



# **PERSONS LIVING WITH HIV NEEDS ASSESSMENT SURVEY REPORT**

# Introduction

The mission of the North Dakota Department of Health and Human Services (HHS) is to “improve the length and quality of life for all North Dakotans” (HHS, 2020). This is accomplished through a range of programs, initiatives, and services aimed at providing support and ultimately improving the lives of North Dakotans. The North Dakota Department of Health and Human Services’ Health Equity Office (HEO) ensures that everyone in North Dakota has the same opportunity to the highest level of health care that meets their needs. To achieve this goal, the Health Equity Office conducts various surveys among different populations to identify gaps in care and access across the state. The purpose of this study is to identify the unmet needs within the community of people living with HIV in the state.

North Dakota is a recipient of Health Resource’s and Services Administration’s Ryan White Part B funding. North Dakota’s Ryan White program funds services including case management, HIV-related medical care, medication, dental care, vision care, mental health, and support services for persons living with HIV (PWH) in North Dakota whose household income is below 500% of the federal poverty level. North Dakota also has Expanded Medicaid to provide comprehensive medical services to residents at or below 138% of the poverty level. The survey aims to identify unmet needs in the community and will help guide initiatives aimed at improving the lives of persons living with HIV in North Dakota.

North Dakota is a rural and low HIV-incidence state. As of December 31<sup>st</sup>, 2020, there were estimated 500 PWH in North Dakota. Of those 62% were enrolled in Ryan White. Care continuum for retention in care and viral suppression for 2020 shows that those enrolled in Ryan White program have better medical outcomes with higher viral load suppression (86%), compared to those not enrolled (75%). HIV medical care is provided by a limited number of private infectious disease providers located in four major cities.

The rural nature of the state, distance to provider, and limited number of providers all pose barriers to accessing HIV medical care in North Dakota. The purpose of this survey was to identify areas of need that PWH have in accessing medical care, treatment, finding affordable housing, as well as dealing with negative beliefs, experiences, and stigma. Understanding the needs of North Dakotans’ living with HIV will help HHS to and its partners to guide initiatives through the Ryan White and other programs to improve access to services, improve health equity, and improve overall health and wellbeing of its citizens.

## Methodology

A 61-question survey was developed with the help of HHS's Health Equity Office and Sexually Transmitted and Bloodborne Diseases Unit. The questions were developed using questions from similar questionnaires and questions developed to suit the interests of this survey. HIV is one of mandatory reportable conditions in North Dakota (North Dakota Administrative Code 33-06, North Dakota Century Code 20-07) and information is collected in surveillance system, MAVEN. This survey was distributed to all persons with HIV living in North Dakota at the time (March 2021) with the exception of those who specified that they did not wish to be contacted by HHS, those that did not have valid addresses, or those that had an institutional address.

Of the estimated 500 PWH in ND as of December 31<sup>st</sup>, 2020, 489 had valid addresses in MAVEN, and were mailed a letter with survey information (see Appendix). Of those, thirty-seven letters (8%) were returned as undeliverable. Letters were mailed on March 18<sup>th</sup>, 2021, and responses were collected through May 31<sup>st</sup>, 2021. Clients were given the option to complete the survey online via Qualtrics, print and mail the survey, or call and request a copy to be mailed to them. Upon completion of the survey, participants were offered a \$25 Wal-Mart gift card. The gift card information was collected in a separate survey to maintain the anonymity of the participants.

Participants could select more than one race as it applies to them. The multiracial responses were compressed into multiple-race categories. Those who reported a single race were reported as that race. Participants who reported two races where one was white were recoded as then non-white race. Those who reported more than one non-white race were recoded as the first non-white race reported. The uncompressed reported races can be found in the Appendix at the end of the report.

This needs assessment survey was followed up by telephone interviews with participants who indicated they would like to provide additional feedback.

## Results

Of the 452 potential participants, 100 (22.1%) responses were received. Of those, 93 (93%) were used for this analysis. Seven were excluded due to having limited data reported.

## DEMOGRAPHICS

Participants ranged in age from 17 to 77 years with an average of 46 years. Of the 93 respondents, 58 (62.4%) identified as male and 32 (34.4%) females. No respondents identified as transgender. Fifty-three (57.0%) of respondents identified as White or Caucasian, while 30 (32.3%) of respondents identified as Black or African American. Only 4 respondents identified as Native American, and one person identified as Asian or Pacific Islander. Seventy-four (79.6%) respondents identified as Non-Hispanic and eight (8.6%) identified as Hispanic. Sixty-one of the 93 respondents (67.7%) reported being enrolled in Ryan White.

Figure 1: Race of the Survey Respondents

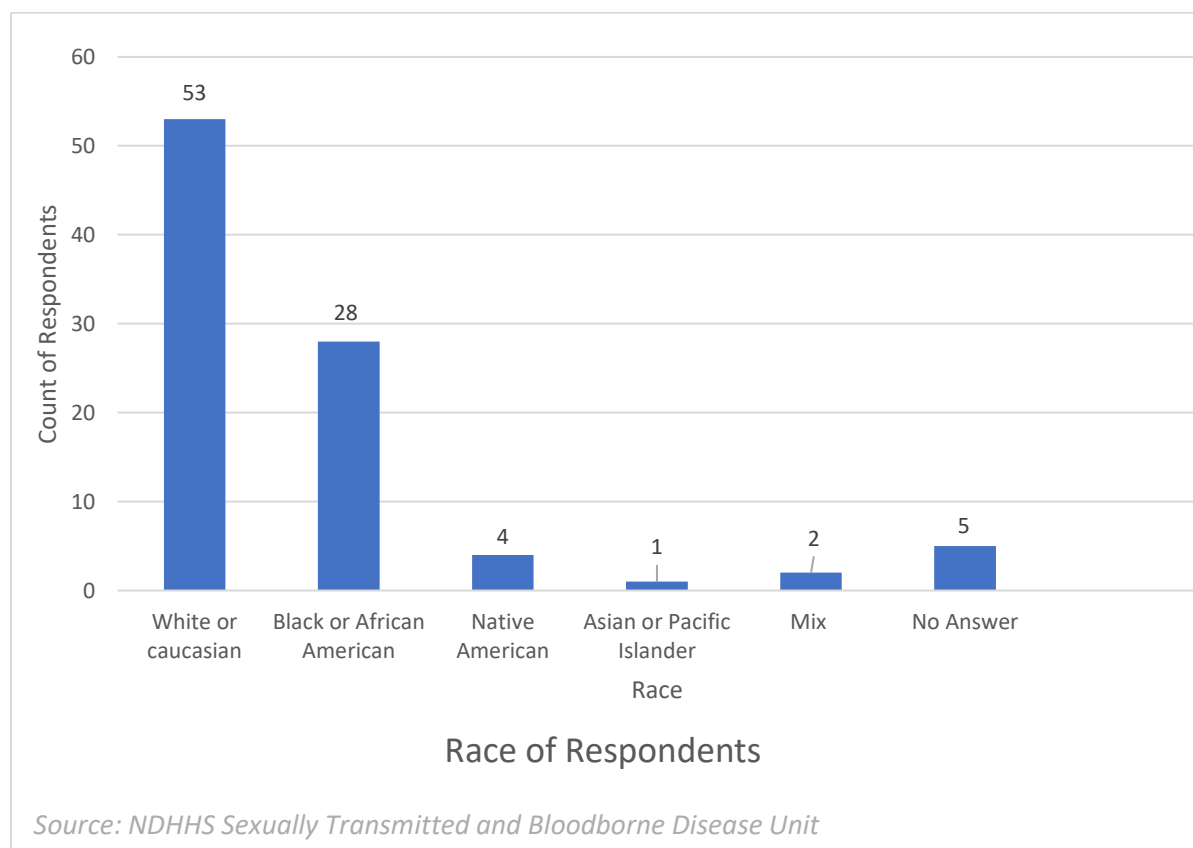


Figure 2: Age of the Survey Respondents

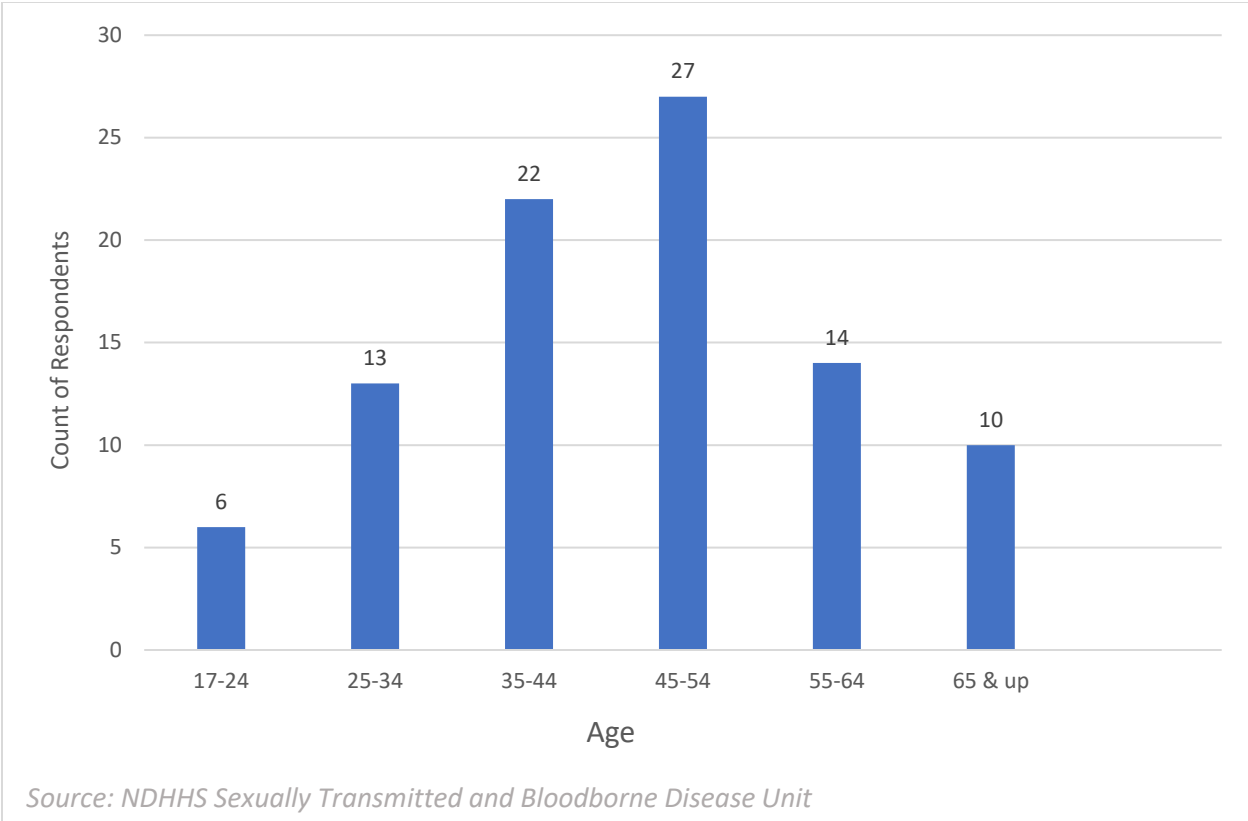
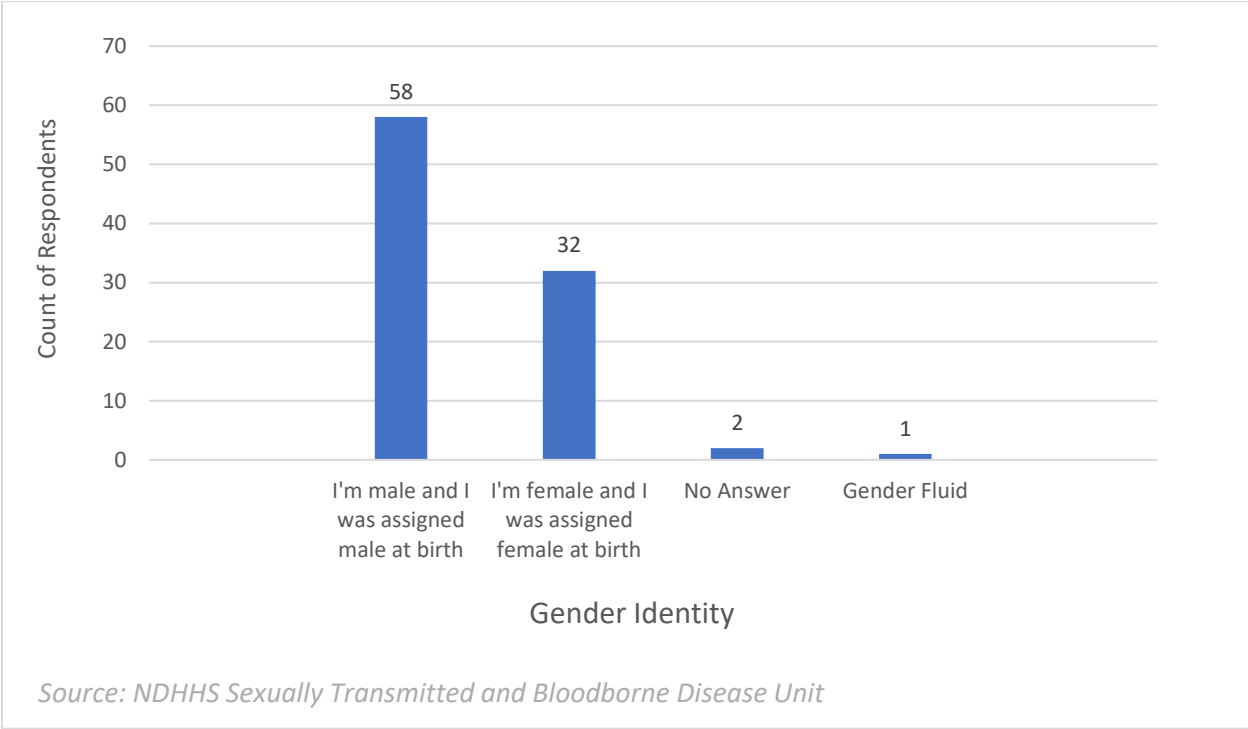


Figure 3: Gender Identity of Survey Respondents



## OUTPATIENT/AMBULATORY HIV MEDICAL CARE

Of the 93 respondents, some identified not knowing where to go (3), other priorities (3), and not feeling sick (3) as top reasons for not seeking medical care. Other barriers identified were cost (2), transportation (2), and access to transportation and childcare. Due to the small number of responses, it is not possible to do a robust subgroup analysis.

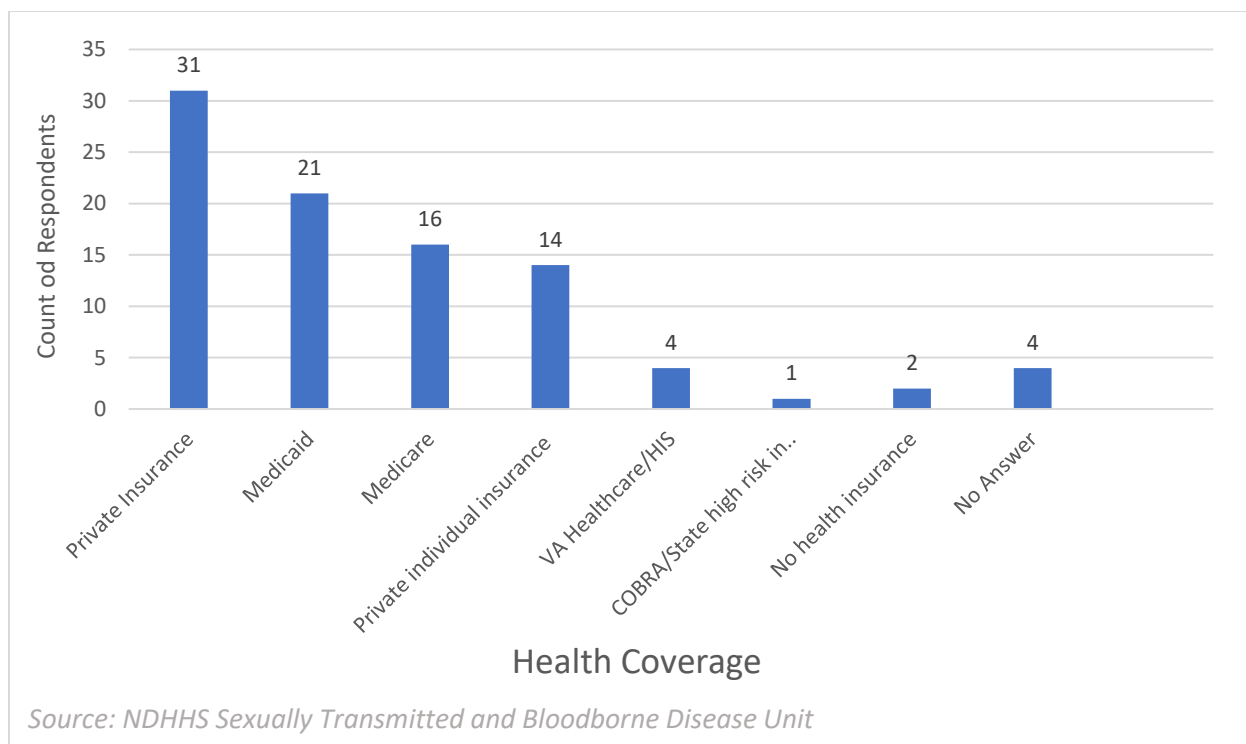
Of the 93 respondents, 86 (92.5%) reported taking their medication as prescribed. Of those who reported not taking their medication as prescribed, the most common reasons for not adhering were not being able to get their prescription filled (2), feeling healthy (2), or the medication making them feel sick (2).

## HEALTH COVERAGE

Most participants were covered by Medicare (24.7%), followed by Medicaid (23.7%), and Private-individual insurance paid by Ryan White (21.5%). Only one person reported paying exclusively out of pocket for their care. This respondent also reported being enrolled in Ryan White.

Of those who stated they did not have coverage, only two participants gave reasons, and they were cost of insurance and having proper residency documents. Some who stated they have health insurance also gave barriers to obtaining other health insurance. These reasons were being told they did not qualify (2), not knowing where to get insurance (2), not being able to afford it (1), and not being a priority (1).

Figure 4: Health Coverage of Survey Participants



## MEDICAL SERVICES

All participants were asked whether they needed, received, and were satisfied with medical services including Ryan White covered core services such as outpatient HIV-related medical care, prescription drugs, mental health care, substance use treatment services, dental care, and vision care. Participants were also asked about access to services not covered by Ryan White such as inpatient medical care, emergency room care, and maternity and newborn care.

Of the 93 participants, 42 (45.2%) needed and received outpatient medical care. Of those, twenty (47.6%) stated their needs were met by the services; the rest (52.4%) either did not respond or entered an uninterpretable response. All the responses are displayed below. Most participants who received services did not respond to the question pertaining to whether their needs were met with that service. Mental health, dental care, and vision care had the highest unmet need. Numbers of people reported needing these services and not receiving them.

Figure 5: PLWH and Care Services

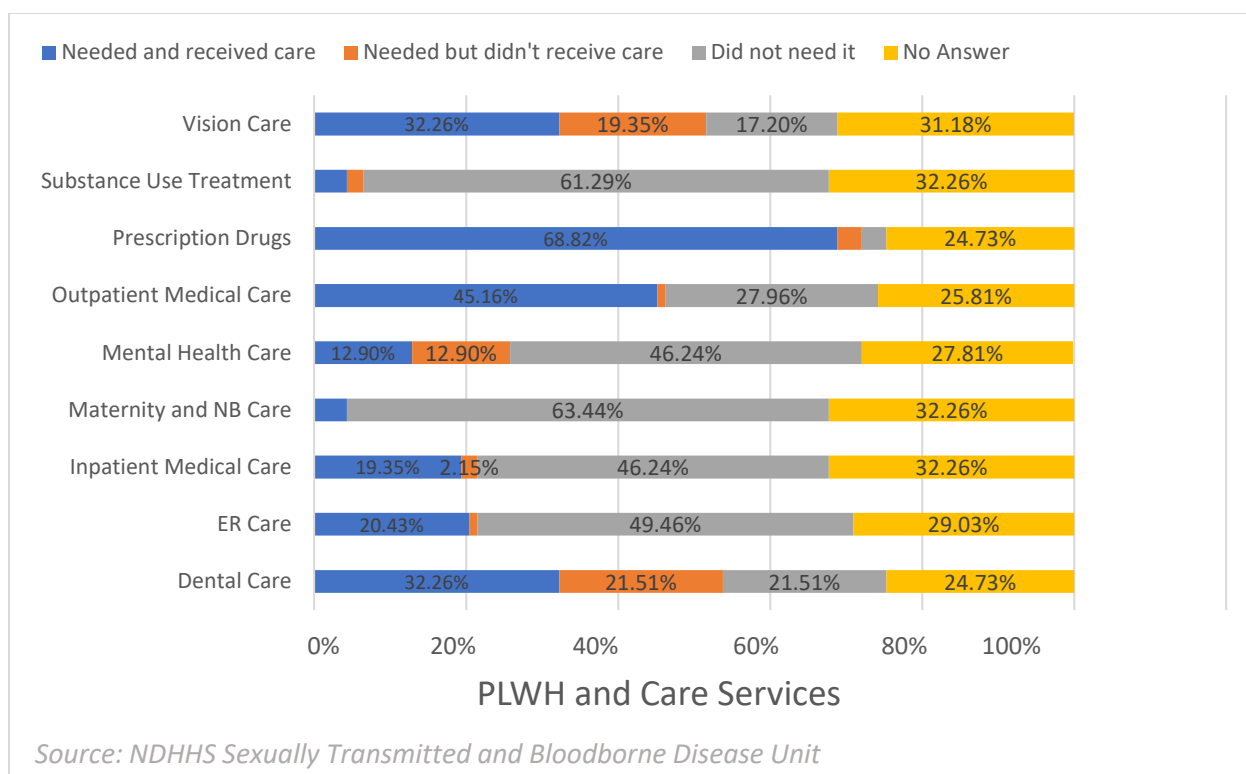
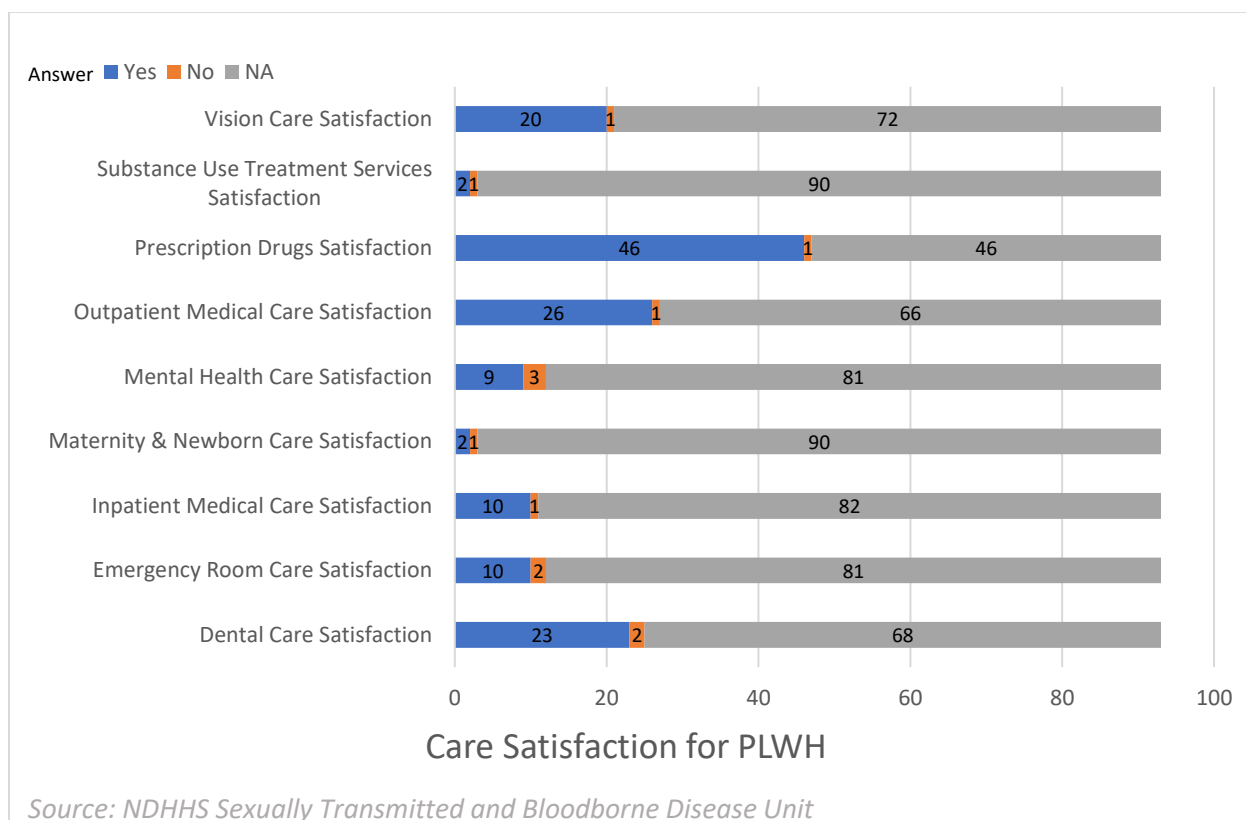


Figure 6: Care Satisfaction for PLWH



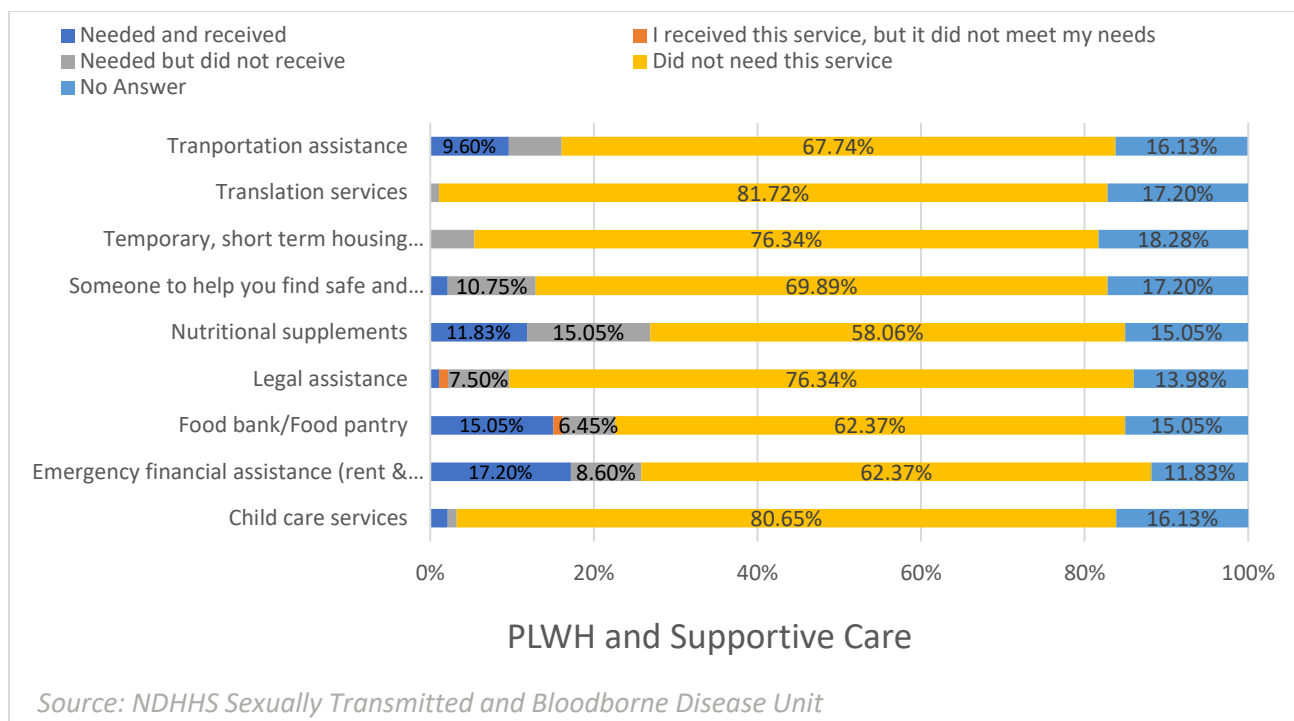
Fifty-two participants (55.9%) reported that they had received all the care they needed. Out of the 41 participants who did not receive all the care they needed, the most common reason cited was not being able to afford the care or insurance not covering medical care (15.1%). Other commonly cited reasons for not seeking care were not knowing where to go (6.5%), feeling too overwhelmed (6.5%), and having other priorities (4.3%). Other reasons written in were COVID, having no medical issues, and doctors not setting up referral appointments.

## SUPPORTIVE CARE

Respondents were asked about what support services they used in the last year and whether that service met their needs. Support services included emergency-financial assistance for rent and utilities, transportation assistance, nutritional supplements, help with finding housing, short-term housing, food bank/food pantry, childcare, legal services, translation services, and other. Psychosocial services include different types of counseling (individual, group, crisis/emergency, and peer-support). Psychosocial services and assistance with EFA, transportation and nutritional supplements are reimbursed through Ryan White. Other services are available through local agencies such as Community Action, Medicaid, and other programs for low-income persons.

Majority of participants (21.5%) did not need supportive services. Top three support services that participants stated they needed but did not receive are nutritional supplements (16.1%), help with finding affordable housing (10.7%), and emergency financial assistance for rent and utilities (8.6%). Additional services identified through the open-ended other option were filling out taxes, dental services, and paying medical copays. The most cited reason for people not receiving supportive services was feeling too overwhelmed (10.8%), not knowing where to go (8.6%), financial concerns about paying for it (4.3%), and having other priorities (4.3%). Ten participants did not respond to this question. There is a significant difference in emergency financial assistance usage and overall service usage between those who are enrolled in Ryan White and those who are not enrolled. There is not a significant difference by reported race.

Figure 7: PLWH and Supportive Care



## Psychological Services

Participants were asked about how their psychosocial service needs were addressed throughout the last year. The forms of psychosocial support services discussed were Individual, group, crisis, and peer support counseling. Many participants indicated that they needed psychosocial services but did not receive them. Group counseling had the highest need where 19 participants (20.4%) stated they needed but did not receive the service. The most common responses for not receiving counseling services were not knowing where to go (10.7%), feeling overwhelmed (8.6%), and not being able to afford the needed services (6.4%). Participants were given the opportunity to write in their own reasons and four people identified COVID as a reason for not seeking care in the last year. One person specifically said that the group they wanted to attend was shut down due to COVID.

## SUPPORT AND NETWORK COMMUNICATION

Participants were asked about who they get support from and how often they receive support. People at church or in the community were most identified as not being a source of support. The support received was split between spouse/partner, family, friends, people in their community, employer, or other. Only six of the 93 respondents (6.4%) indicated that they never or rarely receive support from these sources.

When asked about how they prefer to communicate with their Ryan White case managers or providers, over 50% identified that in-person meetings were preferred. Virtual meetings were the least preferred method of communication, but those who preferred it tended to be younger. The younger respondents were open to different types of communication, including virtual communication, while the older participants preferred methods like in-person, telephone, email, and paper mail.

When asked how individuals prefer to meet or communicate with others living with HIV, 40 (43%) stated they did not want to attend group support or meetings with other persons living with HIV. Those who did wish to talk preferred a group setting compared to individual meetings. Another option identified in the write-in option was communication apps like Twitter and "gay apps". The group was divided on whether they preferred public meetings versus private ones.

While most participants preferred some version of face-to-face or telephone communication, only 5 (5.4%) reported not having any access to the internet. Most respondents (78.5%) reported having access to a smartphone or tablet and overall (86.0%) reported either having a smartphone, tablet, or home computer. Overall, most participants reported being comfortable using a computer, but 8.6% reported being uncomfortable using a computer. Participants who reported being uncomfortable using computers were over the age of 45.

## HOUSING

Most participants (80.6%) reported renting or owning an apartment or home. Nine participants (9.6%) reported that they are temporarily living with a family member or friend. None of the participants reported living in a homeless shelter or domestic violence shelter. Four respondents (4.3%) indicated that they have spent at least one day homeless/without a place to sleep. All four of those reported that they at a minimum had a place to stay at the time of the survey, though two of them identified their living situation as temporary.

Housing situations varied significantly by race. Black/African American participants were more likely to be renting than owning. When asked about barriers to affordable housing, bad credit (7.5%), not having money for the deposit (6.5%), and trouble finding affordable housing (5.3%) were identified as barriers to obtaining housing. Other common answers were not qualifying for housing assistance, needing transportation to search for housing, being put on a waiting list, and having a criminal record.

Of the 93 responses, 30 (32.3%) reported having difficulty paying rent/mortgage or utility bills in the past year. Participants were asked about factors related to housing that

stop them from taking care of their HIV and the most common response was that people did not want housemates to know they have HIV (14%).

## **SUBSTANCE USE**

Of the 93 participants, 35.5% reported they use tobacco/nicotine, 35.5% use alcohol, and 19.6% use marijuana. Additionally, participants reported using injected (1.1%) and non-injected (10.8%) prescriptions or street drugs. Twenty-five percent reported not using any of the listed substances.

## **SEXUAL ACTIVITY**

Of the 93 participants, 48 (51.6%) reported that they did engage in sexual activity in the last year. Of those who reported having sex, most reported that they only had one partner in the last year.

## **HIV TRANSMISSION KNOWLEDGE**

Participants identified their sources of information about HIV transmission. The top four responses were Infectious Disease provider (61.3%), Ryan White case manager (37.6%), Internet/TV/social media (28.0%), and primary care provider (22.6%). Eight (8.6%) participants said they do not receive HIV information.

Participants were then asked to identify HIV-related topics health professionals have discussed with them including ways to prevent transmission of HIV, how to use condoms, importance of taking antiretrovirals for treatment of HIV, discussing their status, and others. The most common topics discussed were importance of medication for lowering the viral load (44.1%), ways to prevent HIV transmission (32.3%), and that they should be tested annually for other STDs (21.5%). Thirty individuals (32.3%) responded that none of the listed topics were discussed with them in the past year.

## **STIGMA**

Participants were asked about their experiences and beliefs about stigma around HIV. Participants were asked to agree or disagree with a series of statements. Most participants disagreed with statements about losing friends/family due to HIV. Participants agreed that telling someone they have HIV is difficult, that they are very careful who they tell they have HIV, and that they hide their HIV status from others.

Participants also agreed that people with HIV are treated like outcasts, that people believe that a person who has HIV is dirty, and that they feel that most are uncomfortable around someone with HIV.

Participants were also asked about negative experiences they've had due to their HIV status. The most cited negative experience is people talking behind their backs with 46.2% reporting this outcome. Other highly reported experiences were sexual rejection (30.1%), verbal insults/harassment/threats (20.4%), and being excluded from social events (19.4%). Within the free written comments on this question people mentioned avoiding negative experiences by not disclosing their status or disclosing to only a small group of people. Another free written comment mentioned an experience where friends will ask about open wounds before coming into physical contact with them (high fives).

Participants identified mental illness (depression and anxiety), withdrawal and isolation from support groups, and missed days of work and income loss as impacts of discrimination and stigma. Most participants (82.8%) did not respond to a question pertaining to who specifically they felt discriminated or stigmatized from in the past 12 months. Those who did respond reported discrimination from office staff, doctors (infectious disease, primary care, emergency room), nurses (infectious disease, emergency room), and dentists/dental hygienists at roughly equal rates.

Respondents were asked to identify actions they've taken to combat discrimination/stigma and most said that they have not done any of the provided actions themselves. People who did act mostly confronted, challenged, or educated were the ones who were discriminating against them or someone else with HIV. Participants were asked to recommend what organizations should do to address stigma/discrimination. Over 50% of respondents suggested more education about HIV.

## Conclusion

Certain challenges come up across all surveyed categories. A common challenge unique to years 2020 and 2021 was COVID. Disruption of care and support networks due to COVID came up across all categories. Some participants noted COVID's impact on employment while others noted its impact on normal support groups that had to be canceled or modified due to COVID. It is also possible that COVID contributed to the large number of people who noted being overwhelmed and having other priorities in the last year. While this impact is hard to quantify, we can learn from unique support and care models that emerged in the last year. While virtual platforms emerged in the last year, this survey highlights that many participants in North Dakota still prefer in-person and telephone communication methods.

A second barrier cited is affordability. Across categories, having money to pay for medical and support services is a barrier to many participants. Some of these participants are already enrolled in Ryan White and others may qualify, but financial concerns are still a challenge for many PWH in the state. Financial concerns for citizens who do not qualify for Ryan White was a topic that came up consistently within the free write sections. At least one participant self-identified as being over the income guideline to qualify for Ryan White, but still needed financial help getting medication and care. There is also challenge with accessing services that Ryan White does not cover such as medical care not related to HIV, inpatient or emergency room care, and assistance with rental deposits.

A third common challenge is not knowing where to go for help or services. Respondents highlighted not knowing what services were available to them, what health coverage they qualify for, or how to find affordable housing. Both RW and non-RW clients noted needing help finding services and affordable care. Participants specifically noted needing money for rent and utilities as barriers to care. Along with not knowing where to go, many said they do not have transportation to get to the locations where services and care are provided. In a rural state like North Dakota, distance to care and services is a barrier for many. Ryan White does provide transportation assistance in a form of a bus ticket or a gas card, but for participants who are not RW clients or who do not have their own car and live in a rural area, transportation is a barrier.

Another common challenge is choosing to not get care. Common responses within this category were participants stating they thought treatment would not help, that HIV was manageable without treatment, or that treatment was not necessary because they felt good. Regular medical care and treatment are essential, so PWH need more education on the importance of regular medical care and treatment both in preserving and improving one's own health and in preventing transmission of HIV.

Stigma and discrimination were expected barriers and they came up consistently. Those who identified stigma/discrimination as a barrier identified concerns about not wanting people to know they have HIV. When broken down by potential misconceptions, participants identified people with HIV as being treated like outcasts or "dirty" when interacting with others. Participants reported being careful about who they tell about their HIV status or even hiding it. They reported that other people's attitudes about HIV made them feel worse about themselves. They also reported a wide range of social situations that HIV has impacted such as sexual rejection, social exclusion, and people talking about them behind their back.

Discrimination and stigma also impacted their mental, social, and economic health. While we cannot identify which specific experiences had most negative impact, responses note that PWH in North Dakota are experiencing negative social

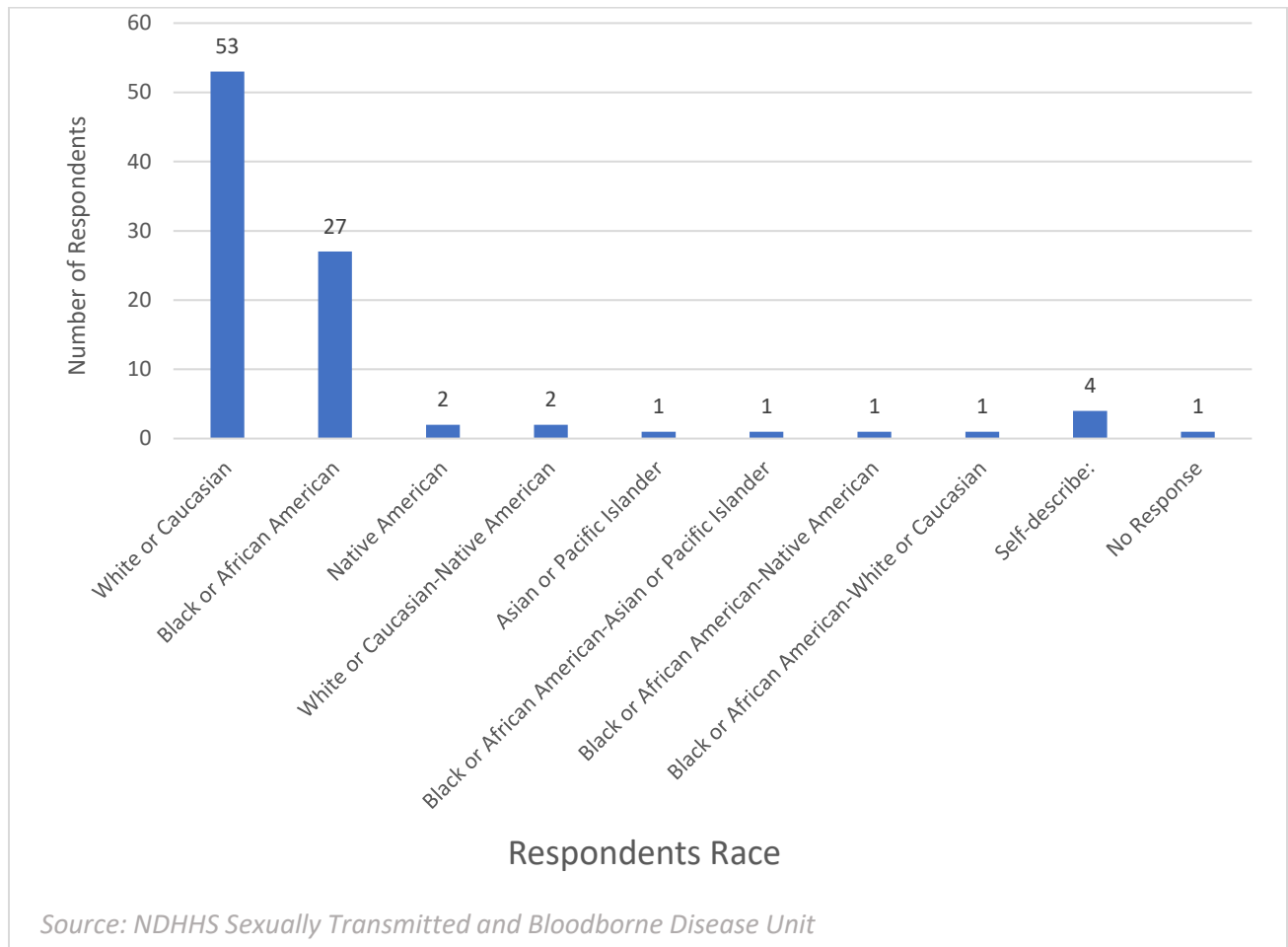
consequences of their diagnosis. This impact is felt within their relationships (romantic, platonic, and familial), their mental health, and in the workplace. The wide-reaching umbrella means that addressing these issues will require a multifaceted approach to create an environment of understanding and inclusion.

Discrimination was not limited to social situations and participants reported feeling discriminated against or stigmatized by health care providers including doctors, nurses, public health officials, and dentists/hygienists. Participants recommended as a solution a wide range of advocacy, but the number one suggested action for organizations was to educate people about HIV. There are still misconceptions about HIV and educating the public about HIV should continue to be a priority. Persons with HIV can also be part of the solution by speaking out about their experience, providing peer support to others, and providing input through various community boards.

Survey concluded by asking participants to write about what they wish they knew when they were diagnosed or what they would like others to know. Many participants reported feeling that their lives were over when they got their HIV diagnosis, and that the diagnosis was a death sentence. With that mindset, many believed their lives were going to be short and painful, so they pulled out of relationships and regret it. Participants encouraged more education of both the general population and health care professionals. A few reported negative experiences with doctors and health department staff that they feel can potentially be rectified with sensitivity training. Another common theme within the essay questions was a general lack of qualified and sensitive care, particularly around vulnerable and stigmatized groups. These groups include the LGBTQ+ community, those who use injection drugs, sex workers, and those who are incarcerated. One participant reported that their doctor gave them factually inaccurate information, so knowledge gaps exist across the healthcare spectrum and more education would benefit everyone.

## Appendix A: 2021 North Dakota HIV Needs Assessment

Figure 1: Race of Respondents



# Appendix B: 2021 North Dakota HIV Needs Assessment

## 2021 North Dakota HIV Needs Assessment

The North Dakota Department of Health is distributing this questionnaire in order to identify needs and barriers to care faced by individuals living with HIV in North Dakota. The information gathered from this survey will help improve access to healthcare services for persons living with HIV. The completion of this survey is **voluntary and you can end the survey any time**. Information collected through this survey is confidential and anonymous. Your services will not be affected by whether you complete this survey or not.

Each individual is only allowed to take this survey ONE TIME. This survey should take 20-30 minutes to complete. As a 'thank you' for completing the survey, **you will receive a \$25 gift card to Walmart**, if you choose to return the completed gift card request form. Do not provide your name, email, or mailing address anywhere else on the survey, to ensure you remain anonymous.

**Risks:** Some of the questions in the survey may be uncomfortable. You may end the survey any time if you wish. To ensure your responses are anonymous, be sure not to include your name or contact information in the survey and to mail it separately from the gift card request form.

**Benefits:** The information gathered will help improve services provided to individuals with HIV.

Please call the North Dakota Department of Health at 701-328-2378 with any questions about this survey. This survey is also available online at: [health.nd.gov/HIVsurvey](https://health.nd.gov/HIVsurvey)

## Demographics

1. How would you describe your gender?
  - a. I'm male and I was assigned male at birth
  - b. I'm male and I was assigned female at birth
  - c. I'm female and I was assigned female at birth
  - d. I'm female and I was assigned male at birth
  - e. I'm non-binary or genderqueer

- f. Self-Describe: \_\_\_\_\_
2. Which of the following best describes you?
- a. Heterosexual/straight
  - b. Gay/lesbian
  - c. Bisexual
  - d. Prefer not to answer
  - e. Self-Describe: \_\_\_\_\_
3. What is your age? \_\_\_\_\_
4. What ND county do you reside in? \_\_\_\_\_
5. How would you define your race? (circle all that apply)
- a. Black or African American
  - b. White or Caucasian
  - c. Asian or Pacific Islander
  - d. Native American
  - e. Self-Describe: \_\_\_\_\_
6. What is your ethnicity?
- a. Hispanic
  - b. Non-Hispanic
  - c. Self-Describe: \_\_\_\_\_
7. What country were you born in?
- a. United States
  - b. Outside the United States, please list: \_\_\_\_\_
8. What is the highest level of education you have completed?
- a. Less than high school
  - b. High school graduate/GED
  - c. Some college but no degree
  - d. Associate's degree/technical school
  - e. Bachelor's degree or higher
9. What is your average annual household income?
- a. <\$10,000
  - b. \$10,000 to \$30,000
  - c. \$30,000 to \$50,000
  - d. Over \$50,000

10. How many household members are in your household including you?

\_\_\_\_\_

11. What is your current employment status?

- a. Unemployed
- b. Employed full-time
- c. Employed part-time
- d. Other: \_\_\_\_\_

12. If you are not working, why not?

- a. Disabled
- b. Retired
- c. Student
- d. Between Work/Looking for a Job
- e. Criminal Background
- f. Not applicable
- g. Other: \_\_\_\_\_

## HIV Medical Care

13. What is your HIV/AIDS status?

- a. Diagnosed with HIV Infection
- b. Diagnosed with AIDS (ever had a CD4 count lower than 200 cells/mm)
- c. Don't know

14. In what year were you first diagnosed with HIV? \_\_\_\_\_

15. How do you believe you got HIV? (circle all that apply)

- a. Consensual sex with a man
- b. Consensual sex with a woman
- c. Sexual Assault/Intimate Partner Violence
- d. Blood transfusion
- e. Sharing of injection equipment
- f. Perinatal (mother to child)
- g. I do not know
- h. Other: \_\_\_\_\_

16. How would you describe your overall health today?

- a. Excellent

- b. Very good
- c. Good
- d. Fair
- e. Poor

17. If you chose fair or poor health for #16, do you believe that is due to your HIV infection?

- a. Yes
- b. No
- c. Not applicable

18. How many HIV-related medical care visits did you have with provider in the last year?

- a. Two or More
- b. One
- c. None
- d. I do not have a HIV care provider

19. If you have not received HIV medical care in the last year, what were the reasons? (circle all that apply)

- a. Not applicable, I have received HIV medical care
- b. I didn't know where to go
- c. I couldn't get an appointment
- d. I couldn't get transportation
- e. I couldn't get childcare or time off from work
- f. I couldn't afford it
- g. I had other things on my mind/other priorities
- h. I didn't want anyone to know I was living with HIV
- i. I didn't feel sick
- j. I had a language or cultural barrier
- k. Other: \_\_\_\_\_

20. Where do you regularly receive your HIV-related medical care? (circle all that apply)

- a. Infectious disease provider
- b. Primary care provider
- c. Emergency room (ER)
- d. VA hospital/clinic
- e. Community health center
- f. I don't regularly receive medical care

g. Other: \_\_\_\_\_

21. At your last HIV medical care provider visit, what was your reported viral load?
- a. Virally suppressed or <200 copies/mL
  - b. 201 - 10,000 copies/mL
  - c. More than 10,000 copies/mL
  - d. I don't know
  - e. I have never had HIV laboratory tests.
22. Are you currently taking HIV medications as prescribed to you by a doctor?
- a. Yes, I take my medications as prescribed
  - b. No, I do not take medications as prescribed
  - c. No, I have never been prescribed HIV medications
23. If you answered no to the question above, what were your reasons? (circle all that apply)
- a. I haven't seen a doctor yet/no prescription prescribed.
  - b. I couldn't get my prescription filled
  - c. I couldn't afford them
  - d. They made me feel sick
  - e. I needed a break
  - f. I felt healthy
  - g. I had trouble remembering to take them
  - h. I didn't have transportation to the pharmacy
  - i. I was concerned what others will think
  - j. I did not want charges to appear on my insurance explanation of benefits statement
  - k. Other: \_\_\_\_\_

## Health Insurance

24. Are you currently enrolled in the Ryan White program in North Dakota?
- a. Yes
  - b. No
25. How are your HIV-related medical care and medications covered? (circle all that apply)
- a. Medicaid
  - b. Medicare
  - c. Private employer insurance
  - d. VA Healthcare/IHS

- e. COBRA/State High-risk insurance pool
- f. Private individual insurance paid by the Ryan White program
- g. I am enrolled in the Ryan White program, but I do not have health insurance
- h. I do not currently have any health coverage – pay out of pocket
- i. Other: \_\_\_\_\_

26. If you do not currently have health insurance, what is preventing you from getting insurance? (circle all that apply)
- a. Not applicable, I have health insurance
  - b. I can't afford it
  - c. I don't know where to get insurance
  - d. I was told I don't qualify
  - e. I don't have proper U.S. residency (immigration) documents
  - f. It is not a priority for me at this time
  - g. I can't use due to sexual orientation or gender identity
  - h. It is confusing, I don't understand what I need to do
  - i. Other: \_\_\_\_\_

## Medical Services

27. In the last 12 months, please indicate whether or not you needed, received, or did not receive the following types of medical care. (Place an X where appropriate)

	Did not need this service	Needed and received care	Needed but <u>did</u> <u>not</u> recei ve care	If you received this service, did it meet your needs? (yes/n o)
<b>Outpatient Medical Care</b>				
<b>Prescription Drugs</b>				
<b>Inpatient Medical Care</b>				
<b>Emergency Room Care</b>				
<b>Mental Health Care</b>				
<b>Maternity &amp; Newborn Care</b>				
<b>Substance Use Treatment Services</b>				
<b>Dental Care</b>				

<b>Vision Care</b>				
--------------------	--	--	--	--

28. If you needed healthcare but did not receive services, what was the reason? (circle all that apply)

- a. Not applicable, I received all the services I needed
- b. I couldn't afford it/insurance didn't cover it
- c. I didn't know where to go
- d. I didn't have transportation
- e. I had other priorities
- f. I was too overwhelmed
- g. The clinic is too far away
- h. The office wasn't open when I could get there
- i. I couldn't get an appointment quickly enough
- j. I thought I could handle it without treatment
- k. I didn't think getting treatment would help
- l. I was worried what people would think
- m. I had a language or cultural barrier
- n. I have experienced or expect to experience discrimination
- o. Other: \_\_\_\_\_

29. What conditions have you been diagnosed with in the last 12 months or are currently living with? (circle all that apply)

- a. Chronic diseases (high blood pressure, high cholesterol, diabetes, etc.)
- b. Hepatitis B
- c. Hepatitis C
- d. Substance use disorder
- e. Sexually Transmitted Infection(s)
- f. Other: \_\_\_\_\_
- g. None of the above

### Supportive Care

30. In the past 12 months, please indicate whether or not you needed, received or did not receive the following types of supportive services. (Place an X where appropriate)

	Did not need this service	Needed and received	Needed but <u>did not</u> receive	I received this service, but it did not
--	---------------------------	---------------------	-----------------------------------	---

				meet my needs
Emergency financial assistance (rent & utilities)				
Transportation assistance				
Nutritional supplements				
Someone to help you find safe and affordable housing				
Temporary, short-term housing (shelter, or money for hotel/rent/mortgage)				
Foodbank/food pantry				
Childcare services				
Legal assistance				
Translation services				
Other:				

31. If you needed supportive services but did not receive them, what was the reason? (circle all that apply)

- a. Not applicable, I did receive all the services I needed
- b. I couldn't afford it/insurance didn't cover it
- c. I didn't know where to go
- d. I didn't have transportation
- e. I had other priorities
- f. I was too overwhelmed
- g. The clinic is too far away
- h. The office wasn't open when I could get there
- i. I couldn't get an appointment quickly enough
- j. I thought I could handle it without treatment
- k. I didn't think getting treatment would help

- l. I was worried what people would think
- m. I had a language or cultural barrier
- n. I have experienced or expect to experience discrimination
- o. Other: \_\_\_\_\_

## Psychosocial Services

32. In the past 12 months, please indicate whether or not you needed, received, or did not receive the following types of supportive services? (Place an X where appropriate)

	Did not need this service	Needed and received	Needed but <u>did not</u> receive	I received this service, but it did not meet my needs.
Individual counseling				
Group counseling/support groups				
Crisis/Emergency counseling				
Peer Support counseling				

33. If you needed counseling services but did not receive them, what was the reason? (circle that apply)

- a. Not applicable, I received all the services I needed
- b. I couldn't afford it/insurance didn't cover it
- c. I didn't know where to go
- d. I didn't have transportation
- e. I had other priorities
- f. I was too overwhelmed
- g. The clinic is too far away
- h. The office wasn't open when I could get there
- i. I couldn't get an appointment quickly enough
- j. I thought I could handle it without treatment
- k. I didn't think getting treatment would help
- l. I was worried what people would think
- m. I had a language or cultural barrier
- n. I have experienced or expect to experience discrimination
- o. Other: \_\_\_\_\_

34. Over the past 12 months, how often would you say you have received support from:  
(Place an X where appropriate)

	Always	Often	Less Often	Rarely	Never	N/A
<b>Spouse or partner</b>						
<b>Family members</b>						
<b>Friends</b>						
<b>People at church/community</b>						
<b>Employer</b>						
<b>Other:</b>						

35. How do you prefer to meet or communicate with your case manager or provider? (circle all that apply)

- a. Meet in-person
- b. Virtually online via Zoom or another platform
- c. Telephone call
- d. Email
- e. Texting
- f. Paper mail

36. How do you prefer to meet or communicate with other persons living with HIV? (circle all that apply)

- a. Group in-person meetings in a confidential or private area
- b. Group activities in a social setting (e.g., lunch or dinner, boat ride)
- c. Group virtual online meetings via Zoom or another platform
- d. Group telephone calls
- e. Individual in-person meetings with a peer advocate
- f. Individual online meetings with a peer advocate
- g. Individual calls with a peer advocate
- h. I am not interested in support groups or meetings with others who are living with HIV
- i. Other: \_\_\_\_\_

37. Do you have internet access? (circle all that apply)

- a. Smartphone or a tablet
- b. Home computer
- c. Other: \_\_\_\_\_
- d. No internet access

38. I feel comfortable using a computer.

- a. Strongly agree
- b. Agree
- c. Neutral
- d. Disagree
- e. Strongly disagree

## Housing

39. What is your current living situation?

- a. Renting an apartment/house/mobile home
- b. Own an apartment/house/mobile home
- c. Temporarily live with family or staying with someone else
- d. Homeless shelter or domestic violence shelter
- e. In a facility
- f. In jail or prison
- g. Other: \_\_\_\_\_

40. In the past 12 months, how many nights did you spend homeless or without a place to sleep?

- a. None
- b. 1-7
- c. 7-30
- d. More than 30 days

41. What barriers did you have in obtaining affordable housing in the past 12 months? (circle all that apply)

- a. None, I have access to stable and affordable housing
- b. I didn't have enough money for the deposit
- c. I couldn't find affordable housing
- d. I was put on a waiting list
- e. I had no transportation to search for housing
- f. I had bad credit
- g. I didn't qualify for housing assistance
- h. I had a criminal record

- i. I had a mental/physical disability
- j. I felt discriminated against
- k. I had substance issues
- l. Other: \_\_\_\_\_

42. Have you had difficulty paying rent/mortgage or utility bills in the past 12 months?

- a. Yes
- b. No

43. In the past 12 months, have you received any of the following? (circle all that apply)

- a. Emergency rent/utility assistance through Ryan White
- b. Section 8/Housing voucher
- c. TBRA/HOPWA assistance
- d. STRMU/HOPWA assistance
- e. Other: \_\_\_\_\_
- f. I have not received any housing assistance in the past 12 months

44. Do you believe that your current home/living situation is in a safe area?

- a. Yes
- b. No
- c. N/A, I am homeless

45. Thinking about your housing situation now, do any of the following stop you from taking care of your HIV/AIDS? (circle all that apply)

- a. I don't have a private room
- b. I don't have a place to store my medications
- c. I don't have a telephone where someone can call me
- d. I don't have enough to eat
- e. I don't have money to pay rent
- f. I don't have heat and/or air conditioning
- g. I don't want anyone to know I'm HIV positive
- h. I can't get away from drugs in my neighborhood
- i. None of the above

### Other Health Questions

46. Have you used any of the following during the past 12 months? (circle all that apply)

- a. Tobacco or nicotine

- b. Alcohol
  - c. Marijuana
  - d. Prescription or street drugs – injected
  - e. Prescription or street drugs – not injected
  - f. Other: \_\_\_\_\_
  - g. None of the above, I have not used any substances
47. In the last 12 months, have you been sexually active?
- a. Yes
  - b. No
48. If yes, how many partners have you had in the last 12 months?
- a. 1
  - b. 2-5
  - c. More than 5
  - d. Not applicable

### HIV Transmission

49. Where do you receive information about HIV transmission? (circle all that apply)
- a. Infectious disease provider
  - b. Ryan White case manager
  - c. My primary care provider
  - d. Local public health
  - e. HIV support group
  - f. Brochures and/or handouts
  - g. Friends/family/my partner
  - h. Internet/TV/social media
  - i. Mobile app
  - j. Other \_\_\_\_\_
  - k. I do not receive information
50. In the last year, has a health professional discussed the following information with you? (circle all that apply)
- a. Ways to prevent the transmission of HIV
  - b. How to use condoms
  - c. How taking medication lowers your viral load and prevents spread of HIV
  - d. That I should be tested for other STDs annually
  - e. How to discuss status
  - f. Legal issues and criminalization of HIV

- g. How to protect HIV-negative partners with PrEP
- h. No one has explained any of these things to me in the last year

## Stigma

The following section discusses yourself perceptions about any HIV-related stigmas you may feel. Please answer as honestly about your own personal experience.

51. Please let us know how you feel about the following statements.

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
People avoid touching me if they know I have HIV.					
People I care about stopped calling after learning I have HIV.					
I have lost friends by telling them I have HIV.					
Telling someone I have HIV is difficult.					
I hide my HIV status from others.					
I am very careful whom I tell that I have HIV.					
Concerns about public attitudes					
People with HIV are treated like outcasts.					
Most people believe that a person who has HIV is dirty.					
Most are uncomfortable around someone with HIV.					
I feel guilty because I have HIV.					

<b>People's attitudes about HIV make me feel worse about myself.</b>					
<b>I feel I'm not as good as others because I have HIV.</b>					

52. Have any of the following negative things have ever happened to you because of your HIV status (circle all that apply)

- a. I'm aware people have been gossiping about me and my HIV status
- b. I have been verbally insulted, harassed, and/or threatened
- c. I have been excluded from social gatherings or activities
- d. I have been excluded from family activities
- e. I have been physically harassed and/or threatened
- f. I have experienced sexual rejection as a result of my HIV status
- g. I have been discriminated against
- h. Other negative experiences:

\_\_\_\_\_

i. I have not experienced any of these due to my HIV status

53. Which of the following have you experienced as a result of stigma/discrimination?

- a. Depression
- b. Anxiety
- c. Withdrawing from family/friends
- d. Income loss
- e. Skipped doses of medication
- f. Increased drug or alcohol intake
- g. Withdrawing from faith-based or spiritual support
- h. Avoiding healthcare
- i. Avoiding social support
- j. Reduced exercise, physical activity or sleep
- k. Missed days at work or school
- l. Other experiences: \_\_\_\_\_
- m. None of the above

54. Which of the following types of healthcare workers do you feel you were discriminated against or stigmatized by in the last 12 months due to your HIV status? (circle all that apply)

- a. Office staff

- b. Infectious disease doctor
- c. Infectious disease nurse
- d. Primary Care doctor
- e. Emergency Room Doctor
- f. Emergency Room Nurse
- g. Obstetrics/Gynecology Doctor
- h. Obstetrics/Gynecology Nurse
- i. Dentist
- j. Dental Hygienist
- k. Local Public Health Provider/Staff
- l. Other: \_\_\_\_\_
- m. None of the above

55. Which of the following have you done personally to combat HIV stigma/discrimination? (circle all that apply)

- a. Sought out help from organizations/groups to resolve stigma/discrimination issues
- b. Confronted, challenged, or educated someone who was stigmatizing/discriminating against you
- c. Confronted, challenged, or educated someone who was stigmatizing/discriminating against someone else with HIV
- d. Know about organizations/groups that you can go to if you experience discrimination
- e. None of the above.

56. Which recommendations would you have for organizations to address HIV stigma/discrimination? (circle all that apply)

- a. Address poverty, homelessness and trauma
- b. Build networks & supporting advocacy efforts
- c. Advocate rights & provide support for people who identify as men who have sex with men, transgender, sex workers, incarcerated and persons who inject drugs
- d. Providing emotional/physical/referral support
- e. Educate people about HIV

57. Thinking back to the time in which you received your HIV diagnosis, what do you wish you would have known that you were not told?

---



---



---

58. If you were diagnosed with HIV in North Dakota, what was your experience with the North Dakota Department of Health staff? (Field epidemiologist who conducted your initial interview, Ryan White program staff, etc.)

---

---

59. What would you like others living with HIV to know about HIV?

---

---

60. In your opinion, what could the North Dakota Department of Health do to serve you better?

---

---

Please tell us any final comments that you have.

---

---

**THANK YOU for completing the survey! Please mail in one of the envelopes provided.**

**Be sure you do not include your name on the envelope or survey.**

If you would like to receive a \$25 Walmart gift card for participating in this survey, please complete the gift card request form and mail it in the other envelope provided.

*Appendix C: Needs Assessment Letter*

March 18, 2021

Greetings,

The North Dakota Department of Health (HHS), Division of Sexually Transmitted and Blood Borne Diseases, is conducting a needs assessment to identify needs and barriers experienced by those living with HIV in North Dakota. The information gathered from this survey will help improve access to medical care, treatment and support services.

This survey is **voluntary** and **anonymous**. It will take 20-30 minutes to complete. As a thank you for completing the survey, you will receive a **\$25 electronic Walmart gift card or you can receive a physical card, which will be mailed to you**. You will be asked at the end of the survey if you would like an incentive and will have an opportunity to provide your email or mailing address. Do not put your name, email address, mailing address anywhere else on the survey to ensure you remain anonymous.

**To complete the needs assessment survey, please click on this URL or QR code:**



**[health.nd.gov/HIVsurvey](https://health.nd.gov/HIVsurvey)**

If you would like to complete this survey via telephone or request a paper copy to be mailed to you, you can contact me at 701-328-2379 or your Ryan White Case Manager.

Your feedback is greatly appreciated! Feel free to let me know if you have any questions by calling 701-328-2379 or via email at [gcokrlc@nd.gov](mailto:gcokrlc@nd.gov).

Sincerely,

*Gordana Cokrlc*

Gordana Cokrlc  
Ryan White Program Coordinator