

# LabCoP Cookbook of best practices

## RECIPE #3: DEMAND CREATION



# 1 BACKGROUND

To measure—and improve—HIV treatment outcomes among people living with HIV, we need to monitor their response to antiretroviral therapy (ART). The current gold standard for monitoring this response is through routine viral load testing (RVLT), which has been recommended by the World Health Organization (WHO) in its treatment guidelines since 2013.<sup>1</sup> This recommendation comes from research demonstrating that viral suppression is associated with decreased HIV disease progression and mortality among people living with HIV, and the prevention of HIV transmission to sexual partners.<sup>2</sup>

WHO recommends viral load (VL) monitoring six months after treatment initiation, 12 months after treatment initiation, and every 12 months thereafter,<sup>3</sup> if the initial VL is suppressed. If the VL is not suppressed, a repeat VL test is recommended after 3 rounds of intensive adherence counseling conducted at one-month intervals. The repeat VL test supports the clinical decision to either maintain the current treatment regimen (if re-suppression takes place) or switch to a higher treatment regimen (if VL is still not suppressed).

Community-driven demand creation refers to the concept of generating demand for optimal treatment and care from the community of people living with HIV. Demand creation for RVLT begins with building awareness among people living with HIV and key civil society partners about its importance, as well as a health system that supports requests for, execution and utilisation of, and access to RVLT – ensuring that it is used in the management and care for people living with HIV. One cannot demand what they know nothing about.

Actors who should be involved in RVLT demand creation are; people living with HIV, healthcare providers, policy makers, civil society partners, and program managers.

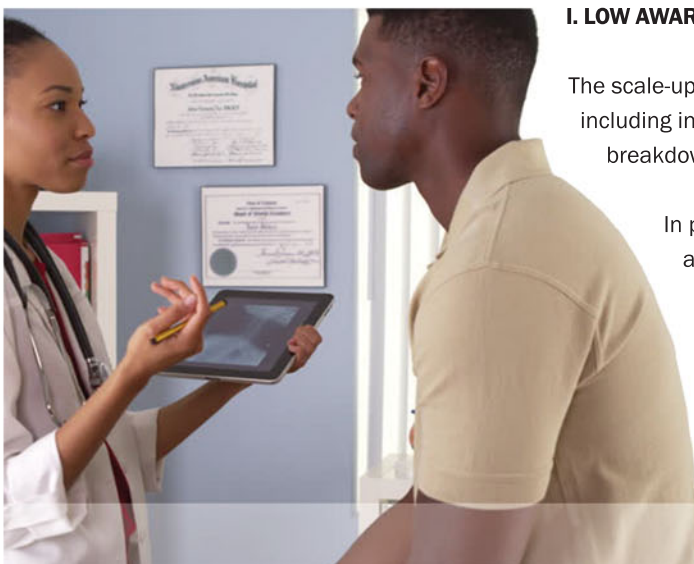
As illustrated in Figure 1, supporting country-level demand creation for RVLT is a step-wise process, which should entail:

- Baseline assessment to understand existing gaps
- Developing educational tools and resources
- Facilitating education and mobilising initiatives to encourage uptake of the tool(s)
- Developing community-driven advocacy plans to address identified gaps
- Providing small grants to support community-led advocacy
- Evaluating the outcomes of the advocacy work to see the changes it has achieved



Figure 1: International Treatment Preparedness Coalition’s community-led demand creation model

# 2 BARRIERS TO ROUTINE VIRAL LOAD TESTING ACCESS



## I. LOW AWARENESS AMONG PEOPLE LIVING WITH HIV AND HEALTHCARE PROVIDERS

The scale-up of RVLT has been met with major barriers due to its cost and complexity, including insufficient operational budgets, delays in procurement, equipment breakdown, and insufficiently trained personnel, among others.<sup>4</sup>

In places where RVLT does exist, there is a general lack of awareness about it among both clinicians and recipients of care.<sup>5</sup> In a case study in Zambia, International Treatment Preparedness Coalition (ITPC) found low knowledge about WHO HIV treatment guidelines among both people living with HIV and healthcare workers in select districts. In addition, a 12-country ITPC survey found that only 40% of the countries involved had RVLT, and demand was driven by healthcare providers. In many of the cases, patients who were undergoing RVLT did not know what they were doing and why. This gives a sense that VL testing is done for the benefit of the clinician rather than the patient.

## II. GOVERNMENT POLICY AND IMPLEMENTATION

Execution of government policy remains a barrier to access of RVL. In 2016, Roberts et al. reported that although 47 of 54 low- and middle-income countries had adopted the current WHO recommendations to ensure RVL, only a handful were implementing it.<sup>6</sup> In six countries, VL testing was only recommended for suspected treatment failure, and most countries continued to recommend immunological treatment monitoring rather than RVL.<sup>4</sup>

When government policies are in place, they need to be implemented. The ITPC 12-country survey in 2015 reported that despite a government policy mandating RVL in eight countries, only three of them had instituted RVL – highlighting a clear gap between policy and implementation.



## III. COST OF SERVICE

More than half of the countries included in the ITPC survey reported that people living with HIV had to pay for VL testing out-of-pocket. Some countries were paying too much for tests, despite an initiative providing lower prices. (Diagnostic Access Initiative granting access to US \$9.40 VL tests to 77 countries).<sup>7</sup>

## IV. LABORATORY CAPACITY AND TESTING COMMODITY STOCK-OUTS

All of the 12 countries in the ITPC survey reported stock-outs of test kits and/or commodities within the past 12 months, as well as staff shortages. The Zambia case study reported very low coverage of VL machines in select districts, particularly in rural areas.



## 2 BARRIERS TO ROUTINE VIRAL LOAD TESTING ACCESS

### IV. SYSTEMIC BARRIERS ALONG THE VIRAL LOAD CASCADE

ITPC reported that the process for VL testing varied within countries, with turn-around times ranging from 1-5 weeks to several months before people living with HIV received their test results. Many patients had not yet received the result from their first VL test by the time they took their second test, at a 6-month interval.

As illustrated in Figure 2, any lapse along the VL cascade could disrupt service delivery. For example, the sample can be collected from the patient at a health facility, but never reach a laboratory facility due to transport challenges, so a VL test is never run.

Alternatively, a VL test may be run at a laboratory facility, but the results are not promptly communicated back to the health facility that requested the test, with negative implications for the monitoring of the recipient of care's treatment.

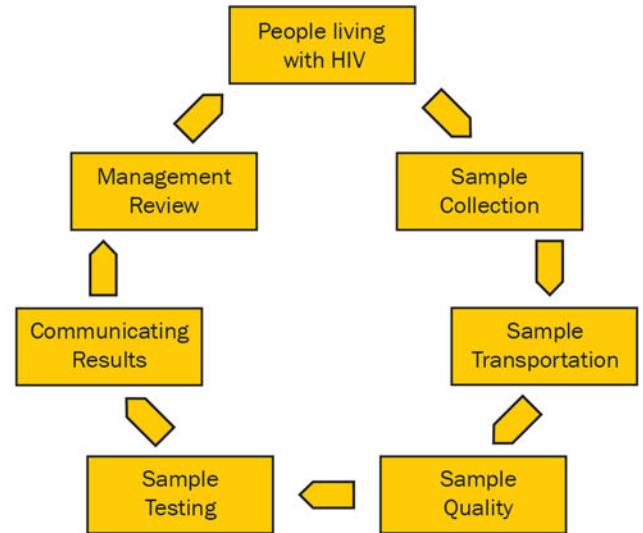


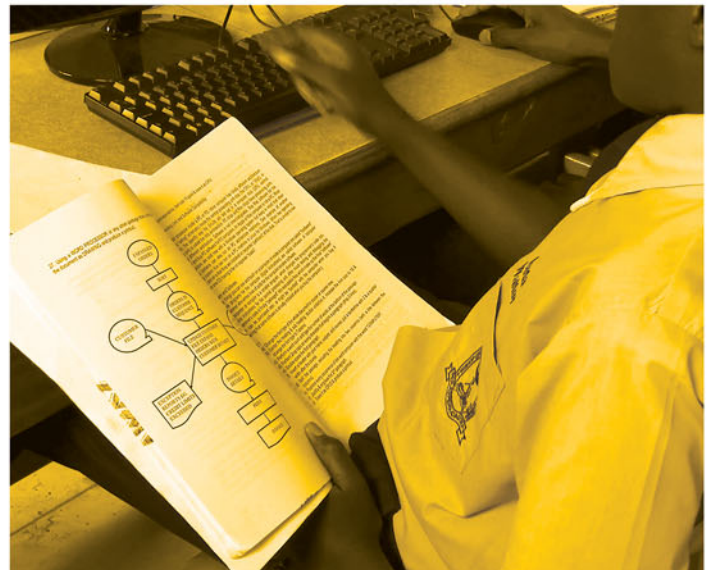
Figure 2. VL Testing Cascade

### V. LACK OF INNOVATION

There is a need to innovate new ways of doing some things in order to get around limitations. For example; using the dried blood spot sample overcomes the access limitation posed by the delicate fresh sample. We should also innovate new ways of doing counseling, and providing support to the community using peers.

## 3 KEY CONSIDERATIONS

- WHO HIV treatment guidelines, including RVLT, need to be adopted into countries' National Guidelines and be fully implemented. It is important to assess the cost of RVLT and ensure that it is prioritised in national HIV budgets.
- The logistical challenges, including specimen collection and handling, laboratory operations, and supply chain management, including transportation and stock-outs of reagents and equipment maintenance, that delay test results need to be identified and addressed.
- Countries need to scale up demand for RVLT to ensure coverage for recipients of care and health facilities in non-urban areas.
- All recipients of care should be offered RVLT six months after ART initiation.
- Countries need to monitor and improve turn-around times for test results, including when they are actually delivered to recipients of care.



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## I. ESTABLISH LEADERSHIP AND COORDINATION

### a. Review demand and service availability.

- Develop/review a plan for demand creation that is incorporated into a national implementation plan for VL testing. Such plans typically include:<sup>8</sup>
  - o Policies to outline VL processes and procedures
  - o Clinical guidelines, standard operating procedures and job aids, including human resource training plans for compliance with national guidelines
  - o Laboratory VL testing capacity (specimen collection, processing, results return, training)
  - o Commodities forecasting plans
  - o Guidance and activities for demand creation for VL testing
  - o Guidance for VL monitoring and evaluation (clinical, laboratory, commodities) and process and outcome evaluations
  - o Standards and processes for management of recipients of care with virologic failure, including enhanced adherence counseling and switching to second- or third-line ART
- Establish a VL dashboard to track the number of ART clients per facility and VL coverage. An example of a VL dashboard for Nigeria can be found here: <https://aidsfree.usaid.gov/resources/vl-eid/archive/nigeria-viral-load-dashboard>.
- Share VL coverage targets for national, regional, district and facility teams to mobilise district health officers and implementing partners' support.

### b. Understand community perceptions and support demand creation interventions.

- Perform a desk-review of existing literature or conduct surveys to understand community perceptions of RVLТ.
- Give priority to understanding the needs of the pediatric and adolescent communities<sup>9</sup>, as well as pregnant women and other key populations.<sup>10</sup>
- Use the RVLТ results to design interventions implemented by communities of people living with HIV, making use of existing organisational structures from the national to community levels, for demand creation and coordinated by advocacy structures at national, district and community levels.



## II. RAISE AWARENESS AMONG PEOPLE LIVING WITH HIV AND HEALTHCARE WORKERS

Workshops and policy-engagement meetings can sensitise people living with HIV and healthcare workers to the importance of RVL. Also, RVL training materials need to be integrated into the general training curriculum at ART centers. For example, in Zambia, the Treatment Advocacy Literacy Campaign, a network of people living with HIV, conducted a community RVL mapping exercise that subsequently informed their demand creation workshops and policy engagement meetings. Patients should know why and when they should undergo VL testing. When results come back, they should be informed whether they are suppressed or not suppressed.

The practice of explaining results to only non suppressed patients should discontinue. Suppressed patients also need to know their results, which motivates their continued testing adherence. Moses Nsubuga, aka Supercharger, a community advocate for VL testing, lives in a discondant relationship. His partner takes great interest in his suppressed VL status, as suppression has enabled them to discontinue the use of condoms. She regularly reminds him about his next appointment and is keen to know the outcome. For healthcare workers, a comprehensive plan is needed too, so they systematically request and interpret VL test results. Capacity among HCW can be built by adhering to the following steps.

### a. Train healthcare providers to systematically request and interpret test results.

- Develop local training capacity through training of trainers.
- Raise awareness through VL campaigns targeting clinicians.

### b. Monitor and evaluate demand for VL testing at the district level.

- Conduct monthly, national-level data review meetings for implementing partners/districts.
- Conduct district/hub-level meetings to review rates of testing coverage, viral suppression, and any refusals to test.
- Set up quarterly, district-level testing targets for each facility, using the number of people receiving ART as the denominator.
- Engage and support recipients of care, who are powerful agents in monitoring HIV service delivery (as illustrated by the Regional Community Treatment Observatory (RCTO) project found at <http://watchwhatmatters.org/about/>), as part of the solution to addressing gaps in access to RVL.
- Monitor and evaluate results for development and review of targeted action plans.



### III. ASCERTAIN GOVERNMENT POLICY IMPLEMENTATION AND GOVERNMENT ACCOUNTABILITY

In addition to community-led advocacy, a community monitoring system needs to be in place to constantly identify barriers to access and to measure the quality of services. Community monitoring systems ensure that existing government policies that benefit people living with HIV are being implemented.

#### a. Engage civil society in decision making and advocacy.



- Include groups of people living with HIV in national-level technical working groups to be involved in decision making and planning, (e.g., in the roll-out of dolutegravir-based treatment).
- Establish peer support for people living with HIV.
- Encourage people living with HIV to voluntarily monitor VL services and return of results at the facility level as VL champions, as is implemented in Kenya.

#### b. Sensitise and mobilise communities about the importance of RVLT through media or community campaigns.



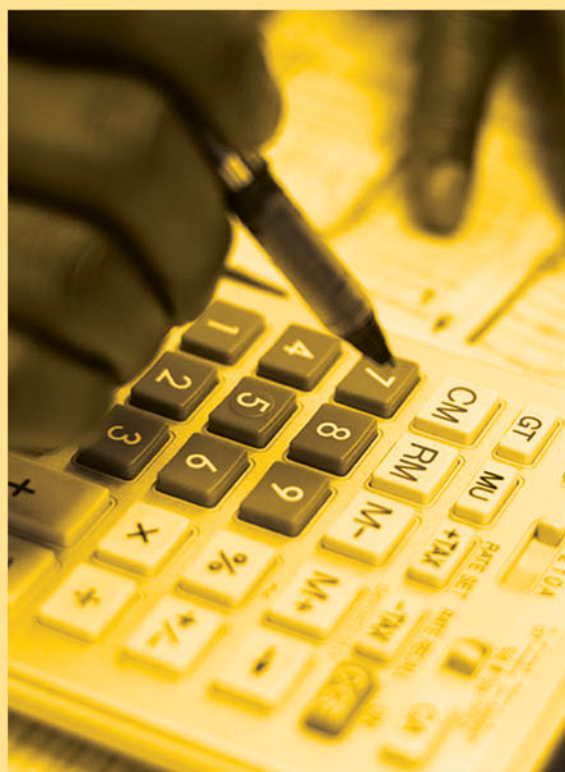
- Produce radio shows, TV spots and videos about health (e.g., ITPC developed an advocacy video based on an RVLT toolkit found at <https://www.youtube.com/watch?v=6Pfk3yAH0ec&t=16s>). Community groups then showed it to policymakers to advocate for RVLT access.
- Create standardised messaging materials for recipients of care and targeted communities.
- Support community organisations to conduct treatment education campaigns and empower people living with HIV with the knowledge to demand greater access to RVLT (e.g. ITPC RVLT toolkit found at <http://itpcglobal.org/resources/the-activist-toolkit/> is an education initiative).
- Disburse small grants to community organisations to facilitate community-led advocacy and stakeholder accountability (a JIAS article describes the ITPC demand creation model found at <http://itpcglobal.org/itpc-publishes-model-demand-creation-routine-viral-load-testing/>).

### IV. ADDRESS COSTS OF VLT

Since prices are still a barrier to access in many countries, it is important to project costs for RVLT at the beginning of a reprogramming cycle to allot specific funding for community-led demand creation activities. This process includes:

- Costing activities related to RVLT
- Accounting for demand creation initiatives in country operational plans and Global Fund reprogramming cycle
- Building on the work of existing local organisations
- Including support for demand creation activities in the budget of HIV programs
- Seeking funding from charities

Program managers should consider polyvalent technologies, which enable testing for multiple diseases and bundled pricing, and multi-manufacturer platforms, as sourcing products from multiple suppliers creates competition, which leads to lower prices and improved after-sales services. Program managers should also consider instrument and/or reagent leasing options, while awaiting newer and more efficient technologies to enter the market.<sup>5</sup>



## V. DEVELOP STANDARD OPERATING PROCEDURES FOR ROUTINE VIRAL LOAD TESTING

To ensure consistent RVLT procedures among national and regional treatment and laboratory facilities, standard operating procedures should be developed, documented, and used by all relevant stakeholders. It is important to strengthen the laboratory-clinic interface for effective planning and use of results by establishing technical working groups at the national and institutional level and establishing communities of practice, such as the LabCoP (<http://www.aslm.org/labcop/>). These entities will create spaces where best practices and procedures are shared among partners, thus increasing the quality of RVLT services.



## VI. ADDRESS STOCK-OUTS

It is important to establish a community monitoring system for stock-outs. The Association of People Living with HIV-Pakistan (APLHIV) implemented a complaint management system where people living with HIV can raise grievances encountered in accessing ART or RVLT, highlighting stockouts for example, thus informing APLHIV's advocacy messages.

## VII. SUPPORT PATIENT ADHERENCE AND DEMAND FOR ROUTINE VIRAL LOAD TESTING

Strategies to support patient adherence and demand for RVLT, may include:

- Mobile phone or SMS reminders for VL-specific appointments
- Supporting faith-based leaders to create a forum for creating information, education and communication materials about VL and other HIV issues
- Faith based leaders should be sensitised on the importance of adherence to treatment for their followers and not assume they are healed just because they have suppressed VL
- Calling clients for VL appointments and/or using community health worker visits
- Aligning treatment education initiatives for recipients of care with drug refill days at clinics

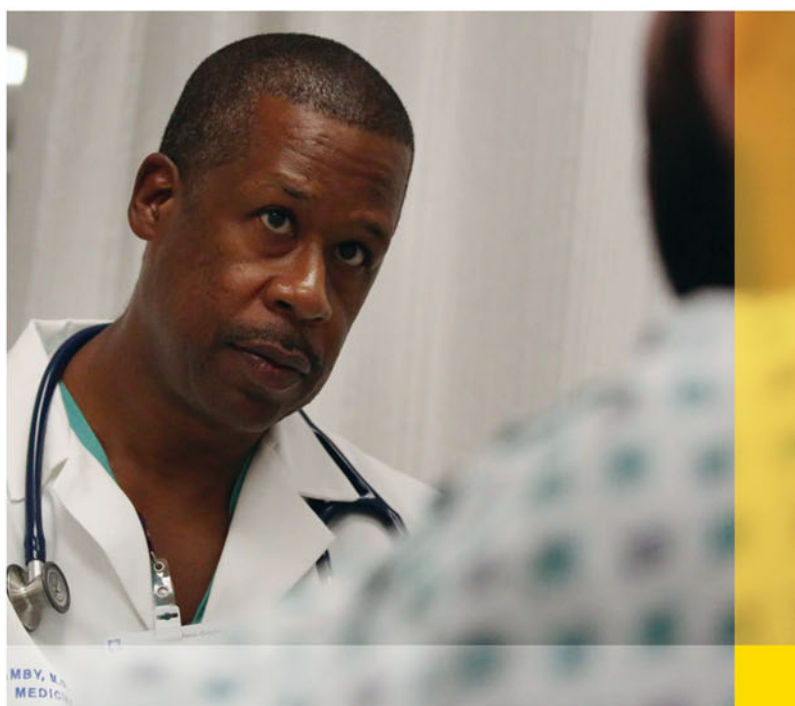
## VIII. MONITOR AND EVALUATE

As physicist William Thompson said, “only that which is measured gets accomplished”. So, it is essential to monitor the outcomes and impact of systems supporting demand creation. This will quickly identify what works and where the bottlenecks occur, and to take swift corrective action.

The following indicators can be used to monitor demand creation efforts:

- Proportion of ART facilities whose staff have been trained and have unhindered access to VL testing
- Proportion of eligible ART clients who receive a VL test
- Therapy (ART) change immediately, or within two months of receiving repeat (second follow-up) high VL test results (or according to the national guidelines)
- Percentage of clients on ART with unsuppressed VL who received a follow-up/repeat VL test within 3–6 months after enhanced adherence counseling (or according to national guidelines)
- Percentage of clients on ART with unsuppressed VL who have received enhanced adherence counseling

More specific indicators are proposed in the technical guidance ‘Considerations for Developing a Monitoring and Evaluation Framework for viral load testing’.<sup>11</sup>





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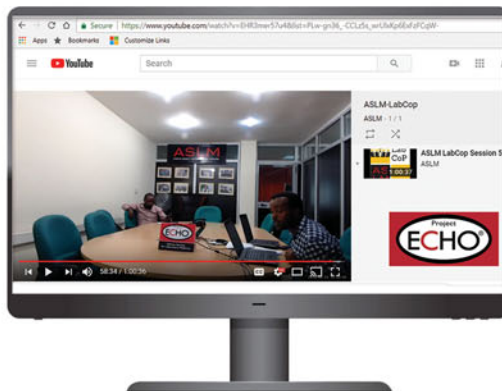


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