Sample Data Collection Tools

Introduction and user guide

# Introduction

## What are the “sample data collection tools”?

They are templates that serve as a foundation for national PrEP programs to create or adapt their own data collection tools for facility management and program monitoring. They are designed to provide the minimum required data to monitor a PrEP program and should be adapted to meet the specific needs of each country.

## Who are they for?

They are intended for national PrEP program managers in the Ministry of Health and anyone else involved in developing or updating national data collection tools and systems.

## Why were they developed?

The MOSAIC M&E Working Group convened from 2020 to 2023 with the goal of sharing best practices and simplifying and enhancing PrEP monitoring and evaluation. Our efforts aimed to improve the tracking of PrEP usage, as well as to measure the scale, impact, and resource requirements of PrEP programs. As part of this initiative, the Working Group developed [a new set of indicators](https://www.prepwatch.org/wp-content/uploads/2024/09/Strengthening_PrEP_Indicators_for_choice.pptx) that focus on measuring the cumulative duration of PrEP use:

1. Volume of PrEP Dispensed
2. PrEP Visits
3. Person-Years of PrEP Dispensed (PYP)

To facilitate the reporting of these indicators, the Working Group developed sample data collection tools illustrating how to collect the requisite data at the facility level.

The sample tools include a client register and a monthly reporting form and are intended to be used along with a client card, which is not included in the toolkit. The client card should include all the information needed for client management at the site. The client register is designed to record key visit information for all clients, aiding in site-level management. The monthly reporting form consolidates data from the client register into monthly totals of PrEP visits and volume of PrEP dispensed. These monthly totals can be aggregated across facilities for national-level reporting. Countries can adapt these tools as appropriate for use in PrEP sites. Figure 1 illustrates the flow of healthcare visit information through the client card, client register, and monthly reporting form.

A diagram of a health visitor

Description automatically generated

Figure 1. Data collection tools

# Client Register

## Format

The most notable characteristic of the sample client register is its visit-based format, where each row represents a unique patient interaction. **This is different than the ubiquitous longitudinal register**, in which each row represents a unique patient with multiple patient visits per row. One advantage of the visit-based structure is **ease of data entry**. In a longitudinal register, the user must locate the specific row containing an individual patient’s record, which is likely on a different sheet associated with their first visit or first visit of the year. If a facility sees many patients, locating a patient’s record in the register can be inconvenient and time consuming. In the visit-based structure, the user simply records visit information in the next available row. Another strength of the visit-based structure is that it **facilitates data aggregation over time**. In a longitudinal register, visits are not listed chronologically, requiring careful review of every row to identify data entries within the specified period. In the visit-based format, users can simply identify the first and final rows within the specified period and aggregate data from all rows between. Early adopters of the visit-based format include the Kenya Ministry of Health, which developed a visit-based PrEP client register in 2021-2022. This new register is in the process of being rolled out as of August 2024.

## Data Fields

The client register includes the minimum set of data fields required for facility management (Figure 2). Other data fields, such as HIV test type, creatinine testing, and STI testing, while possibly important in some settings, may not be necessary for facility management in all situations. We focused the sample client register on the minimum data requirements common across all PrEP programs.

A close-up of a visit form

Description automatically generated

Figure 2. Data fields

## Coding system

Countries may be interested in tracking different client populations, different reasons for stopping PrEP, and new PrEP methods as they become available. To support this flexibility, we’ve included a legend containing numerical codes for population, PrEP method, and reasons for stopping PrEP (Figure 3). Codes can be edited, added, or removed to fit each country’s needs.

*Notes:*

* *If a client is a member of more than one listed “population”, they should be categorized under the population with which they most closely identify.*
* *If a client receives two PrEP methods at a single visit (e.g., CAB PrEP and Oral PrEP), the data manager may choose to represent this in the register as two separate visits.*

A close-up of a screen

Description automatically generated

Figure 3. Coding system

## Client Privacy

To protect personal health information and uphold client privacy, the client register does not include personal identifiers such as names, dates of birth, phone numbers, or addresses. Instead, each client is assigned a unique ID number. While these IDs can be traced back to the client's name, generally through a client card, they provide an added layer of separation and privacy.

## Proposed Indicators

A primary motivation for these tools was to facilitate collection of PrEP Visits and Volume of PrEP Dispensed. In addition to the “PrEP Visit Categorization” and “PrEP Product and Volume” data fields, we’ve included a summary section that provides a snapshot of these indicators (Figure 4). The “Total this page” row allows users to tally the number of visits and months of PrEP recorded on the page. In the “Total this month” row, users can add “Total this page” to the cumulative total for the month. Facility managers can use the summary section to monitor progress throughout the month before data is compiled into the monthly reporting form. It is also useful for validating the monthly reporting form to ensure accurate totals.

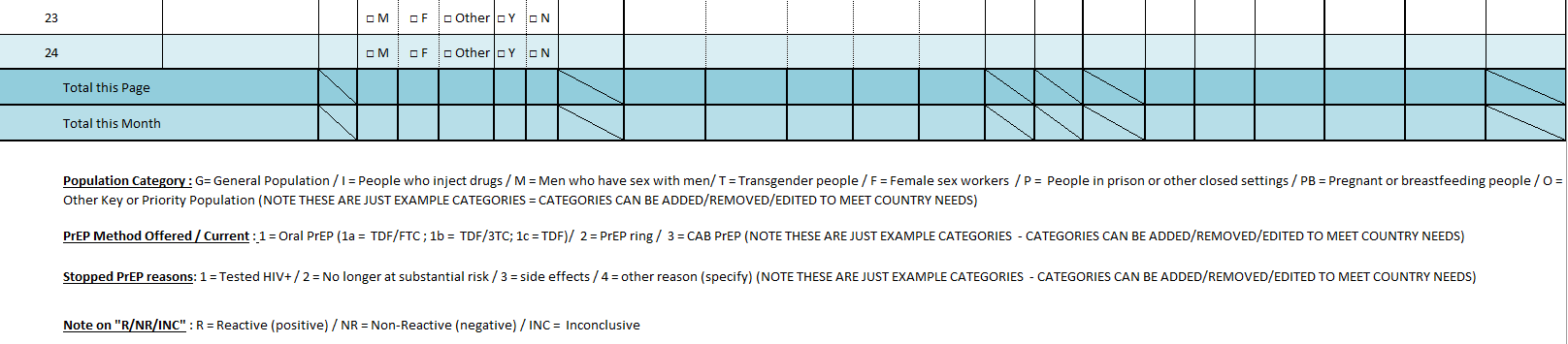


Figure 4. Summary section

# Monthly Summary Form

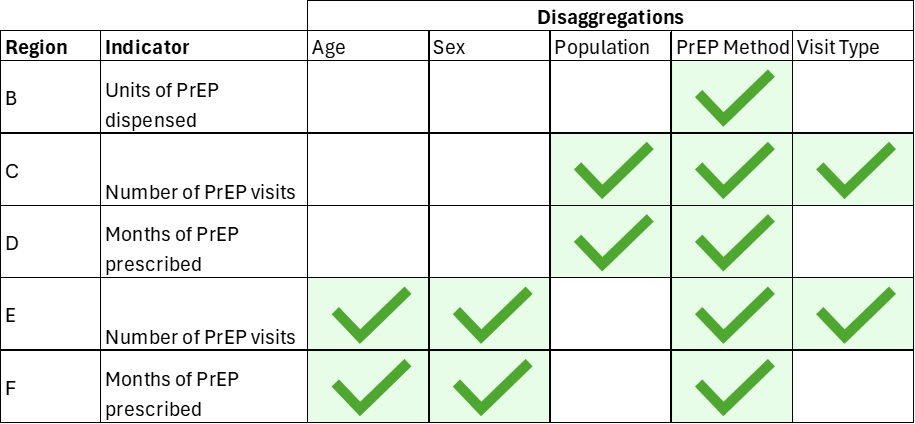
The monthly summary is designed to further consolidate client visit information for reporting up to national PrEP programs. It is focused on PrEP visits and PrEP dispensed with totals disaggregated by age and sex, population, PrEP method, and visit type. This information can be translated from the client register over a one-month period. Figure 5 indicates the seven regions of the monthly summary form:

1. Metadata.
2. Units of PrEP dispensed by PrEP method. Here, a “unit” is either a one-month supply of oral PrEP, a single ring, or a single injection.
3. Number of PrEP visits by population, PrEP method, and visit type.
4. Months of PrEP prescribed/dispensed\* by population and PrEP method (if available).
5. Number of PrEP visits by age, sex, PrEP method, and visit type.
6. Months of PrEP prescribed/dispensed by age, sex, and PrEP method (if available).
7. Validation section. These cells automatically populate based on data entered in regions C-F and indicate to the user if there is a data mismatch.

\*Some programs may have data about product dispensed associated with individual client characteristics, but many programs only have the information about amount prescribed associated with client characteristics. Space is provided to report the aggregate units dispensed and the # of months prescribed or dispensed, depending on data availability.

The differences between regions B-F are also summarized in Table 1.

Table 1. Disaggregations in the monthly summary form



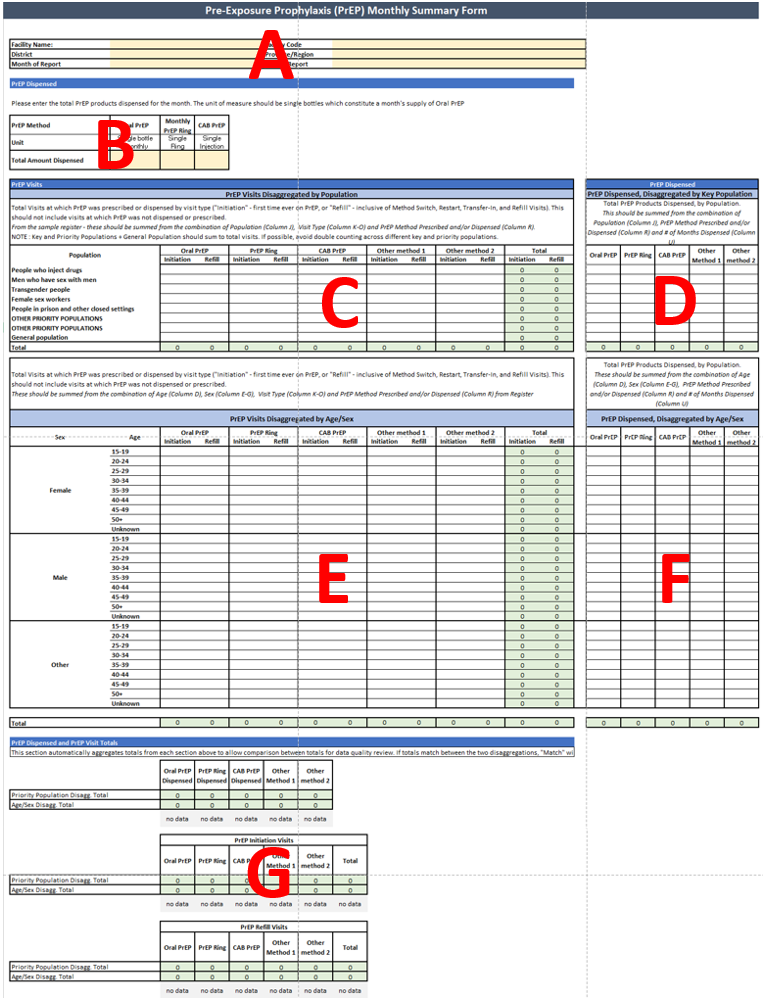


Figure 5. Regions in the monthly summary form

Translating data from the client register to the monthly summary form should be done carefully to ensure accuracy. Though users may develop an approach that suits them, we recommend trying the following if aggregating manually:

1. Locate the first page of the client register for the month.
2. For the first row in the client register, note the PrEP method and visit type. Identify the corresponding columns in regions **C-F** of the monthly summary form.
3. Note the population type in the client register. Type a “1” in the corresponding cell of region **C** in the monthly summary form.
4. Note the months of PrEP dispensed in the client register. Enter this number in the corresponding cell in region **D** of the monthly summary form.
5. Note the age and sex in the client register. Type a “1” in the corresponding cell of region **E** of the monthly summary form.
6. Enter the months of PrEP dispensed in region **F** of the monthly summary form. This number should be the same as the number entered in region **D**.
7. Proceed to the second row of the client register and repeat steps 2-6. If a value has already been entered in a cell, add the new value to the existing value. Repeat this procedure for all rows in the client register for this month.

# Summary

The sample data collection tools serve as templates for creating client registers and monthly summary forms for national PrEP programs. The visit-based format of the sample client register simplifies data collection and monthly aggregation. These tools are designed to collect PrEP Visits and Volume of PrEP Dispensed, two key indicators for assessing the scale, impact, and resource needs of PrEP programs. National PrEP program managers can customize these templates to their country’s specific needs by adding or removing data fields or codes from the sample client register.

# Glossary of terms

**PrEP Visit –** refers to a visit to health care facility or site during which PrEP is provided.

**Client ID Number** – refers to an anonymous unique identifier used to designate individual clients and relate entries in the register back to related client records. These forms intentionally avoid using client names or other identifiable details to protect client privacy.

**Initiation** – refers to a visit during which an individual who has previously never used any form of PrEP starts PrEP for first time. An individual should be categorized under “Initiation” only once ever.

**Return** – refers to a visit during which an individual who has previously received PrEP returns for PrEP/PrEP related services. This should be used to capture any non-initiation PrEP Visit. Return visits include “New Method Initiation”, “Refill”, or “Restart”. An additional category of “No PrEP Provided” is also included to allow for documentation of visits during which a PrEP client comes to the clinic but is not provided with PrEP; for example, the client seeks support with product use or side effects, tests positive for HIV, or chooses to cease using PrEP.

**New Method Initiation** – refers to a visit during which an individual who has previously received PrEP initiates a novel (to them) method of PrEP. E.g., a client was previously using oral PrEP but starts using PrEP ring for the first time.

**Refill** – refers to a visit during which a client who has previously received PrEP returns for a refill of a previously used PrEP method. This includes but is not limited to clients who have previously used PrEP and are returning for a routine refill, clients who have accessed PrEP previously but from a different facility, and clients who have switched PrEP methods and are returning to a previously used method. For the purposes of the Monthly Reporting Form, “Refill” refers to all non-initiation visits at which PrEP was provided, including “New Method Initiation”, “Refill” and “Restart”.

**Restart** – refers to a visit during which a client who has previously received PrEP returns for a refill but outside of the window of time when they were expected to return. The window of time may vary based on national protocols. Restart visits are distinguished from Refill visits as they may be associated with different protocols for client counseling, testing, and care than a refill visit.

**No PrEP Provided** – refers to a PrEP-related visit during which a client does not receive PrEP. This includes but is not limited to visits during which a client comes in between refill visits for any reason, a PrEP client returns to discuss adverse events, a client who has previously used PrEP returns for a HIV test after a potential exposure, a PrEP client tests positive for HIV and discontinues, a client chooses to discontinue PrEP for other reasons, or a client is counseled on PrEP but chooses not to initiate.

**PrEP Method Prescribed and/or Dispensed** – refers to the method or formulation of PrEP provided to the client (either prescribed or dispensed) including but not limited to Oral PrEP, CAB PrEP, and PrEP ring. The methods included here can be edited based on methods available in the country and can be updated as new methods become available.

**ED PrEP** – allows for the documentation of whether the PrEP provided was intended to be used as “Event-Driven” (ED) PrEP. This field may be omitted if not necessary for program management.

**# of Months Prescribed** – refers to the volume of PrEP product prescribed during a visit, in terms of months of coverage provided (i.e., 1 month worth of oral PrEP pills). This may differ from the volume dispensed. For ED PrEP, report the quantity as if the client is taking PrEP daily, even if they do not plan to do so.

**# of Months Dispensed** – refers to the volume of PrEP product dispensed during a visit, in terms of months of coverage provided (i.e., 1 month worth of Oral PrEP Pills). This may differ from the volume prescribed. For ED PrEP, report the quantity as if the client is taking PrEP daily, even if they do not plan to do so.

**Client Stopped PrEP** – refers to a client discontinuing PrEP for any reason, with codes used to identify the reason for discontinuation. Those reasons may be edited to include additional categories to provide required information.

**TDF** – Tenofovir Disoproxil Fumarate (PrEP drug)

**FTC** – Emtricitabine (PrEP drug)

**3TC** – Lamivudine (PrEP drug)

**CAB PrEP** – Injectable long-acting cabotegravir for HIV prevention

**PrEP ring** – Dapivirine vaginal ring for HIV prevention