



ANALYSIS

PEPFAR 2021 MER Indicator Refresh

In June 2021, PEPFAR through the Office of the U.S. Global AIDS Coordinator (S/GAC), invited input into the review of its Monitoring, Evaluation and Reporting (MER) indicators, a process to ensure that programmes planned for COP-21 implementation are aligned with management and monitoring practices. Submissions could be made around the 250 pg. Indicator Reference Guide through an online platform.

The Monitoring, Evaluation and Reporting Indicator Reference Guide was made available <https://www.state.gov/wp-content/uploads/2021/01/FY21-MER-2.5-Indicator-Reference-Guide.pdf>.

The analysis that follows is a summary of the specific inputs submitted by Positive Vibes, with contributions from The People's Matrix, Lesotho and Transbantu Association Zambia, focussing primarily on issues concerning LGBTIQ people and sex workers and, to a lesser extent, on implications for adolescent girls and young women. The submission draws on perspectives and insights from systematic engagement with communities and organisations through community-led monitoring and accountability, and from their experiences implementing PEPFAR-related programmes at community level.

The analysis is recorded in this format for distribution, for discussion, and for transparency and accountability to partners in East and Southern Africa whose lived experience informed the submission.

BACKGROUND

The United States government, through the President's Emergency Plan For AIDS Relief (PEPFAR), makes the largest contribution of any nation to address a single disease in history. Since its inception in 2003, the PEPFAR has facilitated investment of over \$85 billion in the global response to HIV and AIDS, representing advancements in testing, in treatment, in expansion of care and services, in strengthening of health systems, in recognition and prioritisation of so-called Key Populations (including sexual and gender minorities, and sex workers); it is an investment that has saved millions of lives around the world.

Annually, in countries around the world, PEPFAR consults with stakeholders to develop a Country Operational Plan. The COP is a strategic plan for programming around the U.S. government's investments in the HIV response of each country, linked to results that are, in turn, informed by data.

In 2021, The Office of Global AIDS Coordination (S/GAC) is reviewing the standard Monitoring, Evaluation and Reporting (MER) indicators to ensure that the programmes planned for COP-21 implementation are aligned with management and monitoring practices. Contributions have been invited to that process of refreshing the indicators by:

- revising an existing indicator (e.g., modify the current indicator definition to better align with programme implementation, language revisions in the indicator reference sheet, changing the reporting frequency, adding or removing disaggregates, proposing revisions to the data entry system, etc.).
- deleting an existing MER indicator (or a numerator or denominator of a MER indicator).
- adding a new MER indicator
- proposing changes in the implementation and planning attributes (IMPATT).

With reference to the *Monitoring, Evaluation and Reporting Indicator Reference Guide (v 2.5; October 2020 release)*, Positive Vibes submits the following observations and recommendations:

1. On Quality Assurance, Quality Improvement and Use of Data

- i. The MER data entry and review process is summarised and illustrated (p.18). The goal of that process is to *"ensure high quality, accurate data at every level!"*. It is understood that this section of the Reference Guide relates primarily to the Information System: data-collection, data-entry, and the DATIM electronic platform. Programmatically, however, what is the link between data-review to ensure high quality, accurate data, and the PEPFAR priority of community-led monitoring? What space does the community occupy in the MER data entry and review process to, for example, verify data (not simply through service-provider Implementing Partners)? Or to review data and interpret or confirm it? How are communities reflected as central stakeholders in the data process?
- ii. Across the MER Reference Guide, no indicators exist for Community-led Monitoring where, conceivably, they might be incorporated into Health Systems Indicators. If community-led monitoring is a priority programme in a data-centric approach to strategy, financing and measurement of impact, the absence of indicators for that programme is concerning.
- iii. Specifically, from colleagues in Lesotho whose organisation is a PEPFAR programme implementer at community-level:

"There are frequent changes on data tools that are confusing our data collectors. On the weekly meetings, EPIC is expecting significant changes which are impossible within a period of a week. We actually have a challenge with weekly meetings and the agenda attached to them."

2. On AGYW_PREV and DREAMS

Compelling evidence confirms that *"..the most vulnerable AGYW"* includes lesbian and bisexual girls and young women, and transgender male boys and young men, who are socially and physically vulnerable to violence and HIV; and to loss of education and opportunity, leading to poverty and exploitation. And, since services are seldom suitably differentiated to correspond to their identities -- queer women are all but non-existent in HIV-related programming -- they are less likely to access care, including HIV testing and treatment, intimate partner violence services, cervical cancer or STI screening and treatment.

The assumptions explicit in the logic model and the concept language for DREAMS and AGYW_PREV, however (p.36;204) are heteronormative (*'male sex partners'*) and passively cisnormative. This is one argument for more explicitly visibilising LBQ women, Trans Men and Trans women in the disaggregates for Key Populations, in general.

The AGYW_PREV guidance may stipulate *"all"*, but it does not draw sufficient consideration to, explicitly, the inclusion of young girls and women who are vulnerable to violence because they identify as queer or express their gender in ways that may be locally unconventional. Or trans men and boys who are biologically female and are implicated in the DREAMS target demographic; they should be reached with the same interventions and services but may be excluded.

PEPFAR is aiming for increasingly granular and person-centred data to expand reach, to effectively reduce vulnerability and risk, and to adjust and adapt local programming and broader strategy. Excluding parts of a population -- who fall in a gap and are left behind -- distorts the strategic information necessary to design, plan, budget and implement effectively, and to achieve programme outcomes.

3. On GEND_GBV

- i. Is it possible to modify *"gender-based violence"* to *"gender-based and/or intimate partner violence"*?

Same-sex partner violence produces similar effects and requires similar responses; it may, however, not be considered as *"gender-based"* by programmers and service providers in certain settings when it is, for example, sexual or physical violence between two male partners, or two female partners, or between a

cis-gendered man and a trans woman. "GBV" is commonly associated with women as victims of violence perpetrated by men; consequently, men who may be at risk of sexual or physical violence (or transwomen) from other men, or from women, may not be considered eligible for GBV-services. Or in some jurisdictions, sexual assault between two men may not be recognised as rape, so GBV-services are not offered, recorded, or reported. That definition within the prevailing concept of gender is too narrow.

- ii. Is it also possible to add as a Narrative Guiding Question (p.50): "*How are clients offered non-clinical care, for example, referrals for counselling? Or support to access justice, safety and security?*"

This MER Indicator set should consider more comprehensively the way gender is constructed and, with it, the way gender-based violence is considered by programmers and service-providers that may make many victims of violence ineligible for services, or subject them to trauma when they do not match a narrow definition.

4. On KP_PREV

- i. For Key Populations -- LGBTIQ people and sex workers especially -- indicators are insufficiently disaggregated to be person-centred. PEPFAR Indicators are disaggregated by biological sex (p.12) but biological sex effectively invisibilises transgender people in data and in reporting -- and consequently in planning and design for service-delivery -- when that population is distinct from cisgendered men and women; is highly vulnerable to HIV; and is likely to have treatment interruptions for reasons that are unique.

LBQ women are unreferenced throughout all 250 pages of the MER guidance. They are not a Key Population. They are not a Priority Population (p.65). They are entirely invisible and unacknowledged, and so are not catered for in differentiated services, despite evidence that suggests their HIV-prevalence is greater than the general population (eg. BTRI study, Zimbabwe, 2013).

Key Populations disaggregations for clinical indicators (p.13) should include, in order to be effectively person-centred and data-driven and : (a) Transgender men; (b) Transgender women (other indicators make explicit gender-specific distinctions, eg. MSM and FSW); (c) lesbian, queer and bisexual women and (d) male sex workers.

- ii. Additional prevention interventions for Key Populations are listed (p.54), and include referrals for STI prevention, screening, and treatment. And yet, no indicators track -- whether clients referred for STI screening, prevention and treatment actually receive services and treatment, when medication, equipment, or personnel necessary for effective treatment are commonly unavailable, out of stock, untrained or -- in the case of equipment -- broken.
- iii. The recommended Unique Identifier (p.54) is welcomed. Programmatically, were a solution developed to make this possible it would simplify de-duplication. At the same time, it would decrease the number of people who are turned away from nearby facilities that are rigidly territorial and competitive to achieve their specific targets amongst specific populations.
- iv. The policy guidance (p.55) on respect for the autonomy of clients to decline the offer of testing is clear and welcomed. In as much as the guidance enables "clients who decline testing [to] still receive other prevention services..." in practice, many services to LGBTIQ people and sex workers at primary health facilities are made conditional upon HIV-testing. Despite this guidance, many clients who present for specific services but decline HIV testing are denied further services by providers.

Such revisions to this MER Indicator set would have, at least, two specific benefits:

- The ability to provide consistent, effective, affordable treatment of STIs is a central consideration for HIV prevention in Key Populations that, largely, goes unmet. Conversely, the inability of facilities to deliver STI treatment services leads to frustration by clients, a loss of confidence in the facility, and reluctance to present for care a second time. This loses a significant entry-point for reaching Key Populations with HTS.

- Data-driven, person-centred programming must take into account the more nuanced diversity of sexual orientation and gender identity, to design programmes that effectively reach unique populations and deliver a health experience that -- because it is comprehensive and appropriate -- retains them in HIV-care and treatment. Marginalizing queer women and homogenizing transgender people contributes to an inaccurate image of the local and national pandemic in most environments.

5. On PREP_NEW

- Is it possible to add (p.74) to the Narrative questions:

At site-level/community-level, what barriers are you perceiving or encountering to PREP-uptake? (community misinformation and hesitancy? Stigma? Certain population groups are ineligible?)

What barriers exist to scaling up?

Analysis of uptake to identify gaps in knowledge and information, and in service-provision, will inform quality improvement in design and delivery.

- Two practical experiences are shared by community-level implementing partners in Lesotho, relevant to PREP tools and indicators:

"...we have a challenge with our Risk Assessment Screening Tool (RAST) that is not aligned to the national and international guidelines. It creates ambiguity and room for over-testing because it forces us to provide PrEP to medium-risk clients. In general RAST is confusing us; the recent change on risk segmentation is leading to most of the clients falling under low risk even though they may be on high risk."

"The Programme has only one PrEP nurse in Maseru, who works at a different organisation, and attends to our clients only on Fridays. This causes inconvenience, not only for our organisations, but also for the clients. Due to the newly introduced indicators (PrEP_referral and PrEP_link), we tend to neglect clients who cannot make it on Fridays and fail to engage our clinical partners to initiate new clients."

6. On CXCA_SCRN and CXCA_TST

It would be beneficial to explicitly include transgender men as a disaggregate group. Or, at a minimum, include a note in the guideline to consider that transgender men should be reached with cervical cancer screening services. Individuals may desire services -- and may even voluntarily present for services -- but are dissuaded by service-provider attitudes and reactions, or by a hostile or unreceptive facility environment. Others may be resistant or reluctant to present for cervical cancer screening services.

An indicator that specifies trans men makes necessary services more directly and explicitly available to a population that is unlikely to access them unless the environment is hospitable, receptive, and intentional.

7. On HTS_Index

- In as much as guidance has been provided for Safe and Ethical Index Testing Services (p.86), it must be recognised that for Key Populations in stigmatizing, criminalizing jurisdictions -- and where sex workers, for instance, base their livelihoods on client confidence in their discretion; where men who have sex with men are commonly in heterosexual marriages with families -- principles of consent and confidentiality cannot only be applied to protect the Index client. They must apply equally to the Contacts identified by that Index client, who cannot give their consent to having their identities, behaviours, sexual orientation; and personal details (phone number; residential vicinity; workplace; etc.) disclosed and recorded on file. Confidentiality may be extended as a professional standard, but it is impossible to obtain the consent of the contacts before their personal privacy is violated, without their knowledge, let alone their consent. The public health strategy is clear, but the ethics are not.

- ii. Are targets set for Index Testing (general targets, and specific targets for Key Populations?) in COP-21? If not, is this a change that should be clearly noted under these considerations?
- iii. For many groups -- communities, organisations, populations -- who are not public health professionals and/or where English is not the first language, the "yield" terminology (p.92) is problematic. For Key Populations, especially, groups report feeling dehumanised by it, especially when they are asked to reflect or report on their yield, or when clients hear programmers and service-providers discussing their community in that way. In common usage, "yield" is something to be collected or harvested at the end of a season, a crop, a commodity. Populations who already feel targeted and stigmatised find the language distasteful and dissuading.

These considerations may not make data collection or analysis easier. They are nonetheless necessary considerations for practice that is ethical and humane and safe, sensitive to the dignity of people who should be at the centre of services.

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