

New York State Department of Health AIDS Institute

The Living Cascade

Welcome to the Living Cascade! The Living Cascade complements the facility-level organizational cascade of care, and consists of a five-page worksheet to be completed by consumers during their scheduled medical visit. Like the organizational HIV treatment cascade, the Living Cascade helps HIV healthcare providers understand the patient experience with each bar on the cascade. Organizational cascades measure quantitative data, or the numbers of patients in each category. The Living Cascade brings the numbers of the organizational cascade to life with qualitative data, or consumers' experiences of HIV care and personal stories.

This instructional guide explains the goals of the Living Cascade for consumers and providers and gives detailed explanation of each question in the worksheet. Tips for assembling a team and aggregating and analyzing data are also offered.

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Project Overview

The Living Cascade is a consumer-driven QI tool developed by the NYSDOH AIDS Institute. It is a five-page worksheet designed to complement organizational HIV Treatment Cascades and capture consumer-reported experiences at HIV outpatient care facilities in New York State. The Living Cascade aims to engage a broad range of consumers in QI work in healthcare facilities. It is also a way to educate consumers about clinical performance measurement definitions, patient self-management, and QI through engagement with the organizational HIV treatment cascade, reflections on their own experience of care, and recounting of their own healthcare journey through the cascade. When the results from an appropriate sample size for a given facility are looked at together, the answers to the questions will paint a picture of consumers' personal journeys towards viral suppression at your organization, highlighting successful engagement and adherence strategies, as well as opportunities for intervention and quality improvement.

The Living Cascade will help your healthcare facility address the gaps in your organizational cascade by complementing facility quantitative data with consumers' reports of their personal experiences of HIV care at your facility. Dissemination and analysis of this patient-centered tool can help healthcare facilities understand consumers' challenges and motivations in their HIV care and self-management. Understanding the patient experience of care at your facility will inform QI plans that respond directly to the experiences of your consumers and deliver more effective and patient-centered care.

Glossary

Quality of Care – The Institute of Medicine (IOM) defines health care quality as “the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”¹ In other words, quality healthcare is the delivery of the correct health services performed at the highest skill level of the provider with improved health outcomes.² According to the IOM, quality healthcare is: effective, efficient, equitable, patient-centered, and safe.³ The Living Cascade project is part of NYSDOH AIDS Institute Quality of Care program.

Quality Improvement (QI) – According to HRSA, quality improvement “consists of systematic and continuous actions that lead to measurable improvement care services and the health status of targeted patient groups.”⁴ QI balances *measuring performance* through data collection, such as treatment cascades or satisfaction surveys, and *implementing QI projects* based on that data.

Cascades⁵ - The HIV Treatment Cascade tracks patients from diagnosis to viral load suppression. When applied to a clinic population, it allows providers to better identify the “gaps” along the path from linkage and engagement in care to viral load suppression, and to guide quality improvement (QI) activities that aim to close these gaps.

Open caseload: Number of patients with a known HIV diagnosis who received services anywhere in the organization (any kind of clinical or non-clinical supportive services) during the year data was collected.

Active caseload: Number of patients with a known HIV diagnosis who received HIV primary care services at the organization during the year data was collected.

¹ National Academies of Sciences, Engineering, and Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century* [Report Brief]. Washington, DC: Institute of Medicine.

² Blumenthal, David. (1996). Part 1: Quality of care – What is it? *New England Journal of Medicine*, 335(12), 891-894.

³ National Academies of Sciences, Engineering, and Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century* [Report Brief]. Washington, DC: Institute of Medicine.

⁴ (n.d.). Retrieved August 15, 2017, from <https://www.hrsa.gov/quality/toolbox/methodology/qualityimprovement/>.

⁵ New York State Department of Health AIDS Institute. (2016). *Organizational HIV Treatment Cascade: Guidance for construction*.

On ART: Number of patients from the active caseload that were prescribed ART (anti-retroviral therapy, or HIV medication) during the year that data was collected. A patient is considered “On ART” if they have been given a prescription from a provider at your facility, even if they haven’t filled the prescription or properly taken medication.

Virally Suppressed: Number of patients from the active caseload with a viral load of less than 200 copies/mL at the last viral load testing during the year the data was collected.

Consumer Involvement is when consumers directly participate in and identify consumer priorities for healthcare programs. Consumer involvement is an important part of quality improvement, and involves having consumers on quality management committees, consumers reviewing performance data and QI activities, and regularly assessing consumer needs.⁶

Patient-Centered Care is respectful of and responsive to individual patient preferences, needs, and values and ensures that patient values guide all clinical decisions. Patient-centered care respects patients’ values, preferences, and needs. Patient-centered care involves the consumer’s family and friends, is collaborative, and supports patient education.⁷

Self-Management is a key element of the chronic care model. It promotes collaborative goal setting and decision making between consumers and providers, and allows consumers to track and manage their own health and healthcare. Consumer education is an important element of self-management. Self-management also supports peer learning, joint decision making, and patient self-monitoring.⁸

Quantitative Data measures the amount (quantity) of something using numbers.

Qualitative Data is data that describes the quality of something, usually using words and descriptive language.

⁶ New York State Department of Health AIDS Institute. (2010). *Understanding Patient-Centered Care, Consumer Involvement & Patient Self-Management*.

⁷ New York State Department of Health AIDS Institute. (2010). *Understanding Patient-Centered Care, Consumer Involvement & Patient Self-Management*.

⁸ New York State Department of Health AIDS Institute. (2010). *Understanding Patient-Centered Care, Consumer Involvement & Patient Self-Management*.

Implementation Instructions

Step 1: Assembling a Team

- As the Living Cascade should be used for QI, it is recommended that a multi-disciplinary team (i.e. HIV Program Director, Quality Manager, clinician, data analyst, consumer, etc.) be active in implementing and utilizing the Living Cascade.
- It is also recommended that a team member with experience analyzing data, particularly qualitative data, assist with Living Cascade aggregation and analysis.
- As this project engages consumers, it is recommended that CAB members, peers, community health workers, and/or case managers be involved in the dissemination and consumer education.
- Other staff members, such as front-line staff and care providers, should be made aware of the project and prepared to answer basic questions consumers may have.

Step 2: Preparing the Worksheet

- The worksheet provided should be customized with the name of your organization or facility and your 2017 organizational cascade data.
- When you open the Living Cascade worksheet in Microsoft Word, utilize the “find and replace” function to change all instances of [Facility Name] to your facility’s name.
- To input your 2017 organizational cascade data, click on one of the bars in the cascade on the first page of the worksheet. At the top of the page, you’ll see options for “Chart Tools.” Select “Design.” To the right of this tab, you’ll see an option to “Edit Data.” Click this option and enter your facility’s data in the pop-up Excel page that opens.
- Depending on the structure of your organization, you may be using the name and cascade data for the entire organization, or the name and cascade data for a specific site or clinic within an organization.

Step 3: Disseminating the Worksheet

- Methods for collecting responses will vary depending on the technology available at your organization and staff’s comfort using technology.

- Some consumers may want to complete the worksheet on their own, without assistance. Others may find that answering the questions out loud while a team member writes or types their answers is easier or more effective.
- Some options for dissemination include:
 - The worksheet is completed on an electronic device, such as a tablet or laptop. Each completed worksheet should be saved with a unique identifier (i.e. “Patient 1”) to maintain anonymity.
 - The worksheet is printed and filled out by hand, and responses are manually transcribed by staff into an Excel worksheet for aggregation.
 - The team member guiding consumers through the worksheet asks the questions out loud and records consumers’ answers electronically. Answers can be recorded directly into an Excel spreadsheet or other tool for aggregating data. It would be useful to also have a copy of the worksheet on hand for the consumer to visualize the cascade.
- The designated team member assigned to disseminate the worksheet should be well-prepared to assist and answer any questions for the consumer as they complete the worksheet.
- It is recommended that the worksheet be disseminated, filled out, and collected on the same day as the consumer’s visit to the HIV outpatient facility. Ideally, a designated staff member will approach the consumer and explain the purpose of the worksheet and the consumer’s potential role in quality improvement at the facility. Let consumers know that the answers they provide will remain completely anonymous and confidential. However, you may offer to provide the consumer with a copy of their own completed Living Cascade, as it may be useful to them as a self-management tool or to discuss with a case manager.
- It is recommended that the Living Cascade worksheet be completed by a representative sample of your patient population. There are resources online for calculating a statistically significant sample size.
- It is recommended that responses be collected for four to six weeks, although this collection period may be longer or shorter depending on the number of worksheets your site aims to complete and how many worksheets are collected each day.

Step 4: Aggregating the Data

- The Living Cascade worksheet can be printed and filled out manually or be completed electronically using Microsoft Word document or an Adobe PDF form that can be duplicated and saved separately for each consumer. If your facility collects manually completed worksheets, a staff person must transcribe the answers to each question and manually enter data.
- If you would like to use an Adobe PDF form and have access to Adobe Pro, AIDS Institute staff can guide you through creating a “fillable” form.
- It is recommended that data be kept in an Excel spreadsheet so that all the answers to an individual question can be looked at together to more easily identify patterns and themes. A template for this spreadsheet is included in the materials for the Living Cascade.

Step 5: Analyzing the Data

- The results of this worksheet are qualitative open-ended responses and are based on consumers’ self-reported experiences rather than numbers or percentages. This will require analyzing the data differently from other data analysis projects.
- It is most important to identify common themes throughout the aggregated data.
- It is also helpful to mark key words that are used many times across responses.
- It may also be helpful to think about certain themes or responses as “internal” or “external.” External factors are related to the facility itself (such as wait time) and internal are not (consumers’ transportation costs).
- Once the data has been sorted and analyzed, think about what findings are actionable, or can be addressed within your facility through QI activities.

Step 6: Sharing the Data

- When a representative sample of your clinic population has completed the Living Cascade, their responses have been aggregated, and themes have emerged, your Living Cascade and/or quality team should use the Living Cascade data to create QI plans or interventions or to bolster existing QI plans. Contact AIDS Institute staff for technical assistance.

- If the Living Cascade data contributed to quality improvements at your facility, these should be shared with consumers! You can print and hang the first page of the worksheet around your clinic, make a poster outlining how consumers' responses to the Living Cascade have been implemented, and engage your CAB to make consumer-driven quality improvements known throughout your organization.

Worksheet Guide

The following section walks through the purpose of each question in the Living Cascade worksheet and will assist the staff member explaining or completing this worksheet with consumers.

Page 1: Help Us Bring [Facility Name]'s Cascade to Life!

This page displays your facility's organizational cascade. Consumers should be able to share their individual journeys and identify where they fall on the cascade with the help of a staff member who may be needed to complete the Living Cascade worksheet. Some consumers will fill out the entire document and others will only fill out certain sections.

Page 2: Your Story of Coming to [Facility Name]

This section addresses the "Open" bar in the cascade to understand how consumers experience initiating care at your facility. This section will help you understand the process of **linking to HIV care** at your facility.

Per the 2018 Organization HIV Cascade Guidelines, patients are considered linked to care when they attend a routine HIV medical visit within 3 calendar days of diagnosis. This category is most important for newly diagnosed patients (those diagnosed with HIV during 2017) because this linkage measurement is a quality indicator. However, for those diagnosed before 2017, it will still be useful to know about the process of linking to HIV care at your facility.

1) Did you receive your HIV diagnosis at [Facility Name]?

1a) If yes, about how long did it take to get your first appointment for HIV primary care at [Facility Name]?

1b) If no, why did you choose [Facility Name] for your HIV primary care?

This question addresses the patient's first contact with your facility. It is helpful to know if patients were diagnosed at your facility, as this will impact how they first linked to HIV primary care services. Because the 2018 guidance measures 3-day linkage to care, it will be useful to know how many patients were linked to care within this time frame, especially for new or newly-diagnosed patients.

2) How did you get linked to care at [Facility Name]? Did any person help you make your first appointment?

This question addresses how patients navigate making appointments and getting linked to care. Answers to this question may help you understand challenges that patients face as they link to care. It will also help you understand the effectiveness of the systems in place for linking patients to care in your facilities (i.e. peer navigators, case managers, etc.)

3) Did you face any challenges getting your first appointment at [Facility Name], at another healthcare organization, or in your personal life? If yes, please describe the challenges.

This question will help you understand the barriers that some consumers have as they begin HIV primary care (either for the first time or at a new facility). For many patients, factors in their personal lives (transportation challenges, fear of stigma, homelessness, etc.) may impact their experience linking to care. Other factors could include difficulty navigating linkage at your facility or challenges in transferring from one facility to another. Answers to these questions could provide information on how to more smoothly link patients to care.

Page 3: Your Story of Becoming an "Active" Patient at [Facility Name]

This section will help you to understand why consumers have chosen to receive care, and continue their care, at your facility. A definition of an "active" patient is included on this page: "An "Active" patient has at least one HIV medical visit each year - even if you're been positive or coming to [Facility Name] for a long time, you aren't "Active" unless you have at least one appointment every year."

4) What was your first visit to the HIV program at [Facility Name] like?

First impressions are important for consumers engaging in care at your facility for the first time. Understanding how patients felt at their first appointment can help you identify areas for quality improvement.

5) Since becoming a patient at [Facility Name], have you ever gone more than a year without coming here for a medical visit?**5a) If yes, why?**

A patient may consider themselves to be “Active” even if more than a calendar year has passed in between appointments. This question is an opportunity to educate patients on the definition of an Active patient and remind them that they should have at least one HIV appointment per calendar year.

6) What helps or motivates you to come to your appointments at [Facility Name]?

Answers to this question may reveal aspects of consumers’ experiences at your facility that keep them motivated to return. Knowing what these are will help guide quality activities and is part of each consumer’s unique journey toward viral suppression.

7) What makes it hard to come to or keep your appointments?

Answers to this question could stem from factors in the healthcare facility or within the consumer’s personal life. Understanding both is valuable in QI planning, as missed appointments due to personal conflicts could still be actionable in your facility.

8) Is there any additional information you would like to share about your experience receiving health care at [Facility Name]?**Page 4: Your Story of Getting on Antiretroviral Therapy (ART) at [Facility Name]**

This section will help you understand how your facility’s consumers engage with ART. Maintaining ART is how HIV care consumers become virally suppressed. Understanding how consumers engage with their treatment will help address the gap between “On ART” and “Virally Suppressed.”

Remind consumers that ART is just HIV medication!

9) Have you been prescribed HIV medication, commonly known as ART, at our HIV program?

9a) If yes, how soon after your diagnosis did you start taking HIV medication?

9b) If no, why have you not been prescribed HIV medication by [Facility Name] staff?

This question addresses consumers' journey to starting ART. Most HIV patients should be prescribed ART. Both the World Health Organization and the Department of Health and Human Services recommend that ART be initiated as close to diagnosis as possible.

10) Overall, do you take your meds the way your healthcare providers recommends?

10a) If no, why?

Consumers who are prescribed ART often struggle to maintain or properly adhere to their ART. Understanding why patients at your facility have trouble adhering to or taking ART as recommended could lead to factors that can be addressed through QI.

11) In the last five years, or since you began taking HIV medication at [Facility Name], have you ever stopped taking this medication for more than one week?

11a) If yes, why did you stop? What helps you get back on track with taking your HIV medication?

Many consumers struggle with the daily demands of taking ART. For some consumers, factors in their personal lives could cause them to miss doses or take a drug holiday. Others may not understand their provider's instructions for taking ART. Understanding why consumers stop taking ART and how they get back on track will help you understand the gap between "On ART" and "Virally Suppressed" and can inform improvement projects.

Page 5: Your Story of Becoming Virally Suppressed at [Facility Name]

This section will help your facility understand the barriers and successes for consumers who are virally suppressed. If a patient does not know if they are virally suppressed, this could be an opportunity to review their lab results or schedule tests.

12) Are you virally suppressed (defined as having a viral load of less than 200 copies/ml)?

12a) What helped you become virally suppressed?

The journey from diagnosis to viral suppression can be long and challenging for consumers. This question asks consumers to think about their own process of becoming virally suppressed, which may elicit feedback about the quality of care at your facility.

13) What has been the hardest part about regularly taking your HIV medication?

Consumers can share what is difficult about taking a daily medication with sometimes-serious side effects, which can help your organization provide more support.

14) What helps you take your HIV medication?

14a) Do you have any tricks, tools, people, or things in your life that motivate you to stay on track with your HIV medication and stay engaged in your health care?

Consumers can share their own strategies and motivations for maintaining viral suppression, which may be useful for your organization (providers, case managers, etc.) to know.

Technical Assistance

For questions or technical assistance, please contact:

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