

You Get What You Measure

Why Monitoring for PrEP Choice
Helps Tell Our Story

WELCOME!

**Thursday, July 11, 2024
9 AM – 10:30 AM Eastern**

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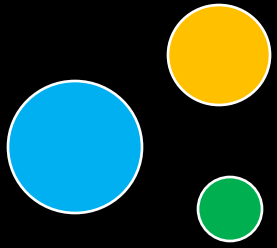
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SOUTH *TO SOUTH*
LEARNING NETWORK

The HIV Prevention Interchange

Thank you!



Today's playlist

Is There Something I Should Know

Duran Duran

Count on Me

Bruno Mars

Yamore

MoBlack, Salif Keita, Cesaria Evora

ABC

Jackson 5

You Get What You Measure: Why monitoring for PrEP choice helps us to tell our story

A PRESENTATION TO THE CHOICE AGENDA



Moderator



Adaobi Lisa Olisa

Technical Officer, FHI 360/MOSAIC, Nigeria

Adaobi Lisa Olisa serves as a technical officer and country focal point for Knowledge Management & Research Utilization and Monitoring Evaluation and Learning (MEL) on the MOSAIC project. MOSAIC (**M**aximizing **O**ptions to **A**dvance **I**nformed **C**hoice for HIV) is a five-year (2021–2026) global project funded by PEPFAR through USAID to help women prevent HIV by accelerating introduction and scale-up of new and emerging biomedical prevention products.

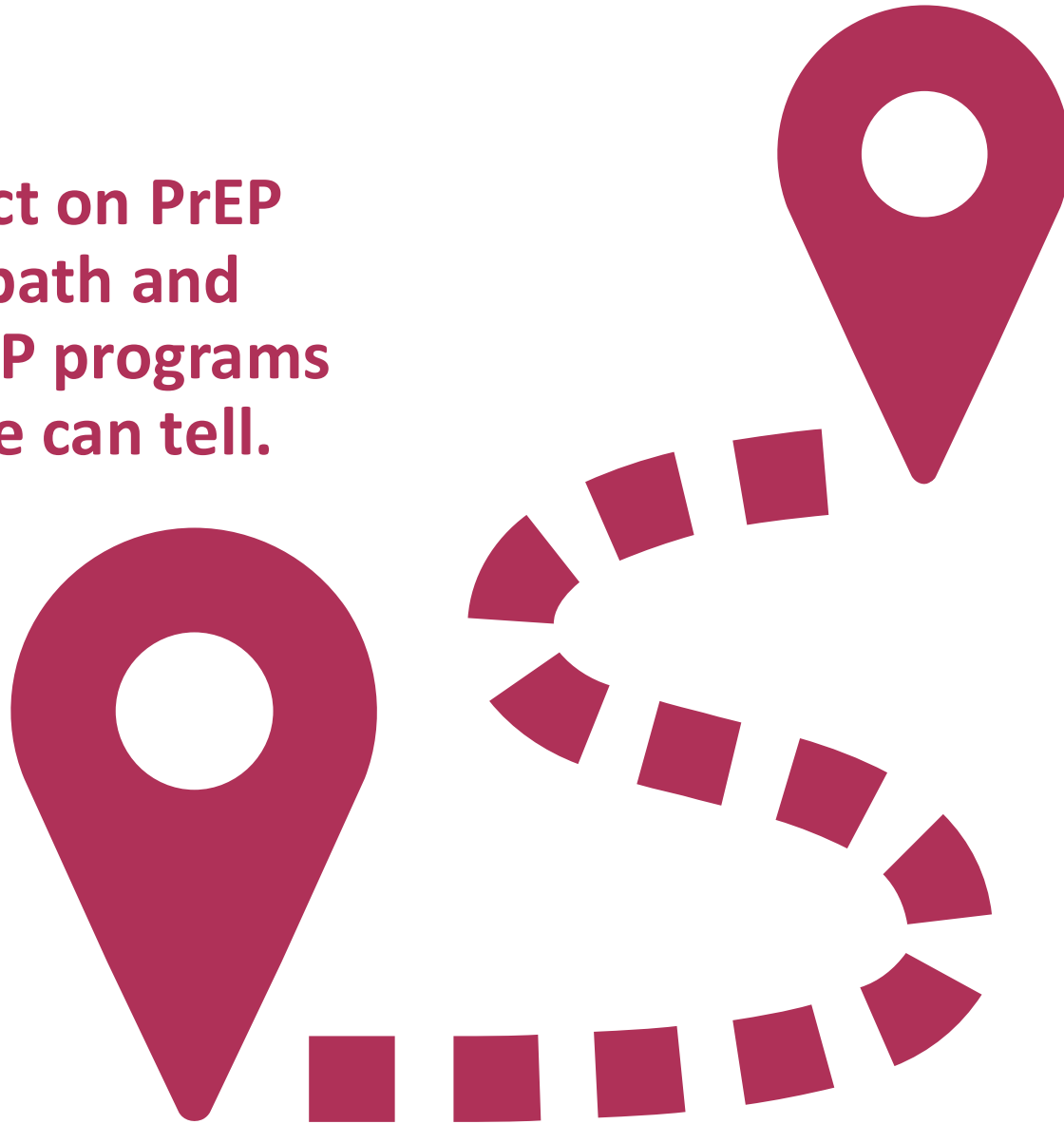
She represents Nigeria on the MOSAIC NextGen Squad—a group of youth advocates from nine African countries that support meaningful youth engagement and gender integration across MOSAIC project activities.

She is a CROI Community Educator Scholar and a fellow for the IAS Advocacy-for-HIV-Cure Academy.



Introduction

The data we collect on PrEP determines the path and priorities of our PrEP programs and the stories we can tell.



Webinar Outline

Session	Presenters
1 What do we need to monitor to understand PrEP programs?	Katharine Kripke, Avenir Health
2 <u>Panel Discussion:</u> What is the current landscape for PrEP M&E?	Omolabake Ekundayo, Ministry of Health Nigeria Dr. Herbert Kadama, Ministry of Health Uganda Ramatsoai Soothoane, Jhpiego/Lesotho
3 How can we improve M&E for PrEP? A proposal for revised PrEP Indicators	Jessica Williamson, Avenir Health
4 <u>Panel Discussion:</u> Adopting new PrEP Indicators at the country level	Omolabake Ekundayo, Ministry of Health Nigeria Dr. Herbert Kadama, Ministry of Health Uganda Ramatsoai Soothoane, Jhpiego/Lesotho

1

WHAT DO WE NEED TO MONITOR TO UNDERSTAND PREP PROGRAMS?

WHAT IF I TOLD YOU

**YOU DON'T HAVE TO
MEASURE PREP ADHERENCE**

How is PrEP M&E data used nationally and globally?

assess
progress
towards
targets



monitor
PrEP
method
choice



assess
resources
used vs.
program
outputs



project
resource
needs



estimate
coverage
of the
PrEP
program



estimate
epidemic
impact





What do we need to measure routinely to understand PrEP programs?

Magnitude of the PrEP program

- Uptake and use over time of each PrEP method
- Needs to take into account discontinuous use patterns

Characteristics of PrEP clients

- Age/sex and membership in key and other PrEP priority populations



A word about routine data collection

- Not everything we want to measure needs to be reported nationally
 - Some data needs to be collected for client management or site quality improvement but not reported up
 - For example, individual client history of PrEP use, other medications, etc.
 - Some data are best collected through research studies
 - For example, dispensing vs. use, method effectiveness, switching patterns
- Routine data collection should be **S**streamlined, **S**imple, and **I**nformative (**SSI**)

Why don't we have to measure adherence?

- People vote with their feet!
 - Adherence is directly related to PrEP effectiveness. Findings from SEARCH and many other studies indicate that oral PrEP effectiveness is high among people who take PrEP in real-world implementation (outside of studies)
- People don't need PrEP all the time (unlike ART)
 - In SEARCH, the protective effect of oral PrEP was HIGHER than reported adherence, suggesting that people taking PrEP were good at taking it WHEN they needed it
- PrEP adherence is not that bad
 - Studies have suggested that oral PrEP adherence is higher in real-world implementation than in randomized clinical trials
- We can't measure it well, anyway
 - Self-reported adherence has little to no correlation with measured drug levels



Do we have to measure continuation?

- For individual client management, yes
- In research studies, we can
- For routine monitoring and evaluation, not so much
 - If we make sure PrEP is accessible to people who want it, we can trust them to know when they need it
 - We can measure the magnitude of the PrEP program without measuring continuation (spoiler!!!)
 - It's hard to measure at a population level without national electronic medical records with unique individual identifiers (potential privacy/safety concern for members of key populations)

Streamlining National PrEP M&E

Indicator	Purpose			Source		
	Individual Client Mgmt.	Site-Level Mgmt.	National / Global M&E	Client Records	National M&E Systems	Research Studies
Magnitude of PrEP program		X	X	X	X	
Characteristics of PrEP Clients	X	X	X	X	X	
Seroconversion	X	X	X	X	X	
Adherence						X
Continuation/use patterns	X			X		X
Method Switching	X			X		X
Pregnancy Status	X			X		
STI Test Results	X			X		
Integration w/ other health services	X	X		X		

What are we currently measuring for PrEP?

Org.	Source	Indicator	Definition	Aggregation
PEPFAR	MER 2.0 (Version 2.7)	PrEP_NEW	# of individuals newly enrolled on PrEP in the reporting period	Can be added across reporting periods
		PrEP_CT	# of individuals, excluding those newly enrolled, that return for a follow-up or reinitiation visit for PrEP during the quarter	Snapshot; cannot be added across reporting periods
UNAIDS	Global AIDS Monitoring 2023	People who received PrEP	Number of people who received pre-exposure prophylaxis (PrEP) at least once during the reporting period (reporting period is one year)	Snapshot: cannot be added across reporting periods

Issues with the Current Indicators, continued

Indicator	Issues
PrEP_NEW (PEPFAR)	<ul style="list-style-type: none">(1) Doesn't measure use over time(2) Often people are counted as "new" multiple times
PrEP_CT (PEPFAR)	<ul style="list-style-type: none">(1) Difficult to collect and interpret(2) Cannot be aggregated across quarters
People who received PrEP (UNAIDS)	<ul style="list-style-type: none">(1) Difficult to track individuals over a year in absence of national EMR(2) Doesn't measure use over time

We can do better!



2

PANEL DISCUSSION: WHAT IS THE CURRENT LANDSCAPE FOR PREP M&E?

Panel Discussion:
What is the current landscape for PrEP M&E?

Panelists



Omolabake Ekundayo
Ministry of Health, Nigeria



Dr. Herbert Kadama
Ministry of Health, Uganda



Ramatsoai Soothoane
Jhpiego, Lesotho



Current Landscape of PrEP M&E in Nigeria with Omolabake Ekundayo: Ministry of Health Nigeria



How is PrEP data collected?

- Paper Based System
- Electronic System: EMR + NDR + NDARS

Key indicators that are currently being used for PrEP:

- No. of individuals who were eligible and started PrEP in the reporting month
- No. of individuals who received PrEP in the reporting month
- No. of individuals returning for PrEP who received repeat HIV testing in the reporting month
- No. of individuals who discontinued PrEP

Key challenges with PrEP M&E:

- Insufficient national data on PrEP
- Shortage / attrition of manpower
- Phasing out of paper tools

Current Landscape of PrEP M&E in Uganda with Dr. Herbert Kadama: Ministry of Health Uganda



How is PrEP data collected?

- Paper based HMIS
- Electronic-PrEP Tracker and DHIS2

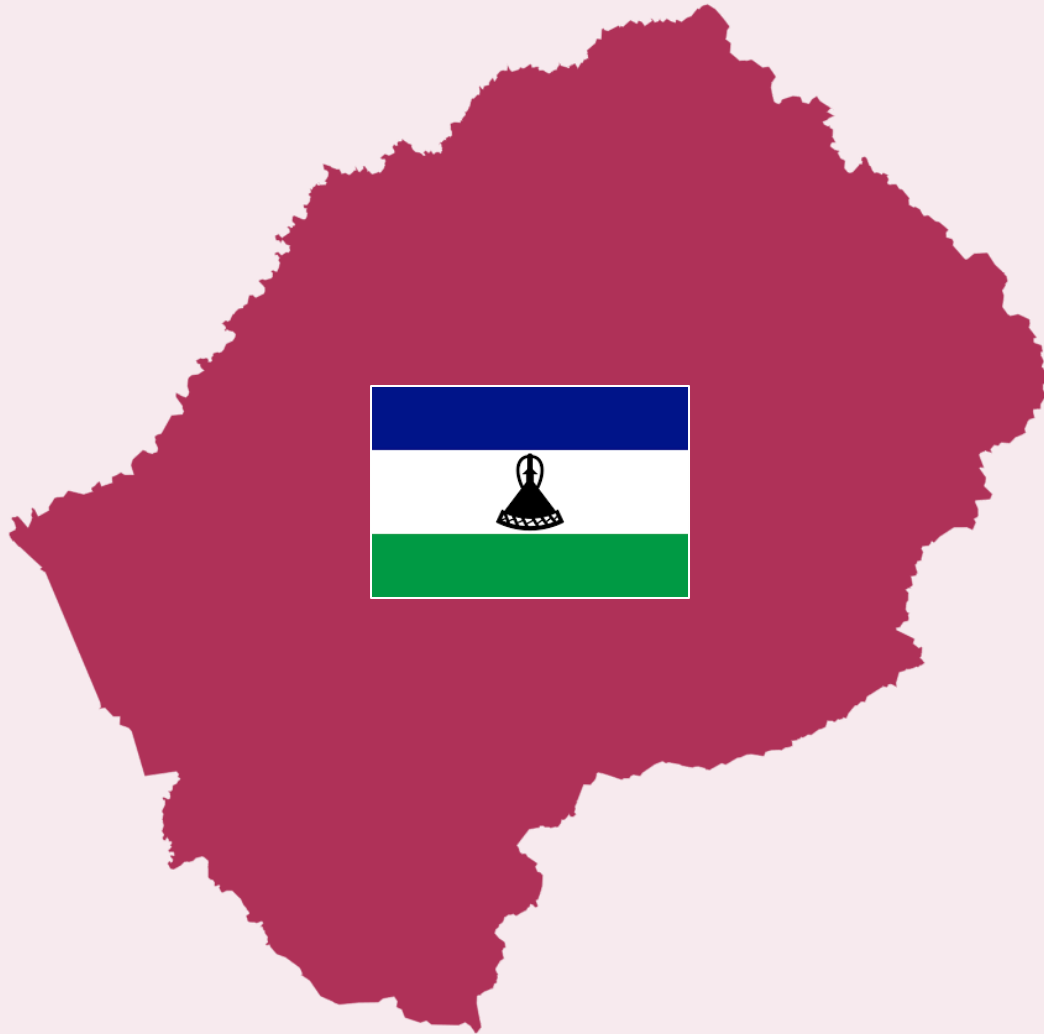
Key indicators that are currently being used for PrEP:

- Number tested HIV negative in quarter
- Number eligible for PrEP
- Number initiated on PrEP
- Number coming for PrEP refill
- Number seroconverted in quarter

Key challenges with PrEP M&E:

- Limited human resource
- Burden of collecting data in many tools and indicators

Current Landscape of PrEP M&E in Lesotho with Ramatsoai Soothoane: Jhpiego, Lesotho



How is PrEP data collected?

- Paper Based System
- Electronic Register (PrEP Module)
- Electronic PrEP Tracker

Key indicators that are currently being used for PrEP:

- PrEP_New: Number of individuals who were newly enrolled on PrEP (MOH + IPs)
- Number of individuals who re-started PrEP (MOH + IPs)
- Number of individuals who discontinued PrEP and linkage to care and treatment (MOH + IPs)
- PrEP_CT (PEPFAR)

Key challenges with PrEP M&E:

- Inconsistent documentation on PrEP data
- Unharmonized PrEP data systems
- Less usage/ analysis of PrEP data



Key Takeaways

3

HOW CAN WE IMPROVE M&E FOR PREP? A PROPOSAL FOR REVISED PREP INDICATORS

Why are we proposing a revision to PrEP indicators?

New learnings about Oral PrEP use and M&E through scale up

Expanding choice in PrEP methods

Why are we proposing a revision to PrEP indicators?

Operationalizing new WHO guidelines and proposed indicators for PrEP

Reported challenges with existing global indicators

New learnings about Oral PrEP use and M&E through scale up

These have already been covered in our earlier sessions

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Why are we
proposing a revision
to PrEP indicators?

Expanding choice in PrEP
methods

New methods of PrEP are being introduced (PrEP Ring, CAB PrEP) while even more are in development.

CHALLENGE: Introduction of these methods requires changes to M&E systems to better reflect choice

OPPORTUNITY: Necessary updates to M&E tools to include new methods represents an opportunity to do more than just disaggregate existing indicators but a chance to make larger improvements to how we collect data on PrEP

New learnings about Oral PrEP use and M&E through scale up

Expanding choice in PrEP methods

Why are we proposing a revision to PrEP indicators?

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Operationalizing New WHO guidelines and proposed indicators for PrEP

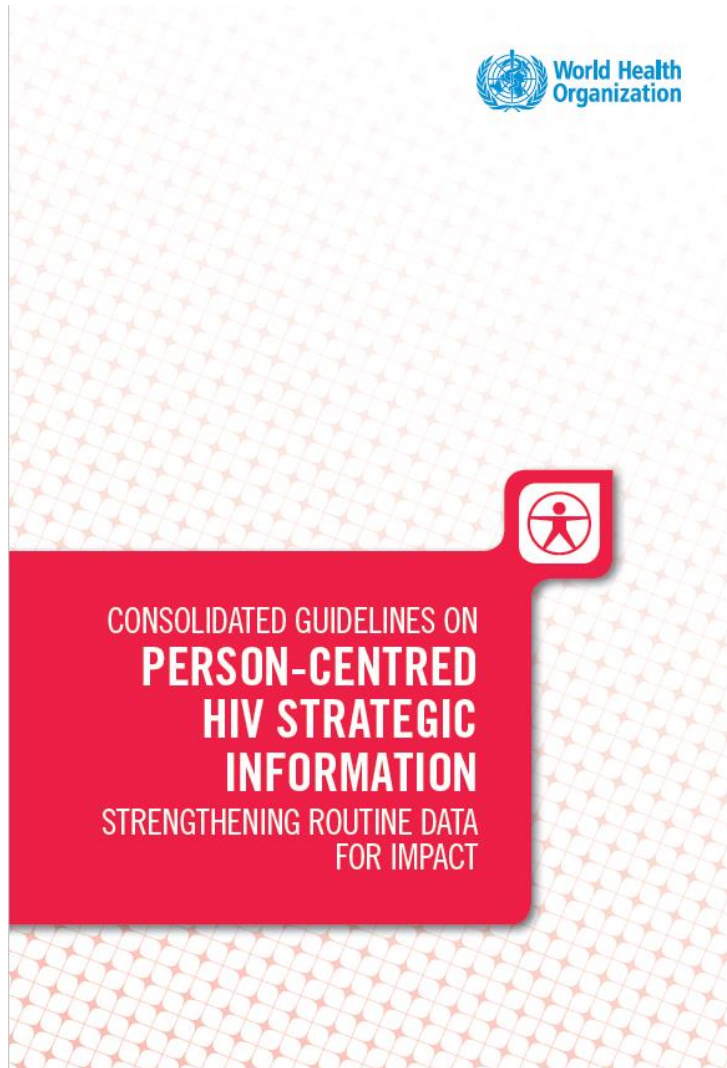
In 2022, WHO released [“Consolidated Guidelines on Person Centered HIV Strategic Information: Strengthening routine data for impact”](#)

- New guidelines and indicators for PrEP M&E
- Guidance on standard minimum data set and priority indicators partially informed by recommendations on PrEP measurement from the MOSAIC PrEP M&E Working Group

Our recommended revisions to PrEP indicators can help to operationalize the new guidelines.

What are we proposing?

What are we proposing?



A group of M&E experts and PrEP implementers from across the MOSAIC consortium developed an approach to operationalize the new WHO guidance based on learnings about the realities of PrEP data systems.

What are we proposing?

WHO's new guidelines include a recommended minimum data set along with a new core indicator for PrEP programs:

Volume of PrEP Prescribed

Table 2.2 Recommended minimum dataset for HIV prevention interventions

Intervention	Minimum dataset
HIV testing	<ul style="list-style-type: none">• HIV test sample date• type of HIV test (for example, rapid test, dual syphilis/HIV)• HIV test result
Condom programming	<ul style="list-style-type: none">• date individual was provided with condoms (where recording this information is practical and appropriate, this could include provision of condoms to people from key populations in the context of outreach)
Pre-exposure prophylaxis (PrEP)	<ul style="list-style-type: none">• date PrEP prescribed (includes initial prescription and repeats)• date PrEP dispensed (if available from dispensing pharmacy or community distribution)• PrEP product prescribed (for example, oral; long-acting formulation/device, such as dapivirine vaginal ring (DPV-VR), injectable cabotegravir (CAB-LA))• volume of PrEP product prescribed/dispensed (for example, number of pills, number of devices)• date individual attends follow-up appointment
Post-exposure prophylaxis (PEP)	<ul style="list-style-type: none">• date PEP prescribed• date individual completes PEP course (ascertained at follow-up)
Needle-syringe programmes (NSP)	<ul style="list-style-type: none">• date injecting equipment provided• number of needles-syringes provided
Opioid agonist maintenance treatment (OAMT) for opioid dependence	<ul style="list-style-type: none">• date OAMT initiated• date OAMT dose received• date OAMT take-away dose(s) dispensed• first date maintenance dose received• date of loss to follow-up or OAMT stopped
Voluntary medical male circumcision (VMMC)	<ul style="list-style-type: none">• date VMMC received• date of follow-up• date of adverse event related to VMMC reported• type of severe adverse event.

Volume of PrEP Prescribed

Definition: Total volume of each PrEP product prescribed or dispensed to PrEP clients within a period

Simply defined, limited room for misinterpretation

Use : This indicator shows the magnitude of *cumulative PrEP access over time* and can be used to forecast future commodity needs

Describes the scale of the PrEP program without requiring tracking of individuals and their patterns of use

Source: ideally available from electronic medical records, but may be sourced from facility or pharmacy records of the quantity of PrEP products prescribed or dispensed to clients.

Generally already available through HMIS or logistics systems

Proposed Disaggregations : PrEP Product, Gender, Age, Key Population, Provider Type, Setting, and Location

Unless collected through electronic medical records, volume data is generally **not** associated with client characteristics

Addressing limitations of Volume of PrEP Prescribed

Proposed Disaggregations : PrEP Product , Sex, Age, Key Population, Provider Type, Setting, and Location

PrEP CLIENT # _____ **HIV PRE-EXPOSURE PROPHYLAXIS (PrEP) CLIENT CARD**

(given at start of PrEP)

District _____ **Facility** _____ **Marital Status** Single Married

Patient Name _____ Divorced Widowed

Biological Sex: M F **Age** _____ **DOB** _____ **Phone (Whose) #1** _____

Physical Address _____ **#2** _____

Headman/Chief _____ **#3** _____

Entry point for PrEP:

- **Community (specify)**
 - Health facility outreach
 - Community program (specify) _____
- **Health facility (specify service delivery point)**
 - Adolescent corner/clinic
 - ANC/PNC
 - ART
 - OPD
 - Other (specify) _____

Population Group

- Sex Worker
- MSM
- Prisoner
- Factory worker
- General population
- Pregnant&breastfeeding
- Transgender
- Adolescent

History of PrEP

Ever been on PrEP: Yes No

Stopping PrEP

Date PrEP stopped: _____

Indication for stopping PrEP: _____

If PrEP stopped due to new HIV infection:

Date initiated on ART _____

Unique ART Number _____

PrEP Initiation

Date of most recent negative HIV test before PrEP initiation: _____

Date of PrEP Initiation: _____ Baseline creatinine: _____

CrCl: _____

Regimen _____

Indication for starting PrEP: _____

Other Details/Tests

LNMP _____

Pregnancy Test: _____

Hepatitis B Screening: _____

RPR/VDRL Screening: _____

While population disaggregations may not be reported in association with product volume data, they are collected as part of each client visit. Collecting PrEP Visits, in conjunction with Volume of PrEP Prescribed can help fill gaps.

PrEP Visits

While not explicitly included in WHO’s guidance, PrEP Visits is included within the recommended minimum dataset.

Definition : total number of client visits during which PrEP is prescribed and/or dispensed within a period

Use : While volume data measures *how much* PrEP was provided, visit data can provide information for understanding *who* is receiving PrEP. Visits data can easily aggregated and used to understand program scale-up (initiation visits) and resource utilization.

Source: Visit data is generally already collected as a fundamental part of PrEP M&E systems.

Disaggregations : visit type, PrEP method, age/sex, population, setting, and location

Table 2.2 Recommended minimum dataset for HIV prevention interventions

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Using Volume of PrEP Prescribed + PrEP Visits

With the **Volume of PrEP Prescribed** (*magnitude of the PrEP program*) and **PrEP Visits** (*characteristics of PrEP clients*) we can estimate the total number of days, months, or years of product dispensed based on the duration of HIV prevention provided by each unit of product (Person-Years of PrEP).

Person-Years of PrEP Dispensed (PYP)

by method, population, age/sex, etc

Use: PYP measures the scale of the PrEP program (overall and by method and subpopulation) and can be used to estimate the coverage and impact of a PrEP program by population, age, gender, and/or location.

Calculating *Person-Years of PrEP (PYP)*

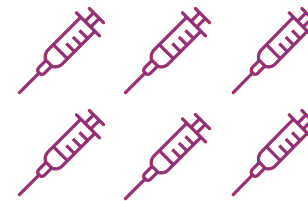
How do we calculate PYP?

- For each method (oral/ring/injectable), the total number of units is multiplied by the duration of HIV prevention provided by one unit of that method.
- Assumptions:
 - 1 bottle of oral PrEP = 1 Person-Month of PrEP = 1/12 Person-Year of PrEP
 - 1 Monthly PrEP ring = 1 Person-Month of PrEP = 1/12 Person-Year of PrEP
 - 1 CAB PrEP injection = 2 Person-Months of PrEP (after first injection) = 2/12 Person-Year of PrEP

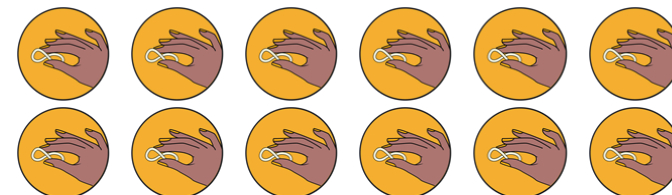
1 PYP (oral PrEP)



1 PYP (CAB PrEP)




1 PYP (Ring PrEP)



Proposing New Indicators for PrEP M&E

Based on data available from routine data collection systems, we propose that operationalizing the WHO guidance could be achieved by collecting:

 **Volume of PrEP Prescribed**
by method

PrEP Visits
by method, visit type, population, age/sex

Using these two indicators together would allow for calculation of

Person-Years of PrEP Dispensed (PYP)
by method, population, age/sex

PrEP Coverage

PrEP Impact

- Goal of these new indicators:**
- Better measure the impact, coverage, and magnitude of the PrEP program
 - Streamline and simplify PrEP reporting for national M&E in the context of method choice

How can we use the proposed indicators?

How can we use the proposed indicators?

assess
progress
towards
targets



monitor
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assess
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project
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estimate
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impact



Person-Years of PrEP Dispensed (PYP)

by method, population, age/sex

Is it feasible to collect and report on the proposed indicators?

Is it feasible to collect and report on the proposed indicators?

Hypothesis : PrEP Volume and PrEP Visits are already available in PrEP facility records and might be available in national M&E systems.

To Assess : “Retrospective Indicator Study” implemented by MOSAIC along with implementing partners in 5 countries to assess availability and demonstrate utility

Details: Data collection conducted in late 2023 and early 2024 across 13 PrEP provision sites implemented by MOSAIC partners in Kenya, Lesotho, South Africa, Uganda, and Zimbabwe.

Through the Retrospective Indicator Study, we sought to answer the following questions:

Can the proposed indicators be collected from facility records?

How do the indicators compare to existing PEPFAR PrEP Indicators?

How can the proposed indicators be used to better understand PrEP programs?

Testing New Indicators for PrEP M&E through the Retrospective Indicator Study: Preliminary Results

National PrEP data collection systems are highly variable and sometimes fragmented and burdensome for data collectors to implement.

Overall, the feasibility of collecting the proposed indicators varied by country.

2 / 5 Countries

Proposed indicators are available through national reporting systems. Indicators could be easily adopted at the national level.

1 / 5 Countries

Proposed indicators are available through facility records, but they required additional aggregation by data collectors. Adoption would require updates to data collection tools

2 / 5 Countries

There was limited availability of one or both indicators (PrEP Volume and PrEP Visits) or disaggregations. Adoption would require alternative data sources or major adaptations.

Testing New Indicators for PrEP M&E through the Retrospective Indicator Study: Additional Findings

PrEP product volume data, where available at the site level, was generally not associated with client characteristics.

The PEPFAR indicators (PrEP_CT and former PrEP_CURR) are often not collected as defined and may actually represent “PrEP Visits” in two countries.

PrEP Volume, as an indicator, was generally well-received and understood by facility staff, who saw value in its potential use.

PrEP Initiations were generally the easiest data to collect, while PrEP Refill Visits were often the most challenging given the structure of data collection tools.

Testing New Indicators for PrEP M&E through the Retrospective Indicator Study: Outcomes

In 4 of the 5 countries, we were able to use PrEP volume data to calculate PYP. We then disaggregated PYP by population using PrEP Visits (or another national PrEP indicator providing client characteristics). With the disaggregated PYP, we were able to estimate the impact of one year of PrEP provision across each of the participating sites.

Uganda: national level PrEP Volume and Visits data was already available and was provided as part of the study, allowing estimation of the national impact and coverage of the PrEP program by population.

Learn more at IAS 2024 :

Come by our posters (#618 and #638) on Tuesday from 12 – 1pm (Track E9)



What's Next?

Considerations for Ministries of Health related to new WHO Guidance

- At a minimum, we suggest that Ministries of Health consider adopting Volume of PrEP Prescribed as a new indicator in national M&E systems based on WHO updated guidelines
 - Ministries of Health may consider also adopting PrEP Visits, to provide supplemental data that may not be available related to volume data.
- We acknowledge that changing data collection systems and adding new indicators is not a simple task. Ministries are already balancing different data and reporting requirements from different organizations while also trying to limit the burden that data collection places on providers.
- As a community, we should be working towards a harmonization of indicators and a simplification of data collection in order to streamline PrEP M&E and improve the utility of the data collected.

4

PANEL DISCUSSION: ADOPTING NEW PREP INDICATORS AT THE COUNTRY LEVEL

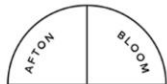


**We're on the path
to improving
PrEP M&E**



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