2020 HIV/AIDS Comprehensive Needs Assessment Survey



## 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 እንድሞሉ 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፡፡

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ኢሜይል፡ <email>

የስልክ ቁጥር፡ XXX-XXX-XXXX

Isin Gamaaggama Fedhiiwwan 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 Ispaanishiitiin 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.

Ii-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/aidsline

**Email:** aidsline@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 |  |  |  |
| 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 |  |  |  |
| 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