PAHO Pan American Health Organization | World Health Organization Americas

TECHNICAL NOTE

Updated recommendations for determining the number of people with HIV receiving antiretroviral therapy

September 2021

1. Introduction and objective

The Consolidated HIV Strategic Information Guidelines[1] published by the World Health Organization (WHO) contain recommendations for improving the monitoring and management of HIV programs.
This technical note summarizes and adapts the recommendations contained in these guidelines to the Latin American and Caribbean context to properly determine the number of people receiving antiretroviral therapy (ART). To this end, it offers guidance on the indicators and methodology for obtaining more accurate knowledge of the number of people receiving ART.

2. People with HIV receiving antiretroviral therapy

Accurate knowledge of the number of people receiving ART makes it possible to determine the effectiveness of services and key aspects related to their planning, such as the need for medicines and other inputs.

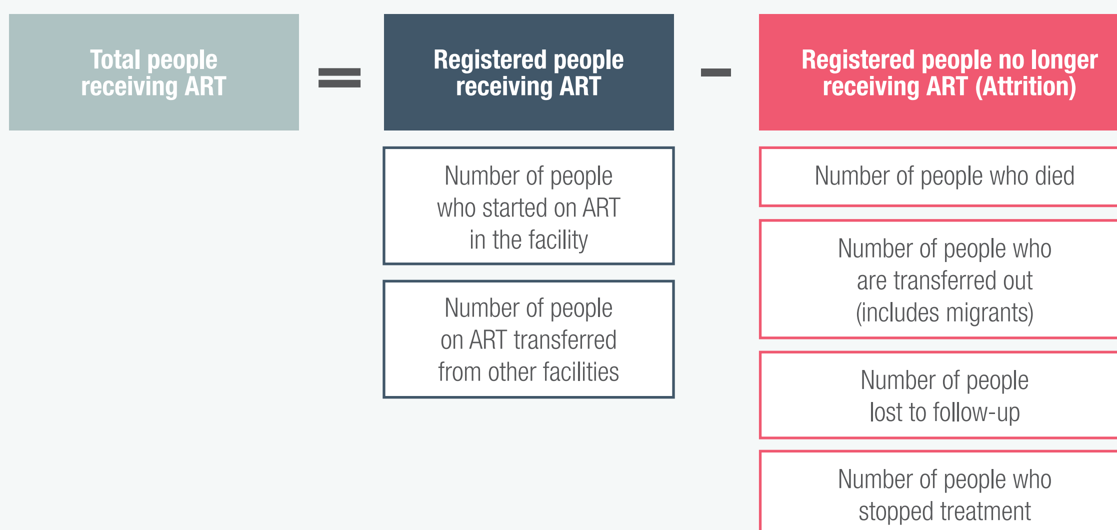
Oftentimes, National estimates of the number of people receiving ART are inaccurate. First, numbers can be underestimated when people receiving ART through other subsectors of the health system, such as correctional institutions, private health services, or social security, are not counted. Second, and more commonly, the number of people receiving ART can be overestimated if the following aspects are not considered when records are updated (**Figure 1**):

1. People on treatment who have died or migrated.
2. People transferred to another health center that are registered two or more times (duplication).
3. People lost to follow-up.

People receiving ART: The number of people receiving ART in a facility at a given time includes all people who started on ART at the facility plus patients who are transferred in, minus patients who are transferred out (including migrants), dead or lost to follow-up or who stopped ART but are still registered in the services (**Figure 1**). These numbers can be summed across facilities for a national total.

[1] WHO. Consolidated HIV strategic information guidelines. Driving impact through programme monitoring and management. Geneva: WHO; 2020. Available from: https://www.who.int/publications/i/item/9789240000735

Figure 1.
Procedure for cleaning data on the number of people in a facility receiving antiretroviral therapy (ART) at a given time



Source: Adapted from Person-Centered HIV Patient Monitoring and Case-Surveillance. Guidelines. WHO, 2017

3. Operational definitions and sources of information for calculating the number of people receiving antiretroviral therapy

Table 1 presents the operational definitions and sources of information for calculating the number of people receiving ART. The information necessary for updating that figure can be found in different information systems, though it generally comes from health facility records.

Table 1.
Operational definitions and sources of information on the main elements for calculating the number of people receiving antiretroviral therapy at a given time

	ELEMENT	OPERATIONAL DEFINITION	SOURCES OF INFORMATION AND REMARKS
A	People with HIV on ART (Indicator AV.1 of the Consolidated Guidelines)	People who started ART, and who, according to their last pick-up date, are on ART at least until their next pick-up date plus 28 days. This number includes people who were lost to follow-up but subsequently reconnected with the service and are now receiving ART.	Health service registries. The information can be supplemented with pharmacy and laboratory information, and in the case of pregnant women, records on the provision of infant formula and other supplies.
B	People who migrated or were transferred outside the analyzed area	People who left the country or area of analysis.	The number of people who migrate and thus stop visiting the health service is generally hard to obtain. Only some countries have systems for collecting that information. Verify whether the country has migration databases; in some cases, people who are planning to migrate may notify it to the health professional, thus the information may be in the patient's records.

	ELEMENT	OPERATIONAL DEFINITION	SOURCES OF INFORMATION AND REMARKS
C	Deaths	People with HIV previously on ART who are documented to have died from any cause	Information sources can include hospital records (which should collect deaths), health services (which should record people on ART who died) and civil registry death records linked to the vital statistics system. The consolidation of civil registry death records takes time; thus, this information is usually cleaned retroactively.
D	Lost to follow-up	People who have not had contact with the health facility 28 days after their last appointment to pick up their medication. **New recommendation** (other cut-off times may be chosen for greater sensitivity or specificity).	This information can be obtained from patient registries, establishing a system to identify people who are no longer in follow-up and should be excluded from the total number of patients on ART. Before considering people as "lost to follow-up," a local procedure should be implemented to rule out other reasons for their missed appointments. This includes calling people to learn about their current situation – for example, to find out whether they are incarcerated, have migrated, or have transferred to another health service. A search for these people should be conducted in other relevant databases.
E	People who have temporarily stopped treatment	People who have stopped ART but continue to receive HIV care. This should be a short-term situation, and during the care process, it should be possible to address the issues that caused the person to stop treatment and enable him/her to resume it as soon as possible.	If treatment records include this category, use that information.
F	Attrition (indicator AV.2 of the Consolidated Guidelines)	People reported on ART at the end of the last reporting period and/or newly initiating ART during the current reporting period who were not on ART at the end of the reporting period. This includes B+C+D+E.	
	People diagnosed and not on treatment (not counted as people receiving ART)	People who have been diagnosed and have not started ART. Special consideration can be given for individuals recently diagnosed to give them time (for example, 1 week to 1 month) to attend care after diagnosis and begin ART.	The information is obtained, for example, by comparing the database of reported HIV cases with that of people on ART. This element is not necessary in order to count people receiving ART. However, knowing the number of diagnosed people that have not started treatment is essential in order to put these people on treatment as soon as possible.

[1] WHO. Consolidated HIV strategic information guidelines. Driving impact through programme monitoring and management. Geneva: WHO; 2020. Available from: https://www.who.int/publications/i/item/9789240000735

All the information in **Table 1** can be consolidated in an individualized database to be able to identify people by their ART status. For this, each individual should be recorded with a unique identifier that can be created using different identifying variables, or ideally, the unique national identification code. The unique identifier permits the comparison of data originating at different times and from different sources. For example, it can be used to compare the data of patients receiving ART with those of people who have stopped taking their medication and those lost to follow-up dead or migrated. This analysis will be done with unique identifiers, but clinical care will be provided with nominal registries (for example, to facilitate the monitoring of people who have been diagnosed, as well as the search for people lost to follow-up). (**Table 1**). The records of people on ART can be cleaned through triangulation of the information from the various data sources. (Figure 1) These data cleaning processes should be conducted on a continuous and automatic way. If this is not possible, the data process should be conducted at least every six months.

Box 1.
Loss to follow-up in monitoring and program efforts to get patients back into treatment

For monitoring purposes, people lost to follow-up are those who have not had contact with the service 28 days after their last scheduled appointment to pick up their medication. However, program activities to get lost patients back into treatment should be conducted as soon as the missing appointment is detected. These efforts should be especially intense during the initial months (which is when more people will be recuperated back into treatment).

To this end, the information system can issue reminders and alerts informing the health care provider about the need to contact the patient. Furthermore, the fact that a person is considered "lost to follow-up" for monitoring purposes by no means indicates that the program should stop searching for this person to resume care. Contact should begin before the appointment to remind the patient about the date or the need to make an appointment.

For this purpose, priority can be given to creating efficient online appointment systems to facilitate patient access to their appointments and treatment.

When patients who have abandoned ART resume treatment, information can be obtained from them about why they had abandoned their treatment and care. This approach can be useful for gaining a better understanding of barriers and guaranteeing the continuity of care and treatment. Note that people lost to follow-up who resume treatment are already counted as receiving ART.

ANNEX 1.
STEPS FOR IMPLEMENTING WHO's 2020 RECOMMENDATIONS AND CLEANING THE DATA ON THE NUMBER OF PEOPLE RECEIVING ANTIRETROVIRAL THERAPY

1. Complete the table with national and facility data. Be sure that the data from all facilities add up to the total national data reported.
2. The number of people receiving ART is calculated as the sum of the people already receiving ART at the facility + people initiating ART + people on ART transferred to the facility – losses (people who have not returned 28 days after their scheduled appointment to pick up their medication) – people who have died – people who have migrated.
3. Calculations can be made for several periods. Confirm that the total reported people receiving ART equals: the sum of the people receiving ART at the beginning of the study period, those who have initiated ART, and those who have been transferred to the study area minus the total people lost to follow-up, people who have migrated, and people who have died.

	National total	Total facilities	Facility 1	Facility 2	Facility 3	Facility…
Total people receiving ART (prior to data cleaning)						
People receiving ART in the facility at the start of the study period (a)						
People on ART transferred to the facility during the year (b)						
People starting ART during the year (c)						
People lost to follow-up (28 days since the last appointment without picking up ART medication) (d)						
People who have stopped ART (e)						
People who have died (f)						
People who have migrated (g)						
ARV prophylaxis (h)* - Among HIV-exposed child - Post exposure prophylaxis (PEP)						
Diagnosed people not linked to the health facility (never began ART)**						
People receiving ART after the data review and cleaning (a)+(b)+(c)-(d)-(e)-(f)-(g)-(h)						

*Sometimes records sometimes include people receiving ARV for other reasons not considered antiretroviral therapy (for example, post-exposure prophylaxis or post delivery antiretrovirals administered to newborns). In such cases, these people should be subtracted from the calculations.
**While this value does not influence the accurate count of people receiving ART, knowing it is essential for determining whether people who have been diagnosed have problems accessing treatment.

ANNEX 2.

CLINICAL ISSUES RELATED TO GETTING PEOPLE LOST TO FOLLOW-UP BACK INTO TREATMENT

The process of cleaning databases to update the number of people receiving ART will identify people who have abandoned treatment. Swift action should be taken to reconnect these people with the services.

First, the relinking services must be activated. Relinking is more successful in the initial months after people stop treatment. Thus, these efforts should begin as quickly as possible (even before the person is classified as lost to follow-up).

Once a patient is relinked, reinitiating treatment should be a priority due to the individual and public health benefits it implies. Any barriers that delay the relinking such as requiring the person to request his turn at the facility or undergo laboratory tests, should be avoided. Normally, people can resume the treatment they were receiving before they stopped it. Their response to the re-initiation of treatment can be assessed after 8 weeks to avoid a premature shift to second- or third-line therapy. In some cases, if the person has suspended treatment many times, has advanced HIV disease, or has new comorbidities (such as tuberculosis), optimizing or changing his treatment can be considered. During treatment optimization, many countries are opting to resume treatment for people who stopped it with dolutegravir-based regimens.

Analysis of strategies for offering antiretroviral therapy

Once clean and updated data on the linkage and retention on ART is available, it is important to know which service models are offering better outcomes in terms of patient retention on ART. Services may be using a variety of strategies (multi-month dispensing of ARV, dolutegravir-based regimens, dispensing of ART in community centers). Studying the outcomes of each model of care can be very useful for making changes that improve the quality of health services for HIV treatment.

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