



PEOPLE-CENTERED METRICS TO SUPPORT HIV SERVICE DELIVERY: PERCEPTIONS OF CLIENTS AND PROVIDERS IN TETE PROVINCE, MOZAMBIQUE

A SUMMARY BRIEF

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Introduction

Achieving the global HIV/AIDS 95-95-95 targets requires monitoring clinical outcomes but also requires attention to the experience of people living with HIV (PLHIV). Issues that affect treatment outcomes and quality of life—such as mental health problems, discrimination, financial burden, and lack of social support—are determinants of treatment success.

Incorporating people-centered HIV metrics into routine care, reporting structures, and quality improvement efforts could drive improvements in the delivery of more holistic HIV care and has the potential to address issues related to determinants of treatment success as part of improving quality of life and clinical outcomes.

The new strategic direction of the U.S. President's Emergency Plan for AIDS Relief (PEPFAR) emphasizes

the importance of improving quality of life and quality of care, including person-centered treatment for conditions beyond HIV, for a sustained response.¹ The intersection of quality of life and the care experience also aligns with the proposed 'fourth 95' target focused on health-related quality of life.

To explore the use of people-centered metrics in HIV care, a U.S. Agency for International Development (USAID) partnership of its Office of HIV/AIDS (OHA), its Center for Innovation and Impact, and the VBC Leapfrog to Value initiative via the Global Development Incubator developed a set of six people-centered indicators for HIV care and an indicator survey tool to collect data on these metrics via client interviews. These indicators build on existing clinical care metrics, going beyond biological outcomes to focus on more complex issues related to quality of life and care experience.

and security, transformative partnerships, and follow the science.

¹ The PEPFAR strategic pillars are: health equity for priority populations, sustaining the response, public health systems

As detailed in Table 1, these indicators focus on a client's experience of care, perceived symptom control and side effects, mental well-being, social support, stigma and discrimination, and financial burden.

TABLE I. PEOPLE-CENTERED OUTCOME INDICATORS FOR HIV

- 1: Percentage of surveyed clients who would recommend an HIV health service as a proxy measure of their own care
- 2: Percentage of surveyed clients who report minimal HIV-related symptoms
- 3: Percentage of surveyed clients who report experiencing minimal mental or emotional problems in the past two weeks
- 4: Percentage of surveyed clients who report feeling socially supported by family and/or friends
- 5: Percentage of surveyed clients who report experiencing minimal discrimination as a result of their HIV status
- 6: Percentage of surveyed clients who report taking out a loan or selling belongings to pay for HIV-related care^a

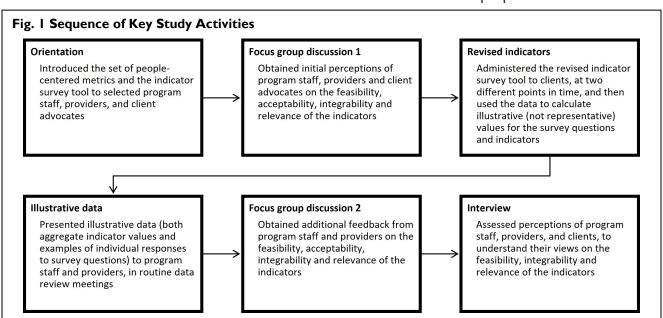
This brief is a follow-on to USAID's report, Putting People-Centered Metrics for HIV into Practice: Proposed Indicators and Practical Considerations for Implementation (Ali et al. 2021). It summarizes findings and draws recommendations from an exploratory qualitative study to assess the acceptability, feasibility, integrability, and relevance of both the indicators themselves and the indicator survey tool employed to gather client data.

Study Overview

The USAID Local Health System Sustainability Project (LHSS) partnered with two government health

facilities in Tete Province, Mozambique, to introduce the six people-centered indicators to program staff, providers, and clients to validate and refine the indicators and to determine how they might drive improved client care. The study aimed to understand the relevance of the indicators and their potential to generate data that can inform improvement in the management and provision of HIV care.

The study team designed a sequence of activities (Figure I) to share information about the indicators, collect and share illustrative data on the indicators, and obtain information on user perceptions of the indicators. The set of people-centered indicators and



^a Indicator was revised during the study (see Findings).

the indicator survey tool were introduced to select program staff, providers, and client advocates in an orientation workshop and focus group discussions were conducted to obtain their feedback on the feasibility and acceptability of the indicators.

The indicator survey tool was administered to clients to generate illustrative scores for the survey questions and indicators, which were presented to program staff and providers in routine data review meetings. Following multiple opportunities to review and consider the set of indicators, program staff and providers were administered semi-structured, openended questionnaires to understand their views on the utility and relevance of the indicators and the acceptability and integrability of the survey questions; a similar questionnaire was also administered to clients.

The study investigated four characteristics of the people-centered outcome indicators:

- Acceptability: The extent to which the indicator is acceptable to those being asked to respond and those responsible for collecting and using the indicator data
- Feasibility: The extent to which the indicator data can be collected, calculated, and used for clinical care or service management and administration
- Integrability: The extent to which the indicator can be integrated into an existing data or care system
- Relevance: The extent to which the indicator can be useful to those collecting data and those with whom the information is shared for decisionmaking

Findings

Providers and clients generally agreed that the six people-centered indicators are necessary for improving PLHIV experience of care, quality of life, and ultimately, clinical outcomes.

Program staff and clients agreed that people-centered indicators are important for understanding the range of issues affecting PLHIV's quality of life and for providing more holistic care to help address these

issues. Study respondents found the indicators and associated survey questions to be <u>acceptable</u> (suitable and likely to be answered by PLHIV), even though questions about mental health and financial hardship were sensitive. At respondents' suggestion and recognizing that HIV care could be provided free of charge, Indicator 6 has been revised to read: Percentage of surveyed clients who experience financial hardship associated with their HIV diagnosis and/or their HIV-related treatment and care.

Providers and program staff agreed that indicators are relevant to helping them pursue closer follow-up with clients, help clients by referring to support groups or mental health care, linking clients to community education, or encouraging clients to seek help from family and friends.

Important considerations arose around the feasibility and integrability of the people-centered indicators in a clinical setting. First, the language and specific wording used to measure these indicators will need to be clear and simple for clients of varied background, literacy, and age. Second, the time required to administer these additional clinical indicators will be a challenge. Their collection will need to be streamlined into existing triage mechanisms, clinical consultation procedures, and data collection processes. Third, it will be important that the right person is asking the survey tool questions—for example, PLHIV might prefer a provider or community worker for some questions such as those related to treatment adherence or other aspects of personal welfare. However, a provider should not be asking about client satisfaction. Fourth, for any indicator or other data collected, there must be a clear pathway to its use. A data clerk or other facility staff must have the time to routinely clean, analyze, and package the data into a usable format. Providers must be able to use the data during clinical consultation and decisionmaking. Arrangements must be in place at the clinical and/or regional level to understand and interpret the data and to appropriately use findings to make changes to clinical processes.

Before integration of the indicators, program leadership will need to ensure that any potential

clinical or social issue raised can be addressed. Although some clinical actions might be relatively simple to implement (e.g., referrals to available services), others will require additional resources and potentially significant changes to program structure and facility policies (e.g., new policies for cross-sectoral referrals). Any program seeking to use the people-centered metrics will need to clearly define what is required at site level, including programmatic and clinical considerations, necessary resources, and staff commitment.

In the two study site facilities in Tete Province, newly developed HIV client cards have a section to check boxes next to possible factors contributing to adherence problems, many of which overlap with the issues addressed by our set of people-centered metrics. While this suggests agreement that these issues are important for treatment adherence, there were differing opinions about whether this data is collected or used, underlining the importance of clear guidance for the use of the set of people-centered indicators.

Recommendations

This section first presents recommendations for OHA and implementing partners in the areas of data collection, analysis, and use based on findings from the exploratory qualitative study. This is followed by recommendations for the next phase of efforts to introduce people-centered metrics in HIV programs around the world.

To support countries to ensure efficient, timely, and accurate data collection for the indicators:

 Map the health information system to identify potential bottlenecks and clarify resource needs before designing a process to integrate the peoplecentered metrics, including for systemizing processes where indicator data is already collected in an ad hoc way. This is an important first step in ensuring that data collection processes respond to concerns about client privacy, burden on facility staff and disruptions to workflow, and the client journey in the facility.

- Develop a roadmap with standardized protocols for the data collection process that defines the appropriate people, places, and times to implement the survey tool. The roadmap should be developed inclusively with program, clinical, support, and community staff as well as client input, and it should be costed. Before beginning data collection, the full cost of implementing the roadmap and systemizing data collection in the longer term should be assessed to ensure appropriate levels of financial and human resources.
- Assess whether all six of these indicators are suitable in the particular context, or whether it would be more appropriate to introduce a subset of them. A critical factor in this determination is whether there are sufficient resources and systems available to address a PLHIV's complex challenges.

To support countries to effectively interpret and act on data to improve the quality of service provision:

 Develop and communicate a clear strategy for how the indicator data can be used to 1) inform the provider-client consultation, 2) influence the strategy and design of service delivery at the program level, and 3) inform policy and budget allocations at the population level.

For future operational research

Introducing these indicators into routine care, monitoring, and quality improvement efforts could improve care and quality of life for people living with HIV. However, more robust operational research is required to determine whether all or some of these indicators deliver impact in practice. The next phase of efforts to support this should focus on:

 Investigating the operational requirements and feasibility of integrating the indicators in different settings. This study provides insight into the acceptability, feasibility, integrability, and relevance of the indicators in a PEPFAR-supported clinical setting with a large client load. It is important to understand capacity and concerns around those four factors of metrics in different settings with



different levels of funding, capacity, client loads, etc.

- Adapting the indicator survey tool for different country contexts. In line with understanding context-specific concerns about the indicators, it would be useful to develop guidance on adapting the tool to local contexts. This would ensure that questions are clear and comprehensible to clients of all backgrounds and education levels and can be administered consistently in different care settings.
- Securing buy-in from national-level decision makers.
 This could include assessing perceptions of how the indicators and data could be integrated into national health information systems and assessing how data can be reused for population-level health services for country-level stakeholders.
- Assessing the cost-effectiveness and impact of integrating people-centered metrics. Truly understanding the utility and added value of these people-centered indicators will require 1) understanding the costs associated with integrating these indicators into routine monitoring of care in HIV programs, and 2) assessing the resources required to use these indicators to effectively respond to PLHIV needs in each country context. Over the long term, assessments of client outcomes, including adherence, will contribute to understanding the value of the metrics in driving improved quality of life for people living with HIV.

Conclusion

Measuring people-centered metrics has been a priority for HIV programs for at least two decades, but the complexity of introducing them in clinical care and unlocking resources to address them has been a challenge. The USAID-proposed people-centered HIV metrics aim to help HIV programs decide whether to monitor these determinants as part of routine clinical care. This is particularly important for country efforts to "reach last mile" and sustain progress with HIV services that are better integrated and more focused on meeting PLHIV needs.

The new set of USAID people-centered HIV metrics aim to help HIV programs systematically consider monitoring these determinants as part of routine clinical care. These indicators measure quality of life and the care experience, including physical, social, mental, and financial well-being of clients as well as their satisfaction with services. Program staff and clients in health facilities in Tete Province, Mozambique, found these indicators acceptable, feasible, and relevant as a way forward in measuring people-centered metrics in HIV programs. Based on these findings, we propose further operational research and support for countries to apply these indicators in clinical practice, including the required resources to implement them.

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Local Health System Sustainability Project

The Local Health System Sustainability Project (LHSS) under the USAID Integrated Health Systems IDIQ helps low- and middle-income countries transition to sustainable, self-financed health systems as a means to support access to universal health coverage. The project works with partner countries and local stakeholders to reduce financial barriers to care and treatment, ensure equitable access to essential health services for all people, and improve the quality of health services. Led by Abt Associates, the five-year project will build local capacity to sustain strong health system performance, supporting countries on their journey to self-reliance and prosperity.

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