Putting People-Centered Metrics for HIV into Practice

Proposed Indicators and Practical Considerations for Implementation

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Abbreviations

ART   antiretroviral therapy

Data.FI   Data for Implementation

EA   expenditure analysis

EMR   electronic medical records

GDI   Global Development Incubator

HCW   healthcare worker

IP   implementing partner

LMIC   low- and middle-income countries

MEL   monitoring, evaluation, and learning

PEPFAR   United States President's Emergency Plan for AIDS Relief

PLHIV   people living with HIV

PROM   patient-reported outcomes measure

SIMS   Site Improvement through Monitoring System

USAID   United States Agency for International Development

VBC   value-based care

Executive Summary

The current HIV landscape and the 95-95-95 goals of the United States President's Emergency Plan for AIDS Relief (PEPFAR) represent a unique and reciprocal opportunity to bring insights from value-based care (VBC) work to the field of HIV, and to harness the momentum in the HIV field (especially in data-driven management) to accelerate the movement toward VBC.

In VBC, measurement of people-centered outcomes is the North Star. It guides how we learn, improve, and innovate. It is the basis for how success is defined and how resources flow.

Routine measurement of people-centered outcomes has the potential to shape the trajectory of HIV care by revealing what clients prioritize and by designing HIV care services, performance improvement loops, and incentives to deliver superior outcomes, ultimately, helping to overcome persistent challenges in retention in care, adherence to treatment, and sustained viral suppression.

The focus of Data.FI's early work has been on measurement of people-centered outcomes. It builds on existing quality improvement efforts by bringing quality of life and the care experience to the forefront as core indicators.

Our approach includes the development of a conceptual value-based framework and a synthesis of people-centered outcomes in HIV. We undertook an iterative process of consultation with global HIV experts and secondary research. We developed indicator reference sheets for the people-centered outcomes and a practical set of implementation considerations.

Now we need to pilot these metrics to validate and refine them and to ensure that they generate meaningful insights, can be collected efficiently, can be implemented in the operational constraints of HIV care, and are sensitive to client needs. In the long-run, we can integrate measurement and delivery with payment, to unlock the full potential of value-based care in HIV.

PARTNERSHIP MODEL

The **Leapfrog to Value-based HIV Care in Sub-Saharan Africa** activity was developed in partnership with United States Agency for International Development (USAID) and implementing partners (IPs).

USAID's Office of HIV/AIDS (OHA), a key implementer of the United States President's Emergency Plan for AIDS Relief (PEPFAR), provides HIV/AIDS technical and programmatic leadership to inform the potential integration of value-based care (VBC) approaches in programming.

USAID's Center for Innovation and Impact in the Global Health Bureau partnered with the Global Development Incubator (GDI) to explore the use of VBC in developing country contexts and is currently exploring new pilots and partnerships around VBC, including with OHA for HIV/AIDS.

Data for Implementation (Data.FI) is a five-year cooperative agreement funded by PEPFAR through USAID. It provides technical expertise and contextual knowledge for how VBC approaches can be integrated in USAID's PEPFAR programming.

Leapfrog to Value, an initiative of the GDI, hosts a global coalition on VBC in low- and middle-income countries (LMIC) that includes funders, innovators, investors, health system experts, and public servants. The GDI leverages its ability to execute effectively and matches leaders, concepts, and capital required to launch and scale transformational development ventures.

Introduction and Background

Despite significant progress, the HIV community has not met the 95-95-95 PEPFAR targets and the COVID-19 pandemic has created additional challenges in sustaining access to HIV prevention and treatment services. Global efforts to address the HIV epidemic have reached a point where investing more in existing programs may not yield desired outcomes. To address this, people living with HIV (PLHIV) spokespersons and HIV experts **have** advocated for a fourth goal beyond the three 95s. The fourth goal focuses on elevating people-centered outcomes that have not been previously measured in a standardized way in HIV programs, specifically health-related quality of life.

Value-based HIV care offers a compelling solution to reorient health systems to people-centered care. VBC aligns clients, payers, and providers around a common goal: achieving people-centered outcomes at the optimal cost (Figure 1). It measures the outcomes that matter most to PLHIV and the longitudinal cost of measuring those outcomes.

Figure 1. A value-based framework

Source: Leapfrog to Value (2020). Available at https://www.usaid.gov/sites/default/files/documents/1864/Leapfrog_to_Value_Report.pdf

To embrace VBC, PEPFAR and the global HIV community can learn from existing programs that already apply elements of VBC.

Measurement: *PEPFAR has established a data-rich ecosystem where stakeholders at various levels routinely collect, analyze, and take action on data for program design, planning, monitoring, and improvement. Data.Fi sees an opportunity to build on this positive momentum.*

Across programs, we see strategic planning, program monitoring, and performance improvement being driven by PEPFAR's standardized Monitoring, Evaluation and Reporting indicators, supported by interventions focusing on data-driven decision making. Digitized clinical case management and client record systems are used in many settings, allowing for interoperability of data across service delivery points, and for data to be aggregated and modeled for advanced analytics and insights. Moreover, routine

processes, like the Site Improvement through Monitoring System (SIMS) and expenditure analysis (EA), support regular monitoring of quality and cost. We believe that innovative approaches, tools, and protocols can be used to interrogate the root causes of program challenges, better estimate costs of programs, and monitor service and non-service delivery functions at PEPFAR- supported sites. Digital health tools with a decision support and feedback loop can also improve provider-client interactions.

Delivery: *Differentiation of care for specific client segments has become standard practice and represents progress toward a more people-centered approach to HIV care. Value-based HIV care can further strengthen these efforts.*

HIV service delivery is increasingly supported by local IPs and technical assistance is provided directly to governments for policy and systems strengthening. They can be leveraged to bring people-centered design approaches to service delivery, increase the use of differentiated care and public-private integrated care models, and standardize tools to decrease stigma and discrimination.

Payment: *The global HIV community has sought to align financing with results; value-based payment builds on this foundation*.

There is increasing adoption of global account budgeting and allocation, government to government funding, and cooperative agreements with IPs. We can build on them to include results-based financing that incentivizes outcomes and efficiency, explores total market approaches that can increase access to and quality of services, and increases strategic purchasing to promote quality and reduce costs.

Measurement is the first step in establishing a value-based approach to HIV care. This requires that we:

- Standardize the collection of people-centered outcomes measurements in HIV beyond ad hoc collection.
- Operationalize the production and use of insightful and actionable data to inform decision making and resource allocation in programs.
- Evaluate the impact of interventions aimed at producing better people-centered outcomes.

This document was developed as a resource for those considering the implementation of people-centered outcomes in HIV in their programs. It includes:

- Indicator reference sheets for people-centered outcomes.
- A practical set of considerations for implementing people-centered metrics.
- Early insights on the way forward to implementing value-based care in LMIC contexts.

Process Overview: Development of Indicators and Practical Considerations for Implementation

The focus of Data.FI's early work has been on measurement of value. It builds on existing quality improvement efforts, but is distinct, in that it maintains a strong focus on addressing quality of life and the care experience as core indicators. To develop the people-centered outcomes for HIV, we embarked on a consultative process that engaged PLHIV directly through community advisory boards, HIV healthcare providers, IPs, and monitoring, evaluation, and learning (MEL) experts. We started by developing a conceptual framework for value-based care and people-centered outcomes, the drivers of those outcomes, and learning from innovative approaches that support VBC in HIV. Building on this foundational work, we developed a set of questions to assess people-centered outcomes and implementation considerations.

In **Phase 1**, we consulted previous initiatives undertaken by PEPFAR and its partners, interviewed 15 subject matter experts, and directly consulted with PLHIV advocates through virtual workshops. We also reviewed more than 50 articles on people-centered HIV care and drew inspiration from 27 innovators selected from more than 300 health organizations. This culminated in a people-centered outcomes [framework described in the next section.](#)

In **Phase 2**, we reviewed HIV patient-reported outcomes measure (PROM) implementation toolkits, validated and custom tools from HIV and non-HIV therapy areas, and PEPFAR tools, and conducted a two-part workshop with leading HIV service delivery providers from Ethiopia, South Africa, and Zimbabwe. We followed an iterative process and solicited ongoing feedback from workshop participants and OHA colleagues through the various stages of developing the indicator reference sheets and guidelines. This culminated in a set of practical implementation considerations and indicator reference sheets to encourage the routine use of people-centered metrics in programs. Additional information is provided in the sections below.

Process limitations:

- The indicators have not yet gone through a validation process.
- The guidelines are considerations for implementation and are not a toolkit.
- The indicators and guidelines are not tailored to a specific country or program context.

In 2021 and 2022, we are planning to strengthen our recommendations by:

- Identifying partners to pilot the people-centered outcomes and integrate them in service delivery programs and existing data collection processes and systems.
- Establishing a baseline of performance on these indicators.
- Revising and potentially scaling up the indicators.

Indicator Overview

People-centered metrics provide a blueprint for how health services and incentives can be designed to provide more people-centered care (i.e., keeping in mind how they affect convenience, access, usability, and motivation for clients and providers).

Our set of people-centered HIV metrics are organized in three categories: clinical outcomes, quality of life, and care experience (Figure 2). In PEPFAR programs, clinical outcomes are routinely measured through the Monitoring, Evaluation and Reporting indicators. However, by including quality of life and client experience of care, we aim to provide a holistic human perspective.

In quality of life, we capture the client's perception of his/her position in life in the context of the culture and value systems in which s/he lives and in relation to his/her goals, expectations, standards, and concerns. In simpler words, this means the degree to which the client is healthy, comfortable, and able to participate in or enjoy life events. It includes symptom control and side effects, mental well-being, social support, stigma and discrimination, and financial burden—most of which are "outside" the health facility.

In the client experience of care, we assess the client's individual perception of how s/he felt about care while receiving it. Although the majority of this is "inside" the health facility, with the extended care continuum, the client experience of care covers services received at home or other places beyond the health facility. It includes privacy, dignity of care, client-provider interaction, and service levels.

Figure 2. People-centered metrics

Overview of the Indicator Reference Sheet

Through our consultative process and literature review, we developed detailed indicator reference sheets for new indicators to cover the full outcome set described in Figure 2 for both the client experience of care and quality of life.

Table 1 provides an overview of the indicators and their proposed use. The full indicator reference sheets can be found in Appendix A and survey questions in Appendix B.

Table 1. Overview of client experience of care and quality of life indicators

Indicators	Definition	Rationale and data use
Client experience of care	Percentage of surveyed clients who would recommend an HIV health service as a proxy measure of their own care experience	The client's experience of care impacts his/her willingness to both seek and stay in care. Effectively, it influences clinical outcomes. Data from this indicator will help identify facility performance improvement initiatives that can improve the care experience. Illustrative improvements could include reducing wait times, task shifting, or providing training to prevent stigma and discrimination. The feedback can inform the design approach when developing training/mentorship models for healthcare workers (HCWs), and financial and non-financial incentives to improve staff performance. By incorporating anonymized data in review cycles, facilities can address client feedback systematically. Better performing facilities can share best practices and mentor lower performing facilities. Social reinforcement and "share and reapply" principles can standardize care experiences across facilities and improve outcomes at a program level. Data from this indicator can also be linked to other PEPFAR monitoring tools, like root cause analysis, to identify improvements in retention and adherence among PLHIV. The information can also build on quality improvement efforts, like SIMS, by providing a more holistic view of quality as viewed from the client's perspective.
Quality of life – Symptom control	Percentage of surveyed clients who report minimal HIV-related symptoms	Optimal quality of life is possible when HIV-related symptoms are minimal. This affects the client's treatment adherence and retention in care, while also positively affecting his/her overall quality of life. It also influences clinical outcomes.

|		Feedback from data collected through this indicator can assist programs to better manage symptoms by adjusting treatment regimens, mitigating antiretroviral therapy (ART)-related side effects, or mitigating other emerging opportunistic infections. Data on client-reported symptoms can be integrated in the client record to sensitize providers to individual client needs and personalize treatment support.
		The data can also inform provider training and the design of decision-support tools. Linking recommended actions to feedback will allow providers to effectively close the feedback loop with clients. Continual reporting can optimize the list of recommended actions over time.
		In addition, the data from the indicator can assist programs in prioritizing support services or referrals for comprehensive managed care.

Quality of life – mental well-being	Percentage of surveyed clients who report experiencing minimal mental or emotional problems in the past two weeks	Optimal mental health impacts the client's ability to stay in care. Moreover, clients with poor clinical outcomes are at the risk of experiencing greater mental and emotional problems. At a program level, this indicator can be used to monitor the state of mental health of PLHIV receiving services from the program, and the risk and protective factors that govern their mental and emotional well-being.

Feedback collected through this indicator can guide provider-client consultation. At a provider level, this will allow earlier diagnosis of comorbid mental health challenges. Linking recommended actions (management of symptoms, referral for counselling services, providing medication, etc.) can assist providers in addressing the feedback. The data can also assist programs in prioritizing capacity development, designing support services, and creating referral mechanisms to support mental well-being.

Most research on mental health interventions for PLHIV has been conducted in high-income countries rather than in LMICs. Moreover, there are limited studies* examining mental health interventions in relationship to HIV care outcomes, relative to studies that focus on mental health outcomes alone. Longitudinal data from this indicator can contribute to filling these gaps and can potentially inform more evidence-based HIV and LMIC-specific mental health interventions.

*Remien, R.H., Stirratt, M.J., Nguyen, N., Robbins, R.N., Pala, A.N., Mellins, C.A. (2019). Mental health and HIV/AIDS: the need for an integrated response. *AIDS, 33* (9), 1411–1420. Retrieved from https://pubmed.ncbi.nlm.nih.gov/30950883/. |
| **Quality of life – Social support** | Percentage of surveyed clients who report feeling socially supported by family and/or friends | Strong social support impacts the client's ability to stay in care and influences his/her mental health. PLHIV who do not receive adequate support are likely to feel isolated and this can influence their care-seeking behavior, and mental and physical health. Ultimately, both can influence clinical outcomes.

Feedback can assist programs to design support services for PLHIV. At an individual client level, the information can be correlated with feedback on mental and financial health to provide comprehensive support. At the program level, the information can assist in prioritizing social support services to more vulnerable client groups across facilities. |

		Several studies** also correlate mental and social support needs with HIV risk behaviors in men and women. Gender-disaggregated data collected through this indicator can help programs tailor HIV prevention programs that focus on psychosocial support.
		**Fang, L., Chuang, D.M., Al-Raes, M. (2019). Social support, mental health needs, and HIV risk behaviors: a gender-specific, correlation study. BMC Public Health, 19 (1), 651. Retrieved from https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-019-6985-9.
Quality of life – Stigma and discrimination	Percentage of surveyed clients who report experiencing minimal discrimination as a result of their HIV status	PLHIV who do not face discrimination are likely to feel less isolated. This can influence their care seeking behavior and mental and physical health. Ultimately, both can influence clinical outcomes. For stigma experienced due to family and/or community, the interventions can include training CHWs and sensitization of community leaders. Based on findings from these indicators, the case for community-based interventions, such as peer-to-peer support groups or adherence clubs can also be considered. Data from this indicator can assist programs in prioritizing interventions, such as staff training, performance reviews, and incentivization to reduce facility-based stigma and discrimination.
Quality of life – Financial burden	Percentage of surveyed clients who report taking out a loan or selling belongings to pay for HIV- related care	Out-of-pocket expenses, loss of workdays, and limited ability to work can limit a client's ability to seek and stay in care. The financial burden can cumulatively impact on quality of life and clinical outcomes. Although HIV treatment (tests and medication) is free of cost in most LMICs, the data can provide a proxy for the extent of out-of-pocket costs and catastrophic expenses borne by PLHIV. Programs can use this information to design service delivery and support services to ease the financial burden. They can include more differentiated care models that make it more convenient to receive care, skills and livelihood development, or training for increased financial literacy.

Implementation

How the set of people-centered metrics is implemented will depend on the program context and will be critical for encouraging and sustaining the collection and use of data through these metrics. To guide implementation of these indicators, we provide the following practical considerations that recognize that each program operates in a unique context, including the program's priorities, budget, and available resources; service delivery design; and existing data infrastructure. We expect the process of operationalizing the indicators will be iterative; however, we present the process in chronological order and propose feedback loops (Figure 3). We also capture the implementation considerations for each step in the process.

Figure 3. Implementation process for people-centered metrics
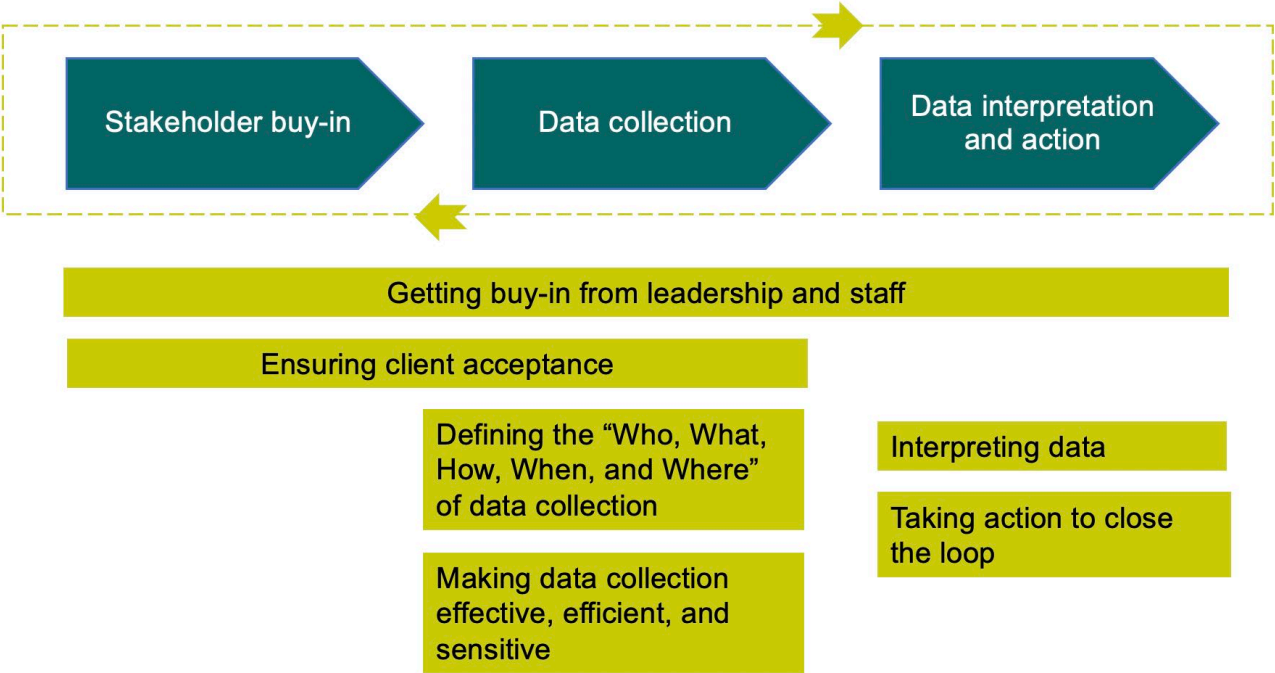
Building Stakeholder Buy-In

GETTING BUY-IN FROM LEADERSHIP AND STAFF

The first step in the implementation process is building buy-in from program leaders and staff, and from clients.

Why is this important?

Clinic leadership and clinic staff are key to ensuring the successful implementation of people-centered metrics. Leadership decides on the priority areas and the overall strategy. It influences organizational culture and can drive support for implementation. Leadership and staff influence HIV service delivery through the allocation of resources, workflow design, training and capacity development, and overall performance loops. The more buy-in that clinical and non-clinical staff demonstrate, the greater the likelihood of sustained success.

What should we consider when making a case for buy-in?

In building leadership and staff buy-in, we suggest four considerations:

- Assess the extent to which leadership and staff understand and believe in the importance of people-centered metrics.
- Understand how people-centered outcomes fit into current program goals and priorities.
- Understand reporting requirements from governments and funders that contribute significantly to how service delivery is designed, what is measured, and how performance reviews and incentives are structured.
- Assess health system readiness to adopt people-centered metrics that can influence how, when, and where data are collected and interpreted.

How can we best achieve this?

To build leadership and staff buy-in, we suggest the following actions:

- Identify and **engage leadership, clinical, and non-clinical staff early on.**
- Conduct research on stakeholder specific concerns and possible solutions. For example, leadership commonly has concerns about the allocation of budget and resources for implementation; clinicians may anticipate the need or requirement for additional time for consultation; and non-clinical staff could fear a disruption in workflow. Addressing the common concerns proactively can build trust and encourage adoption. To demonstrate value, you can refer examples highlighted through our innovation case studies.
- Ensure that **communication** is inclusive, collaborative, and empowering across stakeholders. Each stakeholder will bring his/her individual perspectives and concerns. By encouraging leadership and staff to share their opinion and insights, you can facilitate co-ownership of goals

and shared governance. This can minimize resistance from staff who may fear being held solely accountable for implementation success.

- Link the potential **impact** of the people-centered metrics with the identified **priorities** for the stakeholders. The demonstration of value is best when evidence based and specific for each stakeholder. Short practical examples are likely to be the most effective. For example, if the program priority is the reduction of stigma and discrimination in the health facility, then value-based innovations that champion this priority can be shared.

- Provide relevant information on metrics implementation and a blueprint to **co-design** the implementation process; for example, the likely stages of implementation, human-resource requirements, technical infrastructure, and possible costs.

A recent [health quality study](#) on integrating stigma and discrimination in quality improvement offers a novel, scalable means to implement stigma-reduction interventions in the healthcare setting. It is motivated by the aim of translating what is known about the core drivers of stigma into evidence-based, practical, and population-level impact. Similarly, the challenge of stigma and discrimination can be addressed through mentorship and training programs, similar to those used by the [Beyond Bias](#) project in three countries and more than 200 facilities for sexual and reproductive health. Both innovations are anchored in first measuring stigma and discrimination, and then designing interventions to reduce them.

- Suggest **testing** the metrics before scaling up. Starting small with a few pilots across sites can help streamline the process and generate early evidence to build further buy-in.

- Identify a **clinic champion** to coordinate with other stakeholders and to sustain momentum.

ENSURING GREATER CLIENT ACCEPTANCE

Why is this important?

What matters most to PLHIV is the basis of people-centered metrics in HIV. The process of measurement must therefore provide greater agency and create more trust versus tension in the health system. Early input from clients can facilitate more effective and empathetic implementation. It can better contextualize the metrics to local and cultural sensibilities. Client acceptance is critical at both the start of the implementation process and during data collection.

What should we consider when making a case for buy-in?

In building greater client acceptance, we suggest four considerations:

- Gauge the ability of PLHIV to participate in discussions and the design process. This will be influenced by literacy levels, languages spoken, cognitive abilities, and cultural sensitivities.

- Understand the clients' concerns. They include fears around disclosure, non-participation, backlash due to negative feedback, and use of their data.

- Assess the kind of experiences PLHIV have had when engaging with the health system. For example, PLHIV may have faced stigma and discrimination or undignified care. This could limit their willingness to engage with clinic staff. Alternatively, PLHIV may have benefitted from differentiated care delivery and become champions for change. In both scenarios, the manner of engaging with the client will likely differ. Overall, the kind of experiences PLHIV have had can influence priority areas for implementation.

- Assess various client personas and characteristics relevant to the program. They could be a combination of age, gender, behavioral characteristics, and stage of the client's journey.

How can we best achieve this?

To build client acceptance, we suggest the following actions:

- **When setting up the implementation process:**
  - **Identify and engage early** with a cross section of PLHIV (i.e., different age groups, gender, at different stages [prevention, treatment]). This can be done through conversations with community representatives and advocacy groups. Stating what PLHIV can expect during and after the process can help address common concerns and fears.

- **When collecting data:**
  - Translate **tools** to support local languages, and pre-test for comprehension and sensitivity to cultural contexts to ensure that questions provide insight as intended.
  - Ensure that **consent is explicit**. First, the way consent is obtained should be clear and should include reasons for data collection. PLHIV should be assured that there is no right or wrong answer. Second, the option to not participate should be stated upfront, and the client should be assured that there are no repercussions for non-participation and that no services will be withheld.
  - Provide **privacy, confidentiality, and convenience**. For in-facility data collection, a separate private space should be demarcated and the stage in the client journey/workflow should be pre-defined. For outside facility/telephonic surveys, a suitable time should be requested from the client.
  - **Build trust with PLHIV by closing the loop**. Clients should feel heard and know that their feedback matters. Informing clients that the feedback is being solicited to improve their overall experience is important. In the short term, both survey results and unstructured feedback and complaints should be correlated to identify common categories. A third party can be considered to arrange a callback to receive additional feedback or confirm with the client how his/her feedback was valued and actioned.

Data Collection

The next step is ensuring that data collection is effective, efficient, and can be integrated in existing collection processes.

Why is this important?

It is crucial to have clear definitions on when, where, how, and who will collect data. From the clinical staff point of view, this will influence workflow design, the client's journey in the health facility, and the allocation of budget and human resources. Sustained buy-in from staff will involve a streamlined process that is responsive to their needs and yields desired results. Second, the collection process itself will affect how clients experience providing feedback. A collection process that is inconvenient, causes delays, and/or discomfort will not elicit the desired feedback and may create mistrust. Last, integrated and longitudinal data collection and stakeholder-specific access to data can inform the provider-client consultation, influence the strategy and design of service delivery at the program level, and inform policy and budget allocations at the population level. Over time, data collection can generate baseline evidence on the metrics and be linked to payment incentives for staff and value-based purchasing health financing schemes.

What should we consider?

In designing data collection to be effective, efficient, and sensitive, we suggest three considerations:

- Assess and understand the **level of health information system maturity** to identify opportunities to align data collection efforts with existing workflows in systems. For example, there may be ways to leverage existing digital infrastructure or client management information systems, such as electronic medical records (EMR), to reduce costs, better align with existing processes, and potentially allow for a longitudinal view of data that can ultimately be linked to clinical outcomes.

- Assess the overall **resource constraints** in terms of budget, human resource capacity and training, literacy levels of the population, and Internet and electricity connectivity. They will impact whether surveys are self-administered or administered by a healthcare worker/program staff/third party, and whether they are done in paper or digital format. The availability of resources will also determine the feasibility of data collection and how frequently data can be collected and whether it should be collected within or outside the facility.

- Assess how best to **balance for insight and confidentiality** to ensure ethical data collection. Gauge the level of anonymity necessary at client, program, and/or population levels. The interpretation of data to inform appropriate action is necessary to improve service delivery and the client experience. However, if it breaches the client's need for privacy and non-disclosure, it can create more tension versus trust in the health system. For example, if the client experience rating is made available to providers, it may cause concern for PLHIV if they have shared negative

feedback. Providers should only have access to viewing client-level information on clinical and quality of life outcomes.

How can we best achieve this?

To design the data collection processes, we suggest the following actions:

- **Define the who, how, when, and where**:
  - For programs catering to populations with higher literacy levels, in areas of good connectivity, and with a budget to support a people-centered metric initiative: A self-administered survey via a mobile device may be effective. The digital data collection process could use an online survey, SMS service, or mobile application. This would allow clients to take the survey before consultation, minimize the need for additional human resources to administer the survey and could inform the provider-client consultation.

  - For programs with limited resources and catering to populations with lower literacy levels: Paper-based surveys administered by program (non-clinical) staff are likely more feasible. However, challenges with manual data entry errors and additional workload are likely. Telephonic surveys can be a viable alternative in this case and can be outsourced to a third party using interactive voice response technology. Although telephonic surveys may have a lower response rate because callers need to find a time that is convenient for clients, they will likely have higher frequency rates. Alternatively, clients visiting facilities may be more amenable to responding to a survey; however, the frequency of data collection would be lower because it would be limited by the number of visits. Programs will have to balance for frequency and response rates when deciding between the two options.

- **Optimize for longitudinal data collection**. Ideally, data collected from the people-centered metrics are anonymized but contain unique identification to interoperate with clinical outcomes data recorded in an EMR or case management information system. However, this requires the assessment of existing information systems and intentionality to balance client privacy and confidentiality. In the case of paper-based administration, consider how the longitudinal records can be maintained and accessed easily. Possible options include a scanned image, an electronically transmitted summary form, and/or discrete observations.

- **Define stakeholder-specific access to data.** Access should be aligned with the data use expectations that are shared with clients at the time of consent. The level of anonymization will be different at client, provider, program, and/or population levels. Providers should have access to quality-of-life information and how it relates to clinical outcomes at the client

A three-year study on PROMs in HIV in the Netherlands observed that clients experienced an improved relationship with the provider, more agency, and improved quality of life. Similarly, providers reported better communication with clients and access to clinically relevant information. Alternatively, programs could consider a dedicated data clerk for survey administration, which may mitigate potential issues with increased workload for clinical staff and any discomfort clients may feel when giving feedback. The survey could be conducted remotely before the facility visit or in-facility. A GP consortium practice in South Africa collects client experience and quality of life information via tele-callers. The information is used to ensure compliance with donor/government requirements of public-private service delivery and improve overall client satisfaction.

level, which can inform the consultation itself. Provider access can include the client's experience of care at the cohort level without individual client information so that it can be linked to performance reviews. For programs, the information should be at the facility level and should not include client-level information. This information can be linked to performance management loops, performance review cycles, and routine data review processes. At the population level, access can be anonymized at the cohort level and disaggregated. This can inform the kinds of interventions needed and budgetary allocations. Advanced data techniques, such as artificial intelligence, can help anonymize data without the need for manual intervention.

| Stakeholder buy-in | Data collection | Data interpretation and action |

Data Interpretation and Action

The final step is ensuring that the data are analyzed, used, and linked to an action plan that can close the loop with clients.

Why is this important?

Putting insights derived from the indicators into action is critical. Analyzing the data can help programs identify barriers, gaps, and opportunities to improve the client's experience of care and quality of life, potentially improving clinical outcomes. A data use strategy should be developed with stakeholder input to also align with existing program improvement initiatives. Actioning insights across various stakeholders can sustain momentum for people-centered metrics in the program and is necessary to close the loop. Closing the loop involves acting in a timely and effective manner to address the needs of the client that are captured through data collection. For clients, actioning the feedback provides a sense of trust and of being heard. Clinic staff will feel supported in addressing client concerns and will sustain buy-in for people-centered metrics. At the program level, data interpretation and action can generate necessary evidence to inform performance improvement initiatives that can link to improved clinical outcomes and meeting targets.

What should we consider?

In determining processes for data interpretation and action, we suggest three considerations:

- Understand how **data can be provided at the right time and in the right format** to each stakeholder **to provoke action.** The eventual format and training requirements will be determined by the level of digital infrastructure, characteristics of the EMR or client management system, and existing processes for data and performance reviews, while aligning with program goals and workflows.

- Assess how the interpretation of people-centered metrics and related actions can be integrated in **performance management** approaches**.** Consider linking insights to existing data use

For example, OLVG is the largest HIV care provider in the Netherlands and has effectively incorporated people-centered outcome indicators in its review cycles. OLVG's approach includes designated working groups assigned to specific indicators and a Plan-Do-Study-Act cycle. Challenges with poor performance culture and staff resistance may emerge when attempting to implement the changes. WILD4LIFE Health overcame the issues by using a mentoring approach with 17 clinics that reach more than 70,000 people in three districts in Zimbabwe. It improved provider/HCW performance via skills building, training, confidence building, peer-to-peer support, continuous quality loops, and non-financial incentives. The training and mentorship are informed by data on clients' needs collected via exit interviews and community interactions.

initiatives—like routine data review meetings and data products, such as dashboards. In addition, results can be linked to performance review cycles and staff incentivization.

- Assess how data can be reused for **population-level health services** for country-level stakeholders (i.e., donors, governments). For example, disaggregated information on the mental health of PLHIV can inform decisions to provide counselling services as part of programs. Client experience information can help identify best practices across facilities/programs and drive system-wide quality improvement.

How can we best achieve this?

To facilitate data interpretation and action, we suggest the following actions:

- **Design stakeholder-specific dashboards or reports linked to recommended actions**. Recognizing that many existing programs are already using dashboards or other information products to drive performance improvement, identify initiatives where data from these new metrics can be incorporated, and consider existing data use opportunities and the data needs of each stakeholder. For providers, access to easy-to-comprehend summaries, tables, and recommended actions is important. The dashboard should provide individual client-level information but have scope for wider interpretation. For example, the graphic should include a comparison of individual client scores against "similar clients" and include average scores at the population level. This will help providers understand where their clients are on the spectrum and prioritize interventions. Involving providers in designing and adapting dashboards is important. Provider and staff training should be undertaken to minimize the learning curve and associated inconvenience. Training should include how to collect and/or interpret data. Similar involvement in designing and training should be done for program managers. Where feasible, establish linkages among dashboards for facility, program, and donor-level stakeholders for a comprehensive top-down and bottom-up analysis.

- **Integrate with routine data review meetings and performance management loops.** Existing data-driven performance review initiatives, such as "Epidemic Control Rooms" or routine data review meetings, provide an opportunity to integrate new data from people-centered metrics in the review process. In these review processes, define a framework to close the loop, such as the continuous quality improvement (CQI) framework of Plan-Do-Study-Act. Continuous quality improvement is designed to be executed quickly—and thereby reduce the time needed to test solutions through evaluation—so that stakeholders can see results more quickly. To act on insights derived through the data review process, designate working groups responsible for an

For example, WILD4LIFE Health tracks predefined indicators and does a root cause analysis when they fall below a threshold. This is followed by corrective action and documentation and sharing of successful approaches with network facilities. The organization also recognizes facilities and HCWs for their superior service with certificates of appreciation. It grades clinics against a set of quantitative (e.g., access to HIV services) and qualitative (e.g., viral load) indicators, and provides results-based financing against those metrics. Similarly, reviews should be extended beyond individual staff to facility, district, and provincial levels. This will provide a ground-up view and co-ownership among the different levels of stakeholders. Aravind Eye Care in India provides low-cost high-quality eye care. Based on decades of data on clinical outcomes, it created scorecards benchmarking against the accepted standards of care. Doctors receive their scorecards and relevant information and training for improvement. The scorecards and training/mentoring are used to improve performance, not to penalize doctors.

action area and determine intervals for review, the structure of meetings, and the escalation cascade.

- **Conduct reviews and structure incentives at the individual staff level**. Consider using aggregated data to discuss performance of individual staff members. The individual staff member could receive anonymized summary data on all their clients that will allow staff to see trends across clients to improve their performance, while not compromising client privacy. Staff could also receive de-identified performance data across other providers in the same facility to benchmark and motivate improvements. Positive reinforcement should be used to acknowledge improvements, rather than punitive measures that may lead to staff demotivation. Define both process (execution) and performance (outcome information) indicators and include them in existing review meetings. These indicators should be specific, easy to track and collect, and be time-bound.

Conclusions and Next Steps

People-centered metrics have the potential to shape the trajectory of HIV care.

- **Learn**. People-centered metrics can help HIV providers better understand what matters to clients. They can also drive a research agenda on how meeting these needs can better improve treatment adherence and viral suppression.

- **Improve**. People-centered metrics can be used to drive performance improvements of existing programs, by integrating these metrics into existing efforts to collect, interpret, and take action on data insights.

- **Align incentives**. These metrics present an opportunity to align reward systems (financial and non-financial) with delivering people-centered care.

- **Innovate.** Measuring people-centered outcomes will reveal and inspire opportunities for disruptive innovation to overcome persistent challenges in sustaining client engagement with care.

To realize this potential, programs should first consider piloting these metrics to validate and refine them, to ensure that they generate meaningful insights, can be collected efficiently, can be implemented within the operational constraints of HIV care, and are sensitive to client needs. Ultimately, we can integrate measurement and delivery with payment, to unlock the full potential of VBC in HIV, described in our companion presentation, "Leapfrog to Value-Based Care in sub-Saharan Africa." The three aspects of VBC—measurement, delivery, and payment—should work hand-in-hand to create a synergistic system that drives delivery of better outcomes for PLHIV at a sustainable cost.

Appendix A. Detailed Indicator Reference Sheets

CEC_HIV	Client experience of care
Description	Percentage of surveyed clients who would recommend an HIV health service as a proxy measure of their own care experience
Rationale	Clients' experience of care impacts their willingness to both seek and stay in care. It effectively influences clinical outcomes. A program with a clear understanding of the gaps and opportunities in services can best design solutions to address them.
Type	Outcome
Numerator	Number of clients who scored 3 or 4 out of 4
Denominator	Total number of clients surveyed
Reporting level	Project
Reporting frequency	Quarterly
Definition	This indicator identifies the share of clients who have had a good experience as a percentage of the total number of clients surveyed about their HIV care experience. "HIV care" refers to antiretroviral and key non-antiretroviral therapy clinical services, the treatment of HIV-related infections, and non-clinical services that in combination with ART contribute to the reduction of rates of ill health and AIDS-related deaths among PLHIV. Clients surveyed may include adults receiving prevention, testing, and treatment services. **Clients should be individually surveyed using the following question:** **Based on your experience so far, would you recommend this service to a friend or family member?** 1 (not at all) 2 (somewhat) 3 (quite a lot) 4 (definitely) **What most impacted your score above?** • Cleanliness • Timeliness • Access to useful information • Privacy and confidentiality • Staff

	- Services available at the clinic today - Availability of accessing services outside the health facility (e.g., community ART pick-up points, community health workers, virtual or mobile communication with health facility staff) - Other (Please specify)
Data collection	Please refer to the section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients scoring 1, 2, 3, or 4. Those scoring 3 or 4 should be used as the numerator of this indicator, signifying a recommendation of services. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring 1, 2, 3, or 4. The reasons for low (2 and below) and high (3 and above) ratings should be studied. The three most commonly cited reasons that impact scores 2 and below and 3 and above should be documented. This will provide insight on which aspects of service delivery impacted the rating. Analysis should be done across health facilities at the project level every quarter. The averages across sites and quarters can be compared. Data from this indicator will help identify those facilities whose performances may improve through targeted assistance and/or capacity development. Tracking progress should incorporate early feedback loops to help facilities course correct, as needed.
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate group: **Age/Sex:** >19 F/M, Unknown age F/M
	NUMERATOR and DENOMINATOR Disaggregate group: **Type of service:** - Prevention - Testing - Treatment

QOL_SC_HIV	Symptom control
Description	Percentage of surveyed clients who report minimal HIV-related symptoms
Rationale	Optimal physical health is possible when HIV-related symptoms are minimal, impacting the client's ability to stay in care and positively affecting their overall quality of life. It also influences clinical outcomes. A program with a clear understanding of the client's symptom control status can best design solutions and allocate resources to optimize it.
Type	Outcome
Numerator	Number of clients who scored 3 or 4 out of 4
Denominator	Total number of clients surveyed
Reporting level	Project
Reporting frequency	Quarterly
Definition	This indicator identifies the share of surveyed clients who report feeling minimal HIV-related symptoms. It is taken as a percentage of the total number of clients surveyed in a specific period. **Clients should be individually surveyed using the following question:** **In the past 2 weeks, how often did you feel healthy/symptom free from HIV?** **1** (never) **2** (sometimes) **3** (quite a lot) **4** (all the time) **Which symptoms impacted your score the most?** ● Pain and discomfort ● Gastrointestinal problems (vomiting, diarrhea) ● Body weight changes ● Feeling more tired than usual, unable to move easily ● Skin issues and sweating ● Sexuality-related issues ● Change in sleep pattern ● Change in mood ● Other - Please specify ● None of the above
Data collection	Please refer to section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients scoring

	1, 2, 3, or 4. Those scoring 3 or 4 should be used as the numerator of this indicator, signifying minimal HIV-related symptoms are reported. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring 1, 2, 3, or 4.
	The reasons behind low (2 and below) and high (3 and above) ratings should be studied. The three most commonly cited reasons that impact scores 2 and below and 3 and above should be documented. This will help prioritize interventions at the facility and program levels. The analysis should be done across health facilities at the project level. The averages across sites and quarters can be compared. Tracking progress should incorporate early feedback loops to help facilities course correct, as needed. Data from the indicator can assist programs in prioritizing support services, referrals, etc.
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate groups: **Age/Sex:** >19 F/M, Unknown age F/M

QOL_MW_HIV	Mental well-being
Description	Percentage of surveyed clients who report experiencing minimal mental or emotional problems during the past two weeks.
Rationale	Optimal mental health impacts the client's ability to stay in care. In addition, clients with poor clinical outcomes are at risk of experiencing greater mental and emotional problems. At the program level, this indicator can be used to monitor the state of mental health of PLHIV receiving services from the program, and the risk and protective factors that govern their mental and emotional well-being. A program with a clear understanding of its clients' mental health across age, sex, and health facilities can best design solutions and allocate resources to optimize it.
Type	Outcome

Numerator	Number of clients who scored 1 or 2 out of 4
Denominator	Total number of clients surveyed
Reporting level	Program
Reporting frequency	Quarterly
Definition	This indicator identifies the share of clients who report experiencing minimal mental or emotional problems in the past 2 weeks. This is taken as a percentage of the total number of clients surveyed. **Clients should be individually surveyed using the following question:** **In the past two weeks, have you experienced any of the following (emotional and mental problems)?** ● Feel nervous, anxious, constant worry ● Feel hopeless, depressed, little pleasure in doing things ● Difficulty concentrating ● Memory loss ● Self-esteem and body image issues ● Feel unmotivated, lacking resiliency ● Other emotional or mental problems - Please specify ● None of the above **Follow-up question if clients choose one or more options (Apart from when none of the above is selected):** **If yes, how much have you experienced these problems in the past two weeks?** **1** (not at all) **2** (somewhat) **3** (quite a lot) **4** (all the time)
Data collection	Please refer to section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients scoring 1, 2, 3, or 4. Those scoring 1 or 2 should be used as the numerator of this indicator, signifying minimal mental or emotional problems. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring 1, 2, 3, or 4. The reasons behind low (2 and below) and high (3 and above) ratings should be studied. The three most commonly cited reasons that impact scores 2 and below and 3 and above should be documented. This will help prioritize interventions at facility and program levels. The analysis should be done across health facilities at the project level. The averages across sites and quarters can be compared. Tracking progress should incorporate early feedback loops to help facilities course correct, as needed. Data from the indicator can assist

	programs in prioritizing capacity development, designing support services, and creating referral mechanisms to support mental well-being.
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate groups: **Age/Sex:** >19 F/M, Unknown age F/M

QOL_SS_HIV	Social support
Description	Percentage of surveyed clients who report feeling socially supported by family and/or friends
Rationale	Strong social support impacts the client's ability to stay in care and influences his/her mental health. PLHIV who do not receive adequate support are likely to feel isolated and this can influence their care-seeking behavior and their mental and physical health. Ultimately, both can influence clinical outcomes. A program with a clear understanding of the client's social support system can best design solutions and allocate resources to optimize the support felt.
Type	Outcome
Numerator	Number of clients who rated 3 or 4 out of 4
Denominator	Total number of clients surveyed
Reporting level	Program
Reporting frequency	Quarterly
Definition	This indicator identifies the share of clients who report receiving social support from family or friends. This is taken as a percentage of the total number of clients surveyed.

	Clients should be individually surveyed using the following question: How much support do you get from your family, friends/significant other? (none at all) 2 (some) 3 (quite a lot) 4 (all that I need)
Data collection	Please refer to section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients scoring 1, 2, 3, or 4. Those scoring 3 or 4 should be used as the numerator of this indicator, signifying they are feeling socially supported. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring 1, 2, 3, or 4. The analysis should be done across health facilities at the project level. The averages across sites and quarters can be compared. Data from the indicator can assist programs in designing support services.
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate groups: **Age/Sex:** >19 F/M, Unknown age F/M

QOL_SD_HIV	**Stigma and discrimination**
Description	Percentage of surveyed clients who report experiencing minimal discrimination as a result of their HIV status
Rationale	PLHIV who do not face discrimination are likely to feel less isolated and this can influence their care-seeking behavior and their mental and physical health. Ultimately, both can influence clinical outcomes. A program with a clear understanding of to what extent client's face stigma and discrimination can best design solutions and allocate resources to optimize both.

Type	Outcome
Numerator	Number of surveyed clients who scored 1 or 2 out of 4
Denominator	Total number of clients surveyed
Reporting level	Program
Reporting frequency	Quarterly
Definition	This indicator measures client-reported experiences of stigma and discrimination because of their HIV status. "HIV/AIDS-related stigma" can be described as a "process of devaluation" of people either living with or associated with HIV/AIDS. Discrimination follows stigma and is the unfair and unjust treatment of a person based on his or her real or perceived HIV status. Experiences of stigma and discrimination because of HIV status are a contributing factor that impacts the quality of life. **Clients should be individually surveyed using the following question:** 1.Have you faced any discrimination because of your HIV-positive status in the past month (i.e., isolated, excluded, judged, denied, or threatened)? 1 (none at all) 2 (some) 3 (quite a lot) 4 (a significant amount) **Clients rating 3 or 4 should be asked the following question:** Which of the following impacted your score the most? ● Beliefs and behavior of your family toward you. ● Beliefs and behavior of the community toward you. ● Attitude and behavior of clinic staff toward you. ● Other - Please specify
Data collection	Please refer to section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients scoring 1, 2, 3, or 4. Those scoring 1 or 2 should be used as the numerator of this indicator, signifying minimal discrimination. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring 1, 2, 3, or 4. The analysis should be done across health facilities at the project level. The averages across sites and quarters can be compared.

	Tracking progress with respect to stigma and discrimination due to clinic staff should incorporate early feedback loops to help facilities course correct, as needed. Data from the indicator can assist programs in prioritizing interventions, such as staff training, performance reviews, and incentives.
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate groups: **Age/Sex:** >19 F/M, Unknown age F/M

QOL_FB_HIV	Financial burden
Description	Percentage of surveyed clients who report taking out a loan or selling belongings to pay for HIV-related care.
Rationale	Out-of-pocket expenses, loss of workdays, and limited ability to work can limit a client's ability to seek and stay in care. The financial burden can cumulatively impact quality of life and clinical outcomes. A program with a clear understanding of the financial burden of the clients they serve can best design solutions and allocate resources to reduce the burden so that they can continue to seek and receive care.
Type	Outcome
Numerator	Number of surveyed clients who said "yes"
Denominator	Total number of surveyed clients
Reporting level	Program
Reporting frequency	Quarterly
Definition	This indicator measures the share of clients who experience a financial burden in accessing HIV services such that they take out a

	loan or sell possessions. This is taken as a percentage of the total number of clients surveyed. **Clients should be individually surveyed using the following question:** **Have you taken a loan or sold any belongings to fund treatment of HIV or HIV-related expenses?** 1 yes 2 no
Data collection	Please refer to section on data collection
Data analysis and use	Projects should analyze the data for the proportion of clients reporting yes or no. Those reporting "yes" should be included in the numerator of this indicator, signifying they have experienced financial burden related to HIV care. Projects may consider conducting a qualitative analysis of the data for the proportion of clients scoring yes and no. The analysis should be done across health facilities at the project level. The averages across sites and quarters can be compared. Data from the indicator can assist programs in prioritizing interventions to ease the financial burden, where relevant, through financial packages and support services, (i.e., differentiated care models, and skills and livelihood development).
Reviewing data quality	The total count of the denominator should be equal to the sum of all age/sex disaggregations.
Reporting process	Project level: Project MEL team to aggregate data across facilities and report on a quarterly basis.
Disaggregation	**NUMERATOR and DENOMINATOR** Disaggregate groups: **Age/Sex:** >19 F/M, Unknown age F/M

Appendix B. Survey Questions

Client experience of care	**Based on your experience so far, would you recommend this service to a friend or family member?** 1 (not at all) 2 (somewhat) 3 (quite a lot) 4 (definitely) **What most impacted your score above?** ● Cleanliness ● Timeliness ● Access to useful information ● Privacy and confidentiality ● Staff ● Services available in the clinic today ● Availability of accessing services outside the health facility (e.g., community ART pick-up points, community health workers, virtual or mobile communication with health facility staff) ● Other (Please specify)
Quality of Life- Symptom control	**In the past 2 weeks, how often did you feel healthy/symptom free from HIV?** 1 (never) 2 (sometimes) 3 (quite a lot) 4 (all the time) Which symptoms impacted your score the most? ● Pain and discomfort ● Gastrointestinal problems (vomiting, diarrhea) ● Body weight changes ● Feeling more tired than usual, unable to move easily ● Skin issues and sweating ● Sexuality-related issues ● Change in sleep pattern ● Change in mood ● Other - Please specify ● None of the above
Quality of Life- Mental well-being	**In the past two weeks, have you experienced any of the following (mental or emotional problems)?** ● Feel nervous, anxious, constant worry ● Feel hopeless, depressed, little pleasure in doing things ● Difficulty concentrating ● Memory loss ● Self-esteem and body image issues ● Feel unmotivated, lacking resiliency ● Other emotional or mental problems - Please specify ● None of the above

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	Follow-up question if the client chooses one or more options (except for none of the above)
	If yes, how much have you experienced these problems in the past two weeks?
	1 (not at all) 2 (somewhat) 3 (quite a lot) 4 (all the time)
Quality of Life-Social support	How much support do you get from your family, friends/significant other?
	1 (none at all) 2 (some) 3 (quite a lot) 4 (all that I need)
Quality of Life-Stigma and discrimination	1.Have you faced any discrimination because of your HIV-positive status in the past month (i.e., isolated, excluded, judged, denied, or threatened)?
	1 (none at all) 2 (some) 3 (quite a lot) 4 (a significant amount)
	Clients rating 3 or 4 should be asked the following question:
	Which of the following impacted your score the most?
	● Beliefs and behavior of your family toward you. ● Beliefs and behavior of the community toward you. ● Attitude and behavior of clinic staff toward you. ● Other - Please specify
Quality of Life-Financial burden	Have you taken a loan or sold any belongings to fund treatment of HIV or HIV-related expenses?
	1 yes 2 no

FOR MORE INFORMATION

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