

Understanding Barriers to Linking Persons Living with HIV to Care in the United States: Findings from the Positive Charge Initiative



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Background

The Positive Charge (PC) initiative is a multisite national initiative funded by AIDS United to increase access to and utilization of effective HIV healthcare by persons living with HIV (PLWH). The PC initiatives are being implemented throughout the United States in five locations with a large HIV/AIDS burden.

The five sites are:

- Project Identify, Navigate, Connect, Access, Retain and Evaluate (IN-CARE) in Chicago, IL;
- ACCESS NY in New York City, NY;
- The Bay Area Network for Positive Health (BANPH) in Oakland and San Francisco, CA;
- The North Carolina Access to Care Initiative in Durham, NC;
- Louisiana Positive Charge Initiative in New Orleans, LA;

The PC initiatives are collaborative efforts between multiple local agencies, designed to not only impact individuals' healthcare status but also improve the overall system of care for PLWH. Between the five grantee sites, there are over 30 collaborating organizations actively involved. Each initiative targets a population(s) that experiences great challenges in obtaining health care and utilizes empirically based outreach and linkage strategies to identify, link and retain individuals in care.

Methods

Johns Hopkins University (JHU)'s Department of Health, Behavior, and Society is providing oversight of the national evaluation for PC. The national evaluation uses a three-pronged strategy to answer a set of overarching national evaluation questions. The three-pronged strategy includes: Monitoring of outcomes via **national evaluation indicators**; Assessment of change in service delivery and ties between organizations via **case studies** of organization networks; and Assessment of cost effectiveness via a **cost analysis**.

A set of core national evaluation indicators is used to monitor and evaluate the PC initiative. The measures include process and health outcome indicators across all sites. The data is used to: describe the PC patient population; monitor the program implementation; assess short-term outcomes such as linkage to care and retention in care; and assess intermediate health outcomes such as general health, change in CD4 cell count, and change in viral load. The national evaluation also collects data on perceived stigma, and structural and psychosocial barriers to HIV care. Each site was provided with an excel workbook to complete with a training on how to populate the document.

The national evaluation indicators are collected at four time points (baseline, six, twelve, and eighteen months) across all sites. The third round of data collection was completed by the five sites for participants enrolled from August 1, 2010 to January 31, 2012 and sent in aggregate form to JHU.

Barriers to Care Measure:				
Often people with HIV face barriers to getting HIV care. What factors make it hard for you to get care? Don't read: lack of money, homelessness, immigration, incarceration, drug use, fear, stigma, denial, distrust of medical system, lack of perceived need				
Measure 1: All answer responses (not mutually exclusive)	Baseline	Time 1	Time 2	Time 3
Numerator	# %	# %	# %	# %
Current barriers to HIV medical care?				
Lack of money	0	0	0	0
Homelessness	0	0	0	0
Immigration	0	0	0	0
Incarceration	0	0	0	0
Drug use	0	0	0	0
Fear	0	0	0	0
Stigma	0	0	0	0
Denial	0	0	0	0
Distrust of the medical system	0	0	0	0
Lack of perceived need	0	0	0	0
Competing priorities	0	0	0	0
Transportation	0	0	0	0
Location of care	0	0	0	0
Structure of testing	0	0	0	0
Lack of ancillary services	0	0	0	0
No barriers identified	0	0	0	0
Other (specify)	0	0	0	0
Don't Know	0	0	0	0
Refuse	0	0	0	0
Missing	0	0	0	0
Denominator:				
Total number of clients enrolled	0	0	0	0

Figure 1: Excerpt of Positive Charge initiative's National Evaluation Workbook: "Barriers to Care Measures"

Results

Demographics:

Between August 2010 and January 2012, PC sites enrolled 2,195 participants of whom 54% were over 40 years of age, 73% were male, and 49% were black/African American. At enrollment 45% of participants were out of care, 45% were in sup-optimal care*, 7% were in tenuous care, and the status of 2% were unreported. Figure 2 provides the demographic profile of the PC initiative sites.

*Sub-optimal care: In care but failed to have two visits with a health care provider that were at least two months apart in the past six months

Barriers to care:

PC participants face many barriers to care that are both structural and psychosocial in nature. Transportation was the most frequently reported impediment to care; participants from all five sites (if including North Carolina's "location of care") noted that it was a major barrier that kept them out of care. Poverty related factors such as homelessness or lack of money were also frequently reported as barriers by PC participants. It is worth noting that for whom information was made available, many ACCESS NY participants (47%) reported that they did not face any barriers to health. Figure 3 presents the most frequently reported barriers to care by site.

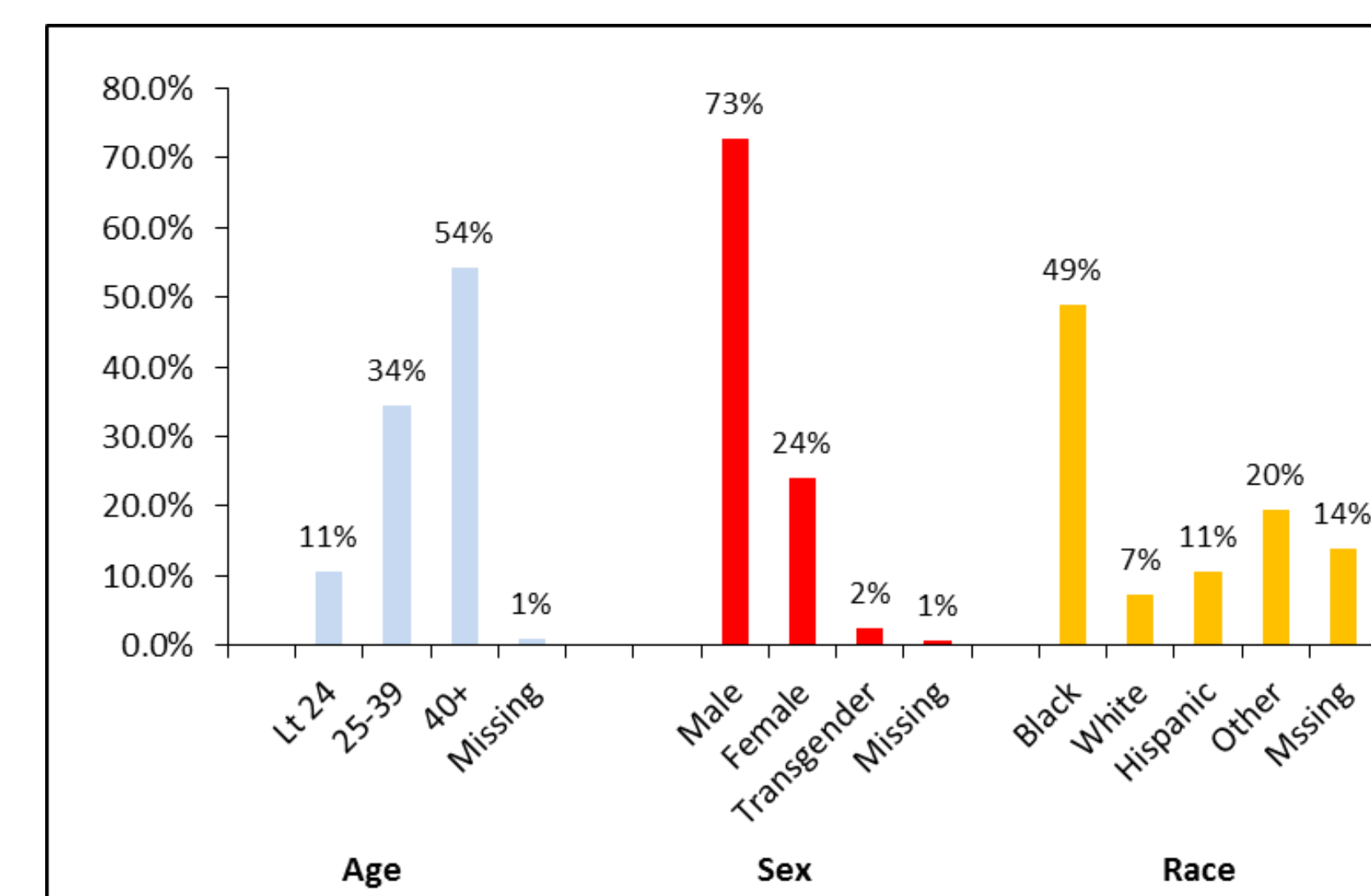


Figure 2: Demographic profile across PC sites

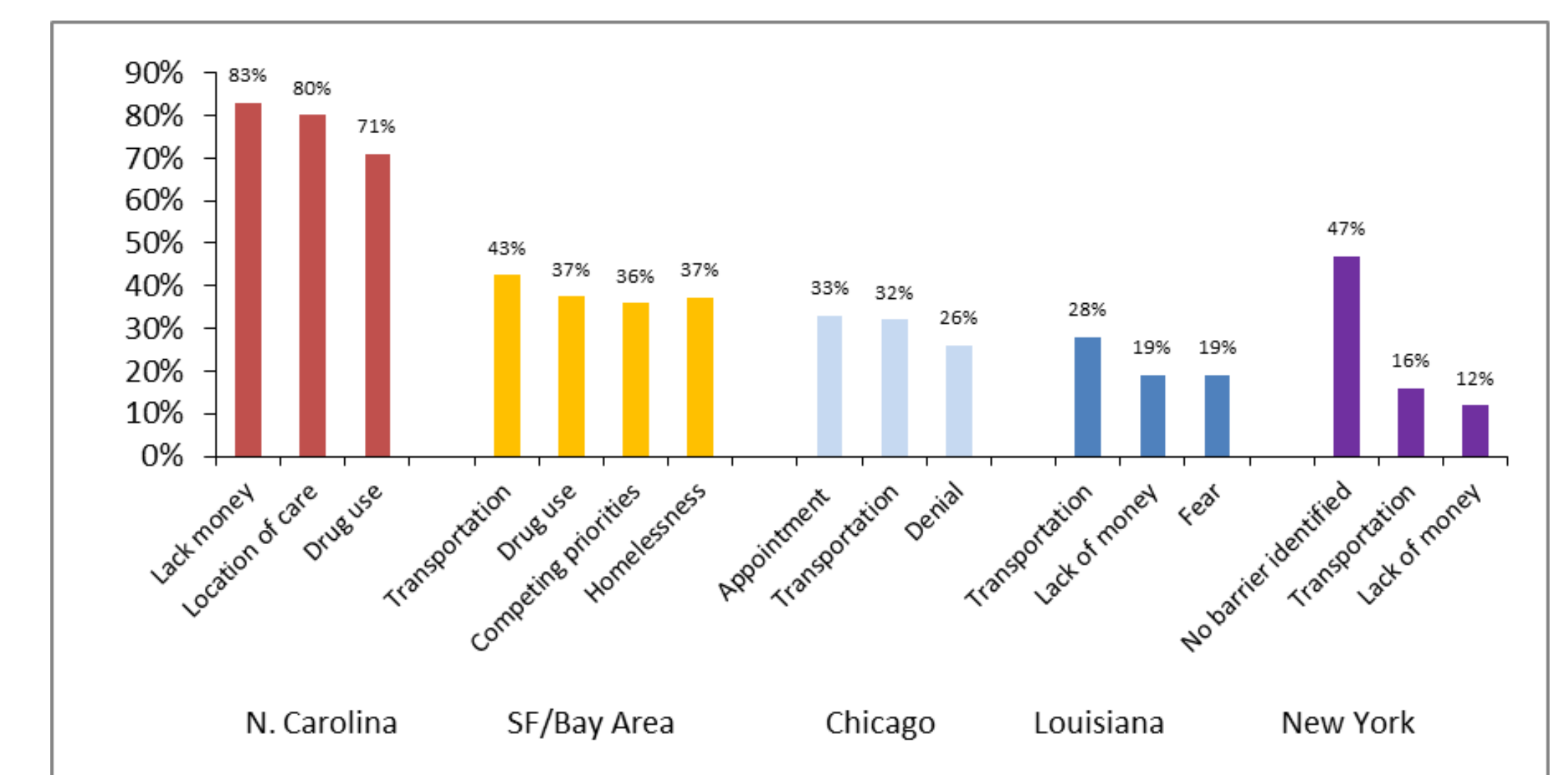


Figure 3: PC participants' most frequently reported barriers to care by site (not mutually exclusive)

Stigma:

Stigma has been cited as a major barrier in the fight against the HIV epidemic, impeding prevention, care, and treatment efforts (Mahajan et al., 2008). PC participant also identified stigma as a barrier to HIV care. The extent to which stigma impeded participants' care, however, varied by site. While as many as 22% of Louisiana participants reported that they sometimes or often avoided HIV treatment in fear that someone might find out about their HIV status, only 2% ACCESS NY participants reported that this was the case. Figure 4 presents PC participants' reported levels of self-perceived stigma by site.

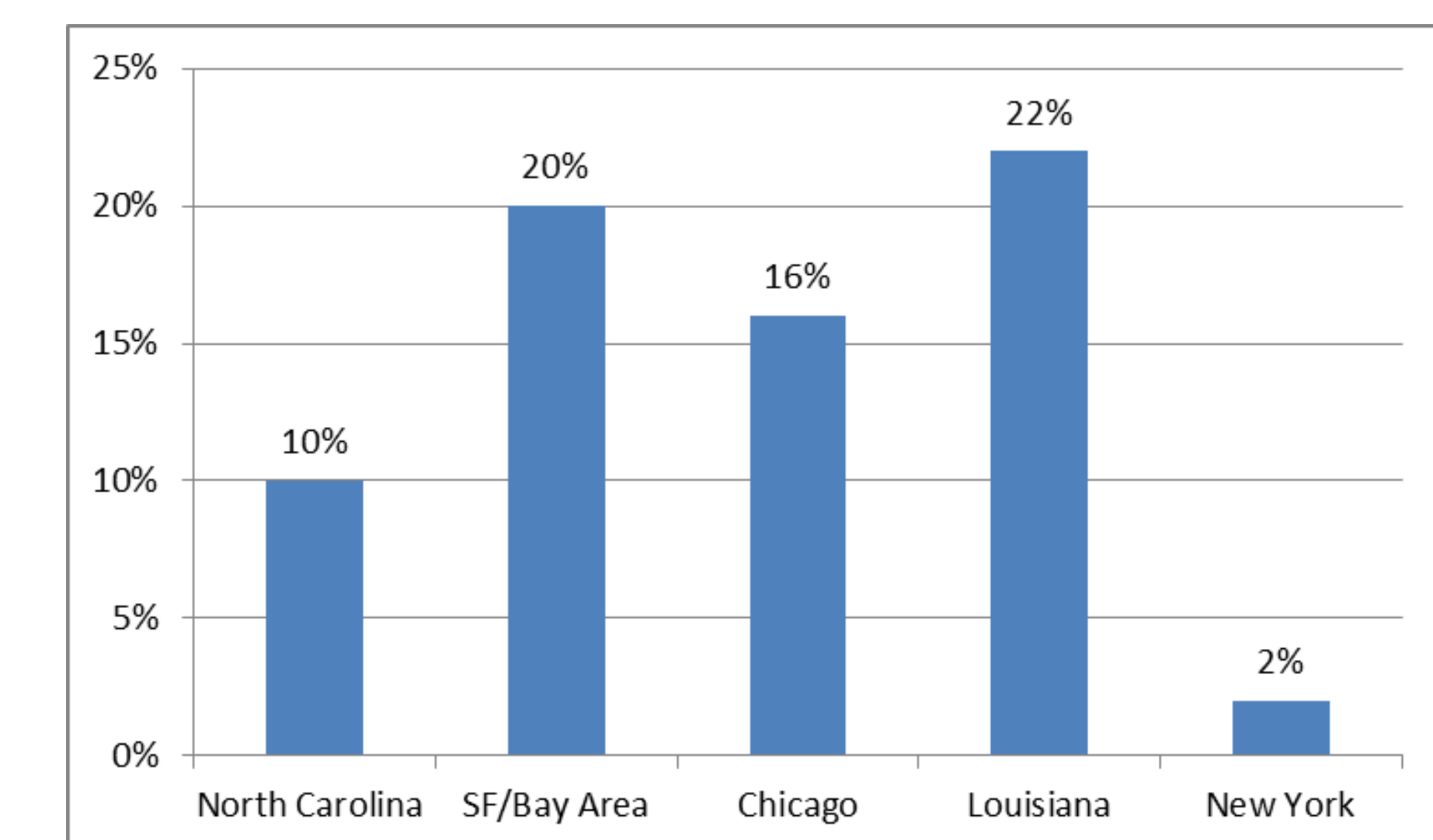


Figure 4: PC participants' self-perceived stigma by site

Conclusion

Research suggests that approximately 50% of PLWH are not engaged in regular HIV care (CDC, 2011; Gardner, McLees, Steiner, Del Rio, & Burman, 2011). Hundreds of thousands of persons in the U.S. have unmet care needs, and the AIDS Drug Assistance Program waiting lists are but the mere tip of the iceberg.

Structural and psychosocial factors affect individuals differently at each stage of the HIV care continuum. Studies funded by the Health Resources and Services Administration (HRSA) found that programs such as transportation assistance, substance abuse treatment, and case management services, were linked with greater engagement in care (Conviser and Pounds, 2002). Since this finding, HRSA prioritized and funded subsequent HIV retention programs to include case management and outreach services. The PC initiative's national evaluation indicators also support HRSA's conclusions.

There is a need to adopt a more holistic approach to HIV care. It is only in first identifying and addressing barriers to care that programs can then successfully link and engage PLWH in regular care. It is also important to conduct further research to better gauge what barriers keep PLWH out of HIV care (Mayer, 2011).

Acknowledgments

The project is supported by a grant from AIDS United

References

1. Conviser R., Pounds M.B. (2002). The role of ancillary services in client-centered systems of care. *AIDS Care*, 14 (Suppl 1): S119-32.
2. CDC. (2011). Vital Signs: HIV Prevention Through Care and Treatment - United States. *MMWR Morb Mortal Wkly Rep*, 60, 1618-1623.
3. Gardner, E. M., McLees, M. P., Steiner, J. F., Del Rio, C., & Burman, W. J. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis*, 52(6), 793-800.
4. Mahajan, A.P., Sayles J.N., Patel V.A., Remien R.H., Ortiz D., Szekeres, G., and Coates T.J. (2008). Stigma in the HIV/AIDS epidemic: A review of the literature and recommendations for the way forward. *AIDS*, 22 (Suppl 2): S67-79.
5. Mayer, K.H. (2011). Introduction: Linkage, Engagement, and Retention in HIV Care: Essential for Optimal Individual- and Community-Level Outcomes in the Era of Highly Active Antiretroviral Therapy. *Clin Infect Dis*, 52(Suppl 2), S205-207.