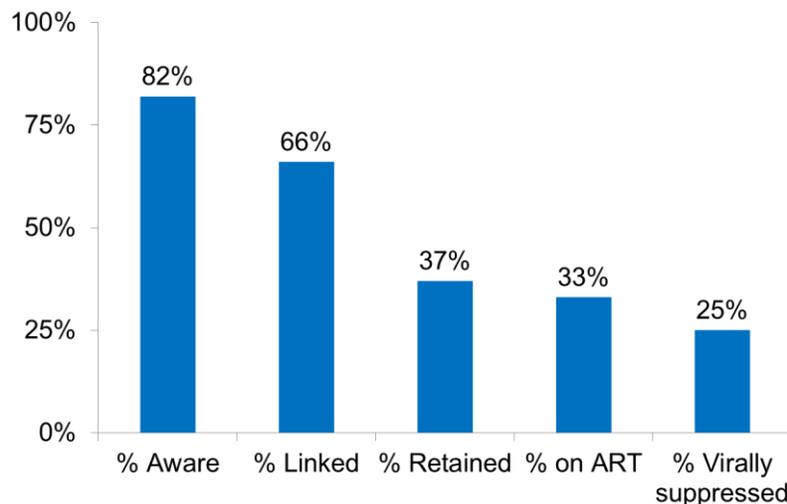


Prioritizing the *Data to Care* Not in Care List

Introduction

The aim of Data to Care is to use HIV surveillance data to identify people living with HIV (PLWH) that are not in care (NIC), link them to or re-engage them in care¹, and support them along the HIV Continuum of Care (Chart 1).

Chart 1: National HIV Continuum of Care, 2010²



The NIC list is generated by surveillance staff applying a pre-determined definition of NIC to eHARS data and matching the NIC list to other datasets to update contact information and vital status and verify care status (e.g., Ryan White HIV/AIDS Program data, AIDS Drug Assistance Program [ADAP] data, state vital records, Social Security Death Index). Depending on the size of the resultant NIC list and available resources, a health department might find that they are unable to follow up on every HIV-diagnosed person on the NIC list. Some health departments may have hundreds to thousands of individuals on their NIC lists. These large NIC lists can be difficult to manage and work through given limited time, staff and resources. Thus, many health departments may decide to prioritize their lists for outreach and linkage/re-engagement on a number of key variables. The goal of prioritization of the NIC list is to have the greatest public health impact given the available resources.

The following questions were developed to help health departments identify variables to use for NIC list prioritization. As health departments consider variables for prioritization, we suggest that they approach the selection from a public health perspective, thinking about how their selection will have the greatest impact on the number of PLWH who are in care and focusing on

¹ “Data to Care” generally refers to the use of individual-level surveillance data to identify persons who are not in care because they fell out of care or were never linked to care (excluding newly diagnosed).

² CDC. Today’s HIV Epidemic. Available at:

<http://www.cdc.gov/nchhstp/newsroom/docs/HIVFactSheets/TodaysEpidemic-508.pdf>

those groups of people that the health department feels should be prioritized for linkage/re-engagement services. Further, health departments should consider the impact on those PLWH who not receive follow-up as a result of prioritization, as well as the impact to ongoing HIV transmission in the population.

Potential variables for prioritization

The following variables can be considered for prioritization of the NIC list. Not all variables will necessarily be used for prioritization; however, it is likely that a health department may decide to use multiple prioritization variables to focus their list (e.g., focus on those NIC that were last seen at two providers within two target areas in the state). Additionally, there are other variables that the health department might identify as important that are not included in the list below. Please keep in mind that high quality data is essential. If a potential prioritization variable is missing a substantial number of observations or is of questionable quality, then it should not be considered.

- Value of last viral load (VL) – e.g., focus on those with an unsuppressed VL on the last measure
- Value of last CD4 count – e.g., focus on those with CD4 count of less than 200 on the last measure
- AIDS diagnosis – e.g., focus on those diagnosed with AIDS
- Time since last medical care visit (as measured by time since last CD4/VL result) – e.g., focus on those whose last CD4/VL was 12 to 24 months ago
- Time since diagnosis – e.g., focus on recently diagnosed, defined by health department as diagnosed greater than 12 months but less than five years ago
- Recency of infection – e.g., focus on more recent infections (e.g., acute infections)
- Time since any new information reported to the surveillance program – e.g., focus on those with most recent information updates
- Geography – e.g., focus on certain areas of the state that the health department wants to target based on incidence, prevalence, resources available for outreach
- Provider or facility³ – e.g., focus on top ordering providers or facilities in the state using surveillance data, such as top ten ordering providers in the state or top ten ordering facilities in the state; exclude patients whose last ordering facility was a jail/prison
- Client characteristics – e.g., focus on groups of individuals based on age, transmission category, and/or race/ethnicity

In determining which variables a jurisdiction will use for prioritizing the NIC list, it might be helpful for the health department to consider the following questions:

- Who is the health department's HIV prevention and care target population(s) or area(s)?

³ With a provider or combination Data to Care model, the health department may want to prioritize based on the facility rather than individual providers since data sharing agreements or memorandum of understanding will likely be in place to share information between the health department and facility on NIC patients.

- Example: Incidence is growing among young Black men who have sex with men (MSM) and young Black MSM is a target population for other health department prevention activities. Thus, the health department will focus their linkage/re-engagement efforts on those NIC who are young Black MSM.
- Given the time that it may take to locate people on the NIC list, who would be the most feasible to locate?
 - Example: PLWH who have had a CD4/VL 12 to 24 months ago are more likely to still reside in the jurisdiction, compared to PLWH whose last CD4/VL was more than five years ago. The health department concludes that it is easiest to locate those with a last CD4/VL result 12 to 24 months ago.

The “Prioritization of Variables Worksheet” attached to this document may be a useful tool for documenting potential prioritization variables based on the number and percent of PLWH representing each variable.

After surveillance has generated the NIC list, matched the list to other data sources to verify care status, update contact information, etc., and applied the prioritization schema, outreach and/or linkage/re-engagement staff (e.g., DIS, providers) may decide to further sort or prioritize the list. Some health departments allow providers to decide, after receiving the NIC list from the health department, who to reach out to first.

Preliminary Analyses

After identifying a list of variables to explore as possible prioritization variables, we suggest that the health department run frequencies on their generated NIC list for each of the selected variables to get a sense of their respective representation on the NIC list. They should also look at the interaction between variables, such as the frequency for a target population (e.g., Black MSM) within a target area (e.g., large city in the state). If the health department has a large NIC list and a potential prioritization variable captures most of the NIC population (80-90%), then it may not be a good choice for prioritization since it will not narrow down the list into a more manageable workload.

The health department should document and review the results from the preliminary analyses of the NIC list before finalizing their list of prioritization variables. Table 1 provides some guidance on how to document results from these analyses. Further, an Excel file is provided for documentation, which includes formulas to automatically calculate percentages based on entered data. Again, not all variables need to be explored. The health department can focus on those variables that match their priorities.

Table 1: Potential prioritization variables for the NIC list: number of PLWH within each category and percentage of the overall NIC population

Potential prioritization variable	Definition of the prioritization variable	Number included in the NIC list	Percentage of the NIC list
Total PLWH included in the NIC list	Total meeting the NIC definition		100%
Target population(s)			
Time since last visit			
Last VL			
Last CD4			
AIDS diagnosis			
Time since diagnosis			
Recency of infection			
Time since new information reported to surveillance			
Geography			
Provider or facility			
Client age			
Client race/ethnicity			
Client transmission risk			
Other			

Example

A southern state in the U.S. intends to use surveillance data to generate the NIC list bi-annually. Their first run of the NIC list includes 3,000 individuals. They have chosen to use a combination model. They plan to use DIS to contact those PLWH not in care. However, the health department only has enough DIS staff in two cities to conduct outreach, linkage and re-engagement (O/L/R) services. DIS can manage 10 NIC cases per month (60 cases over the six month period) in the first city and 20 cases per month (120 cases over the six month period) in the second city. In reviewing their epidemiologic data, they note that the most recent diagnoses are among young, Black MSM between ages 18 and 24. The health department also has an existing relationship with two facilities in the first city that can offer linkage services to their former clients. The facilities can handle 10 cases per month each (60 cases over the six month period per facility; 120 cases total).

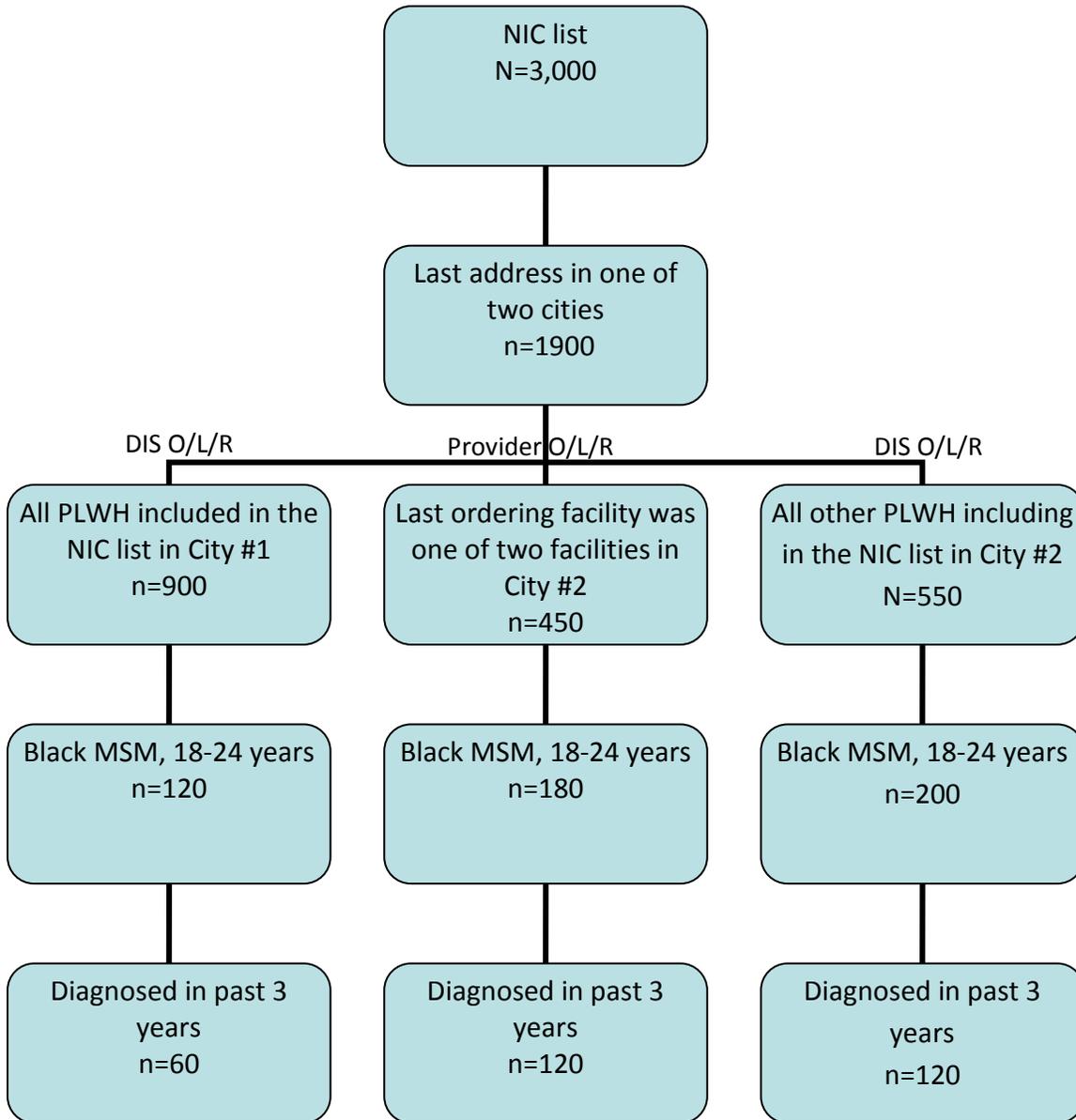
Below is the table that the health department developed to document the initial analysis of their data.

Table 2: Example of a completed table of potential prioritization variables for a state

Potential prioritization variable	Definition of the prioritization variable	Number included in the NIC list	Percentage of the NIC list
Total PLWH included in the NIC list	Total meeting the NIC definition: <i>No CD4/VL reported in 12 or more months</i>	<i>3,000</i>	<i>100%</i>
Geography	<i>City #1</i> <i>City #2</i>	<i>900</i> <i>1000</i>	<i>30%</i> <i>33%</i>
Provider or facility	<i>Two facilities in city #2 that offer re-engagement services to former clients</i>	<i>Facility #1: 250</i> <i>Facility #2: 200</i>	<i>25%</i> <i>20%</i>
Target population	<i>Black MSM, 18-24 years</i>	<i>700</i>	<i>23%</i>
Time since diagnosis	<i>Diagnosed in past three years</i>	<i>340</i>	<i>11%</i>

The frequencies show that: 1) none of the variables encompasses the entire NIC list; and 2) case loads, based on any of these variables alone, would be too high given the limited resources in the two cities. The health department then drills down and looks at the interaction between variables (Chart 2) to further refine the prioritization. The list is first narrowed down to the two target areas and then is broken down by city and target facility. Finally, the list is further refined by the target population (Black MSM 18-24 years old). Given that resources in City #1 can only handle 60 cases over the next six months and City #2 can only handle 240 cases, the list is further prioritized based on time since diagnosis (diagnosed in past three years). As a result, the health department is going to prioritize 60 NIC cases in City #1 and 240 NIC cases in City #2 over the next six months, which matches their available resources.

Chart 2: Example flow chart documenting the relationship between variables for prioritization of the NIC list in the state



Jurisdiction’s Final Prioritization Schema

Finalizing the NIC prioritization variables is an iterative process, based on the size of the list, selection of Data to Care program model, available resources, and/or experience of the health department using a set of prioritization variables. The health department might decide to revisit the prioritization schema after they have had a chance to apply it and use it in the field, and they may select a different set of prioritization variables in the next iteration based on changes in the epidemic, available staff and resources, size of the NIC list, etc.

The space below can be used to record the health department’s final decisions regarding the prioritization schema that they intend use for their current or proposed Data to Care linkage/re-engagement activities. It is important to document decisions along the way to provide background data and rationale for why certain decisions were made and inform future decisions regarding prioritization of the NIC list.

Date: _____