

2020 HIV/AIDS Comprehensive Needs Assessment Survey



**Minnesota Council for HIV/AIDS
Care and Prevention**



**m1 DEPARTMENT OF
HUMAN SERVICES**

Informed Consent

You are invited to complete the 2020 HIV/AIDS Comprehensive Needs Assessment. To take this survey, you must be at least 18 years old, living with HIV/AIDS, and reside in the state of Minnesota, Pierce County (Wisconsin), or St. Croix County (Wisconsin).

This survey was designed to be taken online through a survey tool called Qualtrics. However, if you need this survey in a different format or a language other than English, please contact us at

Email: <email>

Phone: XXX-XXX-XXXX

Lo invitamos a responder la encuesta de Evaluación Integral de Necesidades del VIH/SIDA 2020. Para responder esta encuesta, debe tener, al menos, dieciocho (18) años de edad, vivir con VIH/SIDA, y residir en el estado de Minnesota, el Condado de Pierce (Wisconsin), o en el Condado de St. Croix (Wisconsin).

Esta encuesta fue diseñada para realizarse en línea a través de una herramienta de medición denominada Qualtrics. Sin embargo, si necesita esta encuesta en un formato diferente, o en un idioma distinto al inglés, póngase en contacto con nosotros al:

Correo electrónico: <email>

Teléfono: XXX-XXX-XXXX

የ2020 ኤችአይቪ/ኤድስ አጠቃላይ ፍላጎቶች ዳሰሳ እንድንመለከት ተጋብዘዋል። ይህንን የዳሰሳ ጥናት ለመውሰድ እድሜዎ ቢያንስ 18 ዓመት ሊሆን ይገባል፤ ከኤችአይቪ/ኤድስ ጋር የምኖሩ መሆን አለብዎት፤ እንዲሁም የ Minnesota ግዛት Pierce County (Wisconsin) ወይም St. Croix County (Wisconsin) ነዋሪ መሆን ይጠበቅብዎታል።

ይህ በወረቀት የሚደረግ የዳሰሳ ጥናት በእንግሊዝኛ እና በስፓንሽ ተዘጋጅቷል። ይሁን እንጂ ይንን የዳሰሳ ጥናት በሌላ ፎርማት ወይም ከእንግሊዝኛ ውጪ በሌላ ቋንቋ ከፈለጉ እባክዎን ከታች ባለው አድራሻ ያግኙን።

ኢሜይል: <email>

የስልክ ቁጥር: XXX-XXX-XXXX

Isin Gamaaggama Fedhiwwan Waliigalaa HIV/AIDS bara 2020 akka guuttaniif afeeramtanii jirtu. Qo’annoo kana fudhachuudhaaf, umuriin keessan yoo xiqqaate 18 ta’uu qaba, nama HIV/AIDS waliin jiraatu ta’uu qabdu, akkasumas jiraataa bulchiinsa Minnesota, Pierce County (Wisconsin), yookaan St. Croix County (Wisconsin) ta’uutu isinirraa eegama.

Qo’annoon waraqaadhaan adeemsifamu kun Afaan Ingilizii fi Ispanishiitiin qophaa’ee jira. Haa ta’u malee, qo’annoo kana bifa biraadhaan yookaan Afaan Inigiliziirraa afaan adda ta’een akka isinii dhiyaatu yoo barbaaddan, karaa teessoo armaan gadii nu quunnamaa maaloo.

li-meeyilii: <email>

Lakkoofsa Bilbilaa: XXX-XXX-XXXX

Waxaa laguugu baaqayaa inaad soo buuxiso aftida 2020 ka Qiimeynta Buuxda ee Baahida ee HIV/AIDS (Comprehensive Needs Assessment). Si aad u sameyso aftidan, waa khasab inaad ugu yaraan jirto 18 sanno, aad qabto cudurka HIV/AIDS, aadna degan tahay Gobolka Minnesota, Pierce County (Wisconsin), ama St. Croix County (Wisconsin).

Aftidan oo warqado ah waxaa la heli karaa iyadoo ku qoran Ingiriis iyo Isbaanish. Hadii aad u baahan inaad hesho aftidan iyadoo qaab kale ama af kale oo aan Ingiriis ahayn ah, fadlan nagala soo xiriir,

Email: <email>

Telefoon: XXX-XXX-XXXX

Why are these data being collected?

The results of the survey are used to assist the Minnesota Council for HIV/AIDS Care and Prevention in the annual allocation of Ryan White HIV/AIDS Program funds to services and activities. Your help is needed to determine what services should be prioritized.

Who will have access to my data?

The data submitted through this survey is confidential. Therefore, the number of people who have access to this data is limited. Staff at the HIV Supports Section at the Minnesota Department of Human Services and staff at Hennepin County Public Health will be the only people with access to individual level data. Data is will not be shared with any other parties except under court order to the state or legislative auditor.

No individual level data will be reported publicly. Your responses will be combined with hundreds of others, and only summary data will be reported publicly.

Do I have to complete the survey?

No. The choice to take the survey is entirely up to you. The services you receive from the Minnesota Department of Human Services, Hennepin County, and their funded providers will not be impacted if you choose not to take the survey.

What will you be asked to do?

You will answer approximately 60 questions about yourself. The survey will take about 30 minutes to complete. There are four screening questions at the beginning of the survey, which determine if you are eligible to take the survey.

The rest of the questions are optional. You can skip any questions you do not want to answer. The questions include:

- Information about yourself, such as age and race/ethnicity
- Factors that influence your health, such as income, food, transportation, housing, health insurance, and barriers to care
- HIV health outcomes, such as retention in care, HIV medication adherence, and viral suppression
- Substance use and mental health
- Medical and support services you may have received

You can stop the survey any time. You are only allowed to take the survey one time. If you have already taken the survey, you cannot take the survey again.

How should I take the survey?

You should complete the survey by yourself, and you should not share your answers with others. If you need help taking the survey and are working with another individual to complete the survey, you should complete the survey in a private room, so no one can hear your responses.

If you need this survey in a different format, a language other than English, or require any other assistance completing the survey, please contact us.

Email: <email>

Phone: XXX-XXX-XXXX

Will I be compensated for my time taking this survey?

Yes. You will be eligible for one \$25 gift card after you complete the survey. You will need to provide your name and contact information to receive the gift card. Your name and contact information will be kept in a separate database from the survey responses. Your name and contact information will not be connected back to your survey responses.

What are the risks and benefits to completing the survey?

There are no direct benefits to completing the survey. The results will be used to improve services for people with HIV.

There is a risk of discomfort and personal distress while completing the survey. Some of the questions in this survey could be considered sensitive. If you have questions or concerns about different topics in the survey, you can contact the AIDSLine, which provides information and referral services for people with HIV in Minnesota.

Website: <https://www.justushealth.org/aidline>

Email: aidline@justushealth.org

Phone: 612-373-2437

Text AIDSLine to 839863

If you have concerns or questions about this survey, you can contact any of the following individuals:

Jacob Melson

Ryan White Part B Data Policy Analyst

Minnesota Department of Human Services

Email: <email>

Phone: XXX-XXX-XXXX

Aaron Peterson

Ryan White Data & Outcomes Coordinator

Hennepin County Public Health

Email: <email>

Phone: XXX-XXX-XXXX

This assessment was reviewed by the Minnesota Department of Human Services Institutional Review Board (IRB) to ensure that all human subjects protections are in place. You can contact the IRB if you have concerns about the survey or the people conducting this survey.

Justine Nelson

IRB Administrator

Minnesota Department of Human Services

Email: <email>

Phone: XXX-XXX-XXXX

Initial questions

1. Do you want to complete the survey?

- Yes
- No
- I have already completed this survey

2. Are you at least 18 years old or older?

- Yes
- No

3. Are you living with HIV/AIDS?

- Yes
- No

4. Do you live in the state of Minnesota, Pierce County (Wisconsin), or St. Croix County (Wisconsin)?

- Yes
- No

If you answered “no” to any of the above four questions or have taken the survey before, you are not eligible to complete the survey. Thank you for your interest in this project.

Begin Survey

5. What is your zip code?

(enter 5-digit number) _____

6. In which Minnesota or Wisconsin

county do you live? _____

7. What year were you born?

(enter 4-digit number) _____

8. What is your age? (in years, e.g., "52") _____

9. Are you Hispanic or Latino/Latina/Latinx?

Yes

No

10. Which one or more of the following would you say is your race? Check all that apply.

White

Black or African American

American Indian or Alaska Native

Asian

Pacific Islander

Other (please list) _____

11. Were you born in the United States?

Yes— skip to question 12

No – answer question 11a

11a. If no, what country were you born in?

12. What do you consider your gender identity?

Check all that apply

Male

Female

Trans Male/Transman

Trans Female/Transwoman

Genderqueer/Gender non-conforming

Different gender
identity (please state) _____

Prefer not to answer

13. What was your assigned sex at birth?

Male

Female

Intersex

Prefer not to answer

14. What do you consider your sexual identity?

Check all that apply

Gay, lesbian, or homosexual

Bisexual

Queer

Straight or heterosexual

Pansexual

Different sexual
identity (please state) _____

Prefer not to answer

15. If you know what year you were diagnosed with HIV, please list the year. If you are unsure of the exact year, please give your best guess. (enter 4-digit year)

16. Have you been diagnosed with AIDS?

- Yes, I have been diagnosed with AIDS – *answer question 16a*
- No, I have not been diagnosed with AIDS – *skip to question 17*
- I do not know – *skip to question 17*

16a. *If yes*, if you know what year you were diagnosed with AIDS, please list the year. (If you are unsure of the exact year, please give your best guess)

17. What is the highest level of education you completed?

- Never attended school
- Grades 1 through 8
- Grades 9 through 11
- Grade 12 or GED
- Some college
- Associate's Degree or Technical Degree
- Bachelor's Degree
- Any post graduate studies

18. Please select the category which best describes you. Check all that apply.

- Employed
- Self-employed
- Out of work for 1 year or more
- Out of work for less than a year
- A homemaker
- A student
- Retired
- Unable to work

19. What is your annual household income from all sources?

- \$12,500 or under
- \$12,501-\$17,000
- \$17,001-\$21,500
- \$21,501-\$25,000
- \$25,001-\$34,000
- \$34,001-\$42,500
- \$42,501-\$50,000
- \$50,001-\$67,000
- \$67,001-\$85,000
- \$85,001 or more

20. Including yourself, how many people depend on your annual household income?

21. During the past 12 months, was there a time when you were not able to pay your mortgage, rent, or utility bills?

Yes

No

22. During the past 12 months, did you have problems paying any medical bills?

Yes

No

23. If you get sick or have an accident, how worried are you that you will **not** be able to pay your medical bills?

Very worried

Somewhat worried

Not at all worried

24. During the past 12 months, how often did you run out of food before you had money to buy more?

Often

Sometimes

Rarely

Never

25. During the past 12 months, how often did you cut the size of your meals or skip meals because there was not enough money for food?

Often

Sometimes

Rarely

Never

26. On a typical day, how long is the trip from your home to your HIV medical provider?

Hours _____ Minutes _____

27. During the past 12 months, have you ever put off going to the doctor for HIV medical care because you did not have a way to get there?

Yes

No

28. During the past 12 months, did you ever have trouble picking up your HIV medications on time because of transportation problems?

Yes

No

Not applicable. I have my medications mailed to me – *skip to question 30*

Not applicable. I am not currently taking medications – *skip to question 30*

29. On a typical day, how long is the trip from your home to your HIV pharmacy?

Hours _____ Minutes _____

30. Which of the following best describes your current housing?

Rent/own an apartment or home

Transitional housing

Doubled up in someone else's house, apartment, or room

Emergency shelter

Currently homeless

Other, please specify _____

31. Do you currently receive public assistance to help pay for your monthly rent or mortgage?

Yes

No

32. During the past 12 months, did you or your family miss or delay a rent or mortgage payment because you did not have enough money?

Yes

No

33. During the past 12 months, how often have you stayed in a shelter, somewhere not intended as a place to live, or someone else's home because you had no other place to stay?

Never

Once

Twice

Three or more times

34. During the past 12 months, how many times have you moved?

35. Do you currently have any of the following types of health insurance? Check all that apply

Health insurance or coverage through your employer or your spouse/partner, parent, or someone else's employer

Health insurance or coverage bought directly by yourself, your family, or Program HH/ADAP (not through an employer)

Indian or Tribal Health Service

Medicare

Medical Assistance (MA) or Medicaid, or Medical Assistance for Employed Persons with Disabilities (MA-EPD)

MinnesotaCare

CHAMPUS, TRICARE, or Veteran's benefits

Other health insurance or coverage (please specify) _____

No health insurance coverage

36. During the past 12 months, did you not get or delay the HIV medical care you needed?

- Yes – answer questions 36a-d
- No – skip to question 37 on Page 11

36a. *If yes to question 36*, During the past 12 months, did you not get or delay the HIV medical care you needed for any of the following **cost or insurance reasons**? Check all that apply

- I was worried about the cost
- My health insurance would not pay for the treatment
- My HIV medical provider would not accept my health insurance
- None of the reasons above

36b. *If yes to question 36*, During the past 12 months, did you not get or delay the HIV medical care you needed for any of the following **personal reasons**? Check all that apply

- I did not think the problem was serious enough
- I was too busy with work or other commitments
- I did not have any transportation to get there
- I could not get there when my medical provider was open
- I did not have any childcare
- I was fearful that people would find out I have HIV
- None of the reasons above

36c. *If yes to question 36*, During the past 12 months, did you not get or delay the HIV medical care you needed for any of the following **access reasons**? Check all that apply

- I could not get through on the telephone
- I could not get an appointment soon enough
- It takes too long to get to my medical provider
- Once I got to my HIV medical provider, I had to wait too long to see the doctor
- My HIV medical provider was not open when I got there
- None of the reasons above

36d. *If yes to question 36*, During the past 12 months, did you not get or delay the HIV medical care you needed for any of the following **additional reasons**? Check all that apply

- The doctor's office, clinic, or hospital was not sensitive to my race, ethnicity, culture, sexual orientation, or gender identity
- I experienced discrimination by my HIV medical provider or their staff
- I was worried about lack of privacy by the doctor's office, clinic, or hospital to protect my medical chart
- I was not able to use my preferred language
- I was fearful that I would be reported to immigration or other authorities
- None of reasons above

37. How often do you get the social and emotional support you need?

- Always
- Usually
- Sometimes
- Rarely
- Never

38. How safe do you consider your neighborhood to be?

- Extremely safe
- Safe
- Unsafe
- Extremely unsafe

39. Have you ever spent time in a jail, prison or juvenile detention center?

- Yes, during the past 12 months
- Yes, more than 12 months ago
- No

40. During the past 12 months, did you see a medical provider specifically about your HIV?

- Yes
- No

41. Thinking about the past 30 days, how often did you take all your HIV medication(s) as prescribed?

- Always
- Most of the time
- Sometimes
- Rarely
- Never
- Not applicable – I am not currently taking HIV medication

42. During the past 12 months, have you had a HIV viral load test?

- Yes – *answer question 43*
- No – *skip to question 44*
- I do not know – *skip to question 44*

According to the Centers for Disease Control and Prevention (CDC), if taken as prescribed, HIV medicine or anti-retroviral therapy (ART), reduces the amount of HIV in the body (viral load) to a very low level, which keeps the immune system working and prevents illness. This is called viral suppression. HIV medicine can even make the viral load so low that a test can't detect it. This is called an undetectable viral load.

43. In your most recent HIV viral load test, were you virally suppressed or undetectable?

- Yes, I was virally suppressed or had an undetectable viral load
- No, I was not virally suppressed or had a detectable viral load
- I do not know

44. During the past 12 months, did you ever use a needle to inject illegal or legal drugs?

Yes – answer questions 44a-b

No – skip to question 45

44a. If you answered yes to question 44, during the past 12 months, did you use a needle that you knew or suspected someone else had used before?

Yes

No

44b. If you answered yes to question 44, during the past 12 months, did someone else use a needle after you?

Yes

No

45. During the past 12 months, did using **alcohol** cause you to miss your HIV medical appointments?

Yes

No

46. During the past 12 months, did using **alcohol** cause you to not take your HIV medication as prescribed?

Yes

No

47. During the past 12 months, did using **drugs** (other than alcohol) cause you to miss your HIV medical appointments?

Yes

No

48. During the past 12 months, did using **drugs** (other than alcohol) cause you to not take your HIV medication as prescribed?

Yes

No

49. During the past 12 months, did any problems with your emotions, nerves, or mental health cause you to miss your HIV medical appointments?

Yes

No

50. During the past 12 months, did any problems with your emotions, nerves, or mental health cause you to not take your HIV medication as prescribed?

Yes

No

51. These questions focus on services you received or may have needed during the past 12 months. Select the appropriate response for each service area by putting a check mark in the corresponding column.

Services	Yes, I received this service	I needed but DID NOT access this service	I did not need this service
Medical case management to coordinate HIV-related medical care and access to other services			
Treatment adherence services (education and counseling to help you routinely take HIV/AIDS medications and follow through on HIV/AIDS treatment)			
Emergency housing assistance (one month of rental or utility assistance)			
Short-term assistance to support temporary or transitional housing (more than one-month assistance but less than two years)			
Long-term assistance to support housing (more than two years)			
Emergency financial assistance to help pay for essential utilities (examples: gas, electric, water, phone)			
Emergency financial assistance to pay for rent			
Emergency financial assistance to help pay for food/groceries			
Assistance obtaining and paying for HIV medications			
Financial assistance to maintain continuity of health insurance or medical and pharmacy benefits			
Transportation assistance to health care services			
Food/groceries from a food shelf			
Home-delivered meals			
On-site meals in a community setting			
Mental health services (psychological or psychiatric treatment and counseling services) provided by a licensed professional in an individual or group setting			

51. These questions focus on services you received or may have needed during the past 12 months. Select the appropriate response for each service area by putting a check mark in the corresponding column.

Services	Yes, I received this service	I needed but DID NOT access this service	I did not need this service
Emotional support group for people with HIV			
A medical visit for HIV-related medical care			
Counseling or information related to returning to or leaving the work force, health insurance and disability benefits, and public assistance programs			
Assistance in finding the health insurance option or benefit package that best suits my needs			
Oral health from a dentist, hygienist, or assistant			
Education or counseling about HIV transmission and how to reduce the risk of transmission			
Treatment counseling from non-medical personnel outside of a medical case management and/or clinical setting			
Outpatient substance abuse treatment or counseling			
Inpatient (residential) substance abuse treatment or counseling			
Home and community-based health care services including home health aide services and/or attendant care services			
Home health care services by a licensed health care worker (examples: nurse, home health care worker)			
Information or referrals for HIV services via telephone, online, or printed materials			
Nutritional counseling provided by a dietitian			

51. These questions focus on services you received or may have needed during the past 12 months. Select the appropriate response for each service area by putting a check mark in the corresponding column.

Services	Yes, I received this service	I needed but DID NOT access this service	I did not need this service
Nutritional supplements (examples: Boost, Ensure)			
Child care assistance while attending HIV-related medical care appointments			
Assistance with legal issues related to my HIV status/care (examples: applying for disability, discrimination)			
Rehabilitative services such as physical and occupational therapy, speech pathology, and low-vision training			
Interpretation or translation services			
Respite care (short-term) relief for primary caregiver of client with HIV			
Help making decisions about the placement and care of minor children after their parents or caregivers are deceased or no longer able to care for them			
End-of-life care services in the terminal stage of an HIV-related illness			

You are finished

When you have completed the survey, please return it with the pre-addressed envelope that came with your survey packet. To receive your gift card, please call us at XXX-XXX-XXXX or email us at <email> with the following information:

- Name
- Address
- If you prefer a \$25 Target (online or in-store) gift card or \$25 Walmart (in-store use only) gift card.

Your name and address will be kept in a separate database from the responses to this survey. Your name and address will not be connected to your survey responses.

Thank you for your participation.

November 10, 2021

- The 2020 HIV/AIDS Comprehensive Needs Assessment (NA2020) instrument was developed in partnership by the community body, Minnesota Council for HIV/AIDS Care and Prevention, and the Minnesota Ryan White HIV/AIDS Program grant recipients, Hennepin County (Part A recipient) and Minnesota Department of Human Services (Part B recipient).
- Data collection occurred from March 2020 to December 2020.
- The instrument was available in three modes: online, paper, and phone.
 - The questions in the online version are the same as this paper version.
 - We used Qualtrics as the online data collection platform.
 - The paper version was available in Spanish.
 - Some questions in the phone version differ from the online/paper version.
 - The phone version was available in English and Spanish.
 - Additional languages for the phone version were conducted using a translator.
- Other versions of the survey instrument, reports, and additional information on the NA2020 is available on the Hennepin County website: <https://www.hennepin.us/NA2020>
- We welcome the usage of this instrument in your own community needs assessments.
- Aaron Peterson and Amy Leite-Bennett of Hennepin County Public Health co-supervised the data collection efforts. You can contact either of them if you have questions.
 - Aaron.Peterson@hennepin.us
 - Amy.Leite-Bennett@hennepin.us