

CHICAGOLAND LINKAGES TO HIV CARE

An in-depth portrait of linkage to care services for newly diagnosed and lost-to-care individuals based upon key informant interviews with HIV service providers throughout Chicagoland.

Prepared for **Chicago Department of Public Health**
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Executive Summary

As linkage to care for newly diagnosed and lost-to-care HIV-positive individuals becomes increasingly recognized as a critical and distinct component in the continuum of care, research, training, planning and funding to support best practices becomes increasingly important. Responding to this need, the Chicago Department of Public Health (CDPH) convened the Chicagoland Linkage to Care Workgroup (the Workgroup), a diverse group of community-based organizations, AIDS services organizations, public health planners, hospitals and training organizations facilitated by the Public Health Institute of Metropolitan Chicago (PHIMC). The goals of the Workgroup were to minimize duplication of services, identify opportunities to efficiently share resources and information, identify and determine how to address barriers and challenges, identify best practices and recommend next steps.

Building upon the Midwest AIDS Training and Education Center's (MATEC) *Connections to Care in Chicago* report released in March 2012 that summarized both findings from literature and data collected primarily from Ryan White, Part A-funded providers in Chicago in 2010-2011, the Workgroup conducted a system-wide survey in April 2012 to better understand and characterize linkage to care services from all known providers regardless of funding source(s). While that survey proved to be very useful in beginning to paint a picture of linkage to care practices throughout Chicagoland, the Workgroup wanted more in-depth information about how the services were implemented. Thus, 23 organizations that provide linkage to care services were interviewed in September and October 2012. The aim of these interviews was to get a deeper understanding of what linkage to care services are currently available, understand the gaps in practice and knowledge, get feedback on barriers and gather recommendations on policy and programmatic activities that can support linkage to care work.

Ten major themes emerged through the analysis of these interviews that paint a portrait of linkage to HIV care throughout Chicagoland. These themes are not ordered by frequency or priority but by narrative flow as determined by the author.

Themes from Key Informant Interviews

Theme One: *Chicagoland HIV providers see the necessity and benefit of focusing on linkage to care as a distinct service.*

Theme Two: *Organizations with co-located services have made significant investments in building systems of coordination within their agency to make internal linkage to care a smooth, seamless and efficient process.*

Theme Three: *Collaborations between agencies can be challenging, but organizations remain committed to finding the most effective and relevant approaches.*

Theme Four: *There is no consistent definition of successful linkage to care; however, there are common steps and elements in the linkage process among organizations.*

Theme Five: *While each organization has a different blend of who is performing linkage to care services, most see the need for dedicated linkage to care workers.*

Theme Six: *Peers play a significant role in the linkage process.*

Theme Seven: *Communication with clients in the linkage process happens frequently, requires finesse and is heavily reliant on phone communication.*

Theme Eight: *While research on best practices in linkage to care remains limited, there is an abundance of training resources relevant to linkage to care workers and more that could be developed.*

Theme Nine: *Creating systems for sharing data and information would strengthen organizations' services provision, bolster inter-agency collaboration and improve coordination throughout Chicagoland.*

Theme Ten: *Funding strategies as well as services and resource coordination throughout Chicagoland present many opportunities and barriers for strengthening linkage to care.*

A set of recommendations emerged from interviewees and analysis of interview findings. These recommendations are below.

Recommendations from Key Informant Interview

Funding and Policy

Advocate for more flexible linkage to care funding, lessening administrative burden and supporting providers to stay connected with clients until they are ready for care and remain with clients until they are fully established in care.

Advocate for more consistency and streamlined reporting methods between national, state and local funders.

Advocate for policy and practice changes that help minimize the barrier of getting an individual to return for confirmatory test results.

Resources and Coordination

Support the creation of a common definition for successful linkage to care that focuses more on key milestones and client outcomes than on timeframes.

Support creation of a standardized linkage protocol and common client flow chart that expands on the Chicago Spectrum of Care, allows for flexibility in implementation, and creates consistency of language throughout the region.

Create a continuously updated directory of linkage to care services.

Create systems that increase the ease of sharing client information that can support linkage to care by building upon existing reporting mechanisms.

Training and Research

Collect and make available various models, tools and training that could strengthen intra- and inter-agency collaborations.

Support research that gathers the perspectives and experiences of clients, peers, and non-linkage providers to identify ways that linkage to care services can be further strengthened.

Invest in training and support for linkage workers to avoid burnout and understand boundary issues.

Increase access to peer training and supervision support.

Create a linkage to care training curriculum that includes language considerations, communication tools, motivational interviewing and other topics identified by interviewees.

Create an online portal that allows linkage workers and administrators to share and access forms, protocols, training modules and other helpful tools as well as seek feedback and support from peers.

Offer a consistent meeting opportunity for linkage workers to connect with each other and gain insights and skills that can help them in their work. This report contains a long list of topics that interviewees requested.

Organize bi-annual gatherings for frontline staff, administrators and researchers throughout Chicagoland to gather and get updated information, gain skills and collect information on each other's programs.

Context

According to the Centers for Disease Control and Prevention (CDC), 20% of HIV-positive individuals in the U.S. are undiagnosed, a quarter of those who have been diagnosed delay entry into medical care, and nearly half of those diagnosed are not retained in care.¹ In 2006, CDC recommended that opt-out HIV screening be included as part of routine clinical care in all health care settings to increase the identification of HIV-positive individuals.² As new individuals are identified, linkage to HIV care is an essential next step in the process toward achieving suppressed viral loads, which leads to improved health outcomes and may decrease HIV transmission.³ The National HIV/AIDS Strategy (NHAS) calls on communities to “establish a seamless system to immediately link people to continuous and coordinated quality care when they are diagnosed with HIV”, increasing the proportion of newly diagnosed patients linked to clinical care within three months of their HIV diagnoses from 65% to 85%.⁴

Responding to this call, providers, funders, and planning bodies in jurisdictions throughout the U.S. have been paying closer attention to the services that link newly diagnosed individuals to HIV care, and identify and re-engage those who have fallen out of care. Figure 1, modeled after work conducted by Gardner et al. helps identify the issues and opportunities to engage a person living with HIV in medical care.⁵ The Chicago Department of Public Health (CDPH) estimates that in 2010, 27,023 individuals were living with HIV in Chicago, and that 21,348 (79%) of them have been diagnosed. Of those that know their status, an estimated 16,011 individuals (75%) are linked to care, and 10,674 (67%) are retained in care. The focus of the interviews and subsequent recommendations in this report are focused on improving systems to reduce the 25% who know they are HIV-positive but are not linked to HIV medical care.

¹ Centers for Disease Control and Prevention. Vital sign: HIV prevention through care and treatment – United States. MMWR, 2011, 60(47); 1618-1623.

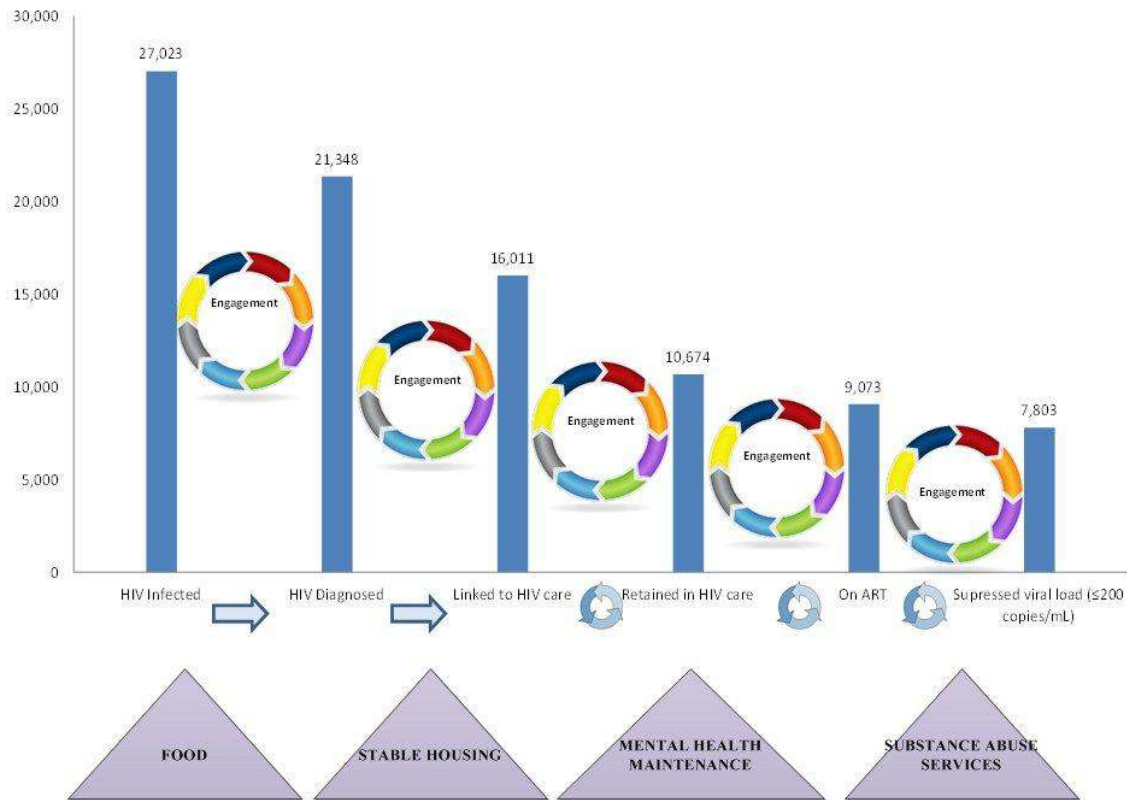
² Centers for Disease Control and Prevention. Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health care settings. MMWR, 2006, 55(RR14); 1-17.

³ Metsch L.R., et al. HIV transmission risk behaviors among HIV-infected persons who are successfully linked to care. Clinical Infectious Diseases, 2008, 47: 577–84.

⁴ Office of National AIDS Policy. National HIV/AIDS Strategy and Implementation Plan. Washington (DC). The White House, Office of National HIV/AIDS Strategy. July 2010.

⁵ Gardner, E.M., et al. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. Clinical Infectious Diseases, 2011, 52(6): 793-800.

Figure 1. Chicago Spectrum of Care, 2010
Chicago, Spectrum of Care, 2010



Approaching Linkage to Care in Chicagoland

With the increasing attention on linkage to care, CDPH has invested resources into exploring national best practices, understanding local resources and efforts, and coordinating strategies to strengthen linkage to care. The results of this investment include the creation of the Chicagoland Linkage to Care Workgroup (Workgroup), a report released by the Midwest AIDS Training and Education Center (MATEC) in March 2012, a system-wide survey conducted in April 2012, and this report of key informant interviews conducted in September and October 2012. These second two efforts were guided by the Workgroup, which was convened by CDPH, facilitated by the Public Health Institute of Metropolitan Chicago (PHIMC).

MATEC report

In 2010, CDPH contracted the regional AIDS training and education center MATEC to explore and describe national best practices and local providers' efforts to link, retain and re-engage HIV-positive individuals into medical care, primarily focused on Ryan White Part A-funded providers. In March 2012, MATEC released their report summarizing the findings. The extensive literature review investigated the major themes below.

- What is entry into care and why is it important?
- Engagement in HIV primary care as a continuum

- Understanding barriers to engagement in care, including a focus on various populations
- Innovation and model programs
- Guidelines for improving entry into and retention in care

The report also included results from a survey administered to 53 persons from 45 distinct organizations throughout the Chicago area (Chicagoland) designed to obtain details about the scope of providers' efforts to link, retain and re-engage HIV-positive individuals into care. Questions covered the areas listed below.

- HIV testing practices.
- HIV care and/or case management services.
- Descriptions of efforts to link, retain and re-engage clients in care.
- Specificity of agency funding related to HIV testing, outreach, linkage, retention and care.

Three major recommendations for CDPH emerged from this work: 1) facilitate the coordination of systems, the sharing of data and the tracking of outcomes; 2) fund and expand the use of best practices, including linkage case management, patient navigation and outreach; and 3) provide training and technical assistance to build skills in implementing and improving the use of best practices. These recommendations are consistent with the recommendations that emerged from the key informant interviews presented in this study.

Chicagoland Linkage to Care Workgroup

The Workgroup, convened by CDPH in 2011 and facilitated by PHIMC, has diverse membership that includes community-based organizations, AIDS service organizations, public health planners, hospitals and training organizations. The Workgroup and its committees met for over a year to better understand and document linkage to care services for people living with HIV in the Chicago metropolitan area and to facilitate coordination and collaboration among all linkage to care projects, funded and un-funded. The goals of this work were to minimize duplication of services, identify opportunities to efficiently share resources and information, identify and determine how to address barriers and challenges, identify best practices and recommend next steps. During the meetings, the Workgroup members learned from each other, CDPH and national experts. They also drafted a set of recommendations to guide CDPH in strengthening linkage to care throughout Chicagoland.

Chicagoland system-wide survey

The Workgroup conducted a survey in April 2012 to better understand and characterize linkage to care services. Twenty-four organizations were identified by the Workgroup as offering some form of linkage to care services. Of this pool, 20 organizations responded: 35% were hospitals, 35% were community-based organizations, 20% were community health centers, 5% were AIDS service organizations and 5% were local health departments. The survey sought to answer the following questions.

- What do programs have in common?
- What is different?
- What can we learn from each other?
- What are the gaps or areas of duplication?
- What are the challenges and barriers?
- What are next steps?

One-quarter of responding organizations were not funded for linkage to care services. Of those that target specific populations, 100% served men who have sex with men and 60% served both injection drug users and high-risk heterosexuals. Of the 15 organizations that reported on the services they offered, 100% offered HIV testing, 87% medical case management, 73% HIV medical care and 73% non-medical case management. Fourteen organizations reported on their methods to verify appointments were kept.

- 14 (100%) follow-up with medical provider
- 11 (76%) attend appointment with client
- 1 (7%) other: self-report
- 12 (86%) used both follow-up with provider and attending appointment

Respondents were asked to identify what barriers and challenges they have experienced while trying to provide linkage to care services. Here is a summary of their responses.

- Inability to contact clients (no information, inaccurate information, transient population)
- Stigma and non-disclosure
- Delays due to need to get information from third parties and/or obtain client consent to get information
- Peers (stigma effects ability to recruit other clients, perception of overlapping roles with case managers, need to ensure they are able to do the job)
- Concern about overlap or duplication of services
- Challenges with and the need for collaboration with other providers
- Clients' readiness for care and/or responsiveness to outreach due to unmet basic needs and behavioral health issues
- Specific or heightened barriers for youth (navigating health care system/insurance, stigma/homophobia, lack of money, housing and transportation)
- Transportation
- Stable housing

Results were reported back to the Workgroup where they were discussed and analyzed. The Workgroup decided it would be useful to have a deeper understanding of these areas and to explore additional components of linkage to care work and commissioned a series of key informant interviews that resulted in this report.

Key informant interviews

The purpose of the key informant interviews was to gain a deeper understanding of how organizations and practitioners are linking newly diagnosed or out-of care HIV-positive individuals into medical care. The pool for key informant interviews was the same list identified by the Workgroup for the system-wide survey. An independent consultant conducted the interviews and analysis, and the questions and methodology were sent to a committee of the Workgroup for review and feedback. In August 2012, an email was sent to each of the 24 organizations, requesting a face-to-face interview with one or more individuals within that organization. Follow-up emails and phone calls were made as needed. See Appendix A for a detailed methodology of the key informant interviews.

In September and October 2012, interviews were conducted with 35 individuals from 23 organizations. The table below summarizes the interviewees.

Table 1. Description of Interviewees and Organizations

Description of Interviewees and Organizations
35 interviewees, some serving in multiple roles
Program administrator (manager, coordinator, director, etc.) – 23
Direct linkage to care worker – 17
Medical care provider – 4
23 organizations, some fitting in multiple categories
Community-based organization – 12
Hospital – 8
Community health center – 8
Multi-agency project coordinator - 6
Research project – 5
AIDS service organization – 4
Local health department – 1

The entire set of questions posed to interviewees and accompanying script can be viewed in Appendix B. The data collected through interviews were recorded and analyzed along with materials collected from interviewees to identify themes and develop recommendations. Some interviewees provided additional information including protocols, client or referral flow charts, staff or peer expectations, memoranda of understanding, client tracking forms or databases, training materials, and new or adjusted survey responses from the prior survey.

One note about language: when this report uses the term “linkage worker”, the author is referring to anyone who is directly providing linkage to care services. This may be a dedicated linkage to care staff person or outreach worker, peer navigator, health navigator, or early intervention service worker. These roles are still being clarified, but for this sake of clarity the term “linkage worker” refers to the individual providing direct linkage to care services no matter his or her official title.

Themes from Key Informant Interviews

Ten major themes emerged from the interviews and documents supplied by interviewees. Overall, there is a great deal of passion and energy focused on linkage to care throughout Chicagoland. Despite a dearth of research on best practices and a lack of consensus among funders and planning bodies about what constitutes successful linkage to care, organizations are taking these services seriously. Innovative approaches are being taken to meet clients where they are and link them to medical care “by any means necessary”, as one linkage worker stated. The most consistent finding throughout the entire interview process was that the people who are doing this work are unique, devoted and not easily deterred. The major themes that paint a deep understanding of linkage to care in Chicagoland are listed below and are ordered for narrative flow not frequency or priority.

Table 2. Themes from Key Informant Interviews

Themes from Key Informant Interviews
Theme One: <i>Chicagoland HIV providers see the necessity and benefit of focusing on linkage to care as a distinct service.</i>
Theme Two: <i>Organizations with co-located services have made significant investments in building systems of coordination within their agency to make internal linkage to care a smooth, seamless and efficient process.</i>
Theme Three: <i>Collaborations between agencies can be challenging, but organizations remain committed to finding the most effective and relevant approaches.</i>
Theme Four: <i>There is no consistent definition of successful linkage to care; however, there are common steps and elements in the linkage process among organizations.</i>
Theme Five: <i>While each organization has a different blend of who is performing linkage to care services, most see the need for dedicated linkage to care workers.</i>
Theme Six: <i>Peers play a significant role in the linkage process.</i>
Theme Seven: <i>Communication with clients in the linkage process happens frequently, requires finesse and is heavily reliant on the phone.</i>
Theme Eight: <i>While research on best practices in linkage to care remains limited, there is an abundance of training resources relevant to linkage to care workers and more that could be developed.</i>
Theme Nine: <i>Creating systems for sharing data and information would strengthen organizations’ services provision, bolster inter-agency collaboration and improve coordination throughout Chicagoland.</i>
Theme Ten: <i>Funding strategies as well as services and resource coordination throughout Chicagoland present many opportunities and barriers for strengthening linkage to care.</i>

Each of these themes is explored further in this section with narrative and quotes from interviewees to explain how linkage to care is understood and executed throughout Chicagoland. There is much more that can be studied, but this report continues the journey toward strengthening linkage to care.

Theme One: *Chicagoland HIV providers see the necessity and benefit of focusing on linkage to care as a distinct service.*

- There is a shift towards recognizing care providers are on the front line of prevention.
- HIV-positive individuals face significant emotional and structural barriers to accessing and remaining in care that providers must address.
- Interviewees see the need for newly diagnosed individuals or those who have fallen out of care to have access to more intensive, shorter-term case management with smaller caseloads and more contact points.

All of the interviewees were passionate about linkage to care and proud of the work they and their organization were doing. It was clear that interviewees from organizations that received funding for linkage to care services had spent time thinking about the concepts, logistics, and models of their service delivery. Interviewees from organizations that did not receive direct funding often expressed an opinion that this work is and always has been intrinsic to the work they and their organizations do.

We made a connection a long time ago between testing and care in community-based programs, always seeing a continuous, seamless continuum of care.
-Medical doctor and administrator, hospital

Though no question directly asked why linkage to care is important, many interviewees discussed this importance. Two researchers from different projects who also provide medical care noted the limitations of individual risk-taking behavior change to decrease the rate of HIV infection. One called care providers the “new front line of fighting the epidemic. They are the ones who will drive down community viral loads.” One interviewee said that the ultimate outcome of his program was to measure a decrease in HIV viral load within communities targeted by his program, a shift from previous measurements of success.

We were wrong for decades. We thought we were doing a service for patients, but the Cohen study showed us that treating people was key to prevention. Treatment is prevention, not treatment or prevention.
-Registered nurse, research project

Interviewees reported many barriers their clients face in accessing and remaining in care. Emotional, mental health and substance abuse issues were discussed at length by most interviewees as the most challenging barriers to overcome. Mental health services, pastoral and counseling care, and mentoring are tapped to help clients overcome these barriers. Structural barriers such as housing

and transportation pose significant barriers to care. Every interviewee mentioned some form of transportation assistance they offer to clients from the moment of first interaction. Housing and employment assistance were reported as the least available resources with which to connect clients. Case management and provision of vouchers for transportation, food and clothing were reported by interviewees as strategies helpful to overcoming these barriers.

Case management is critical to retention in care. They take care of the supportive needs that are necessary for clients to access care.
-Program administrator, hospital

However, unlike traditional case management, most interviewees saw linkage to care services as much more intensive and responsive to clients. They see the need to have staff with smaller caseloads for shorter-term engagements to help HIV-positive individuals integrate care into their regular routine then transition to longer-term case management. This is consistent with existing research on best practices and models that have been proven effective.⁶⁷ One linkage worker in a hospital mentioned how important it was to quickly build rapport with a client and then back that up with real action to address the reasons people have for dropping out of care such as stigma, depression, and homelessness. This is consistent with the underpinnings identified in the Chicago Spectrum of Care diagram.⁸

When someone is ready to do something today, you better be ready to do that right now.
-Linkage coordinator, community-based organization

⁶ Gardner, L. I., et. al. Psychological and behavioral correlates of entering care for HIV infection: The antiretroviral treatment access study (ARTAS). *AIDS Patient Care and STDs*, 21(6): 418-425.

⁷ Gilman, B., et al. Linkage to care for newly diagnosed individuals who test positive in nonprimary care settings. *AIDS Patient Care and STDs*, 26(3): 132-140.

⁸ See Figure 1

Theme Two: *Organizations with co-located services have made significant investments in building systems of coordination within their agency to make internal linkage to care a smooth, seamless and efficient process.*

- All agency staff are seen as part of the linkage to care continuum and need to be prepared with appropriate training and linked through effective communication strategies.
- Tracking methods allow linkage workers to lead organizational strategies that ensure effective linkage, maintain retention and flag clients who are lost to care.

Through the interviews, it became clear that linkage to care organizations have made significant investments to develop or build upon existing strategies to create a seamless flow for clients within their organization.

*The entire organization needs to do linkage to care.
-Linkage coordinator, community health center*

Organizations use different tools and strategies for intra-agency collaboration. The most common strategy is a “warm hand off”. This happens when a staff person walks the client to another staff person to make a human connection. This may involve testing staff walking newly diagnosed individuals to the medical appointment desk, reception staff paging linkage workers when the patient arrives for their appointment, linkage workers sitting in medical appointments with clients or linkage workers introducing clients to case managers. This focus on each person playing his or her role and then overlapping with the next person is a strategy that all interviewees see as central to their intra-agency collaboration.

Methods of tracking clients as they move throughout the organization are also keys to the success of intra-agency collaboration. These tracking methods help create a web that keep clients from “falling through the cracks”, create cohesion in the care of clients, flag concerns that need to be addressed with specific clients and identify areas for improvement in the organization’s provision of services. Tracking methods include patient records, case review meetings, staff meetings and reports. About half of the organizations interviewed use electronic medical records (EMRs) and many are in the process of updating or refining their systems. Most use their organization’s existing system for tracking clients, running reports as necessary to report data to various funders. All interviewees expressed the challenge they face in coordinating their organizations’ tracking system with the different data and reporting systems required by various funders. One program within a small HIV-focused organization developed a complex Excel database for intake and tracking clients that allows for easy flow of information to eight different funders. Another formatted their paper tracking system into a checklist that allows staff to keep track of progress toward meeting linkage goals for each client. One interviewee described a project they are initiating next year to find ways two software programs used by major governmental HIV funding organizations can seamlessly communicate.

Internal tracking systems aid intra-agency collaboration in identifying newly diagnosed clients as well as those who have fallen out of care. For organizations with EMRs, reports of patients who tested positive are run and matched against appointment schedules to ensure linkage or initiate targeted outreach. Both a hospital and a clinic setting described electronic systems that alert the HIV team when a test comes back positive, at which point the team contacts the provider to develop a strategy and appropriate timing for giving the result and making the linkage.

Internal systems for identifying HIV-positive individuals who are lost to care or at risk of dropping out of care are primarily based upon missed appointments. Multiple interviewees described appointment systems that allow data managers, case managers or administrative staff to run reports of clients who miss appointments and pass these names on to linkage staff. Sometimes providers will notify linkage staff of missed appointments in meetings, by phone or through a note in the medical record. In one hospital that receives no funding specifically for linkage to care, the data manager runs a report of people who have not been in care for a year, asks the HIV team who knows about this person and then refers the client to a case finder or manager. A community health center interviewee described two methods used to identify lost-to-care individuals. First, the linkage staff will manually go through reception call logs to see if someone called for care but didn't come in and call them to see if they ended up going in to care elsewhere. Second, every HIV-positive patient who has had one appointment goes on a retention list. Quarterly, these individuals are categorized and given a status of active, inactive, lost to care, dead or moved, flagging people for a retention advocate to outreach. Both of these strategies identify individuals, but the organization lacks the capacity to reach out to everyone and must prioritize for follow-up based upon time available.

Communication between providers and linkage workers can be challenging as providers often have limited time. However, multiple linkage workers have established check-ins with providers before and after each appointment to get a sense of what took place and any assessments the provider may have to guide the linkage worker in supporting the patient. For those linkage workers in settings that provide care, the medical record often provides the greatest source of communication between linkage worker and provider, flagging instances where a check-in is necessary. Many of these settings have standing staff meetings where client cases are reviewed, clients who are facing difficulties or not showing up are flagged and strategies are developed for meeting the client's needs.

One critical element that is common to most organizations is a key point of contact or lead staff person assigned to each client, especially in the first months of engagement with care. This allows people who serve different functions to know whom to approach for concerns, questions or ideas to better serve that client. Another important element, related to consistency of point of contact for each client, is minimizing turnover for linkage staff.

*Keeping people in care takes a team approach, and someone needs to lead that team.
-Program administrator, community health center*

Training is another way that organizations support intra-agency collaboration. Multiple interviewees described all-staff trainings conducted to explain what linkage to care is, the role each staff plays in the linkage process and what each step looks like. One interviewee said that this helps each staff person within that agency express more empathy for the clients as they move through the various steps in the care process, identify barriers the client might be facing and know where to direct clients to overcome those barriers.

We train everyone to play their role – from the phone reception person who is the gateway to the client entering the system all the way through to the nurse who says good-bye.

-Program administrator, local health department

Finally, many interviewees described staff meetings, often held monthly, for all members of the HIV team to come together to discuss program issues. It is in these meetings, that linkage to care processes have been developed. For some providers, these meetings facilitate communication between care providers, testers and support staff. Since referrals are easiest when relationships exist between individuals involved in the referral process, these staff meetings help to build relationships and understanding of the various pieces of the puzzle and how they fit into the whole.

Challenges still remain for organizations in refining intra-agency collaborations. Most organizations grapple with these challenges as they arise through collaborative staff problem-solving methods. One challenge presented by many interviewees was the differing eligibility criteria for linkage to care services that different funders and programs maintain. Most organizations are committed to linking every individual they encounter to care, which means that linkage services provided to some clients are not compensated. It also means that staff at agencies with multiple funding sources have to sort through which program each client is eligible for and fill out the paperwork and collect data unique to the program, increasing the administrative burden and creating inefficiencies. Despite the challenges, organizations maintain an overwhelming commitment to keeping clients at the center of their service and not allowing any challenges to keep them from successful linkage.

Theme Three: *Collaborations between agencies can be challenging, but organizations remain committed to finding the most effective and relevant approaches.*

- Perception of competition and differing approaches and protocols between organizations create difficulties.
- Strategies that support collaboration include agreements with clear expectations, identifying mutual benefit and building personal relationships between staff.
- Collaborative projects present opportunities to create strong relationships between organizations.

Interagency collaborations present more complexity for organizations to manage. One interviewee lamented the loss of opportunity for the “warm hand off” and said that interagency referrals “feel messier”. Many of the organizations interviewed through this project have formal or informal agreements between other organizations interviewed. Many of these agreements and referrals are based upon location, gender, race or age of the clients being served. Despite a fear expressed by some that the need to maintain clients for funding purposes may preclude referrals, most interviewees were very clear that the client is at the center of their decision-making and expressed willingness and examples of making referrals to other care providers.

Interviewees mentioned various strategies that have supported interagency collaborations. One mentioned MATEC as having supported their initial round of relationship-building by providing a list of organizations and contacts within each one. Another mentioned the length of time their linkage worker has been in the field and having worked at various locations in various positions, which increased her knowledge of agencies and relationships with individuals. Four interviewees said they visit various agencies to which they make referrals to develop relationships with gatekeepers and really get to know the organization. One organization that provides testing shares space with another organization that provides medical care, providing their distinct services in the same settings. In doing so, they have created a co-located service delivery model. An interviewee from a community-based organization that provides testing and prevention services has a set of eight medical providers with which they work.

Multiple interviewees described the benefit of having a specific project with which to help build effective interagency collaborations. With one such project, the organizations involved divided the city into various geographic areas so as to avoid overlap of services. To build trust between agencies, staff clearly specified how they would report numbers prior to seeing any clients. Despite only two of the four agencies being funded for this project, the interviewee from one of the unfunded organizations felt it was worthwhile to expand her base of partners. These organizations are working on a joint linkage to care protocol based upon best practices that can be used across organizations.

We lay everything on the table and troubleshoot together. Linkages are smooth. Trust is built. We know what others are doing.
-Linkage coordinator, community health center

Having clearly defined Memoranda of Understanding or Agreement (MOUs or MOAs) was important to most interviewees. These agreements outline roles and responsibilities, the flow of client referral, reporting strategies and communication expectations. Reporting between organizations is a key component of successful interagency agreements. One interviewee said that she reports back monthly or quarterly to testing agencies that refer clients for care to demonstrate the success of the linkage agreement and encourage future linkages. Another interviewee felt that reporting back to referral agencies was important so that if follow-up needs to happen to re-engage someone who has fallen out of care, trust has been built between the organizations that can be built upon to bring the client back into care.

Theme Four: *There is no consistent definition of successful linkage to care; however, there are common steps and elements in the linkage process among organizations.*

- Most organizations leave the definition of timeframe to funders.
- The conceptual outcomes, process steps, and approaches to linkage to care demonstrate some consistency across organizations.
- Attention is more heavily focused on linkage of newly diagnosed individuals and retention in care than on those lost to care.
- Protocols are still in development, but many organizations have client flow charts.

Linkage to care is not a consistently defined concept. Funders, planning bodies, government agencies, and providers all have different definitions of what defines a successful linkage to care. When interviewees were asked to define a successful linkage to care, responses covered everything from the steps involved in linkage to the outcomes expected from the process. Few definitions actually included timeframes for a successful linkage, and, when they did, the timeframes varied from 48 hours to three months, measuring outcomes as varied as the introduction of the linkage relationship to completion of first medical appointment. It appears that most organizations are leaving the timeframe to funders and governing agencies, focusing instead on measuring the client outcomes or provider actions and taking a client-centered approach to the time it takes to reach successful linkage. Below are various definitions of successful linkage initially given by interviewees.

When a client moves from “I want care” to “I need care” to “I can get care on my own”.
-Linkage coordinator, hospital

When a client sees their relationship with the doctor as meaningful.
-Linkage coordinator, community health center

When I define linkage to care, care equals case management, primary care and medical adherence.

-Linkage coordinator, community-based organization

Some organizations define successful linkage through the activities completed in the linkage engagement. For some, this is completion of a first medical appointment. For most organizations, the linkage definition extends to second or third appointments. Three organizations define successful linkage as a first medical appointment wherein lab work is done, a second appointment where results are given and medications prescribed, and a third appointment that serves as the patient's first routine medical visit.

Most organizations do not have a written protocol for linkage to care, though some have a client flow chart that describes the steps from testing or referral to linkage in medical care. One collaborative project between four agencies includes the development of a shared protocol for adolescents that can be used across agencies and grounded in research. Three interviewees said that developing protocols is on their list of things to do and three have drafts in progress. Some interviewees felt like a specific protocol or flow chart was unnecessary as it "naturally" happened, or that they need to maintain a very organic approach in order to be responsive to the unique needs of each individual.

Commonly cited sources that were used for development of agency protocols include the publications by Fortenberry et al. and Gilman et al., Antiretroviral Treatment Access Study (ARTAS) model, and Denver and San Francisco departments of public health protocols.⁹¹⁰¹¹ Interviewees also said they use anecdotal reports from clients about barriers faced, collaboration agreements with other agencies and review by trusted partners in building their protocols. Projects with multiple sites often reported having to develop different processes unique to each setting.

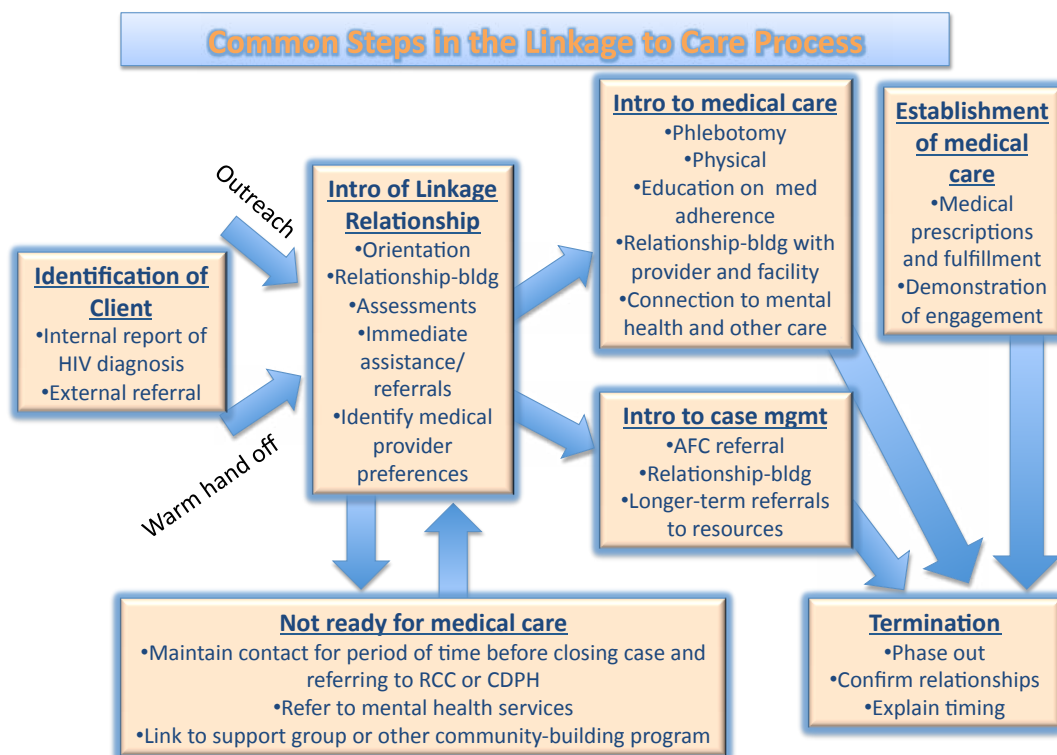
Figure 2 below with accompanying narrative illuminates these common steps. However, each organization has very different approaches to when, how, and with whom these steps are taken.

⁹ Fortenberry, J.D., et al. (in press). Linkage to care for HIV positive adolescents: A multisite study of the adolescent medicine trial units of the adolescent trials network. *Journal of Adolescent Health*, 2012, /S1054-139X(12)00133-4.

¹⁰ Gilman, B., et al. Linkage to care for newly diagnosed individuals who test positive in nonprimary care settings. *AIDS Patient Care and STDs*, 26(3): 132-140.

¹¹ Denver protocol available at <http://www.denverptc.org/SO/Linkage2Care.pdf>

Figure 2. Common Steps in the Linkage to Care Process



Identification of client

Newly diagnosed and out-of-care individuals are identified for linkage to care services through the following methods: internal reports of HIV diagnoses, external referral from testing agencies for newly diagnosed or care providers for out-of-care individuals or through active referral at either the preliminary or confirmatory diagnosis stage. Internal reports of new HIV diagnoses or clients who have fallen out of care are run through client tracking systems often for large institutions, as described in a previous section. As more clinics and hospitals are conducting routine, opt-out testing, these reports and identification strategies are becoming more refined. External referrals are being made to Regional Care Coordinators (RCC) from care providers when a patient has not been in care for six or more months or by testing agencies with which RCCs have built a relationship. However, most of these referrals are done through a more active referral process at the time the individual is given their diagnosis. As most interviewees were from organizations that offered testing and care, little time was spent on external referrals.

Interviewees express that active referral at the point of preliminary or confirmatory test results was the most desirable method for identifying newly diagnosed individuals. Most organizations attempt to have linkage workers in the room at the time the diagnosis is given, making the connection as seamless as

possible. For some organizations, this means having linkage staff available any time that testing is being offered. For others, it means scheduling appointments to give test results when linkage staff can be present. In one organization that works with adolescents, the testing staff gives the preliminary reactive test results and connects the client to the linkage worker to conduct the confirmatory test. When the linkage worker cannot be in the room, another approach is for the linkage worker to be called while the client is in the room with the testing staff. The worker does his or her best to make a personal connection with the individual over the phone.

For those who conduct HIV testing in the field, different strategies are used for making linkages. Testing staff from one community health center drive an individual with a preliminary positive result to the clinic for a confirmatory test. Health educators from another agency will give their names and cards to individuals with preliminary positive results and meet them at the reception desk when they come in for their confirmatory test. Most interviewees indicated that all testing staff has some understanding of linkage to care.

One of the biggest challenges in the linkage to care process is in the delay between receiving a preliminary positive result, getting a confirmatory test and coming back two weeks later to receive the confirmatory results. Multiple care providers interviewed mentioned that they keep open appointments in their schedules to receive individuals with preliminary positive results. One testing agency that does not provide care has an agreement with a care provider that if testing staff comes in with a client, the new patient intake process is waived for conducting a confirmatory test. Returning for the results of confirmatory test is yet another step. One community-based agency has an assessment form they use with preliminary positives to identify barriers to returning for results and asking for best contact person and places frequently visited to facilitate outreach when needed.

Introduction of linkage relationship

The timing of the first linkage to care session varies among organizations. Some conduct this first session at time of confirmatory diagnosis while others arrange a special appointment. Some combine this session with the first medical appointment. Others initiate a linkage relationship at the preliminary positive result but do not begin introduction of services until confirmatory diagnosis.

The following occur during the first linkage session: education, secure consents, collect information, complete assessments, make introductions and referrals, and set appointments. If the diagnosis has not yet been given, this will be the first session. Below is a description of the common elements in the introductory session.

- Education provided often includes answering questions about the process of lab work and medical assessments, legal issues, risk reduction, basic HIV education and disclosure coaching.
- Securing necessary consents for communication with providers, other referral sources or for research projects.
- Information collected may include additional contact information, preferred methods of communication, desires related to care

providers to aid in appropriate referrals and income information to expedite linkage to public assistance and other benefits.

- Assessments may include barriers to accessing care, emotional reaction to diagnosis, and strengths of the client upon which to build for successful linkage into care. Many organizations also include medical assessments such as blood work to make the first medical appointment as efficient as possible. For some, the linkage worker will develop an action plan with the client to identify any barriers to care and what the client and the worker will do to overcome or minimize these barriers.
- The first session often includes introductions to medical providers, case managers and mental health workers. For those who are not ready for care, the connection to the mental health worker is the primary strategy for many interviewees to get the individual ready for care. Referrals to support groups are often made as well.
- Selecting the provider for the patient's first medical appointment is done in this first session. As many interviewees have co-located services, most appointments are made in-house. One interviewee who does not work in an organization that provides care has assessed various care settings through site visits and previous client reports to help him make appropriate connections to meet the specific needs of each individual. He will have the individual choose one or two, sign a release and then call to see which can see the client first.

Not ready for medical care

Different approaches are taken for clients who are not ready for medical care. Some organizations lack the capacity to continue contact with these clients and make a referral to CDPH or RCC. Some make referrals to mental health services, support groups or pastoral care to help maintain contact and move the client toward readiness. Some linkage workers maintain weekly contact with the client, hoping that relationship-building and time will bring the client around to readiness.

Introduction to medical care

As mentioned previously, this first medical appointment may take place in conjunction with the first linkage session, making fewer appointments for the individual to attend. In other organizations, it is kept distinct so as to make for shorter appointments. The length of this appointment varies, depending on what needs to be covered. At one hospital, this is scheduled for 2-3 hours while at another serving primarily adolescents it is 4 hours. At a community health center, where this medical appointment serves more as a preliminary orientation to care, the appointment is scheduled for 40 minutes for an adult and 60 minutes for a youth.

Most interviewees have linkage workers accompany clients to the first medical appointment to build the confidence of the individual, answer any questions and sometimes translate between the provider and the patient. Some workers transport clients in a vehicle to the appointment and return them home afterward. Most provide some type of transportation voucher. Some care settings assign peer

buddies or navigators to go through the initial set of appointments, lab work and pharmacy meetings with the client while a linkage coordinator oversees all the clients in clinic that day.

This serves as the first opportunity to introduce the individual to the primary care provider and the other members of the multi-disciplinary team, including mental health, substance counselor and case managers. In one community health setting the linkage worker passes the relationship on to the provider at this first appointment and then ends the relationship. The design of this organization's linkage plan is that the relationship needs to be focused on the patient and provider instead of the patient and linkage worker. In another community health setting, the linkage worker leaves the appointment to help build the patient-provider relationship and then returns after the appointment to accompany the patient to phlebotomy. If lab work was not conducted already, it is done at this visit. If it was conducted already, then it is reviewed by the provider and a medical regimen is established. In this appointment, a physical is most often conducted and the client educated about medical adherence and healthy lifestyles.

Introduction to case management

The linkage worker or medical provider will often use the first medical appointment or the first meeting with the linkage worker to make a connection with the region's HIV case management cooperative, a centralized system funded by various sources and coordinated by the AIDS Foundation of Chicago (AFC). Interviewees reported that as the assignment of a case manager may require a few days to a week, the linkage worker will stay in continuous contact with the client until the assignment has been made. Linkage workers often assist in building a relationship between clients and case managers by being present with the client during their first interactions with the case manager. Referrals may also be made at this time to mental health or dental services. If a mental health worker is on staff, the patient will often meet with him or her at this time for an assessment and referral to support groups, individual counseling or other services.

Establishment of medical care

Follow-up from the first medical appointment happens differently for those organizations that maintain the linkage services beyond the first visit. In one setting, the linkage worker reads through the notes from the appointment to make sure there is a second appointment scheduled. For most organizations, the linkage worker checks in with the patient to make sure s/he understood everything and was comfortable with the medical provider. If not, referral to another source may be made, which would be considered another first medical appointment instead of subsequent visit.

Subsequent appointments are scheduled depending upon the protocols and expectations of various organizations. Most linkage workers encourage the client to set up the appointments and slowly phase themselves out. With many, the linkage workers combine their client meetings with medical visits, supporting clients to build their confidence in self care and acquire the knowledge and skills necessary to

understand and navigate the care process. With others, these services are offered in other settings or passed on to case managers.

If the lab work was not conducted until the first medical appointment, the second appointment is when labs are reviewed and a medical regimen is determined. For one organization, this second visit happens two weeks after the first, and for another it happens 16 weeks later.

Termination

The timing for termination of linkage to care services and transition into longer term systems varies widely. One interviewee said that she stays with the client until the client is fully settled into care, leaving the choice to the individual. For one organization that provides medical care, after the first appointment, the linkage workers stops direct contact with the client and becomes part of the ongoing tracking and outreach team. Another closes out a client after the 2nd visit but stays informally connected. For another provider, the linkage relationship continues for six months. For two organizations, the relationship continues for nine months. An interviewee from one of these organizations described these nine months in the following three phases.

The first three months is focused on establishing the relationship with the medical provider. The second three months is focused on mental health and other services. The last three months is focused on personal skills and sustainability.

-Director, community-based organization

Other organizations have windows of relationships that extend to 12 months but aim for a 6-9 month timeframe. Linkage workers at one community health center stay with the individual for 3-6 months with a completion of 2 appointments. For each organization, the length and scope of the linkage relationship is clarified with the client at the outset of that relationship and termination is a clear and deliberate step in the process, ensuring that the primary relationships with medical provider and/or case manager are firmly established.

Theme Five: *While each organization has a different blend of who is performing linkage to care services, most see the need for dedicated linkage to care workers.*

- There is disagreement about whether linkage workers should give confirmatory diagnoses or just be in the room while someone else does.
- Opinions vary about where dedicated linkage workers should be housed.
- Characteristics of effective linkage workers are beginning to be articulated.

While most interviewees felt like linkage to care was something that everyone within the organization needs to be involved in, most believe that it is important to have dedicated linkage to care workers. Opinions about when this person should enter the picture and where they should be housed varied. Characteristics of the individuals best suited to serve in the role of dedicated linkage to care worker were articulated throughout the interviews.

The linkage to care services offered throughout Chicagoland and described in this report are provided by a varying blend of staff in different roles with different titles and funded by different programs. These roles include linkage to care coordinator, early intervention staff, peers, health navigators and outreach workers. In many organizations, these positions are filled by the same staff people serving in multiple roles. Some interviewees expressed confusion about how other organizations are using and understanding these titles, some of which have emerged with the new focus on linkage to care as a distinct set of services. However, most interviewees agreed that having dedicated linkage to care staff was important, especially those that are funded directly for these services. Dedicated linkage to care staff is reflected in the literature as best practice.¹²¹³ Reasons given varied among interviewees.

One care provider mentioned that with funding shortages, the organization doesn't have administrative support to keep track of clients to identify who needs outreach and make sure existing patients don't fall out of care. Discussions in multiple interviews revolved around the perception that for newly diagnosed individuals, the first six months to a year are unlike any other time in their lives and require intensive, flexible, and extremely responsive support to get them over the initial hurdles, settling them into routine care. When probed about why testers or case managers should not serve as primary linkage to care workers, most interviewees thought that linkage work required a completely different set of skills and characteristics. The testing relationship is designed to be a one- or two-encounter relationship, and the case management relationship is designed to be long-term. The linkage relationship is ideally a six-month to a yearlong relationship.

¹² Gilman, B., et al. Linkage to care for newly diagnosed individuals who test positive in nonprimary care settings. *AIDS Patient Care and STDs*, 26(3): 132-140.

¹³ Gardner, L. I., et. al. Psychological and behavioral correlates of entering care for HIV infection: The antiretroviral treatment access study (ARTAS). *AIDS Patient Care and STDs*, 21(6): 418-425.

Some interviewees also felt like the linkage to care relationship is much more emotionally binding than others and needs to be for success with the outcomes desired. This is a level of connection that neither the testing nor case management positions could sustain. Interviewees felt that while testing staff needed to be able to make connections quickly, the level of connection was not as deep as required for linkage to care workers. Case managers, due to the longevity of their relationship with clients and size of caseload, do not need to nor are able to make as deep a connection as linkage workers. Some interviewees said that the primary skill required for case management is more about referrals to resources while the primary skill for linkage to care is creating a deep, emotional bond.

Some interviewees felt like the person to give the confirmatory results should be the same one who would provide ongoing linkage services. The rationale was this is an opportunity to build a relationship and create a natural flow from giving a positive result to initiating linkage to care services. However, more interviewees felt that while the linkage to care worker should be in the room when the diagnosis is given, someone else should give the results. The reason given was that the person who gives the results might be stigmatized by the newly diagnosed individual as the bearer of bad news or, as one interviewee called it, “The Angel of Death”.

Where the linkage workers were housed was a point of discussion in many interviews. The overwhelming response was that this person should be co-located with a medical provider. Multiple interviewees, including one who provides primarily external linkage service, felt like having a third party to provide linkage to care services outside of the medical site was too hard to coordinate and added a middle person. However, it is important to note that most interviewees were housed within organizations that provide medical care and that some agencies are located in communities without HIV care providers.

We want to make sure there is no break in the continuum of care. The most important place for a relationship to be made is with the care provider as we will be the ones providing care for the rest of their lives.
-Administrator, hospital

The Regional Care Coordinators (RCC) through AIDS Foundation of Chicago’s (AFC) Connect to Care project were discussed by multiple interviewees. The design of the project is to have an RCC for each region of the city that splits time in direct work with clients and on systems-level work. As described by one RCC in an interview, the systems level work is to collaborate with care providers, case finding work is offered to testing agencies to find individuals and bring them in to care and the client-level work is to link clients once they have been identified. All four RCC staff were interviewed as were staff from AFC who oversee this project. All RCC staff expressed difficulty getting agencies to see the RCC role in the linkage process and feel like it was worthwhile to collaborate, though some progress was being made in that area. Three interviewees who are not directly connected to the project brought up the RCC for their region as a resource for when their patients has not shown up for six months. A hospital expressed frustration that a third party is being funded to

do linkage to care work as a middle person instead of the funding going directly to the care or testing agency, especially for newly diagnosed individuals.

When asked about the key elements to the success of their organization's linkage to care program, interviewees consistently named their current linkage workers as critical. Interviewees were prompted to identify the specific characteristics that were important for linkage workers. Below are characteristics mentioned by multiple interviewees in descending order of frequency.

- Compassion and empathy
- Well connected and knowledgeable of the field, having relationships with other agencies
- Willing to go the extra mile and do anything possible to make the linkage happen
- Non-judgmental
- Quickly build rapport and instill confidence in confidentiality
- Great people skills

Theme Six: *Peers play a significant role in the linkage process.*

- Nearly three-quarters of organizations engage peers in linkage to care work.
- Organizations face challenges in recruiting and helping peers establish boundaries.
- Some organizations have well-established peer training and supervision strategies.

As linkage to care is developing conceptually and practically, peers have been central to the discussion and models. In the survey conducted this spring, 71% of respondents report utilizing peers in their organizations' linkage to care services. The roles peers play vary widely between organizations with the primary linkage roles being outreach and health navigation. In some organizations, peers serve as advisors to the organization's HIV services most often through community advisory boards (CAB), giving the organization feedback on their linkage to care services. In other organizations, peers do outreach either recruiting individuals to come for testing or care, distributing condoms, conducting HIV tests in the field or recruiting HIV-positive individuals who are not currently in medical care. Other organizations engage peers as health navigators for clients, assigning them to new patients for up to 1.5 years during which they provide linkage to and retention in care services. Many organizations hire peers as staff to serve in non-peer-specific positions.

*From a pamphlet for same gender loving men of color developed by one community-based organization interviewed:
A peer navigator is essentially a problem solver, skilled listener and a highly resourceful individual who can help through this difficult time.*

The most common role for peers to play beyond just advisement is as outreach workers. One interviewee said that peers guide staff where to go for outreach and can access spaces like sex parties where some staff cannot. As health

navigators, peers can serve an essential role of helping with disclosure and dispelling myths. One care provider assigns a peer to each new patient to serve as new patient orientation guides. This provider engages 12-20 peers at one time as health navigators and outreach workers. Peers are also stationed at information centers to help patients navigate research. One interviewee identified himself as HIV-positive and identified the strengths he brings because of this.

As a peer who is a professional linkage to care worker, I have been in treatment and care, know the information and research and can connect these with personal stories as well.

-Linkage coordinator, community-based organization

Three interviewees mentioned difficulty in recruiting peers. One interviewee working in a suburb felt having a peer who lived in the community would cause problems dealing with boundaries within such a small setting and was looking to recruit someone outside the area. Another felt recruiting peers on the Southside was a real challenge due to the fear and stigma of being HIV positive.

Other challenges to peer engagement spanned the following issues: boundaries, personal issues of peers, retention, training and supervision. The issue of boundaries was brought up often in interviews. As peers come from the same communities as clients, they often see clients in other settings and may be dealing with their own challenges. The challenge of personal issues with peers revolves around the peer as an individual; peers may have mental health or substance use issues or continue to struggle with taking care of themselves. Retention was brought up as a challenge because of lack of resources for this difficult work. One interviewee mentioned that when the program was incentivized they had a thriving program, but once the funding ended the program dissolved. This brings up the issue of sustainability for peer programs. Finally, interviewees brought up the challenge of finding the time and building the systems to train and supervise peers.

Trainings that interviewees mentioned as effective strategies for dealing with some of these challenges included the peer trainings that cover what case management is, motivational interviewing techniques, how to read and interpret labs, and creating and maintaining boundaries. Two organizations created extensive peer training programs that they report are widely used and have been documented to be successful. Other interviewees mentioned service agreements that peers sign, committing to taking care of themselves, remaining sober and communicating their needs. Finally, multiple interviewees discussed supervision of peers as essential quality assurance and support mechanisms. The two organizations with extensive training programs also offer intensive supervision with clinical social workers to consult on difficulties faced in working with clients.

Theme Seven: *Communication with clients in the linkage process happens frequently, requires finesse and is heavily reliant on the phone.*

- Frequency of contact varies depending upon capacity of organization, stage in linkage process and need of clients.
- Deliberate communication patterns are essential for relationship- and trust-building.
- Phone remains the primary source of contact but new strategies are being tested.

Interviewees used various measurements to determine how often contact with clients should happen. For many, this is determined by capacity of the organization and the individual linkage worker. For some, the client determines this. Some clients are lower intensity and need less contact while others need more attention. Most interviewees with dedicated linkage to care funding and workers maintain at least weekly communication with clients. For another, weekly check-ins begins when the client begins medication. An interviewee working with adolescents said that average frequency is 2-3 times per week. One interviewee from a hospital said that communication happened daily while client was in the hospital until a case manager was assigned.

For many interviewees, the language used with clients in the linkage process is important to the success of the linkage relationship. Both an interviewee from an in-patient hospital setting and an interviewee who does outreach discussed the lexicon they had developed for talking through an HIV diagnosis and subsequent action steps without giving away the patient's status to anyone else who may be within ear shot.

Developing relationships with these individuals is paramount to linkage workers, often placing their organization's resources and requirement of the funders secondary to the client's needs. Recognizing how sensitive the first year after diagnosis is and how critical the role of the linkage worker is in this time, interviewees expressed the care and deliberateness they take in building these relationships. This is partly why so many interviewees believe that there needs to be a dedicated linkage worker for this period of time that can spend more time with clients over this first 3-12 months. One interviewee from a community health center said that it is essential the first time they meet an individual that they build a relationship, so that if the client is not ready for care, they will remember what a good experience it was and will come back into care when they are ready. The various words that interviewees used to describe this approach to relationship-building language included:

- Positive,
- Empowering,
- Self-determination,
- Strengths-based,
- Client-centered, and
- Personal connection.

Linkage workers rely heavily on the phone for communication between appointments. The challenge with this method of communication is that many clients change their phones frequently. Many organizations use text messages for communication, and one community-based organization helps clients get free phones so they can use this method. When asked about the use of social media for communication with clients, only three interviewees said they use Facebook. One of these interviewees said she uses the private components such as inboxes while another said that “a client can be homeless...but will still get to Facebook”. Many of the interviewees said that during intake, the client is asked what forms of communication are preferred, which helps to build confidentiality and rapport.

When clients are unresponsive or miss appointments, one interviewee said that receiving a call from the provider makes the biggest impact on the patient. If the provider is unable to call, then having the linkage worker serve as the spokesperson on the provider’s behalf is the next most effective strategy: “Dr. X sent me to see where you’ve been”. This builds a deeper relationship between provider and patient. Many interviewees said that the sequence of communication method is phone then mail then field outreach, primarily based upon strategic use of organizational resources and respect for patient confidentiality.

Theme Eight: *While research on best practices in linkage to care remains limited, there is an abundance of training resources relevant to linkage to care workers and more that could be developed.*

- There is a wealth of training resources available in Chicago.
- A linkage to care training sequence would benefit linkage workers.
- Linkage workers have ideas about the training and research that would be useful for strengthening their practices.

When asked what training and research has been useful for equipping staff to provide linkage to care services, interviewees had a difficult time answering in regards to research but had many examples of trainings their staff had accessed, primarily in-person trainings in Chicago. Most interviewees said that they require ongoing training for their staff, providing some tailored in-service training and sending them externally for training. Only three mentioned the use of online training modules, while most were focused on in-person training. One described a national linkage to care workgroup that has teleconferences and has been useful for getting models from other places. The most common sources for training in order of frequency mentioned were MATEC, AFC, and CDPH. Two organizations described having designed extensive peer training programs. One interviewee said that the AFC peer training was helpful in moving their patients to become peers. One interviewee mentioned that having all staff participate in the Workgroup was helpful to keep them up to speed on what national best practices and local efforts.

The topic brought up most often and with the deepest discussion was cultural competence, specifically around sexual orientation. One hospital setting described a yearlong training all staff go through to become culturally competent. Another talked about how important it has been to train front desk staff to treat

LGBT clients comfortably and competently. The table below lists the training topics that interviewees identified as helpful to their LTC program.

Table 3. Training Topics that Have Been Helpful

Training Topics That Have Been Helpful	
Knowledge	Skills
Medical adherence	Community outreach
Pharmaceuticals	Communicable Disease Investigation
HIV treatment from A-Z	Engaging clients who are hard to reach or hard to keep in care
Changes to Medicare and Medicaid	Conflict resolution
History of HIV to help dispel myths	Motivational interviewing
Adolescent development and current realities	Scripts when talking with clients
Models	Understanding and working with substance use and abuse
HTPN061 – NIH health navigator model	HIV testing
Harold Freeman Patient Navigator Institute	Customer service
Committed to Caring programs through TPAN	Client charting
ARTAS	Cultural competence
Denver Dept of PH LTC program	Trauma (as part of LGBT cultural competence)
Project SMILE	

Interviewees expressed many needs for trainings they currently could not access. Cultural competency was again one of the topics mentioned most often. The interviewee that described the extensive LGBT cultural competency training said that the trainers often ran out of time to cover competency related to transgender populations. This was a specific topic that many other interviewees brought up as needing. Five interviewees expressed a desire for a specific sequence of training for linkage to care, similar to what HIV testing staff have to go through. The topics they said should be covered in this sequence included:

- HIV 101,
- Treatment adherence,
- Case management approaches and best practices,
- Mental health and domestic abuse issues,
- Understanding public assistance programs,
- Dealing with barriers and problem-solving,
- Cultural competence,
- How and why to track clients,
- Differences in dealing with newly diagnosed and lot-to-care, and
- Crisis management.

One interviewee recommended that trainings include lots of role-playing of what happens in the first session; she felt that this is the most critical time for building a solid relationship which is critical to success of linkage to care.

The table below lists training and research topics that interviewees said would be helpful to have access for them, their staff and their peers in providing linkage to care services.

Table 4. Training and Research that would be Helpful

Training and Research that would be Helpful	
Training	
How to be safe in certain areas of town	
How to talk someone down from high anxiety and anger	
Tactics to get out of a dangerous situation	
Domestic violence: what it looks like and how we adjust our care accordingly	
Using a harm reduction model	
Cultural competency, especially around transgender population	
Culturally specific approaches and understanding of boundaries	
Aging care: HIV and aging	
Navigating and helping clients navigate different systems like Medicaid and disability	
Strengthening relationships with referral agencies and keeping clients engaged when they have to wait for resources from referral agencies.	
Assessing mental health and substance abuse before making referrals	
More DEBI trainings	
How to maintain peers engagement, not burn them out, and help them create boundaries	
Program evaluation of LTC models	
Webcast for agencies in designing their LTC activities to tailor to their organization	
Research	
Best practices for linkage to care for target populations	
Research to Care best practices	
More DEBIs on working with women of color on care readiness	
How DIS syphilis linkage to care model could be adapted for HIV	
LTC program evaluation strategies	
Best practices in linkage to care protocols	

Theme Nine: *Creating systems for sharing data and information would strengthen organizations' services provision, bolster inter-agency collaboration and improve coordination throughout Chicagoland.*

- There is general support for standardized consent form and client information-sharing database.
- An inventory of linkage to care services is widely desired to increase coordination.
- Opportunities are sought for linkage workers to meet with others doing the same work.

Agencies with linkage to care services are seeking opportunities and systems to connect with each other and share information more freely. One system involves the development of a standardized consent form and a client information-sharing database, both of which emerged in the Workgroup planning process and posed to interviewees for reaction. Another system involves a comprehensive, up-to-date inventory of linkage to care services requested by many interviewees. Finally, many interviewees requested opportunities for connecting with other linkage workers to share ideas, trouble shoot problems and better understand each other's services.

Consent form and client database

Through the planning process of the Workgroup in 2012, two ideas were explored to help with information flow throughout the system. One was for a standard multi-purpose consent form that could be used by testing and other service providers throughout Chicagoland to share client data in a way that would support linkage to care. The other idea involved development of a universal database that would facilitate client information-sharing. Reaction was generally favorable to both ideas, though specific concerns about confidentiality and feasibility were raised.

Nearly half of the interviewees raised the concerns about confidentiality in regards to the consent form. Many felt that clients may be concerned about their information being shared and this may deter them from receiving services. One interviewee mentioned that women might be afraid of having their children taken away if their information were shared. Two interviewees specifically said that they would not use this consent form as they felt it would put up yet another barrier to convincing someone to get tested for fear of their information being shared.

A few interviewees recommended that this consent form be administered at the point of entry into medical care or engagement of linkage to care. This decreases the concern about adding a barrier to testing, limits the number of consent forms administered and places the burden of collecting the consent on staff with more time and likelihood of completion. An interviewee from a community health center that conducts a large number of tests per day mentioned that the time it would take testing staff to administer yet another form would be too burdensome when accumulated throughout the day.

An extra five minutes adds up when you have as many testing staff and tests conducted each day as we do.

-Linkage coordinator, community health center

A few interviewees said that to make this work, staff would need to explain the consent very clearly to each individual and the benefits to the client. Other ideas shared by interviewees that may not be supportive of each other are listed below.

- Make it brief.
- Create the form to not just be a consent form but also an assessment tool of client barriers to accessing care.
- Have staff who will be using this form involved in the creation of the form.
- Align the fields with the client information-sharing database.

An overwhelming majority of interviewees responded that they would like to see some form of universal database that would facilitate client information-sharing. Multiple interviewees expressed frustration in having to rely on relationships with other organizations to facilitate information-sharing about clients. One reason for supporting this database mentioned by multiple interviewees was being able to avoid wasting resources on clients who have already been tested or are in care elsewhere. Another reason is to know if a client made it to their provider's office to track that linkage.

Three interviewees said that they would not participate in a system like this. One said that they have their own system for client information and would not be willing to change in order to input into a central database. Another said their organization already reports information to AFC and CDPH and would not be willing to add more reporting requirements until they can have access to that information. Finally, one interviewee expressed concern about a centralized database when all governments do not have standardized policies and HIV criminalization; he felt that putting all this information in one place might endanger HIV-positive individuals.

Interviewees were asked what the minimum information they thought should be included in a database. This is a list of the information most frequently mentioned:

- CD4 count, viral load, and dates of test,
- Locating contact information,
- Diagnosis date, and
- Date of last appointment made and kept.

The following is a list of other items that were mentioned:

- Medications prescribed,
- Prescriptions filled,
- Demographics,
- Case manager name,
- 1st, 2nd, and 3rd appointment tracking,
- Treatment adherence,
- Actions taken for partner notification,
- Where person is in treatment now or if ever, and
- Other medical conditions.

Interviewees were asked what it would take to get their organization to participate in this type of database. Some said that if the database communicated with existing data systems, it might not be so difficult. Others said they would need funding for systems upgrades, software and access to IT specialists to set-up and manage a database like these. Multiple interviewees said that they would likely not input the information directly but could run reports on a monthly or quarterly basis for the city or some other entity to enter.

Multiple interviewees mentioned that this system would not be that difficult if only CDPH and AFC shared their information back so organizations could access the information already reported. Another interviewee mentioned a project they are beginning next year that would help software from different federal funders communicate with each other. He felt that this may be a useful tool for developing a Chicagoland database. Another interviewee felt that instead of trying to build a new database, efforts should go into unifying the city, county, state, and federal systems.

Inventory of linkage to care services

Many interviewees wanted detailed information on existing linkage to care. The concern is that people may be overlapping their services. One interviewee felt like organizations with self-contained linkage to care programs that don't connect with other agencies make coordination difficult when clients move from provider to provider. Another interviewee who serves as an RCC was concerned that the field was over-saturated with linkage to care programs, making it difficult for external linkage workers to know where the gaps exist that they could fill.

Multiple interviewees would like to see a clear inventory of what organizations are funded to provide what linkage services, who they target and where the services are offered. One interviewee recommended a consistently updated geo-map of who is testing, who is providing care, between which organizations referrals are being regularly made, and what linkage to care services are being offered. He felt that tracking clients through a database should be secondary to tracking the services offered to them.

One interviewee would like to see a centralized system that would allow her to make a referral to a linkage worker in a different region that is housed within a care provider, not independent the way Connect to Care is currently arranged. Another interviewee would like to know the linkage protocols or flow charts for each organization and which staff are involved. This would help clarify how and where referrals could be made and provide an inventory of linkage to care programs from which to choose.

Interviewees also expressed other needs in regards to collaboration and coordination of linkage services. One interviewee said that they need collaborations to be based upon the client as center of focus and not the organization or funding sources. He felt like this could represent a shift in planning, funding, and networking throughout Chicagoland. One interviewee from a hospital setting expressed the need for better coordination between routine opt-out testing and outreach and linkage efforts. A need was expressed for better coordination between the work of disease investigation specialists (DIS) and linkage workers, so that a DIS doesn't scare off a client when the linkage worker with a "softer touch" may be more likely

to have success bringing the client into care. Another need expressed by multiple interviewees was better connection, coordination and training with the non-HIV world, since clients have needs beyond the HIV system such as other chronic health issues and support service needs.

I just signed an MOU with a shelter, but it took me four meetings to make that happen. This is an important linkage for me, because many of our clients are in shelters due to homelessness or drug use. They just had a difficult time understanding what I was trying to do.

-Linkage worker, hospital setting

Connections between linkage workers

There was general agreement among interviewees that they would like to have opportunities to connect with peers from other organizations to share ideas and tools, troubleshoot common problems and better understand each others' services and approaches. This supports relationship-building, something that has been identified as key to successful linkages and referrals, and community-building for people who are doing hard work and facing frustration on a daily basis.

Linkage workers and institutions can feel isolated. We as providers need a sense of community much the same as we are creating community for those with HIV.

-Linkage coordinator at hospital

Many interviewees asked that face-to-face meetings be established for frontline linkage workers to get together to share best practices, find innovative ideas, share lessons learned and make recommendations. However, with all the meetings people attend and the multiple roles that many linkage workers play, some felt like linkage to care topics could be integrated into other meetings or have annual, bi-annual or quarterly intensive gatherings. Five interviewees recommended that twice per year, a linkage to care fair could be organized for people to find out what is available throughout Chicagoland, coordinate their services better and engage in some learning and skill shares. One administrator recommended that these sessions could be established from 9am-2pm where administrators, clinicians, researchers and linkage workers could begin the day learning about and discussing topics universal to linkage to care then split off and discuss issues unique to their own work. Some of the universal topics included understanding the Affordable Care Act and associated changes in HIV services and funding. Multiple interviewees also recommended that linkage workers should be involved in decision-making and could serve an advisory role to CDPH.

This should be for agencies to share what they are doing, what they need and for the more experienced ones to give guidance. Don't leave us alone. Continue to give us updates to grow, maintain and improve our services.

-Program director, community health center

Interviewees also expressed a desire for an online space – bulletin or toolkit – where linkage workers and administrators could share tools, lessons learned and engage in collaborative problem-solving in an ongoing way. One suggested a blog or social network. Another suggested that people could post on HIV Care Connect when starting a new program to help increase knowledge of where to refer clients. One interviewee recommended a national case manager portal run by a pharmaceutical company that could serve as a good model, and another interviewee said that the Routine Testing Group had a nice model to explore.

When asked what they would like to learn from their peers in the field, the following topics were presented.

Table 5. Topics to Hear from Colleagues in the Field

Topics to Hear from Colleagues in the Field
How other use incentives and the impact of different amounts and offerings
How others have implemented peer programs
Difference between early intervention services, linkage to care, and medical case management
What people would like to change about their LTC if they could remove funding barriers
Comparison of how agencies are measuring outcomes
One source for gathering new information and publications on linkage to care
What disciplines are doing linkage work – peer, social worker, etc.
Outreach strategies: creative approaches, reaching harder to reach, bridging from testing to linkage to retention
Bridge project that is going in to public assistance offices and finding lots of positives
Client experiences of linkage to care
Plans for sustaining linkage models beyond funding
How people are working with sex workers

Theme Ten: *Funding strategies as well as services and resource coordination throughout Chicagoland present many opportunities and barriers for strengthening linkage to care.*

- Funding silos, reimbursement formulas and eligibility requirements limit services and overwhelm staff.
- Coordinating resources throughout Chicagoland could increase the tools available to linkage workers and limit the overlap of service provision.
- Organizations want the opportunity to continue to advise CDPH on implementation and coordination of linkage to care and related strategies.

Funding challenges

The most pervasive theme regarding challenges to funding and coordination for linkage to care was in the siloing of funding was counter to effective linkage between testing and care. Having siloed funding makes reporting organizational successes difficult because staff have to disconnect groups of clients served while the services provided are part of one seamless whole. Funding silos also create a challenge for staff who have to select which program a client is eligible for, not being reimbursed for those who are ineligible for any programs, filling out completely different paperwork and entering into different databases and needing to manage too many reporting processes.

Multiple interviewees expressed frustration that much of what they do in linkage to care is not fully reimbursed. The design of most linkage to care programs within organizations interviewed is based on a client-centered, “by any means necessary” model, but organizations have to fit these clients into eligibility requirements or cover the costs of services provided with general operating funds. One interviewee mentioned that the way their services were reimbursed and the varied reporting requirements created many problems with sustainability. Another interviewee complained that while health literacy is part of linkage worker’s job and a critical component of linkage, the organization is not funded to do this. Another interviewee described the work necessary when an adolescent is not ready for care and the unreimbursed time this linkage worker must take to maintain the relationship for future success in that linkage relationship.

Linkage to care is still happening when the youth is not ready for treatment. I keep checking in with them to see how school and life are going for them. We need to take this one step at a time. We don’t talk about meds until they are ready. Adolescents want to know someone cares and is there for them as an individual before a successful linkage to care can be made.

-Linkage coordinator, hospital

Finally, an interviewee from a hospital setting with routine, opt-out testing felt like the request for proposals for prevention dollars causes them a problem. They serve whomever comes into the hospital but have to list a priority population.

Resource coordination

Access to resources for clients is a critical component for successful linkage to care. Every organization interviewed described the transportation support they offer clients as critical to their linkage services. However, the coordination of these resources can sometimes be a challenge and prevent access for clients and linkage workers. One recommendation was for a centralized depository of bus cards, food vouchers, and clothing vouchers so these resources were not dependent upon individual organizations.

Interviewees discussed challenges they face with the case management system. Having to leave a message for a case manager and await a return phone call can be a challenge for clients with no phone. One agency's clients can only work with case managers located at one specific agency due to geographic limitations of being in a suburb with no other organization that houses case managers; however, staff from this agency still have to call the central number for that referral. Three interviewees felt like not being able to access tangible resources like food pantries and bus passes without case managers creates a barrier for clients in greatest need, and the ability to get to an appointment to establish the case management relationship often cannot happen without having these resources first. One interviewee mentioned that many case managers are distrustful of patient navigators and need a better understanding of linkage to care throughout the field.

Three interviewees mentioned the case management coordinated system might serve as a model for coordinating linkage to care activities. Elements that this model includes, which they thought could be applicable included: standardized data collection, uniform support for agencies, standardized training and agreed upon principles and leadership from agencies themselves. However, other interviewees mentioned that with the challenges of the case manager system, especially the time it takes for assigning a case manager, it may not serve as the ideal model.

Coordinated planning

Many interviewees discussed the benefits of meeting as a coalition or planning body, including gaining a global view of problems each organization is facing, identifying which of these are systems problems and which are more micro-level problems and allowing opportunity for problem-solving at each of these levels. Interviewees discussed the Workgroup as it has been the primary gathering for linkage to care to date. The challenges interviewees felt this group faced was that it was too big, broad, and thus lacked focus. As it was the only linkage to care gathering in Chicagoland, people were confused if it was designed to provide information- and skill-sharing between linkage workers, develop systemic strategy for Chicagoland, coordinate linkage services throughout the system or advise CDPH on recommendations.

Some interviewees felt the group continued to rehash the same things and that bigger agencies took up more space than smaller ones. Finally, two interviewees mentioned frustration that the decision-makers from community and government agencies were not present at these meetings. Interviewees expressed a need for strong leadership and facilitation of linkage to care as a strategy in Chicagoland. One interviewee mentioned that the Workgroup needs "decisions not

process”. Multiple interviewees felt like if the group was to serve in an advisory capacity to CDPH, then the department needed to have a stronger presence and demonstrate willingness to implement recommendations more readily.

One interviewee said that having a set of unified goals like the National HIV/AIDS strategy would go far to better coordinate resources, rally people behind common goals and create measures for accountability beyond distinct funders. Two interviewees agreed that CDPH and IDPH need to clarify when testing staff should pass on clients to linkage staff. One interviewee felt like trying to develop a definition before federal funding sources did was a misuse of the working group time. Two interviewees from a community-based setting said that in order to develop a consistent definition for linkage to care in Chicagoland, good facilitation of meetings and strategy needed to occur with the criteria listed below.

- People who are doing linkage to care should be in the same room with people who oversee policy development.
- Definition needs to be flexible.
- Definition should be determined between client and linkage coordinator.
- Definition should include developing a relationship with provider.
- Linkage needs to be quality.

Discussion

Chicagoland linkages to HIV care providers are as lively and diverse as the individuals and organizations providing and benefitting from these services. When speaking with these individuals or writing about the work they are doing, it is important to understand that while “linkage to care” has become more common in the lexicon of the HIV world, it is not a consistently defined term. As we are in the first years of focusing attention on this vital component of the continuum of care, the term is more flexible. As we continue in our inquiry, evaluation and comparison of how the concept is being understood and influencing practice, it may become more uniform. However, if these interviews are any indication of where we are going, it is clear that linkage to care will always be a very client-centered practice and, thus, flexibility in approach will always be important.

One of the most promising findings from these interviews is that organizations have established seamless internal systems of care. Even in large institutions with complex infrastructures, the various departments and staff that HIV-positive individual encounter are working more as a cohesive whole to maintain continuous, quality care than ever before. Providers are looking for tools to continue this progress and understand how to interact with other organizations. The next step that needs attention is how interagency collaborations and region-wide systems can be established to create that same web of care based upon the needs and realities of individuals throughout Chicagoland. One major challenge to overcome is the lack of understanding how other organizations’ are doing linkage to care and who is providing what services to which populations. Creating this cross-organizational understanding throughout the region will go far to creating a client-centered web.

A critical first step toward coordination will come from clarification of language and scope of practice. Shared understanding of what is covered under the umbrella of “linkage to care” will be critical. Does this truly include individuals who are lost to care, or is it just newly diagnosed individuals? Interviewees focused heavily on newly diagnosed individuals. When probed, most said that the process was the same for those individuals identified as “lost-to-care” but quickly returned to discussing those who are newly diagnosed. Multiple interviewees said that it took a very different set of skills for each. Some felt like newly diagnosed individuals required much more emotionally bonded engagement while lost-to-care individuals needed more intensive outreach and better provider pairing. Also important in this equation is where retention strategies factor into linkage services. Some linkage workers interviewed were heavily involved in ongoing retention practices to keep individuals from falling out of care. These efforts represent significant activities to sustain linkages but are rarely discussed within the literature or funding proposals. Finally, who provides what linkage services and how previous models fit into this “new” focus on linkage to care seems to be a critical puzzle to solve. How do these new linkage coordinators fit in with outreach workers, health and peer navigators, disease intervention specialists and early intervention service workers?

It may be useful to step back from funding streams and take a look at the continuum of care; match it up against current resources, activities and models; and explore how individuals throughout Chicagoland move through this continuum. In doing so, some systems of coordination and common language may emerge that can be adopted throughout the region and create a seamless system of linkage to continuous and coordinated quality care.

Recommendations

Experts who were interviewed in this process had many great ideas for ways to strengthen linkage to care within their organization and throughout the region. What follows is a series of recommendations that emerged from these interviews, whether directly from the interviews or through analysis of the findings collected.

Table 6. Recommendations from Key Informant Interviews

Recommendations from Key Informant Interview	
Funding and Policy	
Advocate for more flexible linkage to care funding, lessening administrative burden and supporting providers to stay connected with clients until they are ready for care and remain with clients until they are fully established in care.	
Advocate for more consistency and streamlined reporting methods between national, state and local funders.	
Advocate for policy and practice changes that help minimize the barrier of getting an individual to return for confirmatory test results.	
Resources and Coordination	
Support the creation of a common definition for successful linkage to care that focuses more on key milestones and client outcomes than on timeframes.	
Support creation of a standardized linkage protocol and common client flow chart that expands on the Chicago Spectrum of Care, allows for flexibility in implementation, and creates consistency of language throughout the region.	
Create a continuously updated directory of linkage to care services.	
Create systems that increase the ease of sharing client information that can support linkage to care by building upon existing reporting mechanisms.	
Training and Research	
Collect and make available various models, tools and training that could strengthen intra- and inter-agency collaborations.	
Support research that gathers the perspectives and experiences of clients, peers, and non-linkage providers to identify ways that linkage to care services can be further strengthened.	
Invest in training and support for linkage workers to avoid burnout and understand boundary issues.	
Increase access to peer training and supervision support.	
Create a linkage to care training curriculum that includes language considerations, communication tools, motivational interviewing and other topics identified by interviewees.	
Create an online portal that allows linkage workers and administrators to share and access forms, protocols, training modules and other helpful tools as well as seek feedback and support from peers.	
Offer a consistent meeting opportunity for linkage workers to connect with each other and gain insights and skills that can help them in their work. This report contains a long list of topics that interviewees requested.	

Organize bi-annual gatherings for frontline staff, administrators and researchers throughout Chicagoland to gather and get updated information, gain skills and collect information on each other's programs.

Closing

What this report may not sufficiently convey is how much passion, hope, commitment and creativity thrives among the experts who were interviewed for this report. Nearly all of the individuals contacted for interviews were thrilled to speak about their perspectives and experiences in providing linkage to care services. Those from organizations directly funded to provide linkage to care services had invested significant capital in discovering what it would take to truly create meaningful and sustainable linkages to care. Those from organizations not funded for linkage to care articulated how integral these services have always been to the service they provide HIV-positive individuals. Most expressed optimism that a seamless continuum of care was possible to create and, in doing so, significant strides could be made in combating this epidemic. This is a critical time to tap the energy and innovation of individuals on the frontline of uncovering best practices and combine it with the wisdom and insight of those who have been linking individuals to care for decades. In doing so, we may be able to create shared languages and practices that establish and sustain a seamless system of linkage to care that has positive outcomes for individuals, communities and society as a whole.

Interview Methodology for Chicagoland LTC Practices Study

This document lays out the methodology that will be used to conduct key informant interviews for the Chicagoland Linkage to Care Practices Study conducted by Public Health Institute of Metropolitan Chicago (PHIMC) on behalf of Chicago Department of Public Health (CDPH) and the Chicagoland HIV Linkage to Care Workgroup (LTC Workgroup), building upon a survey previously conducted by this workgroup and interviews conducted by Midwest AIDS Training + Education Center (MATEC). The script and questions for the interviews can be found in "LTC Practices Study Interview Questions".

Purpose of the Study

To gain a deeper understanding of how organizations and practitioners are linking newly diagnosed or out-of care HIV-positive individuals into medical care toward the aim of creating seamless linkage to care and retention in care processes throughout Chicago.

Overall Methodology of Study

1. Review of previous surveys and reports from MATEC and Linkage to Care Workgroup.
2. Key informant interviews with providers and administrators from organizations that focus on linkage to care.
3. Collection and analysis of agencies' linkage to care protocols.
4. Report presenting the effective strategies, barriers faced, lessons learned and policy issues identified from key informant interviews set within the context of previous surveys.

Key Informant Interview Methodology

1. Send an email to each of the 52 professionals on the original list of potential respondents for the LTC Workgroup survey conducted in spring 2012 with the email below. These professionals are situated at 25 distinct provider organizations. Follow-up emails and phone calls will begin one week after initial email is sent to encourage response.
2. As people respond, up to 25 interviews will be set with only one interview per organization. Each organization will be asked to identify the most appropriate person(s) for the interview - up to 2 people per interview. In at least five organizations, one administrative supervisor and one direct service provider will be interviewed to assess difference between their perspectives and knowledge. If insufficient response comes from email to get to desired diversity, follow-up calls will be made.
3. Interviews will be conducted lasting 60-90 minutes each. As these are exploratory interviews, the questions asked may vary between interviewees. The interviewer will follow leads to deeply unpackage the understanding sought. Each interviewee will be asked if the interview can be recorded and archived. At the beginning, interviewees will be asked if their organization can be identified with their responses. Each response may need different levels of anonymity, and this will be captured and respected. The script and questions can be found in "LTC Practices Study Interview Questions".

4. Prior to each interview, the information gathered from the previous LTC Workgroup survey on the organization's LTC practices shall be gathered for confirmation in the interview, saving time by not duplicating previous information gathering efforts. Some survey responses may lend themselves to clarification or further exploration. Those organizations that did not complete the survey will be asked to do so prior to the interview.
5. Each organization will be asked to share any existing policies or protocols relating to linkage to care and retention in care. These documents will be collated and analyzed.
6. After each interview, a synopsis will be created by the interviewer, allowing for future revisiting of each interview and quality assurance by PHIMC. In this process, some of the interview questions may be adjusted or new ones added for future interviews as new insights are sought based upon findings.
7. Email or phone call follow-up may be done with each interviewee to clarify something that was unclear.

Email requesting an interview

Dear XXX,

As you may recall, a survey was conducted this spring exploring linkage to care practices throughout Chicagoland. The responses to this survey commissioned by the Chicago Department of Public Health's Chicagoland Linkage to Care Workgroup proved to be very useful in beginning to paint a picture of linkage to care practices throughout Chicagoland. We are taking another step to deepen our understanding of that picture and would greatly value your partnership in accomplishing this.

In September, I will be conducting a series of interviews with administrative supervisors and direct service providers to get a deeper understanding of what linkage to care services are currently available, understand the gaps in practice and knowledge, get feedback on barriers, and gather recommendations on policy and programmatic activities that can support linkage to care work. If you would be willing to give me 60-90 minutes of your time for an interview, it would go a long way toward supporting us to create this picture. I am hoping to interview 25 organizations and seeking a diversity of perspectives, positions, and populations served. I plan to conduct one interview per organization and will work with you and your colleagues if there is more than one person who should participate in the interview.

If you are amenable, please email me back by **September 6** with confirmation of your willingness to participate. Please also answer the questions below to help expedite our process.

1. Please provide your name, position, and organization.
2. Would you describe yourself as: 1) administrative supervisor; 2) direct service provider; 3) other (please explain)?
3. What is your availability for a 60-90 minute interview September 8-14 or 19-24, including weekends if you work during those days?

Thanks,
Jonathan Stacks
Research Consultant through Public Health Institute of Metropolitan Chicago (PHIMC)

Email to set interview

Dear XX,

Thank you for responding to my request for an interview. I would like to conduct the interview on XXXX at XXXX. Please confirm the best location for this interview that can provide us the quiet, focus, and privacy we need. If we need to meet outside your workplace, I can provide an appropriate venue for us.

As part of this process, I am collecting protocols from organizations with existing linkage to care protocols to compare and analyze. If you are able and willing to share yours with me, please email it to me at jonathanstacks@gmail.com or bring it with you to the interview.

For the 3 organizations that did not complete the survey this spring:
Since I am using the responses submitted this spring to the LTC Workgroup survey as a foundation for these interviews, it would be most helpful if you would take some time to answer these questions prior to our interview. I am attaching it in a Word document for you to input your responses. ***If you could send this back to me by XXXXX, that would be of great help.***

Thank you again,
Jonathan Stacks
Research Consultant through Public Health Institute of Metropolitan Chicago (PHIMC)

Information from survey that will be available (if agency responded to all applicable questions)

1. Agency name and administrative office address
2. Site address(es) where linkage to care services are provided or based out of, if different from administrative office
3. Funder(s) of Linkage to Care services:
 - a. If funded for Linkage to care services:
 - i. Name of funding organization
 - ii. Scope of work for Linkage to Care services by funder (i.e., number of people to be served)
 - iii. Funding period
 - iv. Programmatic outcomes and expectations
 - v. Any other program expectations from the funder
 - vi. Target population for Linkage to Care services
 - vii. Geographic area(s) served by Linkage to Care services

- viii. Definition of linkage-to-care, including any time frames that linkages should be made within
- 4. Type of agency
- 5. Does your organization offer HIV testing onsite?
- 6. Does your organization offer HIV medical care onsite?
- 7. Does your agency offer medical HIV case management on site?
- 8. Does your agency offer non-medical HIV case management on site?
- 9. Does your agency have formal, written service agreement(s) with HIV providers? If yes, with what type?
- 10. How does your agency define a successful linkage, if different from your funder(s)' definition?
- 11. Does your agency have a written Linkage to Care protocol?
 - a. If yes, would you be willing to send a copy with these responses or bring to the interview?
 - i. Does the protocol specify a timeframe for linking a client to HIV medical care? If yes, what is the timeframe?
 - ii. Does the protocol specify a length of time for staying engaged with a client? If yes, what is the length of time?
 - i. Does the protocol define minimum standards for Linkage to Care? If yes, please provide the definition.
- 12. Does your agency's Linkage to Care program have written goals? If yes, please list the goals here.
- 13. What type of Linkage to Care client does your agency serve?
- 14. Does your Linkage to Care program utilize peers? If yes, in what capacity?
- 15. What methods does your Linkage to Care program utilize to engage and retain clients?
- 16. How does your Linkage to Care program verify that care services were accessed?
- 17. How does your Linkage to Care program document its work?
 - a. If an electronic data system exists, please name the system(s).
 - b. Is this system integrated with or able to communicate with other service systems in your organization? If yes, please list the service systems.
- 18. How does your agency define retention in care? What does your agency consider to be best practices in linkage to care?
- 19. What barriers and challenges have you experienced while providing linkage to care services?

Interview Questions for Chicagoland LTC Practices Study

This document lays out the script and questions that will be used to conduct key informant interviews for the Chicagoland Linkage to Care Practices Study conducted by Public Health Institute of Metropolitan Chicago (PHIMC) on behalf of Chicago Department of Public Health (CDPH) and the Chicagoland HIV Linkage to Care Workgroup (LTC Workgroup), building upon the survey previously conducted by this workgroup and interviews conducted by Midwest AIDS Training + Education Center (MATEC). For explanation of the methodology for the interviews, see "LTC Practices Study Interview Methodology".

Opening script for interview

Thanks for taking the time to meet with me. This interview and resulting report will do much to strengthen linkage to care activities throughout Chicagoland. As I mentioned in my email, we hope from this study to get a deeper understanding of what linkage to care services are currently available, understand the gaps in practice and knowledge, get feedback on barriers, and gather recommendations on policy and programmatic activities that can support linkage to care work. This builds upon a survey conducted this spring for the Chicagoland Linkage to Care Workgroup and interviews conducted by MATEC in 2010-2011.

You are one of 25 organizations that provide linkage to care services identified by the Chicagoland Linkage to Care Workgroup. The audience for this report includes CDPH, community planning groups, linkage to care providers, and other HIV providers. As this is a fairly intimate group, anonymity can be somewhat challenging. Here is what I propose. I am going to record this interview if you are open to that. However, the only people who will have access to the recording and any transcript of our interview that has your name or organization associated will be myself, the lead consultant for the project, and the project director at PHIMC. When I report on something you say in this interview or quote you, I will provide the context (e.g., a primary care organization that serves many African-Americans on the west side of Chicago) which may lead people to identify the source. If you say anything that you would not like to have linked back to you, please let me know and I will either not provide the context when reporting or will report it as part of a composite.

I have a set of questions that will guide our interview today. However, as this is designed to be a deeper exploration of linkage to care, I may pursue avenues of questioning based upon your responses to these questions that we did not preplan. You know these services better than I do so please feel free to let me know of anything I don't address but you feel is important. We hope the result of this study will be beneficial to you, your colleagues and your clients. Thus, your feedback and participation in guiding this process is greatly appreciated.

Unless you have any questions or concerns, let's get started. [Recorder is turned on at this point.]

Interview questions

1. *For those organizations that completed the survey:* I have your responses from the survey conducted by the LTC Workgroup this spring. I may refer to them throughout the interview. Have there been any significant changes related to your linkage to care activities since that time?
 - a. If yes, then:
 - i. What has changed and why?
 - ii. How do you view this (these) change(s)?
2. How do you define a successful linkage to care? *Refer to survey response.*
 - a. Is this different from your organization's definition?
 - b. From your funder(s) definition(s)?
 - c. Have you experienced dealing with different definition of linkage to care. If so, what problems have you experienced from the differing definitions of linkage to care currently existent in the field?
3. In what ways are your linkage to care activities standardized across your organization or tailored to individual clients or population groups?
 - a. If you work with different high-risk populations, what are the differences in how you approach linkage to care between these populations?
 - b. How do clients' opinions, stories and experiences shape the design of your linkage to care and retention in care efforts?
 - c. If you work with clients who are recently released from incarceration, what strategies have proven most effective in linking them to care?
4. *Choose question depending upon survey response.*
 - a. You mentioned in your survey response that your organization does not have specific linkage to care protocols.
 - i. Is there movement to create these?
 - ii. Why do you think they have not yet been created?
 - iii. What elements would you include in these protocols?
 - b. You mentioned in your survey response that your organization has specific linkage to care protocols.
 - i. How long have they been around?
 - ii. What sources were drawn upon to create these?
 - iii. What do you find to be the most vital elements of these?
 - iv. How sufficient do you believe them to be?
 - v. What staff do you think have the greatest grasp of these?
 - vi. How are they used for training or evaluation of staff?
 - vii. How closely linked are they to the actual practice with clients?
 - viii. May I have a copy to analyze in comparison with other organizations'? *If not sent ahead of time.*
5. What do you believe is currently working well within your organization's linkage to care activities?
 - a. Why do you think this is working so well? What do you believe are the most critical elements contributing to these successes?

- b. What communication strategies (e.g., social media, phone, text, mail, visit) have shown promise or been proven effective with linking your clients to care?
 - i. Were these externally or internally created and managed?
 - ii. What social media or other communication tools that you currently do not have access to would you think to be most useful in strengthening your organization's linkage to care activities? Why and what are the barriers to using them?
 - c. What strategies have you found to be effective in overcoming the structural barriers (e.g., transportation, stable housing) for your clients being linked to care? What do you think should be tried and tested?
 - d. What strategies have you found to be effective in overcoming the emotional barriers (e.g., denial, readiness for care) for your clients being linked to care? What do you think should be tried and tested?
 - i. How do you assess if a client is ready for care, and what do you do if they are not?
 - e. Do you have measurements that show the success of these activities? If so, what are they?
 - f. What do you think your colleagues or funders in the field could learn from your linkage to care efforts?
6. What have you heard about other organizations' linkage to care activities that you find compelling and would like to explore further?
- a. How did you hear about these activities?
 - b. What systems of communication have you found most useful or could be most useful for sharing lessons learned between organizations involved in linkage to care?
7. There has been much discussion about the need for and strategies to create data systems that improve linkage to care throughout Chicagoland, specifically around client information-sharing. I would like to go more in-depth with you on this topic.
- a. How can health departments support your linkage to care data needs? How can others?
 - b. What do you think about an idea to create a standard multi-purpose consent form that can be used by testing staff and providers throughout Chicagoland to share client data that supports linkage to care. What is your reaction to this idea and how would you shape it to be most effective in your work?
 - c. As you think about your organization's role in creating an information-sharing system for Chicagoland:
 - i. What would it take for your organization to build its capacity to participate?
 - ii. What is your agency currently willing and able to do?
 - iii. What is the bare minimum information that should be included?

- iv. What is the next level of priority for information/data that should be included?
 - d. Is there anything else you would like to say about this topic? Any additional issues or new ideas that should be considered?
- 8. *For those who reported they did:* You mentioned in your survey the various ways your organization tracks its linkage to care activities, clients' access of care services, and retention in care.
 - a. How sufficient are these methods?
 - b. What tools and strategies do you feel are missing?
- 9. What training and research have you and your organization used in developing your linkage to care activities?
 - a. What training has your LTC staff had?
 - b. What training and research have you found to be most helpful in creating a seamless linkage to care process?
 - c. How available are trainings or publications on these topics?
 - d. What additional training or research do you wish your staff could access?
 - e. What do you wish you could ask your colleagues involved in linkage to care?
 - f. What do you wish you could share with your colleagues doing this work?
- 10. In what ways do your organization's prevention staff connect with care and treatment staff? If you house only one set of these workers, how do they communicate with others involved in linkage to care?
 - a. With whom does your organization currently have MOUs for linkage to care? Which of these are proving to be most useful and why?
 - b. In what ways do your prevention staff connect with and get trained on care and treatment services and vice versa?
- 11. *For those that do:* You mentioned in your survey that your organization utilizes peers. I would like to discuss this more in depth with you.
 - a. What are the greatest successes you have had with your peer program?
 - b. What are the greatest challenges you face in working with peers?
 - c. What have you found to be effective strategies for overcoming these challenges?
- 12. Beyond client information-sharing, what do you currently find in Chicagoland's HIV systems to be useful and effective in supporting your organization's linkage to care activities?
 - a. What do you find in the Chicagoland HIV systems that are creating barriers to your organization's linkage to care activities?
 - b. What changes in funding, other than additional funding, would better assist your organization in linkage to care efforts?
- 13. Is there anything else you would like to share about your organization's linkage to care activities or anything you would like to learn more about from your colleagues or the field as a whole?

Closing script for interview

Thank you for your time. If you think of anything else you would like to add, please feel free to call or email. If there is anything you shared during this interview that in retrospect you want to make sure cannot be linked back to you, please let me know as well. I may contact you one more time for clarification on one or two items. I will do my best to keep this contact to a 20-30 minute phone conversation or one email. Thank you again.