

Tracking linkage to HIV care for former prisoners

A public health priority

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Improving testing and uptake to care among highly impacted populations is a critical element of Seek, Test, Treat and Retain strategies for reducing HIV incidence in the community. HIV disproportionately impacts prisoners. Though, incarceration provides an opportunity to diagnose and initiate therapy, treatment is frequently disrupted after release. Though model programs exist to support linkage to care on release, there is a lack of scalable metrics with which to assess adequacy of linkage to care after release. The linking data from Ryan White program Client Level Data (CLD) files reported to HRSA with corrections release data offers an attractive means of generating these metrics. Identified only by use of a confidential encrypted Unique Client Identifier (eUCI) these CLD files allow collection of key clinical indicators across the system of Ryan White funded providers. Using eUCIs generated from corrections release data sets as a linkage tool, the time to the first service at community providers along with key clinical indicators of patient status at entry into care can be determined as measures of linkage adequacy. Using this strategy, high and low performing sites can be identified and best practices can be identified to reproduce these successes in other settings.

Though effective antiretroviral therapy (ARV) has markedly improved life expectancy for those living with HIV, efforts to reduce new HIV infections in the US have been significantly less successful. Indeed,

HIV incidence has been stable since 1991. Calls for expanding universal testing and treatment for HIV have been made based on models which suggest that aggressive expansion of HIV testing and treatment, a strategy now termed “Seek, Test, Treat and Retain,” may dramatically lower HIV incidence.¹ The recent trial HPTN 052 which demonstrated a profound reduction in HIV transmission through antiretroviral therapy provided to infected persons provides key evidence to support the potential impact of these expanded testing and treatment strategies on new incident infections in the community.² The success of this strategy will depend on the ability of testing programs to identify and engage in care the 25% of persons who do not know their HIV status.³

Since the early years of the HIV epidemic, HIV has disproportionately impacted prisoners. In 2008, the HIV prevalence was 1.6% among the state prisoners, representing 20,449 people.⁴ It is estimated that approximately 150,000 HIV-infected persons, 14% of all Americans with HIV, pass through corrections each year.^{5,6} The prevalence of HIV within correctional settings ranges from 2.5 to more than three times that of the general population with prevalence in high prevalence communities such as Baltimore and Washington DC as high as 6.6%.^{4,6,7} Following release from prison, former inmates are often marginalized in their communities due to addiction, mental health disorders, unemployment and racial disparities, which can lead to decreased access to health care.^{8,9} Incarceration is often the only time these individuals access HIV testing, education, counseling and

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treatment services.¹⁰ With as many as a quarter of HIV-infected individuals are unaware of their status, incarceration represents an important opportunity to provide testing and treatment for a high risk, underserved population.¹⁰

Periods of incarceration represent both opportunities and, as they reenter the community, challenges for those living with HIV.^{11,12} Incarceration may provide an opportunity to establish persons in care and to initiate therapy in an observed and highly structured manner. The success of antiretroviral therapy in these settings may account for a portion of the decline in AIDS related deaths among prisoners.¹³ For those from medically underserved communities, the healthcare received in corrections may be markedly better than that available to them in the community. Disturbingly, the benefits of HIV-care in prison, however, may not extend beyond the prison gates as released prisoners often have difficulty accessing community HIV care in a timely manner.¹⁴⁻¹⁷ In studies of those reincarcerated following release into the community, CD4 counts were shown to be lower and viral loads higher at the time of follow-up than at last assessment prior to release.^{14,18} Among HIV infected prisoners leaving corrections in Texas, only 5% were found to fill antiretroviral prescriptions in time to avoid an interruption in care.¹⁶ In this same study, only 30% had filled prescriptions by 60 d post release suggesting very significant interruptions in antiviral treatment.

The reason for the delays in connecting people to care upon release in a timely fashion are not entirely clear, but may involve a number of community-based factors including inadequate care resources in the community, delays in reinstating public and private health care benefits, social stigmatization of persons with HIV and other challenges surrounding reentry.¹⁹ In a representative sample from four states, 75% of former inmates were found to have no public or private insurance 2 to 3 months after release.¹⁹ Additionally, during the transition back to the community, former inmates are faced with a number of personal challenges which may obstruct their timely linkage to care. These include locating secure housing, finding employment, reestablishing

ties with family members and in many cases coping with substance use and mental health problems.¹⁹⁻²¹

African Americans and Hispanics are incarcerated at rates six and two times those of whites, respectively.²² Similarly, African Americans and Hispanics face seven and three times the respective rates of HIV infection as whites.²³ The twin epidemics of HIV/AIDS and incarceration are intricately interrelated; incarceration may contribute to and compound racial disparities in HIV infection.²⁴⁻²⁶ The 2010 National AIDS Strategy calls for reduction in HIV incidence and reductions in racial disparities in HIV infection.²⁷ Expanding linkage to HIV care following release from correctional settings therefore represents a prime opportunity for addressing racial disparities in HIV infection in the US.²⁸

Though model programs to support linkage to care exist in some areas of the country, there is no systematic framework for evaluating linkage to HIV care and supporting the development of programs to improve linkage to HIV care on a larger scale.²⁹⁻³⁴ Development of metrics which measure prisoner's linkage to community HIV care may offer an empirical starting point for identifying best practices for supporting HIV-positive prisoners' healthy and successful return to the community. This article reviews the problem of assessment of linkage to care and proposes a framework for the development of such metrics based on available corrections and clinical care data sets.

Assessing the Adequacy of Linkage to Care

Adequacy of linkage to care is defined both in terms of the timeliness and the quality of care received by former prisoners on reentry. Time to receipt of first service is the most basic metric of timeliness of care following release. This metric requires a means of linking corrections release data for HIV-positive prisoners with the dates of services of received in the community. More informative measures could be generated if data are available describing the former prisoner's health status at the time of their first clinic visit. This strategy has been used in prior evaluations of outcomes for released prisoners with

HIV.¹⁴ Data regarding the clinical status at the time of release, where available, may be important as well to allow more accurate assessment of changes in clinical status prior to their initial care visit in the community. Though virologic suppression and CD4 count remain priority indicators of health status, it is also important to consider the adequacy of treatment of mental health and substance abuse disorders after release given the profound impact that these comorbid conditions can have on outcomes for patients living with HIV. Demonstrating the success of linkage to ancillary care services may give some indication of the quality of care in the community.

Linking corrections and outpatient clinical care data are challenging at multiple levels. Protections exist around the confidentiality of information related to HIV status that may limit the ability to access information of HIV infected persons both from corrections and from outpatient care settings. In addition, at the time of release, individuals may not have identified their site for HIV care in the community. For those with prior relationships with providers, at the time of release they may relocate to other geographic areas or change providers based on the loss of insurance. Identifying the site of initial follow-up therefore, may require pooling data from multiple providers in the community. Lastly, the use of aliases and misreporting of other personal identifiers such as birth date makes systematic linkage between data sets without a common identifier challenging.

The three largest public payers of HIV care are the federal-funded Medicare and federal- and state-funded Medicaid entitlement programs, and the discretionary Ryan White HIV/AIDS Program.^{35,36} The Ryan White HIV/AIDS Program is the only federal program which is solely designed to support services with people with HIV/AIDS. Unlike the entitlement programs, Ryan White is designed to be a "payer of last resort" and specifically targets uninsured and underinsured HIV-infected individuals. This includes individuals who have not yet progressed to advanced HIV disease, thereby meeting disability requirements for the entitlement programs. Although not the largest public program for HIV care, Ryan White is

the major source of care for recently released inmates because this population often lacks health insurance (including Medicaid) and, especially if maintained on HAART throughout incarceration, released inmates are often too healthy to qualify for HIV-related disability.³⁷ In addition to providing direct support for ambulatory medical care services, Ryan White funds may support the cost of medications through the AIDS Drug Assistance Programs (ADAP) and funding other wrap-around services such as case management, mental health, substance abuse treatment, oral health, housing and other ancillary care services.

Starting in 2009, all Ryan White funded HIV/AIDS care programs were required to submit client level data to the Health Resources and Services Administration (HRSA) for reporting. The goal of these submissions is to obtain a single, unduplicated count of all persons receiving care from Ryan White providers across the nation. The reporting of client level data on HIV care through the Ryan White HIV/AIDS Program represents an unprecedented opportunity to evaluate, in tremendous detail, the care provided and client health outcomes across Ryan White CARE sites. Given that HIV care in many locations reflects the complementary effort of multiple independent providers, the aggregation of client-level data across clinical sites allows for the development of metrics which reflect the quality of care across an entire system.

Optimal Record Linkage Strategy

An optimal strategy to match and link records between prison and community databases would allow for a high level of accuracy in record matching across databases while preserving the confidentiality of the patients whose data are being accessed. In order to assure scalability of the linkage strategy, this strategy would need to require only the minimum of invested effort on the part of the community care and correctional sites. In order to support the amalgamation of client level data across Ryan White funded care sites, HRSA developed a strategy for linking records based on the use of an encrypted Unique Client Identifier (eUCI). This

identifier is generated using the first and third characters of the first and last names, the full date of birth, and the gender which are combined and encrypted using a secure hash algorithm SHA-1 developed by the National Security Agency.^{38,39} This algorithm has the important property that once the encryption has taken place, the source identifiers cannot be reconstructed from the encrypted identifier, thus maintaining the confidentiality of individual patients.

Though developed for use with the Ryan White care program, the algorithm for generation of the eUCI can be applied to any data set containing name and birth date data. Generation of eUCIs in both correctional prisoner-release data, which is public record, and Ryan White client-level data, could provide a means to efficiently and scalably link these data sets for the generation of metrics of quality of linkage to care. Use of aggregated incarceration data through the Bureau of Justice Statistics National Corrections Reporting Program would minimize the need for multiple independent requests to correctional systems.

In small scale testing, the reported false positive and false negative error rates are 3.8% and 5% respectively.³⁹ False positive matches occur when the same eUCI is generated for persons for different individuals. False negative matches occur when two eUCIs are generated for a single individual based on differences in recording of their name, date of birth or gender. Though identifiers including segments of the social security number were considered as part of strategies to make the eUCI, collection of social security numbers at clinical care sites raised confidentiality concerns and risked deterring some patients from care. In addition the improved accuracy of the match based on SSN (where available) would be offset by the potential for reductions in accuracy based on incomplete or inaccurate reporting of SSN. Given that the level of error achieved with the implemented eUCI was deemed acceptable by HRSA for quality review and reporting, the final identifier was based on name, date of birth and gender only.

Obtaining accurate linkages between corrections release data and aggregated community clinical care data poses some unique challenges. The deliberate use of

aliases among populations involved with the criminal justice system is common. Inconsistencies in recorded birthdates, variable patterns of hyphenation in names, and the use of maiden names by female prisoners have also been frequently noted. Since these are key components of the eUCI these variations may have a significant impact on the observed error rates when using the eUCI for matching. A linkage strategy that incorporates generation of eUCIs based on aliases and other potential modifications of the name may be important to minimize the number of false negative linkages.

The tolerance for error in linkage assessments will vary based on the goals of the assessment. In order to establish a precise estimate of the success of linkage to care, a high level of linkage accuracy is required. This level of accuracy may not be achievable using the eUCI or other similar scalable metrics. Nonetheless, linkage strategies with higher error rates may still be useful as a means to distinguish high performing and low performing sites. As shown in Table 1, even with error rates substantially beyond the 8.8% combined false positive and false negative error rate reported from the HRSA validation, high performing sites could be distinguished from low performing sites with manageable samples sizes. Given the use of aliases by persons in corrections and other potential inconsistencies in the recording of data between the correctional and clinical data systems, we expect that false negative matches will be more prominent than false positives though this assumption needs to be validated.

Metrics of Linkage Adequacy and Best Practices

Once data sets have been linked, effective metrics for assessing linkage adequacy need to be developed. These metrics should include measures of both time to linkage and the quality of linkage as reflected in the clinical status of the releasee at the time of the first encounter and the types of services obtained. Key indicators could include detectable viremia for those meeting CD4 criteria for treatment, time to fulfillment of first antiviral prescription, as well as receipt of ancillary case

Table 1. Simulated linkage estimates by true linkage rate and net error rate

Net Linkage Error Rate*	High Performing Site		Low Performing Site		Sample Required to Demonstrate Difference**
	True Linkage Rate	Linkage Estimate	True Linkage Rate	Linkage Estimate	
-0.4	0.6	0.84	0.3	0.42	48
-0.3	0.6	0.78	0.3	0.39	57
-0.2	0.6	0.72	0.3	0.36	68
-0.1	0.6	0.66	0.3	0.33	81
0.1	0.6	0.54	0.3	0.27	116
0.2	0.6	0.48	0.3	0.24	139
0.3	0.6	0.42	0.3	0.21	170
0.4	0.6	0.36	0.3	0.18	210

*Defined as the percent of false negative links—false positive links. **Calculated based on the comparison of proportions by χ^2 test with continuity correction, $\alpha = 0.05$, power = 0.80

management, substance abuse or mental health services where that data are available. Because the need for ancillary services will not be documented in release records, it will not be possible to draw conclusions regarding failure to link to necessary services. High rates of linkage to ancillary services if correlated with high performing sites may suggest that these are important components of a successful strategy for linkage to care. Immunologic status and detectable viremia at follow-up, time to follow-up and time to filling of ARV prescriptions have been used as measures of adequacy of linkage to care in prior studies. Where clinical data are available from the time of release, declines in CD4 count can be an additional indicator of linkage failure.

Measures of linkage adequacy using this strategy could be utilized in multiple ways. Serial measures at a given site would allow program managers to assess the success of linkage programs and interventions as well. Comparing quality measures across sites and across regions would allow identification of model programs and best practices which could potentially be replicated at other sites. Lastly, generation of regional or national statistics regarding the adequacy of linkage may provide important feedback for policy development related to correctional health and HIV.

Tracking Linkage in a Changing Healthcare Environment

Although Ryan White funded care programs are likely the first point of contact

on reentry in most jurisdictions, access to other public and private insurance programs as a result of healthcare reform may significantly change this in the years to come. A linkage strategy validated using Ryan White care data could similarly be applied to aggregated client level data from other data sources or even multiple data sources. The confidentiality protection inherent in the use of the eUCI as a linkage strategy would be key in negotiating access to alternate clinical data sets. Other potential sources of data for linkage include Medicaid programs, state health programs such as Mass Health, pharmacy prescription data, data from the Veterans Administration health system, and urgent care and emergency care providers, and state or national laboratory surveillance data (see Fig. 1). Each of these data sets would include the necessary information to generate the eUCI and details of specific services funded or tracked through those programs. If accurate matching can be performed across data sets, the potential for aggregation of data from multiple data sources in a manner that would create a composite picture of all the services received by an individual, enhancing the accuracy of linkage estimates.

Evaluating Reasons for Variability in Linkage Success

Once metrics are established for linkage to care, both from a research and from a quality and program planning point of view follow-up investigations will need to

be performed to identify the differences in performance between sites and within a site over time. This may include quantitative investigation of determinants of adequacy of linkage to care. Qualitative research that thoroughly explores the social processes and factors that influence how and whether inmates are effectively linked to care is an important complement to these analyses. First, qualitative analyses may help unpack and explain the observed linkage trends. Second, qualitative analyses will also help reveal how the “macro” level factors such as the local and national policy environments, resources, health infrastructure, leadership and other institutional factors impact access to care upon release. For example, focus groups and interviews with Ryan White Care providers and correctional administrators may illustrate the local factors and policies that explain linkage trends. Similarly, qualitative analyses that explore the inmates’ experiences with treatment and care services upon release may help highlight the “micro” or individual-level factors that affect inmates’ continuity in care. These might include substance abuse, stable housing, health insurance status, mental health, employment and other factors. In summary, qualitative research is an essential and complimentary component of understanding trends in linkage to care services for recently released inmates, and may help shed light on social factors and processes not observed in quantitative trends alone. Taken together, the quantitative and qualitative investigations will inform efforts to develop

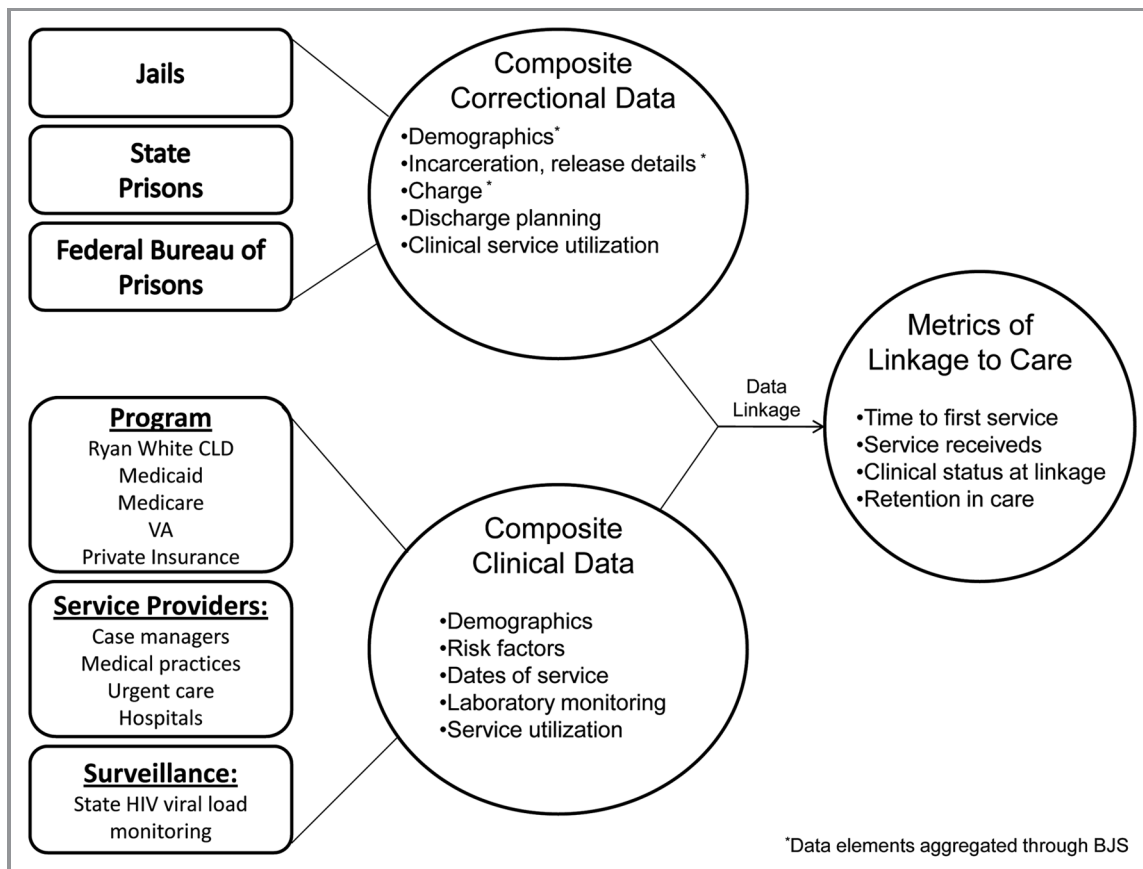


Figure 1. Linking correctional and clinical data sources to evaluate linkage to care for returning prisoners with HIV.

effective programs supporting linkage to care for persons on reentry.

Challenges and Opportunities

There are several key challenges to be addressed in order to build a scalable system of assessment of linkage to care on entry. In order to be successful, a program of systematic analysis of the adequacy of linkage to care must be built in a collaborative manner with input and buy-in from all involved parties. This is particularly important with regard to the involvement of the correctional health system which faces the ongoing challenge of trying to provide the linkage services for detainees who have complex psychosocial needs, high rates of comorbid mental illness and substance addictions, and limited resources to care for themselves post release. Maintaining this support on the corrections side will require that corrections officials be involved from the outset in the review and dissemination of

data. Deficiencies identified need to be addressed as systems challenges rather than singular failings on the part of one agency. Assuring optimal linkage to care may require additional support for correctional linkage programs and these analyses may provide an important first step in making the case to policymakers for the need for additional support for discharge planning within the departments of corrections.

On the clinical side, assuring adequate measures are taken to maintain confidentiality is key. This involves the development and validation of linkage procedures that minimize disclosure of personal identifiers and protected health information. In addition, developing strategies for data linkage that use aggregated data either at the State or Federal level will minimize the need for transmission of data and thereby minimize the risk of unintended disclosures. If HRSA is able to link aggregated client level data for all Ryan White funded

providers to corrections release data, this would offer the real possibility that assessment of linkage to care across jurisdictions could become a standard component of quality monitoring for Ryan White care sites with a minimum risk to confidentiality. Aggregation of release data across correctional systems would in a similar way enhance the scalability of these linkage analyses. Use of aggregated data from the federal corrections system may provide a potential model for the use of centralized corrections data to assess linkage success across correctional systems.

Conclusions

Reporting of client level data allows an unprecedented opportunity to assess the adequacy of linkage to care to newly released HIV positives individuals. Linkage of the Ryan White Client Level Data to corrections release data may provide an important tool for the development

of metrics of linkage adequacy that can be used to monitor quality improvement and program development. If proved successful this strategy with the confidentiality protections built into the use of the eUCI can be used with other data sets to evaluate service linkage across a variety of care environments. Ultimately, enhancing linkage to care services for

prisoners and recently released inmates will likely contribute to several important goals outlined in the 2010 National AIDS Strategy, including reducing: HIV incidence, reducing racial disparities in HIV infection and AIDS-related adverse health events. If individuals are successfully linked to care and maintained on treatment, this strategy can contribute to

efforts to reduce community viral load which may have demonstrable impacts on HIV incidence.

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