respondents provided a range of responses from 2 to 1,500. The majority of responses were less than 200.

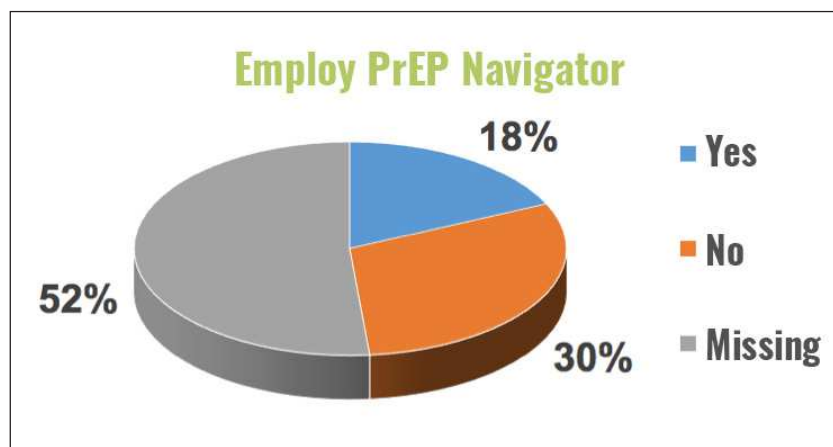
The final question within this section asked whether the respondents could be contacted to provide **additional program information** via NMAC's **texting app**, and 63% of participants indicated *Yes*.

Navigation Summaries

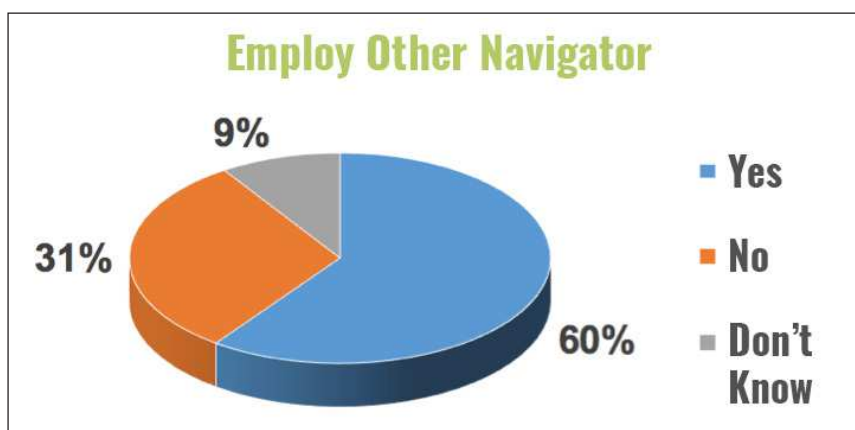
When asked whether their organization employs an **HIV navigator** who helps to recruit, link, and retain consumers in HIV treatment, care, or HIV biomedical interventions, over two-thirds of respondents (68%) indicated *Yes*, 27% indicated *No*, and 5% indicated *Don't Know*. If the respondents indicated *Yes*, they were asked to provide the number of HIV navigators employed. Responses ranged from 1 to 30.



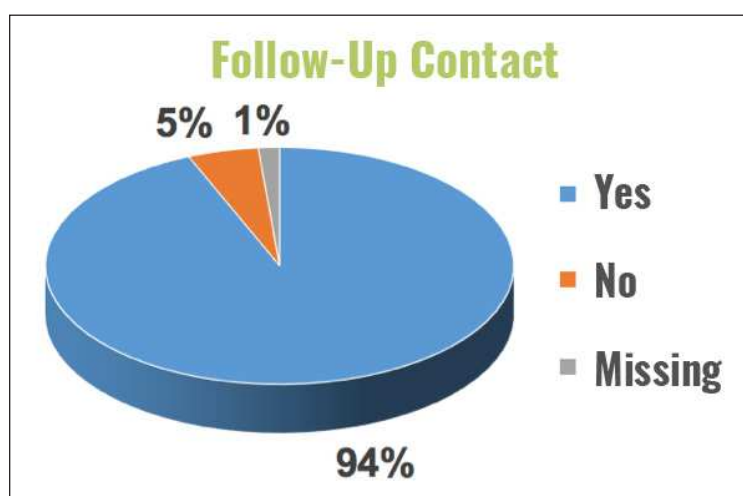
When asked whether their organization employs a **PrEP navigator** who helps to connect consumers to PrEP counseling, treatment, or other supports, nearly 1 out of 5 respondents (18%) indicated *Yes*, 30% indicated *No*, and the largest proportion (54%) indicated *Don't Know*. The large proportion of *Don't Know* responses may illustrate that there is uncertainty regarding titles and roles among staff who incorporate PrEP within a broader range of prevention activities for consumers. The number of PrEP Navigators employed ranged from 1 to 8.



When asked whether their organization employs **another type of navigator** who helps to connect consumers to services, nearly two-thirds of respondents (60%) indicated *Yes*, nearly one third (31%) indicated *No*, and 9% indicated *Don't Know*. The number of other navigators that they employed ranged from 1 to 30.



A final question asked whether they or a member of their staff could be **contacted for further information**. A very large majority (94%) indicated *Yes*, only 5% indicated *No*, and 1% of respondents skipped this question.



Geographic Reach

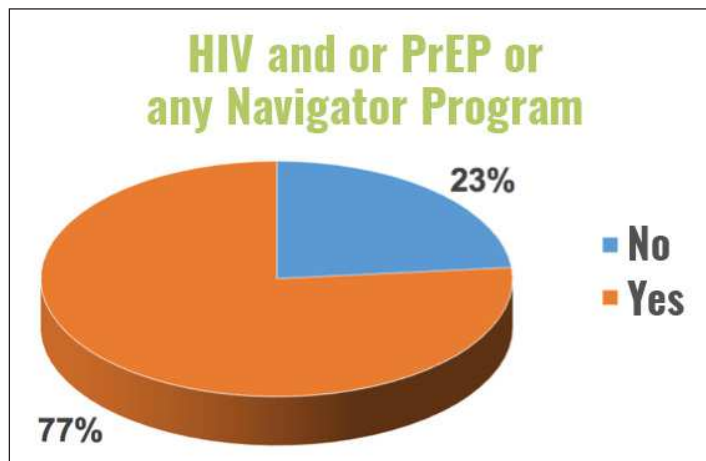
The following image illustrates the clustered distribution of survey participants in the United States.



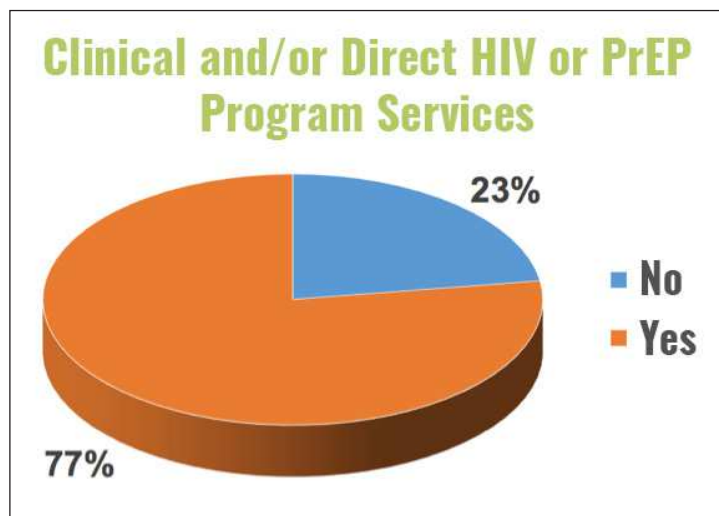
NATIONAL PREP AND HIV LANDSCAPE SURVEY

The NMAC National PrEP and HIV Landscape Survey successfully gathered responses from 745 unique participants working for community based organizations or other professional entities providing PrEP and HIV navigation services.

Respondents were intentionally limited to those experts who could provide information regarding PrEP and/or HIV or any navigator program. Among the 745 participants asked whether they **provide PrEP and/or HIV or any navigator program**, 77% indicated *Yes* and 23% indicated *No*.

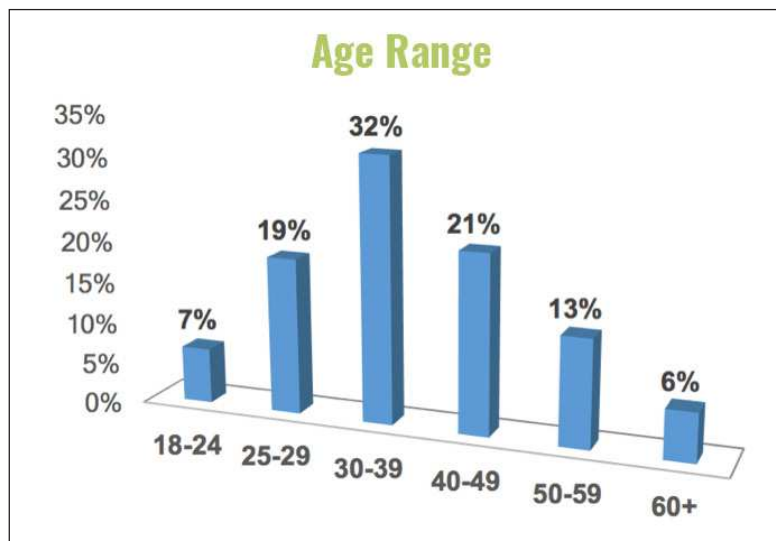


When asked whether they **provide clinical and/or direct HIV or PrEP navigator program services**, 77% of 539 respondents indicated *Yes* and 23% indicated *No*.



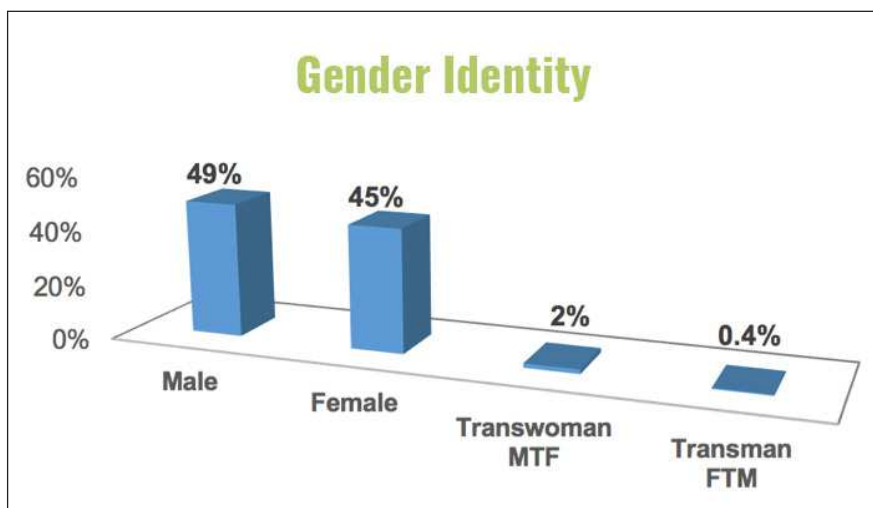
Participant Demographics

When asked to provide **demographic profile** information, participants provided the following data:

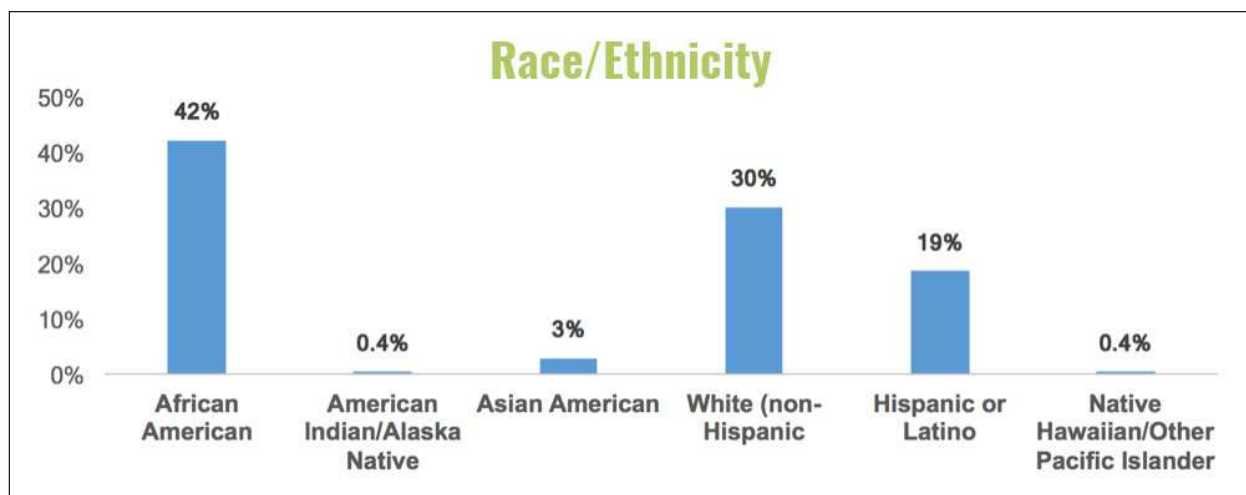


Participants ranged in **age** from 18 to more than 60 years, with a majority (32%) aged 30 to 39 years ($n = 249$).

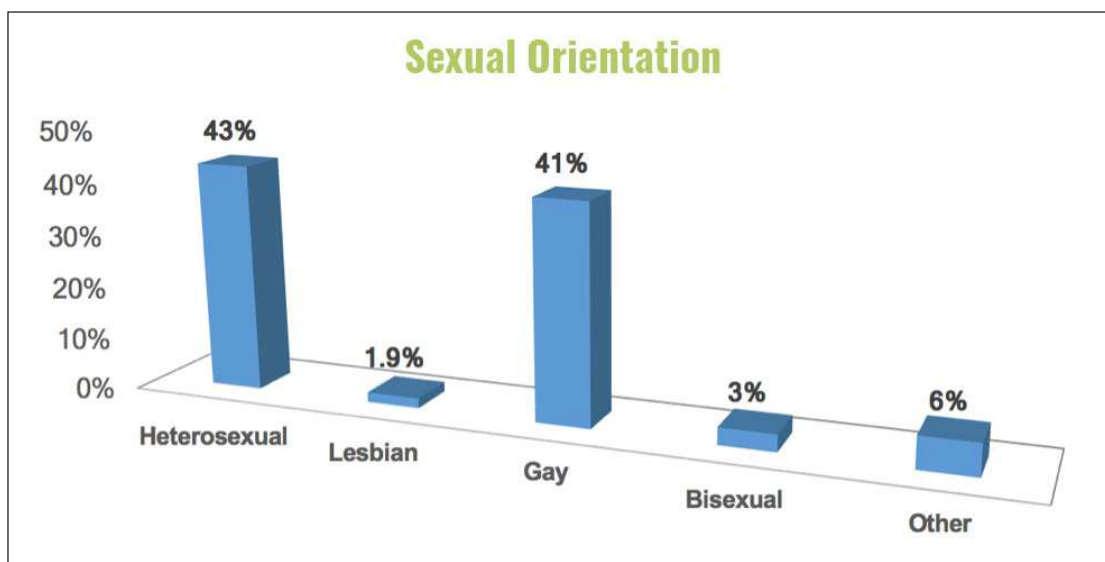
When asked for their **Gender Identity**, participants ($n = 243$) indicated 49% *Male*, 45% *Female*, 2% *Transwoman Male-to-Female*, 0.4% *Transman Female-to-Male*.



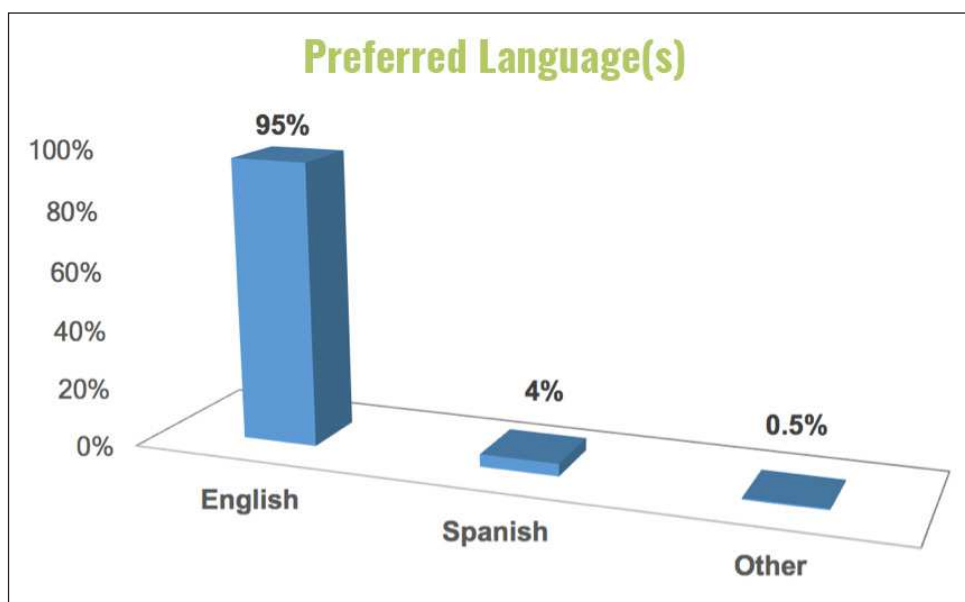
When asked to indicate their **Race/Ethnicity**, responses from 229 participants indicated the following:



When asked to indicate their **Sexual Orientation**, responses from 216 participants indicated the following:



The **Preferred Language(s)** among the participants (n = 214) included *English* (95%), *Spanish* (4%), and *Other* languages (0.5%).

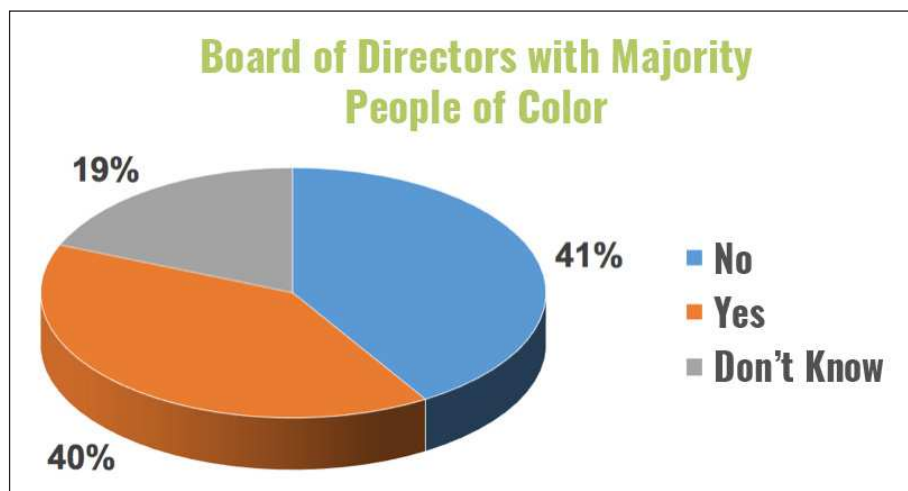


Organizational Profile

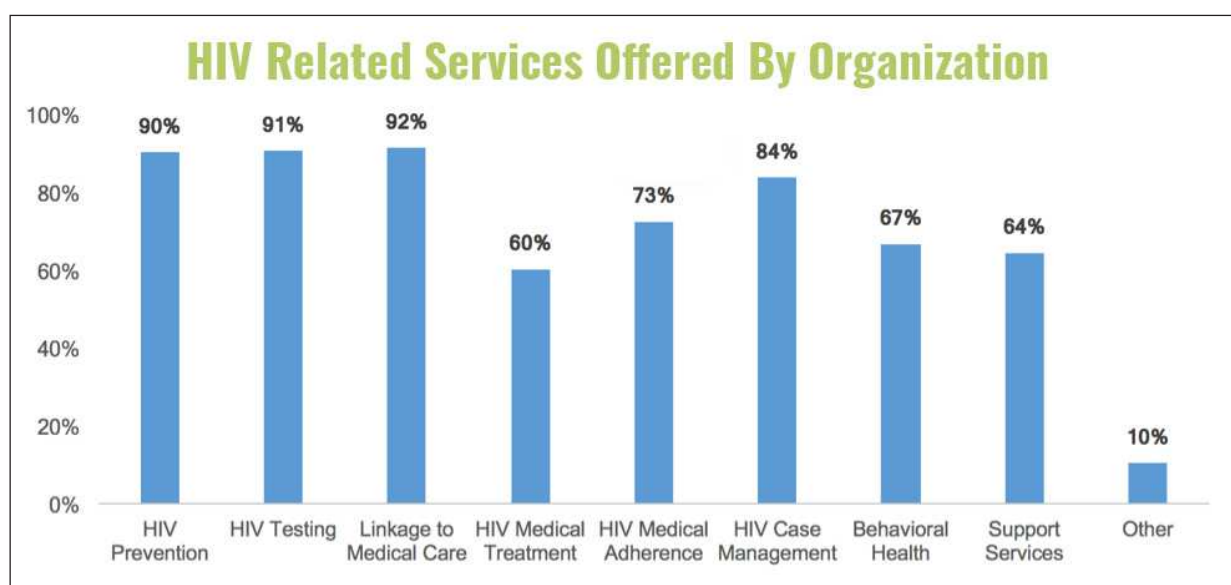
Among the 279 participants who provided the specific **name of their organization**, over 35 of the write-in responses included the words “HIV” or “AIDS” within the title, in addition to many that included the terms “care” and “health.”

Geographic Reach

When asked for their organization’s **Zip Code**, responses from 233 participants indicated the following clustered distribution of their locations across the United States.



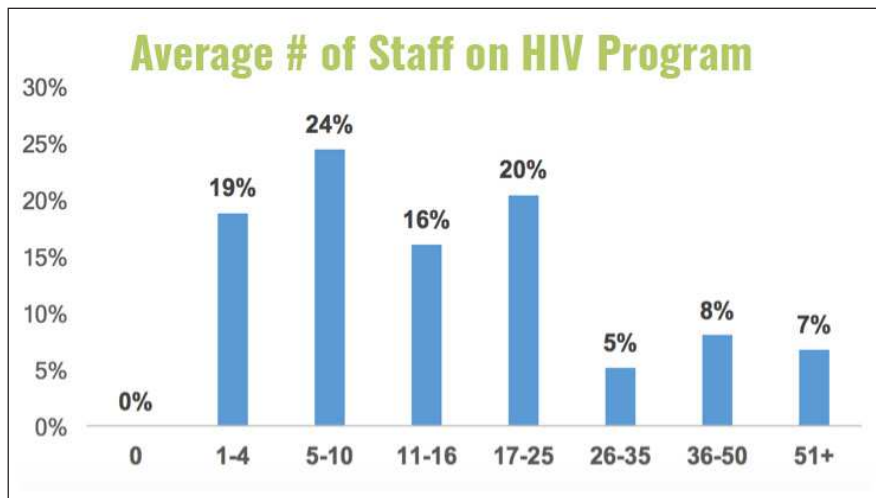
Large proportions of participants indicated that their organization provides a wide range of HIV-related services. When asked what specific **types of HIV-related services are offered**, 259 participants provided the following responses:



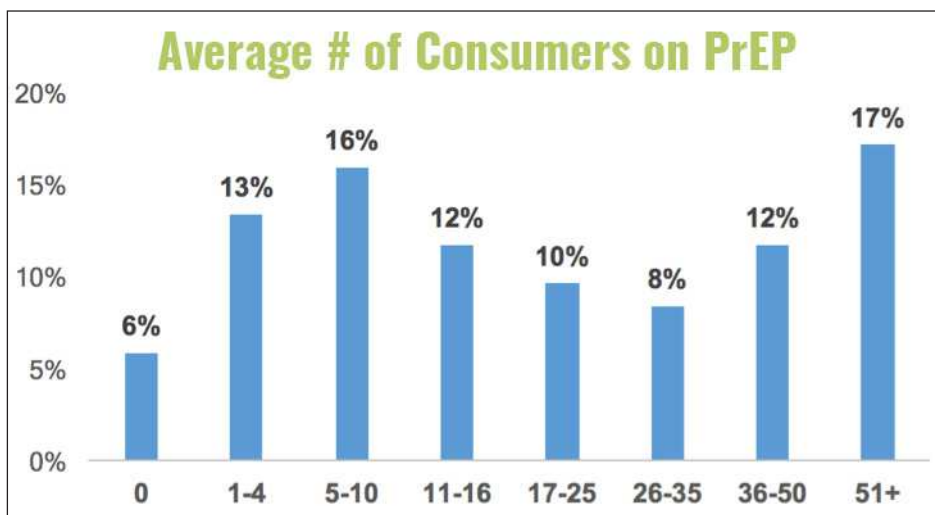
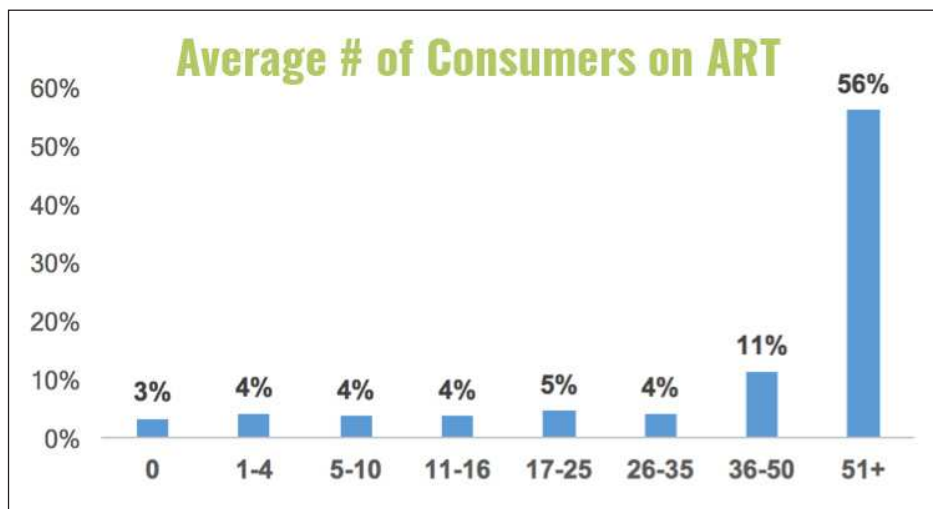
When asked to specify the **demographic profile of the target population(s)** that their organizations serves, 244 participants provided write-in responses that illustrate how their organizations specify demographic categories. For example, nearly all (98%) of participants target specific ages (youth, adults), gender identities (male, female, trans women, trans men), races/ethnicities (American Indian, Asian American, Hispanic/Latino, Native Alaskan/Pacific Islander, white), and/or sexual orientations (lesbian, gay, bisexual, heterosexual).

When asked to provide an **average number per month** regarding staff ($n = 249$) and consumers ($n = 239$), participants provided the following:

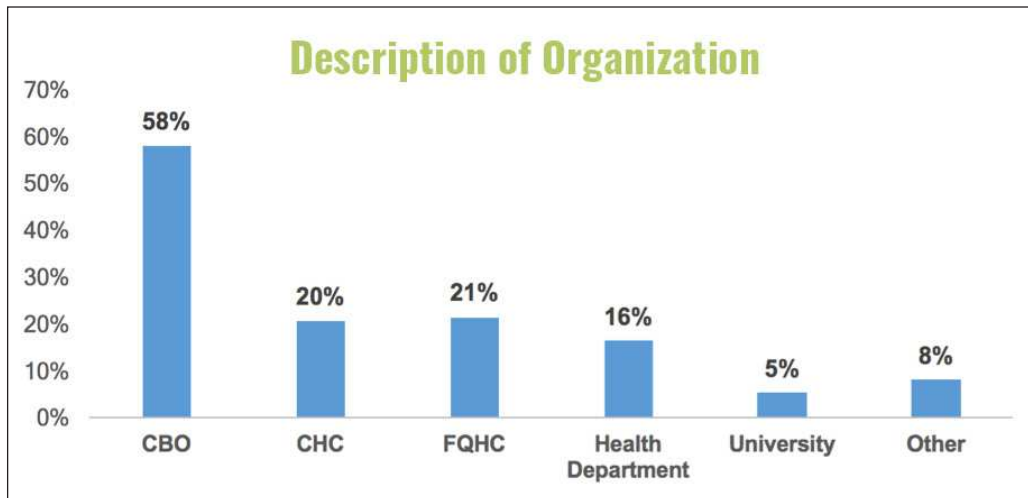
Staffing



Antiretroviral (ART) and PrEP Consumers

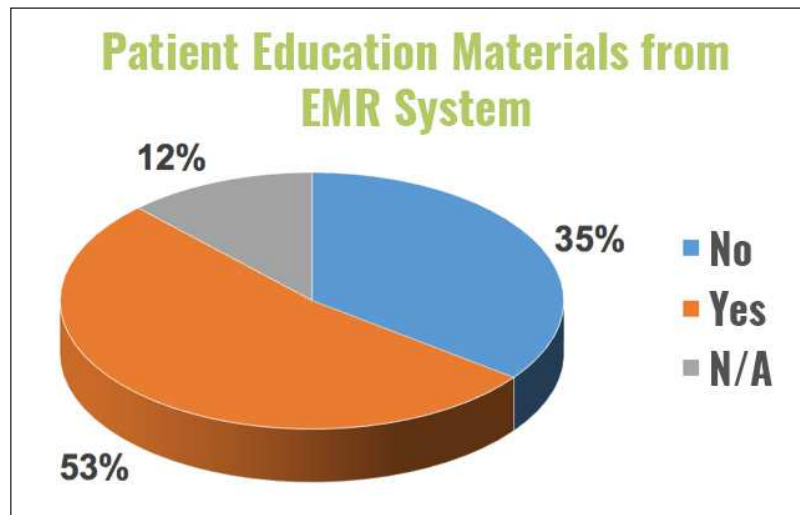


When asked how best to **describe their organization**, the majority (58%) of participants indicated *Community-Based Organization (CBO)*, followed by *Federally Qualified Health Center (FQHC)* (21%), *Community Health Center (CHC)* (20%), *State Health Department* (16%), and *Other* (8%) ($n = 254$).

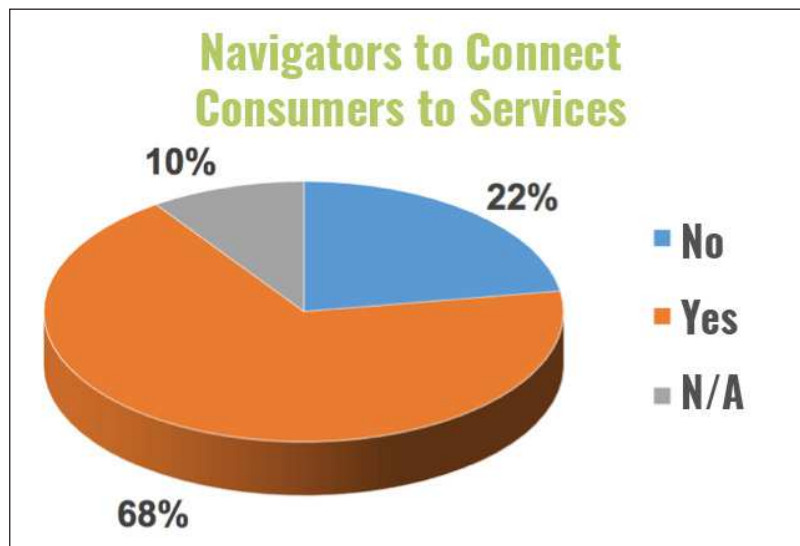


Organizational Capacity

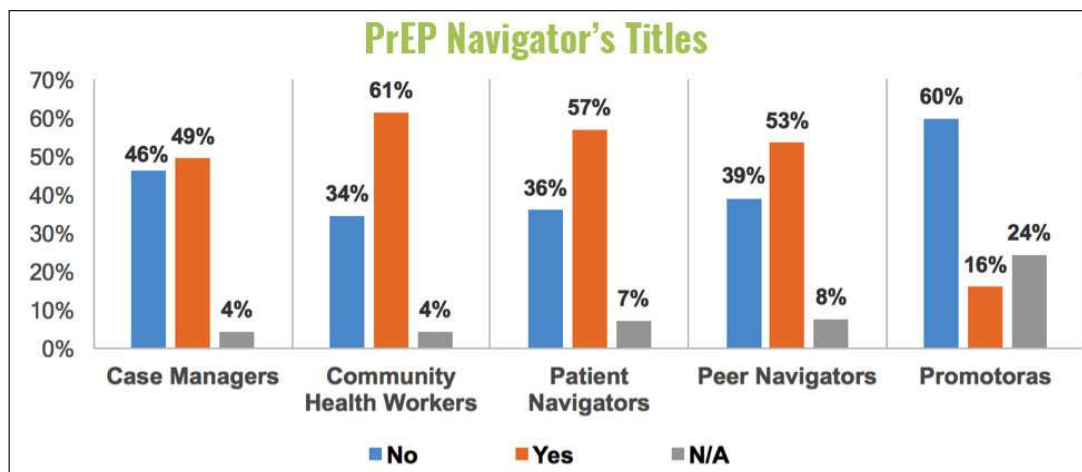
Participants were asked whether their organization has the **capability to generate patient education materials from an electronic medical record (EMR) system**, which yielded the following results ($n = 247$):



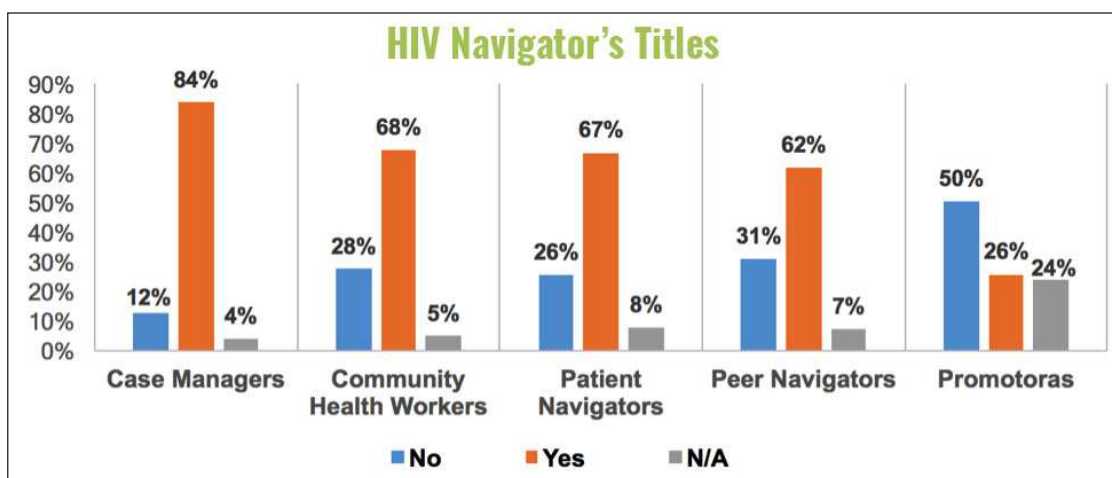
When asked whether their organization **employs navigators (in addition to HIV and PrEP navigators)** who help to connect consumers to services, the majority (68%) of 249 participants indicated Yes.



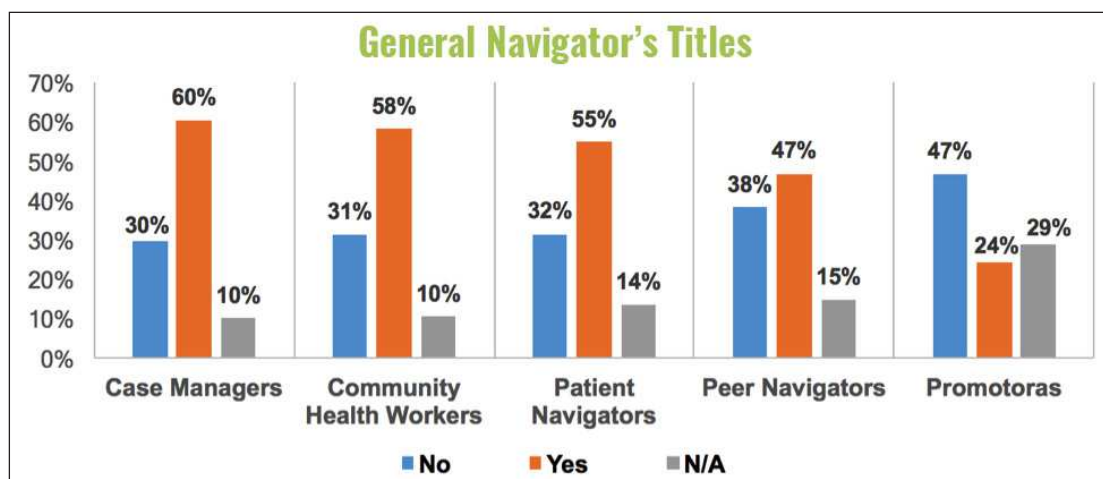
When asked what **other titles**, if any, that **PrEP navigators are known by** within their organizations, nearly half of the participants indicated titles that included *Case Manager*, *Community Health Worker*, *Patient Navigator*, and *Peer Navigator*. The title *Promotoras* was indicated by 16% of participants.



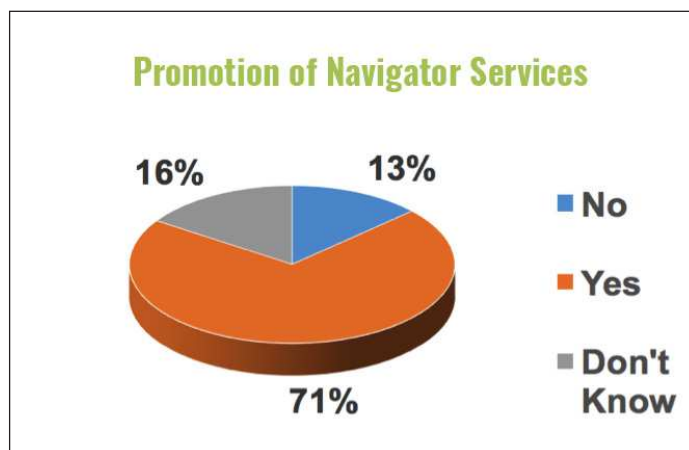
When asked what **other titles**, if any, that **HIV navigators are known by** within their organizations, the majority (84%) of participants indicated *Case Manager*.



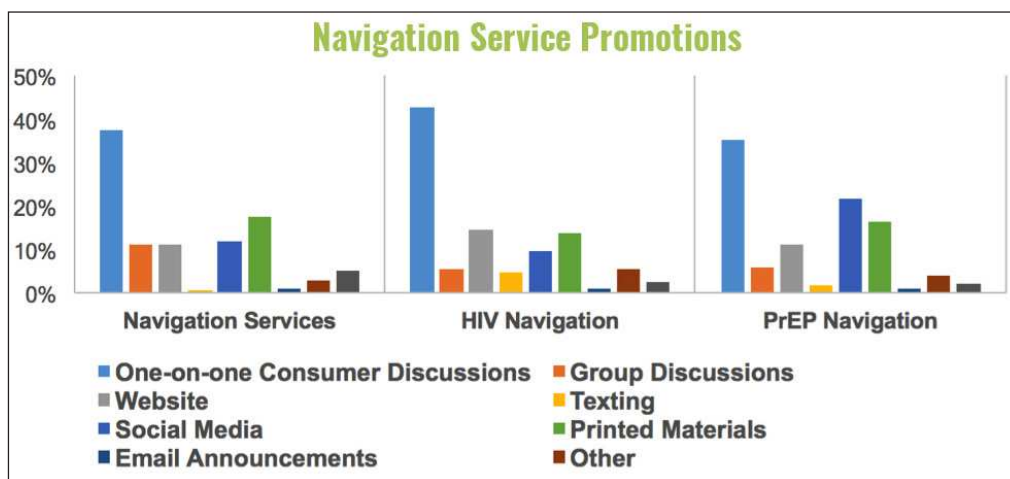
When asked what **other titles**, if any, that **general navigators are known by** within their organizations, nearly half of participants indicated titles that included *Case Manager*, *Community Health Worker*, *Patient Navigator*, and *Peer Navigator*. The title *Promotoras* was indicated by 24% of participants.



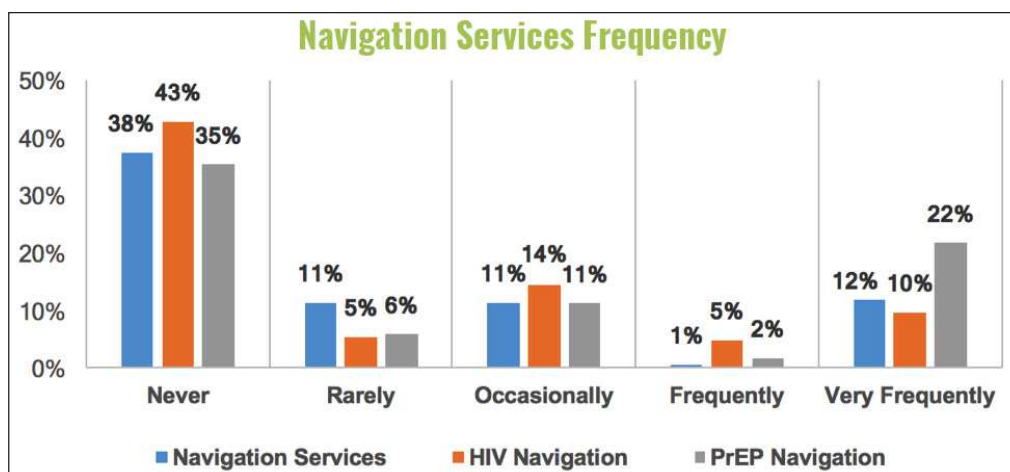
When asked whether their organization **promotes its navigator services**, the majority (71%) of 243 participants indicated *Yes*. The proportion of *Don't Know* responses was slightly greater than the proportion of *No* responses.



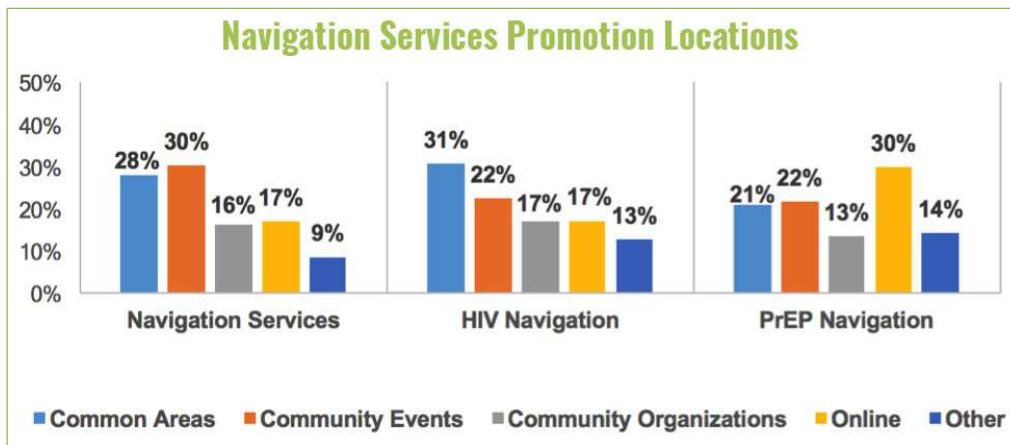
Among the participants who indicated *Yes*, a follow-up question asked them to specifically describe **how their organization promotes its navigation services**. The majority of HIV, PrEP, and navigation services are promoted through one-on-one consumer discussions.



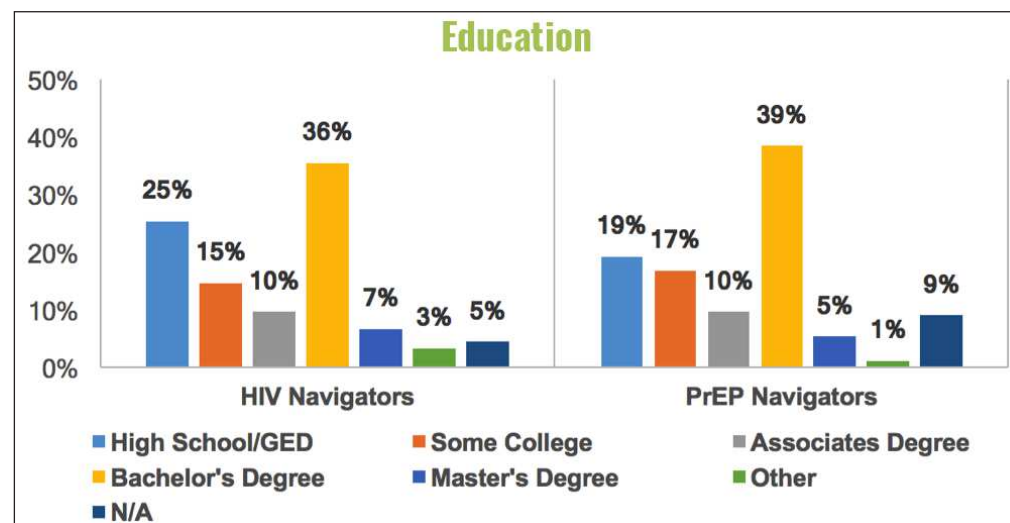
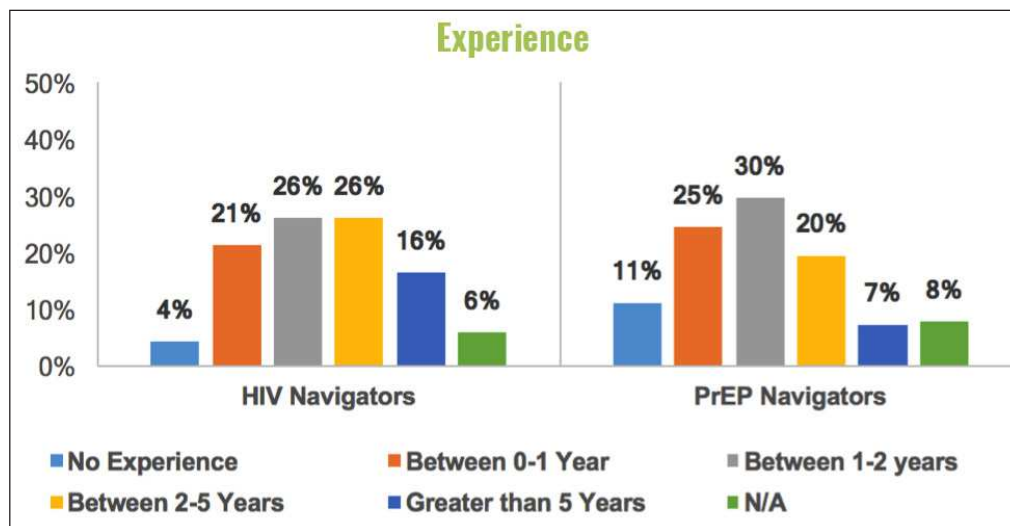
When asked **how often navigation services are promoted** by their organizations, participants indicated high levels of PrEP promotion activity.

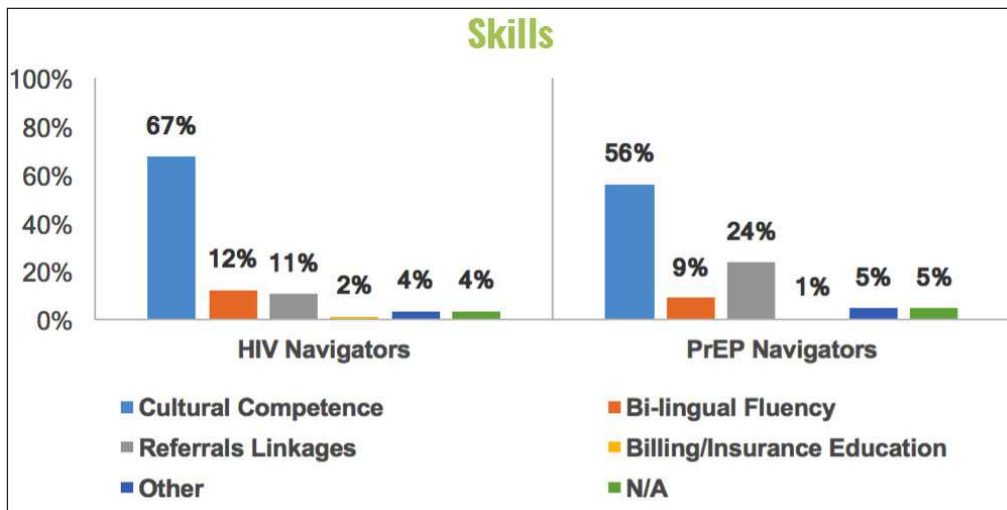


When asked **where navigation services are promoted** by their organizations, participants indicated a high degree of online promotions for PrEP and in-person community events for general navigation services.

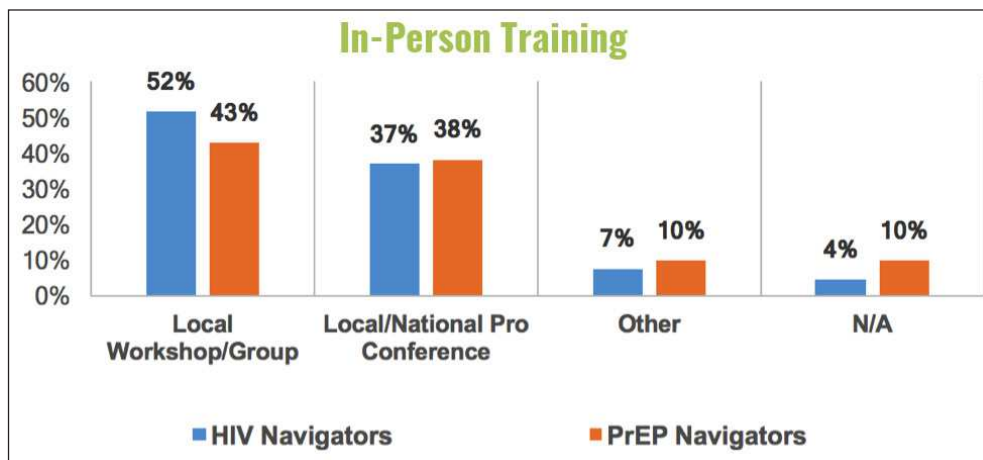
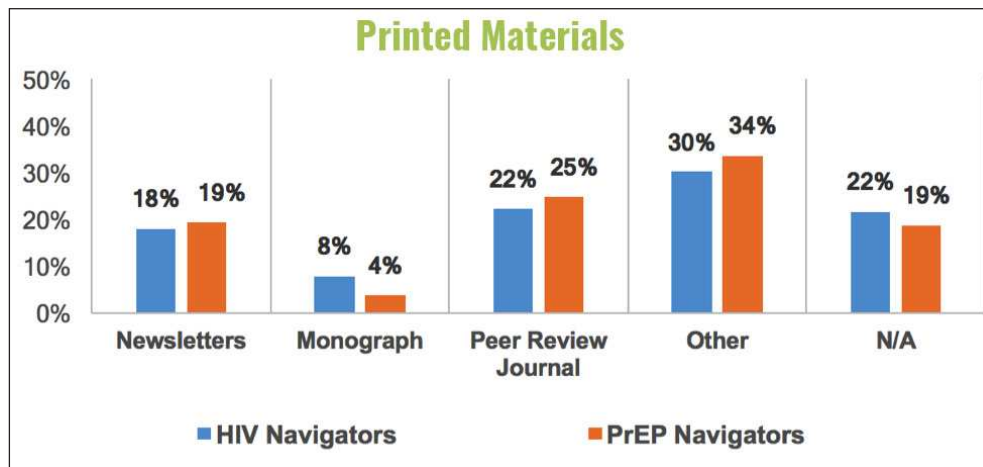


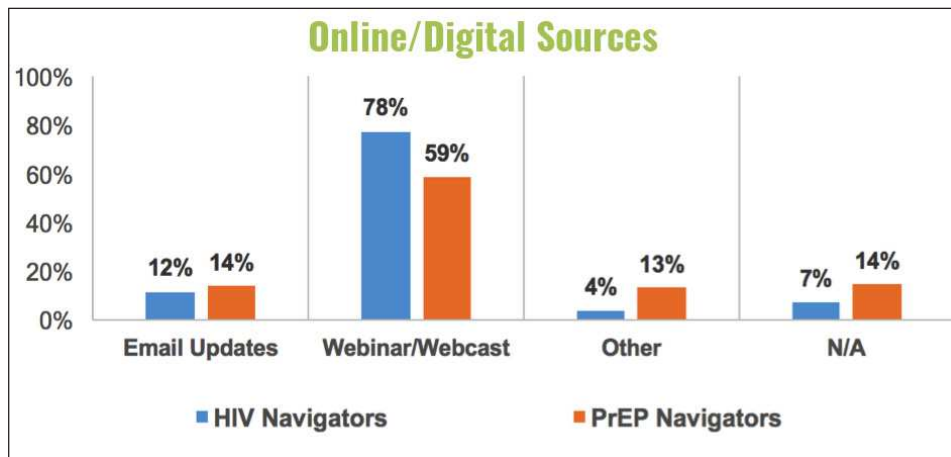
When asked what the **primary qualifications** are as they specifically pertain to **HIV and/or PrEP Navigators**, participants indicated the following:





When asked **how PrEP and HIV navigators are trained** and **where they obtain their information**, participants indicated the following:

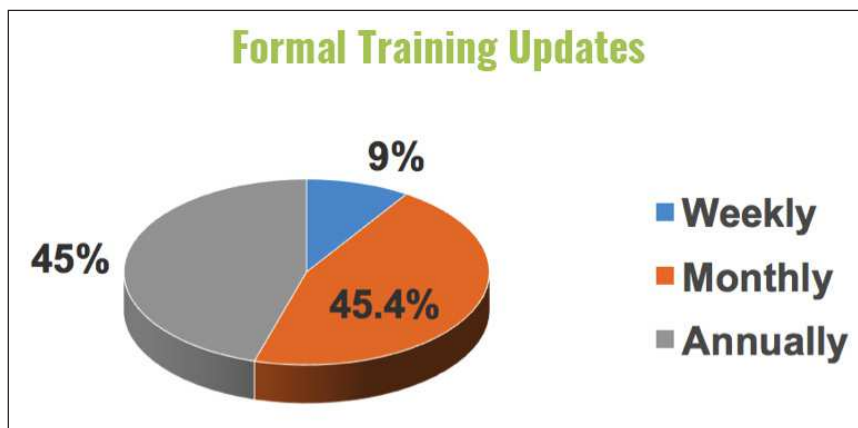




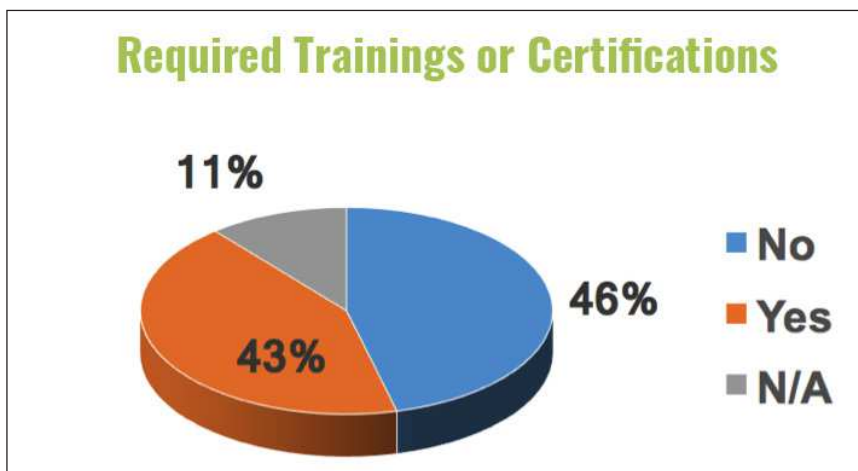
Among the participants who use online/digital services, participants provided write-in responses regarding the **specific websites that they use**. These included federal websites, including CDC.gov, HIV.gov, social media websites, and various technical assistance and capacity-building providers (NMAC, AETC).

When asked to provide an example of the **information included within a formal training**, participants provided write-in responses that included a range of evidence-based practices (e.g., motivational interviewing), health insurance navigation, PrEP introductory information, risk reduction, and HIV statistics.

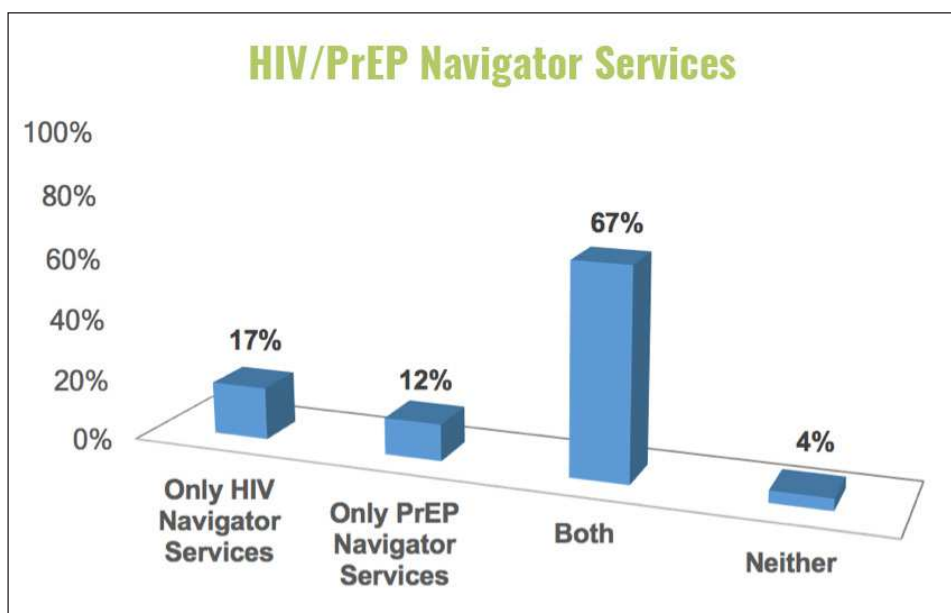
When asked **how often navigators receive formal training updates** at their organization, 174 participants indicated the following frequencies:



When asked whether there are **other trainings or certifications that navigators are required to have**, 43% of 191 participants indicated Yes.

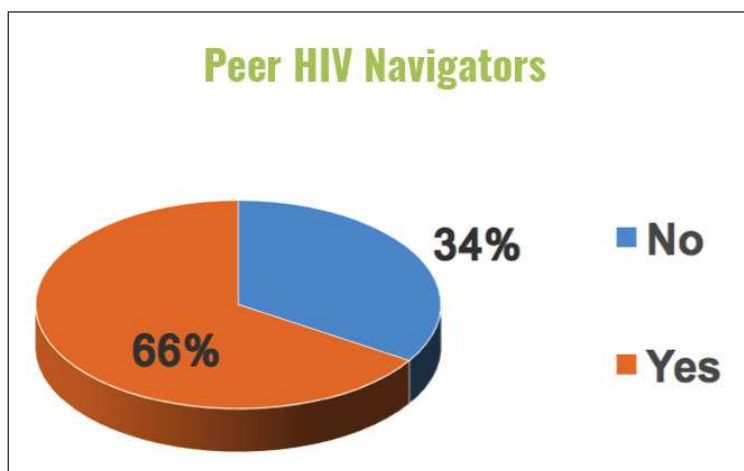


Participants ($n = 235$) indicated the following data regarding whether their organization provides **only HIV navigator services**, **only PrEP navigator services**, **both**, or **neither**. A large proportion of participants (67%) provide both services.

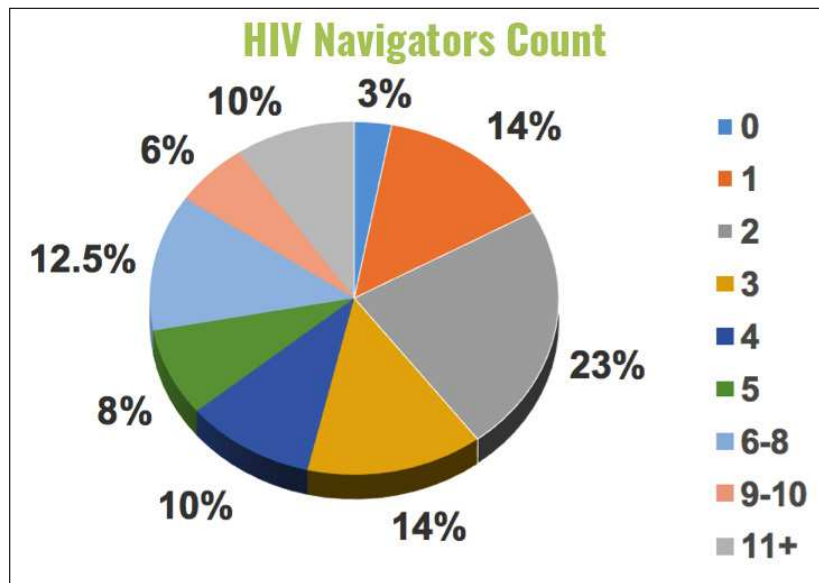


HIV Navigation

When asked if they use **peer HIV navigators** (defined as “a person who uses his or her lived experience related to HIV, plus skills learned in formal training, to deliver services”), the majority of the 144 participants (66%) indicated *Yes*.



When asked **how many HIV navigators** their organization employs to recruit, link, and retain consumers in HIV treatment, care, and HIV biomedical interventions, the large proportion of the 136 participants indicated one or two.

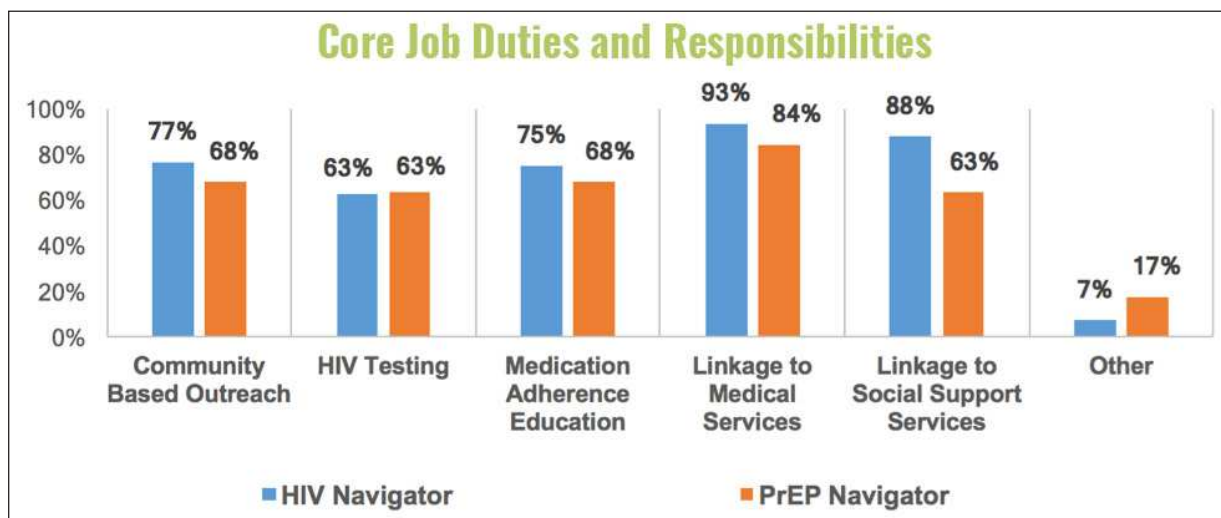


HIV Navigator Demographics

When asked to provide **demographic profile** information for their HIV navigators, participants provided the following write-in responses:

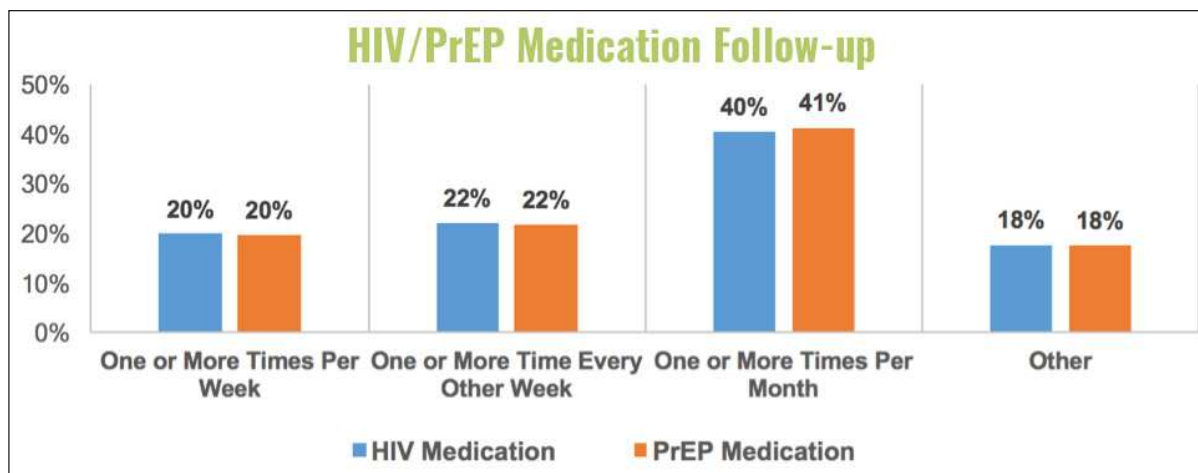
- HIV Navigator **ages** ranged from 18 to more than 60 years
- When asked about the **gender identity** of their organization's HIV navigators, participants indicated *female*, *male*, *transwoman*, *transgender*, and *transman*.
- When asked to indicate the **race/ethnicity** of their HIV navigators, participants provided the following responses: *African American/black*, *Asian*, *Hispanic*, *Latina/Latino*, *multiracial*, *Native American/Alaska Native*, *Native Hawaiian/other Pacific Islander*, and *white/Caucasian*.
- When asked to indicate the **sexual orientation** of their HIV navigators, participants provided the following responses: *heterosexual*, *lesbian*, *gay*, *bisexual*, *transgender*, *questioning*, and *all sexual orientations*.

When asked to indicate **core HIV navigator job duties and responsibilities**, 137 respondents indicated the following:

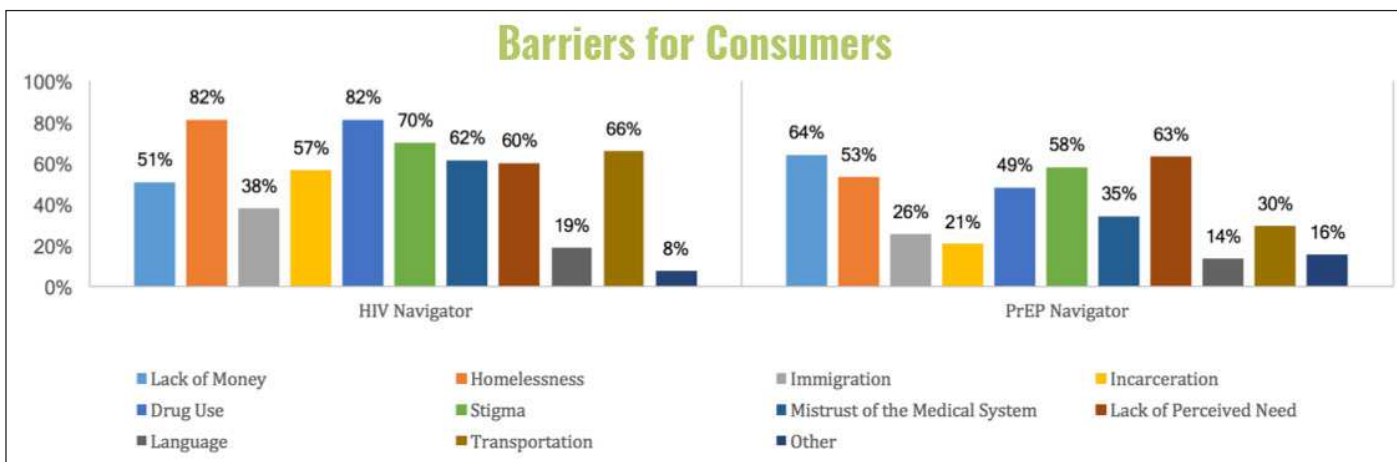


Consumer Services Engagement

When asked **how often follow up occurs regarding PrEP/HIV medication adherence** after a consumer starts taking medication, the majority of 136 participants indicated *one or more times per month*.



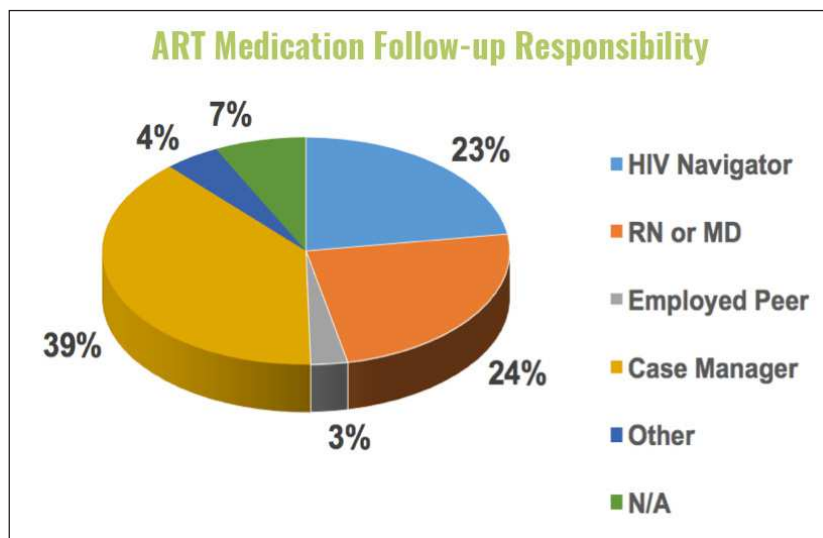
When asked to estimate the **overall percentage of consumers who begin services but then completely disengage with services or are lost to care** (i.e., are never connected with again), 129 participants provided write-in responses that ranged from 1% to 50%. 141 participants provided the following **consumer barriers to HIV navigation** (compared to the barriers for PrEP navigation):



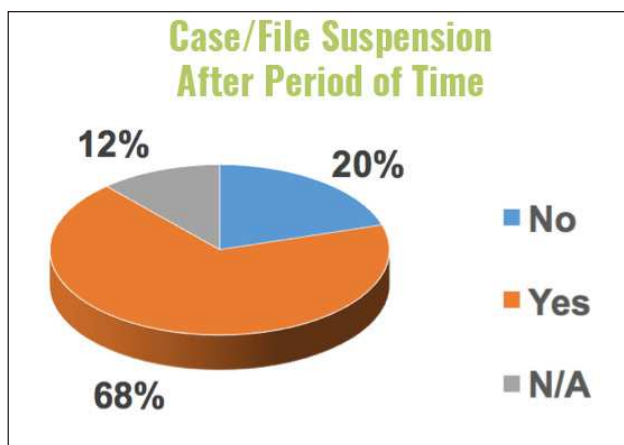
When asked to indicate any specific **steps that are taken to connect with consumers who disengage with HIV navigator services or are lost to care** (e.g., miss appointments), participants provided the following data (compared to the steps for PrEP navigation):



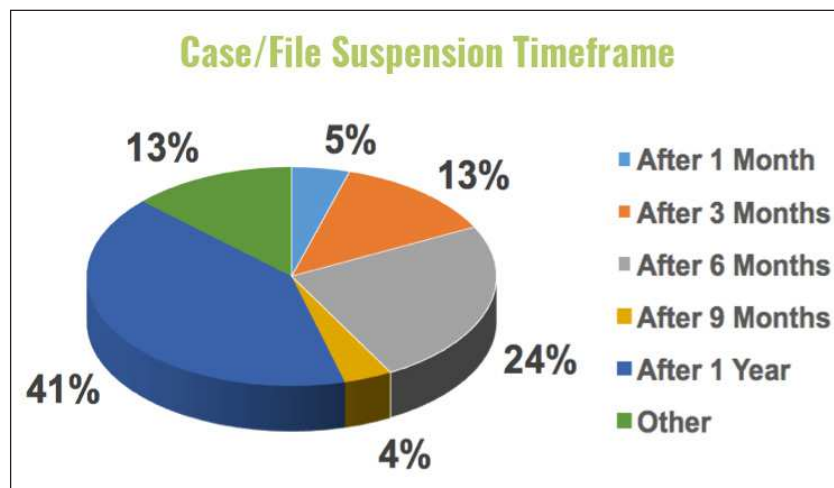
When asked **who specifically follows up regarding medication adherence** when a consumer starts taking ART medication, the majority (39%) of participants indicated *Case Manager*.



When asked whether a consumer's **HIV navigation case/file is suspended** (e.g., marked inactive or closed) after a period of time without any contact, the majority (68%) of participants indicated *Yes*.

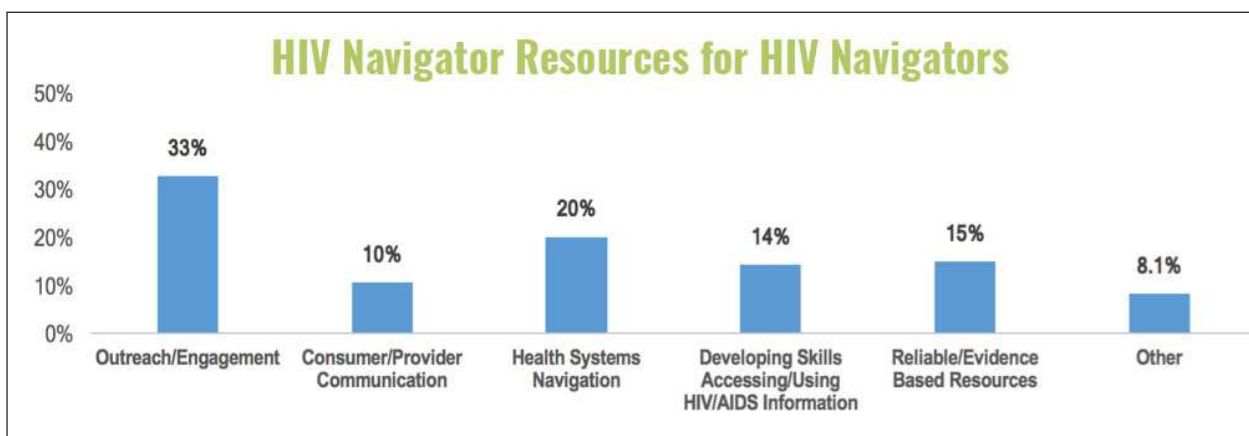
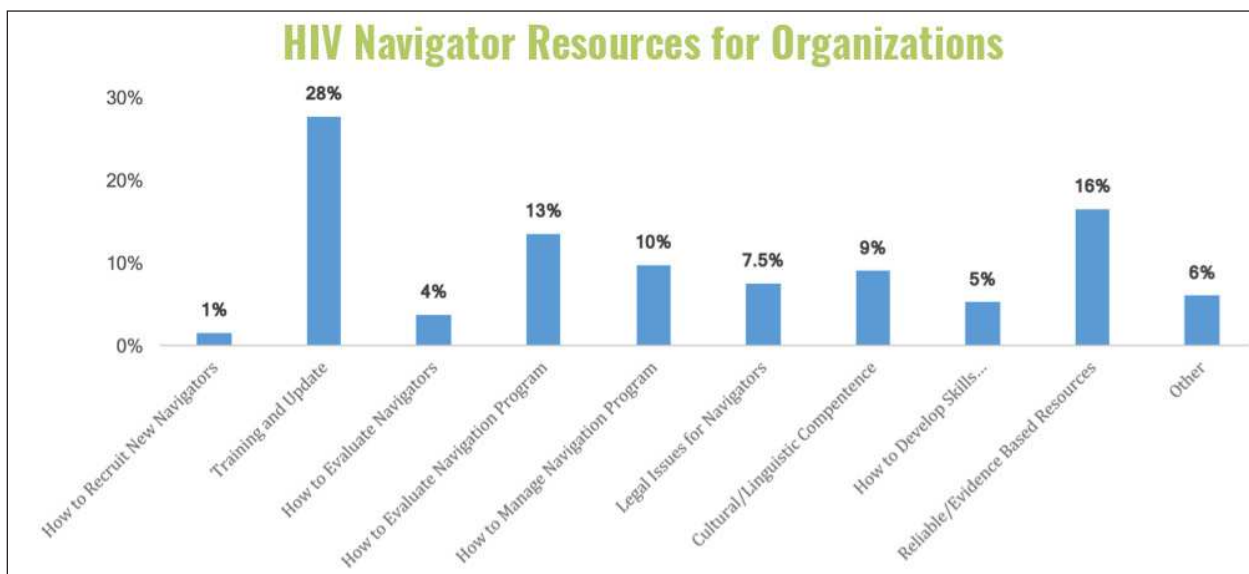


When asked to indicate the **timeframe typically designated to suspend or close an HIV navigation case/file**, the majority (41%) of participants indicated *After 1 Year*.

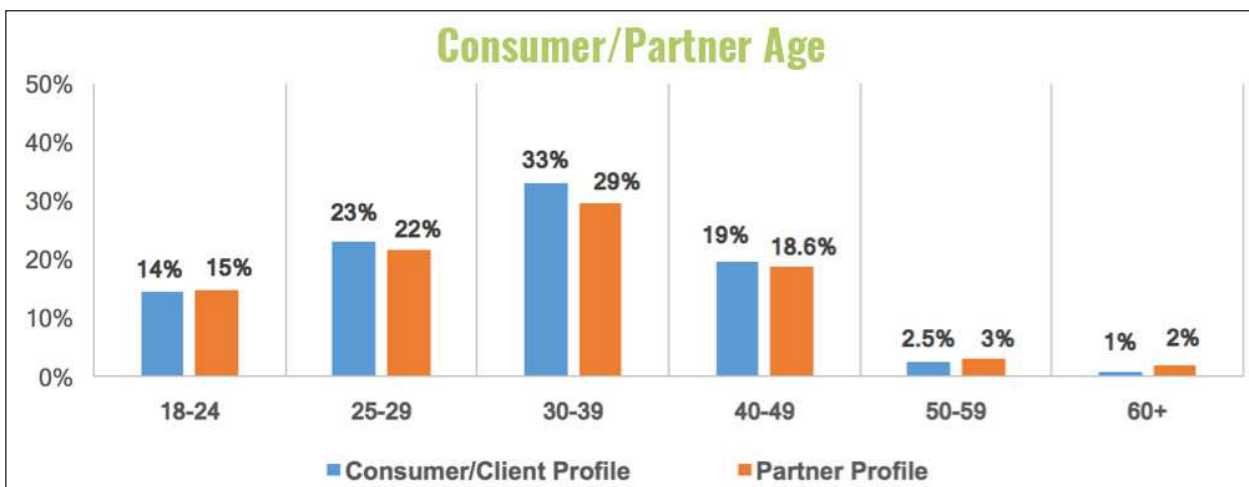


HIV Navigation Training, Technical Assistance, & Capacity Building Needs

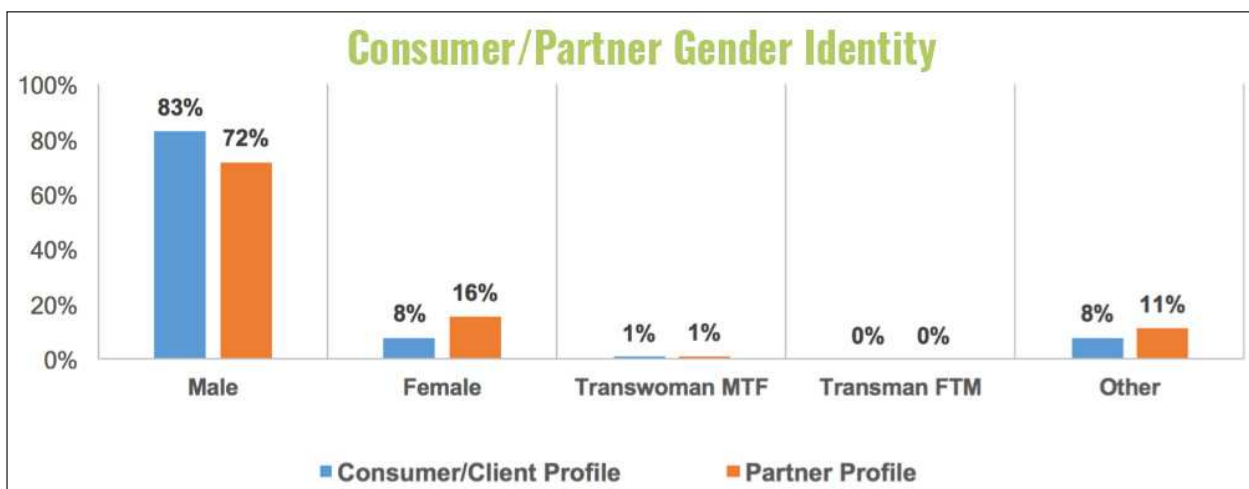
When asked to indicate specific training, technical assistance, or capacity building **topics/resources that would be helpful for HIV navigators**, 134 participants indicated the following resources/topics that are needed for their organizations:



Participants provided the following data regarding the average **demographics of primary consumers who currently receive HIV navigation services** and **partners** of these primary consumers who currently receive HIV navigation services:

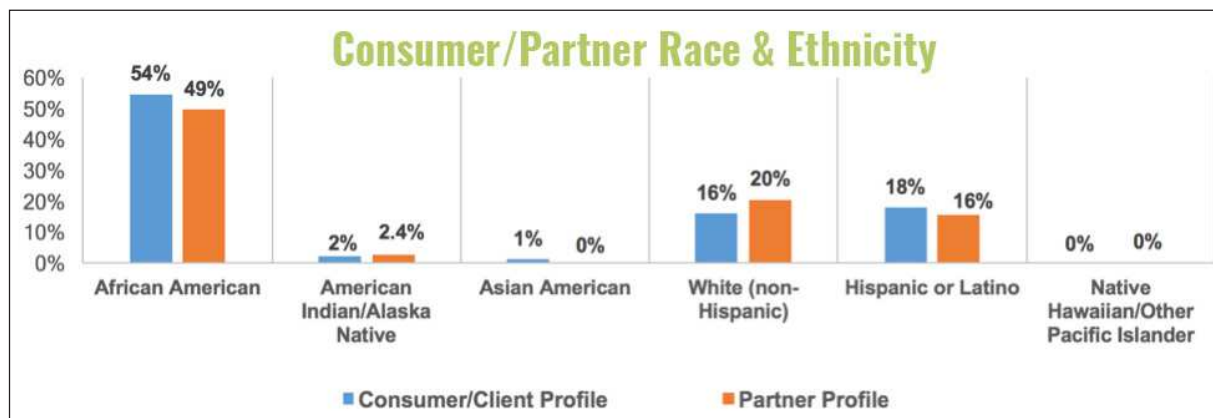


The **ages** of consumers and their partners who currently receive HIV services ranged from 18 to more than 60 years, with a majority between ages 30 to 39 years.

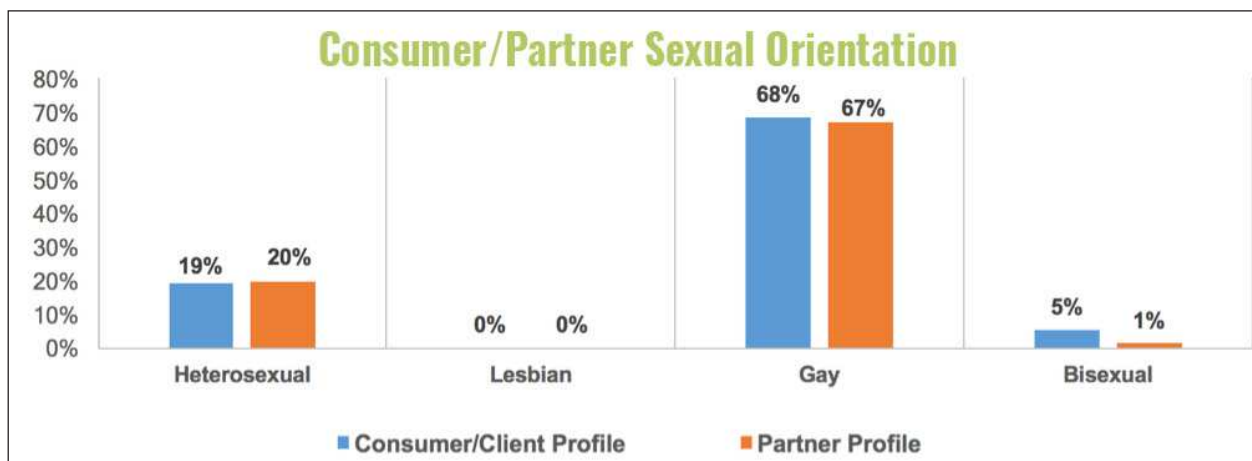


Large proportions of participants indicated that the **gender identity** of consumers and their partners who currently receive HIV services is *Male*.

When asked to indicate the **race/ethnicity** of consumers and their partners who currently receive HIV services, participants provided the following responses:

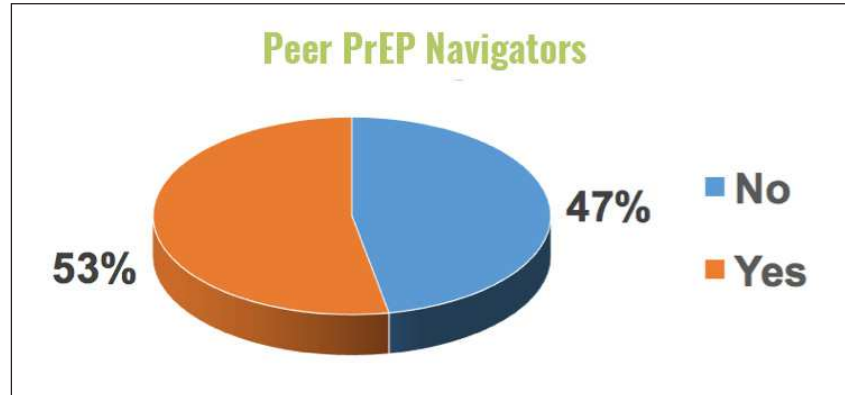


When asked to indicate the **sexual orientation** of consumers and their partners who currently receive HIV services, participants provided the following responses:

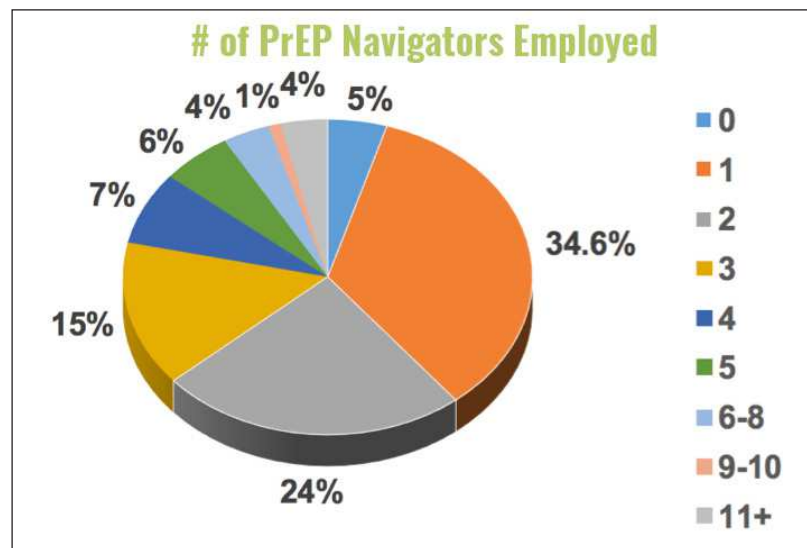


PrEP Navigation

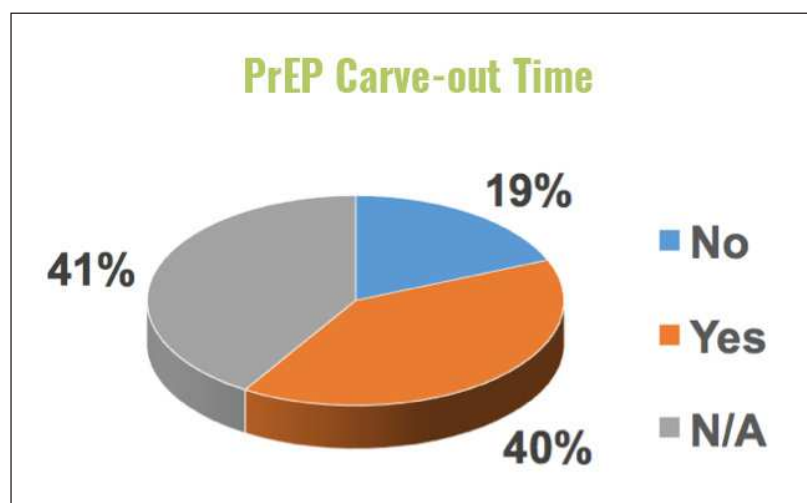
When asked if their organization uses **peer PrEP navigators** (defined as “a person who uses his or her lived experience related to HIV, plus skills learned in formal training, to deliver services”), nearly half of 117 participants (53%) indicated *Yes*.



When asked **how many PrEP navigators their organization employs** to connect consumers to PrEP counseling, biomedical interventions, or other supports, 107 participants provided the following data:



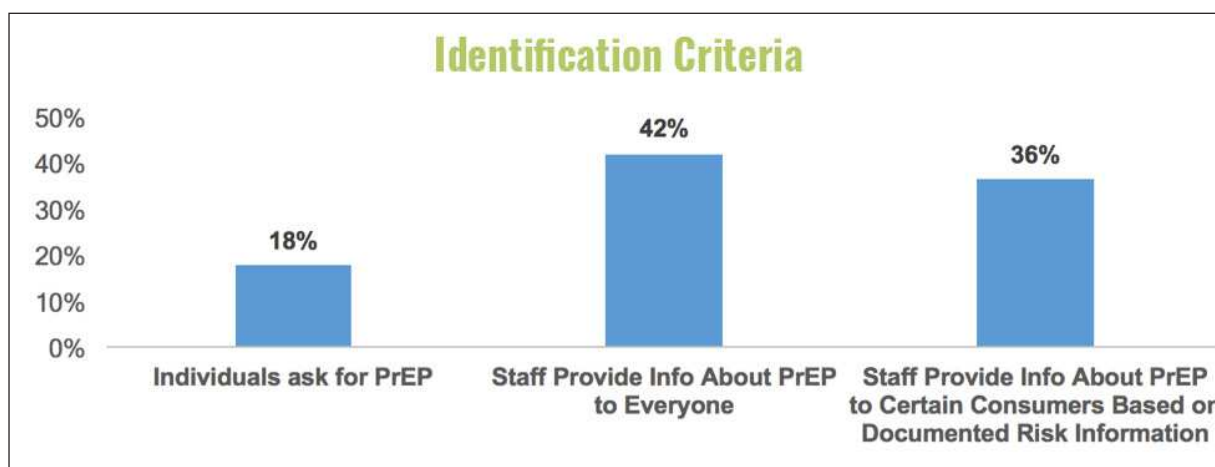
When asked (if there are not specific PrEP Navigators) whether there is a specific **carve-out of time** (% of FTE or number of hours per week) **for navigators to focus on PrEP**, 40% of 107 participants indicated *Yes*.



When asked to provide a **demographic profile** of their organization's **PrEP navigator(s)**, participants provided the following write-in responses:

- PrEP navigator **ages** ranged from 18 to more than 60 years
- When asked about the **gender identity** of their organization's PrEP navigators, participants indicated *female, male, transwoman, transgender, and transman*.
- When asked to indicate the **race/ethnicity** of their PrEP navigators, participants provided the following responses: *African American/black, Asian, Hispanic, Latina/Latino, multiracial, Native American/Alaska Native, Native Hawaiian/other Pacific Islander, and white/Caucasian*.
- When asked to indicate the **sexual orientation** of their PrEP navigators, participants provided the following responses: *heterosexual, lesbian, gay, bisexual, transgender, questioning, and all sexual orientations*.

When asked whether there are specific **criteria used to identify someone who is served by PrEP by their organization**, the majority (42%) of 103 participants indicated that staff provide information about PrEP to everyone, 36% have staff who provide information about PrEP to certain consumers based on their documented risk information, and 18% rely on individuals to ask for PrEP.

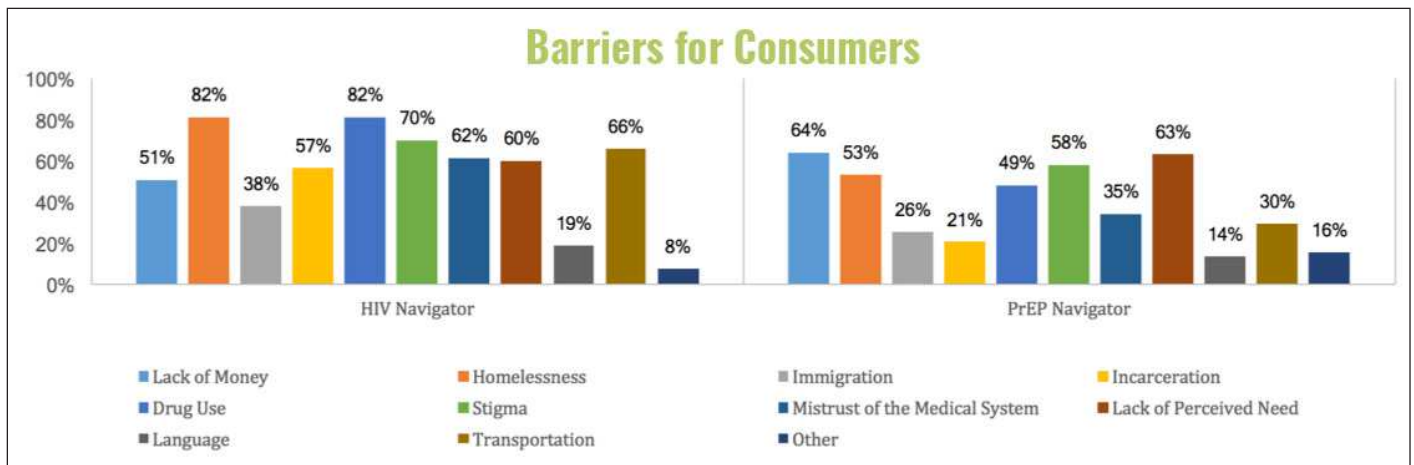


When asked to describe the **immediate next step for someone identified as likely to benefit from PrEP**, 91 participants provided a range of write-in responses. Several recurring thematic examples include the following:

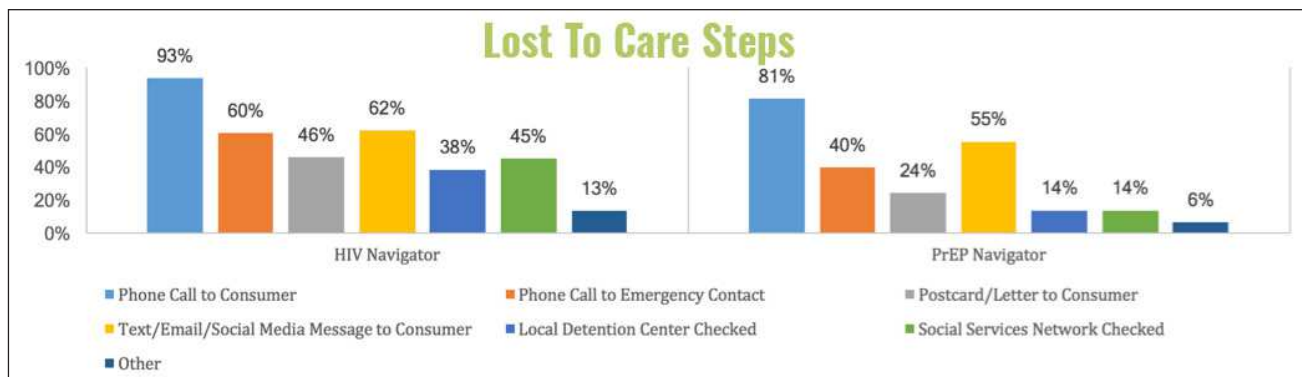
- Set appointment with provider;
- Make a referral;
- Screen for appropriateness/risk;
- Screen eligibility for insurance; and
- Provide PrEP education

When asked **how often follow up occurs regarding PrEP medication adherence** after a consumer starts taking medication, 97 participants provided a range of write-in responses that included specific time intervals (e.g., *weekly, monthly depending on insurance, every 3 months*) and a need for follow up (e.g., *never, no follow up is in place, no specific timeline created yet*).

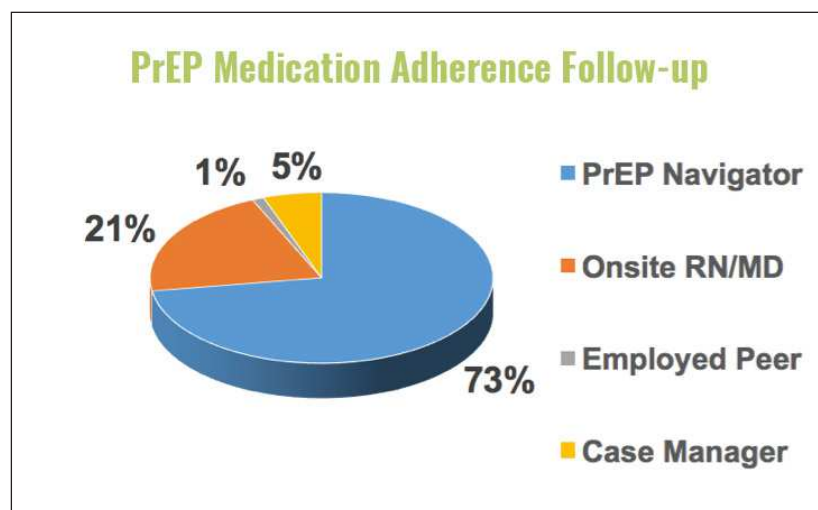
When asked to estimate the overall **percentage of consumers who begin PrEP services but then completely disengage with services** or are lost to care (i.e., are never connected with again), 87 participants provided write-in responses that ranged from 1% to 80% of consumers. Participants provided the following **consumer barriers to PrEP navigation (compared to the barriers for HIV navigation)**:



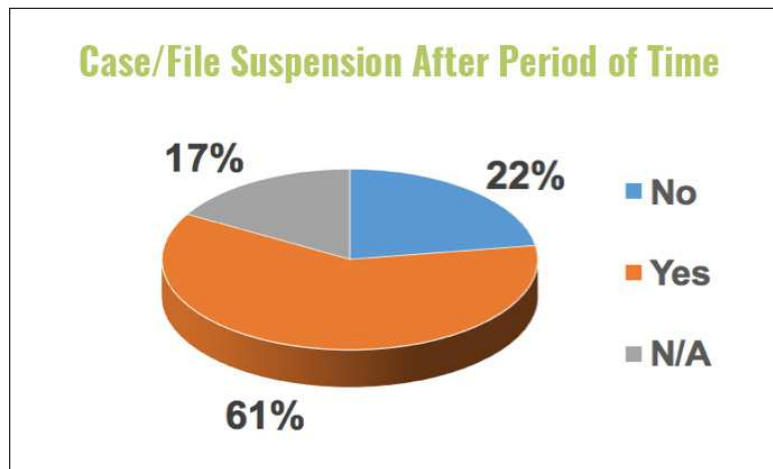
When asked to indicate any specific **steps that are taken to connect with consumers who disengage with PrEP navigator services or are “lost to care”** (e.g., miss appointments), 96 participants provided the following data (compared to the steps for HIV navigation):



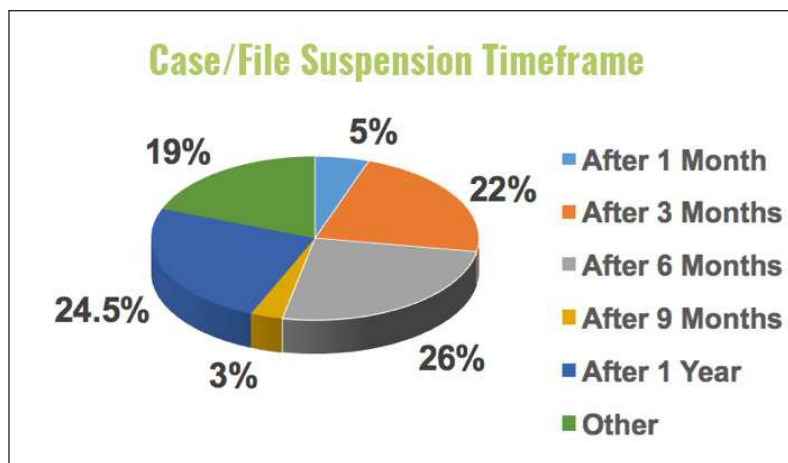
When asked **who does the follow up regarding PrEP medication adherence** after a consumer starts taking medication, the majority (73%) of 91 participants indicated the *PrEP Navigator*, followed by an *Onsite RN/MD* (21%), a *Case Manager* (5%), and an *Employed Peer* (1%).



When asked whether a consumer’s **PrEP navigation case/file is suspended** (e.g., marked inactive or closed) after a period of time without any contact, the majority (61%) of 102 participants indicated *Yes*.

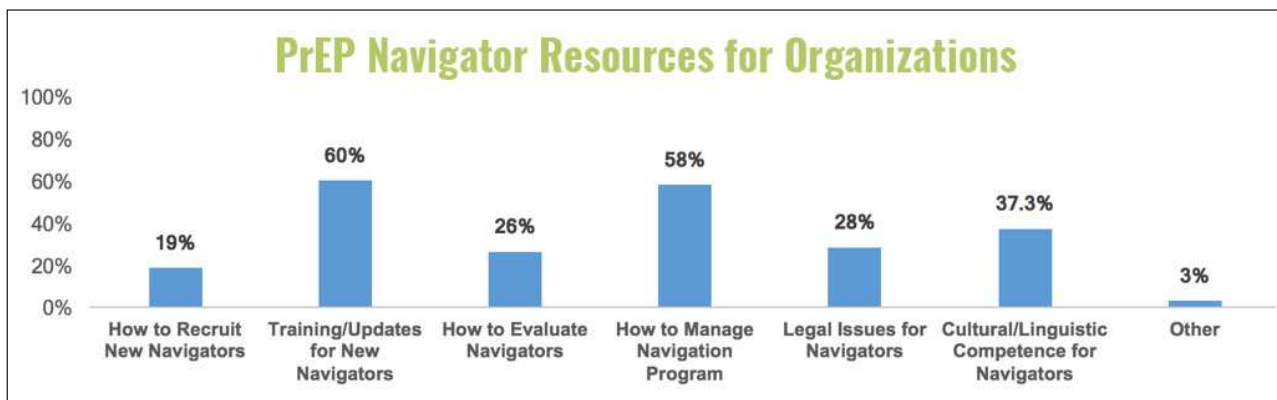


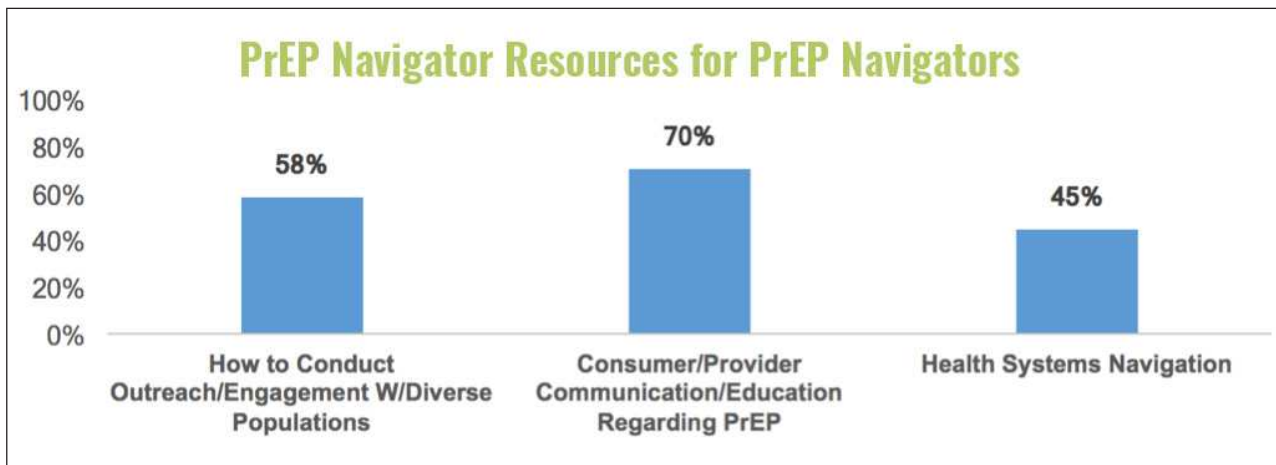
When asked to indicate the **timeframe typically designated to suspend or close a PrEP navigation case/file**, the majority (24.5%) of participants indicated *After 1 Year*.



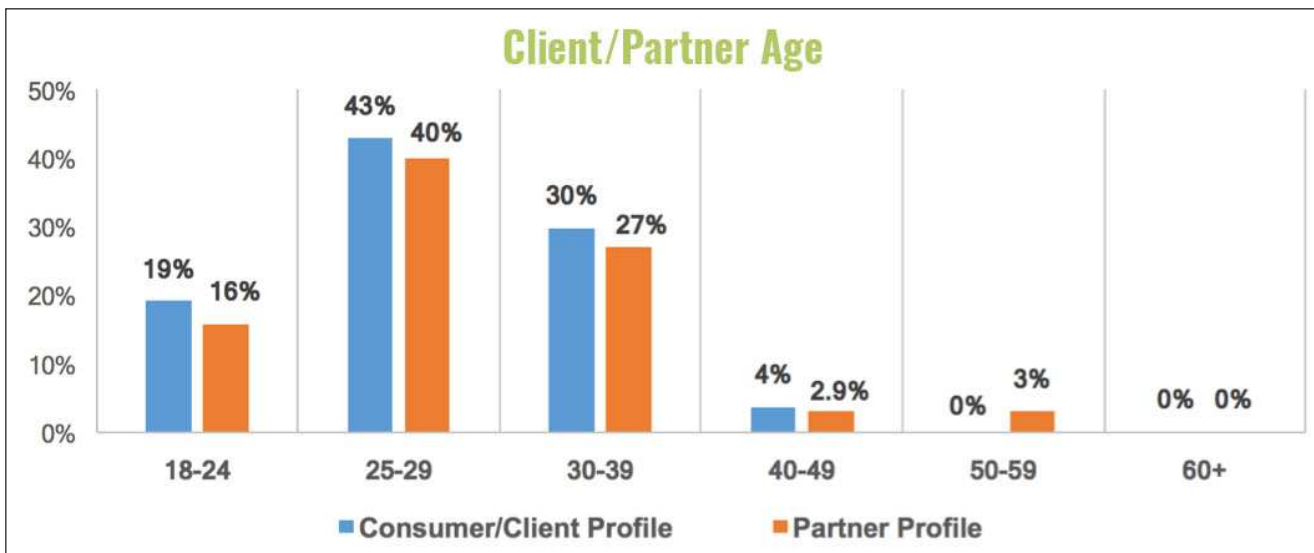
PrEP Navigation Training, Technical Assistance, & Capacity Building Needs

When asked to indicate specific training, technical assistance, or capacity building **topics/resources that would be helpful for PrEP navigators**, 102 participants provided the following resources /topics that are needed for their organizations:

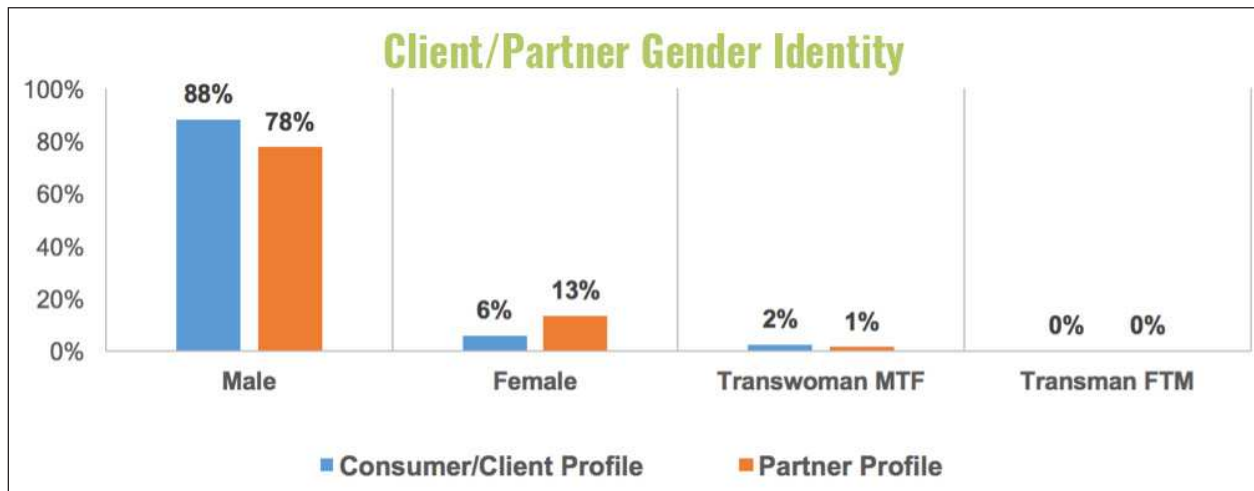




Participants provided the following data regarding the average **demographics of primary consumers and their partners who both currently receive PrEP navigation services**:

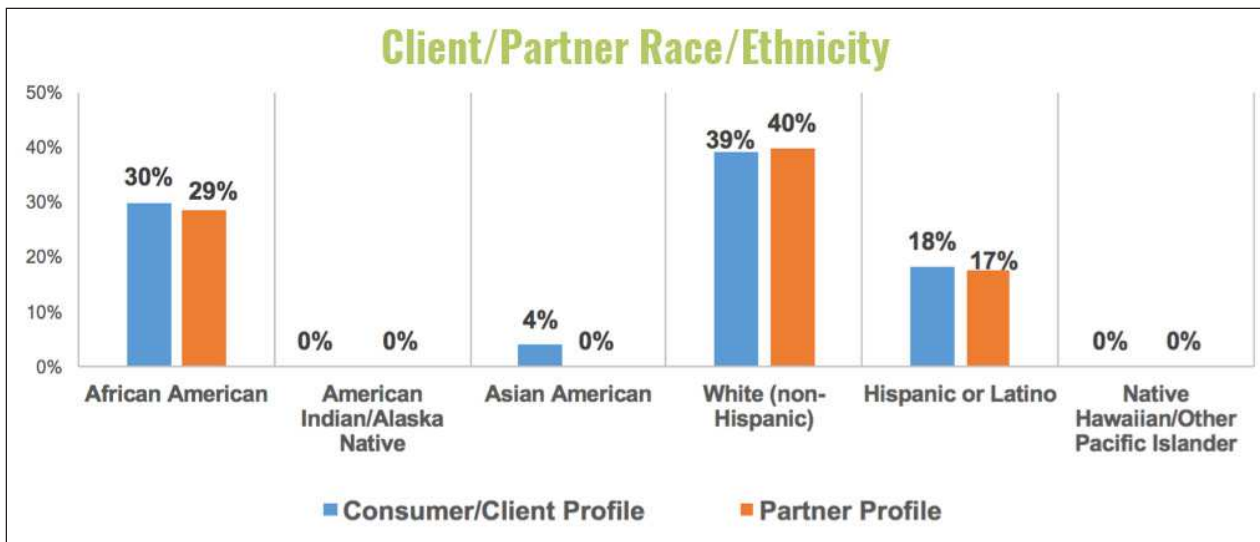


The **ages** of consumers as well as their partners who currently receive PrEP services ranged from 18 to 59 years, with a majority between ages 25 to 29 years.

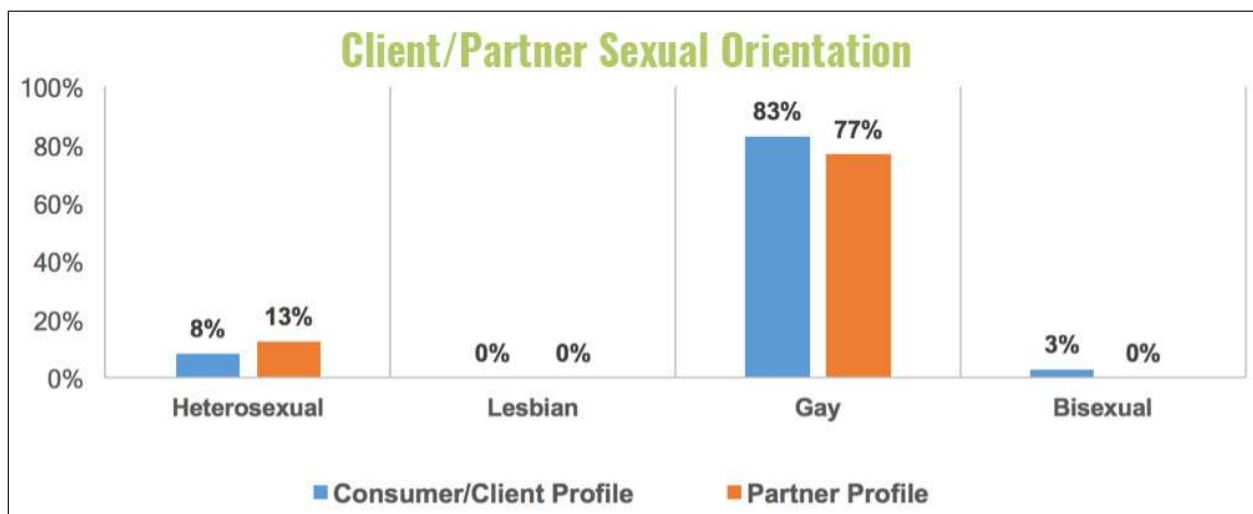


Large proportions of participants indicated that the **gender identity** of consumers and their partners who currently receive PrEP services is *Male*.

When asked to indicate the **race/ethnicity** of consumers and their partners who currently receive PrEP services, participants provided the following responses:



When asked to indicate the **sexual orientation** of consumers and their partners who currently receive PrEP services, participants provided the following responses:



SITE VISITS & KEY INFORMANT INTERVIEWS

During April to early May 2017, site visits were conducted to gather in-depth qualitative data from sites in 10 cities that represent major regions of the United States where PrEP and HIV service needs are prevalent. These observational studies included key informant interviews with over 20 PrEP and HIV service providers to gain an understanding of commonalities and differences in current practices, opportunities, and contexts for PrEP and HIV navigation.

Sites

1. Baton Rouge, Louisiana
2. Washington, DC
3. Baltimore, Maryland
4. New York City, New York
5. Jackson, Mississippi
6. Houston, Texas
7. Chicago, Illinois
8. Ft. Lauderdale/Miami, Florida
9. Los Angeles, California
10. San Francisco, California

The following map illustrates where the national site visits were conducted:



(National Geographic MapMaker Interactive, 2017)

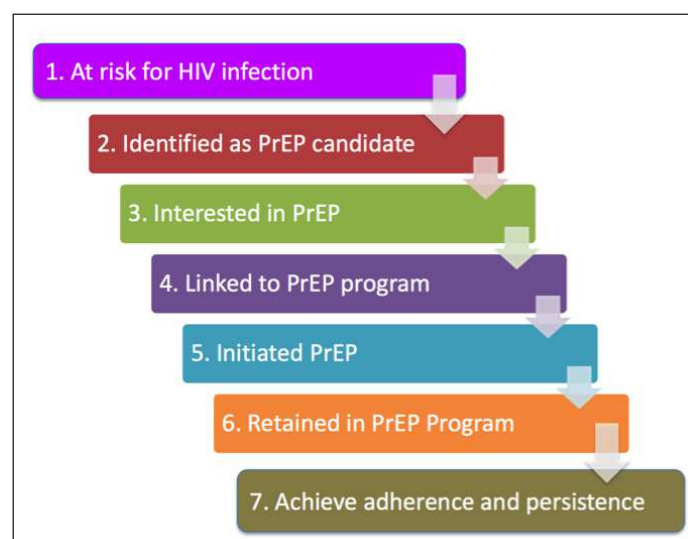
Site 1 – Baton Rouge, Louisiana



Baton Rouge, Louisiana has been recognized at various times for “leading the nation” in HIV and AIDS cases per capita (WAFB, 2012), and CDC specifically cited Baton Rouge as among the “hardest hit” urban areas nationally (among cities with HIV cases per 100,000). CDC surveillance reports consistently demonstrate high rates of infection (CDC, 2016, p. 4) in Baton Rouge.

At the **Open Health Care Clinic**, a community health center (CHC) in Baton Rouge, Louisiana, the PrEP coordinator explained that their typical client profile is 18 to 28 years of age, including African Americans, MSM, high-risk HIV-negative populations, transgender people, injection drug users (IDUs), and sex workers. The core resources that they use are from CDC’s 2014 Clinical Providers’ Supplement focused on PrEP. This resource contains an assessment tool (i.e., risk index), handouts (i.e., information sheets), and what was described as a contract (i.e., patient/provider checklist). The PrEP coordinator explained that they “do the contract initially at the first visit, and at every 3-month follow-up and retesting to instill in the patients their responsibilities [for] taking PrEP and being in the PrEP program as well as the clinic and provider responsibilities.” An additional form that they use is the required “State testing form” (i.e., the Louisiana Office of Public Health HIV testing form).

Another resource that the PrEP coordinator cited following is the *Spectrum of Engagement in HIV Prevention: Proposal for a PrEP Cascade*, which was a presentation at the 7th International Conference on HIV Treatment and Prevention Adherence (Liu et al., 2012). This presentation contains the following PrEP Cascade:



The PrEP Coordinator printed and used this cascade to provide an overview of how their efforts align. For Step 1 (At risk for HIV infection), they have what was described as a general marketing campaign, in addition to specific targeted outreach efforts to specific populations (e.g., college students, the uninsured). The approach that they use to communicating about PrEP was characterized as “sexual health with a healthy focus on PrEP, rather than just PrEP, since it can be stigmatizing to people that the focus is on pushing PrEP.”

Their assessments regarding sexual health line up with Step 2 on this cascade (Identified as PrEP Candidate), and they have promotional messages and materials that line up with Step 3 (Interested in PrEP). The PrEP coordinator has an office at the community health center and provides direct linkages to PrEP services (aligning with Step 4 (Linked to PrEP program). For Step 5 (Initiated PrEP), they provide resources regarding payment assistance (i.e., patient assistance programs). Their evidence-based practices (e.g., CLEAR) line up with Step 6 on this cascade (Retained in PrEP program), and follow-up steps are taken to ensure that consumers have their medication (aligning with Step 7 [Achieve adherence and persistence]).

The PrEP coordinator made a concerted effort to differentiate the roles of a “navigator” versus a “coordinator.” A navigator was said to focus primarily on Steps 1 through 3 of the PrEP Cascade whereas a Coordinator was said to focus primarily on Steps 5 through 7. Step 4 (Linkage to PrEP program) was described as an area of overlap that is shared by the two roles. When asked to further describe this difference, the PrEP coordinator explained that a navigator focuses on social networking and outreach (e.g., promotions, referrals), while a coordinator focuses on linkage and clinical services (i.e., engagement).

“It’s not just the one person we’re helping, but all the other people they’re connected to.”

When asked whether they have data from their EHR system regarding risks and needs (e.g., sexual behavior, ICD-10 codes, prior STIs/STDs), the PrEP coordinator said they do, but that they do not use these as flags for PrEP eligibility/need. It was explained that “all medical staff are trained on flags,” and that the doctor has to make the recommendation for PrEP rather than the coordinator finding flags. If the doctor provides this recommendation or a referral to PrEP follow-up, then the PrEP coordinator joins the medical visit if available. Their EHR has a mechanism (i.e., an on-screen button) to refer based on the data from a person’s sexual health history survey.

When asked if there is any specific orientation or training for the PrEP coordinator position, the PrEP coordinator said that he relied primarily on information from CDC regarding CDC’s PrEP clinical guidelines.

The PrEP coordinator described an interest in following marketing and promotional campaigns from other areas of the United States, such as the #Truvotter Twitter and t-shirt campaign (Note: this is from the University of California San Francisco.). This example was cited as a way to adapt marketing campaigns to what will work in certain communities. The PrEP coordinator said it is best to avoid using stock photos in awareness campaigns and that PrEP users themselves are the best advocates (e.g., “It’s not just the one person we’re helping, but all the other people they’re connected to”). In addition, HIV testers in the field should always have information about PrEP to give to consumers.

The PrEP coordinator also discussed opportunities for resource development. While the CDC-based risk tools that they use provide an overall risk scan, it was said that, while this does a good job of assessing individual risks, there is an opportunity to expand upon this tool to further assess community-based risk (an especially pressing issue in high HIV prevalence areas such as Baton Rouge). In addition, it was said that there is a need for a prompt on the state-required HIV testing form regarding PrEP.

The PrEP coordinator was familiar with the stages of change trans-theoretical model for consumers (Prochaska & DiClemente, 1992) and provided the following examples of how PrEP activities line up with this model:

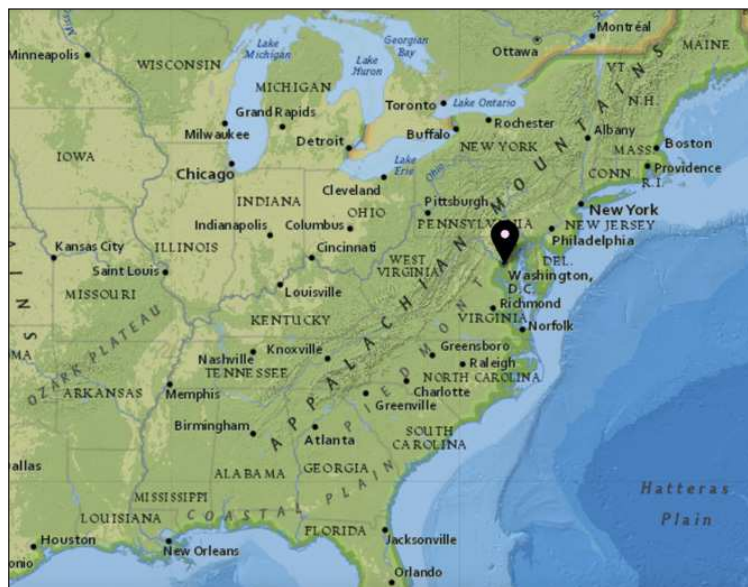
- **Pre-contemplation** – Outreach and asking consumers, “Since we talked, have you engaged in risk behaviors?” This stage also includes reassessing every 3 months.

- **Contemplation** – Information sharing and consultation.
- **Preparation** – Labs and screenings during clinical visits.
- **Action** – Prescribed PrEP.
- **Maintenance** – Risk assessed continuously.

The PrEP coordinator described how the “biggest hurdle” for motivating consumers is to engage in the first visit. Once this is complete, he said that approximately 80% of consumers will be on PrEP. The largest barrier to PrEP uptake that they see is the perception that consumers cannot afford it.

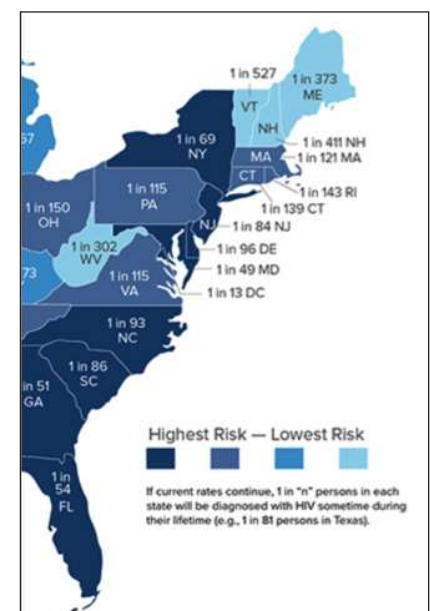
When asked about the timing/sequencing of PrEP services, the PrEP coordinator estimated that it takes nearly 1 week between an initial visit and PrEP medication, followed by “regular follow-up every 3 months” (involving labs, risk/harm reduction counseling/education every visit and adherence counseling regarding any side-effects). Every year there is an initial consultation, and if someone skips their 3-month follow-up visit, then the clock starts over again. Their “CDC contract” form is for 1 year.

Site 2 – Washington, DC



Washington, DC has a high prevalence rate of HIV and is among city metropolitan regions where minorities became a majority of the overall population over the decade from 2000 to 2010 (U.S. Census 2010; Morello & Mellnik, 2011). According to CDC (CDC, 2016), Washington DC has an estimated lifetime risk of HIV diagnosis of 1 in 13 people (i.e., a person living in Washington DC has a 1 in 13 chance of being diagnosed with HIV at some point in their life).

Howard University Hospital, located in Washington, DC, focuses on the HIV care continuum and hosts an annual conference on HIV stigma each year. HIV testing is conducted on the first floor of the hospital, and the confidential intake form used by the HIV testing specialist includes a question, “Are you currently on PrEP?” This question provides the testing specialist with an opportunity to explain PrEP and answer questions in a way that is non-stigmatizing and culturally and linguistically competent.



The **International Conference on Stigma** is planned and coordinated by the Coalition for Elimination of AIDS-related Stigma (CEAS), which is composed of a group of professionals, community leaders, concerned individuals, and organizations focused on efforts to diminish and eliminate the stigma associated with HIV (Whocanyoutell.org, 2017). Conference tracks include practical ways to eliminate sigma through education and personal storytelling, scientific poster presentations, and panels that include people who have lived experience with stigma and HIV, in addition to international experts in the field.

Site 3 – Baltimore, Maryland

Baltimore, MD is another major metropolitan area that has a high prevalence rate of HIV. According to CDC (CDC, 2016) and the *Baltimore City Annual HIV Epidemiological Profile* (Maryland Dept. of Health & Mental Hygiene, 2016), the Baltimore-Columbia-Towson metropolitan statistical area (MSA) had the 10th highest estimated HIV diagnosis rate among major U.S. metropolitan areas. Blacks/ African Americans account for over two-thirds of Maryland's HIV diagnoses, and Maryland's HIV continuum of care data (through May 30, 2016) clearly illustrates the need for navigation services to address gaps in diagnosis, linkage to HIV care, retention in HIV care, and viral suppression (Maryland Dept. of Health and Mental Hygiene, 2016; 2017).



The **Baltimore City Health Department** contracts with community-based organizations and clinical partners to provide PrEP and HIV services (e.g., Star Track Adolescent Health Program, Johns Hopkins). Targeted outreach is conducted to engage with African Americans, MSM, transgender populations, and other underserved communities. Specific risks among consumers include prevalent “couch surfing” (linked to unstable housing), survival sex “for having a roof over one’s head,” and the lower priority HIV has in people’s lives since “so many people have so many other issues in their lives.”

It was explained that as individuals “come into the clinics, they are referred to navigators who talk about getting on PrEP.” There is an emphasis on hiring navigators from the communities that are most affected by HIV because they not only have expertise and lived experience but “Having a job is HIV prevention.”

Uptake of PrEP after offering to provide linkage is approximately 20%, and repetition of this offer was said to help with acceptance. The EHR system tells physicians that a consumer is PrEP eligible (per a risk algorithm) among the 10,000 individuals who are screened for HIV annually. Risks are addressed within outreach training programs, and partner services connect with people who were recently exposed to HIV. Trainings are held in partnership with the **AIDS Education and**

“Having a job is HIV prevention.”

Training Center (AETC) in Baltimore, and there are specific training resources for providers.

There is recognition of stigma surrounding PrEP and HIV within Baltimore, with people “stigmatizing of each other” within specific community groups (e.g., discussions of someone being a “whore”). There are also “mixed feelings” regarding perceptions among providers and within the community about increases in sexually-transmitted infections (STIs/STDs). Efforts to overcome this stigma include educational campaigns, community activities, and direct outreach by community-based providers. Examples of successful education and promotional efforts include social media, websites, social marketing, and community conversations (e.g., <https://www.facebook.com/BaltimoreInConversation>). There are also bloggers from the community, in addition to a documentary in development and story-telling nights.

Site 4 – New York City, New York

New York City’s HIV prevalence is 107,280 people living with diagnosed HIV in 2015, according to CDC. HIV incidence, the number of new HIV diagnoses, was 3,123, 44% of whom were black/African American, 34% were Hispanic/Latino, and 18% were White (AIDSvu, 2017).

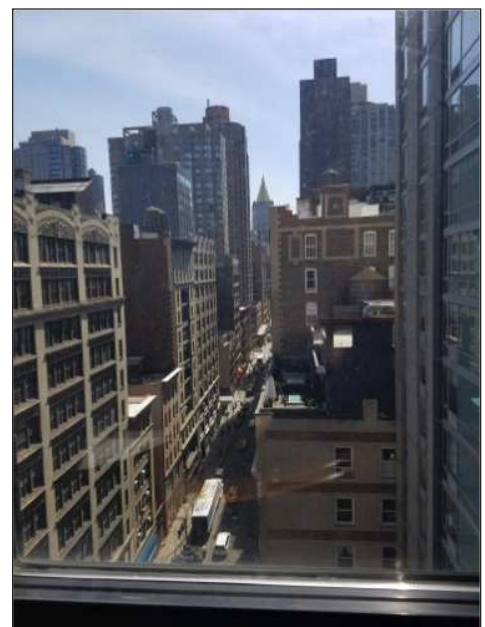
Gentrification and housing instability are top-of-mind concerns among providers working with minority populations in New York City. Rent-controlled apartments are giving way to mixed-income residential developments, or people are getting priced out of certain areas entirely. As a result, there is crowding within existing spaces and commutes are shifting to outlying areas. Housing is an ongoing point of friction in the city’s political process (Feuer, 2017). The link between housing and HIV has been well established through a number of prominent initiatives such as the National AIDS Housing Coalition.



Site 1

Mount Sinai Health System is a large-volume HIV provider with 7 hospitals, a medical school, and more than 300 locations (MSHS, 2017). All staff are cross-trained to work on HIV testing, PrEP, Post-Exposure Prophylaxis (PEP), and STIs. Services specifically include rapid syphilis and hepatitis C testing. This health system receives different funding for prevention services, with 3 to 4 staff per project. Deliverables are complimentary. The timing between consumer education and linkage to providers is an area of focus for this health system, since “a patient can lose interest without follow-up.”

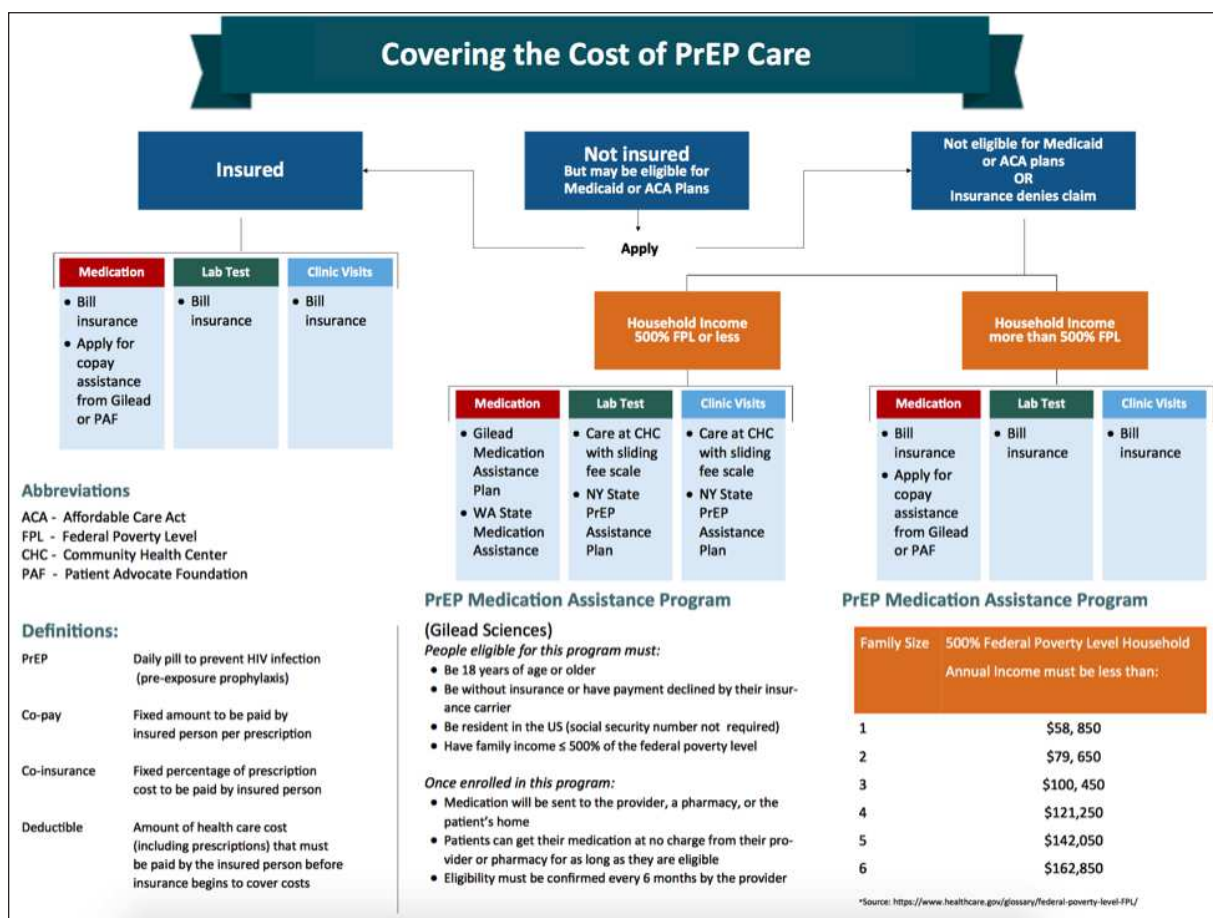
Clinical sites receive on average approximately 3 PrEP referrals daily, and over 800 consumers are currently on PrEP. Consumers have access to assistance programs including “PrEP-DAP,” which is a waiver for ADAP funds to be used for PrEP services. This includes PrEP medical visits and STI screening and treatment, and hepatitis A and B



vaccination. Consumers receive a sexual health assessment per visit and testing for kidney and liver functioning, a complete blood count (CBC) panel and HIV panel. If an HIV test is negative and someone wants to receive PrEP medication, it can take 7 to 10 business days for approval and approximately 2 days for pharmaceutical company approval. If someone is insured and Medicaid eligible, it can take one week. They can receive same-day approval with a Medicaid identification number within 48 hours (which sets them up with a doctor).

There is a set of options regarding payment for PrEP medication, which involves a mix of private insurance, PrEP-DAP, self pay, and Medicaid. For example, if someone has a high co-payment on their insurance, they can receive a co-pay card from the pharmaceutical company (up to \$3,600 per year). If it is \$50 to \$00, then all costs are covered; if it is \$5,000, then there are funders/foundations that help to provide assistance per the Patient Access Network (PAN) Foundation. PAN is a non-profit organization “dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the out-of-pocket costs for their prescribed medications” (PAN, 2017, p. 1).

The following workflow diagram from CDC’s National Center for HIV/AIDS, Viral Hepatitis, STD, and TB prevention, Division of HIV/AIDS Prevention, outlines how consumers can cover the cost of PrEP care (CDC, 2015).



Mt. Sinai Health System collaborates with many community-based organizations to hold community events. For example, they will host a panel with physicians for the community to ask about PrEP and inform them regarding available resources. They can set up their appointments immediately.

They will also refer to community-based organizations to expand their capacity. They have five infectious disease (ID) clinics throughout the city. Based on availability and wait-time, they can call Cornell for assistance. Buy-in for PrEP was said to be important from the front-desk to CBOs to the providers. Mt. Sinai Health System

provides education to providers in New York City on how to implement PrEP into their health services.

Every person who walks through the door was said to receive a sexual health assessment and discussion regarding PrEP. They hold “PrEP Fridays” as part of a CDC-funded intervention that uses a Many Men, Many Voices (3MV) video regarding condom negotiation, and this incorporates PrEP. This was described as an intervention (condoms) plus PrEP.

Broader prevention messages have been more successful than narrow, PrEP-only education, (e.g., to avoid the potential perception of “pushing pills,” educational messaging needs to be reframed as providing a set of resources and options). If someone is at high risk for HIV infection and is not on PrEP, then they can also receive information on access to PrEP.

Supervisors hold quality assurance meetings each month regarding projections versus performance. They are creating templates with smart-phrases and flags to conduct followup on PrEP with their EHRs.

When asked whether there are consumers who are falling through the cracks or are being left out of the equation regarding access to PrEP, women were said to need focus. The current focus is on MSM and transgender populations. For transgender individuals and sex workers, difficulties were described regarding trust (e.g., “Don’t treat me as a number/use me”). Mt. Sinai Health System provides surgery and hormone therapy for the transgender population. Sex workers are at high risk for HIV due to the higher premium they can charge for condomless sex. Educational messaging is more successful if presented as a negotiation (e.g., not telling them what they need, but that they are choosing to receive treatment and care).

There are mixed messages and understanding among consumers regarding PrEP adherence. For example, if someone was able to take PrEP soon before a condomless sexual encounter or another exposure without an HIV transmission, then there is a misperception that PrEP can be taken whenever/inconsistently.

All pharmacists are held responsible for following up regarding prescription reminders (e.g., within 1 month). They try to make appointments ahead of time rather than depending on consumers to call in. They ask consumers how they will get to the service location and schedule a couple weeks before to get labs done, etc. for providers to release supply.

Since PrEP medication needs to be taken daily, they have an individualized plan with consumers that indicates the best time to take PrEP medication (AM or PM), as well as any other medication intake information (e.g., “Make it structured.”).

Site 2

Interviews were also held at the **Callen-Lorde Community Health Center** in New York City. This high-volume community health center provides “comprehensive care, provided free of judgment and regardless of ability to pay” (Callen-Lorde, 2017). Programs and services include primary care, sexual health, behavioral health and social services, health insurance outreach and enrollment, and pharmacy services. Callen-Lorde also focuses on housing, poverty, discrimination, and other issues underlying health disparities.

Walk-in HIV testing and community advisory board meetings are posted online on a calendar of events. There are approximately 2,400 individuals on PrEP; an estimated 50% are private-pay, 25% are uninsured, and 25% receive public assistance. Among the transgender and gender non-conforming (TGNC) community, 50% receive public assistance.

If someone is a primary care client, then there is no wait time to get on PrEP (i.e., there is same-day PrEP) when

To avoid the potential perception of “pushing pills,” educational messaging needs to be reframed as providing a set of resources and options.

someone can ask to come in for labs. If someone has an external primary care provider (PCP), then individuals will frequently come to Callen-Lorde if their PCP discourages PrEP. If someone wants to initiate PrEP, then it was said that they are encouraged to come in for HIV testing. There are many programs to apply for financial assistance, though there can be a process where there are many documents that are needed to prove income and need (notarized letters, etc.). If someone is not a current “PCP patient,” then their earliest appointment date for scheduling can be three weeks out due to high volume demand that exceeds capacity. They can jump-start PrEP at the New York Department of Health (NYDOH) clinic to receive same-day service to obtain a 30-day supply of medication (at the Central Harlem Clinic currently, and they are working to expand this service to other clinics).

At the Callen-Lorde sexual health clinic, consumers see a prevention counselor and receive comprehensive risk-reduction and adherence counseling. They have a PrEP program assistant who calls everyone every two weeks to check in when they initiate PrEP, in addition to calls for routine check-ins (asking questions regarding filled prescriptions, any side-effects, and, if there are any, transfer the consumer to triage to speak with a registered nurse[RN]). Navigators experienced situations when consumers were not filling their prescriptions, “which is why the two-week call is important.” PrEP consumers also meet with their provider every three months.

Transgender populations come into Callen-Lorde for hormone injections, which is a point of PrEP linkage where they are actively doing inreach. They address concerns and misunderstandings regarding PrEP medication interactions with different hormones. There were also misunderstandings regarding the scheduling of reassignment surgery and the use of PrEP (e.g., individuals told to go off all of their medications before surgery). They have a booklet of information for consumers to address misunderstandings. They also have a “User’s Guide to PrEP” brochure, which was developed from a study. Brochures are given at Callen-Lorde, and the New York Department of Health has adopted text from the brochure.

Callen-Lorde also has a rapid treatment program for people who are HIV positive and are treatment-naïve, where they can receive same-day anti-retroviral (ARV) medication, meet with an HIV case manager, and access emergency ADAP if needed. They will meet with an RN and a PCP, and the RN will observe them taking medications for the first time. They actively track days to viral load decrease. It was said that they do see high rates of STIs/STDs among their PrEP consumers, “which demonstrates the importance of regular STI testing.”

When asked whether there is stigma associated with PrEP, consumers were said to experience the same dynamics of stigma that people living with HIV experience when their HIV is virally suppressed. The approach to constructively address this stigma is to provide “holistic care.” Callen-Lorde also provides training to providers in homeless shelters regarding how to not discriminate against individuals who are transgender and gender non-conforming (TGNC).

Medication adherence is addressed by identifying missed doses and developing strategies such as using an alarm, taking medication to coincide with a daily habit such as brushing teeth, taking PrEP medication with other pills, and using keychains as part of a kit (provided by the NYDOH).

When asked how navigators receive their educational information and what sources of information would be most helpful for navigators, NYDOH educational campaigns were cited. There are also online community groups where information is exchanged, such as PrEP Facts FAQ and The Stigma Project, which are both on Facebook:

- <https://www.facebook.com/PrEPFactsFAQ>
- <https://www.facebook.com/TheStigmaProject>

When asked whether there are communities or populations that are left out of PrEP efforts, outreach to cis women was said to be needed, and a specific resource was suggested regarding cis black women (Black Women’s Blueprint, which is an organization in Brooklyn, NY). They had also heard that Planned Parenthood had started prescribing PrEP to cis women.

Site 5 – Jackson, Mississippi

Jackson, Mississippi has been recognized as having the fourth highest rate of HIV infection in the United States and was recently profiled in the New York Times article “America’s Hidden H.I.V. Epidemic” (HRC, 2014; Villarosa, 2017). According to CDC and the Mississippi State Department of Health, HIV disproportionately impacts MSM, with 4 out of 10 gay or bisexual men in Jackson having HIV (the highest prevalence rate in the United States) (Fowler, 2016). The change in policy regarding the state Health Departments beginning to charge a fee (\$25) “for all STD and HIV tests and lab work,” given the high rates of poverty in Jackson, Mississippi, is a top-of-mind concern (Fowler, 2017).



My Brother’s Keeper (MBK) is a non-profit organization with three offices in the Jackson, MS metropolitan area (headquarters in Ridgeland) and two offices in South Mississippi (Hattiesburg and Gulfport)(MBK, 2017). MBK provides education and training, health promotion, policy change advocacy, and many other health equity services. At its **Open Arms Healthcare Center (OAHCC)** located in Jackson, MS, services include specialized/holistic care with an emphasis on HIV/AIDS and cardiovascular disease by providing primary care, sexual health services, and social services research (OAHCC, 2017).



The MBK OAHCC PrEP coordinator provided a walkthrough at their clinical and research services location in Jackson, MS, and followed-up with a detailed set of steps and forms that they use for PrEP services. The following information summarizes these details regarding how navigators (1) create a welcoming clinical atmosphere and positive rapport with consumers, (2) maintain regular contact with consumers, (3) provide PrEP specific and general sexual health education materials, and (4) assist consumers with acquiring coverage and or navigating their existing coverage.

- **Creating a welcoming clinical atmosphere and positive rapport with consumers:** Many consumers receive their medication at the clinic, and some receive their medications from the specialty pharmacy. Upon arriving at the clinic for medication pick-up, the consumer is taken to a private room and asked about any side effects/challenges with the medication. Additionally, the consumer is asked about how they are doing as a person. This combination of adherence inquiry and life check increases the level of trust consumers have with the clinic and the navigators.



- **Maintaining regular contact with consumers**

- **Calling, texting, and/or emailing:** The type of contact depends on consumers' communication preferences and needs. If allowed by the practice, navigators may look into using a Google Voice number attached to their work email to maintain contact without divulging their personal contact information. The consumer should be informed that the number is a direct line especially during work hours. If funding allows, it may be beneficial for navigators to have practice-provided cellular devices for greater flexibility in contacting consumers regarding retention. The devices may also possibly benefit recruitment as consumers may refer people they know directly to a navigator after working hours.
- **Medication adherence:** Navigators contact consumers 7 days after an initial appointment to see if prescription has been filled and picked up (if not, why?) and ask about side effects, 30 days after initial appointment to check for side effects and adherence, once a month to check in for general retention (For example, consumers have been known to lose coverage and not report it until their next appointment).
- **Appointments:** Navigators contact consumers the week before the appointment to check in/remind them of the appointment, the day before to confirm, and the day of (if the consumer is not seen by the scheduled time to 10 minutes after).
- **Missed appointments:** Consumers should be contacted later on the day of the missed appointment and 7 days later if the consumer has not contacted the clinic themselves for rescheduling. Requesting that consumers arrive 30 minutes before their scheduled appointment time allows for the completion of as many administrative tasks (checking in, billing) and clinical tasks (vitals, HIV test, research if applicable) as possible before they see the provider. It may be helpful to maintain a physical and/or digital calendar with each contact person listed.

- **Providing PrEP specific and general sexual health education materials:**

- **Memory/reminders:** Pill caddies for traveling or just in case , and pill trays for daily doses.
- **Conversation starters:** Wrist bands, t-shirts, mugs, water bottles, and artwork.

- **Assisting consumers with acquiring coverage and or navigating their existing coverage:**

- **If a consumer is uninsured:** Navigators will process Medicaid Family Planning waivers and/or the pharmaceutical company's Advancing Access forms to help pay for medication and visits if possible. Applications should be sent within 24 hours or less of an appointment and followed up on between 24 to 48 hours or less of original submission to verify the quality of received documents. As a general observation, it is sometimes possible that a pharmaceutical company representative will process an application while a navigator is on the phone, which may expedite the coverage process.
- **If a consumer is insured:** they are provided a pharmaceutical company co-pay card to activate when needed or made a print out in the office where a physical copy will be sent to their specified address within 7 to 10 business days.
 - If a consumer's insurance does not provide prescription drug coverage, then an application to the pharmaceutical company for the consumer assistance program is completed. Navigators should develop positive rapport with representatives of pharmacies and support/coverage services, as this can sometimes lead to faster processing time of applications.

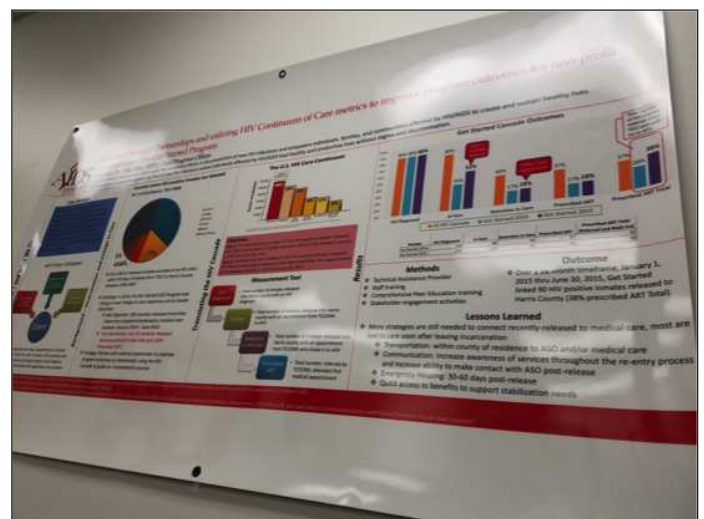
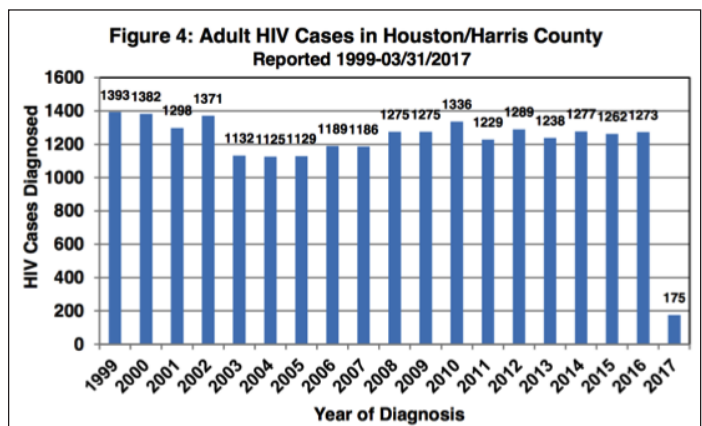
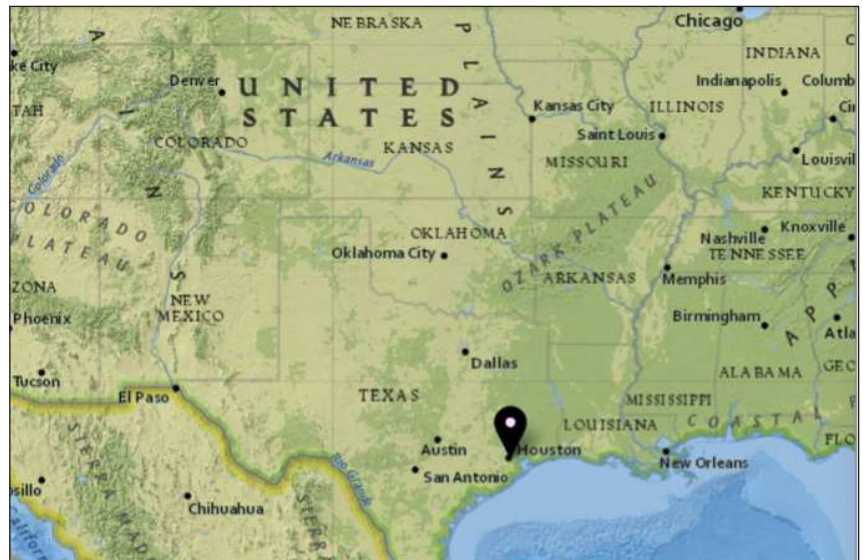
Site 6 – Houston, Texas

The number of adult HIV cases in Houston/Harris County has remained relatively steady since 1999, as illustrated in the accompanying figure from the Houston Health Department Bureau of Epidemiology (HHDBE, 2017). Among the 26,916 reported adult HIV cases (regardless of AIDS status) in Houston/Harris County, the demographics by race include black/non-Hispanic (13,762 or 51%), Hispanic (7,207 or 27%), white / Non-Hispanic (4,990 or 18.5%), and other (non-Hispanic; 957 or 3.5%).

Interviews were held with **AIDS Foundation Houston (AFH) and Houston Health Department** staff. AFH has a “Why PrEP” section on its website (www.aids-help.org) that provides PrEP 101 information, a page for questions and answers, and other resources (including where to find PrEP in Houston). Staff explained that the greatest barrier to PrEP is that people do not know how to start the conversation about PrEP.

AFH conducts education campaigns that focus on African American and young MSM, and they cited difficulty using stock photos because it was challenging to find two black/African American men embracing. AFH also conducts research regarding the benefits of strategic partnerships and using HIV continuum of care metrics to improve program outcomes for non-profit organizations through their “Get Started” program (the accompanying figure provides a sample publication).

All of the staff on the Prevention Team at AFH are educated on PrEP, and they address risks using a form that is “part of the conversation.” They also use a referral form and host Learning Collaboratives as part of a Black AIDS Institute (BAI) initiative that includes other community-based organizations (They hold monthly calls with BAI, and each organization represented has an improvement plan as part of the collaborative). Their approach to engaging consumers in their partner network includes (1) making sure everyone is educated regarding resources, (2) ensuring access by addressing social determinants of health and cultural needs, and (3) identifying and overcoming barriers. It was also said that it is important to have faith-based organizations represented, since they “need to be at the table” to address HIV. Pastors have “so much influence in the community,” which affects how black gay men or non-gay identified MSM are treated. HIV ministries have the potential to make HIV a priority, especially among other faith-based organizations when



they see that one in the community doing the work. Efforts are continually made to have “PrEP presentations” delivered to congregations.

AFH staff cited working closely with the Thomas Street Health Clinic (the “county health clinic”), which has a PrEP clinic. As part of their overall HIV Prevention Program (PrEP), this clinic provides HIV counseling and testing, screening and treatment of STIs and HIV prevention. Clients specifically listed on their website (www.harrishealth.org) include “sero-discordant couples (one partner is HIV positive, and one is HIV negative), clients who have multiple sexual partners. and intravenous drug users” (TSHC, 2017).

AFH staff cited several examples of structural barriers for people who want to access PrEP:

- Incarceration and reentry challenges for continuously accessing services;
- Individuals are not disclosing as gay (i.e., PrEP/Truvada is misperceived as a gay pill);
- Among YMSM of color in particular, PrEP is not a priority (primarily because consumer media and other resources are not focusing on them); and
- Young people who are on their parent’s insurance have concerns about confidentiality and difficulties with co-pay requirements.

There are also restrictions regarding certain policies regarding laboratory testing and the requirement that consumers come to clinic locations. This requirement applies to HIV testing, yet it was pointed out that drop-off stations are located everywhere for other blood-related testing. When someone is screened for life insurance, a phlebotomist comes to the person’s home.

Another barrier cited was the late introduction of PrEP to the U.S. South. Culturally minorities still have a Tuskegee feeling, such as “Why are we just now hearing about this?” Among transgender and YMSM populations, they can have the sense of being “treated like guinea pigs.” The recommendation is “so start with why and why not” when discussing PrEP. There are also perceptions among providers regarding sexual judgment if someone asks for PrEP, including inferring that the person is at increased risk of STIs. AHF team members work with PrEP providers to have conversations with consumers regarding adherence and to the risks of non-adherence. Some providers require consumers to return within 30 days with their pill bottles to check adherence. If a pill count indicates poor adherence, then some providers have stopped treatment which was said is “not helping.” It varies practice-by-practice what providers will accept.

PrEP overall was described as “not a norm” in provider settings because of stigma, discomfort, and misperceptions about following a PrEP protocol that is “complex when it’s not.” When asked whether there is same-day PrEP anywhere in Houston, it was said that “nobody, including the health department has the capacity or infrastructure...there is huge opportunity for provider practices to offer that service.”

“There is a huge opportunity for providers to offer that service” [referring to same-day PrEP]

Since Texas is a non-Medicaid expansion state (per the federal Patient Protection and Affordable Care Act [ACA]), PrEP can be a “hard sell” because of costs on the provider and patient side. If someone does not qualify for Medicaid and is not on an ACA insurance plan, their options are limited. They are exploring the use of Medicaid waiver funds within state working groups, but this is “way off.” The Houston Health Department is addressing the service level regarding how to implement PrEP in their health department locations and support organizations to provide direct services.

Messaging regarding PrEP was suggested is more successful when it is global. For example, when birth control was made available, the way that it was normalized, made common, and non-stigmatized was by incorporating its use as part of larger holistic approach to health needs. Successful messaging is also informative and non-

judgmental. There are also opportunities to overcome potential disconnects between what providers think the community needs to know and what the community thinks they need to know. For example, providers may tend to communicate too much information about PrEP, whereas the community just needs a “I need to look into this” message first. Another strategy for successful PrEP messaging is to emphasize that “PrEP is for everyone.” Other suggestions included using sex positive language and strengths-based messages focused on remaining HIV-negative.

There are opportunities to increase community voices on the local Ryan White Care Council among black MSM, yet they are not coming to the Council meetings despite efforts to pay for transportation. They would be especially beneficial for mentoring other BMSM, given the HIV prevalence rates of among BMSM.

In addition, “transportation constantly comes up” as a barrier. The Houston Health Department has a dedicated team of services linkage workers to provide transportation to appointments. They are also working on having an “HIV negative and HIV positive balance” by increasing capacity to better link to providers. They are also focusing on data that examines the bridge between referrals and linkage as well as refining/expanding their definition of linkage (e.g., scheduling of the intake appointment; following up within a month to verify the appointment; flagging the provider for the intake; and gaining information from providers regarding linked, refill on file, and other information).

Site 7 – Chicago, Illinois

Staff from many community-based organizations attended a 2-day workshop during April 2017, entitled *Providing Culturally Responsive PrEP Services for Black Gay Men (BGM)*. This was hosted by the **Center for Health & Behavioral Training (CHBT)**, the developers of the **Many Men, Many Voices (3MV)** evidence-based practice, in collaboration with the **Chicago Department of Public Health**. It is important to note that an update to 3MV that includes PrEP was in development at the time of this workshop and is imminently scheduled for release.



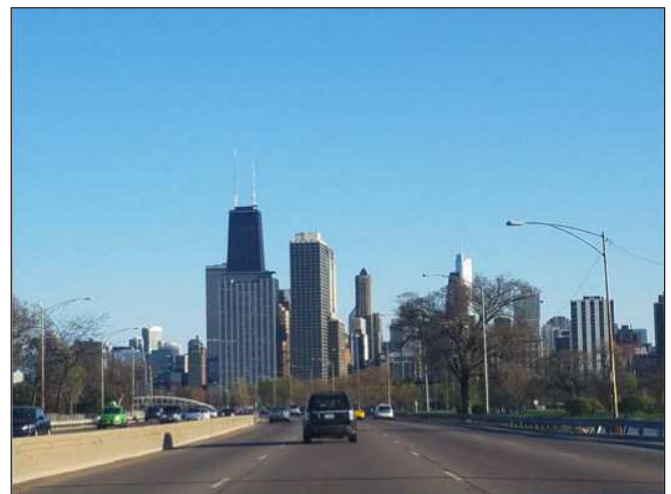
The framework of the workshop included the following eight modules and focal areas:

Module 1: Cultural Responsiveness – Part A

- Making the Connection: Social and Behavioral Determinants of Health of BGM & Resilience

Module 2: Cultural Responsiveness – Part B

- Recognizing Challenges for BGM in Getting PrEP Services – Initiation, Retention, Medication Adherence
- Barriers to Getting PrEP Services – What Do BGM Say?



Module 3: Challenges for Health Care Providers Working with BGM – Initiation, Retention, Medication Adherence

Module 4: Cultural Responsiveness – Part C

- Recognizing Privilege
- Understanding Privilege

Module 5: Cultural Responsiveness – Part D

- Demonstrating Cultural Responsiveness through Provider/Patient (P/P) Communication
- P/P Communication Skills with BGM – Managing Microaggressions
- Microaggression Reactions with Case Examples
- Using Strengths-based Messages and Recognizing Resilience

Module 6: Sexual Health Needs of BGM: HIV/STD/VH

- STD/VH Screening and Vaccines
- Disclosure
- Relationship Dynamics: Tops and Bottoms, Power Balances, Partner Negotiation & Communication

Module 7: Cultural Responsiveness – Part E

- Demonstrating Cultural Responsiveness through Structural Interventions
- Tailoring Health Care Settings for BGM
- Tailoring Health Care Services for BGM

Module 8: Next Steps

Among the many important points that were raised during the workshop, one that was emphasized is the inequity of HIV/STDs among BGM, which is not explained by their behavior alone. Research shows that BGM actually engage in less risky sexual and substance use behaviors than white or Hispanic/Latino MSM (Mayer, 2011). Since BGM are among a high HIV prevalence sexual network, their risk is also driven by community-based viral load.

Another major point of discussion was the gap between estimated percentages and numbers of adults who are eligible for PrEP (which roughly matches the number of people living with HIV) and the current estimate of over 100 thousand who are on PrEP. Given that PrEP has been available for nearly four and a half years, uptake has been relatively slow and is slowest among BGM.

The social determinants of health provide a multi-level framework for understanding and addressing HIV and STD inequities among BGM (Bronfenbrenner 1979; Gamache & Lazear, 2016). This includes individual, interpersonal, community, and larger social structural levels for navigators to understand and address the drivers of HIV risk.

The social determinants of health can also be used by navigators to help consumers with their readiness for PrEP depending on their stage of change (Prochaska & DiClemente, 1992). Examples include:

- Readiness to receive PrEP or take medications versus only wanting to find out more about PrEP; and
- If receiving PrEP, taking medications consistently versus ambivalence or not ready to take medication daily.

PrEP navigators need to demonstrate cultural responsiveness at each stage of the major PrEP related behaviors/needs to ensure that barriers are addressed and overcome:

- Seeking/obtaining a PrEP provider;
- Making an appointment;
- Getting to the appointment;
- Disclosing to the provider that you have sex with men;
- If uninsured, completing multiple steps to obtain a payment source for medications and visits/laboratory tests, producing required documentation;
- Completing bloodwork and other testing;
- Obtaining PrEP medication;
- Adhering consistently to the PrEP treatment regimen;
- Returning for PrEP clinical appointments every three months; and
- Continuing to complete bloodwork and other testing and getting additional PrEP medication.

A small-group discussion explored the major challenges healthcare providers working with BGM face regarding PrEP initiation, retention, and adherence. This discussion identified and explored ways to overcome the following major themes:

- (1) Stigma, disclosing partners, and the need for a safe place to disclose;
- (2) Insurance concerns (e.g., if on a parent's insurance plan, then PrEP may be perceived as a disclosure of sexuality);
- (3) Consumers who are not ready to change, mistrust the healthcare system, perpetuate community-based myths (e.g., HIV is manufactured), or do not perceive their risks;
- (4) Transportation problems getting to appointments; and
- (5) Unstable housing and transient populations (e.g., mailing/securing medications).

Constructive communication approaches for PrEP navigators include demonstrating acceptance and connections, building trust, offering choices, minimizing surprises, and demonstrating fairness. For example, when providing education about PrEP, several suggestions included providing a warm and friendly greeting, asking and not telling (e.g., What do you already know about PrEP? What is your biggest concern about taking PrEP? What questions would you like to discuss today?), and asking consumers about their lives.

For more information regarding this highly engaging and interactive workshop, please contact Dr. Leo Wilton or the Center for Health & Behavioral Training (CHBT). The mission of CHBT is to bridge science and practice through training and capacity-building to advance STD/HIV prevention and community health.

Site 8 – Ft. Lauderdale/Miami-Dade, Florida

The City of Wilton Manors, Florida, a community with a population of 12,385, operates with a Commission-City Manager form of government, and draws populations from the Miami-Dade County and Ft. Lauderdale areas (WMIC, 2017). Miami-Dade County, Florida, has been recognized as first in the nation in its rate of new HIV diagnoses (Chang, 2016).

The Wilton Manors community is home to **Latinos Salud**, a community-based organization that provides:

- HIV rapid testing and STI/STD testing;
- Linkage to Ryan White medical and support services;
- “Diverse is Safe” (condoms, treatment-as-prevention (TasP), PrEP, negotiated safety, PEP, live healthier);
- Life coaching for people living with HIV and transgender communities;
- The Somos, Juntos, and Miamigo social networking groups;
- Positive Social (a bilingual and multicultural group that is open to everyone living with or affected by HIV);
- “Free, Safe & Proud” (condoms and lube education/distribution);
- MPower evidence-based practice meetings; and
- United Miami (where “HIV-negative and HIV-positive individuals can come together and enjoy different activities free of stigma, judgments, and discrimination” (LS, 2017).

Latinos Salud has a major focus on Latino immigrants (first generation or direct), and this population comes from many different host countries and cultures. There is typically no sexual health education within these countries, and there are various cultural perceptions/acceptance of someone identifying as gay or as a man who has sex with men.

Latinos Salud staff described the need for providers to understand the importance of cultural values and perceptions, particularly among the Hispanic/Latino community. Examples cited included *respeto* (respect) and *familias fuertes* (strong family connections) as they relate to disengagement and engagement with health services and providers (e.g., asking questions to a physician is considered an affront). When the organization initially attempted to hold PrEP town halls, attendance was poor due to the messaging and purpose of this event. By retuning their efforts with an understanding of local cultural values and perceptions, these events were successful.

Since “everyone is potentially indicated for PrEP,” they address it through wide promotions. This helps to increase awareness and address potential misperceptions and suspicions. There is great interest in PrEP among their clients who ask about or are recommended PrEP. The Patient Assistant Program (PAP) was described as easier than insurance for gaining PrEP coverage. The organization Care Resource is involved with the cost of laboratory work, and there is high demand (i.e., an estimated two weeks to two months to get an appointment).

There are, however, “big drop-offs” on every level of the PrEP continuum/cascade, including gaining access to PrEP. If someone “sticks with it [PrEP]” to their first appointment, there is then a 50% drop-off to their next step



to receive a prescription. Then there is another 50% drop-off.

A major challenge is the requalifying process and laboratory testing, particularly at the second and third cycle. For example, insurance will provide approval for the PrEP medication “by thinking that someone is HIV positive and then deny later.” People wind up giving up. There are also providers that hold misperceptions and concerns regarding the link between PrEP and HIV resistance, which provides an opportunity for education.

Every staff meeting at Latinos Salud is also a training, and they review readings together on updates regarding PrEP and HIV. Questions are discussed, and they explore the reasons for any failures of navigation and linkage and ways to overcome them.

When asked about successful PrEP promotion strategies, staff said to “advise, but don’t push it.” The focus should be comprehensive HIV prevention, not just PrEP medication. Examples of multiple options include PrEP medication, condoms, TasP. Staff described their Diverse is Safe initiative, which provides a diversity of approaches to stay safe. This was described as an effective way to market and promote PrEP. Their first conversation with consumers is about Diverse is Safe, where they sit down and discuss PrEP information and navigation. They also hold focus groups and conduct surveys in-person and online. They discuss condoms, TasP, PrEP, personal beliefs regarding health, linguistic needs, and cultural readiness.

When asked what populations are being left out of the PrEP equation or falling through the cracks, the heterosexual population, particularly the black/African American heterosexual population, was said to not receive attention by major media campaigns or publications. Latinos Salud promotional efforts include advertising on mobile phone apps, their website, print advertisements, and events (e.g., Pride, Diverse is Safe town halls).

PrEP was described as an “equalizer” among HIV sero-different consumers, and the strongest advocates for PrEP are HIV positive people who have been rejected by partners. Someone who is HIV negative taking the same medication/pill as someone who is HIV positive means “now people can’t say we’re different.”

PrEP as an “equalizer” among HIV sero-different consumers:
“Now people can’t say we’re different.”

Site 9 – Los Angeles, California

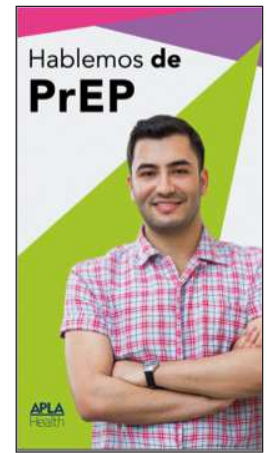
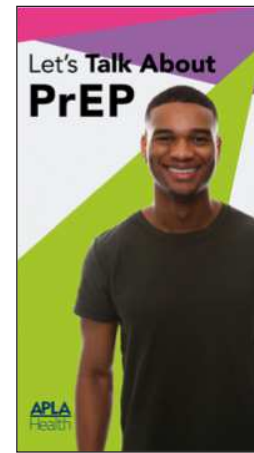
APLA Health (AIDS Project Los Angeles) provides primary care, dental, counseling, PrEP and PEP, HIV testing, STI/STD screening and treatment, insurance enrollment, HIV medical care, and vaccinations (APLA, 2017).

The APLA Health PrEP navigator provided an informant interview to describe APLA Health services and community needs. He described how there is stigma regarding PrEP within Los Angeles communities that they are addressing through education and materials. For example, they use “bullet” keychains (small plastic containers) for consumers to have something to place their pills in overnight. This is sometimes so that their friends will not know that they are using PrEP.



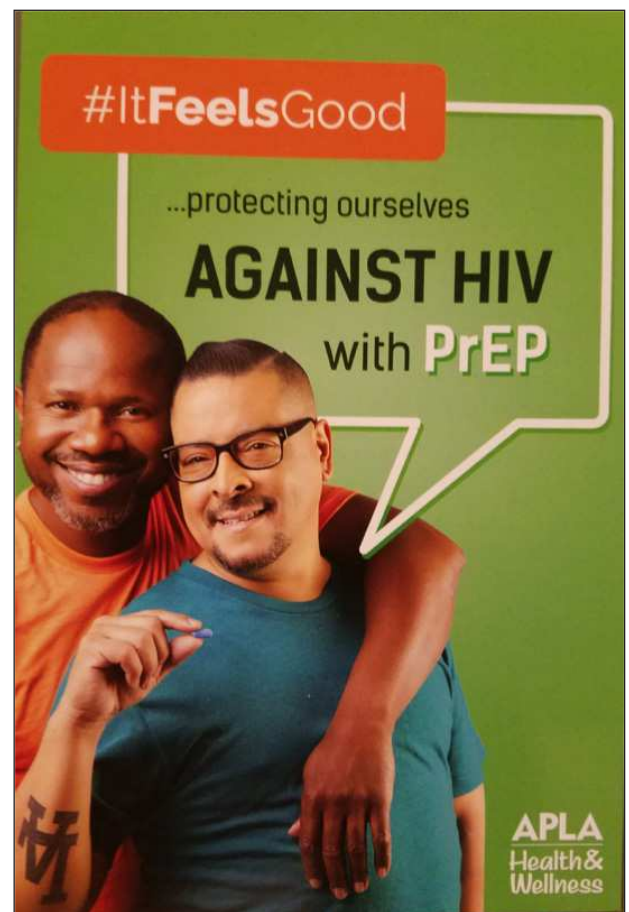
The PrEP navigator provided the following major steps for PrEP:

- (1) Education and linkage to PrEP;
- (2) Proof of residency (enrollment);
- (3) Speaking with a benefits specialist (for insurance billing);
- (4) Meeting with a provider who orders laboratory tests and writes a prescription for medication; and
- (5) For PAP, they can potentially expedite requests if there is something especially time sensitive (such as running out of pills).



The PrEP navigator also discussed the following considerations regarding the process of PrEP navigation:

- Consumers need a notarized letter of income to request PAP from the pharmaceutical company. This is challenging for people who are homeless or for sex workers. A notary is \$12, and people are making the choice between paying this \$12 and obtaining food.
- For consumers who are less than 26 years and are on their parent's health insurance plan, there are significant concerns regarding disclosure to their parents.
 - Similarly, if someone is on their partner's health insurance and does not want their partner to know they are on PrEP, there are significant concerns regarding disclosure to their partner.
- Consumers frequently ask "How long after I stop taking my PrEP medication will it still work?" They are monitoring the research and professional literature for the latest science regarding questions such as this.
- The \$75 co-payment required when a consumer's insurance is out of network was cited as a challenge for many consumers. If someone does not have insurance, then they assist with applying for MediCal (Medicaid).
- There are differences in how providers in Los Angeles provide access to PrEP.



Examples:

- There are delays that prevent same-day PrEP, such as providers waiting for laboratory processing (kidney, liver, and STD panels were cited).
- There was a provider who gave a consumer a prescription for a year with refills without doing any laboratory tests.
- A consumer reported disclosing to the doctor that this person was going to do sex work and wanted PrEP for protection, and this provider said to come back when doing sex work. Since it takes 7 to 21 days for the medication to go into effect depending on tissue/blood stream considerations, this was described as a challenge.

- Consumers have reported that their providers will not prescribe PrEP because they do not think that someone needs it.
- APLA Health uses its EHR system to flag PrEP candidates, such as a second time into the clinic with chlamydia or another STI/STD, in addition to someone who is frequently tested for STIs/STD.
- Risk is person-centered, where someone may not perceive that they are sexually active but may engage in receptive anal condomless sex once or twice per year receives the message that “HIV transmission takes only one time.”
- Taking PrEP was described as a “commitment,” since it involves ensuring stable employment and insurance coverage, that daily medication adherence, and appointment adherence (going to the MD for follow-up labs, etc.).

Men’s Health Foundation (MHF), located in Los Angeles, California, provided key informant interviews regarding PrEP and HIV navigation services. The mission of MHF is to “connect men at risk to comprehensive healthcare and wellness through education, partnerships and collaboration, inspiring and empowering all men to live longer healthier and happier lives” (MHF, 2017, p. 1). Clinic and research collaborators include Mills Clinical Research, led by Dr. Tony Mills. Successfully implementing over 100 clinical trials and conducting Phase I, II, III, and IV research studies, their expertise includes immunology, infectious disease, men’s health, and cardiovascular conditions. Serving over 15,000 consumers, MHF addresses the social determinants of men and transgender women’s health, especially focusing on young men of color, though programs that address racism, stigma, substance abuse, gender-based violence, homelessness, and homophobia.

Site 10 – San Francisco, California

Similar to New York City, San Francisco experiences challenges regarding residential affordability and gentrification. Within San Francisco, for example, several inner-city bridges have evidence of many people living underneath them (i.e., tent cities with trash, mattresses, and people seen sleeping). There are also long rows of mobile home campers parked at the edges of the city. According to a respondent from the San Francisco Department of Public Health, the African American male population in the city decreased significantly (from 14% to 4% of the total population) due to a host of challenges with employment, income, and residential affordability.



An interview participant from the **San Francisco AIDS Foundation (SFAF) Strut** program (Clinical and social services are provided at the Strut location on Castro Street in San Francisco, California) relayed that access to PrEP “follows the same disparities with HIV.” This was especially said to be the case for people of color and those with unstable housing. They have approximately 2,000 enrollees and operate programs that are funded by the San Francisco Department of Public Health and CDC, among others. SFAF provides walk-in consumer services that include free testing and treatment for HIV and sexually transmitted infections (STIs), medical services in

addition to PrEP and HIV counseling, PrEP benefits navigation, individual and group counseling for alcohol and use of other drugs, free condoms, care coordination for people living with HIV/AIDS, and syringe access (SFAF, 2017).

SFAF is operating a **San Francisco Department of Public Health** program in collaboration with community-based organizations that specifically focuses on Latino MSM, Black MSM, transgender people, and sex workers, and young MSM younger than age 24. Their approach is to use an ambassador model (i.e., Popular Opinion Leader), where peers from specific communities are trained to conduct outreach within their own communities. They also created a “Navigator Bootcamp” for different providers in the city (including prescribers). It was explained that people get lost on the insurance side when attempting to access PrEP. Many people do not realize that they are underinsured, so there is a need to provide continual training on different payment avenues/options.

SFAF provides same-day PrEP and does not base their approach to accessing PrEP on risk. For example, someone may identify as low risk, but their behaviors may indicate risk that they do not perceive (e.g., fewer sexual partners, same level of condom use). They use an intake form that includes a sexual health questionnaire, and counselors will address PrEP with consumers. They typically answer questions that consumers are not comfortable asking their medical providers, friends, etc.

Many MSM of color were said to know about PrEP, but are unsure that it can be covered/paid (e.g., they ask, “If cost is not an issue, would you be interested?” If the response is “Yes,” then they work to find a way). They want to ensure that there is the same level/access to care. For some consumers, there is pressure to be on PrEP, since it is reasoned that if someone is not on PrEP then they are not having sex. It was explained that the language used with consumers needs to be specific; for example, the term “unprotected sex” is really “condomless sex” since there are other ways to be protected (e.g., PrEP).

Among the transgender population, they provide education regarding questions about interactions with hormones. This population was described as not wanting to feel like guinea pigs. Other populations that were discussed included youth living on the streets and their need to have a safe place to store their medications (e.g., lockers). Undocumented individuals also fear going to the hospital or engaging with health providers. Sex workers, the unstably housed, and injection drug users are also provided with drop-in PrEP, which is needed because “if they have to wait two weeks for an appointment, then their priorities shift.”

Please PrEP Me is a PrEP program of the University of California San Francisco (UCSF) and includes collaborations between **Project Inform** and **HIVE**. Their locator is available at pleaseprepme.org. A PrEP Navigator explained how the program is linking to PrEP services through a statewide and national directory. They also offer a bilingual (English and Spanish) chat service, which provides a safe space for people who may not be comfortable approaching their regular medical provider about PrEP and who want a referral to a PrEP specialty provider. This service also helps people living in certain areas of California where they have to travel miles to a provider.

The greatest initial barrier for underserved communities to access PrEP was described as not knowing what to expect. There are also “many insurance- and medication assistance program- related questions,” such as cost and how to apply for assistance (e.g., “I don’t know what to ask?” “What do I say when I call?”). They establish a follow-up protocol and plan to address specific steps. For example, if a consumer is making an initial contact, they will ask questions such as, “Do you currently have a provider? Do you feel comfortable talking with your provider (which may be a family provider); Do you have insurance?” Some consumers were said to have “very high out-of-pocket deductibles” (e.g., \$6,500), and some have to wait to change their insurance. California has a statewide “PrEP-DAP” resource, which “layers on top of ADAP.”

The navigators of a current project are part of a Google Group where they share lessons learned, share tips on how to overcome barriers, and hold quarterly video conference calls. They are continually updating their website

with resources such as “things to print out and take to the doctor,” follow-up questions to ask, videos of people navigating, and special topics for women, transgender, “sero-different,” youth, and other populations. They are also creating a PrEP navigation manual, which will serve as a “101 manual for new staff.” It will include the following three main components, which will be refined through feedback from the field:

- (1) PrEP Research – Studies demonstrating effectiveness;
- (2) PrEP Care – Focusing on the process (e.g., assessing what to expect during clinic visits, laboratory testing, frequency, medical terminology); and
- (3) PrEP Navigation – Payer programs and healthcare system information.

The final major point that was raised during the key informant interviews in San Francisco was from Montica

Levy, the Citywide PrEP Coordinator at the City Clinic, Population Health Division of the **San Francisco Department of Public Health**, who provided permission to quote, “There is no reason that same-day PrEP could not be provided to all consumers, since all you really need is an HIV test.” All of the other laboratory tests can occur concurrently.

“There is no reason that same-day PrEP could not be provided to all consumers, since all you really need is an HIV test.”

- Montica Levy

DATA-DRIVEN RECOMMENDATIONS TO BUILD THE CAPACITY OF PREP AND HIV NAVIGATION PROGRAMS

The key findings and recommendations from this NMAC National PrEP and HIV Landscape Assessment provide a path forward for how funders, administrators, professionals, and advocates can support and develop PrEP and HIV navigation resources. Communities across the United States shared lessons learned from their local initiatives, programs, and services to inform the field.

Recommendations Based on the Navigator Needs & Resources Assessment & National Landscape Assessment Survey

- Since the promotion of navigation services are largely informal, one-on-one consumer discussions, and nearly half of respondents indicated that their navigation services are *Never* or *Rarely* promoted, organizations would greatly benefit from **capacity-building resources that provide a mix of successful and up-to-date print, online, and social/mobile media efforts**.
 - Since there are variations in how a potential consumer is identified as someone who could benefit from PrEP (i.e., nearly 1 out of 5 respondents rely on individuals to ask for PrEP, and over a third provide information about PrEP to certain consumers based on documented risk information), two-way messaging strategies can be added to expand capacity.
- While cultural competence skills were indicated by many respondents as a primary qualification for navigators, this was not a universal core requirement. Thus organizations would greatly benefit from **capacity-building resources that focus on cultural competence**, particularly for the many PrEP and HIV navigators that respondents indicated have *No Experience*, *Between 0-1 Year*, and *Between 1-2 Years*.
- Given the variation in how often navigators receive formal training updates (nearly 1 in 10 respondents indicating *Weekly* and nearly half each indicating *Monthly* and *Annually*), organizations would greatly benefit from **a mix of capacity-building resources that provide more frequent brief updates with in-depth semi-annual state-of-the-field summaries**.
- Since peer engagement (i.e., a person who uses his or her lived experience related to HIV, plus skills learned in formal training, to deliver services) is a recurring need in the field and nearly a third of respondents indicated that they do not use peer navigators, organizations would greatly benefit from **capacity-building resources that focus on how to develop peer engagement**.
 - Since respondents indicated that employed peers are underused to **assist with PrEP and ART medication follow-up**, this component can be added to expand capacity.
- While respondents indicated that much of the emphasis of navigators' core job duties and responsibilities is on linkage (i.e., to medical and social support services), PrEP and HIV navigators are less engaged in community-based outreach, HIV testing, and medication adherence. Organizations would greatly benefit from **capacity-building resources that focus on stage-based approaches across the PrEP/HIV care continuum**.
- Given the many types of barriers to PrEP and HIV navigation that consumers experience, in addition to the specific steps that are needed to connect with consumers who disengage with PrEP/HIV navigator services or are "lost to care" (e.g., miss appointments), organizations would greatly benefit from **capacity-building resources that focus on how to prevent disengagement and monitor the effectiveness of follow-up methods**.
 - Since there are wide variations in whether (or when) a consumer's PrEP and HIV navigation case/file is suspended (e.g., marked inactive or closed) after a period of time without any contact, case-load management best practices are needed as a component of capacity-building.
 - Given the variation in the frequency and timing of follow up regarding PrEP medication adherence (e.g.,

“never,” “weekly,” “monthly depending on insurance,” “every 3 months,” “no specific timeline created yet”), best practices for follow up are needed as a component of capacity-building.

- Additional priority training, technical assistance, and **capacity-building topics/resources that would be helpful for PrEP Navigators** include:
 - Consumer/provider communication/education regarding PrEP;
 - How to conduct outreach/engagement with diverse populations; and
 - Training/updates for new navigators.
- Additional priority training, technical assistance, and **capacity-building topics/resources that would be helpful for HIV navigators** include:
 - How to conduct outreach/engagement with diverse populations;
 - How to best use reliable, evidence-based resources; and
 - How to evaluate navigation programs.

Recommendations Based on Site Visits and Key Informant Interview Recommendations

- Since many training resources are “home grown” to meet the immediate needs of local projects and funder requirements, there is a need to **organize and share these resources** so that they are accessible, timely, and relevant to multiple organizations and programs.
- Since providers cited encountering distrust, stigma, and gaps in awareness and uptake of PrEP and ART—particularly among minority and underserved communities—**consumer focus groups** would inform provider strategies to address consumer needs and overcome challenges.
 - Consumer focus groups would identify ways to motivate consumers, change behaviors (according to the stages of change), and develop messages that are relevant to minority and underserved communities regarding how to best provide inclusive and welcoming services.
- Providers cited the need to balance narrow (e.g., PrEP for specific populations) versus broad (e.g., PrEP as part of community health and wellness) messaging and promotion strategies based on lessons learned regarding specific languages and cultural influences. Organizations would greatly benefit from **further examples of promotional efforts and materials** that have worked well and not worked well for their particular communities.
 - For example, there are multiple give-away items such as push cards, pill container key chains, timers on pill bottles, wrist bands, chap-stick, water bottles, lanyards, t-shirts, stickers, magnets, condoms, and other items that are widely distributed at agency locations and promotional events (health fairs, Pride parades, HIV testing events, etc.), in addition to major media market placement (e.g., billboards; taxi, bus, subway advertisements) that serve to raise awareness among a broad audience. Community-based organizations use these materials selectively either to develop new, “home grown” messaging or as part of their overall messaging.
- Several providers noted that they are primarily focusing on uptake and new consumer engagement; others cite high rates of disengagement (medication discontinuation, missed appointments, etc.) in addition to inconsistent/non-existent follow-up monitoring/tracking. Organizations would greatly benefit from **capacity-building resources regarding successful adherence methods and how to best evaluate follow up and reengagement of consumers who are lost to care**.
 - Organizations would also greatly benefit from capacity-building resources for navigators regarding analytics support (e.g., GIS mapping HIV incidence/prevalence with PrEP outreach and uptake).

APPENDIX A: DATA COLLECTION INSTRUMENTS

NHPS Navigator Needs & Resources Survey

Organization Information

Organization Name:	
Zip Code	
Minority-led?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Types of HIV related services offered:	<input type="checkbox"/> HIV prevention <input type="checkbox"/> HIV testing <input type="checkbox"/> Linkage into HIV medical care <input type="checkbox"/> HIV medical treatment <input type="checkbox"/> HIV medical adherence <input type="checkbox"/> HIV case management <input type="checkbox"/> Behavioral Health <input type="checkbox"/> Support services (please specify:) _____ _____ _____
Population of focus (Target population):	<input type="checkbox"/> African American <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> White (non-Hispanic) <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Native Hawaiian/Other Pacific Islander <input type="checkbox"/> Two or more races <input type="checkbox"/> Other: _____
Total number of staff:	
Number of consumers on HIV antiretroviral therapy (ART):	
Number of consumers on PrEP:	

Organization Information Re: Navigator Capacity

Does your organization employ an HIV Navigator who helps to recruit, link and retain consumers in HIV treatment, care and HIV biomedical interventions?

- ☐ Yes
- ☐ No
- ☐ Don't know

**If Yes,
How many HIV Navigators do you employ? _____**

Does your organization employ a PrEP Navigator who helps to connect consumers to PrEP counseling, treatment, or other supports?

- ☐ Yes
- ☐ No
- ☐ Don't know

**If Yes,
How many PrEP Navigators do you employ? _____**

Does your organization employ another type of Navigator who helps to connect consumers to services?

- ☐ Yes
- ☐ No
- ☐ Don't know

**If Yes,
How many of these other types of Navigators do you employ? _____**

May we please contact you or a member of your staff for more information?

- ☐ Yes
- ☐ No

Staff contact information:

Name: _____

Email: _____

Phone: _____

National PrEP and HIV Landscape Survey

Organization Information

Organization Name:	
Zip Code	
Minority-led?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Types of HIV related services offered:	<input type="checkbox"/> HIV prevention <input type="checkbox"/> HIV testing <input type="checkbox"/> Linkage into HIV medical care <input type="checkbox"/> HIV medical treatment <input type="checkbox"/> HIV medical adherence <input type="checkbox"/> HIV case management <input type="checkbox"/> Behavioral Health <input type="checkbox"/> Support services (please specify:) _____ _____ _____
Population of focus (Target population):	<input type="checkbox"/> African American <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> White (non-Hispanic) <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Native Hawaiian/Other Pacific Islander <input type="checkbox"/> Two or more races <input type="checkbox"/> Other: _____
Total number of staff:	
Number of consumers on HIV antiretroviral therapy (ART):	
Number of consumers on PrEP:	

#. Does your organization have the capability to generate patient education materials from an Electronic Medical Record (EMR) system?

- ☐ Yes
☐ No

Organization Information Re: Navigator Capacity

Does your organization employ an HIV Navigator who helps to recruit, link and retain consumers in HIV treatment, care and HIV biomedical interventions?

- ☐ Yes
- ☐ No
- ☐ Don't know

**If Yes,
How many HIV Navigators do you employ? _____**

If Yes, are these HIV Navigators known by any of the following titles within your organization?

- ☐ Case Managers
- ☐ Care Coordinators
- ☐ Community Health Workers
- ☐ Patient Navigators
- ☐ Peer Navigators
- ☐ Promotoras
- ☐ Other (please specify):_____

Does your organization employ a PrEP Navigator who helps to connect consumers to PrEP counseling, treatment, or other supports?

- ☐ Yes
- ☐ No
- ☐ Don't know

**If Yes,
How many PrEP Navigators do you employ? _____**

If Yes, are these HIV Navigators known by any of the following titles within your organization?

- ☐ Case Managers
- ☐ Care Coordinators
- ☐ Community Health Workers
- ☐ Patient Navigators
- ☐ Peer Navigators
- ☐ Promotoras
- ☐ Other (please specify):_____

Does your organization employ another type of Navigator who helps to connect consumers to services?

- ☐ Yes
☐ No
☐ Don't know

**If Yes,
How many of these other types of Navigators do you employ? ____**

If Yes, are these HIV Navigators known by any of the following titles within your organization?

- ☐ Case Managers
☐ Care Coordinators
☐ Community Health Workers
☐ Patient Navigators
☐ Peer Navigators
☐ Promotoras
☐ Other (please specify):_____

Navigator Demographics

#. From the following list, please indicate the primary demographic profile of your organization's Navigators:
(please select all that apply)

<i>By Age</i>	<i>By Gender</i>
<input type="checkbox"/> 18 to 24 <input type="checkbox"/> 25 to 29 <input type="checkbox"/> 30 to 39 <input type="checkbox"/> 40 to 49 <input type="checkbox"/> 50 to 59 <input type="checkbox"/> 60+	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender
<i>By Race/Ethnicity</i>	<i>By Sexual Orientation/Identity</i>
<input type="checkbox"/> African American <input type="checkbox"/> American Indian/Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> White (non-Hispanic) <input type="checkbox"/> Hispanic or Latino <input type="checkbox"/> Native Hawaiian/Other Pacific Islander	<input type="checkbox"/> Heterosexual <input type="checkbox"/> Gay <input type="checkbox"/> Lesbian <input type="checkbox"/> Bisexual
<input type="checkbox"/> Other (please specify):_____	

#. Do you use Peer Navigators (defined as “a person who uses his or her lived experience related to HIV, plus skills learned in formal training, to deliver services”)?

- ☐ Yes
☐ No

Navigator Qualifications

#. Please indicate the minimum experience that Navigators are required to have:

- ☐ No experience
☐ Between 0 to 1 year
☐ Between 1 to 2 years
☐ Between 2 to 5 years
☐ Greater than 5 years

#. Please indicate the minimum education that Navigators are required to have:

- ☐ High school graduate/GED
☐ Some college, no degree
☐ Associate's degree
☐ Bachelor's degree
☐ Master's degree
☐ Other (please specify): _____

#. Are there other trainings or certifications that Navigators are required to have?
(e.g., Certified Application Counselor, HIV testing)

- ☐ Yes (If Yes, please specify): _____
☐ No

#. From the following list, please indicate the types of skills that Navigators are required to have?

- ☐ Cultural competence working with specific populations (e.g., racial/ethnic minorities, MSM, etc.)
☐ Bi-lingual fluency (e.g., proficiency communicating in English and another language)
☐ Referrals and other linkages with local health and human services organizations
☐ Third-party billing
☐ Other (please specify): _____

Navigator Job Duties & Responsibilities

#. From the following list, please check the core job duties & responsibilities that Navigators perform:

(please select all that apply)

- ☐ Community-based outreach
- ☐ HIV testing
- ☐ Medication adherence education
- ☐ Linkage to medical services
- ☐ Linkage to other social support services
- ☐ Other (please specify): _____

#. Is there a specific carve-out of time (% FTE or # of hours per week) for Navigators to focus on PrEP?

- ☐ Yes
- ☐ No

Navigation Practices

#. From the following list, please indicate how someone who is served by your organization is specifically identified as someone who would likely benefit from PrEP?

- ☐ Individuals ask for PrEP
- ☐ Staff provide information about PrEP to everyone
- ☐ Staff provide information about PrEP to certain consumers based on documented risk information
- ☐ Other (please specify): _____

#. After someone is identified as someone who would likely benefit from PrEP, what is the immediate next step for this person?

#. After a consumer starts taking PrEP medication, how often does follow-up occur regarding medication adherence?

- ☐ One or more times per week
- ☐ One or more times every other week
- ☐ One or more times per month
- ☐ Other (please specify): _____

Navigator Training & Sources of Information

#. From the following list, please check the top 4 formats that Navigators use to receive educational information regarding PrEP?

Print Materials

- ☐ Newsletter
- ☐ Monograph
- ☐ Peer reviewed journal

In-person training

- ☐ Local workshop/workgroup
- ☐ Local or national professional conference

Online/Digital Sources

- ☐ Email updates
- ☐ Webinar/webcast
- ☐ Other (please specify): _____

#. How often do Navigators receive formal training updates?

- ☐ Weekly
- ☐ Monthly
- ☐ Annually
- ☐ Other (please specify): _____

Navigator Challenges & Needs

#. From the following list, please indicate the barriers for consumers to receive PrEP Navigation services:
(please select all that apply)

- ☐ Lack of money
- ☐ Homelessness
- ☐ Immigration
- ☐ Incarceration
- ☐ Drug use
- ☐ Stigma
- ☐ Mistrust of the medical system
- ☐ Lack of perceived need
- ☐ Language
- ☐ Transportation
- ☐ Other (please specify): _____

#. Please estimate the overall percent (%) of consumers who begin services but then completely disengage with services or are “lost to care” (i.e., are never connected with again)

_____ %

#. From the following list, please indicate any steps that are taken to connect with consumers who disengage with services or are “lost to care” (e.g., miss appointments)

(please select all that apply)

- ☐ A phone call is made to the consumer
- ☐ A phone call is made to an alternate/emergency contact person
- ☐ A postcard or letter is sent to the consumer
- ☐ A text message, email, or other online communication (e.g., social media message) is sent to the consumer
- ☐ Local detention center (jails, prisons) are checked
- ☐ A social services network is checked
- ☐ Other (please specify): _____

#. After a period of time without any contact with a consumer, is their case/file either suspended (e.g., marked inactive) or closed?

- ☐ Yes
- ☐ No

If Yes,

#. What timeframe is typically used to suspend or close a case/file?

- ☐ After 1 month
- ☐ After 3 months
- ☐ After 6 months
- ☐ After 9 months
- ☐ After 1 year
- ☐ Other (please specify): _____

#. What training, technical assistance, or capacity-building topics/resources would be helpful for Navigators?

- ☐ Outreach and engagement with diverse populations
- ☐ Consumer/Provider communication and education regarding PrEP
- ☐ Health systems navigation
- ☐ Other (please specify): _____

PrEP Client Profile

#. From the following list, please indicate the primary populations that receive PrEP Navigation services:

(please select all that apply)

<i>By Age</i>	<i>By Gender</i>
<input type="checkbox"/> Youth	<input type="checkbox"/> Male
<input type="checkbox"/> Adults	<input type="checkbox"/> Female
<input type="checkbox"/> Seniors	<input type="checkbox"/> Transgender
<i>By Race/Ethnicity</i>	<i>By Sexual Orientation/Identity</i>
<input type="checkbox"/> African American	<input type="checkbox"/> Heterosexual
<input type="checkbox"/> American Indian/Alaska Native	<input type="checkbox"/> Gay
<input type="checkbox"/> Asian	<input type="checkbox"/> Lesbian
<input type="checkbox"/> White (non-Hispanic)	<input type="checkbox"/> Bisexual
<input type="checkbox"/> Hispanic or Latino	
<input type="checkbox"/> Native Hawaiian/Other Pacific Islander	
<input type="checkbox"/> Other (please specify): _____	

PrEP Promotion Activities

#. From the following list, please indicate how PrEP navigation services are promoted?

- ☐ One-on-one consumer discussions
- ☐ Group discussions
- ☐ Website
- ☐ Social media
- ☐ Printed materials (e.g., flyers, posters)
- ☐ Email announcements
- ☐ Other (please specify): _____

#. How often does your organization promote PrEP navigation services?

- ☐ Never
- ☐ Rarely
- ☐ Occasionally
- ☐ Frequently
- ☐ Very frequently

#. From the following list, please indicate where your organization promotes PrEP navigation services?

- ☐ Common areas within our organization (e.g., waiting area, hallways)
- ☐ Outside of our organization at community events (e.g., Health Fairs, social events)
- ☐ Outside of our organization at community organizations
- ☐ Online (e.g., website, social media)
- ☐ Other (please specify): _____

APPENDIX B: RECOMMENDED RESOURCES

The following core information resources are recommended for PrEP navigator orientation and the development of basic to intermediate service guides (please note that exact web addresses can change):

AIDSinfo

<http://AIDSinfo.nih.gov>

AVAC, Global Advocacy for HIV Prevention: PrEP

<http://www.avac.org/prevention-option/prep>

AVERT: Averting HIV and AIDS: What is PrEP?

<https://www.avert.org/hiv-transmission-prevention/prep>

The Body: HIV Prevention Resource Center: Pre-exposure Prophylaxis (PrEP)

<http://www.thebody.com/content/72493/pre-exposure-prophylaxis-prep.html>

Capacity Building Assistance (CBA) Provider Network

<http://www.cbaproviders.org>

Centers for Disease Control and Prevention (CDC)

<https://www.cdc.gov/hiv/basics/prep>

<http://www.cdc.gov/hiv/research/interventionresearch/compendium/index.html>

Gilead: Medical Assistance Program

<https://start.truvada.com/paying-for-truvada>

Greater than AIDS: Let's Talk about PrEP

<https://www.greaterthan.org/lets-talk-about-prep/>

Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB): TARGET Center (Technical Assistance Resources, Guidance, Education & Training): Ryan White HIV/AIDS Program and PrEP

<https://careacttarget.org/library/ryan-white-hivaids-program-and-prep>

HIV.gov: PrEP

<https://www.aids.gov/hiv-aids-basics/prevention/reduct-your-risk/pre-exposure>

My Brother's Keeper (MBK)

<http://mbkinc.org>

National HIV PrEP Summit (NMACC)

<http://hivprepsummit.org>

National Library of Medicine: HIV Prevention: PEP/PrEP

<https://aids.nlm.nih.gov/topic/1173/prevention/2015/pep-prep>

National Center for Biotechnology Information (NCBI). HIV PrEP Trials:

The Road to Success

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3882078/>

Patient Advocacy Foundation: Copay Relief Program

<https://www.copays.org/diseases/hiv-aids-and-prevention>

Please PrEP Me

<https://pleaseprepme.org>

POZ: HIV Prevention: PEP and PrEP

<https://www.poz.com/basics/hiv-basics/pep-prep>

PrEP Locator (Emory University)

<https://preplocator.org>

<https://www.greaterthan.org/get-prep/>

Prevent HIV: Pre-Exposure Prophylaxis

<https://www.preventhiv.com/comprehensive-prevention-strategies>

Project INFORM: PrEP (Pre-Exposure Prophylaxis)

<https://www.projectinform.org/prep/>

Substance Abuse and Mental Health Services Administration (SAMHSA): HIV, AIDS, and Viral Hepatitis

<https://www.samhsa.gov/hiv-aids-viral-hepatitis>

World Health Organization, HIV/AIDS 2016 Guidelines

www.who.int/hiv/pub/guidelines

The following organizational links provide information regarding PrEP and HIV navigation services (please note that exact web addresses can change):

AIDS Foundation Houston

Houston, TX

<https://www.aidshep.org>

AIDSource

<https://aids.nlm.nih.gov/>

AIDS Project Los Angeles

Los Angeles, CA

<https://aplahealth.org>

Baltimore City Health Department

Baltimore, MD

<http://health.baltimorecity.gov>

Brother's Health Collective

Chicago, IL

<http://www.4mybrothers.org>

Callen Lorde Community Health Center
New York City, NY

<http://callen-lorde.org>

Care Resource
Ft. Lauderdale/Miami, FL

<http://www.careresource.org>

Center for Health & Behavioral Training
Rochester, NY

<http://www.chbt.org>

Center of Excellence for Transgender Health
University of California San Francisco

<http://transhealth.ucsf.edu>

Department of Public Health
Commonwealth of Massachusetts

<http://www.mass.gov/eohhs/gov/departments/dph/>

HIPS
Washington, DC

<http://www.hips.org>

HIVE (University of California San Francisco)
San Francisco, CA

<https://www.hiveonline.org>

Houston Health Department
Houston, TX

<http://www.houstontx.gov/health/>

Howard University Hospital
Washington, DC

<http://huhealthcare.com/healthcare/hospital>

Latinos Salud
Wilton Manors, FL

<http://www.latinossalud.org>

Men's Health Foundation
Los Angeles, CA

<http://mhfoundation.org>

Metro Wellness & Community Centers
Tampa, FL

<https://www.metrotampabay.org>

Mount Sinai Health System
New York City, NY

<http://www.mountsinai.org>

My Brother's Keeper, Inc.
Jackson, MS

<http://mbkinc.org>

National AIDS Housing Coalition (NAHC)
Washington, DC

<http://nationalaidshousing.org/>

New Jersey Department of Health
Trenton, New Jersey

<http://www.nj.gov/health/>

Open Arms Healthcare Center
Jackson, MS

<http://oahcc.org>

Open Health Care Clinic
Baton Rouge, LA

<http://www.ohcc.org>

Patient Access Network (PAN) Foundation
Washington, DC

<https://panfoundation.org>

Project Inform

<https://www.projectinform.org>

San Francisco AIDS Foundation/Strut
San Francisco, CA

<http://sfaf.org>

<http://strutsf.org>

San Francisco Department of Public Health

<https://www.sfdph.org/dph/default.asp>

Thomas Street Health Clinic (TSHC)
Houston, TX

<https://www.harrishealth.org>

University of California San Francisco (UCSF) - HIVE

<https://www.hiveonline.org>

Women's Collective
Washington, DC

<http://womenscollective.org>

APPENDIX C: MEDIA AND PROMOTIONS EXAMPLES

The following data illustrate the major media markets where PrEP was promoted within the past 12 months, according to the NewsBank, Inc. *Access World News* database:



Access World News
 Explore news articles from 1978 - Current [overview of content](#)

New Search

All Text ▾

PrEP

AND ▾

Date(s) ▾

past 12 months

AND ▾

All Text ▾

HIV

Add Row

Remove Row

Sort by:

Most recent matches first ▾

search

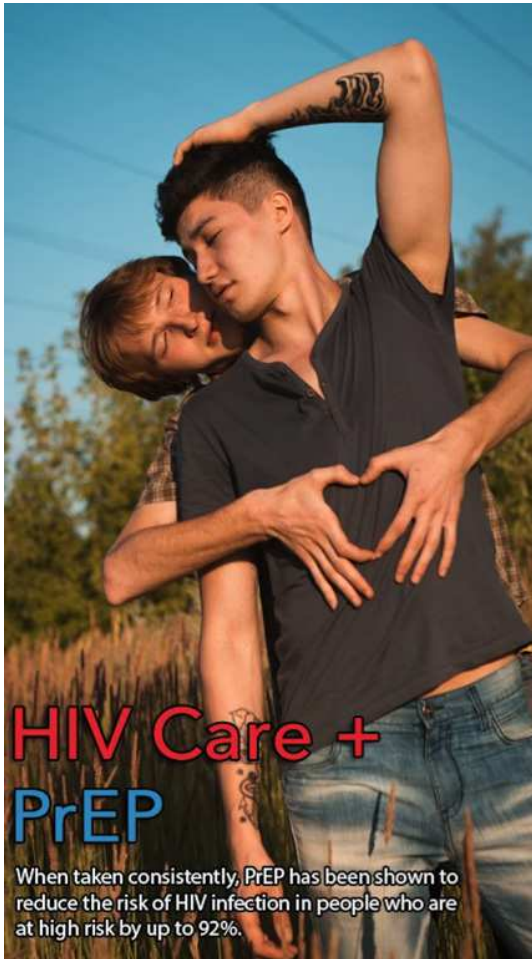
Filter Regions below

Region	States	Results
USA - East North Central	IL, IN, MI, OH, WI	46
USA - East South Central	AL, KY, MS, TN	18
USA - Middle Atlantic	NJ, NY, PA	117
USA - Mountain	AZ, CO, ID, MT, NM, NV, UT, WY	20
USA - New England	CT, MA, ME, NH, RI, VT	15
USA - Pacific	AK, CA, HI, OR, WA	49
USA - South Atlantic	DC, DE, FL, GA, MD, NC, SC, VA, WV	76
USA - West North Central	IA, KS, MN, MO, ND, NE, SD	9
USA - West South Central	AR, LA, OK, TX	18

9 Regions, listing 1 to 9



In addition to major media markets, community-based organizations provide a large amount of promotional events and materials. Several examples are provided on the following pages:



As women, it is important to have an HIV prevention method that is in our hands.

Consider PrEP if you are a woman who:

- Worries about her HIV risk
- Has condomless sex with partners of unknown HIV status
- Recently had gonorrhea or syphilis
- Wants to have a baby with a man living with HIV
- Injects drugs
- Exchanges sex for \$/food/housing/drugs

has a male sex partner who:

- Has condomless sex with others
- Has sex with men
- Injects drugs
- Has HIV or sexually transmitted infections

contact@pleasepreme.org



PrEP and Trans / Gender Non-Conforming People

WHAT YOU
SHOULD KNOW

CALLEN LORDE
COMMUNITY HEALTH CENTER

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