Recommendations for Providing Health Care Services to People Living with HIV within the Alaska Tribal Health System

ALASKA NATIVE
TRIBAL HEALTH
CONSORTIUM

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Acknowledgement

We dedicate this report to all Alaska Native peoples living with HIV. We would like to thank the Steering Committee for their involvement in implementing the Alaska Native HIV Stigma Project and contributions to developing recommendations for this report based on the study findings. This report would not have been possible without their support and assistance. We are especially grateful to our study participants who shared their experiences of living with HIV, to the Alaska Native Tribal Health Consortium's Early Intervention Services Consumer Advisory Board, as well to those who shared their experiences of providing services to Alaska Native peoples living with HIV in the Alaska Tribal Health System (ATHS).

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Acronyms

AIDS – Acquired Immunodeficieny Syndrome
AN/AI – Alaska Native and American Indian peoples
ATHS – Alaska Tribal Health System
CDC – Centers for Disease Control
GNP+ – Global Network of People Living with HIV
HIV – Human Immunodeficiency Virus
MSM – Men who have sex with Men
PrEP - Pre-Exposure Prophylaxis
PEP – Occupational Post-Exposure Prophylaxis
nPEP – Non-Occupational Post-Exposure Prophylaxis
PLWH – People Living with HIV
PWUD – People Who Use Drugs
STI – Sexually Transmitted Infections
U=U – Undetectable equals Untransmittable
UVL – Undetectable Viral Load
2SLGBTQIA+ – Two Spirit, Lesbian, Gay, Bisexual, Transgender, Questioning, Intersexual or Asexual

Introduction

After almost 40 years, the HIV epidemic continues to be a serious public health challenge in the United States. Despite advances over the past four decades, progress in reducing new HIV infection has slowed to about 38,000 new infections a year throughout the US between 2014 and 2018.[4] By comparison, 41,113 people were infected with HIV in 2000, indicating that the annual incidence of HIV has remained fairly steady in the US.[19] The national goal is to reduce the number of new HIV infections by 75% by 2025 (<10,000 annually) and by 90% (<4000 annually) by 2030.[18] The Alaska Department of Health and Social Services (DHSS) Epidemiology Section reported 1,294 cases of HIV first diagnosed in Alaska between January 1, 1982 and December 31, 2020. During 2020, 68 cases of HIV infection were reported to the Section of Epidemiology, 30 (44%) of which were initially diagnosed in Alaska, yielding a 2020 statewide incidence rate of four cases per 100,000 persons.[5] Among all newly diagnosed cases, 57% resided in southcentral, 20% in southwest, 10% in Interior, 10% on the Gulf Coast and 3% in southeast Alaska. Based on annual infectious disease data available through the State of Alaska Epidemiology section, the proportion of newly diagnosed persons with HIV who are AN/AI has been increasing over the past several years from 21% in 2012, to 45% in 2016 and 2017 and 43% in 2020.[5]

The HIV National Strategic Plan for the United States: A Roadmap to End the HIV Epidemic (2021-2025) identifies "stigma, discrimination, medical mistrust, safety and lack of access to mental health care" as barriers to seeking HIV services.[4] Goal 3.1 of this strategic plan is to reduce HIV-related stigma and discrimination and identifies "addressing stigma, discrimination and other social and structural determinants of health that inhibit HIV prevention, testing and care" as one of five key areas of focus. A core indicator in the strategy is to decrease stigma among people living with HIV by 50%. One way to meet this goal is to ensure that health care services are delivered in an inclusive and respectful manner.

The Centers for Disease Control and Prevention (CDC) also reports that HIV-related stigma is associated with decreased: HIV testing, condom use, Pre-Exposure Prophylaxis (PrEP) updates, medication adherence, linkage to care and retention in care.[6] While patient perspectives of stigma have been studied extensively,[7,8] studies of provider perspectives are limited.[9,10] A recent publication systematically reviewed HIV-related stigma by health care providers in the United States and found only six out of 619 articles met certain inclusion criteria. The main findings included 1. Provider attitudes, beliefs and behaviors associated with HIV-related stigma, such as homophobia, transphobia, and racism [9,11–15]; 2. Diminished quality of patient care [11–13]; and 3. Lack of education and training – providers with limited HIV-related stigma training were more likely to show stigmatizing behaviors towards patients.[11,13] The authors suggest that increasing health care provider awareness of clinical policies that address HIV-related stigma are important in achieving national HIV prevention and care goals and ultimately ending the HIV epidemic.

Within the Alaska Tribal Health System (ATHS), the Ryan White Part C Early Intervention Services (EIS) Program provides clinical care to AN/AI People living with HIV in urban and rural Alaska. Under this program, ANTHC has provided HIV-related specialty clinical care, medical case management, care coordination, and psychosocial support since 2002. EIS provides direct clinical care through the Alaska Native Medical Center's Internal Medicine Clinic, field clinics, and video telemedicine appointments. EIS clinical providers are available for consultation from any provider statewide, and often present training sessions regarding HIV care, treatment, and prevention to providers across the state. The EIS team provides outreach, one-on-one prevention counseling and linkage to care for HIV-positive individuals and HIV prevention services to those at risk of transmitting or acquiring HIV infection. There is a close working relationship between the State of Alaska's Epidemiology Disease Investigation Services and ANTHC EIS staff to transition new HIV diagnoses into care with the EIS program. Likewise, various HIV service providers collaborate extremely well in Alaska. Rural providers know to contact ANTHC EIS for recommendations and referrals. The EIS team also provides field clinics in the Tribal Health Organizations' hub clinics and maintains contact with patients via phone or text to keep them engaged and allow early identification of adherence or other issues. Through these efforts, viral suppression rates of AN/AI people living with HIV who receive services through EIS have increased significantly.[23]

Study Objectives

The overall goal of this study was to develop recommendations to create a safe, supportive health care environment for AN/AI people living with HIV.

Methodology

Ethical Approvals

The Alaska Institutional Review Board reviewed and approved the study protocols (AAIRB #2020-02-012 and AAIRB #2021-03-013). The Alaska Native Tribal Health Consortium, Southcentral Foundation, Bristol Bay Area Health Corporation, Yukon Kuskokwim and Southeast Alaska Regional Health Consortium approved the study.

Study Design

The study consisted of two cross-sectional electronic quantitative surveys. One focused on AN/AI PLWH and one focused on health care facility staff and providers. We adapted the People Living with HIV Global Stigma Index ("Stigma Index") survey to fit the local context. The survey was developed and validated by GNP+ and the International Community of Women Living with HIV or AIDS. It was first launched as a tool to measure the extent of stigma and discrimination experienced by PLWH in 2008.[16] More than 100 countries have implemented the Stigma Index survey, but this is the first time it was focused on an Indigenous population. The survey is divided into eight main sections: 1) demographics; 2) experience of disclosure; 3) experience of stigma and discrimination; 4) internalized stigma and resilience; 5) interactions with health care services; 6) experiences of human rights abuse; 7) experience of stigma and discrimination not related to HIV status; and 8) further experiences of stigma and discrimination. One of the core principles of the survey is community engagement to empower AN/AI PLWH, their networks and local communities. This includes involving PLWH in the research process, including administering surveys.

We utilized the Health Policy Project questionnaire to collect information about health care facility-based experiences. The questionnaire is a globally tested tool for measuring HIV-related stigma and discrimination in health facilities. We adapted the survey to document barriers as well as health care provider and staff experiences at facilities within the ATHS. The survey contains four domains that are especially relevant to stigma and discrimination in health care settings: 1) fear of HIV infection among health facility staff; 2) stereotypes and prejudice related to people living with or thought to be living with HIV; 3) observed and secondary stigma and discrimination; and 4) policy and work environment.[16]

Community Engagement

The study has been guided by a steering committee that includes HIV service providers and prevention specialists, allies and advocates throughout the state of Alaska with significant experience and understanding of the needs of people living with HIV. The committee has provided guidance and feedback throughout the study process. Key tasks of the committee included: 1) recommendations for adapting the survey to reflect local and cultural context of AN/AI PLWH; 2) recommendations on study design; 3) reviewing preliminary results; and 4) assistance in drafting recommendations based on the findings.

Additionally, members of the EIS Ryan White Part C Consumer Advisory Board (CAB) provided input and suggestions for cultural appropriateness, readability and understandability of the People Living with HIV Global Stigma Index survey. The CAB is composed of AN/AI consumers of services of the EIS clinic with the purpose of providing feedback and suggestions for improvement regarding all EIS operations. The onset of the COVID-19 pandemic significantly delayed the study and impacted efforts to continuously engage AN/AI PLWH. As a result, we were not able to adequately train AN/AI PLWH to administer the People Living with HIV Global Stigma Index survey and had to rely on study staff instead. However, this study has provided an opportunity to gain experience and best practices to work in partnership with AN/AI PLWH.

Eligibility criteria

People living with HIV with the following criteria were eligible to participate:

- Receiving care through the ANTHC EIS
- 18 years or older
- Living with HIV for at least 12 months
- English speaking

Study population

At the time of sampling, the ANTHC EIS served approximately 223 AN/AI PLWH from across Alaska. We had 21% participation from the total 223 people (48 surveys collected). The COVID-19 pandemic and resulting challenges in recruitment and data collection, such as restrictions on travel and in-person gatherings impacted our overall participation rates. Thus, the study sample may not reflect experiences and perception of the overall population of AN/AI PLWH in Alaska.

Confidentiality

To ensure confidentiality, each participant received a unique study ID, and we did not collect any identifiable information. All data were stored in a confidential database with restricted access.

Study procedures and data collection

Recruitment of participants occurred in collaboration with EIS staff. For eligible participants, clinic staff 1) introduced the possibility of the study using a standard script and asked if study staff may contact the patient, or 2) provided the approved recruitment flyer and asked them to contact the study staff if interested in participating. Clinic staff also distributed recruitment flyers to the Community Advisory Board (CAB) members. All data collection occurred in a private and safe location agreed upon by participants, and all participants provided electronic consent prior to completing the survey. Study staff and participants went through the survey questions together on a digital device. All responses were directly recorded using a secure and HIPPA compliant online database called REDCap. Participants received a $50 Visa Gift card as a thank you for their time. Due to the COVID-10 pandemic, there were delays in data collection. As a result, data collection occurred between July and December 2022.

Data analysis

We performed descriptive statistical analysis. Results are presented as proportions. Answers to demographic variables including age, sexuality, and time of diagnosis were categorized. Responses to Likert-type disclosure questions were dichotomized into those that answered “agree” and somewhat agree” versus “disagree”. Responses to HIV-related stigma and discrimination, abuses of rights, and stigma and discrimination experiences were dichotomized into those who answered, “yes within the last 12 months” and “yes, but not within the last 12 months” versus “no.”

Limitations

The study provides an understanding of experiences from the perspectives of AN/AI PLWH. However, it has several limitations. Due to the small number of participants, we are not able to explore differences in experience between urban and rural individuals. Most participants were recruited in Anchorage and although there is significant migration from rural to urban areas in Alaska, the sample is not representative of all AN/AI PLWH in Alaska nor generalizable to all AN/AI PLWH’s experiences in urban and rural health care settings. Participant recruitment was through the ANTHC EIS, rather than random selection, and represents individuals who were engaged in care and receiving support at the time of their participation. Although we adapted the People Living with HIV Global Stigma Index survey to better align with the local context, the questions are primarily quantitative in nature and could not adequately capture the many diverse experiences of participants. Any future study should focus on collecting qualitative data to gather stories in more depth.

Results

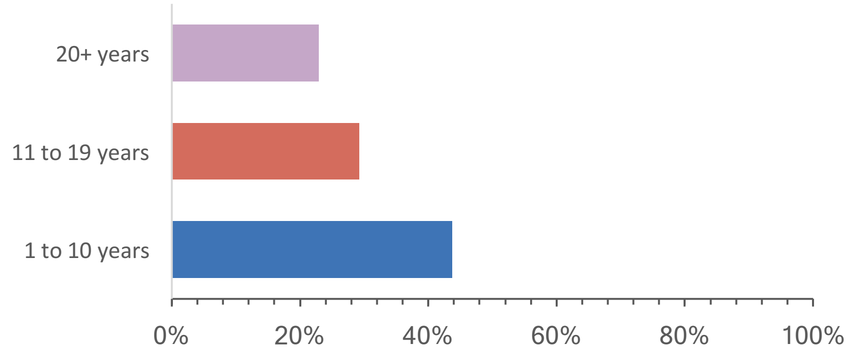
Who participated?

Forty-eight English speaking adults (18 years and older) who receive care from ANTHC EIS and are currently living with HIV for at least 12 months participated in the People Living with HIV Global Stigma Index survey. Data collection took place from June 2022 to December 2022. The age of participants ranged from 22 to 70 years old, with an average age of 48 years old. Participants identified as male (65%), female (31%) and Two-Spirit (4%). Of the participants who identified as male, half (54%) identified as gay or bisexual, and 7% identified as heterosexual. Of the participants who identified as female, 20% identified as bisexual and 19% identified as heterosexual. Participants were able to choose all answers that applied. Sixty-seven percent of participants reported having completed high school or an equivalent, 25% reported having had some university education, and 8% trade/vocational education. Participants also reported being employed full-time (42%), being unemployed (42%), being retired (8%), or being employed part-time (8%).

HIV testing, diagnosis and treatment

Participants shared their experiences with testing, diagnosis and treatment. Almost half (46%) were diagnosed between 1 and 10 years ago, 29% 11 to 19 years ago, and 23% 20 or more years ago (Figure 1).

Figure 1. Time of HIV diagnosis (n=48)



Forty percent indicated that they hesitated to be tested due to fears about how others would respond if they tested positive. Although a majority (73%) stated that they were tested by choice, 7% reported that they were pressured into being tested by others, 16% that they were tested without their knowledge and 4% that they were tested without their consent (Figure 2.). The largest proportion reported getting tested for HIV because they believed they were at risk (28%), a quarter (25%) because a provider recommended testing as a part of other care, 17% because they felt sick, 14% because they wanted to know and 8% because it was mandatory (Figure 3.).

Figure 2. Decision to test for HIV (n=45)

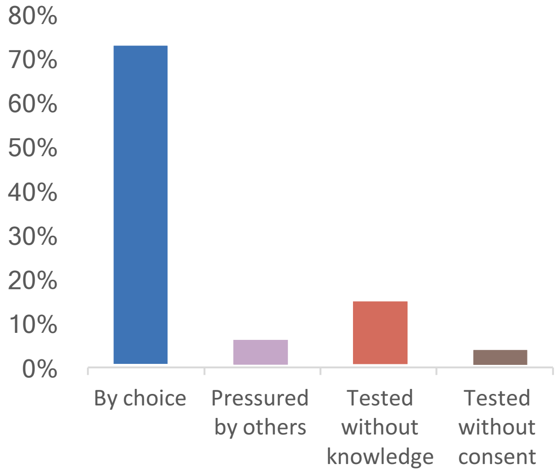
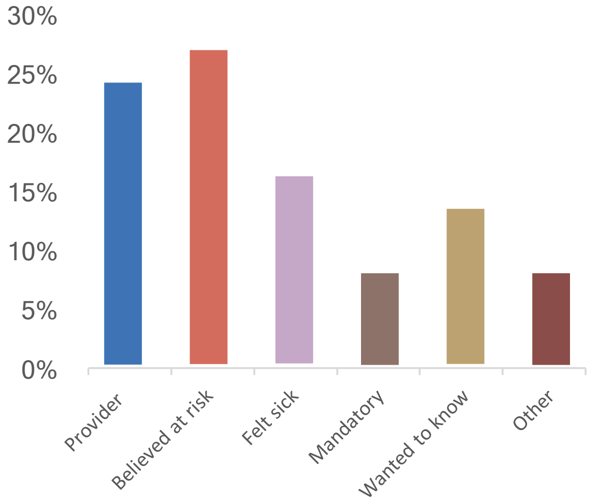


Figure 3. Main reason for HIV test (n=36)



A large majority (98%) of participants were currently, or had been, in treatment for HIV. Fifty-six percent began treatment immediately or within six months of diagnosis and 20% between six months to 2 years (Figure 4.). Eighty percent reported viral suppression of HIV or UVL within the last 12 months. This is higher than the national HIV viral suppression rate average of 66%.[18] However, participants reported a variety of reasons as to why they delayed treatment for HIV (Figure 5.). The largest proportion (47%) reported hesitation or delay of treatment because they did not feel ready to deal with being HIV positive; 33% did so because they were worried that other people would find out; 30% feared that providers would treat them badly or disclose their diagnosis without consent; 26% were worried that their partner, family and friends would find out; and 23% had had a previous bad experience with a health care worker.

Figure 4.
Length of time to start treatment (n=45)

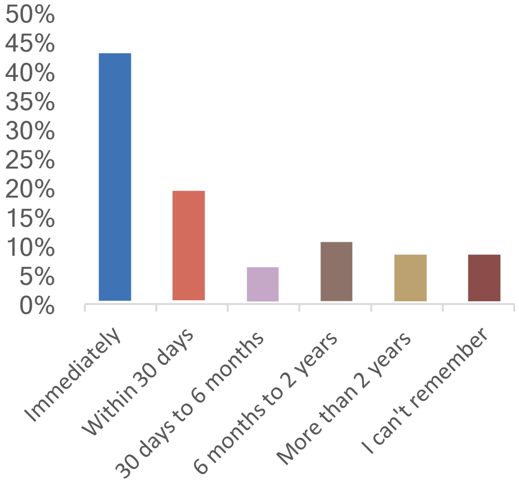
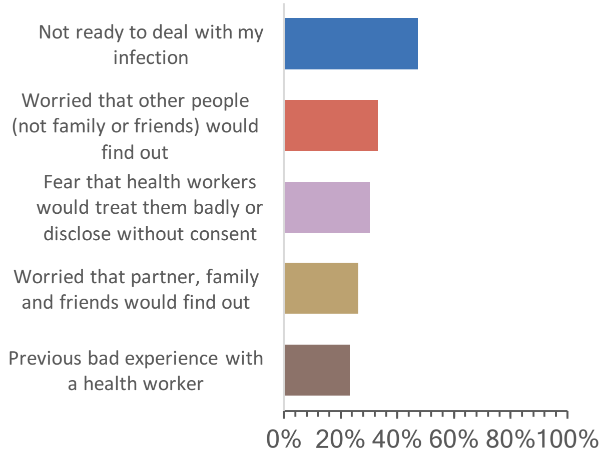


Figure 5.
Reasons to delay treatment (n=45)
Participants could check all that applied



HIV disclosure

Participants were asked about who knows their status, and the specific groups of people that they had disclosed their status to. Ninety-two percent of respondents had disclosed their HIV status to others. However, there was variation within people or groups of people who know their HIV status. When asked about disclosure with consent, participants most often disclosed to spouses (92%), other family members (83%), and friends (73%). At the same time, for disclosure without consent, participants cited other family members (20%), partner/spouse (19%) and friends (16%). Participants most often did not disclose their HIV status to classmates (86%), teachers/school administrators (83%), local leaders (79%), neighbors (78%) or co-workers (67%), among others. Participants overall reported a supportive disclosure experience. Seventy-eight percent of participants agreed and 20% somewhat agreed that people were supportive when they first learned about their status, while 2% disagreed (Figure 6.). Sixty-five percent agreed that disclosing to people they are close to was a positive experience, while 22% somewhat agreed and 13% disagreed (Figure 7.).

Experiences of stigma and discrimination

When asked about perceived discriminatory behavior due to their HIV status, respondents reported verbally harmful remarks about their HIV status from people other than family (51%), family members (35%) and general verbal harassment (32%) such as yelling and scolding due to their HIV status (Figure 8.).

Figure 6.
Supportive disclosure (n=46)

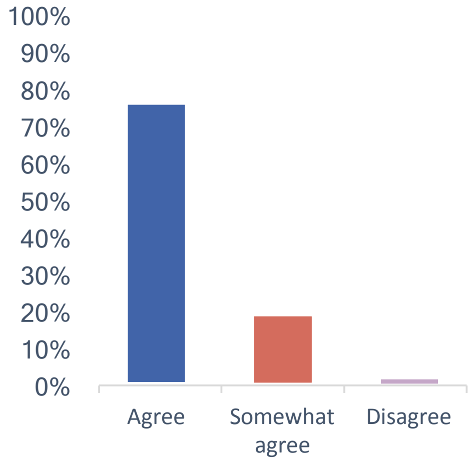


Figure 7.
Positive disclosure experience (n=46)

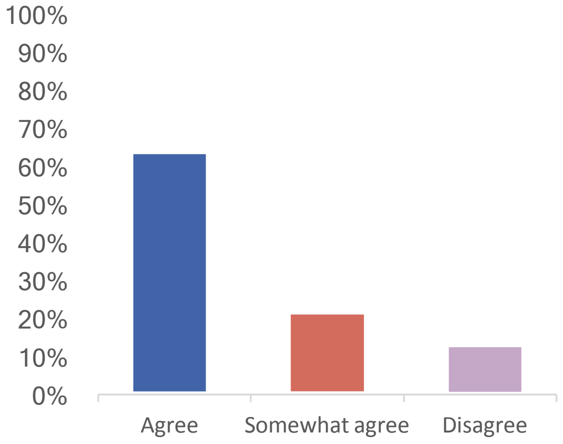
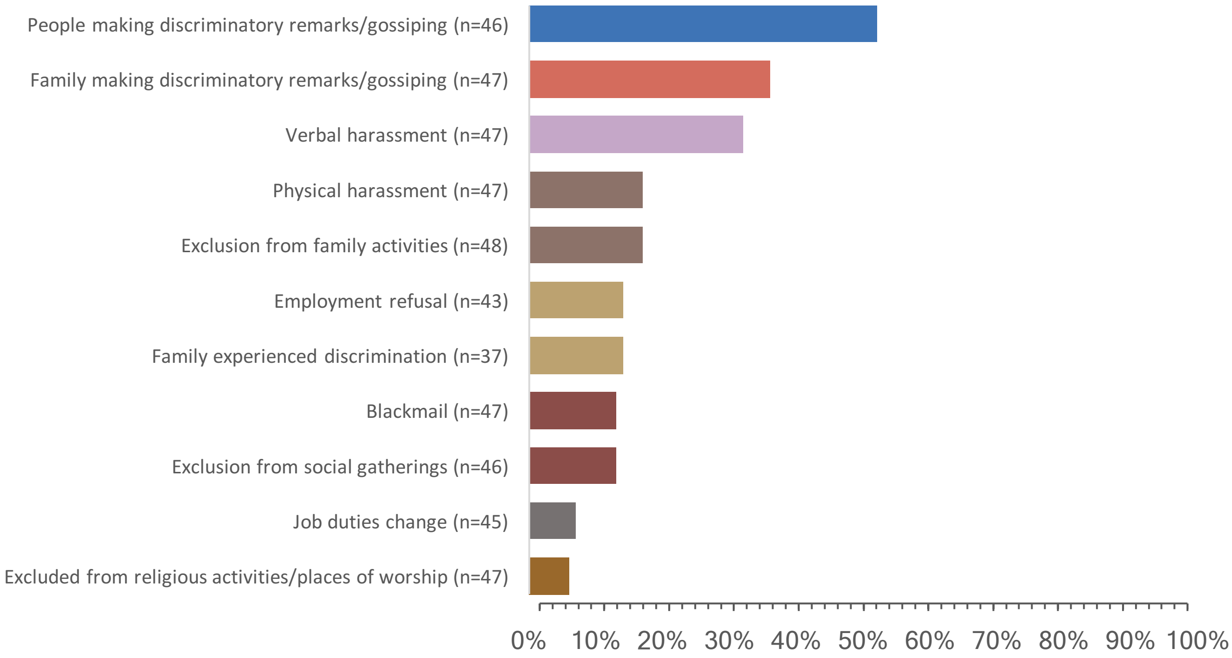


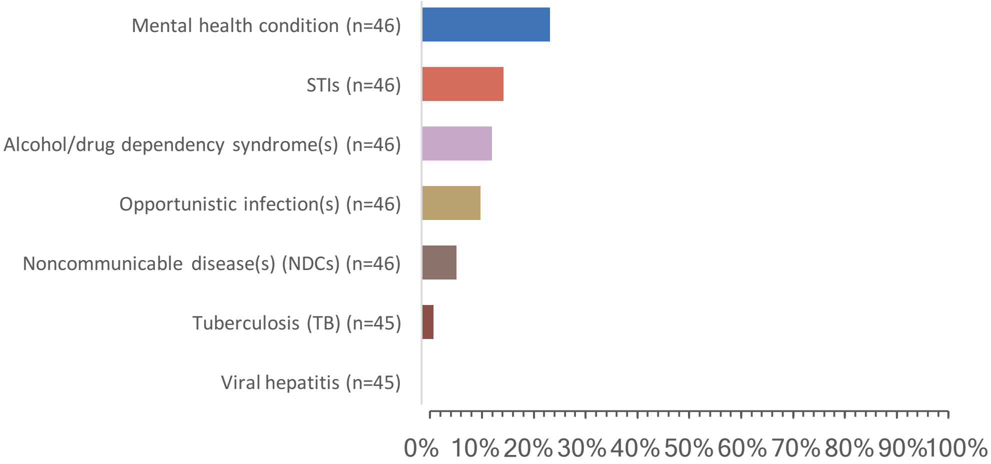
Figure 8. HIV-related stigma experiences ever



Health and wellness

Fifty-seven percent of participants described their current overall health status as "good" or "fair" (39%). Four percent reported poor current health status. Participants were asked to respond with "yes" or "no" to each response option to the question "In the last 12 months, have you been diagnosed with any of the following?" The most reported diagnoses within the past 12 months were mental health conditions (24%) such as anxiety, depression, insomnia and post-traumatic stress; sexually transmitted infections (STIs) (15%); and alcohol dependency (13%) (Figure 9). Ninety-six percent of participants who reported diagnoses were offered treatment in the past 12 months.

Figure 9. Common diagnoses in the last 12 months



Interactions with health care services

Ninety-three percent of participants indicated that they receive their regular HIV care and treatment at a tribal clinic or facility within the ATHS. Respondents reported that they have access to the following HIV-related services: HIV information (97%), peer support (55%), medication counseling (68%), prevention services (75%), HIV treatment (91%), case management (86%), and HIV care and testing (86%). Participants were not asked where (tribal, public or private) they go to receive non-HIV-related health care, so participants may have reported experiences outside of the ATHS. Seventy percent of participants think that their medical records are being kept confidential, while 22% are unsure whether they are being kept confidential, and 9% believe that they are not being kept confidential.

HIV related health care

Participants were asked: "In the past 12 months, when seeking HIV specific health care, have you experienced any of the following from health facility staff working in the place you receive your HIV care?" Choices were "yes" or "no" for each response option. The types of reported experiences during HIV-related care included disclosure of HIV status without consent (15%), advised not to have sex (12%), avoidance of physical contact (5%), being talked or gossiped about (5%), and verbal abuse (5%).

Non-HIV related health care

Participants were then asked, "In the past 12 months, have you sought healthcare for non-HIV related health needs (i.e., dental services, vaccination or injuries)?" Sixty-seven percent responded with "yes" and were also asked: "In the past 12 months, when seeking care for non-HIV related health needs, have you experienced any of the following treatment by health facility staff? Response options were "yes" or "no". The types of reported experiences perceived by participants during non-HIV related health care visits included disclosure of HIV status without consent (19%), avoidance of physical contact/taking extra precautions (i.e. wearing double gloves) (16%), being talked about or gossiped about (10%), advised not to have sex (6%), verbal abuse (i.e. yelling, scolding, name calling or otherwise verbally abused) (6%), physical abuse (i.e. pushing, hitting or being otherwise physically abused) (3%) and denial of health services (3%). Fifty-two percent reported not usually disclosing their HIV status when seeking non-HIV related health services.

Please note: The survey results are based on self-reported experiences and as such reflect participants' perceptions. It is difficult to ascertain the specific context for these responses. HIV status disclosure in the context of a health care visit may be perceived as without consent due to a lack of understanding that it is part of the medical record. At the same time providers may advise someone to abstain from sex if they are newly diagnosed and/or have not yet reached viral suppression, which means that HIV can be transmitted more easily. We are unable to establish where specifically any of the reported experiences occurred, and whether participants reported any instances when they were denied health services or when they experienced physical and/or verbal abuse due to their HIV status.

Support, advocacy and affecting change

Participants reported actively advocating for the rights of persons living with HIV. Thirty percent stated that they provide emotional, financial, or other support to help someone else living with HIV deal with stigma and/or discrimination, and 27% confronted or educated someone who was engaging in stigma or discrimination against other PLWH. Overall, participants expressed interest in increasing visibility of PLWH and suggested sharing their personal experiences at conferences, being a role model for others, and doing more advocacy on social media.

> **"If they had more things and assessments like what you are doing it would help people with HIV and then people that don't have it."**
>
> – ANONYMOUS STUDY PARTICIPANT

Eligibility criteria

Participants who met the following criteria were eligible to participate:

- 18 years or older
- Clinical or hospital staff who provide customer-owner or patient services
- Work in the Alaska Tribal Health System

Study population

This survey was disseminated among health care facility employees who provide direct services to customer-owners in four ATHS health care facilities. We used a non-probability-based convenience sampling approach. The target number of surveys was 354 based on the estimated overall population of health care workers involved in customer-owner care and services. We collected a total of 215 surveys (61% response rate).

Confidentiality

Survey responses are anonymous and neither names nor contact information can be linked to responses. All data are stored in REDCap, a secure ANTHC housed database with restricted access.

Study procedures and data collection

Participating ATHS health care facilities distributed recruitment flyers among eligible staff via email and other appropriate internal communication methods. We used the REDCap platform with HIPAA compliance to conduct this one-time, self-administered online survey. Participants provided electronic consent prior to completing the 10–15-minute survey. We raffled off 12 (three per facility) $100 gift cards to those who provided their preferred contact information immediately after completing the survey. Surveys were collected between December 2021 and August 2022.

Data analysis

The final analytic sample consisted of 195 surveys, after we excluded 20 surveys from participants who consented, but did not answer any of the questions. We analyzed all data using descriptive statistics; counts and frequencies for categorical variables, means and standard deviations, or medians and interquartile ranges for quantitative variables. Because of the sample size, we collapsed the categories of Likert-type questions into two levels: agree versus disagree. We also reported the number of missing responses for each variable since many of the questions did not apply to non-clinicians in the sample.

We grouped participants into two groups based on responses to the following five statements: 1) Most people living with HIV do not care if they infect other people; 2) People living with HIV should feel ashamed of themselves; 3) Most people living with HIV have had many sexual partners; 4) People get infected with HIV because they engage in irresponsible behaviors; 5) Women living with HIV should have babies if they wish. Responses to the fifth statement were reversed to be in line with the other four statements. If a participant answered that they agreed or strongly agreed with any statement, they were considered to have unfavorable attitudes and beliefs. All others were considered to have positive attitudes and beliefs. We conducted bivariate analysis of individual HIV-related questions, clinic HIV-related questions, and policy HIV-related questions. We tested significant differences in categorical variables using the Chi Square test of independence. We created a summary variable for each set of questions. Finally, we examined the role of several variables (demographic, individual, clinic, and policy) played in predicting attitudes and beliefs using logistic regression. All statistical analysis was performed using R version 4.3. Response categories with “n” less than five were removed to avoid any potential for identifying individuals. We considered p-values less than 0.05 statistically significant.

Limitations

Data collection was completed with tribal health organizations who approved participation. Recruitment only occurred with health care employees at tribal health facilities in the Southwest, Southcentral and Southeast regions of the state. The survey also used convenience sampling which may have resulted in selection bias for participation. We also did not reach the goal of 354 surveys, and once we validated all responses, the total number of valid surveys was reduced to 195. The findings are not generalizable to, or representative of, all health facilities (rural or urban) within the ATHS, or to the experiences of all AN/AI people living with HIV. The results do however provide an initial understanding of the barriers customer-owners living with HIV may experience in the ATHS, and we include recommendations to address them.

Results

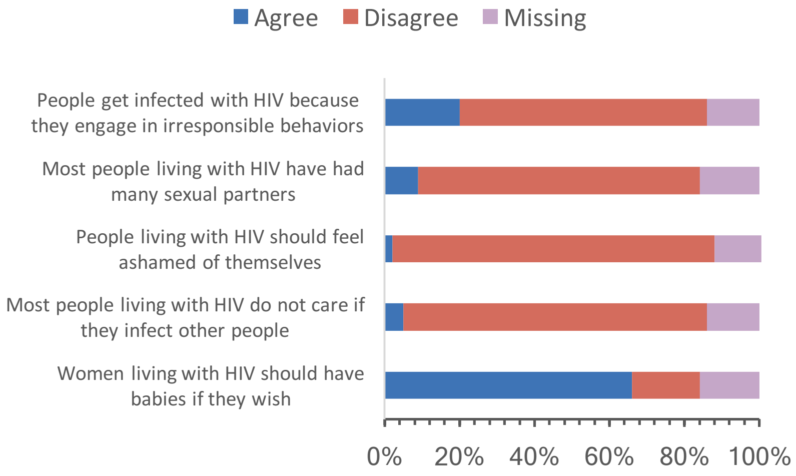
Who participated?

Participants represented health care workers (clinical and non-clinical) at ATHS facilities in the southcentral (75%), Yukon-Kuskokwim (9%) and Bristol Bay (9%) tribal regions (6% of participants did not report their region). Most participants identified as AN/AI (49%) or White (40%). Thirty-five percent were between 30-39 years old, followed by those under 30 years old (24%), older than 50 years old (22%), 40-49 years old (19%), and over 60 years old (11%). Eighty-one percent of participants self-identified as female, 16% as male, 2% as Two-Spirit, and 2% as other. In terms of positions, 65% worked as clinicians or clinical support, and 35% served as administrative support. Seventy percent had more than 16 years of experience in tribal health care, 60% had 0-5 years, 19% had 6-10 years, and 12% had 11-15 years. In regards to overall health care experience, 34% had 0-5 years of work experience, 28% had 6-10 years, 16% had 11-15 years, 10% had 16-20 years and 11% had more than 20 years of experience.

Individual level indicators

Individual level indicators include HIV-related attitudes, fear of HIV infection and confidence in being able to provide HIV-care. In general, participants indicated positive attitudes regarding people living with HIV. Eighty-six percent of respondents disagreed that people living with HIV should feel ashamed of themselves, 81% disagreed that PLWH did not care if they infected others, and 75% disagreed that PLWH had had many sexual partners. Sixty-six percent agreed that women living with HIV should have children if they wished. Sixty-six percent believed that infection with HIV was not the result of irresponsible behaviors (Figure 10.). Overall, 51% (n=99) of respondents agreed with at least one statement listed in Figure 10 below.

Figure 10. HIV-related attitudes among health care workers (n=195)



Participants expressed worries about contracting HIV while: providing services (24%); dressing wounds (27%); and/or drawing blood (25%) (Figure 11.). These worries were reflected in patient care or unnecessary precautionary practices, such as avoiding physical contact, special infection control precautions, and/or excessive glove utilization. The highest proportion of respondents reported that wearing gloves during all aspects of the patient's care was good practice (31%), and that wearing double gloves during high-risk procedures was necessary (25%) (Figure 12.). Overall, participants felt confident about their ability to provide care to people living with HIV (71%) and 2SLGBTQIA+ customer-owners (79%).

Figure 11. HIV-related worries about contracting HIV among health care workers (n=195)

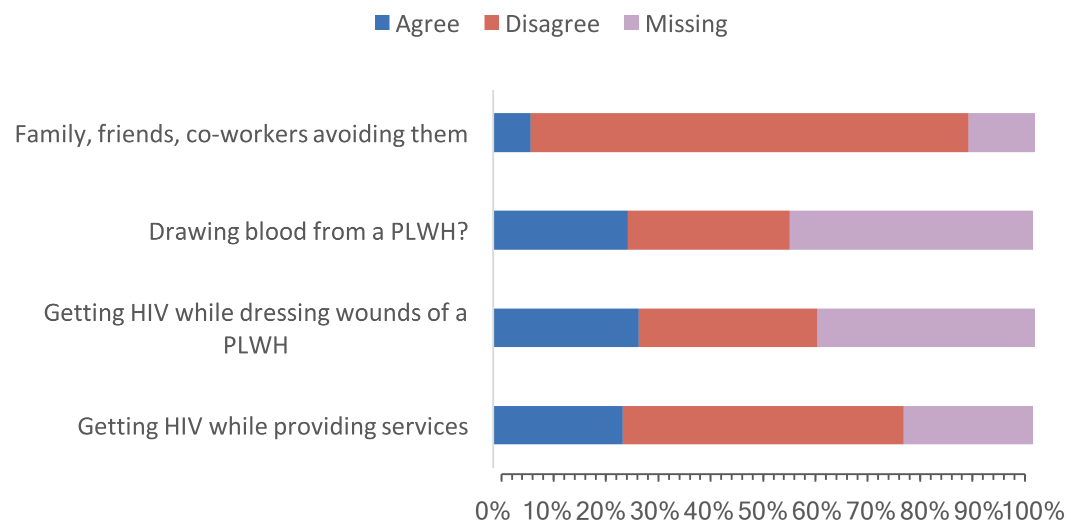
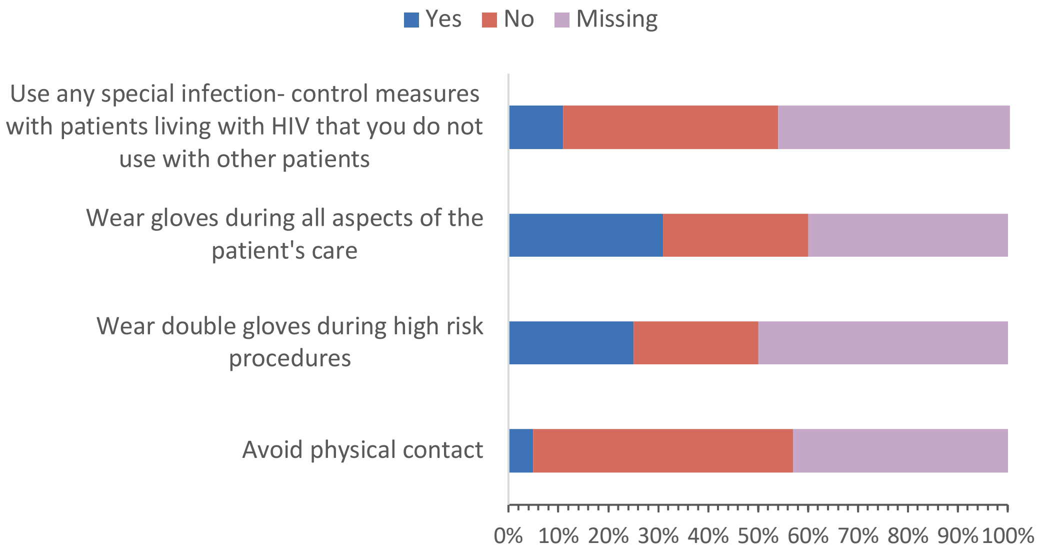


Figure 12. HIV-related precaution practices among health care workers (n=195)



Please note: HIV transmission in health care settings is extremely rare (only one confirmed case reported since 1999).[21,22] The CDC recommends the use of standard or universal precautions to protect all customer-owners as well as health care workers, regardless of HIV status.[21, 22]

Clinical level indicators

Clinical level indicators include HIV care experience, access and knowledge of Pre-Exposure Prophylaxis (PrEP) and non-occupational Post-Exposure Prophylaxis (nPEP) for HIV prevention and risk reduction, clinical support for providing services, and observed HIV-related stigma. Participants were able to choose "not applicable" if they did not have the ability to describe nPEP or PrEP. Forty-two percent of participants reported experience working in a clinic that provided care for PLWH, and 38% reported experience directly interacting with someone living with HIV in the past 12 months (Figure 13.). However, only 9% reported ever having prescribed PrEP or nPEP. Seventy-seven percent of participants said they felt supported to provide services to people who are HIV positive (Figure 14). Participants indicated observing minimal stigmatizing behavior towards patients in their respective clinical settings (Figure 15.).

Figure 13. HIV care experience among health care workers (n=195)

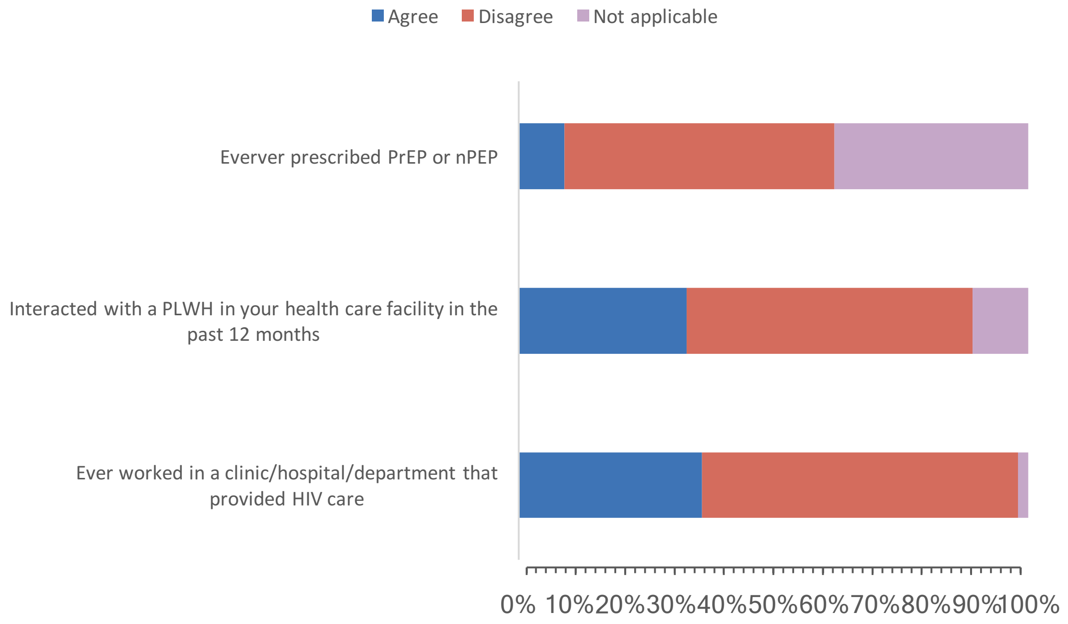


Figure 14. Clinical support among health care workers (n=195)

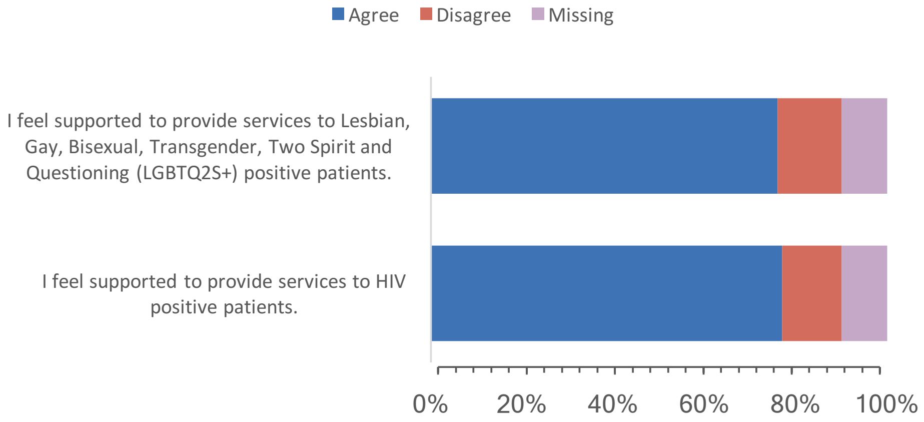
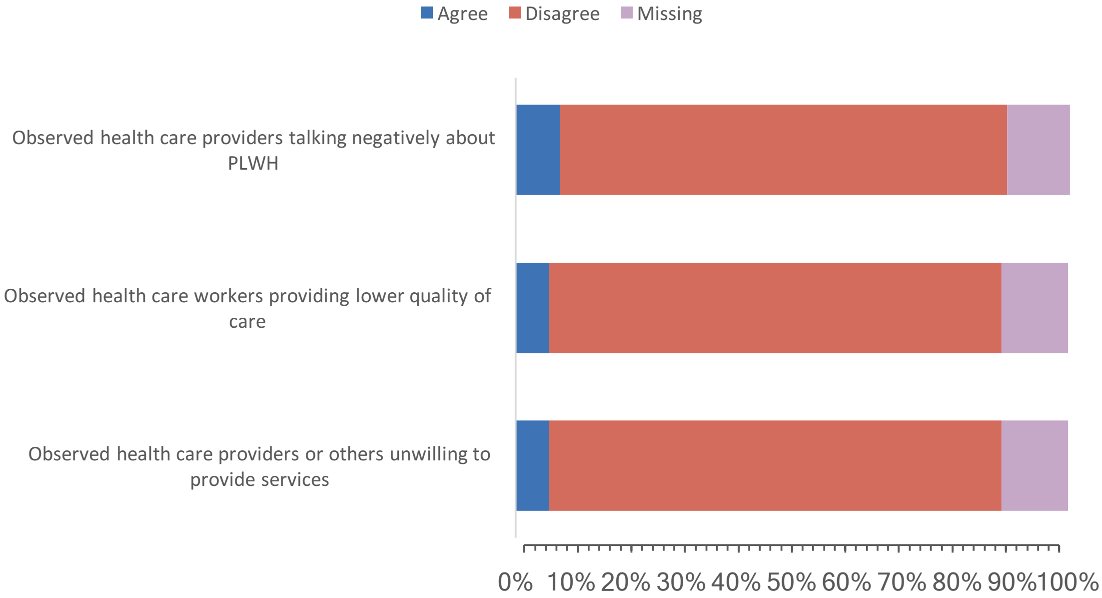


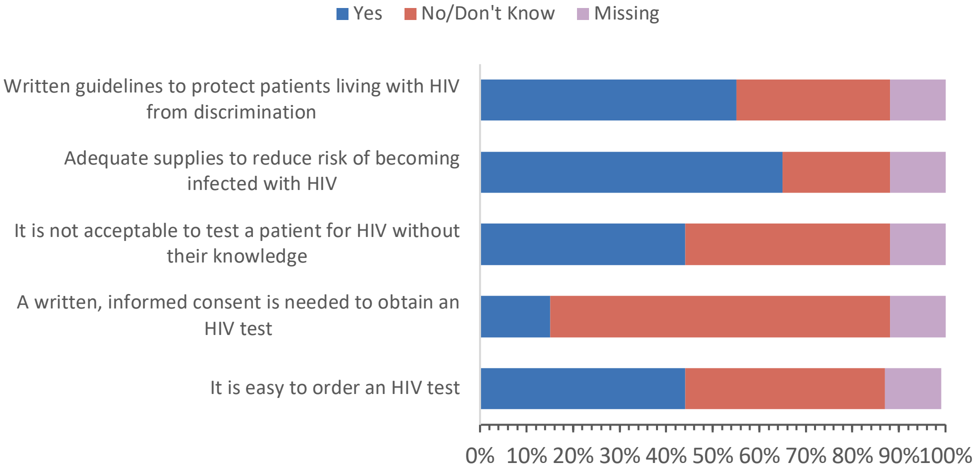
Figure 15. Observed attitutes among health care workers in the past 12 months (n=195)



Institutional level indicators

Institutional level indicators include institutional policies regarding infection control, HIV testing or discrimination as well as access to HIV-related education and training. Sixty-five percent of participants reported having adequate supplies to reduce infection. Forty-three percent reported that it is not easy to order an HIV test at their facility. Participants were split (44% and 44%) over the acceptability of testing patients for HIV without their knowledge at their facility while 15% indicated that a written informed consent was required to obtain an HIV test. More than half (55%) of participants reported that their facility has written guidelines to protect people living with HIV from discrimination (Figure 16.).

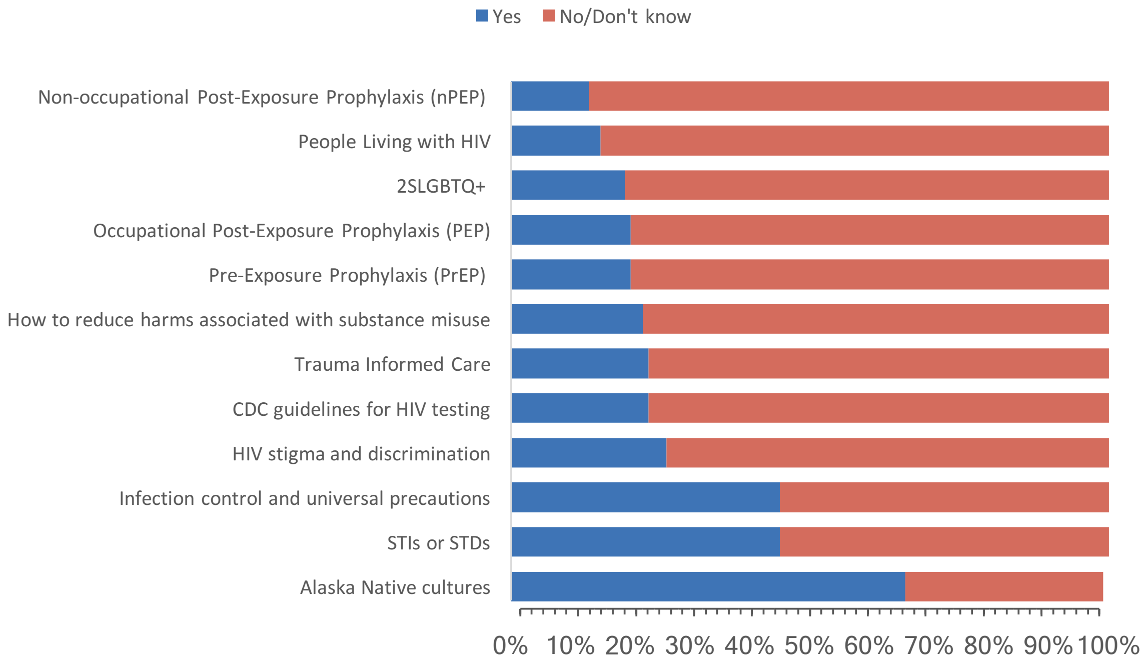
Figure 16. Institutional health care policies (n=195)



Please note: The CDC recommends that written consent should not be required; a verbal consent is sufficient.[20]

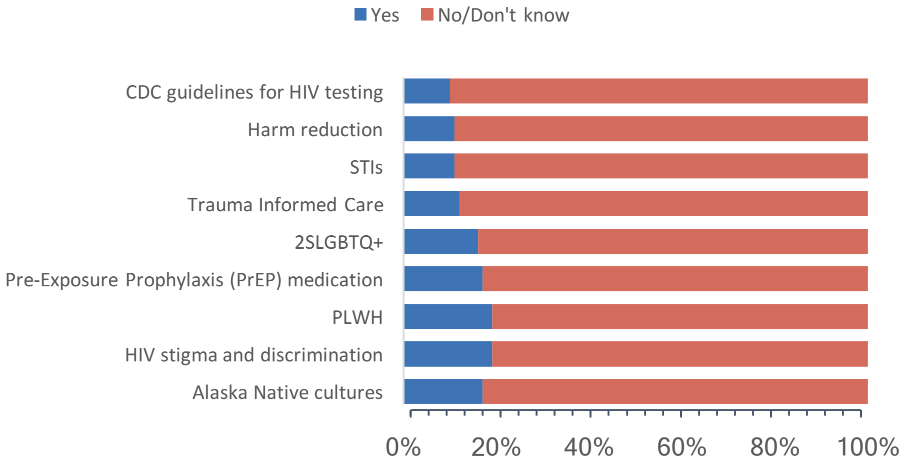
Sixty-six percent reported having received trainings regarding Alaska Native cultures. They reported a lack of training on special populations/subgroups, including people living with HIV (15%), 2SLGBTQIA+ (19%); and current population-specific best practices including nPEP (13%), PEP (20%), PrEP (20%), harm reduction (22%), and trauma informed care (23%) (Figure 17.).

Figure 17. Education and training received by health care workers (n=195)



Participants reported that they would like to receive PLWH-specific, as well as HIV stigma and discrimination training (19% and 19%, respectively), followed by training regarding Alaska Native cultures, PrEP and 2SLGBTQIA+ care (Figure 18.).

Figure 18. Education and training wanted by health care workers (n=195)



Factors associated with provider attitudes and behaviors

Overall, 51% of participants reported unfavorable attitudes. We found statistically significant differences in many demographic, individual, clinic-level, and policy-level variables between respondents. Using multivariate logistic regression, we found that the following factors were significantly associated with unfavorable attitudes among participants:

Providing care in a rural area (p-value = 0.02)

Fifty-three percent of participants who work in an urban health care environment reported positive attitudes towards PLWH, while 36% of participants in a rural health care environment reported positive attitudes.

Being over 30 years of age (p-value =0.008)

Age played a role as a predictor of attitudes towards PLWH. Sixty percent of participants under the age of 30 reported positive attitudes compared to 47% of participants over the age of 30. However, a disproportionate number of participants was over 30 years of age, which may have influenced these findings.

Using unnecessary precaution practices (p-value = 0.002)

Participants who did not have positive attitudes towards PLWH were more likely to use unnecessary precautions when providing care to PLWH, such as using infection control measures that they would not otherwise use, wearing gloves during the entire visit, and/or avoiding physical contact.

Lacking HIV-related institutional policies and guidelines (p-value=0.0004)

Participants who did not have positive attitudes towards PLWH were more likely to indicate a lack of HIV-related institutional policies, such as policies that prevent testing without consent but also do not require written consent, and/or guidelines that protect PLWH from discrimination. However, this could also indicate that participants were simply not aware of such policies or lacked knowledge about these policies and guidelines.

Willingness to receiving training (p-value = 0.03)

Participants who did not have positive attitudes towards PLW were less likely to be open to receiving more training. This finding may indicate that attitudes towards training may also be reflective of attitudes towards PLWH among health care workers overall.

Conclusion

The findings from this study align with previous studies on HIV-related experiences and underscore the complex and multifaceted challenges people living with HIV face, including experiences of stigma and discrimination, mental health concerns, and health care-related issues. While there is room for improvement, a large majority of participants reported receiving antiviral treatment for HIV, and 80% reported viral suppression of HIV or UVL within the last 12 months. Respondents also displayed resilience and a commitment to advocating for the rights and the well-being of people living with HIV. Health care workers within the ATHS demonstrated an overall positive attitude toward PLWH. They also face some challenges related to HIV attitudes, best practices, policies and guidelines, that can result in unintentionally stigmatizing care. The findings highlight the need for targeted training and policy improvements to create a safe, enabling health care environment for AN/AI people living with HIV within the ATHS.

Recommendations

As a result of the study findings, recommendations have been developed in coordination with the Steering Committee. They fall under the following categories: (1) Education and training; (2) Policies and best practices; (3) Inclusivity and respect campaigns; and (4) Engaging and supporting people living with HIV (Table1.).

Table 1. Recommendations

(1) Education and training:

- Increase and improve health care workforce training and education to promote inclusivity.
- Increase provider knowledge around general sexual health topics, including HIV and STIs, to improve ability to talk about sensitive topics.
- Offer more education regarding harm reduction principles for all health care workers.
- Improve training for providers on the use of HIV-appropriate universal precautions.
- Reinforce training for health care workers on HIV and privacy, including non-clinical staff.
- Increase education for providers on CDC guidelines and best practices regarding HIV testing.
- Increase education to normalize HIV testing and PrEP access as part of routine care.
- Offer more health care worker training on 2SLGBTQAI+ inclusive language and communication.
- Provide education for PLWH to know their rights to privacy, how their records are kept confidential, and when HIV status disclosure is necessary within the ATHS to provide services.

(2) Policies and practices:

- Review guidelines and standard operating procedures for HIV testing to follow CDC best practices and ensure that customer-owners are aware that they are being tested for HIV. If no guidelines are in place, develop guidelines that follow national standards.
- Develop, implement and reinforce policies that promote inclusivity and provide training to healthcare workforce on those policies. Policies should also be available to healthcare workers and PLWH.

(3) Inclusivity and respect campaigns:

- Design and execute campaigns for healthcare workers with information about U=U (Undedectable equals Untransmissible) to address the use of unnecessary precautions when providing care to PLWH.
- Design and execute inclusive U=U campaigns for the general public with information about HIV transmission that reinforces that PLWH can lead long and productive lives.
- Implement campaigns to normalize regular HIV testing and promote the range of testing options available (including self-testing, clinic-based testing, and community-based testing).
- Inclusivity and respect campaigns also need to address the unique context and compounded stigma related to sexual orientation, gender identity, drug use and sex work.

(4) Engaging and supporting people living with HIV:

- Create pathways of care between HIV care, general healthcare, and mental health, and social support services and programs.
- Provide more access to safe networking and support groups for PLWH.
- Offer services that support PLWH in making important lifestyle choices that are right for them and that foster confidence when they decide to disclose.
- Resources are needed to support the empowerment and education of PLWH regarding existing laws that protect them from discrimination.
- Engage PLWH utilizing inclusive language through open communication.
- Empower PLWH to be engaged in research, advocacy, outreach, and peer support.
- Recognize that PLWH are resourceful, resilient, and have the knowledge to help their communities.

Local, National and International Resources

Table 2. Resources

Local Resources	
Name and Description	***Website Links***
ANTHC's Early Intervention Services provides HIV/AIDS patient services, case management, and counseling for Alaska Native and American Indian people.	• https://www.anthc.org/what-we-do/clinical-and-research-services/hivaids-services/
Alaska Integrated HIV Advisory Group (AIHAG) serves as a voice for HIV prevention and care in Alaska by engaging stakeholders in meaningful discussions about prevention and care needs; working with AIDS service organizations and medical care providers to plan HIV prevention and care activities; and identifying gaps in resources for HIV prevention and care.	• https://health.alaska.gov/dph/Epi/hivstd/Pages/hppg/default.aspx
Alaskan AIDS Assistance Association (4As) supports and empowers people living with, or affected by, HIV/AIDS, and works toward the elimination of HIV infection and its stigma in all Alaskan communities.	• https://www.alaskanaids.org/
iknowmine has been a trustworthy health resource for youth and their allies – providers, parents, teachers, aunties and uncles, and other trusted adults – since 2009.	• www.iknowmine.org
Interior AIDS Association's (IAA) mission is to improve the quality of life of people living with, affected by, or at risk for HIV/AIDS, and other stigmatized conditions (often related to sex or drug use). They do this through harm reduction, resource development and advocacy.	• https://www.interioraids.org/
National Resources	
Name and Description	***Website Links***
Centers for Disease Control and Prevention has the latest HIV data, prevention science, program resources and policy updates.	• https://www.cdc.gov/hiv/default.html • https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm • https://www.cdc.gov/stophivtogether/index.html • https://www.cdc.gov/globalhivtb/who-we-are/features/health-equity-stigma.html
U=U is a campaign by the National Institute of Allergy and Infectious Disease. It stands for Undetectable = Untransmissible, which means thatpeople with HIV who achieve and maintain an undetectable viral load (UVL) (the amount of HIV in the blood) by taking antiretroviral therapy (ART) daily as prescribed, cannot sexually transmit the virus to others. Treatment for HIV is a powerful HIV prevention tool.	• https://www.preventionaccess.org/ • https://www.niaid.nih.gov/diseases-conditions/treatment-prevention • https://www.niaid.nih.gov/diseases-conditions/10-things-know-about-hiv-suppression • https://aidsinfo.nih.gov/guidelines
Mountain West HIV Training Center (MWAETC) delivers innovative education and training to improve access to care and quality of life for people with, or at increased risk for acquiring, HIV.	• https://mwaetc.org/ • https://mwaetc.org/training/mwaetc-hiv-echo
University of Washington STD Prevention Training Center (UWPTC) is dedicated to increasing the knowledge and skills of healthcare providers in the area of sexual health.	• http://uwptc.org/ • https://www.hiv.uw.edu/ • https://www.std.uw.edu/

Ending Stigma through Collaboration and Lifting All To Empowerment (ESCALATE) is an innovative training and capacity-building initiative specifically designed to address HIV-related stigma that creates barriers at multiple levels of the HIV care continuum.	• https://targethiv.org/escalate
Northwest Portland Indian Area Health Board (NWPAIHB) works to prevent human immunodeficiency virus (HIV), sexually transmitted infections (STIs), and the Hepatitis C virus (HCV). The project has provided training and technical assistance to tribes and tribal organizations throughout the U.S. on implementing and evaluating culturally appropriate sexual health and STI/HIV prevention programs since 1988.	• https://www.npaihb.org/project-red-talon-old/ • https://www.indiancountryecho.org/indigenous-hiv-aids-syndemic-strategy/ • https://www.indiancountryecho.org/resource-hubs/hiv-resource-hub/
Urban Indian Health Institute decolonizes data: for Indigenous people, by Indigenous people.	• https://www.uihi.org/projects/urban-indian-hiv-and-aids/
Fenway Health works to make life healthier for the people in our neighborhoods, the LGBTQIA+ community, people living with HIV/AIDS, and the broader population.	• https://fenwayhealth.org/aac/
National Harm Reduction Coalition builds evidence-based strategies with and for people who use drugs.	• https://harmreduction.org/
Health Resources and Services Adminstration (HRSA) provides equitable health care to the nation's highest-need communities. HRSA programs support people with low incomes, people with HIV, pregnant people, children, parents, rural communities, transplant patients, and the health workforce.	• https://www.hrsa.gov/library/hiv-aids
International Resources	
Name and Description	***Website Links***
The **Health Policy Project** training guide is designed to help promote "stigma-free" HIV services through training of health facility staff.	• *Comprehensive Package for Reducing Stigma and Discrimination in Health Facilities: https://www.healthpolicyproject.com/pubs/281_SDTrainingGuide.pdf*

References

1. CDC. Let's Stop HIV Together: HIV Stigma. Centers for Disease Control and Prevention. Published November 3, 2022. Accessed November 28, 2023. https://www.cdc.gov/stophivtogether/hiv-stigma/index.html.

2. Jain Aparna, Carr Dara, Laura Nyblade. Measuring HIV Stigma and Discrimination Among Health Facility Staff: Standardized Brief Questionnaire User Guide. *Health Policy Proj.*

3. Rebekah Webb, Pim Looze, Omar Syarif. Measure it, act on it, do it: Using the PLHIV Stigma Index to achieve change. *2020 Glob Netw People Living HIV GNP*. Published online 2020.

4. U.S. Department of Health and Human Services. HIV National Strategic Plan for the United States: A Roadmap to End the Epidemic 2021–2025. Published online 2021.

5. State of Alaska Section of Epidemiology. HIV Surveillance Report – Alaska, 1982-2020. 2021. https://health.alaska.gov/dph/Epi/hivstd/Documents/HIV%20Surveillance%20Report%20-%20Alaska%201982-2020.pdf.

6. Centers for Disease Control. Understanding the HIV Care Continuum. https://www.cdc.gov/hiv/pdf/dhap_continuum.pdf.

7. Turan B, Budhwani H, Fazeli PL, et al. How Does Stigma Affect People Living with HIV? The Mediating Roles of Internalized and Anticipated HIV Stigma in the Effects of Perceived Community Stigma on Health and Psychosocial Outcomes. *AIDS Behav*. 2017;21(1):283-291. doi:10.1007/s10461-016-1451-5.

8. Eaton LA, Driffin DD, Kegler C, et al. The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. *Am J Public Health*. 2015;105(2):e75-82. doi:10.2105/AJPH.2014.302322.

9. Belenko S, Dembo R, Copenhaver M, et al. HIV Stigma in Prisons and Jails: Results from a Staff Survey. *AIDS Behav*. 2016;20(1):71-84. doi:10.1007/s10461-015-1098-7.

10. Geter A, Herron AR, Sutton MY. HIV-Related Stigma by Healthcare Providers in the United States: A Systematic Review. *AIDS Patient Care* STDs. 2018;32(10):418-424. doi:10.1089/apc.2018.0114.

11. Davtyan M, Olshansky EF, Brown B, Lakon C. A Grounded Theory Study of HIV-Related Stigma in U.S.-Based Health Care Settings. *J Assoc Nurses AIDS Care JANAC*. 2017;28(6):907-922. doi:10.1016/j.jana.2017.07.007.

12. Fredericksen RJ, Edwards TC, Merlin JS, et al. Patient and provider priorities for self-reported domains of HIV clinical care. *AIDS Care*. 2015;27(10):1255-1264. doi:10.1080/09540121.2015.1050983.

13. Stringer KL, Turan B, McCormick L, et al. HIV-Related Stigma among Healthcare Providers in the Deep South. *AIDS Behav*. 2016;20(1):115-125. doi:10.1007/s10461-015-1256-y.

14. Varas-Díaz N, Neilands TB, Malavé Rivera S, Betancourt E. Religion and HIV/AIDS stigma: implications for health professionals in Puerto Rico. *Glob Public Health*. 2010;5(3):295-312. doi:10.1080/17441690903436581.

15. Walcott M, Kempf MC, Merlin JS, Turan JM. Structural community factors and sub-optimal engagement in HIV care among low-income women in the Deep South of the USA. *Cult Health Sex*. 2016;18(6):682-694. doi:10.1080/13691058.2015.1110255.

16. Healthy Policy Project. Comprehensive Package for Reducing Stigma and Discrimination in Health Facilities. Published 2015. Accessed August 18, 2023. http://www.healthpolicyproject.com/index.cfm?id=StigmaPackage.

17. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa.

18. America's HIV Epidemic Analysis Dashboard | AHEAD. HIV.gov. Published November 7, 2023. Accessed November 28, 2023. https://ahead.hiv.gov/?indicator=282&measure=rate.

19. Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report (MMWR). 2002;51(27):592-595. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5127a2.htm.

20. Centers for Disease Control and Prevention. Morbidity and Mortality Weekly Report (MMWR). 2006;55(14);1-17. https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm.

21. Centers for Disease Control and Prevention. HIV and Occupational Exposure. 2019. https://www.cdc.gov/hiv/workplace/healthcareworkers.html.

22. Centers for Disease Control and Prevention. Human Immunodeficiency Virus (HIV) in Healthcare Settings. 2011. https://www.cdc.gov/hai/organisms/hiv/hiv.html.

23. Steering Committee Meeting, 2023, Presentation of Stigma Index survey findings, February 1, 2023.

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