

Investigating the Not in Care List to Verify Care Status and Complete Missing Data: Overview of Potential Data Sources

Background

Once a health department's HIV surveillance program creates a line list of HIV-diagnosed persons who appear to be Not in Care (NIC), other sources of information should be reviewed to determine if the individuals on the NIC list are truly not in care and to update or complete any missing data. It is important to determine if the individuals are truly not in care in order to minimize the expenditure of resources locating individuals, since outreach is resource and time extensive.

Jurisdictions with existing Data to Care programs have found matching to other data sources useful to corroborate information about patient care status and/or contact information. For example, Seattle/King County and New York City use a variety of data sources including other government health and social service databases (e.g., homeless services, social welfare, housing authority, department of finance, correctional facilities), social media (e.g., Facebook, online dating websites), and online searches (e.g., LexisNexis/Accurint).^{1,2} Los Angeles County found with implementation of their activities that the most effective data sources for contact information included: HIV surveillance data; clinical medical records, and Ryan White HIV/AIDS Program (care) data.³

The purpose of this document is to provide an overview of the different types of data sources that jurisdictions can use to further investigate and refine their NIC lists. Matching can help verify care status, update an individual's contact information, and prioritize the NIC list into a more manageable, workable list for outreach staff given limited time, staff and resources.

Questions for Consideration

The following questions should be considered by jurisdictions prior to identifying data sources which they intend to match to their NIC lists:

- 1) What matching is already done with eHARS data to update an individual's care status and contact information? How often is this matching done?
- 2) What other internal health data sources are available to the surveillance program that can be used to match and complete or update care status and contact information for individuals on the NIC list?
- 3) Within the health department, who will be responsible for matching the NIC list to other government health data sources to complete missing information or update existing information?
- 4) How often will matching to other data sources be done?

¹ Seattle/King County. NW Public Health CFAR Consortium Out of Care Investigation Protocol.

² New York City presentation to Data to Care Workgroup. 11 December 2013.

³ Linkage and Re-engagement Programs. Presentation to National Quality Center in+care Campaign. 5 March 2014. Available at:

<http://www.incarecampaign.org/files/85234/Linkage%20and%20Reengagement%20Programs%2003052014.pptx>

- 5) What non-health data sources external to the health department can be used to complete/update missing data and verify care status? How often will these non-health department external data sources be reviewed and who in the health department is responsible for reviewing these non-health data sources?
- 6) When is contact/location information considered to be current? For example, a jurisdiction may consider an individual’s contact information to be current if their contact information has been reported or collected from an individual within the past two years.
- 7) How will any new information that was missing from eHARS be provided to the surveillance program, assessed for accuracy, and who will be responsible for updating the surveillance database?
- 8) How will HIV surveillance data be matched to other databases while maintaining security and confidentiality standards?
- 9) What is technically needed to conduct the match? Staff with certain skillsets? Matching software?

Potential Data Sources

Table 1 lists examples of health department data sources that might house information that can help determine current HIV care status and/or obtain updated contact information for NIC individuals.

Table 1: Examples of Health Department Data Sources That Might be Used to Investigate the Care Status and Update Contact Information of Not in Care Individuals

Health Department Data Sources To Match to the NIC List	Potential Information Available To Update Care Status and Contact Information
eHARS	Recent laboratory and medical provider information; evidence patient might have moved, transferred care or was diagnosed in another state
Ancillary HIV surveillance laboratory databases	Recent laboratory and medical provider information
STD Surveillance Databases	STD-related history and any new medical provider information; recent CD4 counts and viral load data; new contact information
Viral Hepatitis and Tuberculosis Databases	Recent diagnoses; new medical provider information; contact information
Disease Intervention Specialist (DIS) Files	History/notes of DIS interactions; risk factor information such as IDU or MSM
CAREWare (or state equivalent)	Recent evidence of HIV care and provider information; contact information
AIDS Drug Assistance Program (ADAP) databases	Recent prescription and provider information; contact information; recent evidence of HIV care
State Vital Record Databases, Social Security Death Index (SSDI), and National Death Index (NDI)	Vital status, date of death

Table 2 below lists data sources external to the health department that can be used to verify or update an individual’s contact or location information.

Table 2: Examples of External Data Sources That Might be Used to Verify or Update an Individual’s Care Status and/or Contact Information

External Data Sources	Potential Available Contact Information
Lexis/Nexis (Accurint)	Address changes, telephone number, email addresses; social security numbers; vital status
Other State Surveillance Programs	Contact other health departments if there is evidence in eHARS that the individual is living in or was diagnosed in another state
Social Media (Facebook, LinkedIn, Twitter, etc.)	Reviewed to see if contact information is revealed
Post Office Searches	Request sent to post office to see if a forwarding address has been requested
Driver’s license databases	Recent address changes
Prison and Jail Searches	Current imprisonment
Shelter Searches	Current location information
Voter Registration Lists	Recent address changes
Hospital- or clinic-based Electronic Medical Records (EMRs)*	Recent evidence of HIV care, provider information; updated contact information or evidence that the patient has moved out of the area
State Medicaid Databases*	Recent evidence of HIV care, provider information; updated contact information
Social Security Death Index (SSDI), and National Death Index (NDI)	Vital status, date of death

*Some health departments/jurisdictions have access to these systems/databases internally.

Another step of the investigation process, if possible, is to contact the last known care provider to verify care status and obtain any missing or updated patient contact information. In addition, by speaking with the last known provider, the health department could assess whether the physician has any interest in collaborating with the health department to outreach and attempt to re-engage the patient in care.

Jurisdiction’s Matching Plan

Table 3 below can be used to record current and future matching practices occurring in the health department and to identify new sources to match against the NIC list for Data to Care program purposes. Some database matching may be done as part of routine surveillance activities (i.e. matching vital statistics data with eHARS) and recording these databases in the table below could be helpful and would document the matching that is already occurring in the health department.

It is important to document decisions along the way to provide background data and rationale for why certain decisions were made and to inform future decisions regarding matching of data sources to the NIC list. Health departments should monitor which of their databases they use to match to their NIC lists provide the most useful information and which of their databases might not be worth the effort to match to. Jurisdictions can contact their CDC HIV Incidence and Case Surveillance Branch (HICSB) assigned epidemiologist to obtain more information on the electronic matching of databases and can also obtain more information on the HICSB password protected SharePoint website.

Table 3: Data Source Matching Practices: Types of Information to Document

Data source	Frequency of matching	Staff responsible for matching	Information provided	Other information (costs, data sharing agreement required, etc.)	Health department staff provided with matching results	Procedures for documenting results of matching
<i>Example: State vital records</i>	<i>Monthly</i>	<i>Surveillance coordinator</i>	<i>Vital status</i>	<i>Available through state vital records office – no cost or data sharing agreement required</i>	<i>Surveillance staff</i>	<i>eHARS update data collection form is completed</i>
<i>Example: LexisNexis</i>	<i>When NIC list is run</i>	<i>Prevention staff</i>	<i>Contact/location information</i>	<i>Cost is \$XXX annually</i>	<i>Surveillance staff</i>	<i>eHARS update data collection form is completed</i>