Organizational HIV Treatment Cascade Review Guidance

Introduction

This guidance document provides organizations with the necessary tools and resources to submit their Organizational HIV Treatment Cascade Review. As part of the 2019 annual HIV Quality of Care Program Review, organizations that provide medical care to people living with HIV (PLWH) in New York State (NYS) will be expected to complete the 2019 Organizational HIV Treatment Cascade Data Submission Excel Template for care provided in 2018. The Excel template should be submitted to the New York State Department of Health (NYSDOH) AIDS Institute via the Health Commerce System; submissions that pass validation checks will be incorporated into a secure AIDS Institute database. The Data Submission Excel Template includes a section to input patient-level data, a section visualizing cascade indicator results into charts and tables (these will be automatically generated from the provided patient level data), and a section for the organization's methodology, key findings, and quality improvement plan, which contains consumer involvement and updates on recent QI projects including stigma reduction activities.

Background

Organizational HIV Treatment Cascade

Ensuring that all PLWH receive high-quality medical care remains a top priority in combating the HIV/AIDS epidemic in the United States, yet achieving this goal remains a challenge. For providers to have an accurate understanding of the quality of care they are delivering to PLWH in their organizations, they must be able to collect, analyze, and visualize data on their performance. The HIV Treatment Cascade, when applied to a clinic population, allows providers to better identify gaps along the care continuum, starting from linkage and engagement in care to viral suppression. This represents a key strategy in our efforts to End the Epidemic in NYS by 2020. The Organizational HIV Treatment Cascade provides health care institutions with a standardized tool to:

1. Monitor the extent and quality of care being delivered to all PLWH seen at an organization, and not just those who are actively engaged in their HIV program.
2. Identify gaps in the sequence of steps between diagnosis and viral suppression.
3. Develop data-driven plans to assess and improve gaps within an organization's care continuum through QI activities.

4. In addition, organizational HIV treatment cascade data is integrated into New York State regional quality improvement collaboratives and quality learning networks to drive our collective efforts and progress toward ending the epidemic.

2019 Organizational HIV Treatment Cascade Data Template Overview

The 2019 Organizational HIV Treatment Cascade Data Submission Excel Template consists of the following components:

1. A spreadsheet to input patient-level data (See Table 1). This will include;
   - Patient names and demographic data (See Table 2).
   - Care continuum data (linkage to care for newly diagnosed patients, antiretroviral (ARV) prescription, viral load testing and viral suppression).
   - Data validation features to ensure the integrity of the inputted patient level data.
2. Automated cascade charts from inputted patient level data.
   - Newly diagnosed/new-to-care (if applicable)
   - Previously diagnosed
     o Open caseload
     o Established Active caseload
3. Automated PivotTable report to allow drill-down table of Active caseload by key characteristics and similar sub-analysis.
4. Methodology section
   - A narrative of the methodology used to collect data
5. Key findings of the current review
   - Document the findings from the analysis of the cascade data.
6. Quality improvement plan
   - An update on an organization's 2018 cascade quality improvement work
   - A quality improvement plan for 2019 detailing how the organization intends to reduce the gaps in care identified by their cascades.
     - Consumer Involvement
       o Develop a specific, measurable, time-bound improvement goal based on recommendations and meaningful involvement by consumers
       o Explain how, by whom, and when these steps will be measured and assessed
       o Explain how consumers will be informed if goal recommended was successful

All submissions will be reviewed by the Quality of Care Program staff in the Office of the Medical Director and will be approved by senior medical staff. Formal approval of submissions will be sent subsequently after review by the Quality of Care program.

Approvals will involve a review of an organization's adherence to required submission components described in this document, as well a satisfactory analysis of cascade data leading to a responsive quality improvement plan. Feedback will be provided to guide the integration of the cascades into organizations' ongoing quality management programs.

Table 1: Patient level data to be collected

Type of Patients	Patient level Data
All Patients	First name of patient
	Last name of patient
	Initial letter of patient's middle name
	Patient's date of birth
	Patient's sex at birth
	Patient's current gender
	Patient's ethnicity
	Hispanic subgroup if applicable (multiple entries are allowed, separated by comma(s))
	Patient's race (multiple entries are allowed, separated by comma(s))
	Asian subgroup if applicable (multiple entries are allowed, separated by comma(s))
	Patient's housing status on last assessment/report during the review period
	Patient's HIV exposure risk (multiple entries are allowed, separated by comma(s))
	Primary insurance on final status check during the review period
	Patient's enrollment status
	Did the patient receive antiretroviral therapy (besides PrEP) during the review period?
Previously Diagnosed	If the patient was diagnosed prior to the review period (or diagnosis date is not known), did he/she receive a viral load test during the review period?
	Standardized abbreviation for the clinic within the organization where patient receives care (active patients)
Open & Active	If the patient was diagnosed prior to the review period (or diagnosis date is not known) and tested during the review period, was the patient virally suppressed (< 200 copies/mL) on final VL during the review period?
Unknown Status	Service line or facility where patient last received care during the review period (inactive patients)
	If patient was seen on a service line other than those we have listed, specify where the patient was seen.
Newly Diagnosed	Was the patient newly diagnosed during the review period, and if so, internally or externally?
	If the patient was diagnosed during the review period, what was the date of the patient's diagnosis?
	If the patient was newly diagnosed as an inpatient during the review period, when was the patient discharged from inpatient care?

	If the patient was newly diagnosed during the review period, was he/she seen for HIV care during the review period?
	If the patient was newly diagnosed and seen for HIV care, what was the date when the patient was first seen for HIV care?
	If the patient was diagnosed during the review period and tested during the review period, was the patient virally suppressed (< 200 copies/mL) on any test during the review period?
	If the patient was diagnosed during the review period and tested during the review period, what was the date of the first VL test?
	If the patient was diagnosed during the review period and suppressed during the review period, what was the date of the first suppressed VL (< 200 copies/mL)?

Table 2: Categories of key characteristics for the active caseload drill down

Characteristic	Categories (adapted from CDC, NYS Bureau of HIV/AIDS Epidemiology, and HUD)
Age	0-12; 13-19; 20-24; 25-29; 30-39; 40-49; 50-59; 60+; Unknown
Sex at Birth	Male; Female; Intersex; Unknown
Current Gender	Male; Female; Transgender Man; Transgender Woman; Other (Transgender other, non-binary, gender non-conforming); Unknown
Race	White; Black or African American; Asian; Native Hawaiian or Pacific Islander; American Indian or Alaska Native; Unknown
Ethnicity	Hispanic or Latina/Latino; Non-Hispanic, Latina/Latino; Unknown
Risk Category	Men who have Sex with Men (MSM); Intravenous Drug Users (IDU); Heterosexual contact; Hemophilia or coagulation disorder; Blood transfusion or Blood products; Perinatal transmission; Other; Unknown
Housing Status	Stable permanent housing; Temporary housing[1]; Unstable housing[2]; Unknown

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[1] Defined as short-term arrangement with family or friends, transitional housing or temporary institutional placement including substance abuse treatment facilities and psychiatric hospitals.
[2] Defined as emergency shelters, jail/prison, places not meant for human habitation

Visualizing Cascade Indicator Results and Charts

Indictor eligibility is dependent on care status. Please see the care status chart in the glossary for details.

Please note, however, that all HIV positive patients who were seen at the organization in 2018 should be included in the patient-level submission, including those who died during the review period or were incarcerated, relocated or confirmed to be receiving ongoing HIV care at another site as of the end of the review period.

The Cascade Data Template will automatically generate reports and cascades as follows:

1. **Newly Diagnosed Patients:** One cascade will automatically be generated for all patients diagnosed in 2018 who were seen at an organization.

   - **Linked-to-Care:** All patients diagnosed with HIV at the organization in 2018 who were linked to care within 3 days. A patient is considered to have been linked to medical care if the individual attended a routine HIV medical visit within three calendar days of diagnosis with HIV by a treating physician.[3] We will also analyze this based on post-discharge care within 30 days for inpatients.
   - **ARV Therapy**: All newly diagnosed patients who were prescribed ART in 2018. Eligible patients include those enrolled in care ("active") or of unknown care status as of the end of the review period.
   - **Viral Load Testing:** All newly diagnosed patients with a recorded viral load test within 91 days from diagnosis. Eligible patients include those enrolled in care ("active") or of unknown care status as of the end of the review period.
   - **Viral Suppression:** All newly diagnosed with viral load <200 copies/mL within 91 days from diagnosis. Eligible patients include those enrolled in care ("active") or of unknown care status as of the end of the review period.

2. **New-to-Care Patients:** One cascade will automatically be generated for all patients who are new to an organization's HIV program in 2018 (or returning after not being seen in the 2 prior calendar years), regardless of the year in which they were diagnosed.[4]

   - **ARV Therapy**: All new-to-care patients who were prescribed ART in 2018. Eligible patients include those enrolled in care or lost to follow up as of the end of the review period.
   - **Viral Load Testing:** All other new-to-care patients with a recorded viral load

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[3] A *routine HIV medical visit* is defined as any medical visit with a clinician with ART prescribing privileges. PLWH are considered linked if they successfully attend this initial medical visit, irrespective of whether ART is initiated during that visit.

[4] The *date of diagnosis* is defined as the date on which a diagnosis of HIV is made by a treating physician.

during the review period. Eligible patients include those enrolled in care or lost to follow up as of the end of the review period.

- **Viral Suppression:** All other new-to-care patients with a viral load <200 copies/mL at last VL test of 2018. Eligible patients include those enrolled in care or lost to follow up as of the end of the review period.

3. **Previously Diagnosed Patients:** Two cascades will automatically be generated for all previously diagnosed patients.
   - One for all open patients (established active and open non-active).

   - One for all established active patients that are broken down by HIV care site, if there are multiple care sites.

   3.1 **Open Caseload:** All previously diagnosed patients who received any services from the organization within 2018, except those who were new to care in 2018 (or returning after two or years) or who were deceased, incarcerated or confirmed to be in care elsewhere by the of the year.
   - **ARV Therapy:** All open patients who were prescribed ART in 2018.
   - **Viral Load Testing:** All open patients with a recorded viral load test in 2018.
   - **Viral Suppression:** All open patients with a viral load <200 copies/mL at last VL test of 2018.

   3.2 **Established Active Caseload:** All previously diagnosed patients who received HIV primary care services within the organization in 2018, except those new to care in 2018.
   - **ARV Therapy:** All established active patients who were prescribed ART during 2018.
   - **Viral Load Testing:** All established active patients with a documented viral load test in 2018.
   - **Viral Suppression:** All established active patients with a viral load <200 copies/mL at last test of 2018.

4. **Automated Drill Down of Established Active Caseload by Key Characteristics:** This will help identify ongoing disparities in clinical outcomes among subpopulations of PLWH enrolled in an organization's HIV primary care program.
   - We will automate calculation of the active caseload, prescription of ART, receipt of a viral load test, and viral suppression rate for each of these subgroups.

5. **Service Delivery Points for Non-Active Caseload:** To better target re-engagement interventions among PLWH without evidence of ongoing HIV care, organizations will be expected to report the **service delivery points** visited by open-caseload PLWH who did *not* receive HIV primary care services within the organization (and who were not

incarcerated, relocated or deceased as of the end of the review period). In other words, organizations will be expected to report the delivery points at which non-active open caseload patients received services.

- Report service delivery points for non-active patients.
- We will automate calculation of how many non-active patients were seen at each delivery point.
- Service delivery points include:
    i. Emergency Department/Urgent Care
    ii. Inpatient care, including ICU, surgery and psychiatric care.
    iii. Primary care (outside of HIV clinic(s))
    iv. Faculty practice HIV care
    v. Non-HIV specialty care such as cardiology, pulmonology, etc.
    vi. Reproductive health services
    vii. Mental and behavioral health services
    viii. Dental services
    ix. Supportive services
    x. Other (please specify)

Reporting methodology

For cascades to be understood by internal and external stakeholders, the methodology underlying their construction should be transparently reported. Organizations will therefore be expected to provide detailed answers to the following questions:

✓ What sources of data were used for the patient level data?

✓ How was service delivery point determined and verified for non-active open caseload patients?

✓ How were patients determined to be deceased, incarcerated, or in care at an outside organization?

✓ How were date of diagnosis, first care date, first viral load date and first suppressed viral load date determined for the newly diagnosed patients?

✓ How were patients newly diagnosed internally distinguished from those externally diagnosed?

✓ What are the limitations specific to each data source?

Key Findings

This description should cite specific data from the cascades and explain how these indicate suboptimal outcomes in the context of internal, state, and/or national HIV treatment performance goals.

✓ A detailed description of significant gaps in care that are revealed during the review year, as well any disparities that emerge through disaggregation of outcomes by key characteristics.

✓ A narrative description of changes (if any) between the 2017 and 2018 cascade results.

Developing a Quality Improvement Plan

Organizations will be asked to submit an analysis and quality improvement plan that uses the identified significant gaps in the cascades to develop a formal strategy that addresses these gaps. This plan should feature **an analysis of significant gaps, as well as disparities that emerged through disaggregation of outcomes by key characteristics.** The results of the Organizational HIV Treatment Cascades should be incorporated into an organization's broader improvement activities regarding HIV treatment. At a minimum, each organization's improvement plan should include the following:

✓ A list of specific, measurable, and time-bound improvement goals that specifically address the gaps. Numerical goals described as percentages should consider what the actual net improvement will be based on that percentage (e.g., a 5% goal for 20 patients only represents a difference of one patient).

✓ Each improvement goal should have a detailed description of proposed action steps (including how and by when these steps will be measured and assessed) and a roster of staff members responsible for implementation.

✓ A list of organization staff, including the HIV medical director, who will be responsible for execution of the proposed improvement plan. If applicable, organizations should also list any institutional or external partnerships that will be leveraged to implement the proposed improvement plan.

✓ A plan to disseminate the cascades to all relevant stakeholders (e.g., display of cascades in clinics for staff and patients to see, dissemination to organization leadership). Organizations will be strongly encouraged to include regional HIV quality conferences, meetings, and webinars (e.g., NYLINKS meetings) as potential forums for dissemination of their cascades and improvement plans.

Update on Previous Quality Improvement Plan

A progress report on 2018's improvement goals and quality improvement plan.

✓ Include a description of quality improvement interventions that were tested throughout 2018.

✓ Explain if there were any barriers that were faced when implementing the quality improvement interventions. In addition, describe how the improvement plan was modified in response to changes.

✓ Were the stated goals achieved by the end of 2018?

Consumer Involvement

Each organization must provide an explanation of how consumers were engaged in the process of developing the quality improvement plan based on the data in the cascades.

✓ Explain how consumers were given the opportunity to learn about the methodology used to define each indicator and construct each bar on treatment cascades, including how the numerator and denominator were derived.

Submission Process Steps

1) Health Commerce System Registration

The cascade review will require the submission of patient-level data into a secure database through the Health Commerce System. To ensure a fully confidential process, organizations will need to identify appropriate staff to use the Health Commerce System (HCS) for data submission.

Registration Process:
1) Identify someone at the organization responsible for submitting the data. While only one upload is needed per organization, you may wish to identify a backup person as well.
2) Provide HCS access for these staff:
   a) If your organization is already registered to use the Health Commerce System, contact the organization's HCS Coordinator to register additional staff as needed.
   b) If the organization does not have a HCS Coordinator or do not know if the organization has an HCS coordinator, contact Joe Kobilca at Joseph.Kobilca@health.ny.gov, and provide your organization's name and the name and address of the clinic where you work.

2) Completion of Data Template

See Organizational Treatment Cascade Data Collection and Reporting Instructions.

3) Health Commerce System Submission

Submissions are due by Monday, April 1, 2019. Submissions should be uploaded via the Organizational Treatment Cascade Data Upload application in the Health Commerce System site. **DO NOT EMAIL, MAIL OR FAX PATIENT LEVEL DATA**. In addition, **DO NOT USE OLD VERSIONS OF INTERNET EXPLORER (IE 10 or earlier) when accessing the upload application.** See Organizational Treatment Cascade Data Collection and Reporting Instructions for additional details.

4) Ongoing Coaching

Program staff will provide one-on-one technical assistance to organizations with significant needs. **Beginning in March 2019, organizations will be expected to provide their assigned QI coach with regular updates.** These updates should include reports of progress on data

collection in addition to ongoing QI activities to address gaps and disparities in cascade outcomes. Once the data are submitted, beginning in June, coaches will follow-up with organizations on a quarterly basis.

Glossary

Care Status Categories for Indicator Eligibility

Diagnosis

Enrollment	Internally diagnosed as inpatient during the review period	Internally diagnosed during the review period while not on inpatient service	Externally diagnosed during the review period	Diagnosed prior to the review period.	Unknown
Active, new to clinic during review period, continuing in program	"Newly diagnosed Active"			"Other new to care"	
Active, seen prior to the review period, continuing in program				"Established Active"	
Died during review period					
Incarcerated as of end of review period					
Relocated out of New York State during the review period	"Linkage only"		"Excused- newly diagnosed"	"Excused-previously diagnosed"	
Confirmed to be receiving ongoing HIV care at another site as of end of the review period					
Other status, not enrolled in care at your organization	"Newly diagnosed with unknown care status"			"Open non-active"	

Established Active Patients: Previously diagnosed open patients who received medical services in the HIV program of the organization during the measurement year, excluding those new to care in 2018 or returning after an absence of at least two years.

Linkage to care: A patient is considered to have been linked to medical care if the individual attended a routine HIV medical visit within three calendar days of diagnosis with HIV by a treating physician. We will also analyze this based on post-discharge care within 30 days for inpatients.

Newly diagnosed patients: Patients first diagnosed with HIV within the measurement year.

New-to-care patients: Patients who are new to an organization's HIV program, regardless of the year in which they were diagnosed, and patients who were seen prior to 2016, not seen in 2016 or 2017, but then returned in 2018.

Non-active patients: Patients who (1) have had contact with a healthcare organization during the measurement year but have not been seen by the HIV clinical program and (2) who cannot be confirmed to have died by the end of the year, to be in care elsewhere by the end of the year, or to be incarcerated at the end of the year.

Open patients: Previously diagnosed patients who were not incarcerated at the end of the measurement year, deceased by the end of the measurement year, or confirmed to be in-care elsewhere at the end of the measurement year, and excluding those new to care in 2018 or returning after an absence of at least two years.

Previously diagnosed patients: Patients diagnosed with HIV before the measurement year.

Viral suppression: Patients are considered virally suppressed when their last viral load test conducted in 2018 returned a value of less than 200 copies/mL.