



CQUIN RECIPIENT OF CARE SATISFACTION TOOLKIT

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HIV Learning Network
The CQUIN Project for Differentiated Service Delivery



ACKNOWLEDGEMENTS

We would like to express our gratitude to the expansive list of colleagues who provided a wide range of technical assistance in designing, developing, and reviewing this toolkit including members from several CQUIN communities of practices (Quality Management, Monitoring and Evaluation, and Community Engagement). We extend our sincerest appreciation for the International Treatment Preparedness Coalition including Solange Baptiste, Krista Lauer, Helen Etay'ale, and Bactrin Killingo for their significant contributions. Special acknowledgement is stated for Kombatende Sikombe (CIDRZ), Hudson Balidawa (Uganda MoH), and Tatenda Makoni (ZNNP+) for sharing the toolkit case studies. We direct our deepest thanks to the members of the Community Advocacy Network for amplifying the community voice and ensuring that people living with HIV, including recipients of care and their advocates, participate in designing and evaluating high-quality health services.

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ACRONYMS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
CAN	Community Advocacy Network
CHASA	Community HIV and AIDS Support Agents (in Zimbabwe)
CIDRZ	The Center for Infectious Disease Research in Zambia
CLM	Community-led monitoring
CQUIN	The HIV Coverage, Quality, and Impact Network (cquin.icap.columbia.edu)
CSS	Client Satisfaction Survey
DSD	Differentiated service delivery
HCD	Human-centered design
HIV	Human immunodeficiency virus
ITPC	The International Treatment Preparedness Coalition
MOH	Ministry of Health
PEPFAR	United States President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure prophylaxis
ROC	Recipient of care
RCS	Recipient of care satisfaction
SMS	Short message system (e.g., texting)
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
ZNNP+	Zimbabwe National Network of People Living with HIV

BACKGROUND AND INTRODUCTION

The CQUIN learning network is designed to support the scale-up of high-quality HIV differentiated service delivery (DSD) by fostering the exchange of best practices, co-creation of tools and resources, and collaborative problem solving by participants from its 22 partner countries. In 2022, network members jointly identified gaps in their ability to systematically define, measure, and improve the satisfaction of people receiving HIV services. Three of CQUIN's communities of practice—those focused on Quality Management, Community Engagement, and Differentiated Monitoring and Evaluation—partnered with CQUIN's Community Advocacy Network to jointly identify resources and best practices related to this critical issue. This toolkit, which is one output of this collaborative process, provides a conceptual framework for recipient of care satisfaction (RCS), highlights key decisions related to RCS assessment and improvement, and includes illustrative tools and resources. This toolkit is designed to be a dynamic resource that evolves over time.

Satisfaction with Health Care Services

The importance of person-centered health care has long been recognized, as has the need to respect the users of health services, typically termed “patients” or “clients.” In 2018, the *Lancet Global Health Commission on High Quality Health Systems* emphasized the critical importance of improving health care quality and highlighted the importance of ensuring trust, confidence, and satisfaction within health systems to optimize outcomes. The commission recommended focused efforts on improving the user experience of health care services, which are crucial to improving retention in care, adherence to treatment, and public trust in the health system. They defined key elements of a positive user experience as being treated with dignity and respect; and having a health provider who communicates clearly, provides autonomy and confidentiality, and avoids discriminatory behaviors. They stressed that health services should be person-centered, easy to navigate, and attentive to users' values and preferences (Kruk *et al.*, 2018).

Satisfaction with HIV Services

In addition to the central role of user experience in health care more broadly, there are issues specific to the design and delivery of HIV services that make user satisfaction even more critical. These include, but are not limited to, the need for lifelong care and meticulous treatment adherence in the context of a stigmatized illness whose symptoms often vary over time. Driven in part by human rights frameworks and public demand for access and accountability, the HIV response is increasingly centered around the experiences of people living with and affected by HIV. The scale-up of DSD reflects the need for choice, autonomy, and HIV self-management (Ehrenkranz *et al.*, 2021). It is in this context that we use the term

“recipient of care” rather than “client” or “patient,” which are perceived as describing more hierarchical and transactional relationships rather than the collaborative and respectful relationship needed for successful outcomes (Shevell, 2009).

Several studies have linked RCS to HIV treatment adherence, a critical pre-requisite to viral suppression and improved treatment outcomes (Roberts 2004; Martinez *et al.*, 2012; Dang *et al.*, 2013, Somi *et al.*, 2021; Leon *et al.*, 2019). Perceived quality of care also appears to indirectly affect adherence with services across the HIV cascade, including prevention, testing, linkage, treatment, retention, and re-engagement (Nwabueze *et al.*, 2011; Murray *et al.*, 2018; Thornton *et al.*, 2012; Brincks *et al.*, 2019; Hailemeskal *et al.*, 2020). Although it is particularly important that members of key and priority population groups feel satisfied with health care services—to ensure that they are accessing services and can share their positive experiences with others in their social networks (Chau *et al.*, 2022; Murray *et al.*, 2018)—there are fewer data on RCS for these groups.

In August 2022, the CQUIN Community Advocacy Network (CAN) asked its members what attributes of HIV service delivery contribute to RCS. The responses from 25 members of CAN and its advisory group (from 20 countries) are summarized in Figure 1.

FIGURE 2. ATTRIBUTES OF SATISFACTION FROM THE CQUIN COMMUNITY ADVOCACY NETWORK



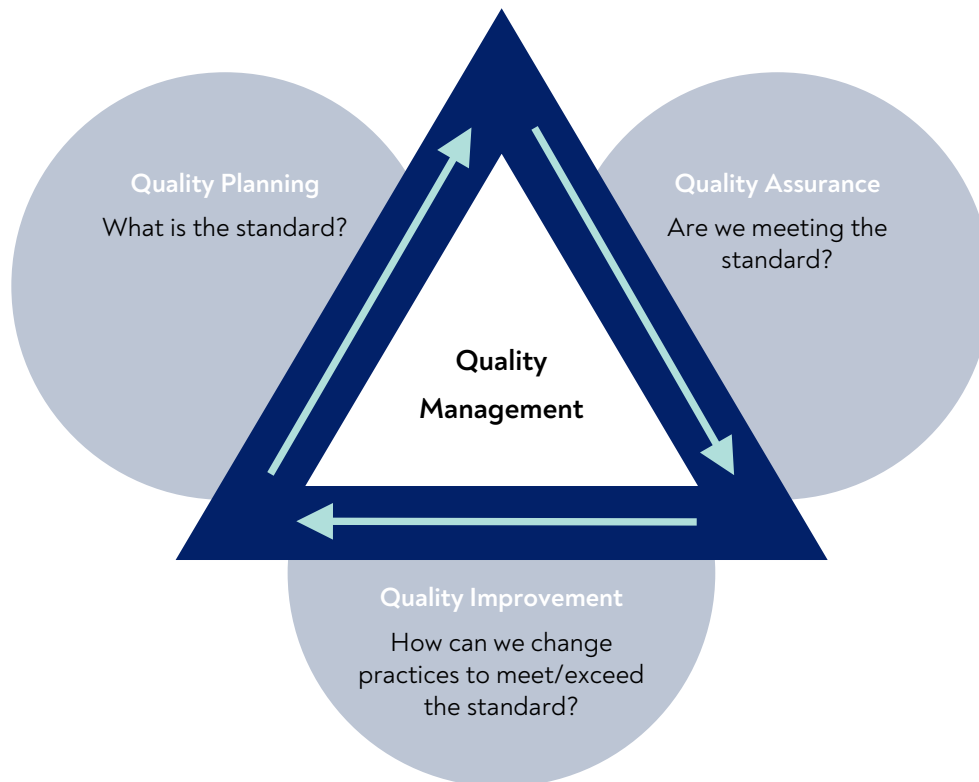
Quality Management and RCC

Quality management centers on defining quality standards, assessing performance *vs.* standards, and using quality improvement methods to enhance performance when it falls short. Through this lens, the purpose of evaluating RCS with

HIV services is to identify and address suboptimal performance. Although this toolkit primarily focuses on assessment, linking results to action is a critical step and should be considered from the start.

This document provides a quality management framework for RCS in the context of DSD and can serve as a conceptual structure to guide the development and implementation of RCS assessment programs. In the sections below, we consider how to define “satisfaction” in the context of differentiated HIV services, review domains commonly used to understand specific elements of satisfaction, compare and contrast assessment methods, and provide resources and tools that can be adapted for local contexts and priorities.

FIGURE 3. THE JURAN QUALITY MANAGEMENT TRIAD



DEFINING “SATISFACTION” WITHIN HEALTH CARE SERVICES

Before starting the RCS assessment process, it is helpful to have a shared mental model around the concepts and terms used within RCS assessment. Unfortunately, there is no single gold standard definition of satisfaction as it relates to health care services. In broad terms, RCS is a measure of the extent to which an individual is content with the health care they receive. RCS is a construct driven by expectations, perceived quality, and perceived value. Put another way, satisfaction is the state of being content or fulfilled with a service or intervention based on one’s needs and desires (Proctor, 2011; Giese and Cote, 2000; Rothschild, 2021). It is a multidimensional and subjective concept—an emotional evaluation shaped by expectations and prior experiences (Batbaatar *et al.*, 2015). RCS is also central to DSD, a person-centered approach that adapts HIV services across the cascade to reflect the preferences, expectations, and needs of people living with and vulnerable to HIV (Grimsrud *et al.*, 2016).

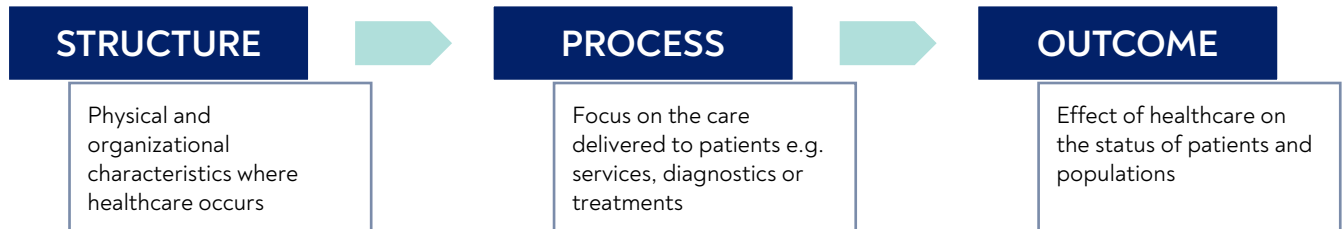
Satisfaction *versus* Quality

Satisfaction with health services is not the same thing as health care quality, although the two are often linked and have an intersecting relationship. Typically, definitions of health care quality revolve around health outcomes. For example, one definition from WHO is: “quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (WHO, 2018). The Lancet *Global Health Commission on High Quality Health Systems*, cited earlier, emphasized that quality health systems optimize health by consistently delivering care that improves or maintains health, by being valued and trusted by all people, and by responding to changing population needs (Kruk *et al.*, 2018)

Donabedian’s classic domains of health care quality, which are illustrated in Figure 3, include **structure** (the context in which care is delivered, including infrastructure, staffing, financing, and equipment), **process** (transactions between providers and recipients of care, *i.e.*, what is done and how it is done), and **outcomes** (the effects of health care on the health status of recipients of care and populations) (Donabedian, 1988).

These frameworks illustrate the point that an individual might theoretically be satisfied with poor clinical quality care or dissatisfied with high-quality clinical care, depending on his or her expectations. Several studies have suggested that recipients of care can have high levels of overall satisfaction despite also feeling that they were treated with disrespect by staff and experienced long wait times (Chimbindi *et al.*, 2014). Furthermore, RCS can itself lead to improved health outcomes. In an ideal scenario, high-quality, person-centered care delivered with compassion can lead to improved satisfaction, thereby improving utilization of services, adherence to medication, retention in care, and, ultimately, improved health outcomes.

FIGURE 4. THE DONABEDIAN HEALTH CARE QUALITY FRAMEWORK

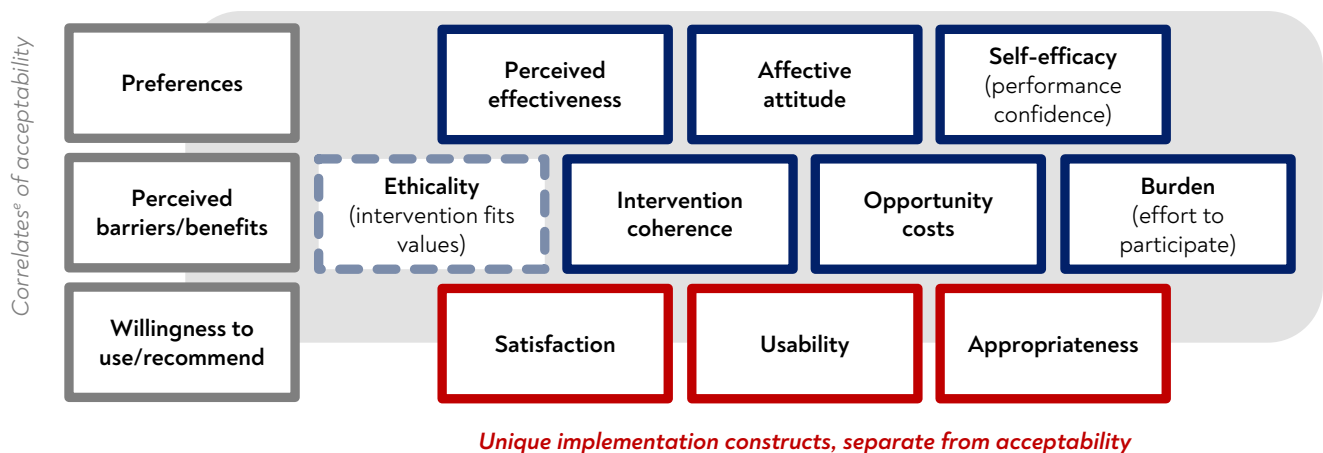


Satisfaction *versus* Acceptability

Similarly, satisfaction is not precisely the same as acceptability of services. Acceptability is defined as a multi-faceted construct that reflects the extent to which people receiving a health care intervention consider the intervention to be appropriate. Typically, the individuals’ perception is based on the anticipated or experienced cognitive and emotional responses to the health care service (Sekhon, 2017).

Ortblad *et al.* (2022) noted that the importance of acceptability has been widely recognized in HIV research, but there is little consensus about how best to define and assess it, leading to weaknesses in implementing acceptability assessments during program design phases. The acceptability framework presented in Figure 4 highlights the importance of elements that include satisfaction, usability, and appropriateness. The authors note that these are often conceptualized as distinct from *acceptability*, which is most often defined as related to effectiveness, attitudes, and costs/burdens of accessing care. As this framework demonstrates, satisfaction is an important element of how acceptable a health program or service may be to recipients of care.

FIGURE 5. ORTLBLAD ET AL. 2022 ACCEPTABILITY FRAMEWORK



- Acceptability^a components from the Theoretical Framework of Acceptability identified in the review
- - - Acceptability^a components from the Theoretical Framework of Acceptability not identified in the review

Satisfaction, Human Rights, and Trust in Health Systems

Human rights frameworks assert that governments are responsible and accountable for implementing health policies and programs that improve the health of their citizens. The argument that this obligation extends beyond health outcomes to include *satisfaction* with health services is reflected in the use of satisfaction as a human rights indicator (Mpinga and Chastonay 2011) and in the use of legal strategies to improve health service quality (Joshi *et al.*, 2022). When people are satisfied with their health services, they are also more inclined to trust the health system (Kruk *et al.*, 2018). Given the health system's role as a core social institution, RCS is also linked to trust in governments (Freedman, 2005).

Measurement Challenges

The absence of a standard definition poses important methodological challenges when it comes to RCS assessment. In addition to asking about overall or “global” satisfaction, a typical approach is to identify dimensions or domains of health services that are assumed to lead to satisfaction or its opposite. For example, the CQUIN Community Advocacy Network (CAN) has discussed the issue of RCS at length and considers it to mean that the health care received by the service user meets the user's expectations. The CAN also asserts that satisfaction generally includes key dimensions, such as that services are provided efficiently with minimum wait time, available without interruption, perceived by the user as high quality, communicated effectively, and provided in an atmosphere in which human rights and dignity are respected and upheld. In the next section, we describe a variety of approaches for assessing dimensions of satisfaction. There is no single best approach, but it is critical to ensure that all stakeholders agree with the selection of dimensions (and associated indicators) prior to assessment.

Other challenges in measuring RCS include lack of consensus on related standards and concerns about the validity of recipient of care perspectives. For some stakeholders, the subjective nature of satisfaction makes assessment unconvincing. For others, the fact that recipients of care may not know what services are clinically appropriate and effective reduces the validity of their opinions (Kash and McKahan, 2017).

WHAT TO MEASURE: DIMENSIONS OF SATISFACTION

Because there is no single best approach to measuring RCS, the first step is to identify and prioritize the dimensions of satisfaction most appropriate to your specific context. Key questions to consider include, but are not limited to: which stakeholders will make this decision, how it will be made, who will see the results, and how results will be used to improve HIV service delivery. Of course, any baseline information about service quality, acceptability, and recipient of care satisfaction should be considered and used to tailor your approach.

The first decision is whether to assess overall satisfaction or to ask questions about specific dimensions. Using a single global dimension may be more efficient, but it may also make it challenging to determine *why* respondents rated satisfaction a certain way and to implement the appropriate improvements. In contrast, using a range of dimensions, such as interpersonal manner of the provider, technical quality of care, availability, health outcomes, and the physical environment will provide more information, but will typically require more time and resources (Shirley *et al.*, 2016).



Table 1 briefly describes illustrative “dimension sets” from diverse contexts to jumpstart discussions and decisions about which may be most appropriate for your setting. Identifying priority RCS dimensions will then enable you to identify optimal, methods, tools, and indicators.

TABLE 1: ILLUSTRATIVE APPROACHES TO PRIORITIZING RCS DIMENSIONS (Cont.)

1. INTERNATIONAL TREATMENT PREPAREDNESS COALITION	
DIMENSION	NOTES
Availability	The necessary health services, infrastructure, equipment, supplies, and medications exist when they are needed and in adequate supply.
Accessibility	Health services are reasonably close to communities, available without long waits, and provided at convenient times; referrals occur smoothly, and access is prioritized fairly.
Acceptability	Health care providers request and respond to feedback from recipients of care related to service delivery. Health care workers are friendly, welcoming, and non-judgmental. Human rights of recipients of care are promoted and protected.
Affordability	No/minimal out-of-pocket payments are required (formal or informal). The health provision model is financially sustainable.
Appropriateness	Health services are formally aligned with national standards, policies, and guidelines so the onus is not on recipients of care to ensure that standards are met. Services are differentiated to meet the needs of all recipients of care, including tailored approaches based on age, gender, and key population status.
2. NG AND LUK, 2019	
DIMENSION	NOTES
Provider attitude	Recipients of care were more satisfied when health care workers were courteous, friendly, kind, and approachable, and when they delivered education and health information while demonstrating respect for their participation in the decision-making process.
Technical competence	Recipients of care tend to be more satisfied if they believe their care provider possesses technical competence and adheres to high standards of technical skill.
Accessibility	Facility cleanliness, comfort, and infrastructure correlated directly to recipient of care satisfaction. Apart from physical factors, process-related issues (such as waiting times for services) were of critical importance.
Efficiency	Recipient of care satisfaction was more likely when they considered their treatment to be effective and their health improved.
3. DANSEREAU ET AL., 2015	
DIMENSION	NOTES
Health personnel practices and conduct	Topics: compassion, respect, honesty, clinical exam quality, privacy, patient involved in decision-making

TABLE 1: ILLUSTRATIVE APPROACHES TO PRIORITIZING RCS DIMENSIONS (Cont.)

Adequacy of resources and services	Medical equipment adequacy, cleanliness, waiting room space, drug availability
Health care delivery	Good diagnosis, prescription of drugs, drug quality, treatment effectiveness
Accessibility of care	Hours of operation, ease of obtaining drugs, distance to health facility, waiting time
Cost of Care	Out of pocket expenses
4. OGAJI ET AL., 2015	
DIMENSION	NOTES
Humanness	Staff conduct, respect, courtesy, receptiveness, and interpersonal skills
Access	Distance to the facility, opening times, availability of appropriate health workers, being able to reach the facility on the phone
Bureaucratic arrangements	Waiting times, promptness in receiving attention, operating times, and service plan
Cost of care	
Information and communication	Counseling, information on illness, treatment and prevention, clarity of communication, and information on planned services
Physical facilities	Physical building, amenities, adequacy of equipment for patient care, patient records, laboratory, and infrastructure for emergencies
Adequacy of supplies	Drugs and other commodities
Technical performance	Perceived skill and competence of providers, perceived quality of consultations, follow-up, and continuity of care
Outcome	Perceived benefits from encounter with the service
Psychosocial aspects of care	Responsiveness, interest in recipient of care, staff willingness to help, personal attention, protection of individual's rights, dignity, privacy, confidentiality, and recipient of care involvement.
Overall view of service	Overall satisfaction with the service. Recipient of care willingness to return to the same facility when the need arose and/or recommend the facility to others

HOW TO MEASURE: METHODOLOGICAL CONSIDERATIONS

Recipient of care satisfaction can be measured in many ways. When planning an RCS assessment, it is critically important to consider not only which domains/dimensions of satisfaction you wish to assess, but which methods are best suited to your project. The optimal assessment design will balance feasibility, accuracy, and impact, giving careful thought to who is collecting data and in which location, as well as to the specific tools and questions being used. Table 2 below illustrates some of the key tradeoffs associated with different assessment strategies.

Feasibility

Realistically, your assessment will be shaped by the available resources. Funding will likely dictate assessment size and methodology. Time is also a resource and the speed at which results are needed may impact decisions about what types of data you will collect. (For example, qualitative data can take longer to analyze than quantitative data). In some cases, the skills needed to conduct the assessment will exist within your organization, while in others, you may need to engage consultants or develop new partnerships.

Accuracy

It is important to understand how assessment design and data collection strategies and tools can influence the accuracy of your findings. Key issues to consider at the design stage include *bias*, *validity*, and *reliability*. A detailed discussion is beyond the scope of this toolkit, but additional resources are included below for more detailed information.

Bias is a systematic flaw in study design, data collection, and/or data analysis that results in inaccurate conclusions. Some relevant examples include:

- *Ascertainment bias* can be caused by whom is being asked about satisfaction. For example, health facility exit interviews may be biased because they only include people who have come to the health facility. This group of people may have very different opinions about RCS than those who have missed appointments or who have interrupted care. Understanding this dynamic may affect decisions about respondent sampling.
- *Acceptability bias* can be caused by who is asking about satisfaction. For example, recipients of care may be more comfortable sharing negative feedback with peers than with health care workers. This may be due to the power imbalance between recipients of care and health care workers, or to *courtesy bias*, in which complaints or critiques are minimized to be polite towards the questioner. Thoughtful consideration of this issue should inform decisions about who will lead data collection activities.

- *Low expectation bias*: As noted above, satisfaction is a function of expectations and, when expectations are modest, recipients of care may report themselves to be satisfied with characteristics associated with poorer quality care. Avoiding simple yes/no questions, triangulating by asking questions in different ways, and the use of both quantitative and qualitative data may mitigate against this type of bias.

Validity relates to how well your assessment results represent true findings. This includes consideration of whether your assessment design, tools, and methods accurately capture RCS among study participants (internal validity) and the extent to which your results can be generalized to a broader population of recipients of care (external validity).

- *Internal validity* can be enhanced by selecting study designs and tools that limit bias, triangulating quantitative and qualitative data where feasible, and ensuring appropriate sample size.
- *External validity* can be enhanced by including diverse participants in your assessment. For example, RCS may be different among people at urban *vs.* rural sites, or younger people *vs.* older people, or members of one key population *vs.* another.

Reliability refers to the ability of a study instrument or assessment tool to produce consistent and reproducible results. Three common methods of reliability testing are the interclass correlation coefficient, Pearson correlation coefficient, and the kappa statistic (Shirley *et al.*, 2016). Using existing tools with proven reliability is often preferable to developing *de novo* tools.

Impact

It is also important to consider in advance how you plan to *use* the data: Who is your audience? What types of data are most likely to have an impact? You may need very different information for a quality improvement project at one health facility than for an assessment intended for national-level advocacy and policy change.

TABLE 2: ASSESSMENT DESIGN CONSIDERATIONS (Cont.)

METHOD	CHARACTERISTICS	TYPE OF DATA	ADVANTAGES	DISADVANTAGES
Feedback box	Facility-based	Can be qualitative (“how was your experience today”) or quantitative (“Rate your experience on a scale from 1-10”)	<ul style="list-style-type: none"> • Easy to administer • Inexpensive • Anonymous 	Very limited validity and reliability
Feedback button	“Satisfaction buttons”	Quantitative – respondents click on happy <i>vs.</i> sad faces (e.g., on a screen or kiosk)	<ul style="list-style-type: none"> • Easy to administer • Often produce high-volume data • Anonymous 	Could be difficult to implement in low-resourced settings; limited validity and reliability

TABLE 2: ASSESSMENT DESIGN CONSIDERATIONS (Cont.)

METHOD	CHARACTERISTICS	TYPE OF DATA	ADVANTAGES	DISADVANTAGES
In-depth Interviews	<ul style="list-style-type: none"> • Facility-based, interviewer administered • Can be administered immediately post-visit or later via phone 	Can be quantitative or qualitative	Typically provides more nuanced and/or explanatory data than surveys or questionnaires	<ul style="list-style-type: none"> • May introduce several types of response bias, including ascertainment, acceptability, and courtesy bias • Require trained interviewers
Surveys – paper or electronic	Facility-based, self-administered either immediately post-visit or later via mail, mobile applications, or online	Frequently quantitative, though may also have open-ended qualitative questions	<ul style="list-style-type: none"> • Easy to administer • Inexpensive • Less likely to have acceptability/courtesy bias than interviews • Respondents can enter data electronically and, therefore, analysis may be faster; some online survey tools provide analytic assistance 	<ul style="list-style-type: none"> • Introduces ascertainment bias (as only people who come to the health facility participate) • Limited to people who are literate • Participants without internet access, with low computer literacy, or who do not wish to share their email address may be difficult to reach with this method
Focus group discussions	Can be facility-based or community-based	Qualitative data	Provides relatively in-depth information about participants’ thoughts and opinions. Typically provides more nuanced and/or explanatory data than surveys or questionnaires.	<ul style="list-style-type: none"> • May introduce several types of response bias, including ascertainment, acceptability, and courtesy bias • Data analysis can be time-consuming • Requires trained facilitators and experts in qualitative coding and analysis methods
Observation through direct methods “Shadowing” recipients of care	Facility-based, trained data collector (can be a health care provider or an expert service user)	<ul style="list-style-type: none"> • Qualitative and quantitative data • Use of a standard feedback form along with narrative observations 	Useful observations and data of the experience through the eyes of the recipient of care and family, noting each step in their process. Can provide first-hand comments and questions raised by health care workers and the recipient of care and family in real-time.	<ul style="list-style-type: none"> • May introduce the ‘Hawthorne effect’* and several types of response bias, including, ascertainment, acceptability, and courtesy bias • Requires trained facilitators

TABLE 2: ASSESSMENT DESIGN CONSIDERATIONS (Cont.)

METHOD	CHARACTERISTICS	TYPE OF DATA	ADVANTAGES	DISADVANTAGES
Observation through indirect methods “Secret shoppers”	<ul style="list-style-type: none"> • Facility-based, trained observers (can be expert recipients of care) 	<ul style="list-style-type: none"> • Qualitative and quantitative data • Use of a standard feedback form to guide the visit along with narrative observations 	Useful observations and data of the experience through the eyes of the recipient of care, noting each step in their process	<ul style="list-style-type: none"> • Health workers may be uncomfortable with this approach • Requires trained facilitators
Community-led monitoring	<ul style="list-style-type: none"> • Facility and community-based • Qualitative and quantitative indicators developed through a community process; collected via data collectors using a variety of tools (checklists, scorecards, individual interviews, focus group discussions) • Important that data collectors (“field researchers”) are trusted by the communities they are interviewing 	Qualitative and Quantitative	<ul style="list-style-type: none"> • Centered on those issues that matter most to recipients of care • Continuous data collection (usually quarterly) enables tracking of trends (are issues improving or getting worse?) • Joint discussion of findings with decision-makers leads to concrete improvements in satisfaction 	<ul style="list-style-type: none"> • Time-intensive process • Not a one-time “snapshot,” but routine, continuous data collection over time • Ongoing data analysis can be time-consuming

**Hawthorne effect* refers to study participants' alteration of behavior solely as a result of being observed (rather than as a result of the intervention). Therefore, for the Hawthorne effect to exist, it is necessary for the subjects to realize they are under observation.

FURTHER INFORMATION ABOUT METHODOLOGICAL CONSIDERATIONS:

- Dunsch, F., Evans, D. K., Macis, M., & Wang, Q. (2018). Bias in patient satisfaction surveys: a threat to measuring healthcare quality. *BMJ global health*, 3(2), e000694. <https://gh.bmj.com/content/3/2/e000694.abstract>
- Jordan, P. J., & Troth, A. C. (2020). Common method bias in applied settings: The dilemma of researching in organizations. *Australian Journal of Management*, 45(1), 3-14. <https://doi.org/10.1177/031289621987197>
- Jann, B., Krumpal, I., & Wolter, F. (2019). Social Desirability Bias in Surveys—Collecting and Analyzing Sensitive Data. Special Issue. <https://boris.unibe.ch/133691/1/mda-13-1.pdf>
- Sedgwick, P. (2013). Questionnaire Surveys: Sources of bias. *BMJ Clinical Research*. 347. <https://www.researchgate.net/publication/275426578> Questionnaire surveys Sources of bias

STRATEGIC PLANNING FOR THE RCS ASSESSMENT: KEY DECISIONS

This section provides an overview of the major issues to consider when planning for RCS assessment processes and systems. The process map presented in Figure 5 below offers a view of typical RCS considerations that can guide the decision-making process in a practical and realistic way. While this section can provide a road map for developing an RCS assessment approach, the map in Figure 5 can also help identify two or three different approaches, leading to a mixed-method platform.

We must begin somewhere and, before embarking on the RCS assessment and improvement expedition, it may be useful to first ask if there are existing RCS initiatives in your context that could be adapted and leveraged to support further program expansion. In many cases, there may already be MOH partners, collaborators, or local organizations who have implemented studies and/or ongoing monitoring and evaluation of RCS within HIV programs or other health care areas (*i.e.*, reproductive health and family planning). Leveraging these existing RCS assessments will be helpful for making planning decisions based on past experiences and lessons learned.



In March 2023, the CAN hosted a meeting in Nairobi to discuss RCS assessment preferences with 30 recipients of care who had various experiences participating in different satisfaction assessments. This meeting produced some important considerations for RCS assessment planners including, a general preference for digital surveys which are brief and ask clear and pointed questions. Many CAN members expressed a preference for a mixed method approach having both health care workers and communities to conduct surveys. Additionally, there is a general agreement that recipients of care would like to choose which assessment they prefer for their participation. Promotion of peer-to-peer surveys is also recommended to help create a more rewarding, open and honest survey experience.

Who

Strategic planning discussions can begin by asking if you are interested in assessing the satisfaction of recipients of care themselves—directly or through alternative methods that include observation from inside the service delivery setting. Answering these questions will help the team select specific options, such as shadowing, mystery shoppers, or methods related to directly engaging with recipients of care.

If the decision is to assess satisfaction through direct engagement with recipients of care, it is important to thoughtfully consider which individuals will be selected for assessment within the selected sampling frame. For example, it will be important to engage with a diverse range of recipients of care. Members of key and priority populations, such as female sex workers, men who have sex with men, people who inject drugs, adolescents, and young people (especially girls) should be included in all assessments as well.

It is also important to consider who will be delivering the RCS assessment and/or asking the questions. Selecting external evaluators will be important to reduce bias and ensure that individuals feel comfortable sharing accurate and insightful responses.

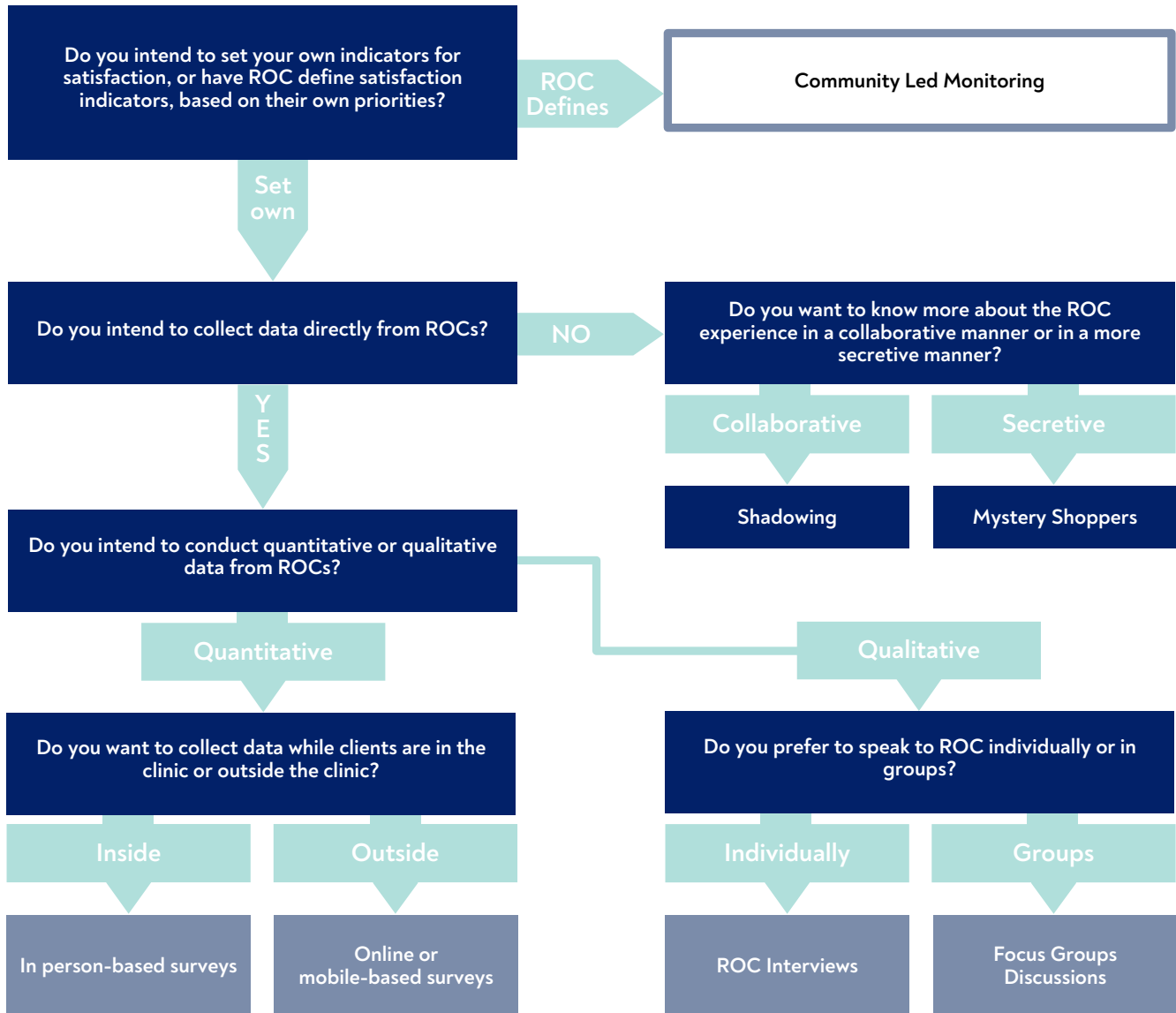
What

The team can then decide what type of data they are interested in obtaining from either the service delivery side or from recipients of care themselves. If the team aims to collect data directly from recipients of care, the question to answer is: *What type of data is desired?* Does the team seek qualitative (richer and more complex) data, or quantitative (quicker and more simplistic) data? If the team aims to collect qualitative data from recipients of care, the team can decide if these interactions should happen individually or in a group. Additionally, the team should consider: *Will the team develop its own indicators for assessment or engage with recipients of care themselves to develop indicators?* Answering these questions will direct the team towards specific assessment methods, such as surveys, individual interviews, focus groups, or community-led monitoring.

Where and When

Additional strategic discussion questions include: *When and where will interviews with recipients of care occur?* For example, the team can decide to obtain data via a paper survey form collected at the health facility immediately after the visit or electronically several hours or days after the health care visit.

FIGURE 6. PROCESS MAP FOR RCS ASSESSMENT STRATEGIC PLANNING



Note: **ROC** = recipients of care

A SPECIAL NOTE ABOUT ETHICAL APPROVALS

Typically, ethical approvals are not required for service delivery projects and quality improvement work. However, it will be important to talk to a representative on your local research ethics committee in case any local protocols need to be followed in relation to specific approaches the team plans to use (such as exit interviews or focus group discussions).

TOOLS, STRATEGIES, AND CASE STUDY EXAMPLES

This section provides explanatory descriptions of RCS assessment approaches and methods, along with a discussion of the tensions that may arise in the selection and application of each tool. Resources for further reading and learning are also included.

Survey Approaches

RCS surveys are quick and easy to administer and, in most cases, can be completed immediately after a health facility visit or within a few days of the visit. Quantitative questionnaire surveys are the most common method used to assess RCS. Surveys can be administered via paper format, handheld tablet computer, an email link to an electronic survey, and/or text message link. Survey questionnaires use mostly closed-ended questions (with a numerical score attached) to assess dimensions of satisfaction. Answer choices are predetermined, and respondents select the answer that fits best. Most surveys are administered immediately after a recipient of care has completed a health care service or within a week of receiving the service. Conducting the survey immediately after the client-provider interaction can help reduce recall bias, as the experience will be fresh in the respondent's mind.

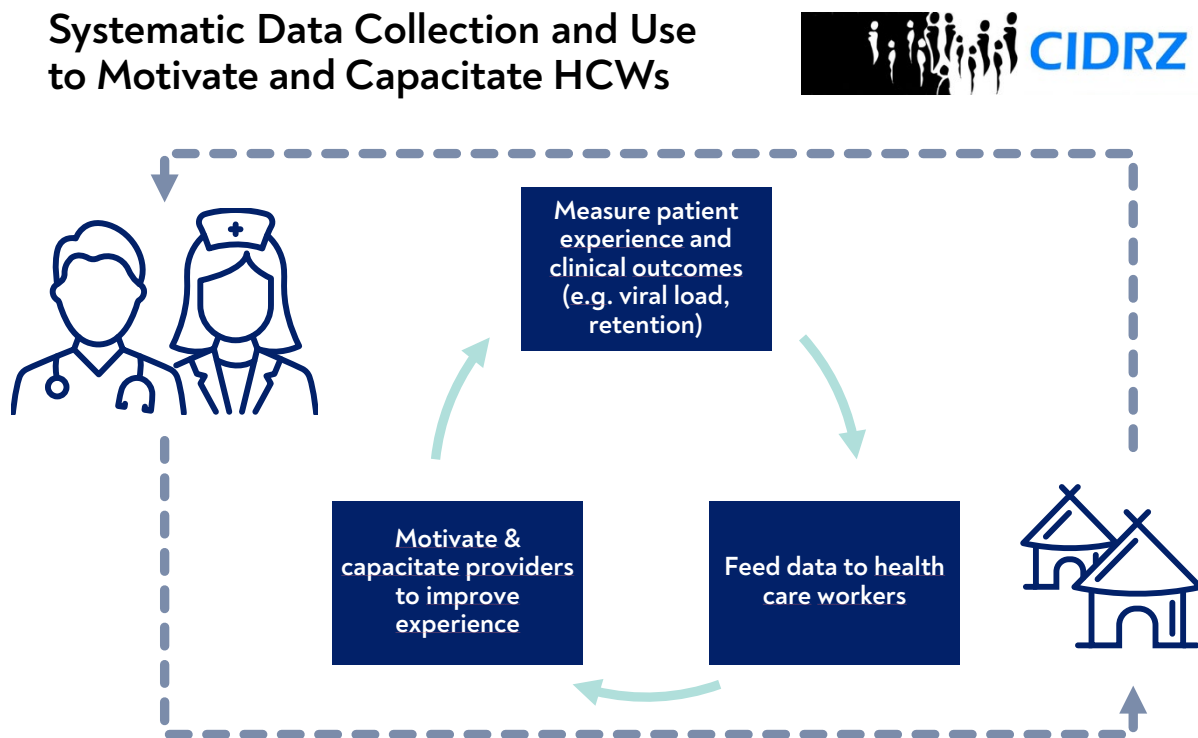
Advantages of this method include gaining a large amount of quantitative data (*e.g.*, patient demographics); the availability of multiple administration approaches; and that there are a range of validated surveys available. **Disadvantages** include that quantitative surveys may produce a more superficial understanding of RCS (and nuanced experience or special circumstances may not be captured as well); close-ended questions tend to be scored higher due to social-desirability bias; and respondents need to be literate (De Silva, 2013)

Depending on the methodology chosen, quantitative survey approaches can be the most effective for collecting data that are comparable across a large population, in a relatively rapid time frame and cost-effective manner. Using a reliable and validated tool is important to reduce bias; however, other biases may be introduced by utilizing this methodology, including response bias (which can result from individuals rushing through the tool and providing inaccurate answers). Other biases to consider include: social desirability bias, courtesy bias, neutral and extreme response bias, and non-response bias.

CASE STUDY: Zambia uses an innovative, mobile exit survey approach to capture recipient of care satisfaction with HIV services

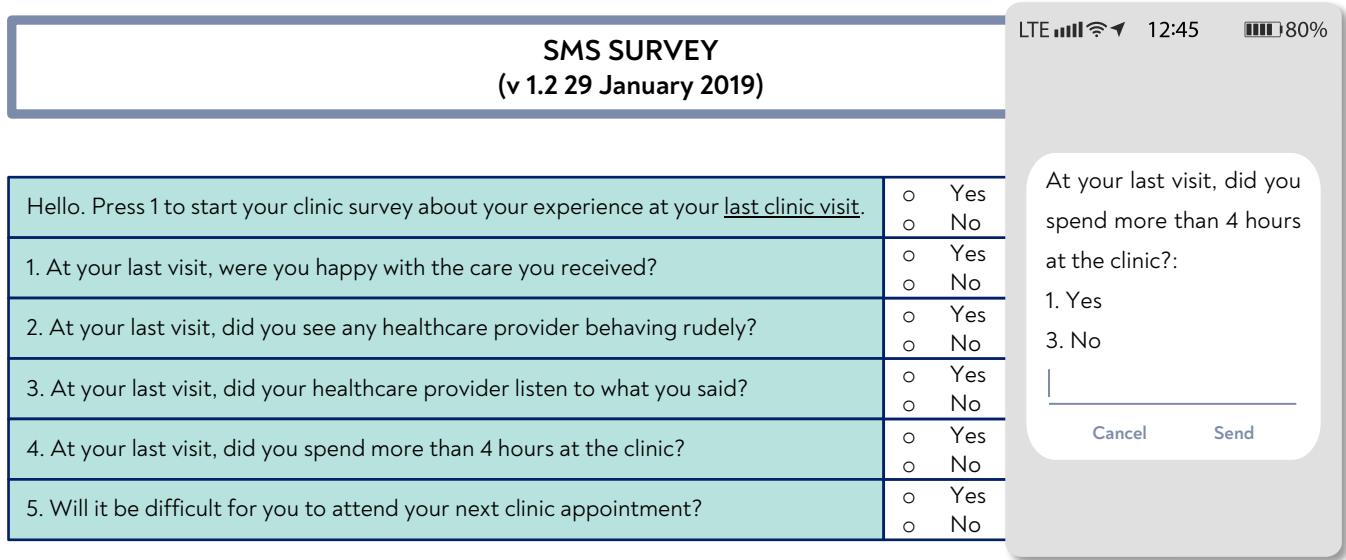
The Zambia MOH received support from the Center for Infectious Disease Research in Zambia (CIDRZ) to implement person-centered public health approaches for HIV treatment to improve continuity in care and viral suppression. CIDRZ integrated measurement of recipients of care experience and satisfaction within this program based on research into clinic, psychosocial, and structural factors that led to recipients of care leaving HIV treatment. In collaboration with CIDRZ, the MOH aimed to improve recipient of care experience and thus reduce loss to follow-up and enhance viral suppression. The MOH and CIDRZ posit that measuring and improving the recipient of care experience is critical to improving viral suppression and reducing mortality. Their recipient of care experience conceptual framework includes three fundamental elements: measure recipient of care experience, feed data to health care workers, and capacitate providers to improve experience (see Figure 6).

FIGURE 7. CIDRZ MODEL FOR SYSTEMATIC RCS DATA COLLECTION, ANALYSIS, AND IMPROVEMENT



The MOH optimized health worker use of an electronic database that monitors recipient of care experience and provides easy-to-understand analytics. These analytics allow quality improvement teams to generate change interventions specifically designed to address recipient of care feedback and improve their experience. The database relies on mobile messaging and mobile-based survey instruments delivered immediately after a recipient of care visits a health facility (see Figure 7). The exit survey contains five yes/no-based questions. If a survey registers as incomplete, SMS reminders are sent after 24 and 72 hours, and a final reminder is sent after seven days. CIDRZ provided a training for a coaching model that focuses on mentoring health care workers to utilize the system and develop sustainable improvement interventions.

FIGURE 8. THE ZAMBIA MOH AND CIDRZ RCS MOBILE SURVEY TOOL



CIDRZ conducted a pilot study six months prior to the start of the recipient of care-centered public health program to test and finalize the design of the satisfaction measurement implementation package. The team addressed the challenge of identifying a low-cost technology solution by using CIDRZ-based software developers to deploy an open-source software. Required resources included: server hosting, server set-up, and tablets. Ensuring ongoing privacy was an important consideration, as cell phones are frequently shared. Given the concern that sharing health information could result in unintended disclosure of status, all individuals were given the option to opt out of the intervention.

FURTHER RESOURCES ON RCS SURVEYS:

- UNFPA. (2016). Client satisfaction survey in pilot health facilities implementing sexual and reproductive health and HIV linkages project. <https://botswana.unfpa.org/sites/default/files/pubpdf/CLIENT%20SATISFACTION%20SURVEY-%20SRHR-HIV%20Linkages%20Pilot%20Health%20Facilities.pdf>
- Mukamba, N., Chilyabanyama, O. N., Beres, L. K., Simbeza, S., Sikombe, K., Padian, N., ... & Schwartz, S. R. (2020). Patients’ satisfaction with HIV care providers in public health facilities in Lusaka: a study of patients who were lost-to-follow-up from HIV care and treatment. *AIDS and Behavior*, 24(4), 1151-1160. <https://doi.org/10.1007/s10461-019-02712-4>
- Dansereau, E., Masiye, F., Gakidou, E., Masters, S. H., Burstein, R., & Kumar, S. (2015). Patient satisfaction and perceived quality of care: evidence from a cross-sectional national exit survey of HIV and non-HIV service users in Zambia. *BMJ open*, 5(12), e009700. <https://bmjopen.bmj.com/content/5/12/e009700.abstract>
- Buluba, S. E., Mawi, N. E., & Tarimo, E. A. (2021). Clients’ satisfaction with HIV care and treatment centres in Dar es Salaam, Tanzania: A cross-sectional study. *PloS one*, 16(2), e0247421. <https://doi.org/10.1371/journal.pone.0247421>

- De Jager, G. A., Crowley, T., & Esterhuizen, T. M. (2018). Patient satisfaction and treatment adherence of stable human immunodeficiency virus-positive patients in antiretroviral adherence clubs and clinics. *African Journal of Primary Health Care and Family Medicine*, 10(1), 1-8. <https://hdl.handle.net/10520/EJC-f84938ee2>
- Amporfro, D. A., Boah, M., Yingqi, S., Cheteu Wabo, T. M., Zhao, M., Ngo Nkondjock, V. R., & Wu, Q. (2021). Patients' satisfaction with healthcare delivery in Ghana. *BMC Health Services Research*, 21(1), 1-13. <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-06717-5>

In-Depth Interviews

Qualitative, in-person interviews are conducted after the recipient of care has received any health facility service (e.g., after a clinical visit, medication pick-up, or laboratory test). Interviews provide an opportunity to obtain information directly from the recipient of care to understand their perspective on the services they received that day (ideally immediately after completing the clinical service to reduce recall bias). **Advantages** of in-depth interviews include having a facilitator able to probe for deeper reasons and being able to explore more sensitive topics that may not otherwise be discussed. **Disadvantages** of this method include that it can be resource-intensive and that the generalizability of findings may be limited (especially with smaller sample sizes) (De Silva 2013).

Typically, the interview is semi-structured, uses standard questions, and is conducted with the recipient of care individually in a private space. The interviewer should be an external reviewer who will record the interview, take notes, and transcribe the recording for further analysis. While exit interviews can provide rich narrative data on personal experiences and preferences, this method can also introduce courtesy bias and social desirability bias and, therefore, may not lead to reliable data. It is important to provide the individual being interviewed with education on confidentiality and how data will be stored. Additionally, conducting the interview in a physical location that is private, secure, and away from the location they received services can help reduce courtesy bias and elicit more accurate responses from the interviewee.

There are a variety of available sampling procedures, including simple random sampling and systematic random sampling. Examples include: interviewing all eligible clients exiting the clinic; randomizing all eligible recipients of care to be either interviewed or not interviewed; selecting every Xth recipient of care exiting the clinic to be interviewed; and/or, after each interview, the interviewer selects the next recipient of care leaving the clinic to be interviewed. Each method has advantages and disadvantages based on the context and other unique considerations. The general recommendation is to select patients randomly as they enter the clinic to participate in the interview (as this selection process may most efficiently reduce bias) (Geldsetzer, Fink, Vaikath, & Bärnighausen, 2018).

Exit interviews aim to obtain a diverse range of opinions from a representative sample of recipients of care. However, since this method is more resource-intensive, selecting an adequate sample size to sufficiently describe and represent recipient of care satisfaction is important. Having too small a sample size risks inadequate and incomplete data, and too large a sample size could waste resources and lead to repetitive data. "Saturation" is a concept in qualitative studies and is said to occur when interviewing more recipients of care does not result in obtaining new or different information. The concept of saturation can also reflect the diminishing returns that occur with larger sample sizes (as more data does not necessarily lead to more information). Research has shown that, in general, 15 to 30 interviews can lead to an efficient and fruitful collection of applicable qualitative data. Some studies suggest that sample sizes of 10 can also yield comprehensive results; however, a rigorous selection process must be safeguarded (Hennink, & Kaiser, 2022).

CASE STUDY: Mozambique utilizes the interview approach to gain insights into recipient of care experiences during DSD data review progress assessments

The Ministry of Health in Mozambique (MISAU) has integrated recipient of care experience exit interviews into their DSD Performance Review (DPR) process, which involves the collection of client-level data from medical records at a purposive sample of health facilities. After DSD data collection, recipients of care are selected at random to provide qualitative information in three key areas:

- Advantages of DSD
- Disadvantages of DSD
- Suggestions for improvement

During the DPR data collection process, three recipients of care enrolled in DSD at each health facility (ideally in three different DSD models) are requested to consent and participate in a short interview during which they answer three open-ended questions. Staff utilize a standard interview form, which includes the following questions:

- What are the advantages of DSD for you and for the health system? (Describe three)
- What are the disadvantages of DSD for you and for the health system? (Describe three)
- What are your recommendations for improving DSD services? (Provide three suggestions)

MISAU leaders and managers then analyze the data and integrate suggestions into their quality improvement activities and program planning systems.

FURTHER RESOURCES ON EXIT INTERVIEWS:

- Chimbindi, N., Bärnighausen, T., & Newell, M. L. (2014). Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews. *BMC health services research*, 14(1), 1-13. <https://link.springer.com/article/10.1186/1472-6963-14-32>
- Geldsetzer, P., Fink, G., Vaikath, M., & Bärnighausen, T. (2018). Sampling for Patient Exit Interviews: Assessment of Methods Using Mathematical Derivation and Computer Simulations. *Health services research*, 53(1), 256–272. <https://doi.org/10.1111/1475-6773.12611>
- Chavane, L., Dgedge, M., Bailey, P., Loquiha, O., Aerts, M., & Temmerman, M. (2017). Assessing women's satisfaction with family planning services in Mozambique. *Journal of Family Planning and Reproductive Health Care*, 43(3), 222-228. doi: 10.1136/jfprhc-2017-101842. <https://srh.bmj.com/content/43/3/222.short>
- Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Social Science & Medicine*, 292, 114523. <https://doi.org/10.1016/j.socscimed.2021.114523>
- Sah, D. C., & Kumar, Y. (2015). Client satisfaction exit interviews: assessing quality of public health institutions through generated feedback. *Vikalpa*, 40(1), 42-61. <https://doi.org/10.1177/0256090915574194>
- Zaky, H. H., Khattab, H. A., & Galal, D. (2007). Assessing the quality of reproductive health services in Egypt via exit interviews. *Maternal and child health journal*, 11(3), 301-306. <https://doi.org/10.1007/s10995-006-0167-y>

Focus Group Discussion Approaches

A focus group discussion typically involves gathering 8-12 persons from similar backgrounds to discuss a specific topic of interest. It is a form of qualitative research where questions are asked about individuals' perceptions, attitudes, beliefs, opinions, and/or ideas (Zacharia, Pai, and Paul, 2021). Focus group methodology includes asking approximately 10 carefully selected questions and allowing enough time for the group to respond and interact with the facilitator. Focus group discussions are a very useful way to bring recipients of care together to share their personal insights and experiences related to health services. **Advantages** include: bringing a group of people together can spark ideas and help reduce courtesy bias; individuals may feel safer expressing their real concerns and issues with others who face the same challenges; and focus groups can be reconvened with the same group over time. **Disadvantages** include: resource-intensiveness (it may not be as cost-effective as other methods) and the fact that groups may experience high dropout rates over time, leading to issues of generalizability and selection bias among those who remain in the focus group(s) (De Silva, 2013).

Planning, implementing, and analyzing data elicited from focus group discussions can require human resources, time, and funding. Carefully consider needs associated with the following: participant recruitment, scheduling focus group session(s), having an external expert facilitator who can ensure equal representation among group members and can elicit the most accurate data, recording the sessions, and having staff or consultants well-versed in qualitative data coding and qualitative analysis methods. (Qualitative data analysis requires a trained specialist equipped to perform specific analysis methods, such as: content, narrative, discourse, and thematic analysis, as well as grounded theory analysis.)

CASE STUDY: Uganda utilizes a mixed-method approach using both quantitative surveys and qualitative focus group discussions to assess RCS

In 2017, the Uganda MOH began planning the scale-up of DSD to all ART facilities; however, there was a lack of information on performance to guide expansion. Through Global Fund support, a country-wide study to examine DSD implementation was conducted to collect data on measures of DSD quality. The Uganda MOH routinely conducts RCS assessments during quarterly supportive supervision, but these assessments are performed on a small sample and are not used to inform broader and national strategic interventions. Therefore, an RCS objective was added to the overall national study examining the quality of DSD implementation.

In 2019, the Uganda MOH implemented the country-wide, facility-based study to assess DSD implementation, including performance, clinical outcomes, and satisfaction with services. The cross-sectional study used a mixed-method approach, collecting data through 8,384 recipients of care exit interviews and 10 focus group discussions with experienced recipients of care (5 male and 5 female). RCS was assessed using five dimensions:

- Accessibility/convenience (*place, time of day, day of the week for drug refill and clinic review*)
- Environment (*cleanliness, ease of finding where to go, privacy*)
- Efficiency (*waiting time, contact time, visit cost*)
- Comprehensiveness (*health education, counseling, number of visits*)
- Humaneness (*friendliness, confidentiality, level of respect and listening, whether enough time was provided, level of involvement*)

Paper-based surveys were conducted immediately after the client visit using a standard questionnaire tool (see Figure 8) and satisfaction was measured on a scale of 1 to 5. Recipient of care respondents who scored 3 and above were considered “satisfied.” A composite satisfaction score was computed for each model, as well as an overall score for all five RCS dimensions.

FIGURE 9. EXAMPLE OF UGANDA MOH EXIT SURVEY

D	Patient satisfaction					
<i>We are interested in receiving your feedback about the HIV care services you are receiving under the current method of care you are using. Your responses are important to us and will help to improve the services.</i>						
	Accessibility / convenience (<i>How convenient to you are the following:</i>)	Extremely inconvenient	Very inconvenient	Convenient	Very convenient	Extremely convenient
D1	Place for drug refill	1	2	3	4	5
D2	Day of the week you are scheduled to pick your drugs	1	2	3	4	5
D3	Time of the day you pick your drugs	1	2	3	4	5
D4	Place for clinic review	1	2	3	4	5
D5	Day of the week you are scheduled for clinic review	1	2	3	4	5
D6	Time of the day you are scheduled for clinic review	1	2	3	4	5
	Environment (<i>Tell me how good are the following:</i>)	Very good	Good	Fair	Poor	Very poor
D7	Neatness and cleanliness	5	4	3	2	1
D8	Ease of finding where to go (clinic flow)	5	4	3	2	1
D9	Privacy	5	4	3	2	1

Focus group discussions were conducted using standard questions related to recipient experience and satisfaction with DSD services. Qualitative data were collected via notes and recordings and were analyzed using a thematic approach (where common themes were identified and coded in matrix tables using excel). Thematic codes were grouped into categories and then both themes and subthemes. In addition, relevant quotations were identified for analysis.

FURTHER RESOURCES ON FOCUS GROUP DISCUSSIONS:

- Guest, G., Namey, E., Taylor, J., Eley, N., & McKenna, K. (2017). Comparing focus groups and individual interviews: findings from a randomized study. *International Journal of Social Research Methodology*, 20(6), 693-708. <https://doi.org/10.1080/13645579.2017.1281601>
- Bogart, L. M., Chetty, S., Giddy, J., Sypek, A., Sticklor, L., Walensky, R. P., ... & Bassett, I. V. (2013). Barriers to care among people living with HIV in South Africa: contrasts between patient and healthcare provider perspectives. *AIDS care*, 25(7), 843-853. <https://doi.org/10.1080/09540121.2012.729808>
- Chiwire, P., Evers, S. M., Mahomed, H., & Hilgsmann, M. (2022). Identification and Prioritization of Attributes for a Discrete Choice Experiment Using the Nominal Group Technique: Patients' Choice of Public Health Facilities in Cape Town, South Africa. *Value in Health Regional Issues*, 27, 90-98. <https://doi.org/10.1016/j.vhri.2021.06.005>
- Lifson, A. R., Demissie, W., Tadesse, A., Ketema, K., May, R., Yakob, B., ... & Shenie, T. (2013). Barriers to retention in care as perceived by persons living with HIV in rural Ethiopia: focus group results and recommended strategies. *Journal of the International Association of Providers of AIDS Care (JIAPAC)*, 12(1), 32-38. <https://doi.org/10.1177/1545109712456>

- Ndirangu, J. W., Gichane, M. W., Browne, F. A., Bonner, C. P., Zule, W. A., Cox, E. N., ... & Wechsberg, W. M. (2022). 'We have goals but [it is difficult]'. Barriers to antiretroviral therapy adherence among women using alcohol and other drugs living with HIV in South Africa. *Health Expectations*, 25(2), 754-763. <https://doi.org/10.1111/hex.13422>
- Pai, P. K., & Paul, M. (2021). Focus Group Discussion as a Tool to Assess Patient-Based Outcomes, Practical Tips for Conducting Focus Group Discussion for Medical Students-Learning with an Example. *Journal of patient experience*, 8, 23743735211034276. <https://doi.org/10.1177/23743735211034276>
- <https://www.ccsu.edu/oira/assessment/files/FocusGroupsHints.pdf>

FURTHER RESOURCES ON QUALITATIVE DATA ANALYSIS:

- Lester, J. N., Cho, Y., & Lochmiller, C. R. (2020). Learning to Do Qualitative Data Analysis: A Starting Point. *Human Resource Development Review*, 19(1), 94–106. <https://doi.org/10.1177/1534484320903890>
- Columbia University Population Health Website <https://www.publichealth.columbia.edu/research/population-health-methods/>
- <https://getthematic.com/insights/qualitative-data-analysis/>

Observation Through Recipient of Care Visit ‘Shadowing’

Shadowing is a direct observation technique that provides an opportunity for a third party to experience and record what happens during interactions along the care pathway. The aim of this method is to see and record the full care experience in real time.

Shadowing raises staff awareness of the recipient of care experience, as well as the possible need for improvements and system redesign. Ideally, shadowing is carried out by a variety of clinic staff, expert recipients of care, volunteers, students, data clerks, admin staff, and others. Some organizations include senior clinical staff and senior leaders on the team conducting the shadowing, as the shadowing experience itself can provide staff with valuable insights. Each ‘shadower’ can bring a fresh set of eyes and a unique perspective. The shadower uses a standard tool to document and capture data related to the experiences of the recipient of care during the visit.

FURTHER RESOURCES ON SHADOWING IN HEALTH CARE:

- Goodrich J, Ridge D, Cartwright T. (2020). 'As soon as you've been there, it makes it personal': The experience of health-care staff shadowing patients at the end of life. *Health Expectations*. (5):1259-1268. doi: 10.1111/hex.13107. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7696112/>
- Goodrich J, Ridge D, Cartwright T. (2022) A qualitative study exploring patient shadowing as a method to improve patient-centred care: 10 principles for a new gold standard. *International Journal of Quality in Health Care*. 16;34(2):mzac018. doi: 10.1093/intqhc/mzac018. <https://pubmed.ncbi.nlm.nih.gov/35311958/>
- <https://www.ihc.org/communities/blogs/layouts/15/ihc/community/blog/itemview.aspx?List=7d1126ec-8f63-4a3b-9926-c44ea3036813&ID=172>
- <https://www.ahrq.gov/health-literacy/improve/precautions/tool17.html>
- <https://www.pointofcarefoundation.org.uk/resource/patient-family-centred-care-toolkit/tools/patient-shadowing/>

Observation by Mystery Shoppers / Secret Shoppers

Health care mystery shoppers are trained and experienced recipients of care who anonymously evaluate the experience within health care organizations. This methodology is a form of participatory research that provides a unique opportunity to monitor and evaluate the performance of health care providers or health facilities from the perspective of the service user. Expert recipients of care are trained to provide a health care provider with an informative narrative of their experience. Typically, standard evaluation forms are completed after the health facility visit to describe their experience. Mystery shoppers don't just uncover problem areas, they also identify elements that contribute to a positive experience for recipients of care.

The Eurasian Coalition on Male Health (ECOM) describes two possible approaches to secret client methodology: the classic and the expert approach (see Table 3). In the classic approach, secret clients who are not specialists in the given service field are deployed. This option is optimally used for regular mass evaluations that are conducted in a limited time frame. The expert approach utilizes secret clients who are specialists in the given service area. This option is more suitable for formative research, as the number of expert clients is always limited (making it impossible to cover a large amount of service providers).

TABLE 3: MAIN CHARACTERISTICS OF SECRET SHOPPER METHOD ASSESSMENT OPTIONS (ECOM, 2018)

CHARACTERISTICS	CLASSIC OPTION	EXPERT OPTION
Predominant aim	Regular assessment	Formative research
Period of administration	Limited duration	Longer period
Quantity of secret clients	Unlimited	Limited to the number of expert clients available
Questionnaire	Highly detailed	General, more open-ended
Preparation of the Secret Client	Time-consuming, intensive	Short, focused on general principles

The manual cited below includes further detail on step-by-step implementation, as well as annexes with practical tools, such as questionnaire templates, an expert assessment form (to help with recruitment), scenario-based training modules, and an outline of a secret client training plan.

CASE STUDY: CIDRZ utilizes standardized patients (“mystery-clients”) to reduce information and social desirability bias found in the exit survey methodology and to improve measurement of poor recipient of care experiences

A CIDRZ study team was grappling with the issue that surveys of recipients of care at the time they exit a clinic are susceptible to several types of measurement error and bias (including social desirability bias), which can impact the validity of the survey results. The study team aimed to use the standardized patient (SP) methodology, which is a hybrid-form of the mystery client approach. In the SP methodology, recipients of care are themselves trained on survey methods and the ideal standards of care within a clinic setting. The CIDRZ team hypothesized that the use of the SP approach, in combination with the exit survey, may represent a more valid method for measuring experiences and could produce a widely usable approach for improving systems.

The CIDRZ team conducted a study to test their hypothesis at 12 MOH-operated clinics in Lusaka, Zambia. They assessed recipient of care experiences among two groups: those exiting care who had no previous exposure to a survey instrument, and SPs, who underwent a single training session on the content of an exit survey and standards of care. The exit survey instrument contained 11 items measuring experience (*i.e.*, wait times, communication, the respectfulness of providers). Health workers were blinded to whether patients had received training or not.

The team compared trained and untrained responses to 11 binary measures using mixed-effect Poisson regression, adjusting for age and sex and reported differences in the presence of each item. Among 11,76 participants on antiretroviral therapy (ART), 920 were untrained (56% female, median age 40 (IQR:33-47)) and 256 were trained SPs (58% female, median age 37.5 (IQR:31-47)). Overall, trained SPs reported more critical assessments of the health care experience. For example, SPs reported increased prevalence of feeling unwelcome by providers (risk difference [RD]: 0.1 [95% CI:0.05-0.15]) and of not being allowed to ask questions (RD: 0.1 [95% CI:0.03-0.17]). The team found that recipients of care who received a brief training provided a more critical appraisal of care, either because they were more alert to the items solicited or because they felt empowered to be more critical.

Further resources on mystery secret shoppers in health care:

- Eurasian Coalition on Male Health (ECOM) (2018). *Manual on the “Secret Client” Methodology for Assessing the Quality of the Services Related to HIV Treatment and Prevention Among MSM and Trans People*. https://ecom.ngo/library/secret_client_en
- Chandra-Mouli, V., Lenz, C., Adebayo, E., Lang Lundgren, I., Gomez Garbero, L., & Chatterjee, S. (2018). A systematic review of the use of adolescent mystery clients in assessing the adolescent friendliness of health services in high, middle, and low-income countries. *Global health action*, 11(1),1536412 <https://www.tandfonline.com/doi/full/10.1080/16549716.2018.1536412>
- Mokwele RN, Schellack N, Bronkhorst E, Brink AJ, Schweickerdt L, & Godman B. (2022). Using mystery shoppers to determine practices pertaining to antibiotic dispensing without a prescription among community pharmacies in South Africa-a pilot survey. *JAC Antimicrob Resist*,4(1). Doi: 10.1093/jacamr/dlab196. <https://pubmed.ncbi.nlm.nih.gov/35146427/>
- Kohler, P., Larsen, A., Sila, J., Wilson, K., Abuna, F., Lagat, H., ... & Kinuthia, J. (2022). Mystery Shopper Assessment of PrEP Service Delivery Quality for Adolescent Girls and Young Women in Kenya: A Cross-sectional Study. *Journal of the Association of Nurses in AIDS Care*, 33(5), 534-541. <https://pubmed.ncbi.nlm.nih.gov/35878051/>
- King, J. J., Das, J., Kwan, A., Daniels, B., Powell-Jackson, T., Makungu, C., & Goodman, C. (2019). How to do (or not to do)... using the standardized patient method to measure clinical quality of care in LMIC health facilities. *Health policy and planning*, 34(8), 625-634. <https://pubmed.ncbi.nlm.nih.gov/31424494/>
- NASTAD (2019). Addressing Stigma in Healthcare Facilities: A “Secret Shopper” Intervention <https://nastad.org/resources/addressing-stigma-healthcare-facilities-secret-shopper-intervention>
- <https://www.aidsmap.com/news/jul-2019/mystery-shoppers-kenyan-pharmacies-highlight-issues-distribution-hiv-self-tests>

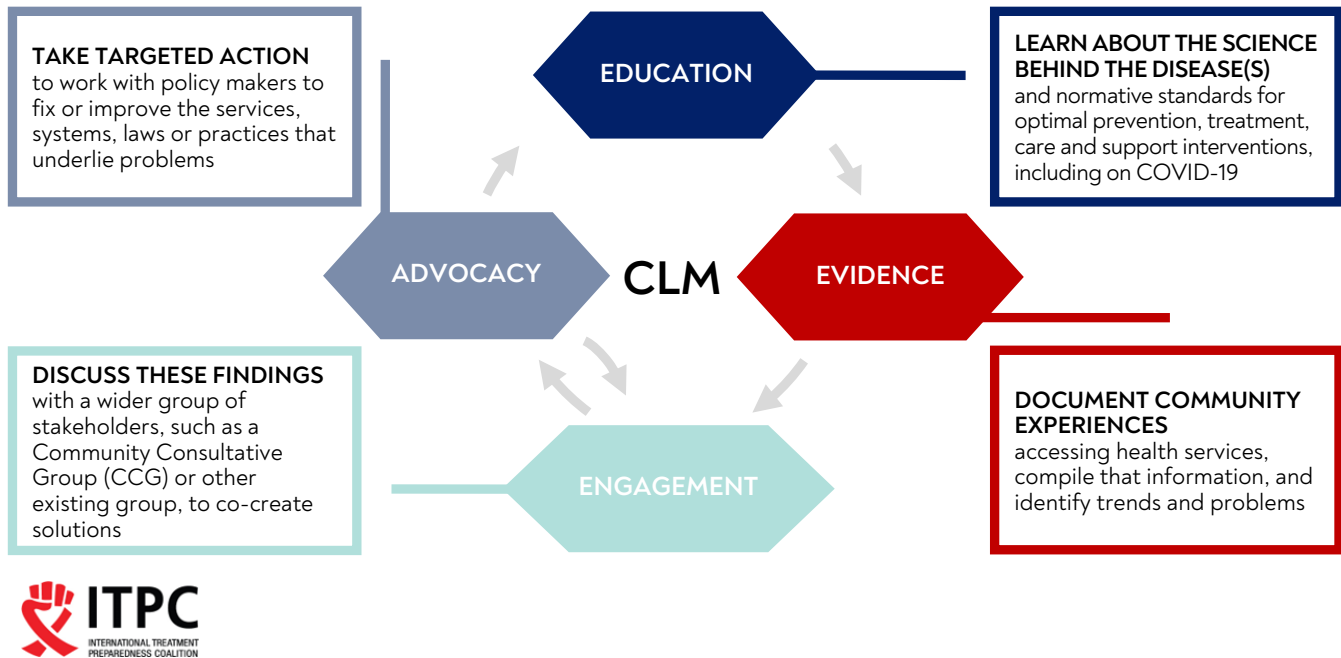
Community-Led Monitoring

Community-led monitoring (CLM) refers to service users themselves conducting assessments of the effectiveness, quality, accessibility, and impact of health programs and services they receive. CLM includes any type of monitoring where communities decide what to monitor and how to act upon the data collected. Unlike monitoring undertaken by health systems, advocacy based on the evidence and observations gathered through CLM is an essential outcome of CLM initiatives (UNAIDS, 2020). Once data have been gathered, they are shared within the community and throughout leadership levels for evidence-based advocacy to improve the quality of services.

The CLM approach strengthens local decision-making, increases access to essential information, improves community capacity-building efforts, and enhances participation in local government. CLM methods also facilitate more inclusive decision-making on issues that are important to members of a community, including complex social, economic, and environmental issues that may be impacting a community. CLM originated in part because community-identified problems have too often been dismissed as “anecdotal evidence.” CLM enables communities to validate their claims and determine the extent of an issue by collecting quantitative and qualitative data on a recurring basis (ITPC, 2020).

The International Treatment Preparedness Coalition (ITPC) CLM toolkit (2021) explains that CLM may be used to track a range of issues within HIV programs. CLM data build evidence on what works well, what is not working, and what needs to be improved—and lead to suggestions for targeted action to improve outcomes. Examples of evidence that could be gathered through CLM include the extent to which stigma has made it difficult for people to access HIV services, the proportion of people who have been denied access to HIV prevention and testing, and the number of people who have discontinued ART and why. This evidence can then be fed back to program managers and policymakers, which enables them to work to increase the “five A’s” (availability, accessibility, acceptability, affordability, and appropriateness), as well as the efficiency and effectiveness of HIV services.

CLM uses a structured platform and rigorously trained peer monitors to collect and analyze qualitative and quantitative data on HIV service delivery (including data from people in community settings who might not be accessing health care) and to establish rapid, systematic, and routine feedback loops with program managers and health decision-makers. The ITPC CLM Hub (www.clmhub.org) provides resources and toolkits developed by ITPC and others that capacitate communities to effectively carry out CLM, ensuring robust and reliable data collection and effective data use to advocate for change. (Resources are available in English, French, Spanish, Portuguese, and Russian.)

FIGURE 10. ITPC COMMUNITY-LED MONITORING MODEL

While systematic CLM systems have driven many health system innovations and improvements—such as the creation and expansion of DSD programs themselves—ongoing challenges exist that hinder its power and limit its effectiveness. Implementers have noted that the acceptance of CLM approaches, and data has improved, yet a skeptical view of the role of communities persists and CLM data continues to be devalued in many cases. This can be evidenced by a lack of substantial investment in CLM-related programs and research (Baptiste S., AIDS 2022 oral presentation). Additionally, CLM programs that are supported by external donors often face the additional challenge of balancing their own indicators with the need to accommodate donor-required indicators.

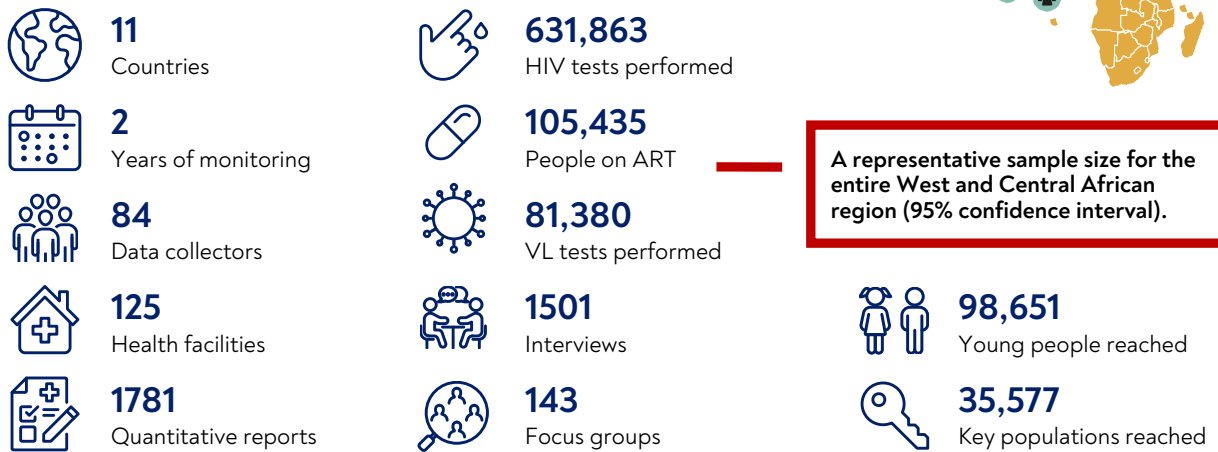
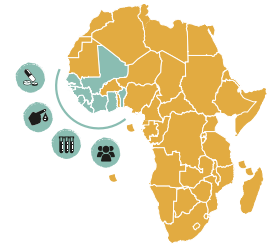
Despite these challenges, there are myriad case studies that demonstrate the power of CLM to quickly identify gaps in health systems, analyze the root causes, and bring partners together to take swift, remedial action.

CASE STUDY: ITPC carries out CLM in eleven countries in two years, leading to improved access and service delivery

ITPC and community partners carried out CLM in eleven countries in West Africa over the span of two years. The West African Regional Community Treatment Observatory (WA-RCTO) was focused specifically on monitoring critical elements of the HIV response. A total of 84 data collectors monitored 125 health facilities on a recurring basis, ultimately conducting 1501 interviews and 143 focus group discussions, and issuing 1781 quantitative reports (Oberth, 2019).

FIGURE 11. SUMMARY OF CLM APPROACH ACTIVITIES LED THROUGH THE WEST AFRICAN REGIONAL COMMUNITY TREATMENT OBSERVATORY

The Power of **BIG DATA** in the Hands of **Activated Communities**

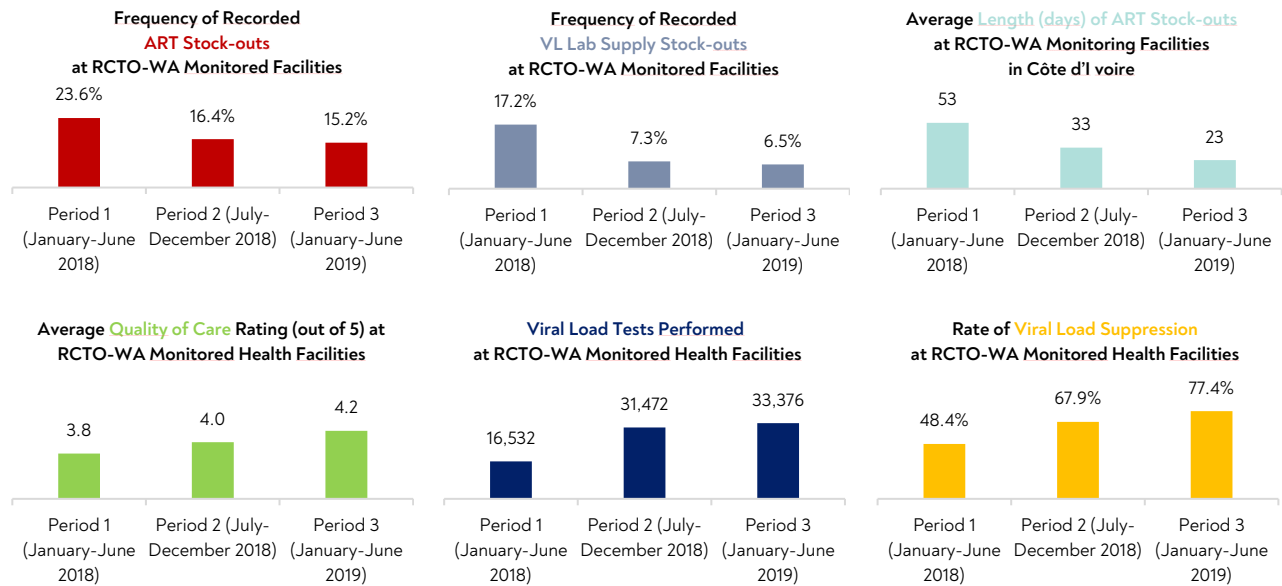


<https://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>

The results of the WA-RCTO are powerful: by engaging in recurring monitoring processes and reporting findings back to a Community Consultative Group composed of a range of stakeholders (including government officials, health care providers, and recipients of care), gaps were identified and mitigated by the collective power of the group. Figure 11 below illustrates some of the signature achievements of this work, including an 8.4% decrease in ART stock-outs, nearly 17,000 more viral load tests performed, and a nearly 30% improvement in viral suppression rates.

FIGURE 12. IMPACT OF THE CLM APPROACH LED THROUGH THE WEST AFRICA REGIONAL COMMUNITY TREATMENT OBSERVATORY

KEY RESULTS of the ITPC RCTO Project (2018)



<https://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>

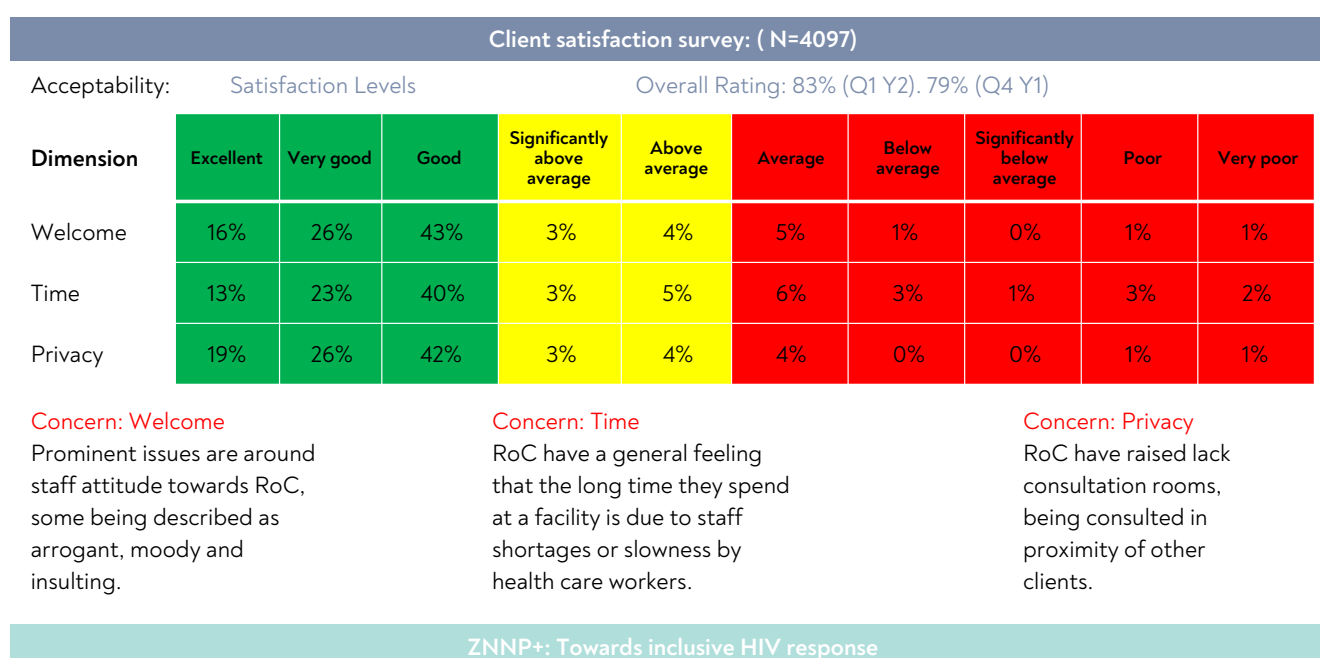
CASE STUDY: The Zimbabwe National Network of People Living with HIV (ZNNP+) leads a large-scale electronic client satisfaction survey-based assessment and improvement advocacy program

The Target, Accelerate, and Sustain Quality Care (TASQC) for HIV Epidemic Control Program was launched in October 2020, with support from PEPFAR through USAID Zimbabwe. The program is led by the Organization for Public Health Interventions and Development, with ZNNP+ as a key implementing partner. ZNNP+ implements the TASQC program in 15 districts of Zimbabwe, supporting community-engaged policy advocacy and program sustainability by capacitating and deploying community members. Using the CLM approach, ZNNP+ collects data to monitor and address community barriers to service provision, while also engaging with faith and traditional leaders to facilitate community buy-in and building the capacity of communities to hold the government accountable for quality HIV services.

ZNNP+ implements a CLM system in 15 districts, engaging 397 Community HIV and AIDS Support Agents (CHASAs) to monitor 315 health facilities. The program utilizes an electronic Client Satisfaction Survey Tool which assesses types of HIV and DSD service models and client perceptions of service quality, with recipients of care rating the quality of services, including their satisfaction with the welcome they received at the facility, time spent at the facility, and privacy issues. On a weekly basis, CHASAs—with support from health staff—randomly select clients to interview at each service point using

the Client Satisfaction Survey Tool. District coordinators and CHASAs then engage health facility staff, service providers, community leaders, and stakeholders to review client feedback and develop an action plan that can subsequently be tracked. Recipient of care satisfaction data are disaggregated by DSD model, age, and sex. In later phases of the project, the ZNNP+ teams will further explore the continued barriers that recipients of care face in obtaining information about DSD programs and accessing DSD services.

FIGURE 13: ZNNP+ CLM RESULTS OF CLIENT SATISFACTION SURVEY, N=4,097 RECIPIENTS OF CARE FROM 315 HEALTH FACILITIES, 2020-2021



ZNNP+: Towards inclusive HIV response

In addition to their working supporting RCS data collection and analysis, CHASAs are heavily focused on community system strengthening activities (including community-based advocacy activities in collaboration with traditional healers and local leaders). Community engagement interventions include conducting community group consultation meetings, community dialogue forums, consumer advocacy forums, and district health team data review meetings, as well as serving on health center committee meetings.

FURTHER RESOURCES ON CLM:

- Baptiste, S., Manouan, A., Garcia, P., Etya’ale, H., Swan, T., & Jallow, W. (2020). Community-led monitoring: When community data drives implementation strategies. *Current HIV/AIDS Reports*, 17, 415-421. <https://link.springer.com/article/10.1007/s11904-020-00521-2>
- Makoni, T., Kadziyanhike, G., Mademutsa, C., Mlambo, M., & Malama, K. (2022). Community-led monitoring: a voice for key populations in Zimbabwe. *Journal of the International AIDS Society*, 25 Suppl 1(Suppl 1), e25925. <https://doi.org/10.1002/jia2.25925>

- International Treatment Preparedness Coalition. “They keep us on our toes”: how the regional community treatment observatory in West Africa improved HIV service delivery, strengthened systems for health, and institutionalized community-led monitoring. May 2020. https://itpcglobal.org/wp-content/uploads/2021/12/1205_ITPC_CLM_Design_FullReport06_compressed.pdf
- UNAIDS (2021). Establishing community-led monitoring of HIV services. https://www.unaids.org/sites/default/files/media_asset/establishing-community-led-monitoring-hiv-services_en.pdf
- EpiC (2021) Community-Led Monitoring Technical Guide. FHI 360; Durham, NC <https://www.fhi360.org/sites/default/files/media/documents/resource-epic-community-led-monitoring-technical-guide.pdf>
- The Global Fund (2020). Community-based monitoring: An Overview https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf

ENSURING THAT RESULTS ARE LINKED TO IMPROVEMENT

The purpose of assessing RCS is to identify gaps and address them when they occur. All the efforts that go into designing and implementing a high-quality RCS assessment should focus on the main objective of improvement and producing data that can help programs identify where and how improvements can be made. Unfortunately, there is scant published literature regarding *how* organizations have made improvements in RCS. RCS researchers recommend that future RCS efforts utilize an implementation science approach to better understand the contextual factors contributing to positive outcomes (Cadel *et al.*, 2022).

Quality management leaders often emphasize the importance of “no measurement without efforts towards improvement.” Thus far, this toolkit has focused on why RCS is important and describing various options for collecting and analyzing high-quality RCS data. This section focuses on the overall goal of RCS, which is to use measurement for improvement. In addition to operationalizing modern quality improvement methods and tools (such as root cause analysis, developing and prioritizing change interventions, and measuring progress towards targets on time series charts), we include the following additional recommendations:

Ensure RCS Policy Within All Levels of the Health System

Because RCS is a dynamic construct driven by individuals’ expectations of health care services, thoughtful consideration should be given to the design of locally driven and contextually appropriate improvement interventions. Evidence from studies focused on the specific determinants of satisfaction with HIV programs can guide policymakers and implementers in selecting dimensions on which to focus interventions.

Because leaders are constantly balancing quality, financing, staffing, and other system factors, RCS is an important lever to apply as they progress towards improving health outcomes. As leaders select and implement HIV program improvement interventions, considering *how* to tailor and adapt innovations through the lens of RCS can lead to a more inclusive and comprehensive approach. Embedding routine RCS into existing quality management, monitoring, and evaluation programs will be an important over-arching goal for national programs.

It should be noted that solely relying on health facility-driven quality improvements and interventions will not be an effective approach for broader, system-wide improvements in RCS. Most facilities will not have the financial and human resources to generate impactful and sustained activities that are likely to generate transformational improvements in RCS. In most cases, improvements in RCS will need to be achieved through system-level reforms and redesigns that occur at national and/or provincial levels.

Engage Meaningfully with Networks of Recipients of Care

The phrase “*nothing about us without us*” was first coined by disability rights activists in South Africa to convey the idea that no policy should be reached without the full participation of members of the group(s) affected by that policy (Charlton, 1998). This empowering concept has been adopted by additional communities seeking increased and more meaningful involvement with the health care system and has become a mantra for activists working to improve the quality and coverage of HIV services.

Meaningful engagement with recipients of care in health facilities and the community during all stages of improvement work is critical to ensuring RCS improvement. We emphasize that it is not just preferable, but vital for leaders to engage with networks of recipients of care in the design, implementation, and evaluation of RCS assessments. There are many reasons for this, including but not limited to:

- **Historically unequal power dynamics:** Recipients of care are best placed to speak with their own communities about satisfaction. Peers can create an environment that fosters genuine feedback about satisfaction and avoids the inherently unequal power dynamic that occurs when a recipient of care is interviewed by a health care worker who implicitly holds power over the recipient of care. As noted above, courtesy bias is also a significant challenge, as recipients of care are more likely to provide positive feedback when asked by their health service provider. This may decrease the validity of assessment results and could possibly compromise the RCS assessment effort.
- **Monitoring issues that matter most to recipients of care:** When networks of people living with HIV are fully engaged in RCS assessment processes, they can help define assessment priorities (for example, issues that reflect specific community “pain points”). This, in turn, enables health care providers, policymakers, and recipient of care networks to more quickly zero in on health system gaps and priority satisfaction challenges, and to develop improvement strategies more quickly. Without this direct, “upfront” community input, RCS assessment and improvement efforts can get off-track, monitoring irrelevant or low-priority satisfaction dimensions and indicators.
- **Ensuring sustained, collaborative follow-up and accountability:** When RCS assessment processes are not formally linked to organizations of people living with HIV and/or key and vulnerable populations, health program leaders may only gain a one-time insight or “snapshot” of RCS from individual recipients of care, and they may lack sustained community engagement and ongoing advocacy for improvement. In contrast, when networks of people living with HIV are fully engaged in the RCS assessment processes, they can identify common themes and trends (*i.e.*, waiting times are a persistent issue for multiple people at multiple health facilities over extended periods of time). Recipient of care networks can then bring these insights to bear not just in one-off interactions with single health service providers or health facilities, but they can engage in a regular and recurring manner with health policymakers, health facility management, health care workers, and all other actors who have a role to play in RCS. When people living with HIV and key population network representatives are invited to sit on health planning committees, the RCS expertise they gain from RCS efforts is shared in a collaborative manner with a range of stakeholders and duty-bearers, laying the groundwork for implementing service improvements and other concrete actions that improve RCS at the system level.
- **Linking quality standards to specific, targeted areas for action:** Recipients of care have first-hand expertise when it comes to identifying disconnects between normative guidance on standards of care and their lived experience engaging with the health system. By ensuring that community networks of people living with HIV, key populations, and other groups are kept up to speed on HIV science and normative clinical standards, a broader

range of recipients of care can regularly assess the health system, document their experiences, and offer specific recommendations for improvements (e.g., using the ‘mystery shopper’ approach). Networks of people living with HIV can participate in the analysis and development of targeted action plans for broader issue areas that are ripe for further investigation and help plan adjustments to improve RCS.

- **Reaching recipients of care who have disengaged from the health system:** Any RCS assessment tool administered in a health facility setting will be automatically biased toward those recipients of care who believe in the system enough to engage with it. What about reaching those recipients of care who have disengaged from health care services, who no longer adhere to ART, and/or who do not follow through on appointments with health care workers? Organized networks of people living with HIV, key and vulnerable populations, and other community civil society groups have a vital role to play in proactive outreach to those individuals who have been lost to follow-up. Lifelong adherence to any medication is difficult and who better to approach and engage recipients of care in a non-judgmental and supportive manner than their peers—who intimately understand the complex and interconnected factors (social, economic, political, structural, familial) that lead to disengagement—and, furthermore, to identify the changes that would improve satisfaction and help facilitate re-engagement?

Utilize Human-Centered Design Approaches and Methods

Human-centered design (HCD) is a rapidly evolving field at the intersection of engineering, psychology, anthropology, public health, and other social sciences. The use of HCD has the potential to ensure that recipients of care and leaders meaningfully collaborate in the design, implementation, and evaluation of health products, services, and/or delivery strategies (Beres *et al.*, 2019). By prioritizing recipient of care experiences, local needs, and other contextual issues, HCD uses evidence-based co-creation processes that, ideally, lead to more acceptable and accessible health care services, thus improving a range of health outcomes (Liebenberg, 2020). While there is a dearth of evidence for the use of HCD within HIV programs, early evidence is demonstrating that specific methods and tools can optimize planning and implementation efforts for evidence-based innovations, such as pre-exposure prophylaxis (PrEP) and differentiated services across the care continuum.

FURTHER RESOURCES ON HCD:

- Bruns, C. (2021). Using human-centered design to develop a program to engage South African men living with HIV in care and treatment. *Global Health: Science and Practice*, 9 (Supplement 2), S234-S243. <https://doi.org/10.9745/GHSP-D-21-00239>
- Mukherjee, T. I., Zerbe, A., Falcao, J., Carey, S., Iaccarino, A., Kolada, B., ... & Abrams, E. J. (2022). Human-Centered Design for Public Health Innovation: Codesigning a Multicomponent Intervention to Support Youth Across the HIV Care Continuum in Mozambique. *Global Health: Science and Practice*, 10(2). <https://doi.org/10.9745/GHSP-D-21-00664>
- Johnson, T., Das, S., & Tyler, N. (2021). Design for health: human-centered design looks to the future. *Global Health: Science and Practice*, 9(Supplement 2), S190-S194. <https://doi.org/10.9745/GHSP-D-21-00608>
- JSI Research & Training Institute (JSI). (2020) Using Human-Centered Design to Build Acceptance for PrEP Introduction in Zambia. https://publications.jsi.com/JSIInternet/Inc/Common/download_pub.cfm?id=23436&lid=3

FURTHER RESOURCES ON LINKING RESULTS TO ACTION:

- Cadel, L., Marcinow, M., Singh, H., & Kuluski, K. (2022). The use of patient experience data for quality improvement in hospitals: A scoping review. *Patient Experience Journal*, 9(1), 174-188. doi: 10.35680/2372-0247.1656. <https://pxjournal.org/journal/vol9/iss1/21/>
- Hailemeskal, M. B., Sereda, Y., Latypov, A., Kiriazova, T., & Avaliani, N. (2020). Perceived quality of HIV care and client satisfaction across different service providers in Ukraine. *European journal of public health*, 30(1), 23-30. <https://doi.org/10.1093/eurpub/ckz124>
- Gleeson, H., Calderon, A., Swami, V., Deighton, J., Wolpert, M., & Edbrooke-Childs, J. (2016). Systematic review of approaches to using patient experience data for quality improvement in healthcare settings. *BMJ open*, 6(8), e011907. <http://dx.doi.org/10.1136/bmjopen-2016-011907>
- Larson, E., Sharma, J., Bohren, M. A., & Tunçalp, Ö. (2019). When the patient is the expert: measuring patient experience and satisfaction with care. *Bulletin of the World Health Organization*, 97(8), 563. doi: [10.2471/BLT.18.225201](https://doi.org/10.2471/BLT.18.225201)

REFERENCES

- Batbaatar, E., Dorjdagva, J., Luvsannyam, A., & Amenta, P. (2015). Conceptualization of patient satisfaction: a systematic narrative literature review. *Perspectives in Public Health*, 135(5), 243-250. <https://doi.org/10.1177/17579139166341>
- Beres, L. K., Simbeza, S., Holmes, C. B., Mwamba, C., Mukamba, N., Sharma, A., ... & Sikazwe, I. (2019). Human-centered design lessons for implementation science: improving the implementation of a patient-centered care intervention. *Journal of acquired immune deficiency syndromes (1999)*, 82(3), S230. doi: [10.1097/QAI.0000000000002216](https://doi.org/10.1097/QAI.0000000000002216)
- Brincks, A. M., Shiu-Yee, K., Metsch, L. R., Del Rio, C., Schwartz, R. P., Jacobs, P., ... & Feaster, D. J. (2019). Physician mistrust, medical system mistrust, and perceived discrimination: associations with HIV care engagement and viral load. *AIDS and Behavior*, 23(10), 2859-2869. <https://doi.org/10.1007/s10461-019-02464-1>
- Buluba, S. E., Mawi, N. E., & Tarimo, E. A. (2021). Clients' satisfaction with HIV care and treatment centres in Dar es Salaam, Tanzania: A cross-sectional study. *PLoS one*, 16(2), e0247421. <https://doi.org/10.1371/journal.pone.0247421>
- Cadel, L., Marcinow, M., Singh, H., & Kuluski, K. (2022). The use of patient experience data for quality improvement in hospitals: A scoping review. *Patient Experience Journal*, 9(1), 174-188. doi: [10.35680/2372-0247.1656](https://doi.org/10.35680/2372-0247.1656)
- Cazabon, D., Pande, T., Sen, P., Daftary, A., Arsenault, C., Bhatnagar, H., ... & Pai, M. (2020). User experience and patient satisfaction with tuberculosis care in low-and middle-income countries: a systematic review. *Journal of Clinical Tuberculosis and Other Mycobacterial Diseases*, 19, 100154. <https://doi.org/10.1016/j.jctube.2020.100154>
- Charlton, J. I. (1998). Nothing about us without us. In *Nothing About Us Without Us*. University of California Press. <https://doi.org/10.1525/9780520925441>
- Chau, L.B., Chang, P.T.H., Duc, D.M., Minh, H.V., Toan, L.Q., Quyen, B.T.T., Vui, L.T. and Ha, B.T.T. (2022) Utilization and Satisfaction with HIV Services at 7 Provinces in Vietnam: A Cross-Sectional Study. *World Journal of AIDS*, 12, 65-82. doi: [10.4236/wja.2022.122006](https://doi.org/10.4236/wja.2022.122006)
- Chimbindi, N., Bärnighausen, T. & Newell, ML. Patient satisfaction with HIV and TB treatment in a public programme in rural KwaZulu-Natal: evidence from patient-exit interviews. *BMC Health Serv Res* 14, 32 (2014). <https://doi.org/10.1186/1472-6963-14-32>
- Dang BN, Westbrook RA, Black WC, Rodriguez-Barradas MC, Giordano TP (2013). Examining the Link between Patient Satisfaction and Adherence to HIV Care: A Structural Equation Model. *PLoS ONE* 8(1): e54729. <https://doi.org/10.1371/journal.pone.0054729>
- Dansereau, E., Masiye, F., Gakidou, E., Masters, S. H., Burstein, R., & Kumar, S. (2015). Patient satisfaction and perceived quality of care: evidence from a cross-sectional national exit survey of HIV and non-HIV service users in Zambia. *BMJ open*, 5(12), e009700. <https://bmjopen.bmj.com/content/bmjopen/5/12/e009700.full.pdf>

- De Jager, G. A., Crowley, T., & Esterhuizen, T. M. (2018). Patient satisfaction and treatment adherence of stable human immunodeficiency virus-positive patients in antiretroviral adherence clubs and clinics. *African Journal of Primary Health Care and Family Medicine*, 10(1), 1-8. doi: [10.4102/phcfm.v10i1.1759](https://doi.org/10.4102/phcfm.v10i1.1759).
- De Silva, D. (2013). Evidence scan: measuring patient experience. London: The Health Foundation. <https://www.health.org.uk/sites/default/files/MeasuringPatientExperience.pdf>
- Donabedian, A. (1988). The quality of care: how can it be assessed? *Journal of the American Medical Association*, 260(12), 1743-1748. doi [10.1001/jama.260.12.1743](https://doi.org/10.1001/jama.260.12.1743)
- Dunsch, F., Evans, D. K., Macis, M., & Wang, Q. (2018). Bias in patient satisfaction surveys: a threat to measuring healthcare quality. *BMJ global health*, 3(2), e000694. <https://doi.org/10.1136/bmjgh-2017-000694>
- Ehrenkrantz, P., Grimsrud, A., Holmes, C. B., Preko, P., & Rabkin, M. (2021). Expanding the vision for differentiated service delivery: a call for more inclusive and truly patient-centered care for people living with HIV. *Journal of Acquired Immune Deficiency Syndromes (1999)*, 86(2), 147. doi: [10.1097/QAI.0000000000002549](https://doi.org/10.1097/QAI.0000000000002549)
- Eurasian Coalition on Male Health (ECOM) (2018). *Manual on the "Secret Client" Methodology for Assessing the Quality of the Services Related to HIV Treatment and Prevention Among MSM and Trans People*. https://ecom.ngo/library/secret_client_en
- Freedman, L. P. (2005). Achieving the MDGs: health systems as core social institutions. *Development*, 48(1), 19-24. <https://doi.org/10.1057/palgrave.development.1100107>
- Grimsrud, A., Bygrave, H., Doherty, M., Ehrenkrantz, P., Ellman, T., Ferris, R., ... & Bekker, L. G. (2016). Reimagining HIV service delivery: the role of differentiated care from prevention to suppression. *Journal of the International AIDS Society*, 19(1). doi: [10.7448/IAS.19.1.21484](https://doi.org/10.7448/IAS.19.1.21484)
- Hailemeskal, M. B., Sereda, Y., Latypov, A., Kiriazova, T., & Avaliani, N. (2020). Perceived quality of HIV care and client satisfaction across different service providers in Ukraine. *European journal of public health*, 30(1), 23-30. <https://doi.org/10.1093/eurpub/ckz124>
- Joshi, A., Schaaf, M. & Zayed, D. The use of legal empowerment to improve access to quality health services: a scoping review. *Int J Equity Health* 21, 136 (2022). <https://doi.org/10.1186/s12939-022-01731-3>
- Kash, B., & McKahan, M. (2017). The evolution of measuring patient satisfaction. *J. Prim. Health Care Gen. Pract*, 4, 2. <https://scientonline.org/open-access/the-evolution-of-measuring-patient-satisfaction.pdf>
- Kruk, M. E., Gage, A. D., Arsenault, C., Jordan, K., Leslie, H. H., Roder-DeWan, S., ... & Pate, M. (2018). High-quality health systems in the Sustainable Development Goals era: time for a revolution. *The Lancet global health*, 6(11), e1196-e1252. <https://pubmed.ncbi.nlm.nih.gov/30196093/>
- Family planning center national training center for quality assurance and quality improvement and evaluation . *Patient experience toolkit*. (2014) JSI. https://publications.jsi.com/JSIInternet/Inc/Common/_download_public.cfm?id=14155&lid=3

- Leon, C., Koosed, T., Philibert, B., Raposo, C., & Benzaken, A. S. (2019). HIV/AIDS health services in Manaus, Brazil: patient perception of quality and its influence on adherence to antiretroviral treatment. *BMC health services research*, 19(1), 1-11. <https://doi.org/10.1186/s12913-019-4062-9>
- Liebenberg, E. (2020). Human-Centered Design and Innovative Research Methods for Healthcare. *Sight and Life*, 34, 50-56. https://sightandlife.org/wp-content/uploads/2020/03/SightandLifeMagazine_2020_Consumer_Insights_Human-Centered-Design-and-Innovative-Research-Methods.pdf
- Martinez, J., Harper, G., Carleton, R. A., Hosek, S., Bojan, K., Clum, G., Ellen, J., & Adolescent Medicine Trials Network (2012). The impact of stigma on medication adherence among HIV-positive adolescent and young adult females and the moderating effects of coping and satisfaction with health care. *AIDS patient care and STDs*, 26(2), 108–115. <https://doi.org/10.1089/apc.2011.0178>
- Murray, M. I., Markowitz, M., Frank, I., Grant, R. M., Mayer, K. H., Hudson, K. J., ... & Margolis, D. A. (2018). Satisfaction and acceptability of cabotegravir long-acting injectable suspension for prevention of HIV: patient perspectives from the ECLAIR trial. *HIV clinical trials*, 19(4), 129-138. DOI: [10.1080/15284336.2018.1511346](https://doi.org/10.1080/15284336.2018.1511346)
- Mpinga, E. K., & Chastonay, P. (2011). Patient satisfaction studies and the monitoring of the right to health: some thoughts based on a review of the literature. *Global journal of health science*, 3(1), 64. https://www.researchgate.net/profile/Kabengele-Emmanuel/publication/50946014_Patient_Satisfaction_Studies_and_the_Monitoring_of_the_Right_to_Health_Some_Thoughts_Based_on_a_Review_of_the_Literature/links/02bfe51005636e1e43000000/Patient-Satisfaction-Studies-and-the-Monitoring-of-the-Right-to-Health-Some-Thoughts-Based-on-a-Review-of-the-Literature.pdf
- Ng, J. H., & Luk, B. H. (2019). Patient satisfaction: Concept analysis in the healthcare context. *Patient education and counseling*, 102(4), 790-796. https://www.sciencedirect.com/science/article/pii/S0738399118310048?casa_token=FPwR40ZxZuMAAAAA:xF66c7sEn32K7d5AZpxtveUFVw9EKIB-L3XcJJ90IAeZK6xKf6NRWyiM70ocJu4amXM_RaH2YE#bib0170
- Nwabueze, S. A., Adogu, P. O., Ilika, A. L., Asuzu, M. C., & Adinma, E. D. (2011). Perception of quality of care in HIV/AIDS programmes among patients in a tertiary health care facility in Anambra State. *Nigerian journal of medicine: journal of the National Association of Resident Doctors of Nigeria*, 20(1), 144-150. <https://pubmed.ncbi.nlm.nih.gov/21970277/>
- Oberth, Gemma. (2019). Data for a Difference: Key Findings, Analysis and Advocacy Opportunities from the Regional Community Treatment Observatory in West Africa. ITPC. Available at: <https://itpcglobal.org/wp-content/uploads/2019/06/RCTO-WA-Data-for-a-Difference-Advocacy-Paper.pdf>
- Ortblad, K. F., Sekhon, M., Wang, L., Roth, S., van der Straten, A., Simoni, J. M., & Velloza, J. (2022). Acceptability assessment in HIV prevention and treatment intervention and service delivery research: a systematic review and qualitative analysis. *AIDS and Behavior*, 1-18. <https://doi.org/10.1007/s10461-022-03796-1>

- Pai, P. K., & Paul, M. (2021). Focus Group Discussion as a Tool to Assess Patient-Based Outcomes, Practical Tips for Conducting Focus Group Discussion for Medical Students-Learning With an Example. *Journal of patient experience*, 8, 23743735211034276. <https://doi.org/10.1177/23743735211034276>
- Roberts K. J. (2002). Physician-patient relationships, patient satisfaction, and antiretroviral medication Adherence among HIV-infected adults attending a public health clinic. *AIDS patient care and STDs*, 16(1), 43–50. <https://doi.org/10.1089/108729102753429398>
- Sah, D. C., & Kumar, Y. (2015). Client satisfaction exit interviews: assessing quality of public health institutions through generated feedback. *Vikalpa*, 40(1), 42-61. <https://doi.org/10.1177/0256090915574194>
- Shevell, M. (2009). What do we call 'them?': the 'patient' versus 'client' dichotomy. *Developmental medicine and child neurology*, 51(10), 770. <https://onlinelibrary.wiley.com/doi/10.1111/j.1469-8749.2009.03304.x>
- Shirley, E., Josephson, G., & Sanders, J. (2016). Fundamentals of patient satisfaction measurement. *Physician leadership journal*, 3(1), 12. [file:///C:/Users/Gillian%20Dougherty/Downloads/Shirleyetal.2016Fundamentalsofpatientsatisfactionmeasurement1%20\(1\).pdf](file:///C:/Users/Gillian%20Dougherty/Downloads/Shirleyetal.2016Fundamentalsofpatientsatisfactionmeasurement1%20(1).pdf)
- Somi, N., Dear, N., Reed, D., Parikh, A., Lwilla, A., Bahemana, E., ... & Esber, A. (2021). Perceived satisfaction with HIV care and its association with adherence to antiretroviral therapy and viral suppression in the African Cohort Study. *AIDS research and therapy*, 18(1), 1-8. <https://doi.org/10.1186/s12981-021-00414-3>
- Thornton, A., Delpech, V., Kall, M. and Nardone, A. (2012), A review of community HIV testing. *HIV Med*, 13: 416-426. <https://doi.org/10.1111/j.1468-1293.2012.00992.x>
- Umeokonkwo, C. D., Aniebue, P. N., Onoka, C. A., Agu, A. P., Sufiyan, M. B., & Ogbonnaya, L. (2018). Patients' satisfaction with HIV and AIDS care in Anambra State, Nigeria. *PLoS one*, 13(10), e0206499. <https://doi.org/10.1371/journal.pone.0206499>
- World Health Organization (WHO), OECD, & International Bank for Reconstruction and Development The World Bank. (2018). Delivering quality health services: A global imperative for universal health coverage. *World Health Organization, OECD & International Bank for Reconstruction and Development*. <http://apps.who.int/iris/bitstream/handle/10665/272465/9789241513906-eng.pdf?ua=1>

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