

Summary of Not in Care (NIC) Definitions Used by Other Health Departments

This document summarizes not in care definitions, inclusion/exclusion criteria, and prioritization considerations after running the not in care list. This information was gathered from health departments implementing data to care activities and can be a useful guide for other jurisdictions as they establish their not in care definitions and criteria.

A. Establishing an operational definition and key inclusion criteria for the “not in care” list

1. Decisions regarding criteria to use for determining whether someone is out of care (e.g., 3, 6, 9, or 12 months with no CD4 or viral load [VL] measure).
2. Decisions about whether to prioritize individuals with no previous evidence of care or individuals who have fallen out of care. The following are examples of criteria/data that can be used to prioritize individuals on the OOC list:
 - Time of diagnosis -recent vs. those with older diagnoses
 - Recent infection (acute infection) vs. long-standing infection
 - Time since last care visit
 - Time since any new information reported to HIV surveillance program
 - Most recent unsuppressed VL
 - Geographic area of current residence
 - Transmission category
 - Race/ethnicity
 - Current age

B. Examples of OOC definitions/prioritization criteria used by other Health Departments currently with Data to Care programs

Jurisdiction	Out of Care definition	Inclusions/Exclusions	Prioritize	DtC Model
<i>City/County Health Departments</i>				
Los Angeles, CA	Eligibility includes HIV+ patients who have not had a primary care visit in the past six months and last viral load >200 copies/mL; or no HIV primary care visits in 12 months ; or newly diagnosed and never in care			Health department
New York City, NY	Included all confirmed HIV-positive in NYC HIV surveillance registry with no CD4/VL results reported for \geq 9 months.	Last HIV medical care at a NYC facility; last known residential address in NYC	NYC did not prioritize based on most recent CD4/VL since the most recent could have been 9 months to several years ago and was considered not indicative of current disease status	Health department

Jurisdiction	Out of Care definition	Inclusions/Exclusions	Prioritize	DtC Model
San Francisco, CA	Included all cases of HIV reported to SF eHARS with no CD4/VL results for ≥ 9 months; VL >200 copies/mL at last measurement obtained 9-15 months before index date (RSVP Project)	Included cases age 18+ years and alive at index date (cutoff date for defining OOC)	Prioritized cases residing in the greater Greater SF Bay area (GBA); had most recent VL or CD4 in GBA; able to speak English; not in jail/prison	Health department
Seattle/King County, WA	Out of care defined as HIV cases who have never had a CD4/VL reported, who have had no CD4/VL results reported for ≥ 12 months, or who have had a CD4 ≤ 500 and VL >500 at time of last report	Included cases diagnosed ≥ 6 months ago; Excluded deaths ascertained through routine surveillance procedures		Health department
<i>State/Territorial Health Departments</i>				
State of Louisiana	<p>First program (LAPHIE): Included all cases of HIV with no CD4/VL reported for ≥ 9 months (used to be 12 months, but switched to 9 months in 2013). For newly diagnosed, no CD4/VL in the six months since diagnosis</p> <p>Second program (CAPUS-funded LA LINKS): OOC defined as: No CD4/VL in past 12 months; Newly diagnosed and have not accessed care in past six months; or sustained high VLs</p>	<p>LAPHIE: Person alive, current address in LA, at least one confirmatory test since 2000 (persons with physician diagnosis excluded). Only shares information with participating hospitals/health systems that can electronically share data (e.g., LSU 8 hospital system)</p> <p>LA LINKS: Only includes three years of surveillance data</p>	LA LINKS has a complicated eligibility criteria to create a rank order in groups	<p>LAPHIE: Provider</p> <p>LA LINKS: Health department</p>
State of North Carolina	Included all cases of HIV with no CD4/VL results reported for ≥ 9 months			Health department
State of Washington	<p>No labs: Included all cases of HIV with no CD4/VL results reported for ≥ 12 months</p> <p>Bad labs: Most recent reported viral load count is < 500 and the CD4 count is < 500 or missing</p>	Current WA residents who were diagnosed 12 months prior to date of inquiry (for running the OOC list)		Health department-Provider combination

Jurisdiction	Out of Care definition	Inclusions/Exclusions	Prioritize	DtC Model
Washington, DC	Providers send lists of their patients that are out of care for at least six months to the HD; The HD matches names to surveillance to determine if actually OOC or seeing another provider; then HD sends updated lists back to providers			Provider

For further information:

- Udeagu CC, Webster TR, Bocour A, et al. Lost or just not following up: public health effort to re-engage HIV-infected persons lost to follow-up into HIV medical care. *AIDS* 2013; 27(14): 2271-9.
- Using surveillance and other data to improve HIV care linkage and retention. A report from a Think Tank convened by Project Inform, held November 6 & 7, 2012, San Francisco CA. Available at: http://www.projectinform.org/pdf/surveillance_0313.pdf
- Buskin SE, Barash EA, Bauer, AL, et al. HIV infected individuals presumed to not be receiving HIV medical care: a surveillance program evaluation for investigations and referrals in Seattle, Washington State, USA. *Journal of HIV/AIDS Surveillance & Epidemiology* 2011; 3(1): 3.
- Two CROI abstracts (PDFs) that JSI shared with health departments over email:
 - Dombrowski JC, Hughes JP, Castel AD, et al. A surveillance-based risk scoring tool to prioritize cases for HIV care re-linkage efforts (Seattle/King County).
 - Buchacz K, Chen MJ, Paris MK, et al. Using HIV surveillance registry data to re-link patients to care: the RSVP Project in San Francisco.
- Data to Care website at effectiveinterventions.org – three Health Department Data to Care Program case studies (States of Louisiana, Washington and North Carolina).