

# Organizational HIV Treatment Cascade

## Guidance for Construction

### Introduction

This guidance document provides organizations with the necessary tools and resources to construct their Organizational HIV Treatment Cascade. As part of the 2018 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 submit cascades reflecting care outcomes achieved in CY 2017 as part of their annual submissions to the New York State Department of Health (NYSDOH) AIDS Institute. In response to feedback from NYS providers, NYS HIV Quality of Care Clinical Advisory Committee members, and HRSA Ryan White HIV/AIDS Program stakeholders on the 2017 guidance document, the guidance document for 2018 has undergone a number of revisions. A summary of these revisions and a glossary of terms can be found in the **Appendix**.

### 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 first develop the capacity to effectively collect, analyze, and visualize data on their performance. The HIV Treatment Cascade, when applied to a clinic population, allows providers to better identify the gaps along the pathway from linkage and engagement in care to viral suppression, and represents a key strategy in efforts to End the Epidemic in NYS by 2020. First implemented in 2017 by the Office of the Medical Director in the NYDOH AIDS Institute, the Organizational HIV Treatment Cascade provides organizations 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; and
3. Develop data-driven plans to assess and improve these gaps through QI activities.

Each Organizational Treatment Cascade submission consists of three components: the **results section**, including the **organizational treatment cascades**; a narrative description of **the methodology** used to create the cascades; and **an analysis and improvement plan**, detailing how the organization intends to reduce the gaps in care identified by the cascades. The submissions will be reviewed by Quality of Care Program staff in the Office of the Medical Director and approved by senior medical staff. Approvals will involve review of organizations' adherence to required submission components described in this document as well as their satisfactory analysis of cascade data leading to a responsive improvement plan. Feedback will be provided to guide the integration of the cascades into organizations' ongoing quality management programs.

## Cascade measures

### *Separate cascades for newly diagnosed/new-to-care patients and previously diagnosed patients*

Organizations will be expected to submit three cascades: one for newly diagnosed/new-to-care patients and two for previously diagnosed patients. If no newly diagnosed or new-to-care patients presented to an organization in CY 2017, then that organization will **not** be required to submit a cascade for newly diagnosed/new-to-care patients.

### *Expanding eligibility for cascade of newly diagnosed/new-to-care patients*

Unlike CY 2016, the cascade for newly diagnosed patients in CY 2017 will also include new-to-care patients—that is, patients presenting to HIV primary care within an organization for the first time, **regardless of the year in which they were diagnosed**. This group of new-to-care patients includes both newly diagnosed patients who were linked to care from an outside organization, and previously diagnosed patients who are seeking HIV primary care within an organization for the first time. It should be noted that new-to-care patients should **not** be included in the previously diagnosed patient cascade, even if they were diagnosed prior to CY 2017. The rationale for expanding the universe of patients captured by this cascade is to ensure that all patients newly presenting to care at an organization are successfully engaged in care and fully integrated into its HIV program.

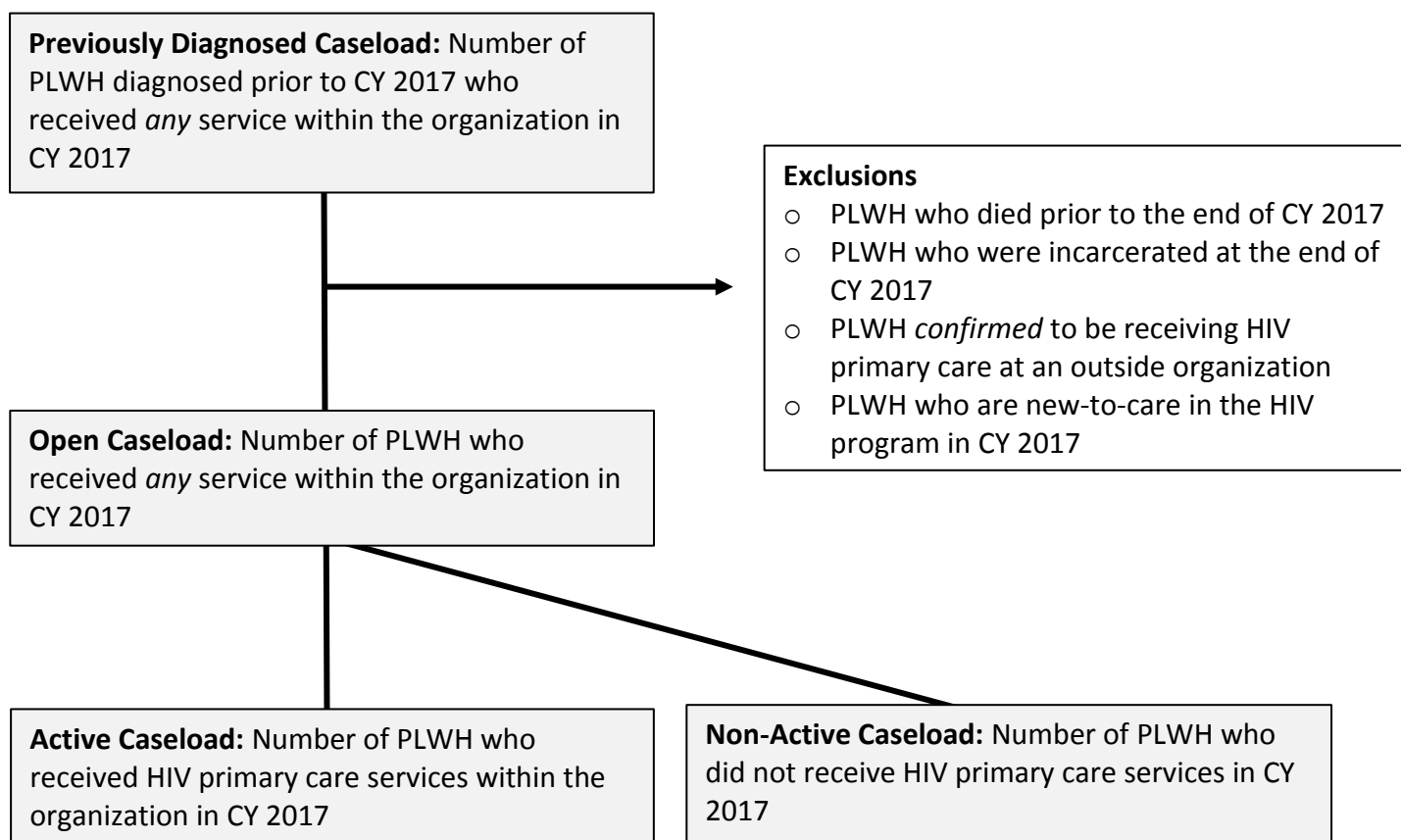
### *Differentiating open and active caseloads of previously diagnosed patients*

The cascades for previously diagnosed patients are designed to assure that all PLWH are engaged in ongoing HIV primary care, regardless of where they receive services within an organization. To underscore the importance of this aim, organizations will be asked to submit **two** cascades for their previously diagnosed patients: one that displays the outcomes of the organization's active caseload, and one that displays the outcomes of its open caseload. **Figure 1** summarizes how to calculate the open and active caseloads. It should be noted that PLWH of unknown disposition (i.e., those who cannot be documented to be deceased, incarcerated, or receiving HIV primary care at an outside organization) must be included in an organization's open caseload. Moreover, organizations are expected, where applicable, to display measures by practice site to facilitate cross-site comparisons.

### *Drilling down open caseload cascade of previously diagnosed patients by service delivery point*

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. In other words, organizations will be expected to report, in table form, the number of non-active open caseload patients (i.e., patients in the open caseload who are not active in the organization's HIV primary care program) who received services, and at which delivery points they received those services. Examples of these service delivery points include, but are not limited to, emergency departments, substance use services, mental health services, non-HIV ambulatory care services, case management services, dental services, and inpatient units.

**Figure 1:** Calculating open and active caseloads



***Drilling down active caseload cascade of previously diagnosed patients by key characteristics***

To identify ongoing disparities in clinical outcomes among subpopulations of PLWH enrolled in an organization's HIV primary care program, organizations will be expected to disaggregate all measures (ART prescription, viral load monitoring, and viral suppression) in their active caseload cascade by key characteristics, including age, gender, race/ethnicity, risk category, and housing status. **Table 1** summarizes the categorizations to which organizations must adhere in their disaggregation of data. Although not required, organizations are encouraged to perform an analogous disaggregation of their open caseload cascade by key characteristics. Organizations are likewise encouraged to perform analyses that may uncover disparities in subpopulations with overlapping characteristics (e.g., Non-Hispanic Black MSM, females with temporary housing). It is recommended that organizations present disaggregation by key characteristics in separate, discrete cascades, but for organizations that are unable to create multiple cascades, tables of disaggregated data will be accepted, provided that the same requirements are met.

**Table 1:** Categories of key characteristics

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
Gender	Male; Female; Transgender <sup>1</sup> ; Unknown
Race/Ethnicity	Non-Hispanic White; Non-Hispanic Black; Hispanic; Asian/Pacific Islander; Native American; Multi-Race; Unknown
Risk Category	Men who have sex with men (MSM); Intravenous Drug Users (IDU); MSM/IDU; Heterosexual; Pediatric risk; Unknown/other
Housing Status	Stable permanent housing; Temporary housing <sup>2</sup> ; Unstable housing <sup>3</sup> ; Unknown

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<sup>1</sup> Organizations with transgender patients are encouraged to further disaggregate their transgender patient caseloads by male-to-female (MtF) and female-to-male (FtM).

<sup>2</sup> Defined as short-term arrangement with family or friends, transitional housing or temporary institutional placement including substance abuse treatment facilities and psychiatric hospitals.

<sup>3</sup> Defined as emergency shelters, jail/prison, places not meant for human habitation.

## Required measures

Measures	Cascade of newly diagnosed/new-to-care patients	Open-caseload cascade of previously diagnosed patients	Active-caseload cascade of previously diagnosed patients
<b>Linkage to HIV medical care*</b>	<p><i>Denominator:</i> Number of PLWH diagnosed with HIV at the organization in CY 2017.</p> <p><i>Numerator:</i> Number of newly diagnosed PLWH who attended a routine HIV medical visit<sup>4</sup> within 3 calendar days of diagnosis<sup>5</sup>. The one exception is PLWH who are <b>newly diagnosed as inpatients</b>; these patients must be shown to have attended a routine HIV medical visit within 30 days of hospital discharge to be considered successfully linked.</p>	NOT APPLICABLE	NOT APPLICABLE
<b>Prescription of ART</b>	<p><i>Denominator:</i> Number of PLWH diagnosed with HIV in CY 2017 and number of PLWH diagnosed with HIV before CY 2017 who were new to care at an organization in CY 2017.<sup>†</sup></p> <p><i>Numerator:</i> Number of PLWH diagnosed with HIV CY 2017 and number of PLWH diagnosed with HIV before CY 2017 who were new to care at the organization in CY 2017 prescribed ART in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in open caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in open caseload prescribed ART in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in active caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in active caseload prescribed ART in CY 2017.</p>
<b>Viral load monitoring</b>	<p><i>Denominator:</i> Number of PLWH diagnosed with HIV in CY 2017 and number of PLWH diagnosed with HIV before CY 2017 who were new to care at an organization in CY 2017.<sup>†</sup></p> <p><i>Numerator:</i> Number of PLWH diagnosed with HIV in CY 2017 and number of PLWH diagnosed with HIV before CY 2017 who were new to care at the organization in CY 2017 who received a viral load test in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in open caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in open caseload who received a viral load test in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in active caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in active caseload who received a viral load test in CY 2017.</p>
<b>Viral suppression</b>	<p><i>Denominator:</i> Number of PLWH diagnosed with HIV in CY 2017 and number of PLWH diagnosed with HIV before CY 2017 who were new to care at an organization in CY 2017.<sup>†</sup></p> <p><i>Numerator:</i> Number of PLWH diagnosed with HIV in CY 2017 and number of PLWH diagnosed with HIV before CY 2017 and who were new to care at the organization in CY 2017 with a suppressed viral load (&lt;200 copies/mL) at last viral load test in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in open caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in open caseload with suppressed viral load (&lt;200 copies/mL) at last viral load test in CY 2017.</p>	<p><i>Denominator:</i> Number of PLWH in active caseload for CY 2017.</p> <p><i>Numerator:</i> Number of PLWH in active caseload with suppressed viral load (&lt;200 copies/mL) at last viral load test in CY 2017.</p>

<sup>4</sup> 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.

<sup>5</sup> The date of diagnosis is defined as the date on which a diagnosis of HIV is made by a treating physician.

\*Organizations may choose to report the Linkage to HIV medical care measure separate from the newly diagnosed/new-to-care cascade. See page 11 for an example.

† May exclude patients confirmed to be in care elsewhere by the end of the year; incarcerated at the end of the year; and deceased by the end of the year.

## Components of an effective cascade

How an organization chooses to visualize its cascades will ultimately depend on its target audience, as well as on how it intends to incorporate its cascades into ongoing QI activities. This section highlights the required and optional components of the cascade visualizations. Examples of cascades, with annotations highlighting key components, can also be found at the end of this document. While cascades should meet the technical requirements listed here, organizations are encouraged to be creative in the process of visualizing their cascades and to find a format that is most useful to them.

<b><u>REQUIRED COMPONENT</u></b>	<b><u>DESCRIPTION</u></b>
✓ <b>TITLE</b>	Title is presented in an easy-to-read font, specifies the patient population being captured (newly diagnosed or previously diagnosed), and the year from which the data are drawn.
✓ <b>AXES</b>	Axes are clearly labeled in an easy-to-read font with applicable units clearly displayed.
✓ <b>LEGEND</b>	Legend includes definitions and sources for all measures featured in the cascade, and is reported in non-technical language that is understandable to all stakeholders.
✓ <b>BREAKDOWNS BY CARE SITE</b>	For organizations with multiple sites of care, site-specific measures are calculated and presented to enable organization-wide comparisons.
✓ <b>MEASURES</b>	Required measures are presented clearly with easy-to-read labels. Proportions and raw numbers are presented to indicate the relationship of measures to denominators, and to specify the number of patients captured by each measure.

## 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 describe, separate from the cascade visualizations, detailed answers to the following questions:

- ✓ What sources of data were used to construct each element of the cascades?
- ✓ Why were the data sources chosen?
- ✓ What are the limitations specific to each data source?
- ✓ What methodology was used to identify newly diagnosed patients? Has that methodology been validated?
- ✓ How was the number of patients newly diagnosed with HIV at the organization in 2017 determined?
- ✓ How was the number of patients newly diagnosed with HIV outside the organization in 2017 determined?
- ✓ How was the number of previously diagnosed new-to-care patients determined?

- ✓ How was the number of newly diagnosed patients linked internally determined?
- ✓ How was the number of newly diagnosed patients linked externally determined?
- ✓ What methodology was used to identify and determine the care status of open patients? How was care status confirmed?
- ✓ How were patients determined to be deceased, incarcerated, or in care at an outside organization?
- ✓ What methodology was used to identify active patients? How was their care status confirmed?
- ✓ How was service delivery point determined and verified for non-active open caseload patients?
- ✓ How were age, gender, race/ethnicity, risk category, and housing status determined and verified for the active caseload?
- ✓ Who within the organization was involved in extraction, analysis, and presentation of cascade data?

## Reporting results

The results section comprises all required measures, including the cascades and data tables. The results section should also include answers to the following questions:

- ✓ How many patients were diagnosed with HIV at the organization in 2017?
  - ✓ How many patients were diagnosed with HIV at another organization in 2017?
  - ✓ How many patients were previously diagnosed with HIV and new to care at the organization in 2017?
  - ✓ How many patients newly diagnosed at the organization in 2017 were linked to care internally?
  - ✓ How many patients newly diagnosed at the organization in 2017 were linked to care externally?
  - ✓ How many patients newly diagnosed at the organization in 2017 were not linked to care within 3 days?
  - ✓ How many patients were identified as deceased, incarcerated, or in care at an outside organization?
- This can be reported in table format or a narrative description.

## Developing an analysis and improvement plan

Organizations will be asked to submit an analysis and improvement plan that interprets significant gaps identified in the cascades to develop a formal strategy that addresses these gaps through their quality management programs. This plan should feature **an analysis of significant gaps in aggregate outcomes, as well as disparities that emerged through disaggregation of outcomes by key characteristics**. To be maximally useful, 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 progress report on last year's (2017) improvement goals, including a description of interventions that were tested, any barriers that were faced, how the improvement plan was modified in response to challenges, and whether stated goals were achieved.
- ✓ A detailed description of significant gaps in care that are revealed by the cascade for CY 2017, as well as any disparities that emerge through disaggregation of outcomes by key characteristics. 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 narrative description of changes (if any) between the 2016 and 2017 cascade results.
- ✓ 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, and suggests common cause variation rather than significant improvement)
- ✓ 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.
- ✓ An explanation of how consumers were engaged in the process of developing the improvement plan based on the data in the cascades.
- ✓ 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.

## Next steps

Submissions are due by 11:59 p.m. on Thursday, May 31, 2018. Submissions should be sent as email attachments to [gocreviews@health.ny.gov](mailto:gocreviews@health.ny.gov), with the organization's assigned QI coach copied. Please note that submissions sent by regular mail will not be accepted. NYS Quality of Care Program staff will be holding webinars and virtual office hours throughout the months of March, April, and May to assist organizations with any questions they may have. Program staff will provide one-on-one technical assistance to organizations with significant needs. **Beginning in March 2018, organizations will be expected to provide their assigned QI coach with updates on a quarterly basis.** These updates should include reports of progress on cascade construction in addition to ongoing QI activities to address gaps and disparities in cascade outcomes.

## Appendix: Glossary

**Active Patients:** Previously diagnosed open patients who received medical services in the HIV program of the organization during the measurement year.

**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. The one exception is PLWH who are newly diagnosed as inpatients; these patients must be shown to have attended a routine HIV medical visit within 30 days of hospital discharge to be considered successfully linked.

**Newly diagnosed patients:** Patients 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.

**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.

**Patients of unknown disposition:** Another term for open, non-active patients

**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 2017 returned a value of less than 200 copies/mL.

## Appendix: Summary of guidance revisions

### *Newly diagnosed caseload definition*

Old	The newly diagnosed caseload includes all patients newly diagnosed with HIV at the organization in 2017	
New	The newly diagnosed/new-to-care caseload includes all patients diagnosed with HIV in 2017 and all patients who are new to an organization’s HIV program, regardless of the year in which they were diagnosed.	Page 2

### *Number of days for linkage to care for newly diagnosed patients*

Old	Newly diagnosed patients are considered successfully linked if they are linked to care within three calendar days if linked within the organization, and within five calendar days if linked outside the organization.	
New	Newly diagnosed patients are considered successfully linked to care if linked within three calendar days, regardless of whether they are linked within or outside the organization.	Page 5

### *Previously diagnosed patient cascade terminology*

Old	A cascade of all patients diagnosed before the measurement year was called the “established patients” cascade.	
New	The cascades of patients diagnosed before the measurement year are the “previously diagnosed patient” cascades.	Page 2

### *Open caseload definition*

Old	The open caseload contains all previously diagnosed patients who touched an organization in the past year.	
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New	The open caseload contains all previously diagnosed patients who touched an organization in the past year <b>except</b> any patient who can be confirmed to have died before the end of the year, transferred to care elsewhere by the end of the year, or to be incarcerated and not receiving medical care at the organization at the end of the year. The numbers of patients in these excluded groups are still expected to be included in the submission. Description of the process of how patients are ascertained to be in care elsewhere should continue to be specified.	Page 2
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*Identify number of newly diagnosed and previously diagnosed patients with viral load tests*

New	Receipt of a viral load test within the measurement year is included in the measurements for the newly diagnosed cascade, the open patient cascade for previously diagnosed patients, and the active patient cascade for previously diagnosed patients.	Page 5
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*Denominator for ART and viral suppression*

Old	Number of patients in the active caseload.	
New	For the open patient cascade, number of patients in the open caseload (all patients in the active caseload plus all patients of unknown disposition). For the active patient cascade, number of patients in the active caseload.	Page 5

*Identify service delivery points for patients*

New	Report number of open, non-active patients (patients of unknown disposition) seen by each service delivery point at an organization during the measurement year.	Page 2
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*Identify disparities across subpopulations*

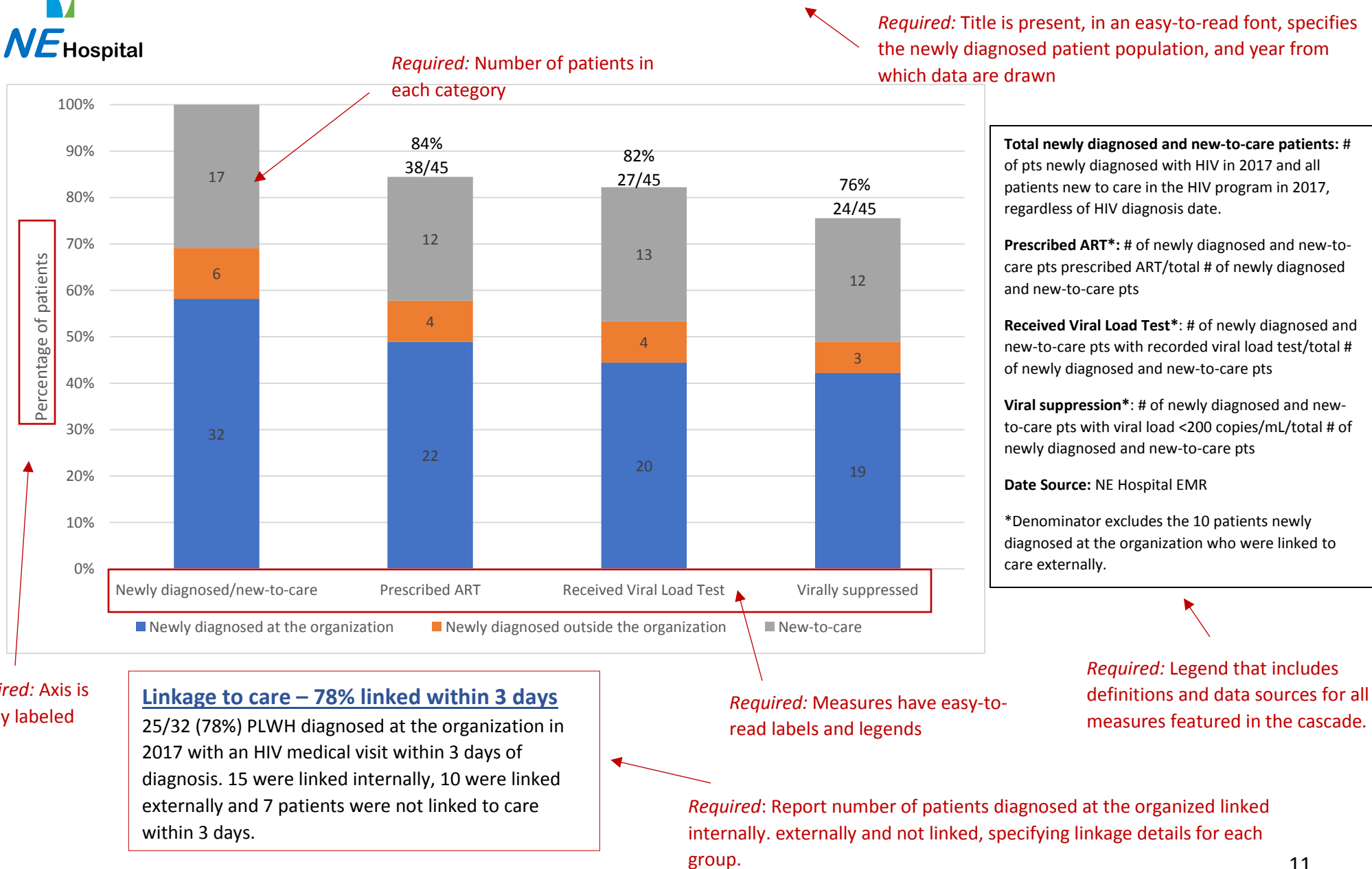
New	Disaggregate the active caseload by age, gender, race/ethnicity, risk factors, and housing status.	Page 3
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*Compare 2017 organizational treatment cascade against 2016.*

New	In the analysis and improvement plan, compare the 2017 results against the 2016 results.	Page 7
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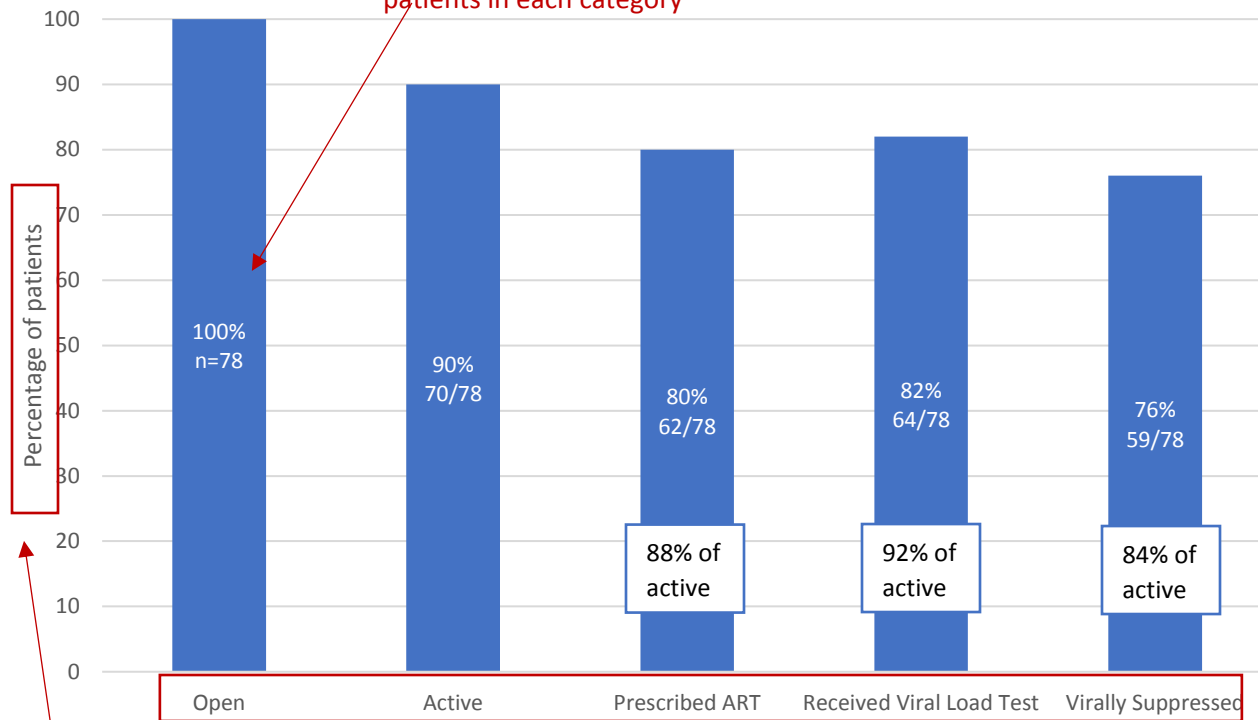
# HIV Treatment Cascade for New Patients 2017: Newly Diagnosed and New-to-Care Patients (Example)



# HIV Treatment Cascade for Previously Diagnosed Open Patients, 2017

*Required: Title is present, in an easy-to-read font, specifies the previously diagnosed patient population, and year from which data are drawn*

*Required: Number of patients in each category*



**Open** – # of PLWH, diagnosed before measurement year, with any visit in last 12 months, except those confirmed to be in care elsewhere, deceased, or incarcerated

**Active** – # of PLWH, diagnosed before measurement year, with HIV visit in last 12 months / # of open patients

**Prescribed ART** - # of open patients with ART prescription in last 12 months / # of open patients

**Received Viral Load Test** - # of open patients who received a viral load test in last 12 months / # of open patients

**Virally Suppressed** - # of open patients with viral load <200 copies/mL at last viral load test in year / # of open patients

**Data Source** – Infinity EMR

*Required: Axis is clearly labeled*

*Required: Legend that includes definitions and data sources for all measures featured in the cascade.*

*Required: Measures have easy-to-read labels*

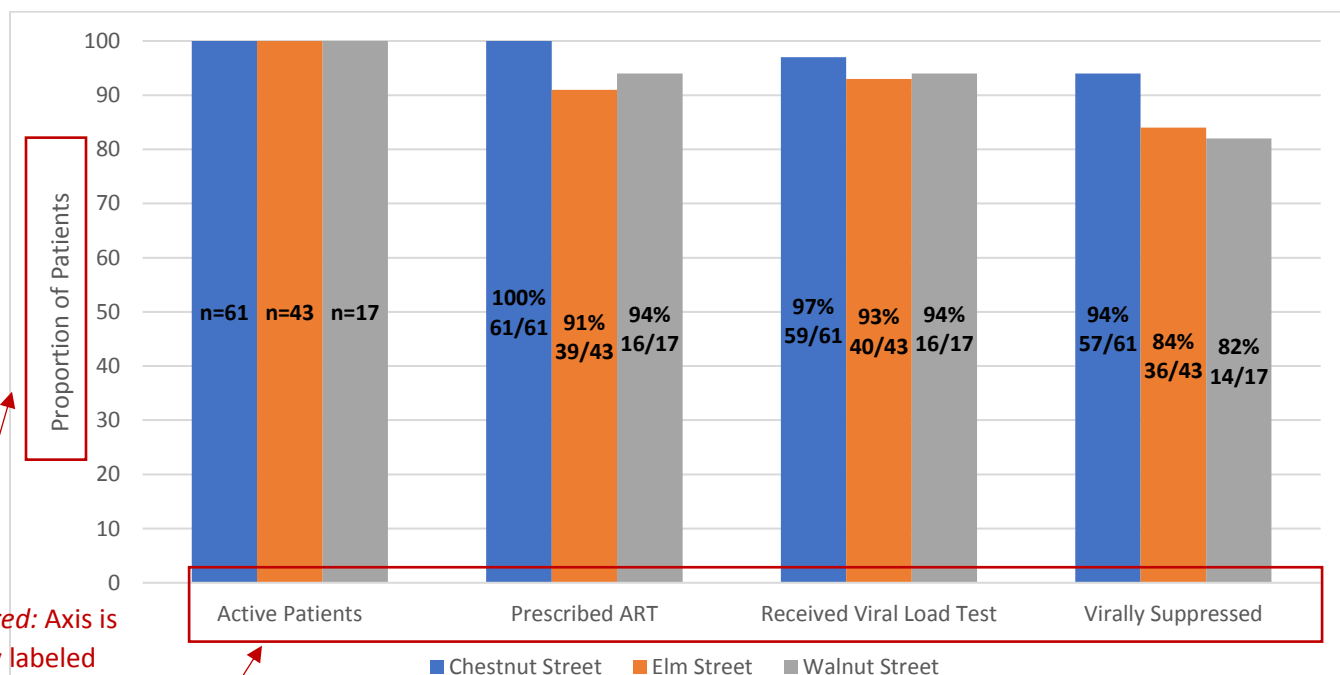


**SouthWest**  
Hospitals and Clinics



## HIV Treatment Cascade for Previously Diagnosed Active Patients (2017)

*Required:* Title is present, in an easy-to-read font, specifies the patient population, and the year from which the data was drawn.



*Required:* Axis is clearly labeled

*Required:* Measures have easy-to-read labels

**Active Patients:** Number of patients seen by the HIV program within the year

**Prescribed ART:** Number of active patients prescribed ART within the year/Number of active patients

**Received Viral Load Test:** Number of active patients who received a viral load test within the year/Number of active patients

**Virally Suppressed:** Number of active patients who were virally suppressed at last test of the year/Number of active patients

**Data Source:** Bright Horizons EMR

*Required:* Legend that includes definitions and data sources for all measures in the cascade