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Data: Access, Sources, and Systems

Wisconsin Integrated HIV Prevention and Care Plan 2017-2021

REGION	Midwest
PLAN TYPE	Integrated state-only prevention and care plan
JURISDICTIONS	State of Wisconsin
HIV PREVALENCE	Medium

The Wisconsin Integrated HIV Prevention and Care Plan described datasets that are used regularly to direct program activities and resource allocation that were used to guide the development of this Integrated Plan. These include eHARS, HIV testing and prevention activities (using state-based EvaluationWeb), partner services data (using state-based PartnersServicesWeb), ADAP data, RSR data, Medicaid data, Wisconsin surveillance data, U.S. Census and American Community Survey data, and Linkage to Care program data. They also conducted qualitative interviews during 2015, both with people living with HIV and key informants for the needs assessment portion of the Integrated Plan. Wisconsin also provided a thoughtful discussion regarding which data are missing from their assessment as well as the ways data policies and practices facilitated the development of the Needs Assessment and HIV Care Continuum.

SELECTION CRITERIA: DATA: ACCESS, SOURCES, AND SYSTEMS

Exemplary Data: Access, Sources, and Systems sections met the following criteria (based on the Integrated HIV Prevention and Care Plan Guidance):

- Description of the ways data was used to develop needs assessment and HIV Care Continuum, including:
 - ▶ Use of RSR data
 - ▶ Use of Surveillance data
 - ▶ Use of Qualitative data
- Description of data policies that acted as barriers to data access
- Description of data that jurisdictions were unable to access but that would be helpful to access as a way to develop stronger epidemiologic profile and HIV Care Continuum.

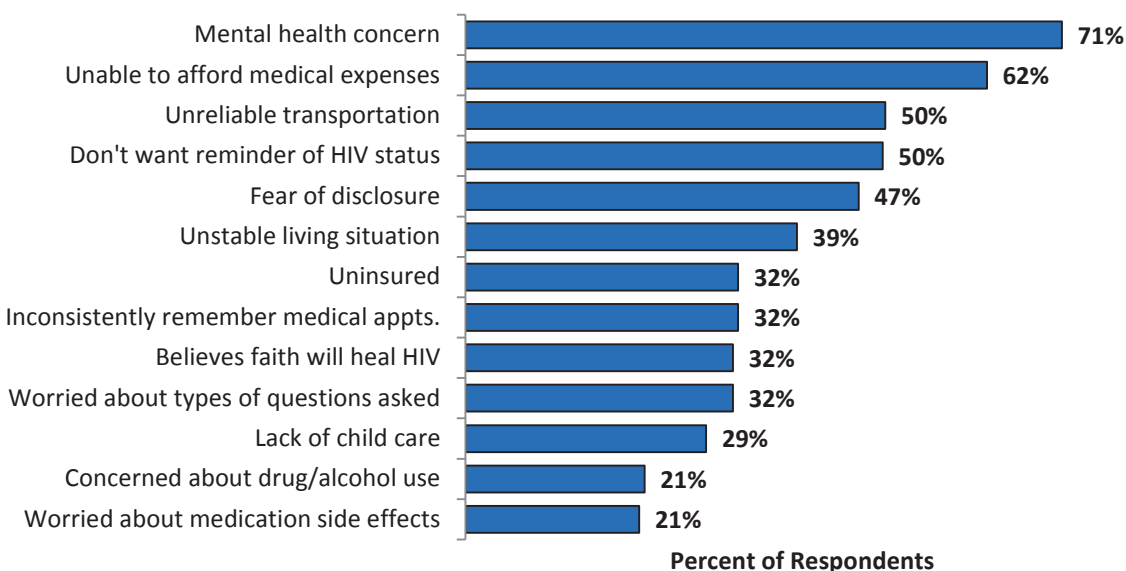


Additional exemplary plan sections are available online:
www.targetHIV.org/exemplary-integrated-plans

Other needs assessment data sources

Section E of the Integrated HIV Plan indicates the numerous data sources, both formal and informal, that the Program consults to assess needs and identify barriers to services. One noteworthy source is the barriers survey, which clients complete upon enrollment to the Linkage to Care program and again at discharge. Its purpose is to identify potential barriers to HIV care and to evaluate whether barriers were reduced as a result of enrolling in the program. The most common potential barriers to care were a mental health concern (71%), inability to afford medical expenses (62%), unreliable transportation (50%), not wanting to be reminded of HIV status (50%), and fear of disclosure when seeking medical care (47%) (Figure 18).

Figure 18. Linkage to care program intake barriers survey†



† Percentages were based on the number of respondents who indicated the potential barrier, divided by the 315 total survey respondents. The child care percentage was based on the 112 respondents for whom the question was applicable. Barriers that were noted by 20% or more of respondents are shown.

When looking specifically at individuals who were out of care for a period of six months or longer, the most common barriers were similar to those shown below. However, there were some barriers to care reported more frequently among out-of-care individuals, such as unstable housing (53%), inconsistently remembering medical appointments (46%), being worried about medication side effects (27%), distrusting the medical system (26% vs. 18% among all respondents), and feeling discriminated against (23% vs. 17% among all respondents).

E. DATA ACCESS, SOURCES, AND SYSTEMS

1. Primary Needs Assessment Data Sources

Described below are the data sources and systems used to conduct the needs assessment and develop the HIV care continuum. Also described are policies that served as facilitators or barriers to conducting the needs assessment and developing the care continuum, as well as data that were not available, but would have been helpful in conducting these activities.

a. Needs Assessment

Wisconsin's HIV needs assessment consisted primarily of qualitative interviews conducted during 2015, both with people living with HIV and key informants. The interview process is described in detail in Section D. Section D also describes other qualitative data sources, including input from the Statewide Action Planning Group, and from the community and AIDS/HIV Program staff members.

In addition to qualitative input, several internal data sources are used regularly to direct program activities and resource allocation and were used to guide the development of this Integrated HIV Plan. Current and future use of these data sources are described below.

- **Enhanced AIDS/HIV Surveillance System (eHARS)** eHARS is the HIV surveillance database used by all jurisdictions that receive federal funding to conduct HIV surveillance activities. Data in eHARS are used to describe the trends in HIV diagnoses and prevalent cases using the demographic information available on individuals infected with HIV, including race/ethnicity, age, county of residence, transmission risk, gender, and HIV-diagnosis related information. eHARS also contains the results of laboratory test results, including CD4 counts, viral load results, and HIV-1 sequences. These data are used to assess HIV care outcomes, including linkage and retention to care, and viral suppression. Laboratory data, in conjunction with demographic data, are used to identify health disparities.
- **EvaluationWeb:** EvaluationWeb is a web-based system developed by Luther Consulting, LLC that is used by federal grantees to collect and report publicly funded HIV testing and prevention activities. The data are used to monitor grantee performance and track and monitor testing activities in Wisconsin. EvaluationWeb is also an important source of risk information for individuals newly diagnosed with HIV infection.
- **PartnerServicesWeb:** PartnerServicesWeb is a web-based system developed by Luther Consulting, LLC that is used in Wisconsin to track PS activities. The database is used both to assign cases to the appropriate jurisdiction and for tracking contact attempts, case notes, linkage to care, and partner elicitation and testing. PartnerServicesWeb is also an important source of information on client location, linkage to care, transmission risk, co-morbidities, and client needs.
- **AIDS Drug Assistance Program (ADAP) Database:** The ADAP database contains information on clients currently or previously enrolled in the ADAP program, including locating information, medical provider, income, and insurance status. The database is used to manage ADAP client eligibility but can also be used to locate out of care clients, monitor insurance status, and has claims data that can serve as markers of HIV care.
- **Ryan White Services Report (RSR):** The RSR is a de-identified client-level data report required by HRSA of all agencies that provide services to clients using Ryan White funds. Ryan White grantees make these reports available to the AIDS/HIV Program to monitor service utilization, linkage and retention to care, viral suppression, and other client outcomes, such as insurance and housing status.
- **Wisconsin Medicaid Program:** The Wisconsin Medicaid program maintains claims information on medical visits, laboratory visits, and pharmaceuticals for its recipients. The Wisconsin AIDS/HIV Program receives aggregate data to monitor service utilization among people living with HIV and has begun to use these data to track uptake of PrEP.

In the future, name-associated Medicaid data would be helpful to identify unreported cases of HIV infection, obtain information on use of antiretroviral medication, and monitor the health outcomes of Medicaid recipients infected with HIV.

- **Wisconsin Electronic Disease Surveillance System (WEDSS):** WEDSS is Wisconsin's communicable disease surveillance and management system. Data include client demographics and locating information for individuals diagnosed with communicable diseases, including sexually transmitted infections, tuberculosis, and hepatitis C. WEDSS data are routinely linked to eHARS to identify individuals co-infected with HIV and to make appropriate follow-up and testing efforts. In the future, HIV case and laboratory data will be integrated into WEDSS, which will reduce the number of systems used to capture HIV-related data (e.g., PSWeb and STD-MIS), enhance disease follow-up for people living with HIV, and share additional data for providers who work with infected individuals.
- **U.S. Census and American Community Survey (ACS):** Data from the U.S. Census and ACS provide demographic information at the census tract that are not available in many of the Division of Public Health and AIDS/HIV Program's internal data systems, including income, employment status, and other markers commonly associated with better or worse health. In conjunction with data on testing, new diagnoses, and care patterns, these data can be used to identify geographies where additional HIV prevention or care services may be needed.
- **National HIV Surveillance Data:** Data published from the Centers for Disease Control and Prevention are used to compare and contrast the Wisconsin and national HIV epidemics.
- **Grantee Performance Measures:** Ryan White grantees that receive Part B funds from DHS are required to submit bi-annual performance measures. These measures are reviewed and discussed during Quality Collaborative meetings to identify best practices and areas for improvement.
- **Linkage to Care Program Evaluation:** In 2011 Wisconsin was one of six states that received federal funding from the HRSA's HIV/AIDS Bureau's Special Projects of National Significance (SPNS) program. The specific initiative was to develop novel systems to improve linkage to care, retention in care, and viral suppression among hard-to-reach populations. Qualitative and quantitative evaluation results on both process and outcome measures, for example, the Barriers Survey results described in Section D have identified needs, barriers, and gaps that will be address in the Integrated HIV Plan.

b. HIV Care Continuum

Wisconsin's HIV care continuum, and those displaying various demographic groups, is based solely on case and laboratory data stored in eHARS. For detailed methods on the development of Wisconsin's HIV care continuum, see the May 2016 issue of [*Wisconsin AIDS/HIV Program Notes*](#), "Wisconsin 2015 HIV Care Continuum: Statewide and Select Population Groups." Available at <https://www.dhs.wisconsin.gov/publications/p00792-16-may.pdf>.

2. Data Policies Impacting the Needs Assessment and Care Continuum

a. Facilitators

These data policies and practices facilitated the development of the Needs Assessment and HIV Care Continuum:

Needs Assessment

- The AIDS/HIV Program prevention, surveillance, and care programs are integrated and co-located, which facilitates the data sharing and data integration required for the needs assessment. For example, authorized staff members have access to eHARS, EvaluationWeb, PartnerServicesWeb, and the ADAP database.
- The AIDS/HIV Program is located within the same Bureau as the STD, HCV, and TB programs, which also facilitates data sharing on co-infected cases. In addition, some staff have access to eHARS and WEDSS, which allows for data matching to identify co-infected individuals.
- While not federally required, Ryan White grantees have agreed to submit their RSR to the AIDS/HIV Program for statewide analyses of recipients of Ryan White-funded care.

HIV Care Continuum

- Wisconsin has had name-based HIV and AIDS reporting since the beginning of the HIV epidemic (initiated AIDS case reporting in 1982 and HIV case reporting in 1985) and therefore has a mature and complete HIV surveillance system.
- All CD4 cell counts and viral load test results have been reportable to the HIV surveillance unit since 2011.
- Over 88% of laboratory records reported to the surveillance unit are reported electronically.
- Lab reports are imported daily. Over 98% of HIV laboratory test results are imported into eHARS within 60 days of specimen collection.
- Wisconsin conducts required surveillance activities in a timely manner to ensure accurate surveillance data, including death matches to local and national vital records data and Routine Interstate Duplicate Review (RIDR).

b. Missing Data

Despite the amount of high-quality data available to conduct the needs assessment and develop the HIV care continuum, some data were unavailable. Missing data are described below, as are policies or practices that served as barriers to conducting the needs assessment of developing the HIV care continuum.

Needs Assessment

- For clients to participate in the qualitative interviews that were part of the needs assessment, the AIDS/HIV Program depended on grant-funded agencies for client referrals. While efforts were made to ensure specific groups were represented (e.g., Black MSM, people of color, individuals living in Milwaukee), all clients who were

referred by a grant-funded agency were offered an interview. As a result, certain groups may be overrepresented and others underrepresented such as transgender persons.

- Statewide data on housing status, mental health service needs, substance use, and sex workers are not available. Housing status is available for clients included in the RSR, however, the data represent a point in time and do not include periods of unstable housing a client may have faced during the year. Utilization of mental health and substance use services are also available via the RSR, but this does not allow a comparison of needs with service availability.
- The Statewide Action Planning Group is a valuable source of input on statewide planning efforts. However, some voices are known to be missing, such as those less than 25 years of age and transgender individuals.

HIV Care Continuum

- Several states use various data sources to develop their HIV care continuum, including eHARS, medical visit data from the Medical Monitoring Project or CAREWare, ADAP fill dates, Medicaid claims data, or a care marker database that integrates data across systems to provide a single source of care pattern data for individuals. Wisconsin does not receive funding to participate in the Medical Monitoring Project nor is CAREWare used. Data from other sources are available but not integrated; therefore, Wisconsin's HIV care continuum is based solely on eHARS data.
- Statewide antiretroviral (ARV) use data are not available for display on the HIV care continuum. However, data are available on a subset of individuals, including those enrolled in the ADAP and those included in RSR. In the future, client level Medicaid data may fill this gap for a subset of individuals.
- Some laboratory data are known to be systematically missing. Prior to 2015, viral load data is known to be missing for individuals receiving HIV medical care at Veterans Affairs (VA) clinics across the state. During 2015, the VA began to submit viral load data electronically to the HIV surveillance program. In addition, laboratory data is known to be missing for individuals living in Wisconsin but receiving HIV medical care in another state. Efforts will be made during 2016 to obtain missing laboratory data on these individuals.
- It is likely that the HIV care continuum underestimates the proportion of PLWH in Wisconsin who are in medical care. First, Wisconsin has a significant number of cases with no laboratory or other data in eHARS in the last five years, indicating that these individuals may be deceased or living out of state. Matches will be conducted during 2016 to update eHARS vital status and state of residence for applicable individuals. Second, the recognized definition of retention (two medical visits separate by at least 90 days during a 12-month period) may underestimate actual retention, as stable individuals may have HIV medical appointments just once per year.