

# **Path to Care Study: Making and Sustaining the Connection to HIV Care**

## **Executive Summary**

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The Path to Care Study (1) defines what the “path to care” should lead to for people living with HIV, (2) identifies where the path to care is beginning for people living with HIV in Minnesota by identifying where the most people living with HIV are getting diagnosed, (3) describes what helps Minnesotans living with HIV get connected to care after they are diagnosed, what helps them stay in care once that connection is established, and considers factors that cause people to discontinue care and what helps these individuals reconnect to care, and (4) suggests opportunities for improving services that support Minnesotans living with HIV to move along or reconnect with a path to care, and then to stay in care once that connection is made.

### *Leading to Chronic Disease Management for People Living with HIV –*

In the United States, AIDS-related deaths have declined dramatically as more and more people have been able to benefit from HIV antiretroviral treatments, making HIV a chronic and manageable disease an attainable goal for effective HIV care. The Path to Care Study starts with the observation that people living with HIV, as with any other people coping with life-long, chronic disease management, need to be connected to a care system based on the chronic care model. The chronic care model suggests, “The effective control of most chronic diseases requires appropriate medical therapy as well as competent self-management... Effective chronic illness management requires an appropriately organized delivery system linked with complementary community resources available outside of the organization.”<sup>1</sup>

### *Screening, Testing & Diagnosis: The “Gateway” to HIV Care –*

The path to effective HIV care begins with screening, testing and diagnosis. The Path to Care Study identifies where this “gateway” to HIV care begins for most Minnesotans living with HIV. A review of the top ten diagnosis sites in Minnesota from 2003 through 2008 revealed a relatively small cluster of providers consistently diagnose the largest number of newly-diagnosed people living with HIV in Minnesota each year. Four diagnosis sites consistently were among the top five reporting sites during each of the six years, 2003 through 2008. These sites were Hennepin County Public Health Clinic/Red Door Clinic, HCMC [Hennepin County Medical Center], Health Partners and Park Nicollet. Combined, these four sites accounted for 38% of all HIV diagnoses reported in Minnesota during the six year period [ranging from a low of 33% annually to a high of 48% annually reported from 2003 through 2008]. Other diagnosis sites that appear among the top five during this six year period were The Doctors, private health clinics in Minneapolis, and Room 111.

Interviews and self assessment surveys with representatives from the top four diagnosis sites, plus one site that primarily provides screening and diagnosis services to Latinos suggest that deliberate efforts to

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<sup>1</sup> Wagner, Edwards, et. al., p. 69 to 70.

implement routine HIV testing in health care settings as recommended by the CDC and described in recent American Academy of HIV Medicine guidelines have been limited in Minnesota. However, people who are diagnosed by one of the state's consistently-reporting diagnosis sites are very likely to be connected to a medical care provider, either through formal or informal referral policies and procedures in place at the diagnosis site. People who get a service from a diagnosis site that is well-connected with the Ryan White system are more likely to learn about and get connected to the wider range of services that are needed for management of HIV as a chronic medical condition, though this is more likely to occur when diagnosis is made in a clinic that provides HIV screening, diagnosis or care as a specialty service, as compared to large hospitals or health systems.

### *Connecting and Staying in HIV Care –*

Sixty three Minnesotans living with HIV participated in the Path to Care Study survey and interview process. While not a statistically representative sampling of people living with HIV in Minnesota, the demographic, geographic and circumstantial diversity of the communities of people affected by HIV in Minnesota is reflected among the study's participants. Participants also reflect the experiences those who were diagnosed relatively recently to long term survivors. Virtually all [97%] of the study participants were in care at the time they were surveyed and interviewed, but 56% either delayed or discontinued their care at some time before reestablishing HIV care. While not statistically representative, the study's systematic collection of information through survey and interview provides a unique and useful picture of what influences the experience of getting into, staying in and reconnecting to care for Minnesotans living with HIV.

Path to Care Study also drew upon interviews with representatives of four of the five diagnosis sites that consistently report the largest number of newly diagnosed people living with HIV annually and a site that primarily provides screening, testing and diagnosis services to Latinos in Minnesota. Interviews with representatives from four HIV service organization providers [each receiving funding from Ryan White Parts A, B, C and D, respectively], an interview with a Part F grantee, and a discussion with the Minnesota HIV Services Planning Council also informed the study.

*Connecting to Care After Diagnosis.* Ready access and connection to the health system is among the most important factors helping those newly diagnosed with HIV get connected to HIV care. Survey responses indicated the most helpful services offered and made available at initial diagnosis were (1) finding a doctor [52%], (2) connecting to an AIDS service organization for services and support [41%], (3) receiving help to prevent infecting others [38%], (4) receiving drugs to treat HIV infection [32%], and (5) meeting with a counselor, therapist or psychiatrist [32%].

Similarly, responses from the interview process supported the survey results by also pointing to the role services from health professionals played in helping people get connected to care after diagnosis. Interview responses indicated the most helpful services offered and made available at initial diagnosis were (1) connecting to an AIDS service organization for services [other than case management, e.g. MAP AIDSLine] [30%], (2) having access to a comprehensive and coordinated medical and social service support system at the diagnosis site [29%], (3) receiving information and referral tools [27%], (4) having a support network – friends, family and/or faith [25%], (5) getting connected to a case manager who could help me [24%] and getting connected to a doctor I liked and trusted [21%].

The experience connecting to care services other than clinical medical care was a little different. Survey results indicated that (1) talking with a person at an AIDS service organization [49%], (2) talking with

another person living with HIV [38%] or (3) a referral from the diagnosis site [37%] were among the more frequently cited aids in learning about and making the connection with a service intended to better coordinate medical care, support self-care management or stabilize a living situation to enable treatment adherence.

*Challenges Connecting to Care After Diagnosis.* Most study participants reported being connected to a doctor shortly after diagnosis, with 63% visiting a doctor within the first month after being initially diagnosed. However, 25% did not have their first visit with a doctor between one and six months after diagnosis, and 12% reporting that it was a year or longer before they saw a doctor after initial diagnosis.

Those who said they faced challenges connecting to care after diagnosis indicated the more notable challenges to connecting to care after initial diagnosis were (1) depression [35%], (2) fear of disclosure and the consequences [e.g. stigma] [30%], (3) continued or increased drug and alcohol use to cope [27%], and (4) poor experience with a person or the service provided at the diagnosis site [22%]. Other challenges of some importance were (1) no peer support, unable to talk with another living with HIV [17%], denial about being infected [13%], surprised by the testing situation and/or diagnosis and not prepared [13%], or loss of social support and connection with family, friends or faith [13%].

*Staying Connected to Care.* The study survey and interview results affirm the chronic care model. A health system with a prepared and practiced team and community supports that help them be informed and activated consumers were of equal importance in helping people stay in care.

Survey responses indicated the most helpful supports keeping people connected to care were (1) my doctor [65%], (2) my case manager or social worker [54%], (3) talking to a friend [52%], (4) talking to another person living with HIV [48%], and (5) talking with someone at an AIDS service organization [someone other than a case manager] [48%]. As part of the interview, participants were asked to describe what helped them stay connected to care. Their responses suggested the most helpful supports were (1) peer support from others living with HIV [68%], (2) the right doctor [62%], and (3) my case manager [62%].

*Delaying or Dropping Out of Care.* Fifty six percent [56%] of the study participants reported either delaying or dropping out of care, while 44% did not. Survey results indicated regular access to health care prior to HIV diagnosis was significant indicator in whether or not a newly diagnosed person with HIV was likely to stay in care [46% reported they had regular access to care prior to diagnosis and 44% reported they did not delay or drop out of care].

Survey findings pointed to a history of irregular visits with a doctor prior to HIV diagnosis, either because of behavior or lack of resources or coverage to sustain routine visits with a doctor, as a likely indicator that HIV care will be delayed or discontinued. Additional factors were described in the Path to Care Study interviews. Interview responses indicated the most notable reasons for delaying or discontinuing HIV medical care were: (1) I moved [40%], and (2) did not like the doctor and how I was treated [29%]. A deeper analysis of the reasons for making a move or for not liking the provider pointed to a variety of social challenges, medical co-factors or health system issues.

*Reconnecting to Care.* For those who discontinued care, having a way to connect with another or others living with HIV who can provide support, information, and informal advocacy and encouragement is important – essentially, as important as finding a trusted medical provider in helping them re-establish their HIV care. Forty eight percent [48%] of those who reported delaying or discontinuing care cited

finding a doctor they liked as a factor in reconnecting to care, with 46%, citing the support, information and help of another or others living with HIV as the factors that helped them reconnect to care.

*Exceptions for People Living in Greater Minnesota, Latinos and African-born.* It should be noted that people living in Greater Minnesota, Latinos and African-born individuals all expressed feelings of isolation and fears about the effects of stigma as part of the interview process. None of these individuals described experiences getting support from other people living with HIV or family, friends or their faith community in their stories of connecting to care. In these cases, it was the support of a professional that made the difference; typically a medical provider or staff involved with providing the initial diagnosis, or a case manager. In addition to delivering services expected from the health system, interviewees also talked about their relationships with these professionals in ways that suggest they also depended upon them to provide the on-going education, encouragement and emotional support that might typically come from those in their family and social communities. This was true both in making the initially connection to care and in re-connecting after care was disrupted. Stigma in these communities creates significant barriers to effective chronic care management based on the chronic care model.

*Conclusion.* What is clear from the Path to Care Study survey and interview results is that it is not an either or proposition for people living with the chronic condition of HIV disease: staying connected to care requires both health system supports, including access to a trusted doctor and a social service professional to help coordinate care, as well as community supports. These community supports include other people living with HIV who provide both emotional support and important information about how to access and use services, as well as a broader network of others living with HIV, friends, family and faith to provide emotional support. For those who delay or discontinue their care, the support and information provided by others living with HIV plays an unusually important role in helping them re-establish care.

#### *Opportunities to Improve Services –*

The study considers how services can be improved to support connecting to care, staying in care or reconnecting if care is disrupted. These opportunities for improving services for people living with HIV are presented with the goal of making service adjustments that provide a connection to not only an HIV specialty medical care provider, but to the a system of care and support that is consistent with the chronic care model. The opportunities for improving services for people living with HIV presented in the study address implications for allocating Ryan White resources in Minnesota, Ryan White quality management and quality improvement activities, adjustments in HIV testing and diagnosis site policies and strategies, and advocacy for broader policy reforms.

*Implications for Allocation of Ryan White Resources in Minnesota.* Allocate resources (1) in a way that helps people living with HIV as a chronic condition by assuring access to a trusted medical care provider, the service of a case manager to navigate the health care system and patient access to information and support for self-care management and advocacy, including information and support from others living with HIV, (2) to develop capacities of individuals and groups of people living with HIV to reach out and provide information and support to those who have delayed or stopped HIV care, (3) to sustain “beacon services” that provide visible and accessible entry points, and to help people living with HIV get information about services to stabilize their living situation – both through formal providers and informal peer networks, and (4) to facilitate and coordinate access to alcohol or drug treatment or mental health services, both to address situational and chronic mental illness.

*Implications for Ryan White Quality Management and Quality Improvement.* Develop (1) an assessment tool and appropriate quality measurements to promote and monitor patient self-care management and advocacy, and (2) patient self care capacities, both in terms of their personal care, but also in terms of supporting quality management and quality improvement in the services they depend upon to support chronic disease management.

*Implications for HIV Testing and Diagnosis Policies and Strategies.* Policies and strategies should (1) promote awareness about recommended guidelines for routine testing and connecting to care, with a focus on the AAHIVM guidelines, including education, training and technical assistance to help providers develop and implement formalized procedures to implement these guidelines and a focused effort to provide this assistance to those providers that report the majority of HIV diagnoses in Minnesota each year, (2) help diagnosis sites formalize procedures for providing access to a counselor, referral to alcohol or drug treatment, and the opportunity to connect with another person living with HIV as part of the process of delivering an HIV positive diagnosis, (3) support public education and awareness about HIV transmission risk and testing, including efforts targeted to communities with high levels of HIV incidence, prevalence or risk, helps people get connected to testing as a gateway to care, and (4) formalize policies and procedures for HIV testing, with clearly identified staff responsible to connect those who are diagnosed with HIV to care, improve the path to care experience for those who test in hospital settings or clinics that are part of a health system – focusing on hospitals and health systems that report the most annual HIV diagnoses in Minnesota annually.

*Implications for Advocacy.* Policy advocacy should (1) promote access to health care, including mental health services and treatment for alcohol or drug abuse, for communities that experience high HIV incidence and prevalence, and (2) promote policies that assure resources are available to support chronic care management for people living with HIV – including both patient and provider capacities, as well as the supports that patients [e.g. support of others living with HIV] and providers [e.g. case management support] need to help people living with HIV connect to and stay in care.