

# **Path to Care Study:**

## **Making and Sustaining the Connection to HIV Care**

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## EXECUTIVE SUMMARY

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 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

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

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 [32%]. 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.

## **PART ONE: INTRODUCTION AND OVERVIEW**

The purpose for the Path to Care Study is to provide information for those planning services for people living with HIV in Minnesota. The information will be most useful to Ryan White grantees, the Minnesota HIV Services Planning Council, providers of HIV services and advocates for services for people living with HIV.

The Path to Care Study addresses the following:

- Define what the “path to care” should lead to. Specifically, provide a description of the chronic care model.
- Understand 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.
- Understand what helps Minnesotans living with HIV get connected to care after they are diagnosed and what helps them stay in care once that connection is established. Additionally, the study considers factors that cause people to discontinue care and what helps these individuals reconnect to care.
- 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.

Sixty three Minnesotans living with HIV participated in the Path to Care Study survey and interview process. In addition to surveying and interviewing people living with HIV, the Path to Care Study 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 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.

### ***Chronic Disease Care***

Part of understanding the path to care is knowing where that path is intended to lead. By some standards, the path to care ends with being connected to an HIV specialty medical care provider. However, appropriate and effective treatment is considered to be something more as HIV disease has increasingly become a manageable, chronic condition that can require decades of 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. This model offers a more comprehensive view of care; more than just a connection with a clinician to provide medical care.

The study describes the chronic care model. It identifies what needs to be in place to support management of a chronic health condition such as HIV. Specifically, it describes how connecting to either key health system or community support for chronic disease management play a role in providing a path of entry into a complete, chronic care system for people living with HIV.

### ***The Gateway to Care: Testing and Diagnosis***

Knowing one's status is often described as the "gateway to care" for people living with HIV. This process starts with HIV screening and testing.

The Path to Care Study asks the question, "If testing and diagnosis create this "gateway" to HIV care, where do most Minnesotans diagnosed with HIV pass through that gateway and start on their path to care? The study reports *where* most Minnesotans living with HIV are getting their diagnosis, and *who* is getting tested and diagnosed at which of the most prominent diagnosis sites. The study also describes key professional standards for the services that should be available when people get tested and receive an HIV diagnosis, and provides an indication of how these standards are put into use at some of Minnesota's most prominent diagnosis sites.

### ***How Minnesotans Living with HIV Make and Sustain their Connection to Care***

Through the Path to Care Study, 63 Minnesotans living with HIV completed surveys and participated in individual interviews that collected information about their testing and diagnosis experiences, how they connected to care and what is most helpful and important for people living with HIV to adhere to HIV care.

The study identifies what seem to be among the key factors that help Minnesotans living with HIV get connected to care, stay in care, or reconnect to care in case of a disruption. It explores what helps or hinders getting connected to care after diagnosis, what helps and is important for adherence to care, why people delay or discontinue care, and what facilitates reconnecting to care.

### ***Opportunities to Improve Services***

Finally, the Path to Care Study identifies opportunities for improving services for people living with HIV. 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.

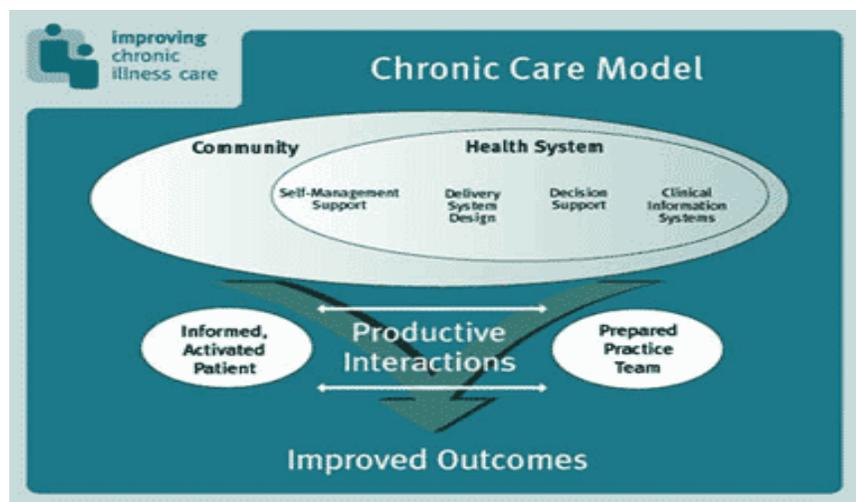
## PART TWO: CHRONIC DISEASE CARE

Conventional approaches to health care focus on responding to acute medical needs. Care systems are commonly organized to respond quickly and efficiently to acute illness or injury as patients come through the door. “The focus is on the immediate problem, its rapid definition and exclusion of more serious alternative diagnoses, and the initiation of professional treatment. The patient’s role [is] largely passive.”<sup>2</sup>

However, advances in health treatment have made it possible for more and more people, facing a wider and wider array of conditions, to live longer and longer through effective treatment and management of their illnesses. This has certainly been the case with HIV as a benefit of advances in drug therapies that became widely available in the United States over the past fifteen years. In the United States, AIDS-related deaths have declined dramatically as more and more people have been able to benefit from HIV antiretroviral treatments. As observed by the Minnesota AIDS Project, “HIV is a chronic and manageable disease, if you have insurance, the right medications, a strong support network of family and friends, a place to live, food to eat,” and the ability to manage your HIV disease.<sup>3</sup>

As treatment of HIV disease has become more suited to chronic disease management, application of the Chronic Care Model has become a more relevant tool to improve quality of care and sustain quality health outcomes. The Chronic Care Model [CCM] was developed by Edward Wagner, Director of the MacColl Institute for Health Care Innovation, Group Health Cooperative of Puget Sound, and the colleagues of the Improving Health Care Program with support from the Robert Wood Johnson Foundation.<sup>4</sup>

The CCM 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>5</sup>



<sup>2</sup> Wagner, Edwards, et. al., “Improving Chronic Illness Care: Translating Evidence into Action,” HEALTH AFFAIRS, Vol. 20, No. 6, November/December, 2001, p. 65.

<sup>3</sup> Minnesota AIDS Project, “HIV Myths and Realities,” 2009.

<sup>4</sup> Institute for Healthcare Improvement, Website.

<sup>5</sup> Wagner, Edwards, et. al., p. 69 to 70.

As prescribed by the CCM, effective chronic disease management is built on *productive interactions* between an *informed and activated patient* and a *prepared and practiced health team of care providers*. In other words, “The effective control of most chronic diseases requires appropriate medical therapy as well as competent self-management.”<sup>6</sup>

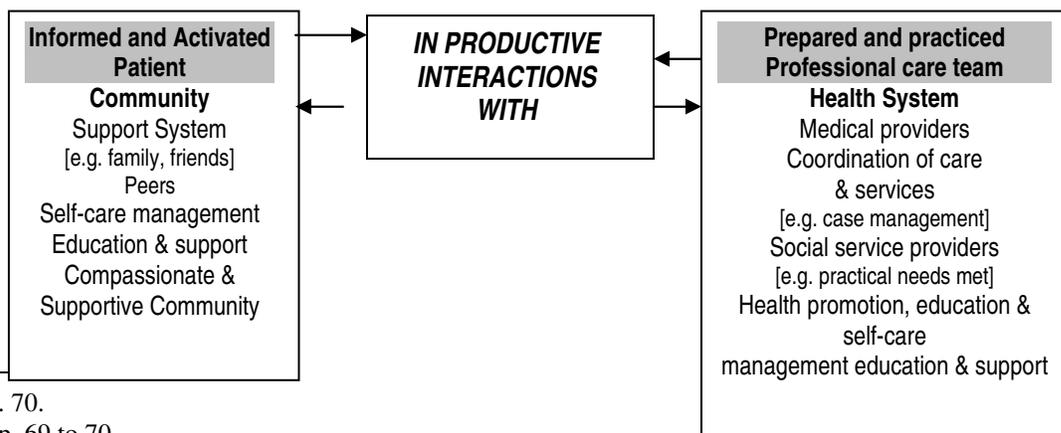
On one hand, the patient benefiting from a system of effective chronic disease management has access to a health system that has (1) a team of skilled health professionals who are organized into a coordinated system to deliver care, (2) clear guidelines based on good evidence to support consistent decision-making and promote quality health outcomes, (3) an information system capable of tracking and coordinating the care of individuals as well as the measurement of the overall outcome of care, and (4) patient self-management education and support.

As an essential complement to the health system is patient self-management skill and ability, and links to patient-oriented community resources that provide information, support and encouragement. This community of support includes disease-oriented service organizations, and a network of family, friends and peers to better cope with the challenges of on-going treatment and integration of disease management into daily living.

This is different from traditional patient education that emphasizes knowledge acquisition and didactic counseling. “Mounting evidence indicates that while such interventions increase knowledge, they were unsuccessful in changing behavior or improving disease control and other outcomes. More recent research has shifted the focus from patients’ knowledge of the disease and its treatment to their confidence and skills in managing their condition.” The patient’s and community’s role are crucial for improving disease management, identifying barriers to sustained care and disease management, and developing workable plans to overcome the barriers.<sup>7</sup>

“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>8</sup>

A system of services to provide effective care for people living with HIV should reflect the CCM, with productive interactions between an informed and activated patient and a prepared and practiced health team of care providers.



<sup>6</sup> Ibid, p. 70.

<sup>7</sup> Ibid, pp. 69 to 70.

<sup>8</sup> Ibid, p. 69 to 70.

The acute care model and its presumption that clinical medical care and treatment are the only or the most important component of HIV disease care and treatment is systemically reinforced, particularly by health care insurance and payment systems – both private and public. Even the Ryan White Treatment Modernization Act and its policies requiring 75% of funds to be spend on primary medical care services with a 25% limit on other chronic care services, reflects this tension between applying an acute care model or a chronic care model in HIV care and tension.

In approaching the Path to Care Study, it was accepted that “persons suffering from major chronic illnesses face many obstacles in coping with their condition, not the least of which is medical care that often does not meet their needs for effective clinical management, psychological support, and information. The primary reason for this may be the mismatch between their needs and care delivery systems largely designed for acute illness.”<sup>9</sup>

### ***Conclusion: Chronic Disease 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; a system that offers more than access to a medical care provider.

While looking at the connection with a “prepared and practiced” team of medical care providers as one important indicator of being connected to care, the study accepts that connections to others within the health system as well as community partners play an important role in helping people living with HIV connect to medical care, stay in medical care or reconnect to medical care if it discontinued.

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<sup>9</sup> Ibid, p. 64.

### **PART THREE: THE GATEWAY TO CARE – TESTING AND DIAGNOSIS**

Knowing one's status is often described as the “gateway to care” for people living with HIV. This process starts with HIV screening and testing.

The Path to Care Study asks the question, “If testing and diagnosis create the “gateway” to HIV care, where do most Minnesotans diagnosed with HIV pass through that gateway and start on their path to care? The study reports *where* most Minnesotans living with HIV are getting their diagnosis, and *who* is getting tested and diagnosed at which of the most prominent diagnosis sites. The study also describes key professional standards for the services that should be available when people get tested and receive an HIV diagnosis, and provides an indication of how these standards are put into use at some of Minnesota's most prominent diagnosis sites.

According to Minnesota state law, all medical providers and laboratories are required to report diagnoses of HIV disease to the Minnesota Department of Health MDH. The Path to Care Study was provided with the following information by MDH that was drawn from the legally mandated provider and laboratory reports:

- The top ten sites reporting HIV diagnoses in each year beginning in calendar year 2003 and ending with calendar year 2008.
- Aggregated demographic information about the people diagnosed each year at each of the *top five* reporting diagnosis sites [i.e. gender, age, race, and location of residence].
- Aggregated reported HIV transmission risk and disease stage at time of reporting [i.e. HIV (non-AIDS) or HIV (AIDS) for the people diagnosed each year at each of the *top five* reporting diagnosis sites.

*[Due to resource constraints, demographic and HIV transmission and disease stage data was only collected for the top five reporting diagnosis sites for each year from 2003 through 2008.]*

Again, these were the *diagnosis sites* – the locations with the reporting doctor or laboratory. It is very possible that the diagnosis site was also the location where the reported individuals were also screened and where the HIV anti-body test was administered. However, that cannot be confirmed with the diagnosis site [or reporting site] data available through MDH.

*What were the Minnesota's top diagnosis sites?* The top ten diagnosis sites are reported below. Together, these sites accounted for an average of 58% of the incidence of newly-reported HIV infections in Minnesota each year beginning in 2003 and continuing through 2008 [ranging from a low of 54% to a high of 62%].

**Ten Top Reporting HIV Diagnosis Sites in Minnesota – 2003 through 2008**

2008	2007	2006	2005	2004	2003
Red Door Clinic Park Nicollet HCMC HealthPartners The Doctors Room 111 Private – Mpls ZBL Plasma University/MN Westside/LaClinica	Red Door Clinic Park Nicollet HealthPartners HCMC Private - Mpls The Doctors Room 111 ZBL Plasma Abbott/NW Private - StP	Red Door Clinic HCMC Park Nicollet Health Partners Private – Mpls Private - StP The Doctors Room 111 Uptown Clinic ZBL Plasma	Red Door Clinic HCMC HealthPartners Park Nicollet The Doctors Room 111 Private - Mpls University/MN Westside/LaClinica Uptown Clinic	Red Door Clinic HealthPartners Park Nicollet HCMC Private – Mpls Room 111 Private - StP The Doctors University/MN Abbott/NW	HCMC HealthPartners Red Door Clinic Park Nicollet Room 111 The Doctors Private - Mpls Abbott/NW Mayo University/MN
60% of 325 Total Reports	54% of 327 Total Reports	59% of 322 Total Reports	62% of 303 Total Reports	54% of 307 Total Reports	59% of 279 Total Reports

Four diagnosis sites *consistently* were among the top five reporting sites during each of the six years, 2003 through 2008. These sites were:

- Red Door Clinic
- HCMC
- Health Partners
- 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.

*What is the profile of people tested at each of the most consistently reporting diagnosis sites?* The four most consistently reporting diagnosis sites were:

- Red Door Clinic – a public health clinic in Hennepin County
- HCMC – a public hospital in Hennepin County
- Health Partners – a private health system [e.g. clinics and hospitals both in and outside of Twin Cities]
- Park Nicollet – a private health system [e.g. clinics and hospitals both in and outside of Twin Cities]

Analysis of the demographic and HIV risk transmission and disease status data provided for each of the most consistently reporting diagnosis sites offers the following profile of who is getting diagnosed at each site and why.

Red Door Clinic – *Public Health Testers*

**RED DOOR CLINIC  
Public Health Testers  
PROFILE OF TESTERS & REASON FOR TESTING**

**White [Annual Avg. 65%]  
Males [Annual Avg. 93%]  
Mostly from Minneapolis [Annual Avg. 61%] or TC suburbs [Annual Avg. 30%]  
Most report MSM as primary risk factor [Annual Avg. 74%]  
Half under age 30**

**Present with early stage HIV disease \*\* [Annual Avg. 94%]**

**\*\* *Risk-motivated testers***

Most of the people diagnosed at Red Door Clinic lived in Minneapolis [61% average for the six year period] or the Twin Cities suburbs [30% average for the six year period]. Those diagnosed at the Red Door Clinic tended to be white [65% average for the six year period] and male [93% average for the six year period]. Half of those diagnosed were under the age of 30. Most reported their HIV transmission risk as male-to-male sexual activity [74% average for the six year period]. Virtually all who were diagnosed at Red Door Clinic presented with early stage HIV disease, i.e. HIV (non-AIDS) [94% annual average for the six year period].

Based upon the stage of infection reported by those newly diagnosed at the Red Door Clinic, it appears these were *risk-motivated testers*; individuals who were not at advanced stage HIV disease when they would be more likely to be experiencing disease symptoms, and were, therefore, more likely to have been tested because they perceived some risk for HIV in their behaviors who had symptoms for another disease [e.g. a sexually transmitted infection].

HCMC – *Public Hospital Testers*

**HCMC  
Public Hospital Testers  
PROFILE OF TESTERS & REASON FOR TESTING**

**Most are People of Color [Annual Avg. 80%]  
More Men than Women [Annual Avg. 58% men; 42% women]  
Higher proportion of women testing than reflected in MN HIV epidemic.  
Mostly from Minneapolis [Annual Avg. 65%] or TC suburbs [Annual Avg. 27%]  
Wide variety of transmission risk factors  
[High Risk Heterosexuals - 38%; Other/Unidentified – 36%; MSM – 26%]  
Older testers  
[25 to 40 – 46%; over 40 – 38%]**

**Present with advanced stage HIV disease \*\*  
[Annual Avg. 42%; ranged from low of 29% to high of 71%]**

**\*\* *Symptom-motivated testers***

Most of the people diagnosed at HCMC [Hennepin County Medical Center] lived in Minneapolis [65% average for the six year period] or the Twin Cities suburbs [27% average for the six year period]. Those diagnosed at HCMC tended to be people of color [80% average for the six year period]. More men [58% average for the six year period] than women [42% average for the six year period] were diagnosed at HCMC, but the percentage of women diagnosed at HCMC was significantly greater than that for the population as a whole [27% average for the six year period]. The age of those diagnosed at HCMC tended to be older with 46% between ages 25 and 40 [average for the six year period] and 38% over age 40 [average for the six year period]. Those diagnosed at HCMC reported a widely varying range of transmission risks [38% high risk heterosexuals – ranging from an annual low of 29% to a high of 52%, 36% other or undetermined risk, and 25% men who have sex with men with all percentages reported as average for the six year period]. The proportion of those reporting with advanced stage HIV disease [HIV (AIDS)] is higher than the two-thirds for the overall population of Minnesotans living with HIV [HIV(non-AIDS)], with 42% [average for the six year period] reporting with advanced stage HIV disease, with an annual range from a low of 29% to a high of 71%.

Based upon the stage of infection reported by those newly diagnosed at HCMC, it appears these were *symptom-motivated testers*; individuals who were more likely to have advanced stage HIV disease and experiencing disease symptoms which was likely to be a reason for getting tested.

HealthPartners and Park Nicollet – *Hospital & Health System Testers*

**HealthPartners and Park Nicollet  
Private Health System Testers  
PROFILE OF TESTERS & REASON FOR TESTING**

**About Half are White [52%] and Half are People of Color [Annual Avg. 48%]  
More Men than Women [Annual Avg. 72% men; 28% women] --  
Similar to what is Reflected in MN HIV epidemic.  
More Suburban [Annual Avg. 57% @ Park Nicollet and 38% @ HealthPartners]—  
More from St. Paul @ HealthPartners or [Annual Avg. 36%]  
About Half are MSM [Annual Avg. 49%] -  
With Park Nicollet reporting more MSM @ 56% and  
HealthPartners more High Risk Heterosexuals @ 30%  
Younger to middle age [25 to 40 – 50%]**

**Present with both early and advanced stage HIV disease \*\*  
[Annual Avg. 68% early stage; 32% advanced stage]**

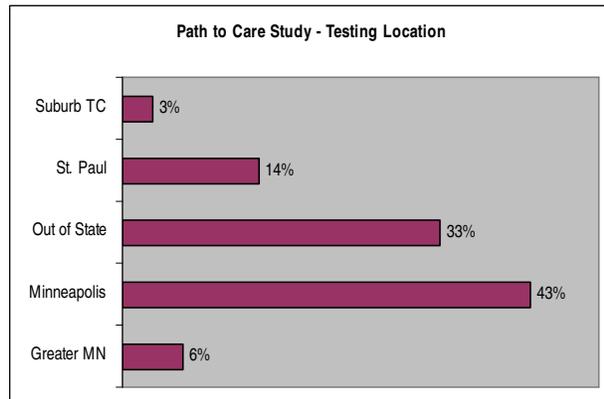
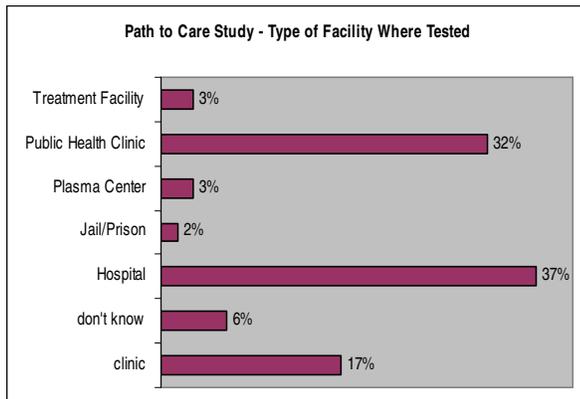
**\*\* Risk & Symptom-motivated testers**

Health system diagnosis sites reported higher numbers of HIV diagnoses among people who live in Twin Cities suburbs [57% average for the six year period for Park Nicollet and 38% average for the six year period for HealthPartners]. Also, HealthPartners reported higher numbers of HIV diagnoses among St. Paul residents [36% average for the six year period]. About half diagnosed at these sites were White [52% average for the six year period] and half were people of color [48% average for the six year period]. More men [72% average for the six year period] than women [28% average for the six year period] were diagnosed at these facilities; a proportion almost exactly the same as that among all

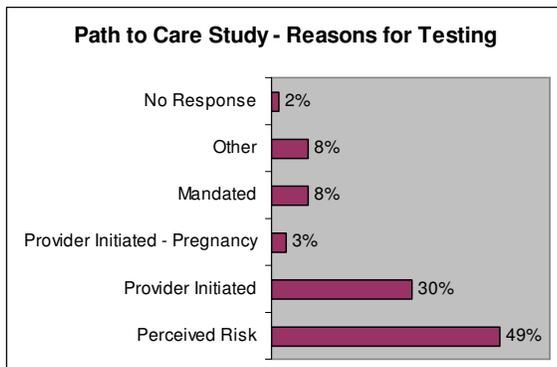
Minnesotans diagnosed with HIV. Half of those diagnosed at these facilities were between ages 25 and 40 [50% average for the six year period]. Half of those diagnosed at these facilities identified their HIV transmission risk factor as male-to-male sexual activity [49% average for the six year period], though Park Nicollet tended to diagnose more who did so [56% average for the six year period] and HealthPartners diagnosing fewer with male-to-male risk reported [41% average for the six year period] and more high risk heterosexuals [30% average for the six year period]. The proportion of those reporting HIV(non-AIDS) and those reporting HIV(AIDS) is comparable to the overall population of Minnesotans living with HIV, with 68% [average for the six year period] reporting with early stage HIV disease and 32% [average for the six year period] reporting advanced stage HIV disease.

Based upon the stage of infection reported by those newly diagnosed at these facilities, it appears they attracted individuals who were both *risk & symptom-motivated testers*.

*Comparison of Diagnosis Site Date with Path to Care Study Survey and Interview Results.* The findings and analysis of motivations for testing at these consistently reporting diagnosis sites in Minnesota are similar to findings from the Path to Care Study survey and interviews [see charts below]. The Path to Care survey and interview participants reported that 37% were diagnosed at a hospital and 32% reported being diagnosed at a public health clinic. Most of the survey participants were diagnosed in Minneapolis [43%]. Additionally, 49% reported getting tested because they perceived a risk for HIV, while 30% were tested at the initiation of a provider, typically in response to presenting symptoms.



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.



Source: Path to Care Study Survey and Interviews, 2009 – Interview Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

Findings from key informant interviews conducted as part of the Path to Care study suggest there may be more testing activity at community health clinics than is evident in the summary of top diagnosis sites in Minnesota, as well as significant testing at plasma centers.

Path to Care Study surveys and interviews provide some support for the observation that community health clinics may offer new options for reaching people who are positive but are undiagnosed. Seventeen percent of the Path to Care survey respondents reported getting a diagnoses at a clinic, and based upon the stories told during the interview process, these tended to be community health clinics and not private clinics. Path to Care Study interviewees who reported getting tested at a community health clinic [some in Minnesota and some out of state], received their diagnosis at that clinic and also tended to stay at that clinic, at least for early intervention care, due to the availability of comprehensive, coordinated care and services.

Some key informant interviewees observed that more testing may be happening at plasma centers than is reflected in the MDH diagnosis site data. Path to Care Study interviewees who received an initial HIV test at a plasma center reported either not learning about their HIV diagnosis until they were contacted by a public health disease investigator, or being referred by the plasma center to a public health clinic to get an HIV test [presumably to confirm a test result received at the plasma center]. In the latter cases, the diagnosis would more likely be reported by the public health clinic. What is suggested from these stories is that plasma centers may lack either staff or staff capacity to support individuals who are tested through their facilities.

*Guidelines for Testing and Connecting to Care - What should be happening at testing and diagnosis sites?* According to the Centers for Disease Prevention and Control guidelines<sup>10</sup> issued in 2006, the following professional standards should guide HIV testing and diagnosis:

- Routine screening in all health facilities for people ages 13 to 64 and for those who present with HIV-defining symptoms
- Testing should be voluntary, in that no one should be tested without their knowledge or should be coerced to test
- Specific informed consent not required, general consent for medical care should be considered sufficient to encompass consent for HIV testing with individuals having the ability to opt-out of testing
- Prevention counseling not required in health care settings, though is encouraged in some settings or situations [e.g. those in STD clinics or seeking treatment for an STD]
- Repeat for individuals at higher risk for HIV infection; at least annually
- Active effort to link to clinical care, counseling & support for those who test positive
- Additional guidelines for pregnant women & infants

In February 2009, the American Academy of HIV Medicine [AAHIVM] published a report on implementation of routine HIV testing for all health care settings. The report addressed best practices for connecting HIV infected patients to care, provided a primer for clinicians about how to help newly

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<sup>10</sup> Branson, Bernard, et. al., "Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings, MMRW, Centers for Disease Control and Prevention, September 22, 2006.

diagnosed HIV infected individuals access care, and a summarized report from a November, 2008 national meeting to explore strategies for implementing routine HIV screening.<sup>11</sup>

The AAHIVM publication noted that that “the benefits associated with routine screening can only be realized if routine screening is coupled with successful approaches to assure that newly diagnosed patients receive timely, appropriate and necessary follow up care and services.”<sup>12</sup> While the CDC guidelines were less specific in providing information about how to implement routine testing and was slight in the focus on connecting those who test positive to care, the AAHIVM publication was intended to expand upon the CDC’s 2006 guidelines by:<sup>13</sup>

- Encouraging practitioners to learn about state laws and processes related to HIV testing, reporting, and potential civil or criminal ramifications associated with testing, and to be informed about partner notification and case management services that may be available in the state
- Identify and establish referral relationships clinicians and support service providers available to serve newly diagnosed patients, and establish clear, internal procedures for acting on these referral relationships [e.g. clear roles and responsibilities, appropriate forms, support for clients to facilitate the referral, training to ensure capacity to response with sensitivity and cultural appropriateness and relevance, engagement of patient as a partner in care, and a process for tracking referrals]
- Patient services [e.g. education about HIV and treatment, assistance with appointment scheduling, attention to establishing a trusting and supportive relationship with the HIV provider, convey acceptance to alleviate stigma associated with sexual orientation, drug or alcohol use, age or race and ethnicity, development of common goals for care, confirming or facilitating health care coverage, post test counseling about wellness, prevention and disclosure, and clear assessment to identify immediate barriers to entering care].
- Provider preparation to understand chronic disease management
- Provider preparation to understand how to explain and discuss test results and the implications of an HIV-positive diagnosis.

Additionally, the AAHIVM publication cited the impact of immediately engaging a case manager and the supportive intervention of another person living with HIV to facilitate efficient and successful connections to care following diagnosis.

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<sup>11</sup> American Academy of HIV Medicine, Connecting HIV Infected Patients to Care, February, 2009.

<sup>12</sup> Ibid, p. 6.

<sup>13</sup> The AAHIVMed publication was produced with funding through a cooperative agreement with the CDC.

**SUMMARY OF AAHIVM CONNECTING TO CARE GUIDELINES**

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Learn about relevant state laws and available support services [e.g. partner services, case management]

Identify and establish referral relationships

Establish clear internal process and procedures for Making

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Provider preparation to be able to provide and discuss diagnosis and provide care consistent with chronic disease management

Provide and discuss diagnosis – clearly, completely & with sensitivity

Deliver patient services – education about HIV and treatment, assistance with appointment scheduling, attention to establishing a trusting and supportive relationship with the HIV provider, convey acceptance to alleviate stigma associated with sexual orientation, drug or alcohol use, age or race and ethnicity, development of common goals for care, confirming or facilitating health care coverage, post test counseling about wellness, prevention and disclosure, and clear assessment to identify immediate barriers to entering care].

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Connect with case manager/social worker

Engage Peers and other Community-based Resources

*How prepared are Minnesota's most frequently reporting diagnosis sites to implement the CDC guidelines and AAHIVM implementation guidelines?* Four of the five most consistently reporting diagnosis sites and one, culturally-specific community health center participated in self assessment interviews. The results of these interviews revealed:

- (1) Professional Standards: CDC guidelines are not generally implemented and there is low awareness about new AAHIVM guidelines. Publicly funded clinics that had well-established HIV screening and testing services tended to continue implementing policies and procedures they had in place prior to the issuances of the new CDC guidelines in 2006. Hospitals and health systems were much less consistent in their application of the new CDC guidelines. A commonly cited reason for this was the complex nature of these organizations and their multiple levels of medical care and service. In this context, the planning and training needed to implement the guidelines was not a great priority when the amount of HIV patient care was compared to the volume and demands of other care offered within their facility and system. In fact, one provider was surprised to see their system was one of the state's most consistent, high diagnosis providers.

It should be noted that none of the providers was aware of the AAHIVM guidelines. Copies of the guidelines were provided to each of the providers.

- (2) Policies and Procedures: Clinics with well-established HIV screening and testing services – both public health clinics and community clinics have formal policies & procedures to manage the connection between diagnosis and care. Clinics with well-established HIV screening and testing services, while not familiar with the AAHIVM guidelines, tended to have policies and procedures in place that were consistent with these guidelines and their goal of connecting newly diagnosed individuals with HIV care.

Hospitals and health systems tended to rely upon a more informal, internal system for connecting newly-diagnosed individuals to HIV care. The connections were made when staff from HIV programs internal to the hospital or system did their own outreach and education within the hospital or system. In fact, even more than the relative visibility of the HIV clinic within the hospital or the clinic, it was this targeted outreach and education, including providing the name and contact information for a specific individual, that facilitated getting a newly-diagnosed person onto the path to HIV care.

The exceptions to this informal approach to making the connection to care were the HIV specialty clinics within hospitals and health systems. When these clinics did the screening and testing, the procedure for getting those diagnosed with HIV into care was clear.

- (3) Connecting to Care: All of the interviewed providers indicated they had good capacity to connect newly diagnosed individuals to early intervention and HIV specialty care medical care. The interviewed providers also expressed confidence that even the informal communication and referral networks within their hospital or health systems tended to successfully connect people to care, though perhaps, not as efficiently.
- (4) Connecting to Support Services: Providers with higher levels of public funding & engagement described greater capacity to connect clients to support services. If a provider delivered a service through a Ryan White contract or participated in the Minnesota HIV Services Planning Council, they knew more about other chronic care services for people living with HIV and how to connect their patients to these services. Conversely, those with less of a direct connection to the public

care and services funding process, tended not to know as much about other services and were less likely to make referrals outside of their clinic, hospital or health system.

- (5) Connecting to Peers and Community Support: Providers are testing strategies to link clients with peers and community support; with varying success. Formal efforts are underway in public health, community health and public hospital HIV clinics to test strategies for connecting those who are newly diagnosed or new to care with HIV-positive peers. Peer-facilitated support groups, peer-facilitated health education activities, and an adaptation of the peer navigator model to help people understand the clinic process and HIV care – particularly for those with language or cultural barriers are being explored. Interviewees described their efforts in ways that suggest they are developmental, either because the service model is being newly created or is being significantly changed, or the funding for the service is not adequate or reliable.

***Conclusion: The Gateway to Care – Testing and Diagnosis***

- A relatively small cluster of providers consistently diagnose the largest number of newly-diagnosed people living with HIV in Minnesota each year.
- Efforts to 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.
- 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 health care provider 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.

## **PART FOUR: MAKING AND SUSTAINING THE CONNECTION TO CARE**

The Path to Care Study survey and interview process sought to provide perspective on

- (1) How Minnesotans living with HIV get connected to care after diagnosis,
- (2) What helps people stay connected to care, and
- (3) What factors contribute to delaying or discontinuing care, and for those who discontinue care, what helps them reconnect after such a disruption?

Sixty three Minnesotans living with HIV participated in the Path to Care Study survey and interview process. In addition to surveying and interviewing people living with HIV, the Path to Care Study 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 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.

This part of the Path to Care Study describes (a) how the Path to Care Study survey and interviews were conducted and who participated in this process, and (b) what was learned about connecting to care after initial diagnosis, staying connected to care, and the experience of delaying or stopping care from the study survey and interview participants.

### ***Path to Care Study Survey and Interviews – Process and Participants***

Sixty three Minnesotans living with HIV participated in the Path to Care Study survey and interviews. Certainly, 63 individuals do not constitute a representative sample of the 6,220 people reported to be living with HIV in Minnesota in 2008<sup>14</sup>, nor were not brought into the study in the numbers or a manner to create a statistically representative sample. However, their experiences and opinions are illustrative. They provide qualitative insights that are suggestive of the factors that influence getting connected to care, staying in care, delaying or stopping care, and reconnecting to care, and the collective experiences of this group of people are instructive.

#### ***Process –***

The Path to Care survey and interviews were conducted between February and April, 2009. Individuals were recruited to participate in the process through outreach to HIV clinics, clinical case management providers and health education and emotional support programs. Participants also learned about the study through word of mouth referrals from peers.

While recruitment did not attempt to create a pool of participants who were statistically representative of the population of people reported to be living with HIV in Minnesota, an effort was made to assure the diverse characteristics of HIV prevalence were represented in terms of geography, race, gender and transmission risk circumstances. Also, an effort was made to assure the experiences of those recently diagnosed individuals as well as those who had been living with HIV for some time were represented.

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<sup>14</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April, 2009.

Sixty-five people living with HIV registered to participate in the surveys and interviews, with 96% showing up for the face-to-face survey and interview [four surveys and interviews were conducted by phone to accommodate participation by people who lived in Greater Minnesota]. Interview “clinics” were set up at two locations in Minneapolis [Minnesota AIDS Project and Hennepin County Health Services Building]. Most of the clinics were held at Minnesota AIDS Project and were conducted outside of routine workday hours [i.e. early evening and during the day on Saturdays and Sundays]. Each survey and interview participant was given a \$50 gift card an incentive and a \$10 transit allowance to facilitate participation.

A team of four people, including the study coordinator, administered the survey and conducted the interviews. The group received training to understand the purpose for the Path to Care Study, to develop consistent practices for collecting study and interview responses and to review confidentiality guidelines. The group also met subsequent to the survey and interview process to discuss and summarize findings. Each member of the interview team was a person living with HIV. They also constituted a diverse representation in terms of race, gender and infection risk circumstances. When describing the study to participants, the interview team members indicated it was being conducted “by and for people living with HIV” on behalf of the Minnesota HIV Services Planning Council.

Each survey and interview session was between 45 to 70 minutes in length. The sessions started with a four question structured interview. After the interview, study participants were asked to complete a 23 question survey [see p. 71].

The survey results were tabulated by the study coordinator and a student assistant. Analysis of the survey results is primarily limited to reporting and interpreting frequencies. However, statistical hypothesis testing [p value] analysis was applied to a limited number of survey questions, specifically, to determine what might be a statistically significant factor contributing to study participants discontinuing HIV care.

Content analysis of the transcribed interview notes produced the frequencies that are included in this report. The study coordinator transcribed the interview notes. A random sample of the transcribed notes was reviewed to identify the frequency of occurrence of key words and descriptions of activities. These were compared to the description of activities identified through key informant interviews conducted at the beginning of the Path to Care Study to help develop the study survey, with the two lists combined to develop the study content analysis coding template. The survey frequencies included in this report are based upon concept analysis of each of the transcribed interview notes, using the coding template that was developed as part of the study.

In addition to information collected through the survey and interview processes, information and analysis in this part of the Path to Care Study draws upon interviews with representatives and readiness assessment surveys involving four of the five diagnosis sites that consistently report the largest number of newly diagnosed people living with HIV annually 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.

### ***Description of Survey and Interview Participants -***

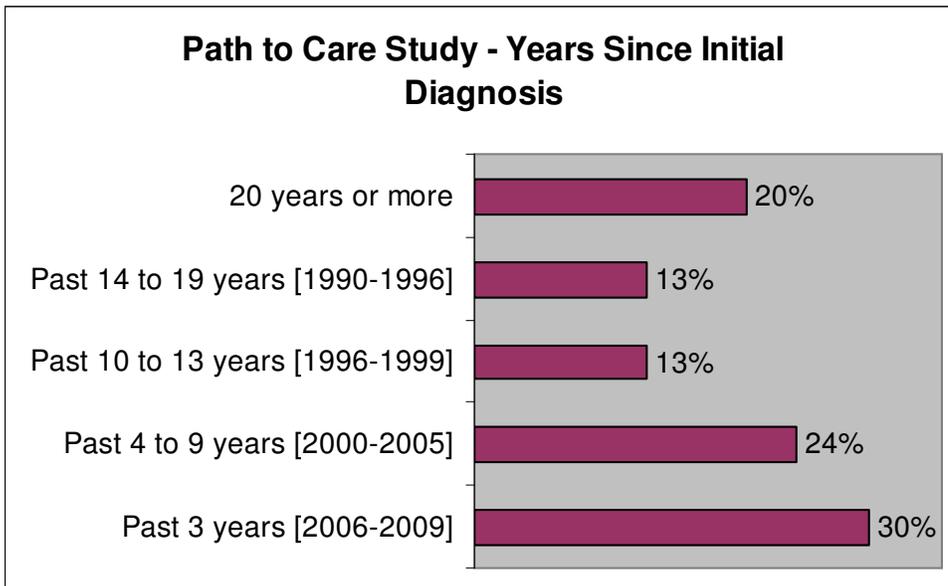
Sixty three Minnesotans living with HIV participated in the Path to Care survey and interview. Generally, the people living with HIV who participated in the Path to Care Study were both recently diagnosed with HIV and longer term survivors. They reflected the diversity of those living with HIV in terms of age, gender, race, geographic location and infection risk circumstances. Virtually all are currently receiving HIV medical care, though many have delayed or stopped care.

It can generally be said this was a group of people who cope with a number of health and social challenges in addition to those presented by HIV. Conversely, and more directly, it can be said this was not a “privileged” group of people living with HIV that conventional stereotypes suggest are those who are willing and able to make the time and effort to participate in a long and in depth survey and interview process.

Seventy six percent [67%] of the participants reported annual income at or below 175% of the Federal Poverty Guidelines. Sixty five percent [65%] reported not having a higher education degree [including 22% of all participants reporting as high school graduates and 6% as having not completed high school]. Anecdotally, the interview team observed that a notable number of the participants were referred through social networks established at The Aliveness Project [an AIDS service organization known for serving people living with HIV who are managing HIV disease along with other health and social complications]; an observation further rooted in the impressions created by the participants’ life stories that revealed a host of challenging health and social circumstances.

All 63 of the Path to Care Study participants were residents of Minnesota and were people living with HIV. As a condition to participate in the study survey and interview, each individual was required to affirm (1) they were currently residents of Minnesota and (2) they were currently living with HIV.

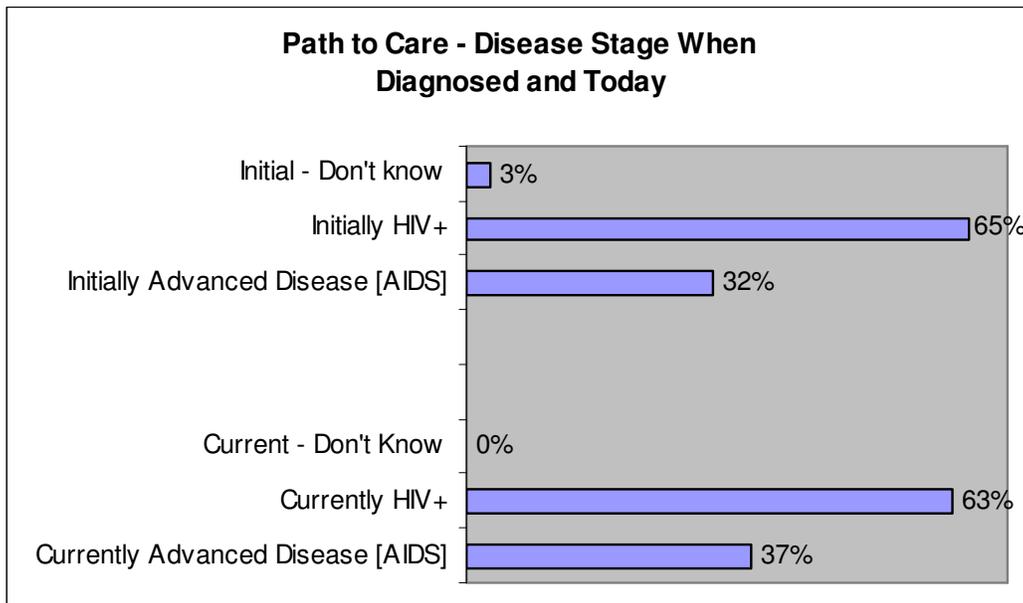
*How long have participants been living with HIV?* All of the survey and interview participants reported having an HIV diagnosis. As part of the survey, participants were asked to record the year in which they received their initial HIV diagnosis. Generally, the people living with HIV who participated in the Path to Care Study were both recently diagnosed with HIV and longer term survivors. Over one half of the study participants received their HIV diagnosis within the past ten years [54%], with nearly one third of the study participants diagnosed within the past three years [30%]. Twenty percent of the participants had been living with an HIV diagnosis for 20 years or more.



Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*.  
 Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

*Do participants represent experience with varying stages of HIV disease?* Of those who participated in the Path to Care Study, just short of one-third [32%] were initially diagnosed at an advanced stage of HIV disease [HIV (AIDS)], with 65% receiving an HIV (non-AIDS) diagnosis. Three percent [3%] reported they did not know their disease progression status at the time of diagnosis. This is generally consistent with the overall experience of people diagnosed with HIV in Minnesota. According to the Minnesota Department of Health, between 2003 and 2007, “the percentage of newly diagnosed persons considered as late testers has remained relatively stable at around 30%.”<sup>15</sup> At the time of the study, 37% of the participants reported an advanced stage HIV disease diagnosis of AIDS, with 63% reporting an HIV+ [non-AIDS] diagnosis. At the time of the study, none of the participants reported not knowing the status of their HIV disease progression.

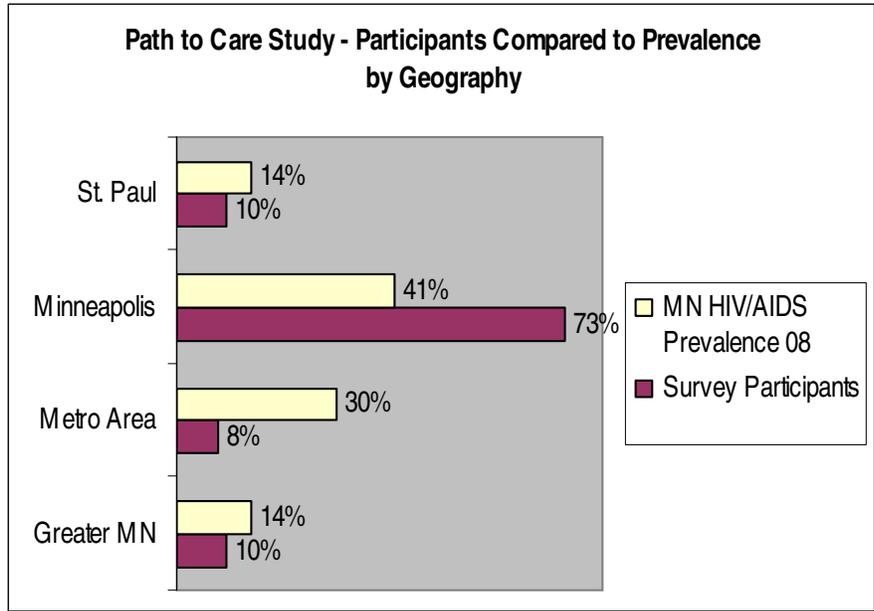
<sup>15</sup> “Epidemiological Profile of HIV/AIDS in Minnesota,” Epidemiology and Surveillance Unit, Minnesota Department of Health, July 2008.



Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*.  
 Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

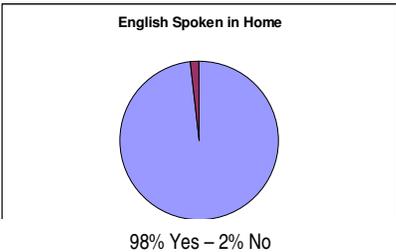
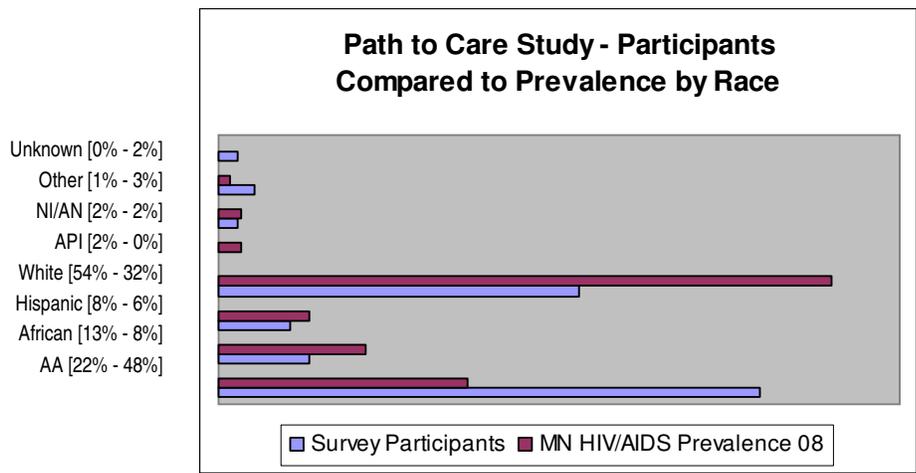
*Where do the study participants live?* All of the study participants were Minnesota residents when they participated in the survey and interview. The geographic distribution of the population of people living with HIV in Minnesota was represented among the study participants. However, people living with HIV who reside in Minneapolis were dramatically over represented in the study and those who live in Twin Cities suburbs were under represented. Seventy-three percent [73%] of the participants reported living in Minneapolis, compared to 41% reported in the Minnesota Department of Health’s 2008 prevalence report.<sup>16</sup> Only 8% of the study participants reported living in the Twin Cities suburbs, compared to 30% reported in the state’s 2008 prevalence report. According to the state’s 2008 prevalence report, 14% of those living with HIV live in St. Paul and 14% live in Greater Minnesota. Ten percent of the study participants reported living in St. Paul and 10% reported living in Greater Minnesota.

<sup>16</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April, 2009.



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results.  
 Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

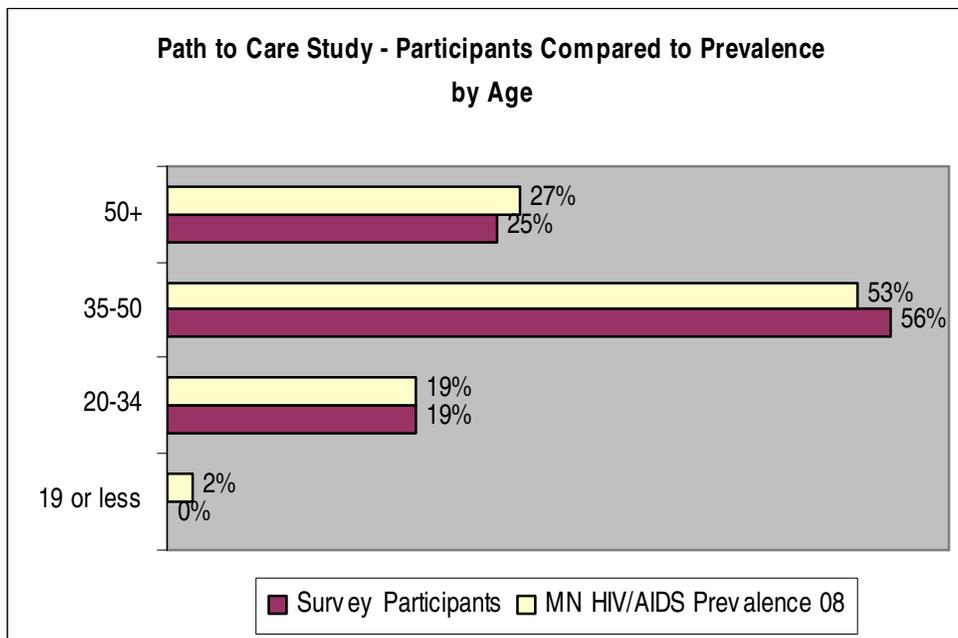
*What is the racial profile of the survey and interview participants?* The racial composition of those participating in the study draws from the communities of people living with HIV in Minnesota. African Americans were over represented and Whites were under represented in the study, as compared to the racial composition of all Minnesotans living with HIV. Forty eight percent of the participants were African American, compared to 22% reported in the Minnesota Department of Health’s 2008 prevalence report<sup>17</sup> and 32% were White compared to 54% in the population of people living with HIV in Minnesota. Eight percent of the participants were African compared to 13% in the population of Minnesotans living with HIV. Six percent were Hispanic/Latino compared to 8% in the population of Minnesotans living with HIV. Native Americans comprised 2% of the study participants, 5% reported as other or no response. No Asian/Pacific Islanders participated in the study. Only 2% of the participants reported that English was not the primary language spoken in their home.



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

<sup>17</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April, 2009.

*What are the ages of the survey and interview participants?* The ages of the people participating in the study closely reflected the of ages of those represented in Minnesota’s HIV/AIDS 2008 prevalence reports.<sup>18</sup> Nineteen percent[19%] of the people participating in the study were between the ages 20 and 34, compared to 19% of the people living with HIV in Minnesota in this age group in 2008. Fifty-six percent were in the 35 to 50 age group compared to a 2008 prevalence report of 53%, and 25% were over 50 compared to 27% in the prevalence report. None of the study participants were under 20 years of age.



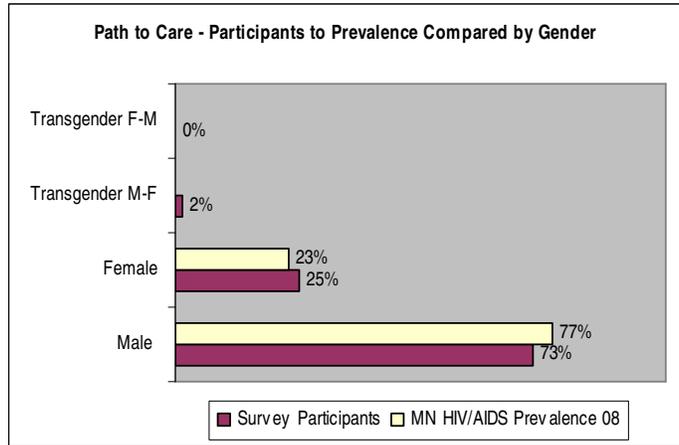
Source: Path to Care Study Survey and Interviews, 2009 – Survey Results.  
 Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

*What is the gender composition of the survey and interview participants?* The gender of those participating in the study closely reflected the gender of those represented in Minnesota’s HIV/AIDS 2008 prevalence reports.<sup>19</sup> Seventy three percent of the study participants were male compared to 77% of the people living with HIV in 2008. Twenty five percent were female compared to a 2008 prevalence report of 23%. Two percent of the study participants reported being transgender [male to female].

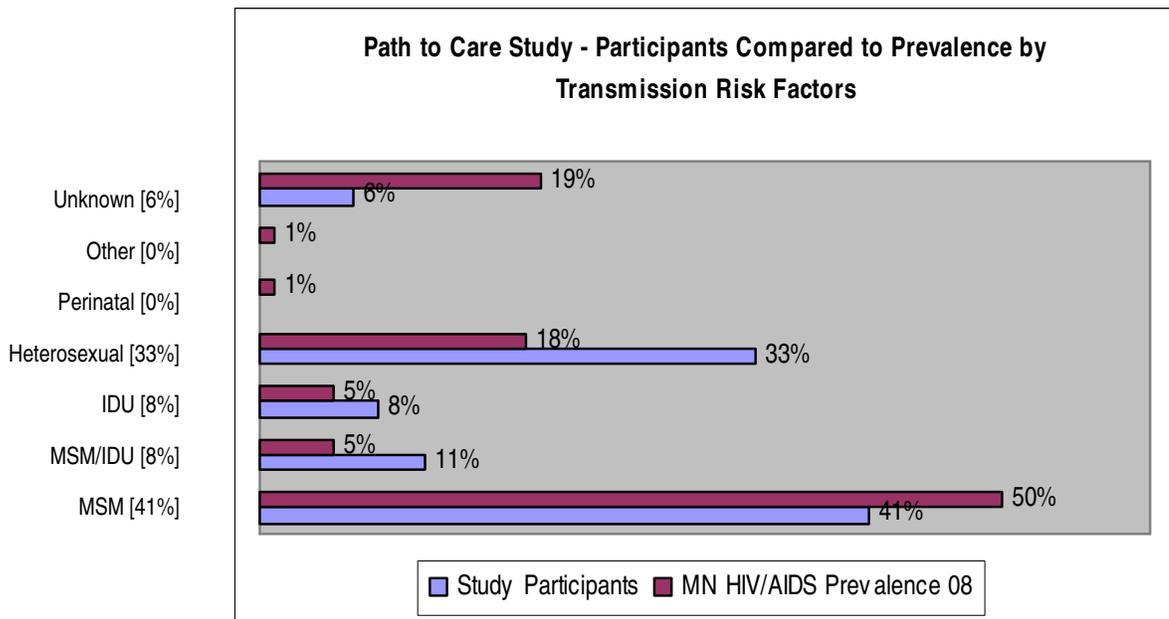
<sup>18</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April 2009.

<sup>19</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April 2009.

Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN,



*What risk transmission circumstances are represented among the survey and interview participants?*  
 Those who reported heterosexual contact as their infection risk circumstance were notably over represented in the study compared to their numbers among those living with HIV in Minnesota. Thirty three percent of the study participants reported heterosexual contact as their infection risk compared to 18% reporting in the state’s 2008 HIV/AIDS prevalence report.<sup>20</sup> Gay and bisexual men and other men who have sex with men, including those who identified injecting drug use as a risk factor, comprised 52% of the study participants, compared to 55% of those in the 2008 HIV/AIDS prevalence report. Eight percent of the study participants reported injecting drug use as a transmission risk factor, and 7% reported other or unknown.

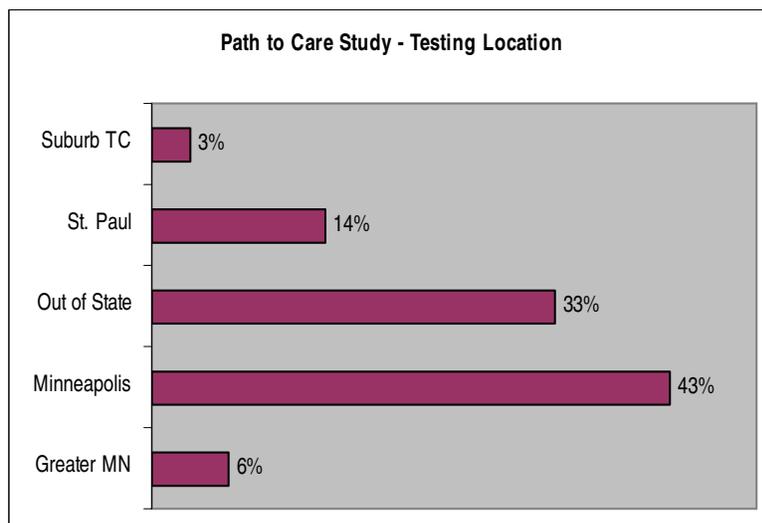
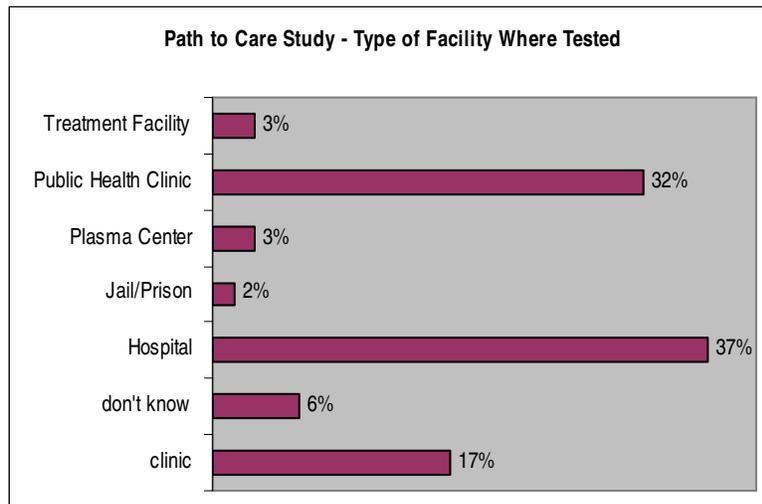


Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

<sup>20</sup> “HIV/AIDS Prevalence and Mortality,” Minnesota Department of Health, April 2009.

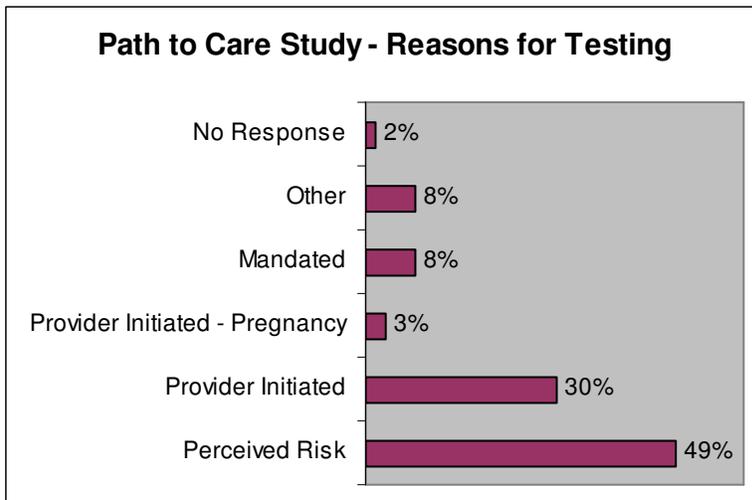
Where did survey and interview participants get tested and diagnosed? Most of the survey participants tested at hospitals [37%], public health clinics [32%] or doctors' clinics [17%]. This is generally consistent with the most prevalent diagnosis sites in Minnesota which are dominated by hospitals and public health clinics [see p. 13].

Sixty percent [67%] of the participants reported they tested or received their diagnosis in the Twin Cities metropolitan area [with most of those being in Minneapolis]. Six percent [6%] reported testing or receiving a diagnosis at a Greater Minnesota location. Thirty-three percent [33%] reported testing or receiving a diagnosis out of the state.



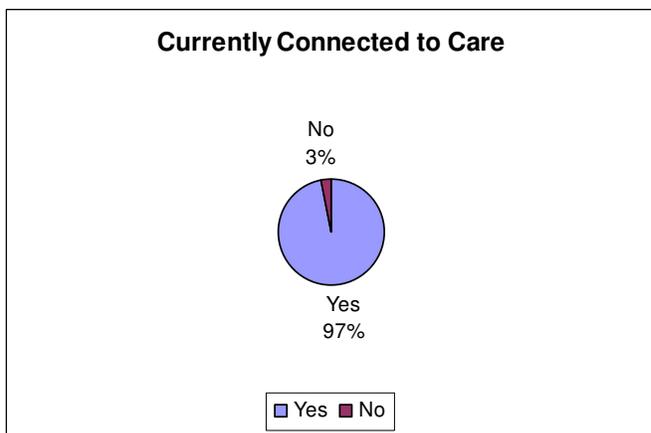
Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*. *Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.*

*What motivated survey and interview participants to get tested?* The survey did not include a question to assess the reason for getting tested, but this information came up in the interviewing process. Analysis of the interview responses indicated that most study participants got tested because they perceived a risk [49%] or at the suggestion of a clinician who was providing medical care [30%].



Source: Path to Care Study Survey and Interviews, 2009 – *Interview Results*.  
*Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.*

*Were the survey and interview participants “in” or “out” of care?* Finally, it should be noted that to an overwhelming extent, participants in the Path to Care study reported to be connected to a medical provider for HIV care at the time when they were interviewed and completed the study survey. Ninety seven percent [97%] of the participants indicated they were in the care of a medical provider. That said, the survey and interview results suggest that at the very least, one third of the study participants had deferred or stopped care at some time during their experience living with HIV.



Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*. *Not a representative sample. Information cannot be generalized to population of people living with HIV in MN,*

***Conclusions: Path to Care Study Survey and Interviews – Process and Participants***

- 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.
- The study reflects the experiences of people diagnosed through the years of the HIV epidemic in Minnesota, ranging from those who were diagnosed relatively recently to long term survivors.
- Again, 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.
- While virtually all of the study participants were in care at the time they were surveyed and interviewed, many either delayed or discontinued their care at some time.

## *Path to Care Study Survey and Interviews – Findings*

The Path to Care Study survey and interview process sought to provide perspective on (1) how Minnesotans living with HIV got connected to care after diagnosis, (2) what helped them stay connected to care, and (3) what were the factors associated with delaying or discontinuing care and then reconnecting after such a disruption?

The primary sources for information to address these questions were the surveys and interviews of 63 Minnesotans living with HIV. Additional information was collected through a survey and interview of service professionals from four of the sites consistently responsible for reporting most of the HIV diagnoses in Minnesota each year, and a community health clinic that primarily services Latinos. Key informant interviews with HIV service providers were used to help develop the survey and interview questions and to inform findings.

The interview part of the study involved a structured discussion, drawing upon the following questions for focus:

- (1) Tell me a little bit about your experience when you were tested and learned that you were living with HIV? *Discussion Probes: What made this process easy for you? What do wish had been different?*
- (2) Based on your experiences getting connected to HIV care, what advice would you give to others who are new to living with HIV or new to HIV care?
- (3) Have you every changed your doctor or stopped seeing your doctor? *Discussion Probes: If no, have you changed or stopped another HIV service [e.g. case management]? What was it that you liked about your care that kept you from making a change or stopping your care? If yes, what did you do to take care of yourself? What did you do to find another doctor or to start seeing a doctor again?*
- (4) Is there other information you would like to share with us about what helped you get connected with an HIV doctor, case manager or other service or provide that has helped you live with HIV?

Participants were also offered the opportunity to provide advice to the Minnesota HIV Services Planning Council addressing services they valued or changes they would recommend.

Participants tended to tell their stories about getting tested and why, how they got connected to care and services after receiving their diagnosis, what helped them stay connected to care and stay well – explained both in terms of what they found to be helpful and what they would advise for others, and either what helped them stay connected to care or a story about why they delayed or stopped care and what helped them reconnect to care.

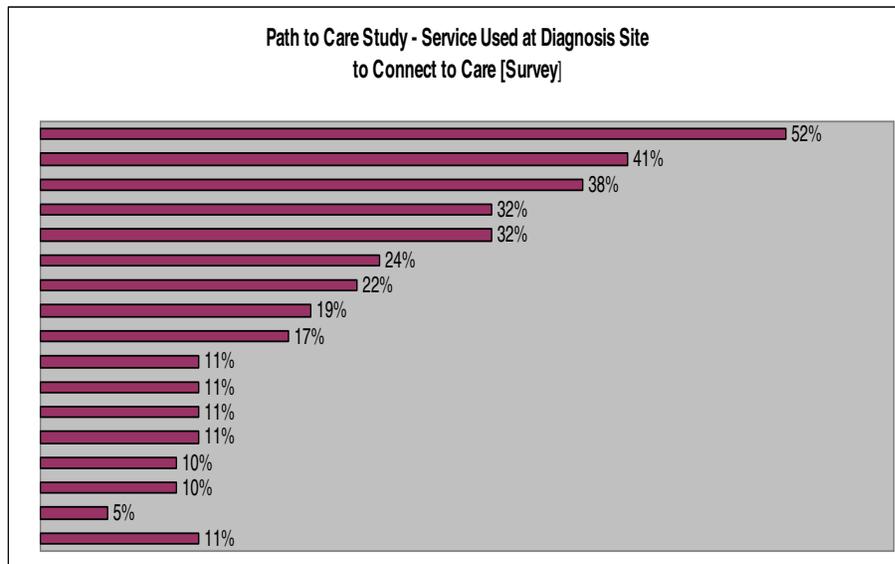
Following the interview, participants completed a 23 question survey. In addition to collecting demographic and geographic information, the survey also collected information about their experiences getting tested and diagnosed, getting connected to care, factors that help them stay in care, and information about any experiences delaying or discontinuing care.

Combined, the interviews and surveys provided both a qualitative and quantitative description of the participants’ experiences. Information received in the interviews assisted with interpreting the survey results; while the survey offered a single list of options for participants to choose from, the interviews provided descriptive information that helped better understand these responses [e.g. *survey responses indicated “connecting to an AIDS service organization for service or support” was an important support for those connecting to care after diagnosis, the interview responses suggested one of the specific services offered by an AIDS service organization that was helpful were services other than a case manager, such as “the AIDSLine”*]. Additionally, the survey results compare to the results of the interview content analysis as a check for consistency between the two versions of the study participants’ “path to care” experiences.

### Getting Connected to Care after Diagnosis

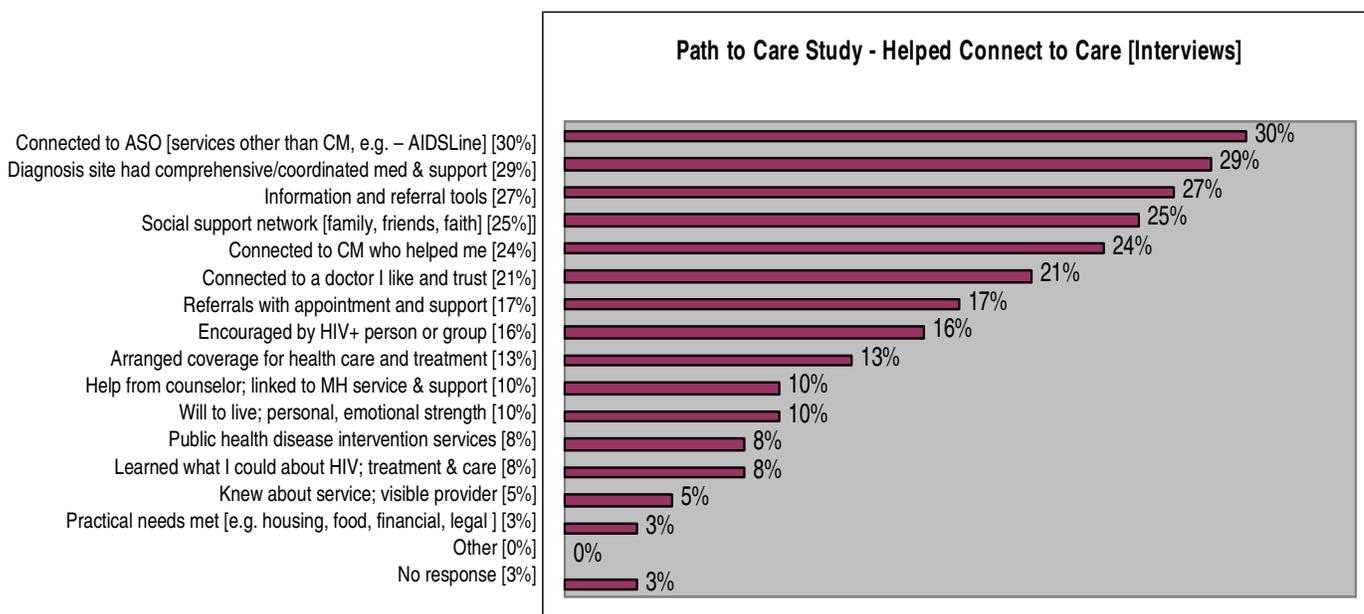
Ready access and connection to the health system is among the most important factors helping those newly diagnosed with HIV get connected to HIV care.

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%]. Other services of some importance were (1) finding a case manager [24%], (2) connecting to an HIV hotline [22%], (3) getting emergency food or financial assistance [19%], and (4) confirming or securing health insurance [17%].



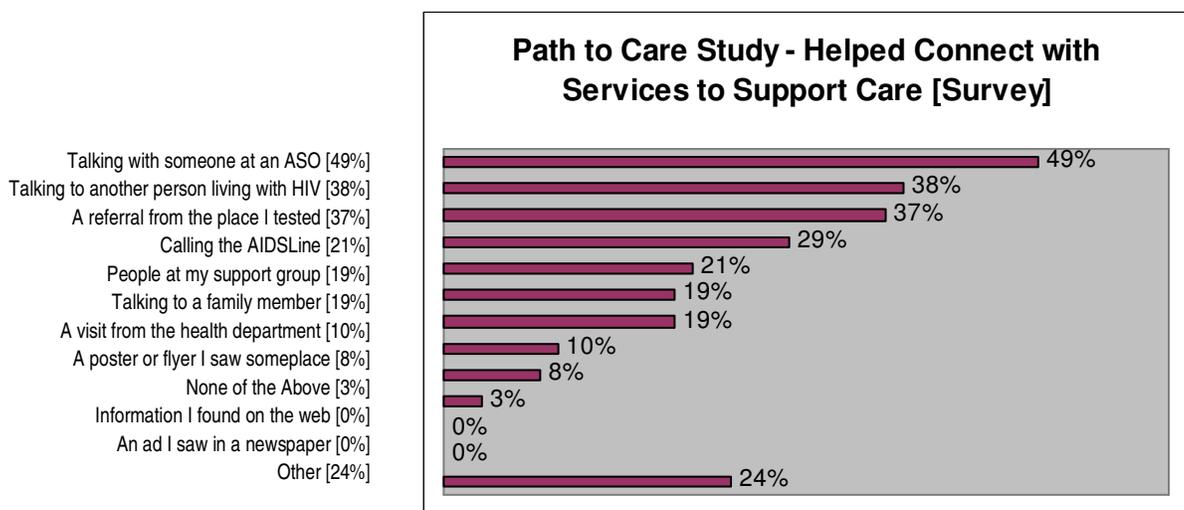
Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

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%]. Other services of some importance were (1) getting a referral with an appointment and support [17%], (2) encouragement from a person or group of people living with HIV [16%], and (3) arranging coverage for health care and treatment [13%].



Source: Path to Care Study Survey and Interviews, 2009 – Interview Results.  
 Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

The experience of connecting to parts of the health system other than primary medical care, for example medical case management, self-care management or assistance to stabilize housing, food or financial problems, was influenced by a slightly different set of factors. 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. Other notable factors were (1) contacting an information and referral service such as the AIDSLine [21%], talking with others at a support group [19%], (3) talking with a family members [19%], along with a variety of “other” factors (most notably, the referral of a doctor a clinic staff person) [24%].



Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

Analysis of the survey and interview results suggest 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, with seamless coordination being a key factor. The ideal situation was receiving an HIV diagnosis at a location where connecting to professional services -- medical care, social services and mental health support could be easily facilitated. However, participants also valued “navigation and support” tools. They identified services that helped provide an orientation to this new situation as being helpful, often times referring to the ability to contact a visible and easy to find resources such as the MAP AIDSLine. A number of respondents also talked about getting brochures and other information from clinics and others places they were going for services that helped them learn more about HIV and the services that were available. Additionally, unpublished findings from a recently completed study coordinated by the University of Minnesota Department of Epidemiology and Public health indicates emerging use of internet resources while waiting for HIV test results or after diagnosis to get information about how HIV works, key terms, information about medical treatment and connection to others living with HIV.<sup>21</sup> An important part of this process was having a supportive social network of family, friends or a faith community to provide emotional support.

Diagnosis site interviews and self-assessment surveys suggested greater readiness to provide access to the comprehensive – medical, social support, mental health support and emotional support – and coordinated post-diagnosis care that study participants found to be most helpful existed at public health or community health clinics that also served as HIV diagnosis sites. Hospital diagnosis sites were less ready to offer a similar connection to care. While comprehensive services are available within the hospital system, coordinating access was more of a challenge. People received diagnoses in various parts of the hospital system, but the ability to facilitate a referral to connect to HIV early intervention and specialty care varied widely. Hospital diagnosis site interviewees described difficulties getting institutional buy-in to develop systematic internal referral systems due to competing priorities or lack of awareness about the prominent role the system plays in diagnosing new HIV infections in Minnesota. Both diagnosis site interviewees and people living with HIV who participated in the Path to Care Study

<sup>21</sup> Horvath, Keith, et. al., “Online Resources for Persons Recently Diagnosed with HIV/IDS: An Analysis of HIV-related Webpages, University of Minnesota, unpublished, 2009.

interviews described the ability to make internal referrals to a specific individual – usually identified by name – as key to coordinating the connection from diagnosis to care.

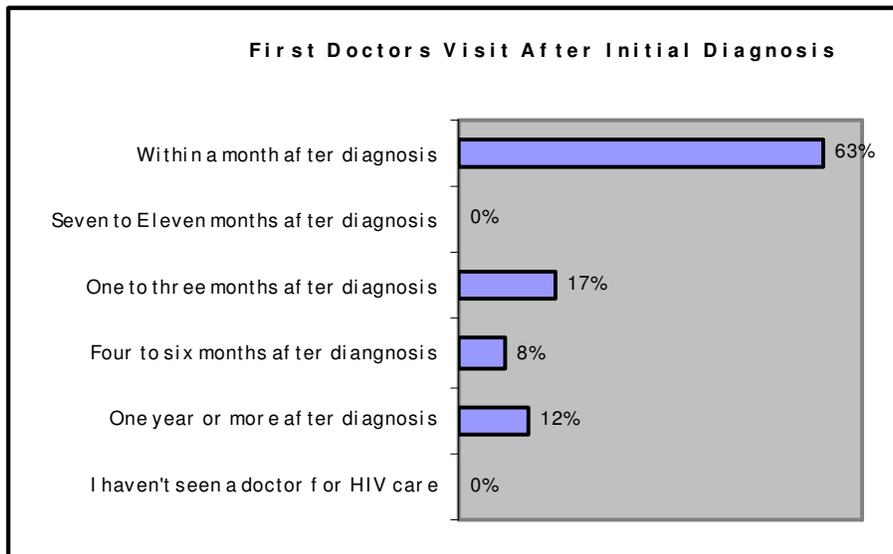
Key informant interviewees raised concerns about the role of plasma centers in the process of connecting people to care after diagnosis. Three percent of the Path to Care survey and interview participants identified plasma centers as their diagnosis site, each telling stories in which they received no services at the plasma center, were informed of their diagnosis by a public health disease intervention specialist, and subsequently went to a public health clinic for confirmatory testing and assistance with getting connected to care. Key informant interviewees also suggested opportunities to reach more people currently infected with HIV but undiagnosed, and to diagnose them in settings where they can benefit from a connection to comprehensive and coordinated care by expanding low or no cost testing to more community health center settings.

Depending upon individual circumstances, other factors facilitated making the initial connection to care: resolving an immediate food, shelter or financial crisis, legal assistance [especially in cases involving individuals who are not U.S. residents or are testing as part of an employment situation], talking with another person living with HIV or getting connected to alcohol or drug abuse intervention or treatment services. For people who were in these unique circumstances, these were vitally important services to have available at the time of diagnosis.

### ***Challenges to Getting Connected to Care after Diagnosis***

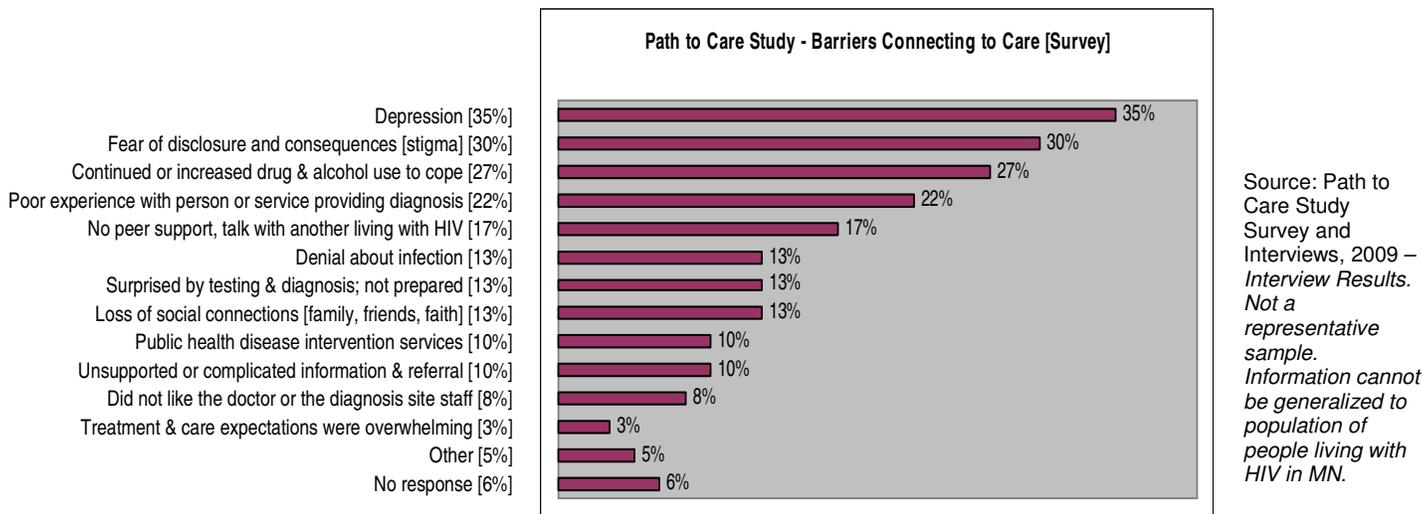
A variety of factors can complicate getting connected to HIV care after an initial diagnosis. Most notable are depression, concerns about the effects of HIV stigma and a poorly delivered or uncoordinated service at the diagnosis site.

Two-thirds of the Path to Care Study survey respondents reported visiting a doctor within the first month after initially being diagnosed with HIV [63%]. Twenty five percent had their first visit with a doctor between one and six months after initial diagnosis. However, 12% reported waiting for one year or more before seeing a doctor after initial diagnosis.



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN,

Interview responses 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%]. [No questions were asked in the survey to assess barriers to getting connected to care.]



Analysis of the survey and interview results indicates that most of the people living with HIV who participated in the study were efficiently connected to clinical care [63% within one month of initial diagnosis]. Conversely, one third of the participants described an experience that resulted in a delay connecting to care ranging from a matter of a few months to over a year.

Mental health – both situational and chronic, intensified alcohol and drug abuse as a coping strategy, and concerns about the effects of HIV-related stigma created barriers to connecting to care after diagnosis. A number of other factors were cited as causes for delaying the initial connection to care, some of which could be interpreted as being similar to or associated with some of the most frequently identified barriers [for example, denial about infection being associated with feelings of depression or lack of social connections feeding feelings of depression, or a bad experience at the diagnosis site being a consequence of poor treatment by a doctor or other clinical staff]. This was illustrated in the stories told by participants in the Path to Care Study interviews in which factors tended to be described in a way to suggest they were associated with each other [e.g. feelings of depression intensifying alcohol and drug abuse and creating isolation from others who might provide support].

Providing easy access to services to assist with depression brought on by the situational impact of learning of an HIV diagnosis seems to be an important part of easing the connection to care, with the availability of mental health services identified as both a significant aid in connecting to care and depression – a condition requiring the attentions of mental health services, identified as a barrier to connecting to care. Key informant interviewees suggest that paying attention to assessing mental health needs and making a referral that is appropriate to the client needs more attention, for example,

connecting an individual who may be experiencing situational depression to counseling or a support group, or therapy or psychiatric care for an individual who may experience further complications of an underlying, chronic mental health condition. Interviews with people living with HIV who had problems managing alcohol or drug use suggested the feelings of depression influenced more intensive alcohol or drug abuse which they notably described, in hindsight, as a “coping” strategy.

Social factors, especially the effects of HIV-related stigma, created challenges connecting to care after diagnosis. Stories told by Path to Care Study interviewees suggested fears about being rejected by family, friends or their faith communities, or experiencing employment consequences, with participants describing perceptions of cultural attitudes uniquely attributable to race or ethnicity, faith or based on statements provided by employers or others in their work place. Conversely, study interviewees who indicated they had a supportive network of family, friends or faith or knowledge about HIV before they were diagnosed did not tend to include difficulties in connecting to care in their stories about receiving their initial diagnosis.

It should be noted that based upon key informant interviews and interviews with representatives from diagnosis sites, it was expected that making a connection with another person living with HIV would be a notable factor in helping people connect to care after diagnosis. Survey and interview results suggest this was not the case for most. However, for those who reported difficulties getting connected to care, *not* having the opportunity to talk with another person living with HIV was cited as something they thought would have been helpful and wished they had.

A small number of those describing challenges getting connected to care after initial diagnosis described situations in which they were surprised by the testing experience or receiving their diagnosis. These tended to be individuals who were tested at plasma centers or who learned about risk of infection or their diagnosis from public health disease investigators. The few testing and diagnosis stories shared by those who were tested at plasma centers consistently included descriptions of situations in which they were not told about their test results until a subsequent visit by a public health staff person, or were simply referred to a local public health clinic. The experiences described with plasma facilities suggested they were unprepared to deliver diagnoses.

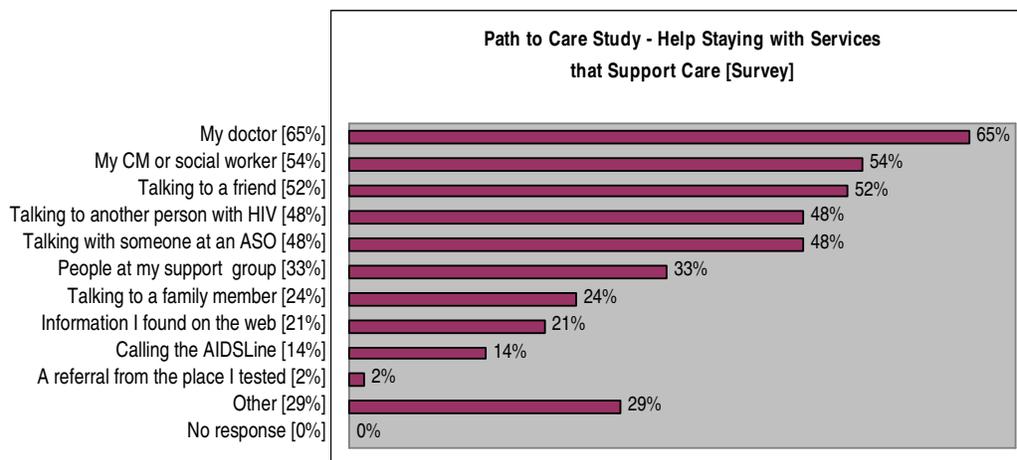
The few participants who told stories about experiences with public health disease investigators were evenly divided. This service was as likely to have a helpful impact as it was to create challenges connecting to care [10% of survey respondents suggesting it helped them get connected to support services and 10% of interview respondents suggesting it created a challenge to connecting to care]. Those who considered the service helpful described the assistance they received getting connected to health services. Those who considered it to be unhelpful described unexpected visits that put them in situations that compromised safety and support within their home, jeopardized their employment, and left them without emotional support or assistance to connect to health services.

### ***Staying Connected to Care***

For people living with HIV, the professional services provided by a doctor they trust and case manager are as important as the information and support they receive from others living with HIV, family and friends and emotional support. One is not more important than the other. It is the service of the health system and community supports that keep people living with HIV connected to care. In other words, the results of the Path to Care Study surveys and interviews affirm the chronic care model; Connection to the health system and a community of personal support are important factors in keeping people living with HIV connected to HIV care.

Overwhelmingly, the people living with HIV who participated in the Path to Care Study survey and interviews were connected to HIV care. Ninety-eight percent of the participants reported being in care, i.e. seeing a primary physician for HIV care at the time of completing the survey. The study collected information about the factors that helped people stay in HIV care in three different ways: (1) through a survey question asking participants to choose among factors that helped them stay in care, (2) through an interview question asking participants to describe, in their own words, what helped them stay in care, and (3) through an interview question asking participants to describe, in their own words, what advice they would give to others newly diagnosed with HIV to help them stay in HIV care.

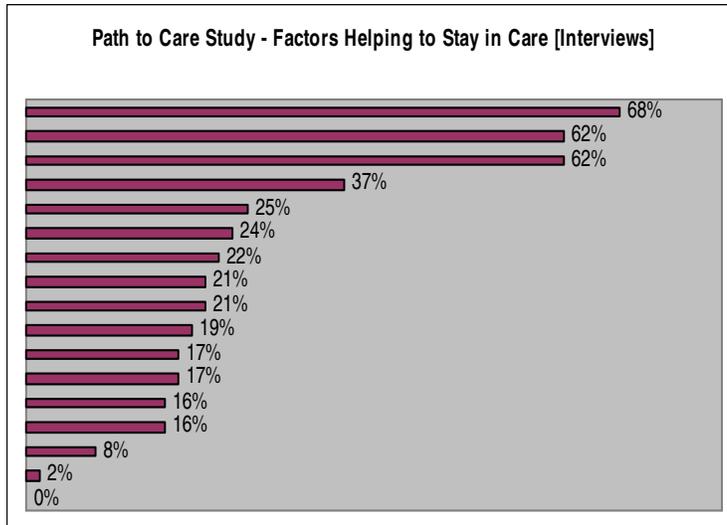
Survey responses indicated the most helpful supports keeping people connected to care were (1) my doctor [65%], (2) my case manager or social worker [54%], (3) talking to a friend [52%], (4) talking to another person living with HIV [48%], and (5) talking with someone at an AIDS service organization [someone other than a case manager] [48%]. Other supports of some importance were (1) people at my support group [33%], talking to a family member [24%], and (3) information I found on the Web [21%].



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

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%]. Another, related, support of some importance was information about services I get from others living with HIV [37%].

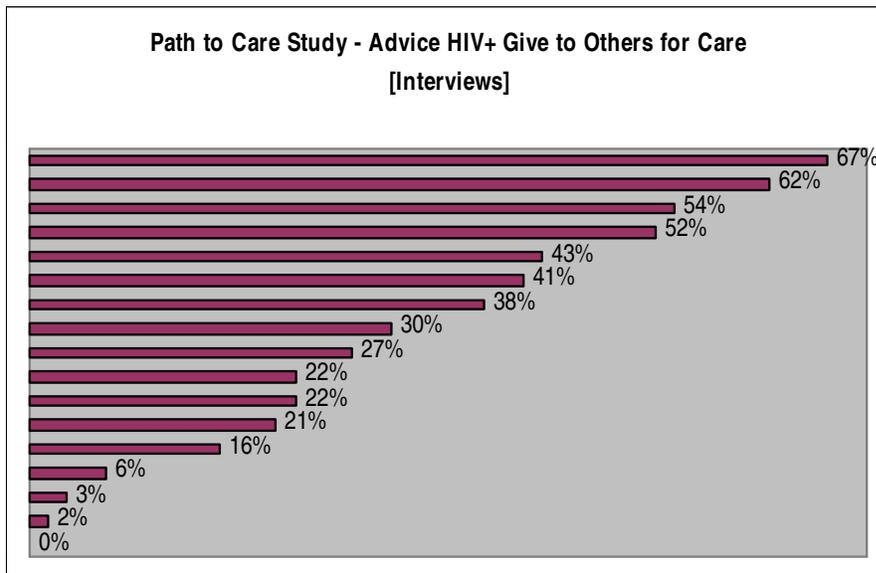
Peer support from others living with HIV; groups or individuals [68%]  
 The right doctor [62%]  
 My case manager [62%]  
 Information about services I get from others living with HIV [37%]  
 Stabilized health coverage; insurance [25%]  
 Improved social connections [e.g. family, friends, faith] [24%]  
 Being productive, working, doing something about HIV [22%]  
 Keep myself informed & learning about HIV care [21%]  
 Mental health services [21%]  
 ASO services [not including CM] [19%]  
 Substance abuse treatment, my recovery [17%]  
 Peer role models of others living with HIV [17%]  
 Practical needs met [e.g. food, financial support, transpo] [16%]  
 Housing secured [16%]  
 Other clinic staff [e.g. nurse] [8%]  
 Other [2%]  
 No response [0%]



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

Interview responses to an additional question intended to understand factors that helped people stay in care by asking participants to reflect upon the advice they would give to those newly diagnosed with HIV to help them stay in care suggest (1) finding others with HIV for support [67%], (2) get a good doctor you can trust [62%], (3) get a case manger; establish a good relationship with a social worker [54%], and (4) find another or others with HIV to help you learn to manage HIV disease and to live [52%]. Other recommendations of note included (1) having a healthy attitude; knowing that you are not going to die, (2) not isolating one’s self; connecting with the social support offered by family, friends and faith [41%], and (3) getting connected with an AIDS service organization [38%].

Find others with HIV for support [67%]  
 Get a good doctor you can trust [62%]  
 Get a CM; good relationship with a social worker [54%]  
 Find another/others with HIV to learn to manage disease & live [52%]  
 Healthy attitude; you are not going to die [43%]  
 Connect with social support, don't isolate [family, friends, faith] [41%]  
 Get connected with ASO [38%]  
 Adhere to treatment & care [30%]  
 Get information; learn about HIV [27%]  
 Do something to prevent or help others with HIV [22%]  
 Get a counselor & help with mental health [22%]  
 Get services that you need ; help with practical needs [21%]  
 Get help with chemical use [16%]  
 Get health coverage; confirm health coverage [insurance] [6%]  
 Pay attention to prevention; tell partners [3%]  
 Other [2%]  
 No response [0%]



Source: Path to Care Study Survey and Interviews, 2009 – Interview Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

Analysis of the survey and interview affirms the chronic care model. Based on their experiences, people living with HIV who participated in the Path to Care Study survey and interviews say both a health system with a prepared and practiced team and community supports that help them be informed and activated consumers are equally important to keeping them in care. *The support and information provided by others living with HIV, the care of a trusted doctor and the services provided by a case manager are considered to be of highest and essentially equal importance in helping people living with HIV stay in care.*

In addition to medical care and case management, people living with HIV depend upon a system that offers other services from AIDS service organizations [e.g. health education and social supports to resolve problems securing basic needs that might disrupt HIV care]. Along with the support and information provided by peers, they depend upon family, friends and faith to and opportunities to be productive, either through employment or opportunities to make a contribution to addressing the impact of HIV, to help them stay engaged with their HIV care.

Key informant interviewees offered observations that were consistent with the results of the surveys and interviews of people living with HIV. They noted the need to have a variety of sources for information and support to help people living with HIV stay connected to medical care to fill in gaps caused by pressures on the time that doctors can spend with patients, and to clarify, expand upon and reinforce information that is provided in the context of primary medical care.

In stories describing the role of medical care providers, interview participants discussed trusting their provider's knowledge and expertise, openness and availability to explain conditions, treatments and care, and personable communication. Interviewees frequently described feelings of being treated "as a human being" with attention given to their unique personality traits, health needs and living situations, as qualities they valued in their providers. Similar features were used to describe positive relationships with case managers, in addition to features of competence and abilities to make connections and secure resources.

Having connections with others living with others living with HIV were not just a source of emotional support, but also an important source of information about connecting with medical and other services. Stories shared during the interviews commonly included descriptions of deliberate efforts to seek out services that provided formal [e.g. support groups] or informal social situations [e.g. drop-in meal services at Aliveness, recreational activities offered through PrideAlive, or events such as the AIDSWalk] to connect with others living with HIV. Usually these were efforts to find emotional support, avoid isolation and sometimes to find others who had information to share about services. But, in most cases, they were described as helpful encounters because of the information and endorsements gathered through informal conversations about medical, social services and health education services.

Additionally, people would tell stories about making connections with visible, peer leaders and the role they played providing guidance, emotional support and information and referral to providers and services. It was not uncommon as part of these stories to hear the names of specific individuals, with several names of the same people coming up in multiple interviews. This suggested high profile peer leaders performed a function similar to high profile organizations that had services designed to help connect peers.

It should be noted that people living in Greater Minnesota, Latinos and African-born individuals all talked about feelings of isolation and fears about the effects of stigma. None of these individuals

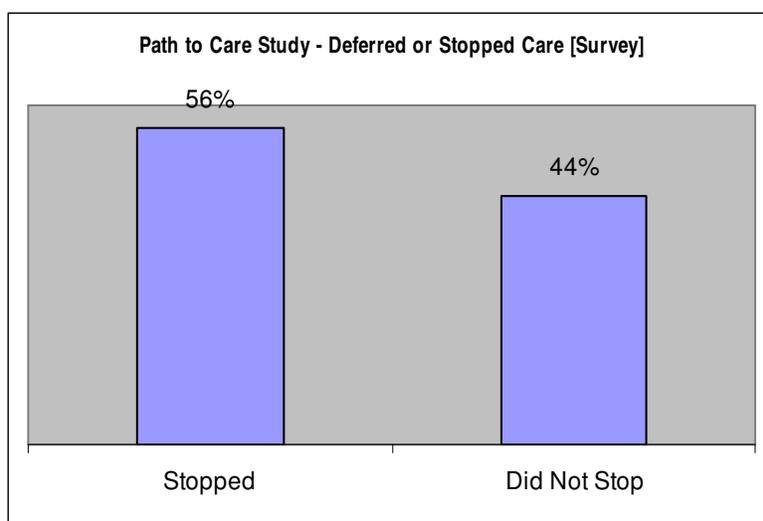
described experiences getting support from other people living with HIV or family, friends or their faith community in their stories of connecting to care. In these cases, it was the support of a professional that made the difference; typically a medical provider or staff involved with providing the 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.

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.

## *Delaying or Dropping Out of Care*

According to the Path to Care Study survey responses, 56% of the study participants reported either delaying or dropping out of HIV care, while 44% did not. The Path to Care Study reveals a mix of factors contributing to delay or discontinuation of HIV care. These include a history of infrequent medical care, a move and the disruptions that come with making a change in where one lives, dissatisfaction in the relationship with a provider, and depression, alcohol or drug abuse, denial or resistance to accepting an HIV diagnosis, and concern about the consequences of stigma [i.e. similar to the factors described a challenges to connecting to care after initial diagnosis described elsewhere in this report].

Fifty-six percent [56%] of the survey respondents indicated delaying or discontinuing care when responding to the survey question.<sup>22</sup>

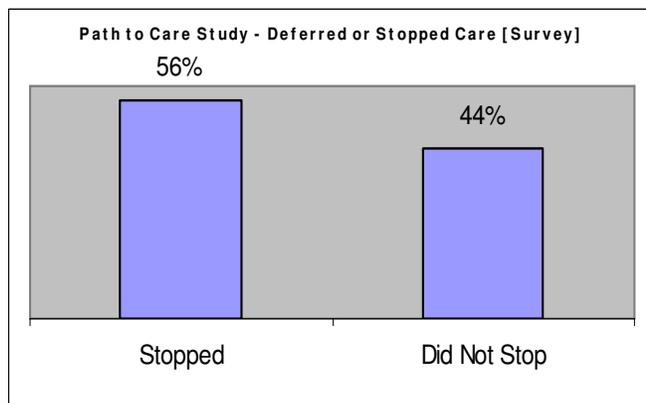
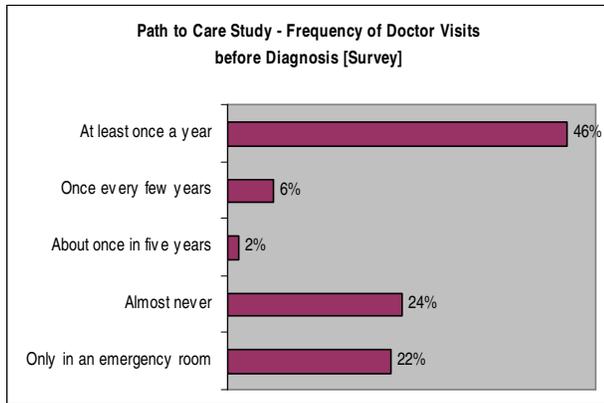


Source: Path to Care Study Survey and Interviews, 2009 – *Survey Results*. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

Forty-six percent [46%] of the survey respondents indicated they saw a health care provider on a regular basis, at least one time a year prior to receiving their HIV diagnosis. This is notable because further analysis suggests a relationship between infrequent doctor's care before diagnosis and likelihood of delaying or discontinuing care after diagnosis. The percentage of study participants who did not have an experience of regular doctor's care before diagnosis [54%] is almost equal to the number of study participants reporting that they had delayed or stopped care [56%], based on responses to the Path to Care Study surveys[see below].

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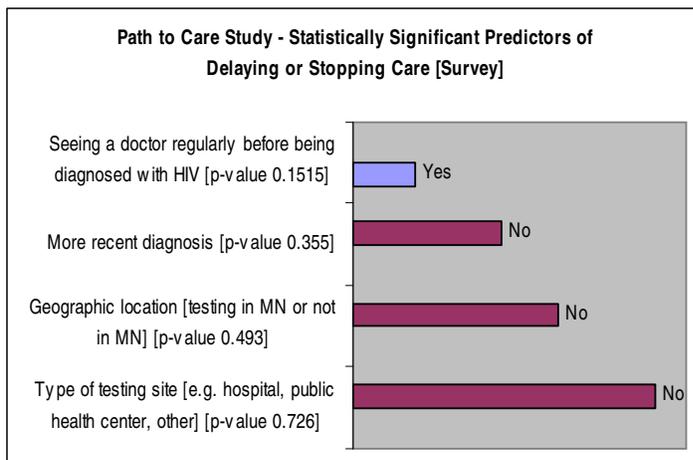
<sup>22</sup> More of the Path to Care Study participants described circumstances in which they either delayed or stopped HIV care. Sixty-seven percent of those interviewed described circumstances and offered reasons for delaying or stopping HIV care, with 33% indicating they did not delay or stop HIV care. The study did not produce information to explain the difference between what was reported in the survey responses compared to what was described in the interviews. However, the average of the responses suggest that approximately one-third of the study participants delayed or stopped HIV care at some time.



Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

While analysis of the Path to Care Study survey results is primarily limited to reporting and interpreting frequencies, statistical hypothesis testing [p value] analysis was applied to a limited number of survey questions, specifically, to determine what might be a statistically significant factor contributing to study participants discontinuing HIV care. This analysis evaluated whether there was a statistically significant relationship between the discontinuation of HIV medical care and (1) receiving a recent HIV diagnosis, (2) whether a person tested in Minnesota or outside of the state [i.e. in another state or another country], (3) they type of diagnosis site [e.g. hospital, public health center or other], or (4) seeing a doctor on a regular basis before being diagnosed with HIV. *Number of survey respondents: 35.*

Of the four factors, the only one with a statically significant relationship to discontinuing HIV care was seeing a doctor on a regular basis before being diagnosed with HIV [p-value = 0.1515], suggesting lack of health care prior to diagnosis as a likely indicator of risk for dropping out of care.

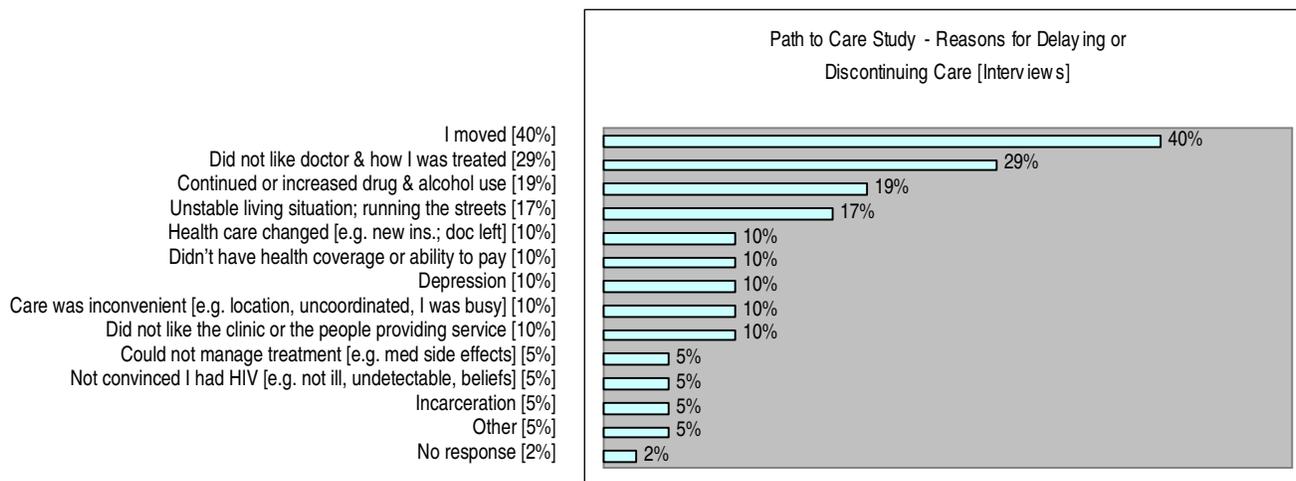


Source: Path to Care Study Survey and Interviews, 2009 – Survey Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

This analysis suggests a history of irregular visits with a doctor prior to HIV diagnosis, that is, infrequent use of health care services either because of behavior or lack of resources or coverage to sustain routine visits with a doctor, is 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%]. Other reasons of some importance for delaying

or discontinuing care were (1) continued or increased drug and alcohol use [19%], and (2) unstable living situation; running the streets [17%].<sup>23</sup>



Source: Path to Care Study Survey and Interviews, 2009 – Interview Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

An analysis of the Path to Care Study findings suggests that no one thing causes a person to discontinue HIV care but at least four situations stand out in the experiences of those who participated in the study:

- (1) *History of Irregular Health Care.* Those with a history of regularly seeing a doctor [46%], including a stable source of health coverage to enable regular visits, are more likely to sustain HIV care. Conversely, those who have not had that routine in their life before diagnosis [54%] are more likely to disrupt their HIV care.
- (2) *Making a Move.* A change in one’s living situation can signal the likelihood that a person with HIV will discontinue HIV care. The stories told during study interview [40% of participants] about moving and discontinuing HIV care were varied. They included (a) moves from town-to-town or place-to-place within a community precipitated by alcohol and drug abuse and associated problems with housing, employment and finances, and family and social relationships, (b) transition in and out of treatment for alcohol or drug abuse, (c) immigration from outside of the country to avoid political or social turmoil or to seek employment, (d) making the transition from criminal behaviors and incarceration, or (e) simply moving from one side of town to another to change or improve one’s quality of life.
- (3) *Alcohol and Drug Abuse.* Alcohol and drug abuse was reported as a factor in disrupting care by 29% of the interviewees. However, the stories told by interviewees about the factors that caused them to discontinue HIV care tended to include a link between alcohol and drug abuse and making a move; either getting to a new place – a new home environment, neighborhood or city, or getting into treatment to break the hold alcohol and drug abuse had on their lives and what it was doing to harm their health and HIV care.

<sup>23</sup> The responses to the Path to Care Study survey question intended to describe reasons for delaying or stopping care are not used in the report’s analysis.

(4) *Poor Relationship with Provider.* Twenty-nine percent of the Path to Care Study interviewees described a poor relationship with their health care provider as a reason for discontinuing HIV care. Usually, this was deterioration in the relationship with a doctor, with interviewees telling stories about feeling they were “being treated like a number,” “not being listened to,” or “not getting answers to their questions.” Clinic practices also influenced attitudes about the relationship with a doctor, for example, “feeling judged” [e.g. for alcohol or drug abuse, criminal history] or inconvenience [e.g. location, hours]. Finally, some interview participants described changes in health coverage or difficulties managing benefits as factors disrupting their relationship with a provider.

Both the stories told by interviewees and observations collected through key informant interviews suggest a “tipping point” phenomenon when it comes to discontinuing HIV care due to a move; with no one factor leading to a disruption of care, but a number of circumstances coming together to create a point of crisis. People drop out of HIV care when circumstances in their life converge to put them a situation where they need to make a move to change where they live. A number of factors contribute to making a move – situational and chronic mental health, alcohol and drug abuse, job or other financial problems, problems with personal relationships, trying to recover from problems create by criminal behavior or legal problems or deteriorating health.

The interviewee stories and key informant interviews suggest that even discontinuation of care due to a poor relationship with the provider is more specific.

The correlation between the routine of regular doctor visit and the likelihood of staying in HIV care suggests those who have a history of seeing a doctor, visiting a clinic and interfacing with the health system on a regular basis have more experience, are more “practiced” or “patient” about working through problems with health care. They knew what to expect, either generally from providers, clinics or health systems, or even specifically from their provider. Conversely, those who talked about discontinuing care during the interviews tended to be in a new relationship with their provider, clinic or health system. When there were problems, they tended to move on. There was not a history of experience to draw upon to help resolve or work through the situation.

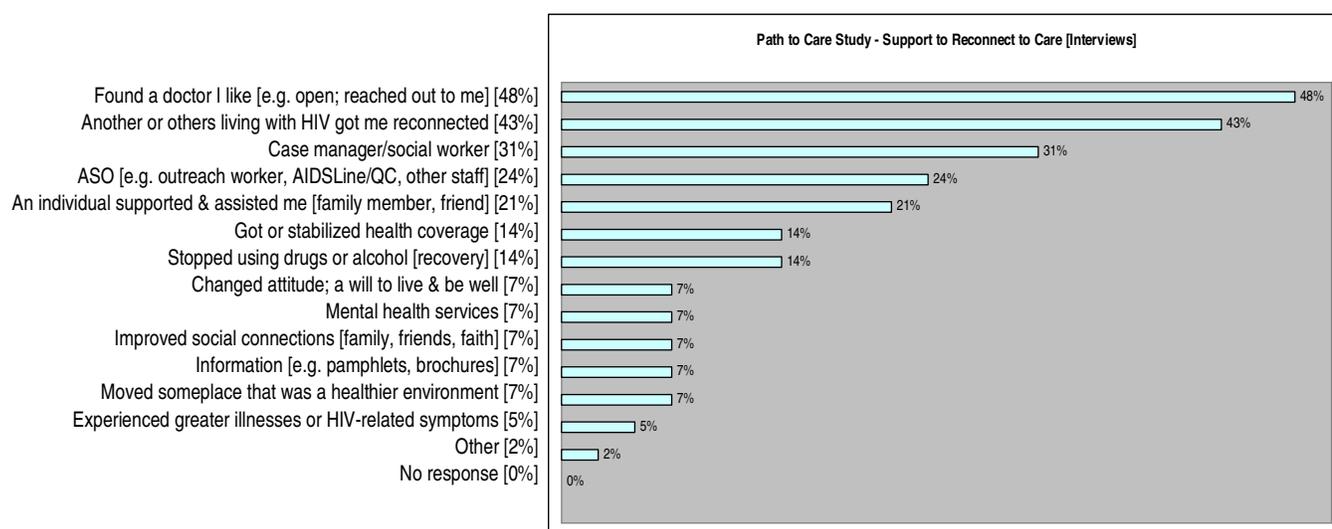
This tendency to change is also reinforced by a culture of HIV care that empowers consumers as partners in care and encourages changing providers if one’s needs are not being met, neither of which is necessarily a bad thing. Trust, competence and good communication are important. Comments made during interviews in response to a question asking interviewees about what advice they would give to those newly-diagnosed or new to HIV care frequently cited the importance of having a doctor who is trusted, competent in HIV care and a compatible communicator. Absent these characteristics, interviewees offered their hypothetical advisee the counsel of changing doctors.

In conclusion, a variety of factors contribute to discontinuing HIV care. These include a history of infrequent medical care, a move and the disruptions that come with making a change in where one lives, dissatisfaction in the relationship with a provider, and depression, alcohol or drug abuse, denial or resistance to accepting an HIV diagnosis, and concern about the consequences of stigma [i.e. similar to the factors described a challenges to connecting to care after initial diagnosis described elsewhere in this report].

## Reconnecting with Care

Making the connection with the right doctor and the support and information provided by another person living with HIV were the most notable factors helping people who stopped HIV care get reconnected.

For those who discontinued care, (1) 48% cited finding a doctor they liked and (2) 46% cited the support, information and help of another or others living with HIV as the factors that helped them reconnect to care. Other notable factors were (1) the help of a case manager or social worker [31%], (2) assistance from other services offered through an AIDS service organization, e.g. AIDSLine/Quick Connect, staff in other programs such as support groups, health education or outreach, or simply staff who worked at an agency and offered information outreach [21%], or (3) personal support from family, friends or faith that provided support and assistance [21%].



Source: Path to Care Study Survey and Interviews, 2009 – Interview Results. Not a representative sample. Information cannot be generalized to population of people living with HIV in MN.

An analysis of the Path to Care Study findings invites two over-arching observations:

First, the importance of the system described in the chronic care model in not only helping people stay in care, but also helping those who discontinue care find their way back and reconnect. The Path to Care Study interview responses suggest a combination of a well-functioning health system [i.e. doctor, medical case management and other service providers, such as health education or support groups] and a well-functioning community system [i.e. ability to connect with another or others who are living with the same condition and a supportive, informed and engaged personal support system of family and friends] play an important role in helping people reconnect to care after it has been discontinued.

Second, for those who have 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 surprisingly important – essentially as important as finding a trusted medical care provider, in helping people re-establish their HIV care.

- (1) *Finding the Right Doctor.* Connecting to the right doctor was a frequently identified reason for re-establishing HIV care [48%]. Trusting the doctor, fostered by confidence in his or her knowledge about HIV and HIV care, a personable and respectful approach to communication, persistent though patient outreach, or help getting other health problems addressed that were making HIV care challenging [e.g. mental health care or treatment for alcohol or drug abuse]. Once the connection was made with the right doctor, study participants who had dropped out of care described a fierce loyalty and sense of appreciation to their provider, and a personal conviction to continue with their care.

Interviewee stories about re-establishing care with the right doctor usually involved changing providers, but not always. In a few of the experiences that were described, it was persistent and patient contact by the doctor who provided early intervention care after the initial diagnosis or the doctor who the individual was seeing prior to discontinuing care. A consistent element in these few stories was that the doctor reached out to communicate with the individual directly.

However, while making the connection with the right doctor was of paramount importance in re-establishing care, for most interviewees their stories of the path to making that connection involved the help of others. These experiences are described below.

- (2) *Help from Another or Others Living with HIV.* Study participants who discontinued care frequently described the help of another or others living with HIV as a factor in helping them re-establish HIV care [43%]. This was either by connecting with another individual or through a group situation.

Support groups, formal HIV education events, informal social events, congregate dining, and drop-in resource or social environments were frequently cited in describing group settings where interviewees connected with other people living with HIV.

In some cases, the initial connection would be with a visible, HIV-positive community leader. The names of a small number of people were specifically cited during the interviews. The connections with these individuals tended to be through an alcohol or drug abuse recovery group, through a personal social network, at an HIV community educational or social event, or through an internet outreach service.

One element of the connection with others living with HIV, either in a group or with an individual, was emotional support. Interviewees would commonly talk about feeling an indescribable sense of relief and comfort being around and able to talk with someone who was “in your shoes,” “had been there,” or “was going through what you were going through.”

Beyond emotional support, people would get useful information about providers and services from others in their group or the individual with whom a connection was established. Interview stories often described exchanges of information

about doctors; a consumer-focused description about how different doctors approached providing care. These exchanges also tended to address services; where case management was offered and who had openings, how to get health coverage, or how to get assistance with practical needs such as transportation, food, housing, or financial assistance.

Finally, those who were out of care found encouragement and, sometimes, hands-on help to re-establish their link with HIV care. Interviewees told stories of having the “hard truths” about both the benefits and consequences of not getting HIV medical care shared with them by peers. In some cases, a peer would support them through the process of reconnecting with a medical provider or other care-related service, either by staying in regular communication through the process or actually accompanying them to an initial visit or appointment.

- (3) *Help from a Case Manager or Social Worker.* Thirty-one percent [31%] of the study participants identified the help of a case manager or social worker as a factor in re-establishing their HIV care. Interviewees would describe the help they received in terms that suggested it was the knowledge about and ability to make connection to services, personal and compassionate attentiveness, and persistence that made the difference in reconnecting with care. For some, the connection with a case manager was made by finding a highly visible HIV service provider [e.g. MAP AIDSLine, Minnesota AIDS Project, Hennepin County Medical Center, Red Door Clinic], or through the referral of another person living with HIV [e.g. informal connections established at The Aliveness Project or through a Positive Link social event]. Another scenario that was described came from individuals who maintained their relationship with their case manager, even though they had stopped seeing their medical provider.
- (4) *Help from AIDS Service Organization.* Connecting with a service other than case management offered through an AIDS service organization was cited by 24% of those participating in the study who had discontinued HIV care as a factor in helping them reconnect. Interviewee stories described relationships with a street outreach worker, a call to the MAP AIDSLine and support through Quick Connect, the support of a health educator, and in several cases, simply meeting someone socially who happened to work at an AIDS service organization and could help facilitate a connection to services.

Key to making such connections was a highly visible provider and service or person living with HIV. Whether they lived in Minnesota or were moving to the state or recently moving to the state, people cited the ability to make the initial connection with a highly visible provider or service as a starting point. It was not uncommon for interviewees to cite a specific service [e.g. The Aliveness Project’s congregate dining and food shelf services, Minnesota AIDS Project and the MAP AIDSLine, Hennepin County Medical Center, or The Red Door Clinic]. They learned about these services either from peers in their social community or through a Web search.

- (5) *Help from Family, Friends and Faith.* Twenty-one percent [21%] of those interviewed who discontinued care described the intervention of a family

member, friend or their faith community to help them get reconnected to HIV care. The most frequent story was of an individual who drew from a restorative or transformative experience with their faith and “a will to live” that motivated them make the changes needed to re-enter HIV care. It took the intervention of a family member or a trusted friend to overcome challenges created by alcohol or drug abuse, or problems with housing, finances, or disruptions in health care coverage.

It should be noted that people living in Greater Minnesota, Latinos and African-born individuals all talked about feelings of isolation and fears about the effects of stigma. 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 reconnecting to care. In these cases, it was the support of a professional that made the difference; typically a case manager or former medical provider. It was the unusual effort by the case manager or former medical provider to reach out, and in some cases re-refer to another provider, that helped re-establish a connection to HIV care. Stigma in these communities creates significant barriers to effective chronic care management based on the chronic care model.

A fully-functioning system of chronic care – both a fully-developed and functioning health system and a community of supportive peers, family, friends and other social structures, needs to be in place to help those who discontinue HIV care get back into care. The entry point for bringing people back into care will vary. Based upon the information provided by the Path to Care Study participants, two particularly important factors are (1) the doctor who pays special attention to re-establishing a trusted relationship, and (2) the personal and social support and information that comes from others who are living with HIV – whose knowledge and experiences are valued because they come from “someone who is walking in my shoes.” However, support, information and encouragement from a service provider – case manager or other HIV service provider, or a family member, friend or faith community member who cares enough to make the special effort of combining compassion with the task of informed intervention, are also frequently identified factors.

### ***Conclusions: Path to Care Study Survey and Interviews – Findings***

- Ready access to a well-coordinated system of health services helps people who are newly diagnosed establish HIV care. Absent that, the diagnosis site's plan and ability to offer coordinated access to medical care, social services and information help establish the connection to care.
- Mental health – both situational and chronic, alcohol and drug abuse, and concerns about the effects of HIV-related stigma create barriers to connecting to care after diagnosis.
- Staying connected to care requires 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. It is not an either or proposition for people living with the chronic condition of HIV disease.
- Irregular medical care prior to receiving an HIV diagnosis is the most important factor suggesting a person may discontinue HIV care. People also drop out of HIV care when something in their life puts them a situation where they need to make a move to change where they live or if they have a poor relationship with their health care provider. Finding a trusted doctor *and* the support and information provided by others who are living with HIV are important factors in helping people who drop out of care reconnect to the health system and HIV care.

## **PART FIVE: OPPORTUNITIES TO IMPROVE SERVICES**

*How can services be improved to support connecting to care, staying in care or reconnecting if care is disrupted?* The following opportunities to improve services are based upon an analysis of the information provided in the Path to Care Study through the (1) examination of the chronic care model, (2) description of where most people in Minnesota receive their HIV diagnosis, the description of what the connection to a path to care should look like according to CDC and American Academy of HIV Medicine guidelines, and (3) the description of how people living with HIV in Minnesota connect to HIV care, stay in care, and discontinue and re-establish care, based upon surveys and interviews with 63 individuals who participated in the study.

The opportunities for improvement address:

- Implications for allocation of Ryan White resources in Minnesota
- Implications for Ryan White quality management and quality improvement in Minnesota
- Implications for HIV screening, testing and diagnosis strategies
- Implications for advocacy

### ***What are the implications for allocation of Ryan White resources in Minnesota?***

1. All components of the chronic care model help people connect to and stay in medical care, including medical care and supportive services that make it effective and patient capacity and supports for self-care.

People living with HIV want a *trusted doctor* – a doctor they consider to be competent, who serves as their teacher by sharing information and delivers services with a personal touch.

People living with HIV rely upon *navigators* – a case manager or social worker who can help them navigate the health care system and who can make connections happen.

People living with HIV look to others living with HIV, both for information and for support. They seek *club houses*, places and groups where they can connect with others living with HIV, as well as *team captains*, peer leaders who are visible, accessible and are a source of both good information and inspiration.

People living with HIV also look to themselves to develop a *will to be well*. They seek to reach a point of knowledge and understanding about HIV, as well as a sense of confidence and a network of support – professional care and emotional – to be effect self-care managers and to be well.

*Allocate resources 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. Information and support from others living with HIV play a strong role in helping people who delay or stop care get reconnected to care.

Access to a trusted doctor, the assistance of a case manager and access to and assistance other than case management provided by AIDS service organizations each are important factors in helping people who delay or stop care get reconnected.

However, information and support by others living with HIV is a factor helping most people living with HIV get connected or stay in care, but seem to be an even more important factor in helping those who have delayed or stopped care get connected to care.

*Allocate resources 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. Making a move is a major factor in delaying or stopping care. Sometimes it is geographic move. Other times it is a matter of coping with unstable housing.

*Beacon Services*, those that are large and have the visibility of sustained marketing, help people get connected. Participants in the Path to Care Study commonly identified *beacon services*, such as the MAP AIDSLine & Quick Connect, or providers such as Hennepin County Medical Center, Red Door Clinic, and The Aliveness Project as places they turned to get connected or reconnect to care.

Stabilizing their living situation by getting practical needs met [e.g. housing, health insurance, assistance with food, emergency financial needs or transportation] helped people who delayed or stopped care refocus on their HIV care. Many got information about services to resolve these problems from others who were living with HIV.

*Allocate resources 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.*

4. Depression after receiving an HIV diagnosis, as well as chronic mental health and alcohol and drug use are factors that make it difficult to connect to care or contribute to delaying or stopping care.

Receiving an HIV diagnosis creates a short term, situational mental health crisis that calls for a range of mental health responses, including psychotherapy, counseling or peer support – in groups or by a peer counselor.

Chronic alcohol or drug abuse or chronic mental illness creates barriers to connecting to care or contribute to delaying or stopping care. Treatment or other interventions to address these health conditions help overcome these barriers and facilitate reconnecting to care after it has been disrupted.

*Allocate resources to facilitate and coordinate access to alcohol or drug treatment or mental health services, both to address situational and chronic mental illness.*

***What are the implications for Ryan White quality management and quality improvement?***

1. People living with HIV in Minnesota tend to be quickly connected to medical care after initial diagnosis. However, a significant number also defer or stop care, reflecting a breakdown in the chronic care model for care. All components of the chronic care model help people connect to and stay in medical care and are part of quality care and achieving desired health outcomes for people living with HIV.

*Develop an assessment tool and appropriate quality measurements to promote and monitor patient self-care management and advocacy,*

2. Effective and successful chronic disease management draws from patient self-care advocacy.

*Develop 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.*

## *What are the implications for HIV testing and diagnosis policies and strategies?*

1. Minnesotans living with HIV suggest the factors that help them most to get connected with care are getting diagnosed at a location that is part of or linked to a comprehensive and coordinated care facility, have a case manager or social worker assigned to them at diagnosis or staff-assisted information and referral to connect them to an AIDS service organization or medical care provider.

These factors are similar to the recommended guidelines for routine testing and connecting to care issued by the American Academy of HIV Medicine in 2009. However, there is limited awareness about these guidelines among providers that report the majority of HIV diagnoses in Minnesota each year.

*Promote awareness about recommended guidelines for routine testing and connecting to care, with a focus on the AAHIVM guidelines. Provide education, training and technical assistance to help providers develop and implement formalized procedures to implement these guidelines. Emphasize providing education, training and technical assistance to those providers that report the majority of HIV diagnoses in Minnesota each year.*

2. People living with HIV who participated in the Path to Care Study expressed feeling depression or a sense of shock after initial diagnosis as factors that complicate getting connected to care. A significant subgroup also identifies intensified drug or alcohol use as a complicating factor.

Access to a counselor, in addition to the medical provider, to help with the initial response to an HIV diagnosis was identified as helpful in connecting to care.

People living with HIV who participated in the Path to Care study indicated that being able to talk with another person living with HIV to help with the initial response to an HIV diagnosis was helpful in connecting to care.

*Diagnosis sites should 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. Most seeking an HIV test in Minnesota do so based upon self-perception of risk; they are risk-motivated, self-motivated. These testers seem to be more likely to get themselves to a public health testing site.

A significant number also test because they are experiencing an illness or a health situation that needs attention. These symptom-motivated and tend to be provider-initiated testers. More of these testers get their diagnosis at a hospital or a clinic that is part of a health care system.

*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.*

*Formalized 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*

1. The most significant predictor that people living with HIV will delay or stop care is whether or not they have regular access to health care before being diagnosed with HIV.

Chronic alcohol or drug abuse or chronic mental illness creates barriers to connecting to care or contribute to delaying or stopping care. Treatment or other interventions to address these health conditions help overcome these barriers and facilitate reconnecting to care after it has been disrupted.

*Advocate for policies that 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.*

2. All components of the chronic care model contribute to helping people connect to and stay in medical care, including social services [e.g. case management] and social support [e.g. support of others living with HIV].

*Advocate for 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.*

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Thank you to . . .

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*The study team remember Elliot Ramos for the passion he brought to our work and the knowledge, skill and experience he shared with each of us to improve our collective effort. Participants in the study recognized and responded to his dedication of purpose. Elliot died in August, 2009.*

## TABULATIONS FROM PATH TO CARE SURVEYS

Age				MN Prevalence
	19 or less	0	0%	2%
	20-34	12	19%	19%
	35-50	35	56%	53%
	50+	16	25%	27%
		n=	63	

Gender				MN Prevalence
	Male	46	73%	77%
	Female	16	25%	23%
	Transgender M-F	1	2%	
	Transgender F-M	0	0%	
		n=	63	

Race/Ethnicity				MN Prevalence
	AA	30	48%	22%
	African	5	8%	13%
	Latino	4	6%	8%
	White	20	32%	54%
	Asian/PI	0	0%	2%
	AI/AN	1	2%	2%
	Multi-race	2	3%	1%
	Unknown	1	2%	
		n=	63	

English Spoken in the Home			
	Yes	58	92%
	No	5	8%
		n=	63

Location				MN Prevalence
	Greater MN	6	10%	14%
	Metro Area	5	8%	30%
	Minneapolis	46	73%	41%
	St. Paul	6	10%	14%
		n=	63	

Highest Level of Education Completed			
	Did not finish high school	4	6%
	High school graduate/GED Cert	14	22%
	Some college/technical institute	24	38%
	Undergraduate college degree/technical institute degree	13	21%
	Graduate course/graduate degree	7	11%

Other	1	2%
	n= 63	

Monthly Income

500 or less	14
501 to 1500	34
1501 to 2000	4
More than 2000	9
not provided	2
	n= 63

When tested positive for HIV

Past 3 years [2006-2009]	20	30%
Past 4 to 9 years [2000-2005]	14	24%
Past 10 to 13 years [1996-1999]	8	13%
Past 14 to 19 years [1990-1996]	10	13%
20 years or more	11	20%
	n= 63	

Currently HIV+	23	37%
Currently Advanced Disease [AIDS]	38	60%
Current - Don't Know	2	3%
	n= 63	

Initially HIV+	20	32%
Initially Advanced Disease [AIDS]	43	68%
Initial - Don't know	0	0%
	n= 63	

How infected with HIV

	Male	%	Female	%	Trans	%
Having sex with a man	23	50%	13	81%	1	100%
Blood products/transfusion	0	0%	0	0%	0	0%
Having sex with a woman	8	17%	0	0%	0	0%
Birth or breast feeding	0	0%	0	0%	0	0%
Sharing Needles	5	11%	2	13%	0	0%
Don't Know	3	7%	1	6%	0	0%
Other	2	4%	0	0%	0	0%
Having sex with a man, and Sharing Needles	5	11%	0	0%	0	0%
Having sex with a man, Sharing Needles, and Having sex with a woman	0	0%	0	0%	0	0%
	n= 46		n= 16		n= 1	

	Total	MN Prevalence
MSM	41%	50%
IDU	11%	5%
MSM/IDU	8%	5%
Het	33%	18%

Perinatal		1%
Other		1%
Unknown	6%	19%
	100%	
n=	63	

Type of facility where tested positive for HIV

clinic	11	17%
don't know	4	6%
Hospital	23	37%
Jail/Prison	1	2%
Plasma Center	2	3%
Public Health Clinic	20	32%
Treatment Facility	2	3%
	n=	63

Where was the facility where tested HIV positive

Greater MN	4	6%
Minneapolis	27	43%
Out of State	21	33%
St. Paul	9	14%
Suburb TC	2	3%
	n=	63

Services that anyone at the facility helped with where you first tested positive for HIV

Other	7	11%
Meeting with a religious leader or spiritual advisor	3	5%
Legal Services	6	10%
Alcohol or drug treatment	6	10%
Talking to a family member or partner about your diagnosis	7	11%
Finding a dentist	7	11%
Getting housing	7	11%
Talking to another person living with HIV	7	11%
confirming or securing health insurance	11	17%
Emergency food or financial assistance	12	19%
Connecting to an HIV "hotline" or "information & referral" service	14	22%
Finding a case manager	15	24%
Meeting with a counselor, therapist, or psychiatrist	20	32%
Getting drugs to treat HIV	20	32%
Help to prevent infecting others	24	38%
Connecting to an HIV service organization for service or support	26	41%
Finding a doctor	33	52%
	n=	63

First visit with a doctor for HIV care

Within a month after diagnosis	40	63%
--------------------------------	----	-----

Seven to Eleven months after diagnosis	0	0%
One to three months after diagnosis	11	17%
One year or more after diagnosis	7	11%
Four to six months after diagnosis	5	8%
I haven't seen a doctor for HIV care	0	0%

n= 63

First talk with someone to help get medical or other services to help you live with HIV

Within a month after diagnosis	37	59%
Seven to Eleven months after diagnosis	1	2%
One to three months after diagnosis	12	19%
One year or more after diagnosis	11	17%
Four to six months after diagnosis	2	3%
I haven't talked with anyone to get help	0	0%

n= 63

Would you say you have ever delayed or stopped medical care

Yes	35	56%
No	28	44%

n= 63

Why?

None of the above	3	9%
Other	10	29%
I did not know where to go for medical care	0	0%
I didn't think medical care would do me any good	0	0%
No one spoke my language	0	0%
I did not see other people like me at the clinic	0	0%
Inconvenient hours	0	0%
Financial Reasons	0	0%
It was hard to get there	1	3%
I was too busy	1	3%
No one told me I needed to get medical care	2	6%
I didn't have health insurance	6	17%
I did not like the doctor	6	17%
I did not like the people at the clinic	8	23%
I was abusing drugs or alcohol and was afraid the doctor would tell me to stop	9	26%
I was worried someone would find out about my HIV status	10	29%
I was afraid to get bad news	15	43%
I was in denial about being HIV+	17	49%
I was abusing drugs or alcohol and just couldn't manage it	17	49%
I was depressed	20	57%

n= 35

Would you say you ever delayed or stopped an HIV service

Yes	34	54%
-----	----	-----

No	29	46%
	n= 63	

Why?

None of the above	2	6%
Other	12	35%
No one spoke my language	0	0%
Financial reasons	0	0%
Others need services more than I do	0	0%
Transportation	0	0%
No one told me about HIV services	1	3%
I didn't see other people like me using the service	3	9%
I did not like the service provider	4	12%
I did not like the people at the place where services were provided	5	15%
Inconvenient hours	5	15%
I was abusing drugs or alcohol and was afraid they would tell me to stop	5	15%
I did not know where to go for HIV services	5	15%
I was afraid to get bad news	7	21%
I was in denial about being HIV+	8	24%
I did not think the services would do me any good	8	24%
I was worried someone would find out about my HIV status	9	26%
I was abusing drugs or alcohol and just couldn't manage it	10	29%
I was depressed	12	35%
	n= 34	

Before you first tested positive for HIV, how often did you see a doctor?

At least once a year	29	46%
Once every few years	4	6%
About once in five years	1	2%
Almost never	15	24%
Only in an emergency room	14	22%
	n= 63	

Do you currently see a primary physician for HIV care?

Yes	61	97%
No	2	3%
	n= 63	

Do you currently get HIV services from a provider other than your doctor?

Yes	45	71%
No	18	29%
	n= 63	

What helped you most to find HIV services after you were first tested?

Other	15	24%
an ad I saw in a newspaper	0	0%

Information I found on the web	0	0%
None of the above	2	3%
A poster or flyer I saw someplace	5	8%
A visit from the health department	6	10%
Talking to a family member	12	19%
People at my support group	12	19%
Calling the AIDSLine	13	21%
Talking to a friend	18	29%
A referral from the place I tested	23	37%
Talking to another person with HIV	24	38%
Talking with someone at an AIDS service organization	31	49%

n= 63

What helps you most to keep using HIV services

None of the above	0	0%
Other	18	29%
A referral from the place I tested	1	2%
Calling the AIDSLine	9	14%
Information I found on the web	13	21%
Talking to a family member	15	24%
People at my support group	21	33%
Talking with someone at an AIDS service organization	30	48%
Talking to another person with HIV	30	48%
Talking to a friend	33	52%
My case manager or social worker	34	54%
My doctor	41	65%

n= 63

## TABULATIONS FROM PATH TO CARE INTERVIEWS CONTENT ANALYSIS

### Reason for Testing

No Response	1	2%
Other	5	8%
Provider Initiated - Pregnancy	2	3%
Mandated	5	8%
Provider Initiated	19	30%
Perceived Risk	31	49%

n= 63

### Assisted Connecting to Care After Diagnosis

No response	2	3%
Other	0	0%
Practical needs met [e.g. housing, food, financial, legal]	2	3%
Knew about service; visible provider	3	5%
Learned what I could about HIV, treatment and care	5	8%
Public health disease intervention services	5	8%
Will to live; personal, emotional strength	6	10%
Help from counselor, linked to MH service and support	6	10%
Arranged coverage for health care and treatment	8	13%
Encouraged by HIV+ person or group	10	16%
Referrals with appointment and support	11	17%
Connected to a doctor I like and trust	13	21%
Connected to a CM who helped me	15	24%
Social support network [family, friends, faith]	16	25%
Information & referral tools	17	27%
Diagnosis site offered medical services & support; coordination of care	18	29%
Connected to ASO [services other than CM, e.g. AIDSLine QC]	19	30%

n= 63

### Barriers Connecting to Care After Diagnosis

No response	4	6%
Other	3	5%
Treatment and care expectations were overwhelming	2	3%
Did not like the doctor or the diagnosis site staff	5	8%
Unsupported or complicated information & referral	6	10%
Public health disease intervention services	6	10%
Loss of social connections [family, friends, faith]	8	13%
Surprised by testing and diagnosis; not prepared	8	13%
Denial about infection	8	13%
No peer support, talk with another living with HIV	11	17%
Poor experience with person or service providing diagnosis	14	22%
Continued or increased drug & alcohol use to cope	17	27%
Fear of disclosure and consequences [stigma]	19	30%

Depression	22	35%		
	n= 63			
Reasons for stopping or deferring medical care				
Not applicable	21	33%		
No response	1	2%	1	2%
Other	2	3%	2	5%
Incarceration	2	3%	2	5%
Not convinced I had HIV [e.g. not ill, "undetectable," beliefs]	2	3%	2	5%
Could not manage treatment [e.g. med side effects]	2	3%	2	5%
Did not like the clinic or the people providing service	4	6%	4	10%
Care was inconvenient [e.g. location, uncoordinated, I was busy]	4	6%	4	10%
Depression	4	6%	4	10%
Didn't have health coverage or ability to pay	4	6%	4	10%
Health care change [eg. new ins., doctor left]	5	8%	4	10%
Unstable living situation; running the streets	7	11%	7	17%
Continued or increased drug & alcohol use	8	13%	8	19%
Did not like doctor and how I was treated	13	21%	12	29%
I moved	18	29%	17	40%
	n= 63		n= 42	
Lack of social support [e.g. family, friends, faith]	0	0%	0	0%
Isolated; no friends or others with HIV to support	0	0%	0	0%
Factors helping to reconnect to care				
Not applicable	21	33%		
No response	0	0%	0	0%
Other	1	2%	1	2%
Experienced greater illnesses or HIV-related symptoms	2	3%	2	5%
Moved someplace that was a healthier environment	3	5%	3	7%
Information [e.g. pamphlets, brochures]	3	5%	3	7%
Improved social connections [e.g. family, friends, faith]	3	5%	3	7%
Mental health services	4	6%	3	7%
Changed attitude; a will to live and be well	3	5%	3	7%
Stopped using drugs or alcohol [recovery]	6	10%	6	14%
Got or stabilized health coverage	6	10%	6	14%
An individual supported and assisted me [e.g. family member, friend]	9	14%	9	21%
ASO [e.g. outreach worker, AIDSLine/QC, other staff]	10	16%	10	24%
Case manager/social worker	15	24%	13	31%
Another or others living with HIV got me reconnected	18	29%	18	43%
Found a doctor I like [e.g. open, reached out to me]	21	33%	20	48%
	n= 63		n= 42	
Factors that help me stay in care				
No response	0	0%		
Other	1	2%		
Other clinic staff [e.g. nurse]	5	8%		

Housing secured	10	16%
Practical needs met [e.g. food, financial support, transportation]	10	16%
Peer role models of others living with HIV	11	17%
Substance abuse treatment, my recovery	11	17%
ASO services [not including CM]	12	19%
Mental health services	13	21%
Keep myself informed and learning about HIV care	13	21%
Being productive, working, doing something about HIV	14	22%
Improved social connections [e.g. family, friends, faith]	15	24%
Stabilized health coverage, insurance	16	25%
Information about services I get from others living with HIV	23	37%
My case manager	39	62%
The right doctor	39	62%
Peer support from others living with HIV; groups or individuals	43	68%

n= 63

Advice provided to newly-diagnosed

No response	0	0%
Other	1	2%
Pay attention to prevention; tell partners	2	3%
Get health coverage; confirm health coverage [insurance]	4	6%
Get help with chemical use	10	16%
Get services that you need [help with practical needs]	13	21%
Get a counselor and help with mental health	14	22%
Do something to prevent or help others with HIV	14	22%
Get information; learn about HIV	17	27%
Adhere to treatment and care	19	30%
Get connected with an ASO	24	38%
Connect with social support; don't isolate [e.g. family, friends, faith]	26	41%
Healthy attitude; you are not going to die	27	43%
Find another or others with HIV to help you learn to manage HIV disease & live	33	52%
Get a case manager; good relationship with a social worker	34	54%
Get a good doctor you can trust	39	62%
Find another or others with HIV for support	42	67%

n= 63

Factors to consider improving

No response	18	29%		
Other	8	13%	7	16%
Keep health care accessible and affordable	5	8%	5	11%
Opportunities for people with HIV to "give back" and be involved	6	10%	6	13%
More transportation support; not just medical; bus passes	8	13%	7	16%
CM/provider training, skills, knowledge	7	11%	7	16%
Expand practical support [e.g. food, financial assistance, housing]	9	14%	7	16%
Information and referral and education for people who are new to HIV	8	13%	8	18%
More diversity in support groups and activities for HIV positive	10	16%	9	20%

Connect to groups of people with hiv for support, info, services	11	17%	11	24%
Information and referral services, "user guide" and AIDSLine	14	22%	14	31%
Connect to another with HIV; especially at diagnois or shortly after	16	25%	16	36%
More public awareness and education; change attitudes [stigma]	19	30%	18	40%
	n= 63		n= 45	

## SURVEY & INTERVIEW TOOL

### INTERVIEWER CHECKLIST:

- *Verbally review the content of the “Consent for Interview” page [see page 2] with the interviewee.*
- Offer the interviewee the opportunity to read the content of the “Consent for Interview” page.
- *Get the interviewee’s signature at the bottom of the “Consent for Interview” page. You should sign the page after getting the interviewee’s signature.*
- *Review the key points covered in the Introduction [see page 3]. This repeats many of the points covered in the “Consent for Interview.”*
- *Review the instructions for the discussion part of the interview [see page 4].*
- *Get the interviewee’s response to the first two questions [see page 4]. If the answer to either of these questions is “no,” do not continue the interview.*
- *Facilitate the interviewee’s responses to the first four questions. Take detailed notes. Ask follow-up questions to confirm what you are hearing and writing. Use the “Topics Checklist” to help you identify key points that you may ask the interviewee to elaborate upon. However, do not feel compelled to get the interviewee to comment on any or all of the topics on the checklist.*
- *At the conclusion of the discussion, provide instructions for completing the survey. Offer to read the questions and write down the responses, if the interviewee would like assistance.*
- *Leave the interviewee alone to complete the survey. Check in once or twice to see how things are going and to see if the interviewee needs to have any of the questions clarified.*
- *After the interviewee completes the survey, resume the interview by asking the last question.*
- *Thank the interviewee. Provide the interviewee with the \$40 gift card to thank him or her for the time, and an additional \$10 gift card to help defray travel costs. Have the interviewee initial the first page of the survey to confirm receipt of the gift card.*
- *Separate the “Consent or Interview” page from the survey. Be sure the interviewee sees you do this and understands this is a step we are taking to manage the confidentiality of his or her responses.*
- *If the interviewee seeks information about services, refer him or her to the MAP AIDSLine. You may provide him or her with a MAP AIDSLine Resource Guide. Do not provide information about any other services.*
- *Invite the interviewee to refer others to participate in a survey or to follow up with Bob Tracy if they have questions about the study. Provide a copy of the informational flier [tear off the last page of the survey].*

**HIV SERVICES ASSESSMENT  
PATH TO CARE ASSESSMENT  
MINNESOTA HIV SERVICES PLANNING COUNCIL  
Consent for Interview**

**Date** \_\_\_\_\_

**Purpose for this assessment.**

We want to better understand your experience finding HIV medical care and other services to help you live with HIV. We hope to learn from you. We want to learn about the things that made it easier for you to find a doctor and other services. Just as important, we want to learn about what made it harder and what you would have preferred to have been different. We hope you will feel comfortable sharing some good ideas with us that you think might make easier for others to find and stay connected with a doctor or HIV service.

**Who are we talking to?**

We are interested in learning about the experiences of many different Minnesotans living with HIV. However, we are making a special effort to talk with people who have

- learned about their HIV status within the past few years,
- lived with HIV for some time, but only recently started to see a doctor or get other services to help them live with HIV, or
- only recently started to see a doctor or get other services to help them live with HIV after going without these services for a period of time.

**What will happen during the interview?**

The interview will take about one hour. We will talk about what it is like when you found out you were living with HIV and what happened as you got connected to a doctor and to other services. We will also talk about any experiences you may have had changing doctors, case managers or other HIV services, or any period of time when you did not receive health care or other services.

In addition to having this conversation, you will be asked to fill out a questionnaire with about twenty [20] questions. We will help you fill out this questionnaire, if you would like. However, the interviewer will not provide you with any feedback or referrals to services or providers.

**What will we do with the information you provide?**

We will pull together the information we collect into a report. That report will be shared with the Minnesota HIV Services Planning Council and others in the community to help them make decisions about how to improve services for people living with HIV in Minnesota. *We respect your privacy and right to confidentiality. We will not share your information in a way that will be personally identifying.* While we are collecting this information to share with the Minnesota HIV Services Planning Council, we are an independent group collecting this information. You may speak freely and with assurance that information you provide or your decision to participate or withdraw participation will in no way affect access to services.

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*Your signature below indicates you are providing your permission to participate in this interview and this study.*

\_\_\_\_\_  
*Interviewee's Signature*

\_\_\_\_\_  
*Interviewer's Signature*

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**Complete at the Conclusion of the Interview:** *Thank you for your participation in this interview. In consideration for your time and contributions, we offer a \$40 gift card. Please initial to indicate you have received your gift card.*

**HIV SERVICES ASSESSMENT  
PATH TO CARE ASSESSMENT  
MINNESOTA HIV SERVICES PLANNING COUNCIL  
Interview**

**I. Introduction**

- This interview and survey is designed to gather information from people living with HIV in Minnesota.
- It is being conducted by a group of people living with HIV on behalf of the Minnesota HIV Services Planning Council.
- The information we collect will be used to improve services for those who are newly diagnosed with HIV, and those who are new to or returning to HIV health and support services.
- We respect your confidentiality. We will not identify you in the reporting of this information. We will report this information in a summary format, and not in a way that will identify you.
- While we are sharing this information with the Minnesota HIV Services Planning Council, nothing you say, nor your decision to participate or to withdraw participation from this interview will in any way affect your access to services.
- The findings will be shared with the Minnesota HIV Services Planning Council when it meets in April, 2009. They will be published in a report in June, 2009.
- This project is being coordinated by Bob Tracy Consulting, as a service for the Minnesota HIV Services Planning Council. If you have questions, you may contact Bob Tracy at 651.329.1794 or [bobtracy@comcast.net](mailto:bobtracy@comcast.net). *[Provide a business card to the interviewee.]*
- Do you have any additional questions about this interview?

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## II. Discussion

- During the first part of this interview, we are just going to have a discussion.
- I am just interested in hearing your story. We are going to talk a little bit about what it was like when you first learned you were living with HIV. We are going to talk about the process you went through to find a doctor, a case manager or any other service you have used to help you live with HIV. We are interested in learning about the things that really helped you, as well as the things you wish were different.
- I am going to take notes.
- We are going to take about a half hour or so for this conversation. After our conversation, I am going to ask you to take a few minutes to fill out a written survey.
- Before we start, I would like to confirm two pieces of information:

### Screening 1.

**Are you currently living with HIV?**

**Yes**       **No**

### Screening 2.

**Are you currently living in Minnesota?**

**Yes**       **No**

If no to either question, conclude interview.

- *Are you ready to talk?*

**1. Tell me a little bit about your experience when you were tested and learned that you were living with HIV?**

*Follow-up Questions – What made this process easy for you? What do you wish had been different?*

**Topics Checklist**

- Tested recently
- Early intervention medical care
- Medical Care - Doctor; an HIV specialist
- Addressed HIV drug treatment
- Emotional or mental health support from a professional
- Substance use service
- Dental care
- Confirm or arrange health coverage
- HIV support service [e.g. case management, other]
- HIV information and referral support
- Experience with public health disease intervention
- Prevention/risk reduction support or service
- Received emotional support from family, friends, faith community others in community
- Connected with others living with HIV
- Legal issues
- Employment issues
- Housing support
- Emergency support with living expenses [e.g. financial assistance, food]

**2. Based on your experiences getting connected to HIV services, what advice would you give to others who are new to living with HIV or HIV care?**

**Topics Checklist**

- Test at the right place
- Find the right doctor
- Emotional or mental health support from a professional
- Substance use service
- Dental care
- Confirm or arrange health coverage
- HIV support service [e.g. case management, other]
- HIV information and referral support
- Experience with public health disease intervention
- Prevention/risk reduction support or service
- Received emotional support from family, friends, faith community others in community
- Connected with others living with HIV
- Find help with legal issues
- Employment issues
- Housing support
- Emergency support with living expenses [e.g. financial assistance, food]

**3. Have you ever changed doctors or stopped seeing your doctor?**

*Follow-up Questions –*

*If, no – Have you changed or stopped another HIV service? What is it you like about the care you are getting that has kept you from making a change or stopping your care?*

*If yes – What did you do to take care of yourself? What did you do to find another doctor or to start seeing a doctor again?*

**Key Points Checklist**

- Insurance issues
- Financial issues
- Relationship with provider
- Experience with clinic or system
- Transportation; hard to get to
- Family or social pressures; afraid people would find out
- Personal health issues [e.g. mental health, substance abuse]
- Didn't need health care; had another strategy for managing health
- Couldn't fit it into schedule, work, life
- Advice from others -- peers, service providers

**4. Is there other information you would like to share with us about what helped you get connected with an HIV doctor, case manager or other service or provider that has helped you live with HIV?**

**Topics Checklist**

- Test at the right place
- Find the right doctor
- Emotional or mental health support from a professional
- Substance use service
- Dental care
- Confirm or arrange health coverage
- HIV support service [e.g. case management, other]
- HIV information and referral support
- Experience with public health disease intervention
- Prevention/risk reduction support or service
- Received emotional support from family, friends, faith community others in community
- Connected with others living with HIV
- Find help with legal issues
- Employment issues
- Housing support
- Emergency support with living expenses [e.g. financial assistance, food]

### **III. Survey**

- Thank you for sharing that information with us.
- Please take the next 15 minutes or so to respond to the questions on this survey.
- If you would like, I could read the question to you and fill in your answers.
- Otherwise, I'm going to step outside and allow you to simply go through the survey and complete it on your own.
- I will come back in a few minutes to see if you have any questions or needs some assistance.
- After you are finished with the survey, we will have a chance to talk about any other information you would like to share with me, I will have your gift card for you, and you will be ready to be on your way.
- *Any questions?*

## LABELING THIS SURVEY RESPONSE

5. a. Today's Date?

\_\_\_ / \_\_\_ / \_\_\_\_\_  
Month      Date              Year

b. Your Birth Date?

\_\_\_ / \_\_\_ / \_\_\_\_\_  
Month      Date              Year

c. Your Mother's Birth Date?

\_\_\_ / \_\_\_  
Month      Date

## DEMOGRAPHIC INFORMATION

6. What is your gender? [check one]

- Male                       Female  
 Transgender – male to female       Transgender – female to male

7. How do you identify your race/ethnic group? [check one]

- Black/African American                       Black/African-born  
 Hispanic/Latino                                       White [not Hispanic/Latino]  
 Asian/Pacific Islander                               American Indian/Alaska Native  
 Multi-race     Unknown

8. Is English the language spoken most frequently in your home? [check one]

- Yes                       No

9. What is your current home zip code?

\_\_\_ \_\_\_ \_\_\_ \_\_\_ \_\_\_

10. What is the highest level of education you completed? [check one]

- Did not finish high school                       High school graduate/GED certificate  
 Some college/technical institute                       Undergraduate college degree/technical institute degree  
 Graduate course/graduate degree                       Other

11. Approximately, how much money (income, government payment, pension, etc) did you receive last month? \$ \_\_\_\_\_

## EXPERIENCES TESTING FOR HIV

12. When did you first test positive for HIV?

- a.  Within the past six months  More than six months ago  
b. In what year were you diagnosed? \_\_\_\_ \_\_\_\_ \_\_\_\_ \_\_\_\_

13. Were you given an “AIDS” diagnosis at the time when you tested for HIV? [check one]

- Yes  No  Don’t Know

14. Do you *currently* have an “AIDS” diagnosis? [check one]

- Yes  No  Don’t Know

15. How do you think you were infected by HIV? [check all that apply]

- Having sex with a man  Blood products/transfusion  
 Having sex with a woman  Birth or breast feeding  
 Sharing needles  Don’t know  
 Other \_\_\_\_\_

16. Where did you get the test the first time you tested positive for HIV?

Name of Facility: \_\_\_\_\_ or  Don’t Remember  
City & State: \_\_\_\_\_ or  Don’t Remember

17. Did anyone at the facility where you first tested positive for HIV help you with any of the following services? [check all that apply]

- Finding a doctor  Getting drugs to treat HIV  
 Finding a case manager  Confirming or securing health insurance  
 Talking to another person living with HIV  Meeting with a counselor, therapist or or psychiatrist  
 Talking to a family member or partner about you diagnosis  Meeting with a religious leader or spiritual advisor  
 Connecting to an HIV service organization for service or support  Connecting to an HIV “hotline” or “information& referral service [such as the AIDSLine]  
 Finding a dentist  Getting housing  
 Legal Services  Emergency food or financial assistance  
 Alcohol or drug treatment  Help to prevent infecting others

Other \_\_\_\_\_

## EXPERIENCES STARTING HIV CARE AND SERVICES

**18. After you first tested positive for HIV, when did you first visit with a doctor for HIV care?**

[Do not include the visit when you received your test results. Please check one.]

- |  |   |
|--|---|
| <input type="checkbox"/> Within a month after diagnosis      | <input type="checkbox"/> Seven to eleven months after diagnosis |
| <input type="checkbox"/> One to three months after diagnosis | <input type="checkbox"/> One year or more after diagnosis       |
| <input type="checkbox"/> Four to six months after diagnosis  | <input type="checkbox"/> I haven't seen a doctor for HIV care   |

**19. After you first tested positive for HIV, when did you first talk with someone to help you get medical or any other services to help you live with HIV?**

[. Please check one.]

- |  |   |
|--|---|
| <input type="checkbox"/> Within a month after diagnosis      | <input type="checkbox"/> Seven to eleven months after diagnosis   |
| <input type="checkbox"/> One to three months after diagnosis | <input type="checkbox"/> One year or more after diagnosis         |
| <input type="checkbox"/> Four to six months after diagnosis  | <input type="checkbox"/> I haven't talked with anyone to get help |

**20. Would you say you have ever *delayed* or *stopped* medical care?** [check one]

- Yes             No

*If you answered "yes," please indicate your reasons?* [check all that apply]

- |   |   |
|---|---|
| <input type="checkbox"/> No one told me I needed to get medical care                        | <input type="checkbox"/> I did not know where to go for medical   |
| <input type="checkbox"/> I was in denial about being HIV+                                   | <input type="checkbox"/> I did not think medical care would do me any good                              |
| <input type="checkbox"/> I was depressed  | <input type="checkbox"/> I was afraid to get bad news   |
| <input type="checkbox"/> Financial Reasons  | <input type="checkbox"/> I did not have health insurance  |
| <input type="checkbox"/> I was worried someone would find out about my HIV status           | <input type="checkbox"/> It was hard to get there [transportation]                                      |
| <input type="checkbox"/> I did not like the doctor  | <input type="checkbox"/> I did not like the people at the clinic  |
| <input type="checkbox"/> I was abusing drugs or alcohol and just couldn't manage it         | <input type="checkbox"/> I was abusing drugs or alcohol and was afraid the doctor would tell me to stop |
| <input type="checkbox"/> No one spoke my language   | <input type="checkbox"/> I didn't see other people like me at the clinic                                |
| <input type="checkbox"/> I was too busy   |   |
| <input type="checkbox"/> The clinic wasn't open when I could get there [inconvenient hours] |   |
| <input type="checkbox"/> Other _____  | <input type="checkbox"/> Other _____  |
| _____   | _____   |
| <input type="checkbox"/> None of the above.   |   |

**21. Would you say you have ever *delayed or stopped* an HIV service?**

[For example, case management, support group, counseling. Check one]

- Yes**                       **No**

*If you answered “yes,” please indicate your reasons?* [check all that apply]

- |   |   |
|---|---|
| <input type="checkbox"/> No one told me about HIV services                                    | <input type="checkbox"/> I did not know where to go for HIV services                              |
| <input type="checkbox"/> I was in denial about being HIV+                                     | <input type="checkbox"/> I did not think the services would do me any good                        |
| <input type="checkbox"/> I was depressed  | <input type="checkbox"/> I was afraid to get bad news   |
| <input type="checkbox"/> Financial Reasons  | <input type="checkbox"/> Others need services more than I do                                      |
| <input type="checkbox"/> I was worried someone would find out about my HIV status             | <input type="checkbox"/> It was hard to get there [transportation]                                |
| <input type="checkbox"/> I was abusing drugs or alcohol and just couldn't manage it           | <input type="checkbox"/> I was abusing drugs or alcohol and was afraid they would tell me to stop |
| <input type="checkbox"/> I did not like the service provider                                  | <input type="checkbox"/> I did not like the people at the place where services were provided      |
| <input type="checkbox"/> No one spoke my language   | <input type="checkbox"/> I didn't see other people like me using the service                      |
| <input type="checkbox"/> I was too busy   |   |
| <input type="checkbox"/> The provider wasn't open when I could get there [inconvenient hours] |   |
| <input type="checkbox"/> Other _____  | <input type="checkbox"/> Other _____  |
| _____   | _____   |
| <input type="checkbox"/> None of the above.   |   |

**22. Before you first tested positive for HIV, how often did you see a doctor?**

[. Please check one.]

- |   |  |
|---|--|
| <input type="checkbox"/> <b>At least once a year</b>      | <input type="checkbox"/> <b>Once every few years</b> |
| <input type="checkbox"/> <b>About once in five years</b>  | <input type="checkbox"/> <b>Almost never</b>         |
| <input type="checkbox"/> <b>Only in an emergency room</b> |  |

**23. Do you currently see a primary physician for HIV care?** [check one]

- Yes**                       **No**

**24. Do you currently get HIV services from a provider other than your doctor?** [check one]

- Yes**                       **No**

**25. What helped you most to find HIV services after you were first tested?**

[Any service, for example seeing a doctor, attending a support group, seeing a case manager. Answer all that apply.]

- Talking to a family member
- Talking to another person with HIV
- Calling the AIDSLine
- A referral from the place I tested
- An ad I saw in a newspaper
- A visit from the health department [e.g. state disease intervention specialist]
- Other \_\_\_\_\_
- None of the above.
- Talking to a friend
- Information I found on the Web
- Talking with someone at an AIDS service organization.
- People at my support group
- A poster or flyer I saw someplace
- Other \_\_\_\_\_

**26. What helps you most to keep using HIV services?**

[Any service, for example seeing a doctor, attending a support group, seeing a case manager. Answer all that apply.]

- Talking to a family member
- Talking to another person with HIV
- Calling the AIDSLine
- A referral from the place I tested
- My case manager or social worker
- Other \_\_\_\_\_
- None of the above.
- Talking to a friend
- Information I find on the Web
- Talking with someone at an AIDS service organization.
- People at my support group
- My doctor
- Other \_\_\_\_\_

#### **IV. Conclusion**

- Were there any questions on the survey that could have been clearer? If so, would you like to review them now so I can answer any questions you might have had about how to answer the question?
- Before we conclude, I would like to ask you one more question:

**27. What do you think we should keep doing to help people get connected to HIV health care and services? What could be improved?**

## CONSISTENT [TOP FIVE] DIAGNOSIS SITE TABULATIONS

Where people who were diagnosed lived?

Minneapolis -					
	Red Door	HCMC	HP	PN	HP/PN
2008	68%	76%	24%	29%	27%
2007	68%	58%	8%	39%	24%
2006	63%	57%	24%	41%	33%
2005	61%	52%	35%	25%	30%
2004	48%	83%	32%	50%	41%
2003	58%	63%	34%	50%	42%
	61%	65%	26%	39%	33%

St. Paul -					
	Red Door	HCMC	HP	PN	HP/PN
2008	6%	8%	19%	0%	10%
2007	9%	4%	50%	4%	27%
2006	5%	7%	33%	9%	21%
2005	6%	15%	41%	0%	21%
2004	15%	8%	44%	6%	25%
2003	8%	9%	31%	0%	16%
	8%	9%	36%	3%	20%

TC Suburban -					
	Red Door	HCMC	HP	PN	HP/PN
2008	27%	16%	57%	71%	64%
2007	23%	38%	42%	57%	50%
2006	30%	37%	43%	50%	47%
2005	30%	33%	30%	75%	53%
2004	36%	8%	24%	44%	34%
2003	31%	28%	34%	45%	40%
	30%	27%	38%	57%	48%

Greater MN -					
	Red Door	HCMC	HP	PN	HP/PN
2008	1%	0%	0%	0%	0%
2007	0%	0%	0%	0%	0%
2006	2%	0%	0%	0%	0%
2005	4%	0%	0%	0%	0%
2004	0%	0%	0%	0%	0%
2003	4%	0%	0%	5%	3%
	2%	0%	0%	1%	0%

What was the gender of people diagnosed?

Men -					
	Red Door	HCMC	HP	PN	HP/PN
2008	93%	52%	52%	64%	58%
2007	96%	54%	85%	79%	82%
2006	93%	70%	67%	77%	72%
2005	94%	41%	70%	70%	70%
2004	91%	67%	60%	83%	72%

2003	92%	63%	69%	82%	76%
	93%	58%	67%	76%	72%

Women -

	Red Door	HCMC	HP	PN	HP/PN
2008	7%	48%	48%	36%	42%
2007	4%	46%	15%	21%	18%
2006	7%	30%	33%	23%	28%
2005	6%	59%	30%	30%	30%
2004	9%	33%	40%	17%	29%
2003	8%	37%	31%	18%	25%
	7%	42%	33%	24%	29%

What was the exposure risk?

MSM -

	Red Door	HCMC	HP	PN	HP/PN
2008	76%	20%	33%	46%	40%
2007	72%	4%	46%	64%	55%
2006	84%	40%	43%	50%	47%
2005	72%	30%	44%	40%	42%
2004	73%	25%	36%	67%	52%
2003	65%	38%	45%	68%	57%
	74%	26%	41%	56%	49%

HRH -

	Red Door	HCMC	HP	PN	HP/PN
2008	9%	40%	43%	29%	36%
2007	2%	33%	15%	11%	13%
2006	5%	33%	24%	14%	19%
2005	4%	52%	30%	20%	25%
2004	9%	29%	32%	11%	22%
2003	8%	38%	34%	14%	24%
	6%	38%	30%	17%	23%

Other -

	Red Door	HCMC	HP	PN	HP/PN
2008	15%	40%	24%	25%	25%
2007	26%	63%	39%	25%	32%
2006	11%	27%	33%	36%	35%
2005	24%	18%	26%	40%	33%
2004	18%	46%	32%	22%	27%
2003	27%	24%	21%	18%	20%
	20%	36%	29%	28%	28%

What was the race of those diagnosed?

White -

	Red Door	HCMC	HP	PN	HP/PN
2008	73%	16%	48%	46%	47%
2007	62%	25%	35%	57%	46%
2006	65%	17%	57%	64%	61%
2005	70%	19%	48%	50%	49%
2004	64%	25%	40%	83%	62%

2003	58%	22%	38%	59%	49%
	65%	21%	44%	60%	52%

African American

	Red Door	HCMC	HP	PN	HP/PN
2008	18%	48%	19%	11%	15%
2007	21%	25%	27%	4%	16%
2006	16%	23%	5%	18%	12%
2005	11%	41%	19%	20%	20%
2004	18%	25%	28%	0%	14%
2003	8%	22%	34%	9%	22%
	15%	31%	22%	10%	16%

African/Latino/Al/API/Other -

	Red Door	HCMC	HP	PN	HP/PN
2008	9%	36%	33%	43%	38%
2007	17%	50%	38%	39%	39%
2006	19%	60%	38%	18%	28%
2005	19%	40%	33%	30%	32%
2004	18%	50%	32%	17%	25%
2003	34%	56%	28%	32%	30%
	19%	49%	34%	30%	32%

What was the age of those diagnosed?

Under 25

	Red Door	HCMC	HP	PN	HP/PN
2008	31%	20%	24%	21%	23%
2007	27%	13%	20%	11%	16%
2006	26%	10%	10%	9%	10%
2005	24%	34%	15%	5%	10%
2004	9%	8%	12%	12%	12%
2003	12%	16%	6%	14%	10%
	22%	17%	15%	12%	13%

25 to 40 -

	Red Door	HCMC	HP	PN	HP/PN
2008	48%	40%	29%	50%	40%
2007	57%	43%	62%	57%	60%
2006	45%	47%	38%	37%	38%
2005	62%	44%	56%	40%	48%
2004	51%	59%	44%	62%	53%
2003	77%	41%	56%	63%	60%
	57%	46%	48%	52%	50%

Over 40

	Red Door	HCMC	HP	PN	HP/PN
2008	21%	40%	47%	29%	38%
2007	16%	44%	18%	32%	25%
2006	29%	43%	52%	54%	53%
2005	14%	22%	29%	55%	42%
2004	40%	33%	44%	26%	35%

2003	11%	43%	38%	23%	31%
	22%	38%	38%	37%	37%

Stage of HIV disease when diagnosed?

HIV Non-AIDS -

	Red Door	HCMC	HP	PN	HP/PN
2008	100%	68%	71%	57%	64%
2007	94%	71%	58%	79%	69%
2006	93%	47%	76%	86%	81%
2005	98%	67%	63%	50%	57%
2004	85%	29%	52%	72%	62%
2003	92%	66%	62%	91%	77%
	94%	58%	64%	73%	68%

AIDS

	Red Door	HCMC	HP	PN	HP/PN
2008	0%	32%	29%	43%	36%
2007	6%	29%	42%	21%	32%
2006	7%	53%	24%	14%	19%
2005	2%	33%	37%	50%	44%
2004	15%	71%	48%	28%	38%
2003	8%	34%	38%	9%	24%
	6%	42%	36%	28%	32%

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