Organizational HIV Treatment Cascades

Frequently Asked Questions, 2018

To assist organizations in preparing their Organizational HIV Treatment Cascades as part of the 2018 Quality of Care Review, the NYSDOH AIDS Institute has prepared a list of Frequently Asked Questions. This document will be amended over the coming months as we receive more questions from providers.

Cascade Methodology Questions

1. ***My HIV facility is part of a much larger health system with multiple hospitals and clinics at various locations. Am I responsible for finding all PLWH who touched the larger health system or just those who enter the facility at which my HIV clinic is located?***

Information should be reported for each clinic providing HIV care in an organization. In addition, the goal is to identify all PLWH who touch the entire organization, not just the HIV clinics. If the organization has several locations, it is responsible for identifying PLWH across this network. Providers are encouraged to get in touch with their coach to discuss the details of their situation.

2. ***Should organizations include a measure of retention?***

A measure of retention in care is not required. Should an organization be interested in developing and tracking its own retention measure as part of its cascade, it is welcome to include one.

3. ***What does it mean for a newly diagnosed patient to be linked to medical care?***

Linkage to medical care means that a patient has had a visit with a medical provider with ART prescribing privileges within 3 calendar days of diagnosis. The provider does not have to prescribe ART at that time, but the visit does have to be related to the patient's new HIV diagnosis.

4. ***For linkage to care, how is diagnosis defined? Does it mean when the lab confirms the test? What about when the physician informs the patient of the diagnosis?***

Diagnosis is defined as the time at which a provider, based on all available evidence and in line with his or her clinical judgment, determines that the patient has HIV.

5. ***Should I include data on 3-day linkage to care for patients diagnosed with HIV in 2017 at another organization?***

Organizations are not required to provide this information; instead, organizations should provide information on 3-day linkage to care for those patients who were newly diagnosed with HIV *at their organization* in 2017.

6. ***Should patients newly diagnosed at an organization in 2017 who were not linked to care internally or externally be included in the denominator of the calculations for prescription of ART, receipt of a viral load test, and viral suppression?***

Yes, these patients should be included in the organization's calculations, unless those patients were confirmed to be in care elsewhere by the end of the year.

7. ***Can patients who were deceased by the end of 2017, incarcerated at the end of 2017, or confirmed in care elsewhere at the end of 2017 be excluded from the calculations for prescription of ART, receipt of a viral load test, and viral suppression for the newly diagnosed/new-to-care cascade?***

Yes. If an organization excludes patients for any of these reasons, document in the methodology section how many patients were excluded and the justification for doing so.

8. ***Should patients with no known viral load tests in 2017 be counted as unsuppressed or excluded?***

Patients with no known viral load tests in 2017 should be counted as unsuppressed.

9. ***How should previously diagnosed patients who have moved out of state or out of the region be counted?***

If an organization has confirmed that they are in HIV primary care in their new location, then they can be excluded from its open caseload. If not, then they should be included in the appropriate caseload (active or non-active), with a note in the methodology section explaining that they have since moved out of the area.

10. ***How should organizations categorize patients whose housing status may be transitory or has changed throughout the year?***

We recommend that organizations start by looking at the housing situation of their patients at the end of the measurement period (end of 2017). However, if an organization thinks that the housing status an individual has at the end of the year is not reflective of the housing status that he or she had for most of 2017, we recommend that the organization categorize him or her in the manner they deem appropriate. For example, it may make sense to categorize someone who was unstably housed for the first 11 months of 2017, then acquired stable housing in December 2017, to be categorized as unstably housed, since that unstable housing situation throughout the year likely affected his or her care outcome.

The objective of disaggregating care outcomes by housing status is to identify potential disparities in care outcomes for people with different housing situations and to target improvement strategies to subpopulations that may be particularly vulnerable to falling out of care because of their housing status. We ask that organizations be consistent in how they categorize such patients and document in the methodology section the reasoning behind how they categorized patients who did not fit neatly into one category.

11. ***How do categorizations of key characteristics of the active caseload cascade vary from Ryan White or NYS surveillance categories?***

The categories for age and race/ethnicity are identical between the cascade guidance and NYS surveillance.[1] Categories used within HRSA's Ryan White HIV/AIDS Program for age and race/ethnicity differ slightly.[2] Risk categories in the guidance are nearly identical to those used by the NYS Bureau of HIV/AIDS Epidemiology, except that they do not include Blood Products and modified the "Unknown" category from NYS surveillance to be "Unknown/other."

The cascade guidance includes the following categories for gender: Male, Female, Transgender, and Unknown, unlike NYS surveillance, which uses sex assigned at birth. The Ryan White HIV/AIDS Program requires reporting on sex assigned at birth, current gender identity, and transgender type, which is reported in the most recent client-level report as Male, Female, or Transgender.

The housing status categories used in the cascade guidance are the same as those used by the Ryan White HIV/AIDS Program, which are categories defined by the U.S. Department of Housing and Urban Development. NYS surveillance does not collect housing status information.

12. ***For the drill down of active patients by demographic information, should organizations submit a patient list or an aggregated list?***

Do not submit unique patient identifiers as part of the cascade submission. An aggregated list – with both total numbers in each category (e.g., 15 patients are male) and the percentage of the total number of active patients (e.g., 45% of active patients are male) – should be included in the submission.

13. ***Does the drill down of non-active patients by service delivery location include duplicates?***

Yes. Do not de-duplicate the list across service delivery points (e.g., it is expected that someone who visited the emergency department and was admitted as an inpatient will be counted in both of those locations).

Resources Questions – Results Section

14. ***What are some resources available for determining if patients are in care elsewhere, incarcerated, or deceased?***

Regional Health Information Organizations

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[1] Bureau of HIV/AIDS Epidemiology, AIDS Institute, New York State Department of Health. New York State HIV/AIDS Annual Surveillance Report: For Cases Diagnosed Through December 2015. Published March 2017. https://www.health.ny.gov/diseases/aids/general/statistics/annual/2015/2015_annual_surveillance_report.pdf

[2] Health Resources and Services Administration. Ryan White HIV/AIDS Annual Client-Level Data Report 2015. Published December 2016. https://hab.hrsa.gov/sites/default/files/hab/data/datareports/2015rwhapdatareport.pdf

Regional Health Information Organizations (RHIOs), which share electronic health information across participating organizations within a given region, can be useful in determining which patients are in care elsewhere, in prison, or deceased. To access data in any RHIO or in the SHIN-NY, 1) an organization must be a participant of a RHIO, and 2) the patient to be queried must have consented to have their records included in the RHIO, except in specific circumstances such as provision of emergency treatment, one-to-one exchanges between healthcare providers, and the sending of care alerts.[3]

Provider portals

The NYS HIV/AIDS Provider Portal allows providers to submit inquiries on patients living with HIV to ascertain whether they are engaged in care, deceased, living out of state, never linked to care, or out of care.[4] A similar service is available in NYC, through the Department of Health and Mental Hygiene, which maintains a web-based platform that can help providers determine if their patient is in care elsewhere or deceased.[5]

Incarceration databases

Most individuals who are, or who have been, incarcerated in prisons or jails (with a few exceptions, including children) can be identified using the Inmate Population Information Search for those in NYS prisons; the NYC Department of Correction Inmate Lookup Service for those held by Bronx, Kings, New York, Queens, or Richmond counties; the Federal Bureau of Prisons database for those in federal prison; or VineLink for those in county jails outside of NYC.[6]

Resources Questions – Analysis and Improvement Section

15. *Where can I go to find resources on creating an improvement plan?*

NYS Quality of Care Program staff will be holding webinars on this topic. Coaches are available to help organizations with every step of the cascade process, including analysis of cascade results and development of an improvement plan. In addition, organizations are encouraged to consult existing resources available through HRSA and the Institute for Healthcare Improvement. For examples of some of last year's submissions, see the Quality Corner of the Ending the Epidemic Dashboard.

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[3] New York State Department of Health. *Privacy and Security Policies and Procedures for Qualified Entities and their Participants in New York State under 10 NYCRR § 300.3(b)(1).* Version 3.4. June 2017. https://www.health.ny.gov/technology/regulations/shin-ny/docs/privacy_and_security_policies.pdf

[4] The Provider Portal can be found here: https://commerce.health.state.ny.us/public/hcs_login.html

[5] The NYC Care Status Report System can be found here: https://www1.nyc.gov/site/doh/health/health-topics/aids-hiv-care-status-reports-system.page?_sm_au_=iVVnqVRSQwZNMZ0f

[6] The Inmate Population Information Search can be found here: http://nysdoccslookup.doccs.ny.gov/kinqw00. The NYC Department of Correction Inmate Lookup Service can be found here: http://a073-ils-web.nyc.gov/inmatelookup/pages/common/find.jsf. The Federal Bureau of Prisons database can be found here: https://www.bop.gov/inmateloc/?_sm_au_=iVVnqVRSQwZNMZ0f. VineLink can be found here: https://vinelink.com/?_sm_au_=iVVnqVRSQwZNMZ0f#/search

Process Questions

16. *Whom do I contact with questions or requests for clarification?*

Questions or requests for clarification can be directed to an organization's QI coach or to qocreviews@health.ny.gov, where they will be addressed by a staff member from the Quality of Care Program.

17*. How can providers determine who their quality improvement coach is?*

Contact qocreviews@health.ny.gov.

18. *When is the due date for submissions? How will organizational cascades be submitted?*

Submissions are due no later than 11:59 p.m. on Thursday, May 31, 2018. Submissions should be sent as email attachments to qocreviews@health.ny.gov, with the organization's assigned QI coach copied.

19*. How will organizational cascades be evaluated?*

Submissions will be evaluated based on their adherence to the criteria in the guidance document. Organizations may use the checklist to help ensure they have completed all necessary components. Ongoing technical assistance will be available to help organizations refine their improvement strategies.

Following submission, organizations will receive an email from qocreviews@health.ny.gov confirming receipt of the submission within two business days. Submissions will be evaluated based on their adherence to the guidance by their assigned coach and then submitted for final review by leadership of the NYS HIV Quality Program.

20. *Will additional guidance be provided beyond this document?*

NYS Quality of Care Program staff will be convening webinars throughout the months of March, April, and May to assist organizations with any questions they may have. Program staff will also be available to provide one-on-one technical assistance and/or schedule a standing time for office hours to organizations.

Four introductory webinars were offered in March. A recording will be made available on www.hivguidelines.org.

Additional webinars, on various topics related to preparing the cascade submissions, will be held every Tuesday, from 12:00-1:00 p.m., starting March 27 and continuing until May 22. Topics for these weekly webinars, along with WebEx connection instructions, will be sent out in advance.