

PENNSYLVANIA HIV PLANNING GROUP NEEDS ASSESSMENT REPORT 2014

Introduction: This report describes a study undertaken by the Needs Assessment Committee of the Pennsylvania HIV Community Planning Group (HPG). The HIV Prevention and Care Project (HPCP) of the Graduate School of Public Health at the University of Pittsburgh collaborates with the HPG, providing research support and expertise throughout the needs assessment process. Research activities include scientific literature reviews on pertinent HIV topics, focus groups and in-depth interviews with populations of interest in Pennsylvania, as well as small-scale surveys used for descriptive statistical purposes.

Report: Linkage to Care Literature Review 2014

Brief Description: A review of the literature was implemented to identify barriers and facilitators with respect to linking HIV+ individuals to care. Search criteria included: 1) no restriction by year of publication, 2) U.S. studies, 3) peer-reviewed publications, and 4) articles focusing on linkage to care. Falk Library within the University of Pittsburgh was consulted with respect to developing the methods for this literature review. PsychInfo, Medline and Google Scholar were utilized. Search strategy began with the union of (HIV or AIDS) and (Treatment, Linkage, Linkage to Care [LTC]) producing 80,025 articles. The second search included the union of (HIV or AIDS) and (Linkage to Care) which produced 208 articles. Discounting non-relevant articles (e.g., non-U.S.; not focused on LTC) produced 58 articles + 10 articles via a Google Scholar search, + 17 articles retrieved as a result of reviewing reference listings within articles, produced 85 final articles for closer review.

Relevant Findings:

Definitions of linkage to care varied. Generally, clinical visit after testing positive (confirmatory results, comprehensive assessment, visit with primary care doctor most common definition). Time periods when visits had to occur varied however, most often within a 3 month period (Christopoulos, Das, & Colfax, 2011).

There may be recent improvement in linking HIV+ individuals to care. A meta-analysis using 1995 – 2005 data suggested that 31% do enter medical care within 4 months post-diagnosis (Marks, Gardner, Craw, & Crepaz, 2010). Similarly, a 2009 CDC report indicated that 28% delayed entry to care beyond 3 months. However, a CDC reported in 2014 found that 20% delayed entry into care beyond 3 months (Gray, Cohen, Hu, et al., 2014).

With respect to demographics, 1) **adolescents** take longer and are less likely to LTC care than adults; adults < age 40 less likely compared to those 40+ (Bamford et al., 2010; Castle et al., 2011; Craw, et al., 2006; Fleishman et al., 2012; Hall et al., 2012; Philbin, et al., 2013; Pollini et al., 2011), 2) findings regarding **gender** are mixed (Fleishman et al., 2012; Minniear et al., 2013; Mugavero et al., 2007; Philbin et al., 2013; Rothman et al., 2012; Stein et al., 2000; Torian et al., 2008; Tripathi et al., 2011; Zetola et al., 2009), 3) **non-whites, especially Hispanic/Latino, experienced greatest delay and non-linkage** (Bamford et al., 2010; Craw et al., 2010 (Hispanics more likely to LTC); Horvath et al., 2013; Mugavero et al., 2007; Philbin, Tanner, DuVal, Ellen, Xu et al., 2013; Tripathi et al., 2011; Turner et al., 2000), 4)

findings with respect to **risk category** are mixed (Bamford et al., 2010; Fleishman et al., 2012; Philbin et al., 2013; Tripathi et al., 2011).

Only one article was found pertaining to transgender individuals (Sevelius et al., 2013) **or individuals with disabilities** (not-related to their HIV status) (Hanass-Hancock et al., 2009) and linkage. However, a variety of data indirectly suggests that these groups may experience greater problems with accessing care compared to other subgroups of HIV+ individuals.

Psycho-social factors associated with less linkage to care: 1) **lack of knowledge** (e.g., If I'm feeling well, I don't need treatment; belief that HIV medications can make you sick; go only if you need medications; misperception of risk associated with delay in LTC; among women, knowledge about risk and benefits of care was important though not sufficient part of LTC) (Beer et al., 2009; Christopoulos et al., 2013; Jenness et al., 2012; Pollini et al., 2011; Quinlivan et al., 2013; Samet, Freedberg, Savetsky, Sullivan, & Stein, 2001), 2) **depression and other MH problems** (though findings are mixed) (Bell et al., 2010; Bhatia et al., 2011; Hightow-Weidman et al., 2011; Wohl et al., 2011), 3) **substance use** (especially recent/current) (Note: strong association with delay or no LTC) (Beer, Fagan, Valverde, & Bertolli, 2009; Bell et al., 2010; Craw et al., 2010; Horvath et al., 2013; Jenness et al., 2012; Mill et al., 2008; Raveis et al., 1998; Samet et al., 1998; Wohl et al., 2011), 4) **personal reactions to finding out one is positive** such as psychological breakdown (Beer et al., 2009; Buseh et al., 2006; Hosek, et al., 2008; Jenness et al., 2012; Mill et al., 2008; Pollini et al., 2011; Quinlivan et al., 2013; Raveis, Siegel, & Gorey, 1998), 5) **stigma** (Note: strong associations with delay or no LTC) (Beer et al., 2009; Buseh et al., 2006; Christopoulos et al., 2013; Fortenberry et al., 2012; Hosek et al., 2008; Philbin, Tanner, DuVal, Ellen, Kapogiannis, et al., 2013; Quinlivan et al., 2013; Samet et al., 2001; Sison et al., 2013; Vyavaharkar et al., 2008), 6) **more developed ethnic/racial or LGBT Identity** (associated with better LTC) (Futterman et al., 2004; Harper et al., 2014), and, 7) **conspiracy beliefs** (Bogart, et al., 2004; Bogart, et al., 2010a), 8) **denial of being infected or the significance of being infected with respect to health risks**, and 9) **loss of autonomy and sense of powerlessness especially among women** (Quinlivan et al., 2013).

Practical factors associated with less linkage to care: 1) **care-giving for others** (Raveis et al., 1998; Stein, Leibman, & Wachtel, 1991; Stein et al., 2000; Vyavaharkar et al., 2008), 2) **insurance status** (Bamford et al., 2010; Hightow-Weidman, et al., 2011; Minniear et al., 2013; Mugavero et al., 2007; Philbin et al., 2013; Pollini et al., 2011; Raveis et al., 1998; Rothman et al., 2012; Stein et al., 2000; Turner et al., 2000; Zierler et al., 2000), 3) **poverty & homelessness** (Craw et al., 2010; Cunningham et al., 1999; Minniear et al., 2013; Philbin, et al., 2013; Stein et al., 2000; Vyavaharkar et al., 2008; Wohl et al., 2011; Zierler et al., 2000), and, 4) **transportation obstacles** (Cohen et al., 2004; Cunningham et al., 1999; Hightow-Weidman, et al., 2011; Hightow-Weidman et al., 2011; Philbin, et al., 2013; Vyavaharkar et al., 2008).

Prior experiences with the health care system associated with linkage to care: 1) **utilizing PCP services before HIV testing associated with better LTC** (most youth did not have routine health-care prior to testing), 2) **anonymous testers, compared to confidential testers, more likely to delay entry into care**, 3) **negative experiences in testing and post-test counseling including a perception of racism, HIV stigma** associated with less LTC (Axelrad et al., 2013; Beer et al., 2009; Bindman et al., 1998; Buseh et

al., 2006; Hosek et al., 2008; Raveis et al., 1998; Reed et al., 2009; Stone, 1997; Turner et al., 2000). For example, a large qualitative study found that 1) providers sometimes failed to provide counsel and information about care, prognosis, and treatment “and sent them away without education.”, 2) women felt significant degrees of stigma, were afraid to enter clinics, afraid of being seen, 3) strong relationships with nurses, doctors, office staff at front desk, helped some of them overcome the stigma, 4) when care for the women was effectively expressed, women were more likely to trust and utilize providers, 5) “Positive clinic attributes, such as friendliness, professionalism, warmth, and discretion were helpful, whereas lack of privacy or discretion would keep women from wanting to return to future appointments.” (Quinlivan et al., 2013)

Structural factors associated with better linkage to care: 1) **adolescents going to general clinics versus adolescent-specific clinics** (Philbin, Tanner, DuVal, Ellen, Xu, et al., 2013), 2) **availability and access to ancillary services**, (Ashman, Conviser, & Pounds, 2002; Messeri, Abramson, Aidala, Lee, & Lee, 2002; Mugavero, Norton, & Saag, 2011; Sherer et al., 2002; Sison et al., 2013), 3) **co-location of services (testing and medical providers)** (Craw et al., 2010; Fortenberry, 2012), 4) **increased confidentiality, decreased waiting time, more flexible hours of operation** (Craw et al., 2010; Fortenberry et al., 2012; Horstmann et al., 2010; Jenness et al., 2012; Minniear et al., 2013; Mugavero et al., 2007; Quinlivan et al., 2013; Tripathi et al., 2011; Vyavaharkar et al., 2008), 5) **Cultural sensitivity and skills of health care professionals** (Fortenberry et al., 2012; Horstmann, Brown, Islam, Buck, & Agins, 2010; Philbin, Tanner, DuVal, Ellen, Kapogiannis, et al., 2013), 6) **collaboration/relationships between testing sites and medical providers** (Craw et al., 2008; Craw et al., 2010; Fortenberry et al., 2012; Philbin, Tanner, DuVal, Ellen, Xu, et al., 2013), **funding and policy issues** (Justice, 2010; Mugavero et al., 2011; Mugavero, et al., 2013; Walensky et al., 2005).

Limitations: This literature review included peer-reviewed articles only. There may be other relevant data that has not been peer reviewed. The exclusive focus on the U.S. may omit other relevant information. The literature about incarcerated individuals was not included.

Recommendations:

1. The review of demographic variables above suggests that resources may need to target certain subgroups more than others.
2. Almost no data exist with respect to transgender individuals and individuals with disabilities (not directly related to HIV status). More research in these areas is needed.
3. There are a wide variety of psycho-social factors that are associated with LTC. These are often co-occurring. Program planners and those implementing LTC programs need to take these into account and develop programs that deal with co-occurring conditions; ancillary services are important.
4. Several important practical barriers (i.e., caregiving of others; transportation problems; insurance status; poverty and homeless) impact LTC and will need to be addressed to improve LTC outcomes.
5. Other structural factors described above impact linkage to care. Prior experiences with health care systems and providers are a major barrier.

6. Stigma is a major factor that prevents many individuals from linking to care.
7. Little data exist with respect to rural LTC.

Additional information:

In addition to the above recommendations the literature suggests the following with respect to services and increasing LTC:

- Strengths-based case-management program is essential (e.g., building a strong relationship with client; helping clients set their own goals and search for their own resources to overcome barriers; identifying informal sources of support; conducting case-management outside of office in the community, in addition to standard in office work) (Craw et al., 2010; Gardner et al., 2005).
- Helping individuals prepare to link to care is important by evaluating and trying to meet medical, physical, psychosocial, environmental and financial needs (with individualized plan), and using a stages of change model to evaluate readiness to engage care.
- A “time-intensive intervention delivered by a non-judgmental and culturally competent peers is very effective in engaging at-risk Latino and African-American YMSM in consistent HIV care....” Weekly contact is important during the early months, and with youth, text messages can be effective (Wohl et al., 2011).
- Formal linkages between testing and treatment sites are critical to overcome fragmentation of care and to help make various stake-holders accountable for linkage processes.
- Community membership (how clinical care sites develop strong relationships with various community organizations including LGBT) is important (e.g., helping a gay kid diagnosed with HIV get linked to a gay health professional).
- Attitudes of care givers about adolescents and LGBT and racial minorities matter.
- Social support can help individuals overcome stigma.
- Patient education is a key component of case management of linkage (about HIV, issues related to disclosure, demands of becoming a patient).
- Case managers often have to help clients deal with a variety of barriers to care: stigma, availability of services, eligibility requirements, consent, payment, housing instability, homelessness, transportation, MH, drug use, the complex criteria and difficult application procedures, and involvement of multiple service providers. (Fortenberry et al., 2012).
- One program ensured that all of their program sites helped newly identified individuals to schedule medical visit, provided transportation to it, used telephone reminder calls, and conducted case finding for clients that missed appointments. Outreach workers escorted individuals to their initial medical visit. Outreach workers coordinated services with case managers, conducted support groups, organized social and educational events, and offered peer support in initiating HIV medications. The authors state that “An important lesson of this research is that even with this level of personal support, linkage and engagement rates varied substantially among sites, suggesting that additional factors influence care engagement.” (Philbin, Tanner, DuVal, Ellen, Xu, et al., 2013)

Report: Needs Assessment on Linkage to Care in Rural Pennsylvania 2014

IRB: PRO14060027

Brief Description:

A scientific literature review of local and national data sources focusing on linkage to HIV/AIDS care (LTC) was conducted and presented to the HIV Planning Group in May 2014. Based on this review, the HPG Needs Assessment subcommittee identified a gap in knowledge regarding linkage to HIV/AIDS care for clients from rural areas of Pennsylvania. An assessment was designed with input from the HPG and implemented by the HIV Prevention and Care Project to identify the specific barriers, challenges and facilitators faced when linking people from rural areas of Pennsylvania to HIV/AIDS care.

The assessment consisted of 15 qualitative structured telephone interviews with frontline staff involved with linking HIV clients from rural areas of Pennsylvania to HIV care from every region of the state. Purposive sampling methods were used to recruit participants with a diversity of roles in the LTC process, including HIV testers, field staff/Disease Intervention Specialists and HIV care staff. Questions focused on identifying specific testing and linking processes and on specific barriers, challenges and facilitators faced when linking people from rural areas of Pennsylvania to HIV/AIDS care. Data were analyzed by two independent researchers using a grounded theory approach and presented to the HIV Planning Group in September. Qualitative analyses of interviews will use inductive (e.g. grounded theory) approaches.

Relevant Findings:

- More than half of the informants identified these factors as facilitators to successful linkage: client-centered approach, active referrals, early intervention, and in-person LTC support at time of confirmatory results with education around HIV, disclosure and LTC resources (insurance, housing, substance abuse, food). Co-location of services, strong provider and community networks and social support were also mentioned as key facilitators.

“When you’re sitting in the room with a newly diagnosed person, okay... You’re helping, you are offering emotional support, you are offering that person hope, you are offering that person acceptance. And when I say acceptance, you know, I am not judging how you contracted the disease. I’m here to help you so that you can have quality to your life, and a long life. I’ll be real practical; making that doctor’s appointment is the easy part. But helping that individual not beat themselves down, to keep them positive in their thinking, to help them in their acceptance, because let’s face it; a newly diagnosed individual just sees everything negative...”

- Challenges with transportation emerged as a key barrier to LTC from rural areas in terms of distance to HIV provider clinics and a lack of confidential transport options for clients.

“Because of shortage of transport and size of territory it becomes inevitable that we have case managers who take active role in getting clients to HIV-related appointments. Biggest barriers or challenges: so costly.”

“Confidentiality and transportation is a major issue – taking them to a DOH clinic. News flies so quickly in rural community.”

- Structural barriers included too few field staff and providers, long waiting time for first appointment and availability and access to dental services.
- Informants also cited negative healthcare experiences in testing and post-test counseling with medical providers and the need to ensure confidentiality within contexts of extreme stigma (HIV, MSM, IDU) as a barrier to LTC from rural areas.

“I think a lot of medical providers, nurses, doctors are uncomfortable with HIV around here, uncomfortable with sexual history taking even or talking about sex let alone talking about sexuality that is different from their own. And so it just feeds into the stigma that already exists.”

“I willingly give results because I don’t want someone giving them who doesn’t know how to talk to the client appropriately. With not only respect to who they are as a person but to their sexuality too. I’ve heard too many times where doctors gave results on phone or tried to make a joke, or basically not knowing how to talk to them. Making them feel uncomfortable.”

- Demographically, younger gay men (<30) and older heterosexually married MSMW were reported as taking longer and less likely to link to care.
- Clients with dual diagnosis, namely depression and substance abuse, faced greater challenges in linking to care.

Recommendations:

These recommendations were compiled from HIV Planning Group Needs Assessment Subcommittee discussions, from a scientific literature review of local and national data sources focusing on linkage to HIV/AIDS care (LTC) and from an assessment focusing on LTC from rural areas of Pennsylvania. They were presented to the HIV Planning Group in January 2015 and passed unanimously.

Policy

1. The DOH should adopt a definition for linkage to care to be used uniformly throughout the state.
2. The DOH should mandate formal linkages between testing and treatment sites when possible to overcome fragmentation of care and to help make various service providers accountable for linkage processes.
3. The DOH should, when possible, encourage and fund co-location of testing, HIV care and nonmedical services to facilitate timely linkage to care, especially in rural Pennsylvania.
4. The DOH should mandate that all funded HIV test sites provide comprehensive patient education around HIV, disclosure and LTC resources at point of confirmatory results.
5. The DOH should support HIV testing providers where possible to establish linkages and provider agreements with those who provide services related to practical barriers to LTC, including: food and housing services, insurance, benefits counseling, health-related transportation, child-care services, disability services, language translation and mental health and substance abuse services.
6. The DOH should create a mechanism to increase the number of PPA-contracted agencies so that the DOH can better track LTC.
7. The DOH should create and implement a plan to reduce stigma related to HIV (HIV, sexual practices, drug use) throughout the state.
8. To address the structural barrier in rural areas of too few field staff to meet the immediate linkage to care needs of clients, the DOH should collaborate with the Bureau of Community Health to identify mechanisms to increase field staff in underserved areas.
9. To address the structural barriers in rural areas of too few medical providers which leads to long wait times for first appointments and limited availability, the DOH should offer training to providers who are interested in working with rural consumers.

10. The DOH should create a plan to make telemedicine available around the state for HIV prevention and care services. The DOH should request technical assistance from HRSA around telemedicine to identify other states with large rural populations with effective programs for rural HIV care in order to increase the utilization of telemedicine for HIV care services in Pennsylvania.
11. The DOH should increase access to dental health services in rural areas by offering training to dentists who are interested. The DOH should also explore the feasibility of using mobile dental health units for rural medical care and facilitate linkages to dental schools.
12. The DOH should implement a cost-effective system for using certified peer specialists in supporting the linkage to care process.
13. The DOH should require a marketing plan from all providers to make sure that demographically-indicated subgroups are being reached.
14. The DOH should encourage culturally competent marketing of HIV services to Spanish-speaking populations in order to reduce barriers to HIV services.
15. The DOH should consider ways to ensure that medical providers, including primary care providers and emergency room providers, are following the CDC recommendations for HIV testing as part of routine care.
16. The DOH should continue efforts to require mandatory lab reporting (all CD4 and viral loads) in order to ensure a more thorough perspective on the continuum of care in Pennsylvania.

Capacity Building

17. The DOH should require all contracted HIV testers, case managers and HIV clinic staff and providers to be trained on client-centered strength-based approaches to timely linkage to care. Such approaches include the following elements:
 - a. In-person LTC support at time of confirmatory results, particularly in rural areas
 - b. Active referrals
 - c. Early intervention
 - d. Conducting meetings in client's chosen location and time
 - e. Transportation assistance
18. The DOH should mandate that ARTAS or other similarly proven evidence-based LTC interventions be available to all HIV-related staff throughout the state.
19. The DOH should make trainings available as new evidence-based interventions are mandated before sites are required to implement them.

20. The DOH should mandate that ALL staff of all HIV prevention and treatment programs be trained in cultural competency in terms of race, gender, age, drug-use and sexual practices in order to offer culturally competent and non-judgmental services.
21. The DOH should create a template that can be used to establish formal linkages between HIV testing and treatment sites, when possible. All HIV testing staff should be trained on how to use and maintain these linkages.
22. The DOH should require that all contracted HIV testers and field staff to be trained on how to offer comprehensive patient education at time of confirmatory results. This includes training on how to evaluate and support clients in meeting medical, physical, psychosocial, environmental and financial needs to support a client's readiness to engage in HIV care.
23. The DOH needs to mandate that all HIV testers, program planners and those implementing LTC programs be trained on dual diagnosis and linkage procedures to mental health and substance abuse services.
24. The DOH and AETC should collaborate and coordinate on training on LTC.

Needs Assessment

25. Challenges with transportation emerged as a key barrier to LTC from rural areas in terms of distance to HIV provider clinics, cost of transportation and a lack of confidential transport options for clients. The DOH should gather data on transportation options and problems faced by clients by region when linking to HIV care from rural areas.
26. The DOH should gather more data on use of HIV services by transgender people.

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