HIV/AIDS Programme

PARTICIPANT TRAINING MANUAL FOR THE THREE INTERLINKED PATIENT MONITORING SYSTEMS FOR HIV CARE/ART, MCH/ PMTCT, AND TB/HIV

3
INTER**L**INKED
PATIENT
MONITORING
SYSTEM

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1. Introduction to patient monitoring systems for HIV care/ART, MCH/PMTCT and TB/HIV

1.1. Learning objectives

By the end of this chapter you should be able to:
- understand the purpose of monitoring patients who are in HIV care, on ART or in MCH/PMTCT programmes;
- describe the minimum data elements of the three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT and TB/HIV, and the flow of information between them.

1.2. Purpose of patient monitoring

Patient monitoring is an important part of high quality patient care. Monitoring involves documenting all patient encounters by keeping regular and accurate records of key aspects of the care and treatment offered to patients. This makes it possible to capture the history of a patient or of a group of patients over time and across different clinical sites, and to collect data for reporting on and evaluating patient care at regular intervals.

At your health facilities, you may already be monitoring various health-care activities such as immunization, antenatal visits or the success of tuberculosis (TB) case detection and treatment activities.

This manual focuses on how clinical teams providing patients with HIV care and ART, maternal and child health (MCH) care, including PMTCT, should monitor these patients in groups, and how the team can monitor some of its own activities. It also demonstrates the linkages to the TB/HIV patient monitoring system.

In the context of facility-based care, monitoring offers three major benefits:
- It provides essential information for individual case management.
- It provides key information for managing the health facility (e.g. for ordering drugs and supplies or for making quality improvements).
- It provides information on operating and improving programmes at district, national, and international levels.

If you attended the Integrated Management of Adolescent and Adult Illness (IMAI) clinical course[1], you learned how to provide individual care to HIV patients, and to start clinical monitoring of the care provided to these patients. You learned how to follow each patient's progress through the clinical stages of HIV infection, and the sequence of key steps that lead from a confirmed HIV test to starting the original first-line regimen. In addition, you also learned something about laboratory monitoring which will help you at facilities with access to laboratory results.

If you have already taken the Integrated Management of Pregnancy and Childbirth (IMPAC)[2] course, you learned how to provide individual care to HIV-positive pregnant women and their newborns, including clinical monitoring of these patients.

In this course you will see how the patient monitoring systems within these services should be able to 'talk to each other'. You will also learn how to use the data on the HIV care/ART card, the pre-ART and ART registers, and the ANC, L&D, and HEI registers to produce reports that assist in monitoring the status of whole groups of patients under the care of the clinical team.

The TB patient monitoring tools, including the TB treatment card, and TB suspects and lab registers are covered in a separate curriculum.

In addition, chapters 10-12 of the *Participant training manual* provide instruction specifically for supervisors/managers and district/regional/national coordinators on how to:
- validate patient monitoring data and use it effectively in supportive supervision;
- aggregate cross-sectional and cohort analysis reports to be able to report up to the national level; and
- operationalize and adapt the patient monitoring system.

1 WHO/IMAI Basic clinical HIV care, ART and prevention training course.

2 WHO IMAI/IMPAC clinical training course for integrated PMTCT interventions.

1.3. Overview of the three interlinked patient monitoring systems

It is agreed that HIV-related services should be delivered across a continuum of care. This requires integrated and linked service provision at all levels of the health system. It is recommended that services for HIV should be linked or integrated with other services in the health sector, including TB, sexual and reproductive health, and maternal and newborn health services. Each of these may warrant different but related patient monitoring activities. Therefore, health services and the data collection systems and tools used to monitor patients who receive them (including HIV services) must be integrated as much as possible in order to decrease duplicated collection of data elements common to all care monitoring systems.

The generic three interlinked patient monitoring systems have been developed with the assumption that services are integrated at facility level. Integration means that HIV services are included on the same visit with ANC, labour and delivery, postpartum and newborn and TB services. However, the illustrative tools and minimum data sets are useful in any setting, even when services are only partially integrated or not integrated at all.

For example, there are facilities that refer co-infected TB patients to the HIV clinic immediately after an HIV diagnosis; ANC sites which will do only testing, clinical and immunological staging, and then refer the patient for ART; or ANC sites which will do only testing, then refer the patient for staging and ART to the HIV clinic. At these sites, the interlinked patient monitoring systems help to track patients as they use services from different points of care. For instance, an HIV-positive patient who is enrolled in HIV care may also be receiving TB treatment from the TB clinic, or a woman may be receiving both TB and MCH/PMTCT services.

The extent to which a country uses the three interlinked patient monitoring systems depends on which care scenario(s) is/are currently in place and/or being planned. It is possible to use the three interlinked patient monitoring systems' minimum data sets in a modular fashion until a fully integrated model of care is feasible. Certain adaptations of the generic three interlinked patient monitoring tools may be more relevant in settings without full integration of HIV services. See the *Patient monitoring adaptation guide* that provides the technical basis for essential and possible adaptations.

The standardized tools of the three interlinked monitoring systems for patients in HIV care, on ART, in MCH/PMTCT programmes or in TB/HIV care fall roughly into three categories:

1. **Patient hand-held cards:**

Patient-hand held cards help the transfer of critical patient-related information across service delivery points in the same facility or other facilities. For instance, the maternal card facilitates transfer of information from the ANC clinic to the delivery ward, and back to the outpatient postnatal service delivery point. In many settings, there are many more ANC facilities (including outreach sites) than there are delivery facilities. This often results in a pregnant woman delivering in a different facility from where she obtained her ANC services. Given the fast-paced nature of delivery services, the woman's patient-held card helps assure the continuity of care not possible through other means, e.g. it would take too long to call the ANC facility to trace the woman's records.

Similarly, patient-held HIV, TB, or child cards (the latter is often known as the 'road to health' card or passport), or any other patient-held card (such as a global health passport) that exist in the local context all help to assure continuity of care across service delivery points. They facilitate the transfer of key data elements such as the patient's ART or TB treatment regimens, history of any complications and other unique identifiers. Their use should be encouraged across all types of services. For example, all staff at service delivery points should encourage patients to bring their patient-held cards to all visits. They should also ask to see the cards each time. This approach should apply to specialized clinics such as TB or HIV services, as well as to all other service delivery points.

2. **Facility registers/records and appointment books**

There is no guarantee that patients will carry their patient-held cards/records with them when they seek care. Therefore, data about patients and their care need to be retained at facilities, as well as being entered into the appropriate patient-held record. This is especially important since it is likely that a patient will seek care at the same facility over time. In chronic care, such as HIV care (including ART), this is achieved by using a facility-held patient card and various registers. The facility-held patient card is the foundation for the entire patient monitoring system. It includes all data elements about the patient's care. Some elements will be entered at every visit, some will be filled in at the first visit only, and/or updated as needed. Meanwhile, the patient-held card for any particular type of care should be standardized across service delivery points.

Longitudinal registers are registers that filter 'up' a portion of information per patient to facilitate tracking key data elements. To provide a better basis for improved chronic care, these registers are designed so that a patient is entered only once and the key variables are filled in as they occur over time. The registers facilitate tracking an individual patient across time, but also make it possible to analyse groups of patients at a glace, as well as to calculate key programmatic indicators. For example, in the case of HIV care, the pre-ART register becomes the facility's list of all patients ever entered in HIV care there (including transfer-ins). It also includes 'outcome' variables that allow you to know how the patient moved on from HIV care (either into ART, died or was lost to follow-up (LTF). In a longitudinal ANC register, each pregnancy and all key data elements associated with that pregnancy are tracked in one row per patient. If staff include HIV care elements (i.e. testing, ART eligibility assessment, the HIV care enrolment date and a unique identifying number) in a longitudinal ANC register, this will help with continuity of care across all services.

3. **Report forms**

Report forms regularly capture aggregate patient monitoring data. Agreed indicators are summarized and their values are used to take action on a regular basis. Most indicators captured on summary report forms are cross-sectional in nature; they capture a snapshot of a particular programme aspect at one point in time. The indicators included in the quarterly report form are relevant examples.

Because of their timing, some indicators are considered cohort indicators. This includes elements such as if a patient is alive12 months after initiation of ART, and all other outcomes at important, standardized intervals included on the ART cohort analysis form. In TB cases, outcomes are reported quarterly on the cohort of patients registered in the quarter that ended 12 months previously.

The calculation of indicators is often cross sectional, but it is usually most meaningful to track changes in indicator values (those that are both locally and nationally useful) across time. This can be assisted by a data-use template that includes samples tables and/or graphs.

Figures 1.1-1.3 on the following pages show the flow of patients and data from individual medical records to registers and reports.

Figure 1.1.Overview of data flow from the HIV care/ART patient card to the two registers, to the two reports

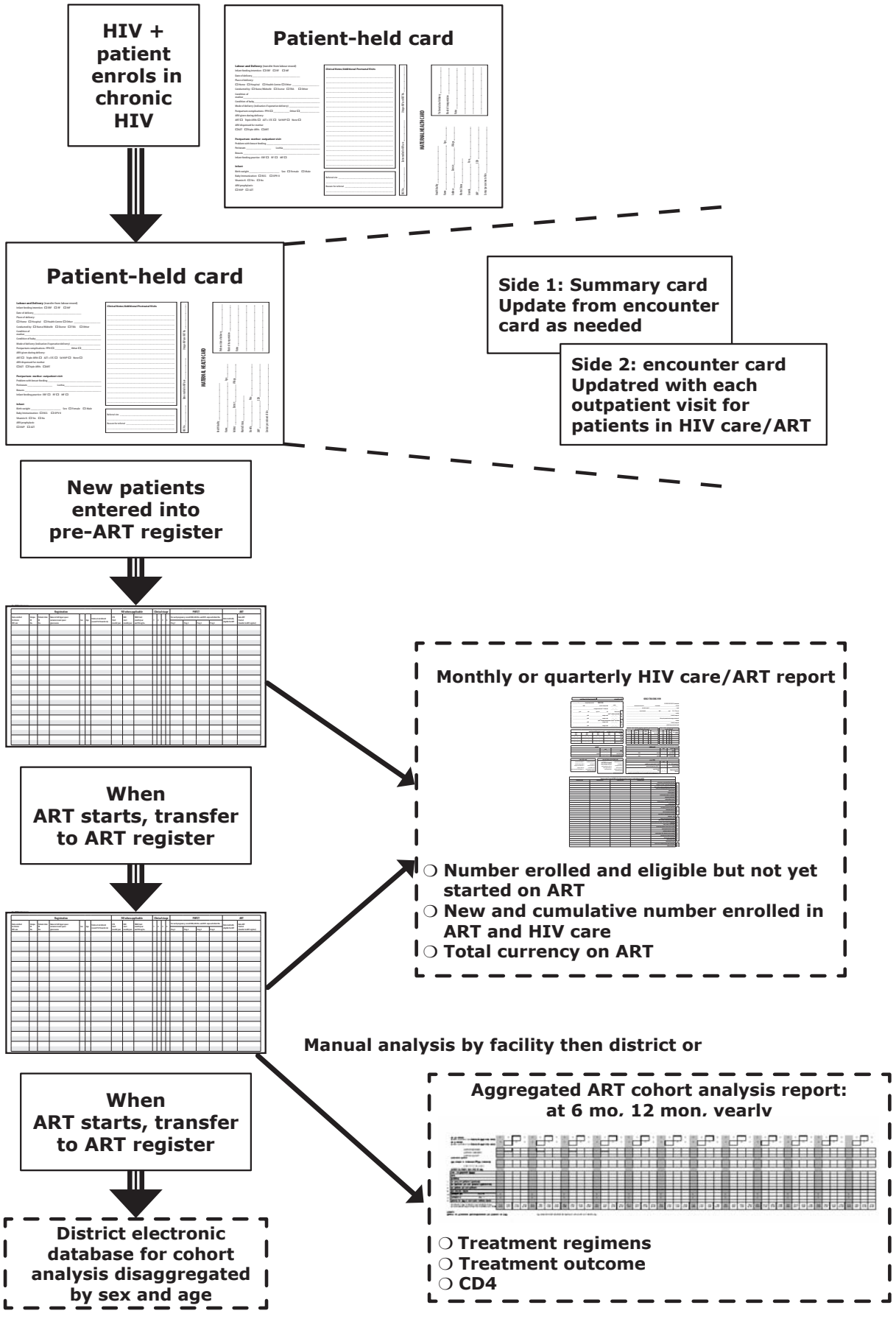
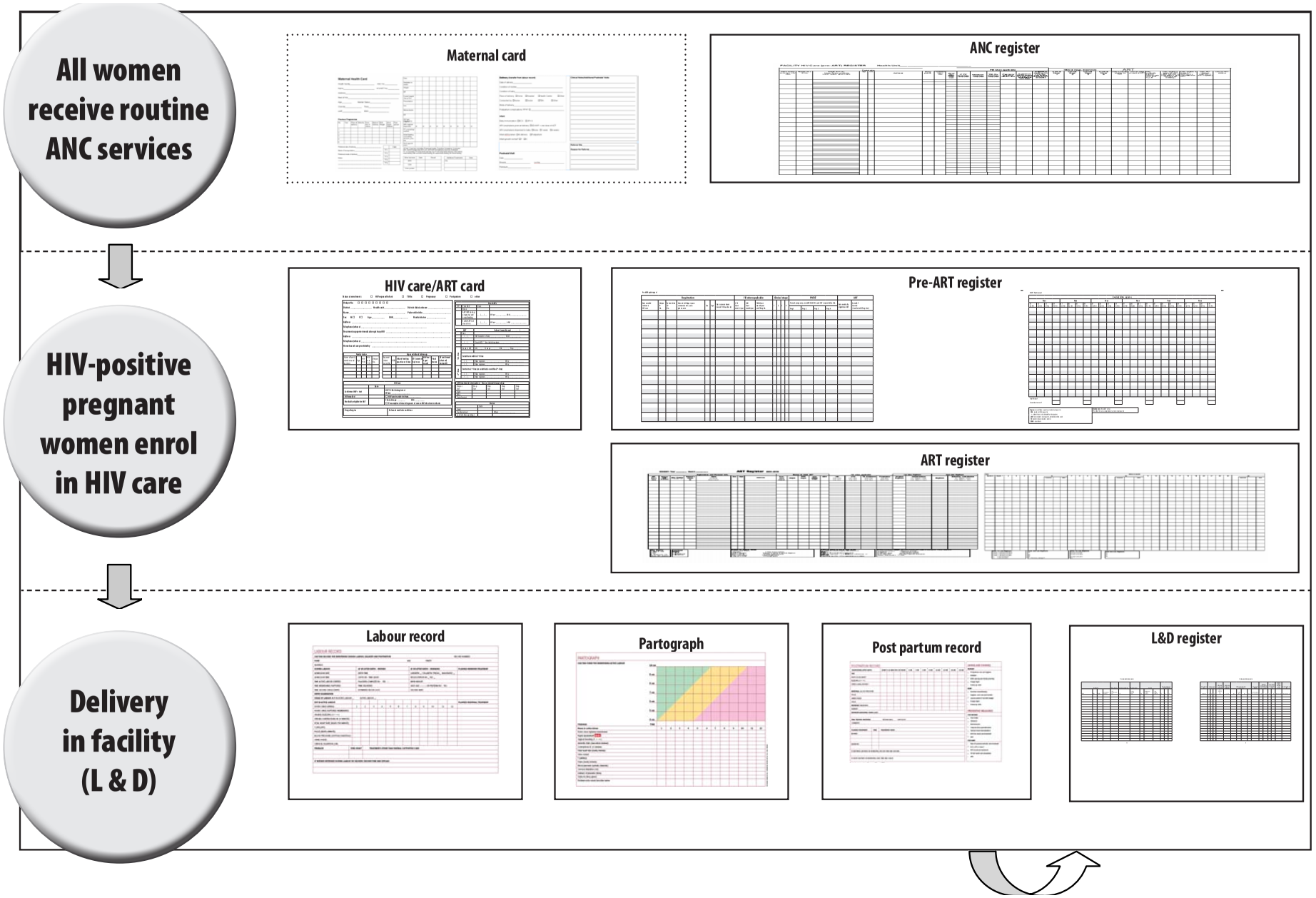


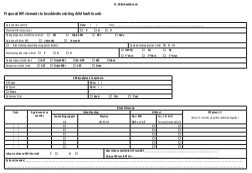
Figure 1.2. Flow of data in interlinked MCH/ PMTCT and HIV care/ART patient monitoring systems



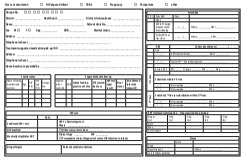
Postpartum/ Infant follow-up

Exposed infant receives own HIV care/ART card and also followed in mother's HIV care/ART card. Mother's pre-ART/ART register entries linked to infant follow-up in HIV-exposed infant register

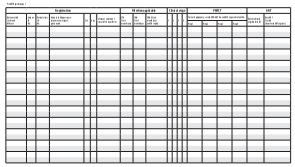
Child health card

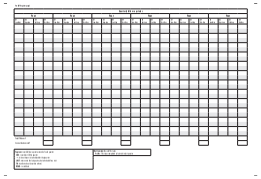


HIV care/ART card



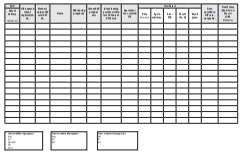
Pre-ART register





ART register

HIV-exposed infant register



Legend:

..... = patient-held

——— = facility-held

Fig.1.3. Flow of data in the TB/HIV patient monitoring system

For TB suspect recording and investigation

1 TB suspect register

HIV status. Smear examination result. Outcome of investigations

2 TB laboratory register

Sputum smear examination
TNB

For confirmed TB patient registration and treatment monitoring

1 TB treatment card

Side 1: Patient clinical details and intensive tx phase monitoring, HIV testing, CPT ART start date
Side 2: Continuation phase monitor comments, HIV care and final treatment outcome data.

2 BMU TB register

Patient details, TB type, smear results.TB treatment outcomes. HIV status , CPT, ART administration

For quarterly cohort monitoring and evaluation

1 Quarterly report on TB case registration

New/retreatment TB category
HIV testing and HIV status.
New cases by age groups
TB suspects examined/positive.

2 Quarterly report on TB treatment outcomes and TB/HIV activities

Cohort analysis of treatment outcomes by type of case.
TB HIV activities: HIV-positive patients on CPT, on ART

Informs quarterly order forms for:

- Laboratory supplies .
- TB drugs

Reports aggregated at regional/provincial and national level

This training manual will teach you how to fill out and use the following basic generic monitoring tools:

For HIV care/ART:
i. HIV care/ART card
ii. pre-ART register
iii. ART register
iv. cross-sectional quarterly report
v. cohort analysis report.

For MCH/PMTCT:
i. maternal health card
ii. child health card
iii. labour record/partograph and postpartum record
iv. ANC register
v. L & D register
vi. HIV-exposed infant register.

See TB recording and reporting training materials for an in-depth description of how to use these tools.

Notes

2. The HIV care/ART patient card

2.1. Learning objectives

For the HIV care/ART patient card, by the end of this chapter you should be able to:
- understand how it is used
- understand its structure
- fill out each item on it.

2.2. Use of the HIV care/ART patient card

Effective chronic HIV care including ART requires keeping track of what has happened with the patient on previous visits. In order to know what to do during the current visit, any member of the clinical team who sees the patient needs to know key clinical details, and the education and support given to the patient on the previous visits. In this chapter, you will learn to use a patient card that stays in the clinic and is used at each patient visit. This card is called the HIV care/ART patient card. It is designed to be used from the time the HIV-positive patient registers for chronic HIV care. **It is not only for ART.**

The patient may also have a health passport or exercise book in which more detailed information on treatment of acute problems can be written. Or your clinic may also keep a chart that includes both the HIV care/ART patient card and additional pages for acute care visits.

An advantage of the HIV care/ART card is that it stores in one place a summary of the patient's chronic HIV care and ART. It helps the clinical team keep track of each individual patient and all patients receiving chronic HIV care. This becomes important as the number of these patients increases.

A general principle of good chronic care:
Use written information - registers, treatment plans and treatment cards - to document, monitor and remind.

2.3. The structure of the HIV care/ART patient card

Your facilitator will give you copies of the card to use during exercises.

The card is divided into three different parts:
- The summary (or «face») page, includes the address, sex, other family members, the summary of the patient's ART history, etc.
- The encounter pages on which one row is filled out at each patient visit.
- On the back of the encounter pages is a summary of the education and counselling the patient has received.

There are different versions of this card in different countries, but regardless of how the card is formatted or arranged, the explanations in this manual still apply.

2.4. Filling out the items of the HIV care/ART patient card

When an HIV-positive patient decides he or she wishes to have ongoing care at your clinic, fill out a card for the new patient. This is called enrolling in chronic HIV care. This does not happen automatically when the patient receives a positive HIV test result. Patients need to understand what is involved in HIV care and they must want to be cared for on an ongoing basis (with follow-up appointments). This is the first step in forming a partnership with the patient. Some patients will need to think about this for a while. Or, if they are not yet symptomatic they may want to come back later to enrol in regular care.

The card on the following page illustrates the information that needs to be filled out on the first visit. On that visit, you will also fill out the first row on the encounter page.

Other information on the card will be added by other health workers and the dispenser at the health facility on subsequent visits. Note that you need to check the written documentation of the HIV test before filling in the results. If the patient provides only verbal results, he or she will need to have another rapid test performed at your facility.

Numbers on the sample HIV care/ART card correspond to the following explanations. Look at these pages when filling out the card.

1 → HIV care/ART card

2 → **Status at enrolment:** ☐ HIV exposed Infant ☐ TB Rx ☐ Pregnancy ☐ Postpartum ☐ other

11 → Prior ARVs

Unique No. ☐☐☐☐☐☐☐☐☐☐ 3

District _____ 4 **Health unit** _____ 5 **District clinician/team** _____

Name _____ 6 **Patient clinic No.** _____

Sex M ☐ F ☐ **Age** _____ **DOB** _____ **Marital status** _____

Address _____

Telephone (whose) _____

Treatment supporter/medication pick-up if ill _____ 7

Address _____

Telephone (whose) _____

Home based care provided by _____

8 → **Family status**

Name of family members and partners	Age	HIV P/N	HIV care Y/N	Unique No.

9 → **Exposed infant follow-up**

Exposed Infant Name/No.	DOB	Infant feeding practice at 3 mos.	CTX started by 2 mos.	HIV test type/ result	Final status	(If confirm +) Unique ID

HIV care		
	Date	
Confirmed HIV + test		**HIV 1 2 Ab/virologic test** **Where** _____
HIV enrolled		☐ **HIV care transfer in from**_____
Medically eligible for ART		**Clinical stage** _____ **CD4** _____ ☐ **Presumptive clinical diagnosis of severe HIV infection in infants**

Drug allergies	**Relevant medical conditions**

Prior ARVs			
Y(P)	Prior ARV	Date	
	None		
	ARV/ART during pregnancy and breast feeding	_ _/_ _/_ _	Where _____ARVs _____
	Earlier ARV not transfer in	_ _/_ _/_ _	Where _____ ARVs _____

12 → **ART** **Cohort (month/year)** _____/_____

	Date	
	_/_/_	ART transfer in from_____ ARVs _____
	_/_/_	Start ART 1st -line initital regimen _____
1st - line	At start ART	Wt _____ Cl.stage _____ CD4 _____ Preg _____
	Substitute within 1st t-line	
	_/_/_	New regimen _____ Why _____
	_/_/_	New regimen _____ Why _____
2nd -line	**Switch to 2nd-line (or substitution within 2nd-line)**	
	_/_/_	New regimen _____ Why _____
	_/_/_	New regimen _____ Why _____

13 → **ART treatment interruption - Stop or missed drug pick-up**

Stop or Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost
Date				
Why				
Date if restart				

Status		
	Date	
Dead		
Transferd out		Where _____
Lost to follow-up (drop)		

Summary Page - FILLED IN AT THE INITIAL VISIT, UPDATE AS NEEDED.

1. **Fill in the number of the HIV care/ART patient card.** If this is the patient's initial visit, this is their first HIV care/ART card, therefore you fill in a '1'. Once all of the encounter lines of the first card are full, if the national guidelines recommend starting a new card, you would fill in a '2' on the second card, and so on. A protocol should be in place for what is done when the encounter page is full. Depending on resources available, the options may be to attach a photocopy of the encounter page to the first card, or to attach a full second card.

2. **Status at enrolment.** Tick the appropriate box for the patient's status at enrolment in HIV care, including whether the patient is pregnant or postpartum, on TB treatment and/or have an HIV-exposed infant. This will allow important linkages between services (e.g. ANC/MCH, TB, etc.) to be identified. Listing the patient's HIV-exposed infant on this card keeps the mother and child's records together on the same standard card.

3. **Write the HIV care or ART unique number.** This number will be assigned according to the system chosen by your national programme. Patients may be issued a unique number when they enrol in care, or they may not receive one until they start ART. Alternatively, patients may be issued a unique HIV care number when they enrol in care, and then another number when they start ART. Either way, the unique number for every patient in HIV care and on ART allows the national HIV care and ART programme to identify and track patients as they move through different facilities. The number also prevents duplication of patient counts. Therefore, a transferring patient will keep this number wherever they go. The unique number also allows HIV care and treatment-related patient information to be accessed, and if possible, linked to other medical information at a higher level so the patient's record can be used as part of wider analyses at the district or country level.

   The patient clinic number field is for other patient ID numbers that an individual may have if they receive other services at your facility.

4. **Write the name of your district and health unit.** For example, Central District, Hilltop Health Centre (H.C.).

5. **Write the name of the district physician or team assigned to oversee the care of the patient.** Circle either 'District clinician' or 'team'. For example, if Jessica Elder is assigned to the clinical team which includes Dr Tambo, you would circle 'team' and write in 'Dr Tambo'.

6. **Write the patient's name, sex, age, date of birth (DOB), marital status, address and telephone number.** Fill in the patient's complete name according to national guidelines which should specify the format for the name, e.g. last name, first name, middle name.

   If the patient knows his or her date of birth, fill this in using the format dd/mm/yy in the DOB field. If they only know their age, derive the birth year by subtracting that age from the current year and use 15 July ('15/07') for the default day and month. If the patient gives you only the month and year, use '15' as the default day.

   Write in their marital status (the choices for this should be defined in your national guidelines). These are usually single, separated/divorced, widowed or married.

   Ask for and fill in as many available details of the patient's physical address as they are able to provide. This may include geographic landmarks or intersections such as 'next to big tree'. To facilitate future tracking, it may be helpful for the patient to draw a basic map of where they live if the address is not clear.

   Ask the patient if there is a telephone number where he or she can be reached. Record this number and in parentheses after it, note whose telephone number it is. For example, if a patient named Anna Abouya has her own cell phone number, write the number and 'self/Anna' in parentheses.

7. **Record the treatment supporter/medicines pick-up information. Explain and ask:** *This information will be very important to continue your care. If you are sick, or for any reason cannot come to the clinic, who could let us know and, if necessary, come to pick up your medication? What is his or her address? Do you or your treatment supporter have access to a telephone or a mobile phone? If so, what is the number?* Record the responses on the card. Fill in as many details about the treatment supporter as possible. Write the person's name and relationship to the patient in parentheses after it. Write out the address, even if it is the same as the patient's, as this information may change and need to be updated.

   Some patients may tell you that if necessary the person who will pick up their medications is their treatment supporter. Or a treatment supporter may be listed on their ID card or in the records. The treatment supporter is someone who lives with or near the patient and helps them with their treatment. (During preparations for antiretroviral therapy (ART), a health worker may help the patient choose the treatment supporter.)

   If the patient has named the treatment supporter as the person who could pick up medications, then circle 'Treatment supporter' on the HIV care/ART card.

   If the patient is receiving home-based care, fill in the name of the organization providing this care, and any contact or identifying information about the organization.

   If your patient is lost to follow-up, this information will become very important to help find them.

8. **Fill in the name, age, HIV status, enrolled in HIV care and unique HIV number (No.) for family members and partners also in care.** Family-based care requires keeping track of the whole family – the patient, their children and partner(s). In this box, there is room for the names and ages of the patient's partner(s) and children and the unique HIV number (if applicable). This way, the entire family can be linked together.

9. **HIV-exposed infant box.** On the mother's card, the boxes are filled in for each infant born to her. On the exposed infant's card, the boxes provide a summary of information that should also be recorded in the appropriate columns on the encounter page.
   - Fill in the name of the exposed infant, and, if available, an HIV-exposed infant number (this is not the unique ID number that will be assigned when the infant is confirmed HIV-positive).
   - Fill in the infant's date of birth.
   - Fill in the infant feeding practise at three months as 'exclusive breastfeeding'; 'replacement feeding'; 'mixed feeding' (MF).
   - Tick if the infant was started on cotrimoxazole by two months of age.
   - Record the HIV test type and results as AB (antibody) or HIV virologic test/ 'positive' or 'negative'.
   - Write in the final status of the infant at 18 months of age, if not sooner if they are dead or HIV-positive. Use the following codes for the infant's final status :DEAD if dead (write in the date of death if known); 'P' if positive (record the infant's unique number in the family box once it is assigned); 'N' if negative and no longer breastfeeding; 'N/BF' if negative and still breast feeding; or 'U' if the infant's status is unknown.
   - If the infant is confirmed as being HIV-positive, assign and record his/her unique HIV ID Number.

10. **HIV care.** Enter the date and location of the HIV test in this section. Also, circle if HIV is confirmed and whether it is HIV 1 or HIV 2. If the patient is less than 18 months, circle whether the test was an antibody test (the rapid HIV test) or a virologic test. See chapter 15 of IMAI's *Chronic HIV care with ART and prevention* for an explanation of this aspect.

    Enter the **date the patient enrolled in HIV care.** This is the date the patient first enrols in HIV care at your facility. It applies to both new and transfer-in patients. Tick if the patient is a transfer-in and specify the location they came from.

The date the patient becomes **medically eligible for ART** should be filled in. One reason for the patient's eligibility should be ticked. It is assumed that every patient has a clinical stage. If the patient is assessed for eligibility using only the clinical stage, check and record it. If in addition, a CD4 count was used to assess their eligibility, select CD4 and fill in the test result on the line provided.

For infants, tick the appropriate box if the medical eligibility criteria is a presumptive clinical diagnosis of severe HIV infection.

11. **Tick the box of the appropriate prior ARV category.** It is important to note whether the patient has prior experience with antiretroviral drugs when they first enter into HIV care. This knowledge will influence how staff should approach a patient who comes for the first time; i.e. whether to refer them as described in chapter 8 of *Chronic HIV care with ART and prevention.*

    In this section, record whether the patient has prior antiretroviral drug (ARV) experience by ticking one of the following boxes:
    None. Check this if the patient has no prior ARV experience (this includes post-exposure prophylaxis (PEP).

    ARV/ART during pregnancy and breast feeding. Check this for women who took or are on ARV prophylaxis in pregnancy, or for an infant born to women who took ARV prophylaxis or ART during pregnancy, labour or breast feeding. Record the start date of ARV prophylaxis, the location where it was administered and the drugs used. ARV prophylaxis drugs dispensed for an HIV-exposed infant should be recorded in the ARV drug column in the encounter page.

    Earlier ARVs, but not a transfer-in. Check this if the patient has taken ARVs for treatment before, but is not a '*Transfer-in' with records*, i.e. the patient bought ARVs on his/her own.

    If the patient has prior ART experience and transfers in to your health centre with records that indicate the regimen they were/are on (i.e. the patient has moved into this district with their records from another district), record this under the ART care section (section 12).

12. **Fill in the ART therapy sequential summary box.** The health worker will need to fill out the part of the right side of the card which includes the date for each step or change in the very important sequence: '**Start ART** first-line initial regimen' ⇨ **'Substitute** within first-line ' (the patient is still on ART first-line)⇨ **'Switch** to second-line'.

    If the patient has transferred in from somewhere else, but was on ART and will continue the ART, it is important to write the date of transfer, the location from which the patient transferred in, and the date ART was started (also put the start month/year in the COHORT box). Fill in as much of the rest of the summary box as you can, based on whether the documentation the transfer-in patient has provided is complete. It is important to keep track of transfers-in and out to facilitate continuity of care throughout the transfer process, and to determine the current numbers on treatment at the facility, thereby avoiding double counting when aggregating data.

    When first-line ART is started, write the date (and the start month/year in the **COHORT** box to identify the ART start-up group) and the first-line regimen. For transfer-in patients, this date should be the same as the date ART started, as described in the line above. Also, record the patient's weight, clinical stage, CD4, and for a woman, whether she is pregnant at the start of ART. For children, you may also add their height.

    If a decision is made to substitute regimens or switch to a second-line regimen, the date of the substitution or switch should be filled in, as well the new regimen. The reason for the regimen change should be recorded using one of the 'why' codes from the list below.

Why SUBSTITUTE or SWITCH codes:

1 = toxicity/side-effects
2 = pregnancy
3 = risk of pregnancy

4 = due to new TB
5 = new drug available
6 = drug out of stock
7 = other reason (specify).

Reasons for SWITCH to second-line regimen only:
8 = clinical treatment failure
9 = immunologic failure
10 = virologic failure.

13. **Record a stop of ART or 'Lost'.** For patients who have started ART and have stopped it, or are temporarily lost (they have missed one or two appointments), circle either 'Stop' or 'Lost', record the date and fill in why they stopped from the 'Why' codes listed below. If a patient stops ART, this can also be recorded in the ARV regimens column. If a patient misses an appointment (Lost), this should also be recorded in the appropriate missed visit encounter.

    Record the reason the patient stopped using the ART drugs from one of the following why STOP codes:
    1 = toxicity/side-effects
    2 = pregnancy
    3 = treatment failure
    4 = poor adherence
    5 = illness, hospitalization
    6 = drugs out of stock
    7 = the patient lacks finances
    8 = other patient decision
    9 = planned interruption of prescription medications
    10 = other (specify)
    11 = exclude HIV infection in an infant.

    If ART is restarted, record the date of the restart.

14. **Record 'Dead' or 'Transfer out' or 'Lost to follow-up (drop)'.** If the patient dies, the date of death should be recorded before the file is closed. If patient is lost to follow-up, the date s/he is declared in this category should be recorded. A patient on ART is declared dropped or lost to follow-up if s/he has not been seen for 90 or more days since the last missed appointment. If the patient transfers to another facility, the date of the transfer should be noted, as well as the name of the transfer-to facility. An effort should be made to send a copy of the patient's record with them.

15. **Drug allergies and/or relevant medical conditions.** In addition to side-effects, it is important to note any drug allergies the patient may have. Record the drug, the type of reaction and the date of any allergy, and update as needed. Also, record any relevant medical conditions the patient may have.

Note: the patient's marital status, address, telephone number, information on their treatment supporter, their home-based care provider, their family and any drug allergies should be recorded at the initial visit, but also updated when there are any changes.

Encounter page(s) - FOR EACH FOLLOW-UP VISIT

The encounter page found on page 25 illustrates the information filled out when the patient comes to the facility on subsequent visits. On the first visit, you will also fill out the first row on the encounter page.

Numbers on the sample encounter page correspond to the following explanations. Look at these pages while you fill out the card.

Each row on the encounter page is to be used for a separate visit. Photocopied blank encounter pages can be stapled to the original HIV care/ART card when the first one is full.

Unique No. □□□□□□□ **HIV CARE/ART CARD** **Name**_____

Date Check if scheduled. Write in alternate pick-up if ill	Follow-up data	Duration in months since first starting ART/ since starting current regimen	**Weight** (kg) Height (m) at first visit If child record +/- oedema	Pregnancy/ RH-FP choices If child record MUAC write age in mos if ≤59 mos	TB status (If TB Rx, record month/year started and TB reg No.)	Potential side-effects	Other problems If child, include nutritional problems	WHO clinical stage	Cotrimoxazole problems Adhere Dose/ Days	INH No. of pills dispensed	Other meds dispensed (including nutritional supplements)	**ARV drugs** (including prophylaxis)		**Investigations**		Refer or consult or link/ provide (including nutritional support and infant feeding) If hospitalized No. of days	HIV transmission prevention for key populations (check) ❑ Discordant couple ❑ MSM ❑ IDU ❑ SW ❑ clients of SW
												Adhere/ Why	Regimen/Dose/ No. days dispensed	CD4 If < 5, record CD4	Hgb, RPR, CXR, TB sputums, Infant Ab/HIV virologic test, other		
						22											
16	17	18	19	20	21		23	24	25	26	27	28		29		30	31

16. **Write the date of this encounter with the patient.** If this is a scheduled visit, check the box. If the treatment supporter comes to collect the drugs, you still fill this in as an encounter by writing the date. (In this case, the entire row is a non-visit client service, and the name of the treatment supporter or other support person can be entered across the whole row. It is critical that you note this person's name and contact information, especially if s/he is different from the person identified in the top left section of the card).

17. **Record the date for the next follow-up appointment.** Record the date the patient is to return for monitoring, re-supply, or for any other reason. In addition, this date should be written down for the patient to take with him or her (in the hand-held patient card or other tool), as well as in a facility appointment book to facilitate follow-up.

18. **Record the duration in months since first the patient first started ART or started their current regimen.** Write in the number of months the patient has been on ART. If the patient has been on ART for less than one month, on the form, record 1 week, 2 weeks or 3 weeks as appropriate. When ART is first started, write «0» in this column. If a patient changes regimens, write a backslash '/' and thereafter record the number of weeks or months the patient has been on the new regimen (beginning with '0'), while continuing to update the number of months the patient has been on ART in total.

19. **Record the patient's weight in kilograms (kg)**. Also, record their height and for children, note the presence or absence of oedema.

    Before ART is started: If the patient has weight loss compared with their previously known weight, put the percentage of loss with a minus sign (for example, -5%). The formula to calculate this is:

    $$\%\ \text{weight loss} = \frac{\text{old weight} - \text{new weight}}{\text{old weight}}$$

    When patients are on ART. Put their weight at the start of ART on the front (summary page) of the card. In patients who have lost weight before starting ART, it is useful to follow their weight gain in the first year to measure their response to ART. After the patient starts ART, use the weight on the day ART was started to compare their current weight.

    $$\%\ \text{weight gain on ART} = \frac{\text{new weight - weight when ART started}}{\text{weight when ART started}}$$

    Most patients should gain weight gradually over the first six-12 months that they are on ART.

    For children ≤ 59 months, record the presence or absence of oedema as +/-.

20. **If a female patient is of childbearing age, ask her at each visit**:
    - Is she pregnant now? If the patient is pregnant, record this as 'P' and write the estimated delivery date (EDD) in the format dd/mm/yy, and the ANC number. If the patient is referred for PMTCT, note this in the last column.
    - Has she recently induced an abortion? Record 'AB' and note when it occurred (dd/mm/yy).
    - Has she recently miscarried? Record 'MC' and note when (dd/mm/yy) it occurred.
    - Does she want to become pregnant now or are she and her partner considering it? Are they not using family planning? If the answers are 'yes', record this as 'Wants P'.
    - Is she already using condoms/other family planning (FP). Record as 'Has FP' and note method(s).
    - Does she want family planning? Record this as 'Wants FP'; note the method(s) provided or that she is referred to obtain. Record the referral in the last column.
    - Does she think she cannot become pregnant, record as 'Unable P'
    - Is she not sexually active now? Record this as 'No sex'.

For several reasons it is essential to check the pregnancy status of women of childbearing age at each visit. These include the need to avoid the use of efavirenz (EFV) during the first trimester of pregnancy; and to provide linkages with or the direct provision of PMTCT interventions. If the patient is pregnant, it is crucial to refer her to PMTCT services, either at your own facility or elsewhere, and to record this on the card. If the woman is given a special PMTCT or ANC number, record it.

Often, as they feel better there is a return to sexuality in patients on ART. During each visit, it is important to discuss safer sex, condom use, dual protection and plans for childbearing.

If the patient is on family planning, record the method(s) using the following codes:
C = condoms
ECP = emergency contraceptive pills dispensed
OC = oral contraceptive pills
INJ = injectable
IMP = implant
IUD = intrauterine device
LAM = lactational amenorrhoea method
D = diaphragm/cervical cap
FA = fertility awareness method/periodic abstinence
TL = tubal ligation/female sterilization
V = vasectomy (of the partner)
UND = undecided.

For children, use this column to record their age in months and their mid upper arm circumference in centimetres (MUAC).

21. **Check and then record their TB status.** Check and record the patient's TB status during each HIV care visit. Each year, five to 15% of HIV patients who are not on ART will develop TB disease. Their TB status will be one of the following:
    - 'TB Rx' (if the patient is on TB treatment). For patients on these TB medicines, record the month and year treatment started and their TB registration number;
    - 'No signs' (enter this if the patient has no signs or symptoms of TB);
    - 'Suspect' (enter this if their sputum is sent out, or the patient is referred for investigation for TB); or
    - 'Not done' (if the patient not assessed for any reason).

22. **Potential side-effects.** Record the possible side-effects using the abbreviations in the following list, or write out the whole word. «Potential» is used in these cases because it is sometimes unclear whether a new sign or symptom is a side-effect or another problem.

    Codes for potential side-effects or other problems:
    N = nausea;
    D = diarrhoea;
    F = fatigue;
    H = headache;
    BN = burning/numbness/tingling of feet or hands (peripheral neuropathy);
    R = rash;
    A = anaemia;
    AB = abdominal pain;
    J = jaundice;
    FAT = fat changes;
    CNS = dizziness, anxiety, nightmares, depression.

    If the patient has other side-effects, write in the symptoms or signs.

23. **Record new opportunistic infections (OIs) or other problems. If the patient is a child, include nutritional problems.** These can be related to HIV or ART or can be problems where the cause is unknown. Use the abbreviations or write the whole word. You can also use the codes from the list above. (A sign or symptom may be a side-effect in one patient, or an OI or another problem in someone else).

    Codes for new OIs or other problems (Write in or use the codes below):
    Z = **Z**oster
    P = Pneumonia
    DE = **DE**mentia/**Encephalopathy**
    Thrush = oral, vaginal
    Fever = **FEVER**
    Cough = **COUGH**
    DB = **D**ifficult **B**reathing
    IRIS = **I**mmune **R**econstitution **I**nflammatory **S**yndrome
    W = **W**eight loss
    UD = **U**rethral **D**ischarge
    PID = **P**elvic **I**nflammatory **D**isease
    GUD = **G**enital **U**lcer **D**isease
    Ulcers = mouth or other.

    If there are other side-effects, write in the diagnosis or the new sign or symptom.

    These code lists are at the bottom of the encounter page.
    If the patient is a child (≤ 59 months), record any nutritional problems in this column using the codes below:
    - Severe complicated malnutrition (SCM)
    - Severe uncomplicated malnutrition (SUM)
    - Poor weight gain (PWG).

24. **Write the patient's WHO clinical stage (1, 2, 3 or 4) on the day of the encounter.** Refer to chapter 3 of *Chronic HIV care with ARV therapy and prevention* for clinical staging of adolescents and adults, and see chapter 12 for paediatric clinical staging guidelines. Newly revised clinical staging guidelines allow patients on ART to go up or down in clinical stage. Record the clinical stage of ART patients with a 'T' before 1, 2, 3 or 4.

25. **Record the patient's cotrimoxazole adherence and drugs dispensed**. For cotrimoxazole prophylaxis, record the numeric percentage or describe adherence as '**G**ood' (≥ 95% or < two doses missed per month), '**F**air' (85-94% or two to four doses missed per month), or '**P**oor' (< 85% or ≥ five doses missed per month) based on once-daily dosing. Write this in the 'Adhere/why' column. Record the dose and number of days of drugs dispensed at that visit.

    Note that dispensing of cotrimoxazole for treatment should be recorded in the 'Other meds dispensed' column.

26. **Record INH** tablets dispensed for TB preventive therapy (TBPT).

27. **Record any other medications dispensed.** If the patient is taking medicine other than ARVs, cotrimoxazole prophylaxis, TB treatment drugs or INH prophylaxis, list the names, doses, and frequency in the 'Other meds dispensed' column.

28. **ARV drugs.** Assess the patient's adherence and record the ARV drugs dispensed to him/her. In the 'Adhere/Why' column, record the numeric percentage or describe adherence as 'Good' (equal to or greater than 95% or ≤ three doses missed per month), 'Fair' (85-94% or four to eight doses missed per month), or 'Poor' (less than 85% or ≥ nine doses missed per month) based on twice-daily dosing. Use the following codes to record the most important reason for non-adherence in patients with fair or poor adherence. If there

is treatment interruption, (ART is stopped or the patient is temporarily lost) record this on the summary page. You may also write 'STOP in the ARV drugs column. Write the full regimen (not the code), dose and the number of days ARVs were dispensed to the patient at this visit in the 'Regimen/Dose/No. of days dispensed' column.

In cases where female patients are concurrently receiving PMTCT and HIV care (pre-ART), the ARV drugs dispensed should be recorded in the ARV drugs column; also write 'PMTCT' in parentheses.

Codes for why there is poor/fair adherence:
1 = toxicity/side-effects
2 = share with others
3 = forgot
4 = felt better
5 = too ill
6 = stigma, disclosure or privacy issues
7 = drug stock-out at the dispensary
8 = patient lost/ran out of tablets
9 = delivery/travel problems
10 = inability to pay
11 = alcohol
12 = depression
13 = other (specify).

29. **Record the investigation that has been sent and the result**: If the patient has had a test to check their CD4, Hgb, sputum, RPR, CXR, infant AB/virologic test or any other tests, note the type of test and when it was sent. Then, fill in results when they are available. If the patient is a child (≤ 59 months), record the CD4 percent value.

30. **Record if any referrals or consultations are needed**. Note whether a patient must be referred, or if you need to consult with the clinician. If the patient has been hospitalized, enter the number of hospital days in square brackets.

    If the patient is being given nutritional support, enter this in the referral column as:
    - therapeutic feeding;
    - infant feeding/counselling (if the infant is <2 years);
    - nutrition counselling only (if the infant is > 2years);
    - food support.

For children <2 years, record all infant feeding practise in the last 24 hours as: exclusive breastfeeding; replacement feeding; or mixed feeding.

31. **HIV transmission prevention for key populations**. Providing targeted prevention intervention for key populations is an essential part of HIV care. This column helps to monitor key HIV transmission prevention interventions to IDUs, MSM, SW and clients of SW.

    Check the key population box or boxes as relevant. If a patient is provided with intervention(s), enter them in this column using the following codes:
    CC = couples counselling
    RR = targeted risk reduction
    C = condom promotion/provision
    NSP = needle and syringe programmes (NSP): the 'NSP' code is checked for all patients with access to NSP or who have access to sterile injection equipment.
    OST = opioid substitution therapy (OST) - this is checked for opioid substitution therapy or any other drug dependency treatment.

Follow-up education, support and preparation for ARV therapy page (the reverse side of the HIV care/ART card) - COMPLETE AS APPROPRIATE AT EACH FOLLOW-UP VISIT

The reverse side of the HIV care/ART card makes it possible for the team keep track of the status of the patient's ARV therapy education, support and counselling.

At each visit, it is important that you remember to review the patient's care, and complete the *appropriate* items with the patient on the reverse of the HIV care/ART card. If there is a counsellor/educator at your clinic, he or she may do much of this. You should also do this with your patients as time permits.

You will *not* be able to cover every item on every visit. You need to prioritize with each patient the most important points to cover each time, based on the patient's clinical and ART history, the time available, the patient's ability to absorb information, their health status, etc.

Example: Education, prevention, post-test counselling, disclosure, the patient's family/living situation, his/her reproductive choices, and PMTCT may be covered in an early visit and noted on the card. The other rows would be blank. On the next visit, the remaining items would be covered and then a determination would be made with the clinical team to assess the patient's readiness for ART.

Your notes should be legible so that other team members can understand them. If there is not enough room on the card, attach a separate sheet.

It is also important to keep your notes up-to-date. Fill them in while the patient is with you. These are not long notes!! You can also write additional information in the patient's exercise book used as a clinical record, if he or she has one. However, this exercise book is not kept at the clinic as an ongoing record.

There are three 'Date/Comments' columns provided on the 'Follow-up education, support and preparation for ARV therapy' page. When you have used all the columns, start a new card and attach it (or a photocopy) to the previous card.

	Follow-up education, support and preparation for ARV therapy [to be revised]			
	Date/comments	Date/comments	Date/comments	Date/comments
Educate on basics, prevention, disclosure				
Basic HIV and TB education, transmission				
Prevention: abstinence, safer sex, condoms				
Prevention: household precautions, what is safe				
Post-test counselling: implications of results				
Positive living				
Testing partners				
Disclosure, to whom disclosed (list)				
Family/living situation				
Shared confidentiality				
Reproductive choices, prevention of MTCT				
Child's blood test				
Progression, Rx				
Progression of disease				
Available treatment/prophylaxis				
CTX, INH preventive therapy				
Malaria prevention, IPT, ITN				
Follow-up appointments, clinical team				
ART preparation, initiation. support, monitor, Rx				
ART – educate on essentials (locally adapted)				
Why complete adherence needed				
Adherence preparation, indicate visits				
Indicate when READY for ART: DATE/result clinical team discussion				
Explain dose, when to take				
What can occur, how to manage side effects				
What to do if one forgets dose				
What to do when travelling				
Adherence plan (schedule, aids, explain diary)				
Treatment supporter preparation				
Which doses, why missed				
ARV support group				
How to contact clinic				
Home-based care, support				
Symptom management/palliative care at home				
Caregiver booklet				
Home-based care – specify				
Support groups				
Community support				

Basic HIV Education & Prevention:

(see chapter 11 of the *Chronic HIV care with ARV therapy and prevention* guideline module).

- **Basic HIV education, transmission**. Be sure the patient has received basic HIV education which includes how HIV is transmitted and how to prevent transmission. Review this with the patient at each visit until you are confident that he/she understands what HIV is and how it is transmitted and prevented. Record the date and your comments about HIV education, transmission and prevention.
- **Prevention: safer sex, condom use screening**. Do not avoid talking about safer sex and discussing condom use with all patients. Have condoms available at each visit and demonstrate their correct use as often as necessary. Record if you give condoms to patients and how many you provide to them. If the patient is sexually active, at each visit ask how many condoms they used until the patient starts to practise safer sex regularly.

Create a comfortable patient/provider relationship that allows for open and honest discussion at each visit. Do not preach. Use open-ended (as opposed to yes/no) questions so the patient will feel encouraged to answer them honestly.

- **Prevention: household precautions; what is safe**. Ensure that the patient understands that HIV cannot be transmitted through household contact, and record this on the card.
- **Post-test counselling, implications of the results** (see Annex A.1 of the *Chronic HIV care with ARV therapy and prevention* module). Provide continued emotional support - just one visit for post-test counselling may not be enough. Record the number of counselling sessions on the card until the patient no longer needs counselling. Ensure that the patient understands the implications of their test results, and on the card record any areas that need further discussion.
- **Positive living** (see section 11.4 of the *Chronic HIV care with ARV therapy and prevention* module). Provide continued education about positive living for PLHAs, and record this on the card.
- **Disclosure, testing partners** (see Annex A.5 of the *Chronic HIV care with ARV therapy and prevention* module). All patients should be encouraged to disclose their HIV status to at least one close family member, friend, or trusted adviser (for example, their minister, teacher or a trusted elder). Record the names of people to whom the patient has already disclosed his or her HIV infection.
  - All patients should be encouraged to have their sexual partner(s) come to your clinic to consider being tested. Record their decisions on the card.
- **Family/living situation**. Record the specifics of the **patient's** family and living situation that will affect their ART adherence and support. Note potential barriers and identify the solutions you have discussed with the patient.
- **Shared confidentiality**. Explain that the clinic has a system of shared confidentiality which means that the patient's HIV status, record, clinical situation and treatments are shared among the clinical team, but not more widely; this is called shared confidentiality. Explain to the patient that the joint HIV/AIDS work of the clinical team and the health centre's record system means it is not possible for only one health worker to know the situation of the patient.
- **Reproductive choices** and **PMTCT**. These should be discussed with all sexually active male and female patients and their choices recorded. All patient need to know about the risk of MTCT and the interventions available to reduce it. See section 8.6 of the *Chronic HIV care with ARV therapy and prevention* module.
  - If appropriate, the decision to have a child's blood tested should be discussed with the patient and noted in their file.

Progression of disease, treatment(s)

- **Progression of disease**. From the patient's first visit and continuing as appropriate, provide education to the patient on the progression of HIV disease. Record your comments on their card until the patient understands how HIV can progress if left untreated, or if treatment regimens are not followed. Explain the services available for chronic HIV care and describe how the clinic provides this care and record your comments on the card.
- **Available treatments and prophylaxis**. After post-test counselling, educate the patient about available treatments and prophylaxis for TB and other OIs and record your comments on the card.

- Patients need to learn that cotrimoxazole prophylaxis is available, and when and why it is used. (Also include INH prophylaxis if this is in the national guidelines.) If the patient is only interested in ART and not cotrimoxazole, note this and provide further education on the issue. After the information that you provide, it will be the patient's decision whether they want to take cotrimoxazole prophylaxis when they are clinical stage 2 or higher. Also, provide educate on malaria prevention with IPTp and ITN.
- **Follow-up appointments, clinical team.** Explain the clinic follow-up schedule and the fact that in your health facility you work as a team on comprehensive HIV care including ART. Point out that the team approach means that it is not possible to guarantee the patient will see only one health worker or counsellor at each visit. Tell the patient the names of the other members of the clinical team. They should also know which medical officer is responsible for the clinical team, even if he/she is not based at this health centre.

ART preparation, initiation, support and monitoring

- **Educate the patients about ART essentials.** Assess the patient's understanding of ART, advise them on the essentials of ARV therapy and record your comments on their card. This education may take several visits. If the patient has important misconceptions, note them.
- **Why complete adherence is needed.** Understanding the need for complete adherence to an ARV regimen is the cornerstone of successful ART treatment for every patient. After the patient has become eligible for ARV therapy, review this at every visit and record your comments on their card.
- **Adherence preparation.** Adherence preparation takes at least several visits and careful counselling. It should begin soon after the patient's HIV test is confirmed as positive, or a patient has been identified as being HIV-positive, and is a potential candidate for ART and their status has been recorded on their card. Indicate the status of adherence preparation at each counselling session. When the patient's adherence preparation is complete, record this information on their card.
- **Indicate when the patient is READY for ART; result of clinical team discussion.** Record on the patient card when he or she is ready for ART. This will require several visits and means that the patient has been prepared for adherence to the ART regimen. The final step in this process is when the clinical team meets and makes a decision as to when a patient is considered to be ready for ART. Record the results of the clinical team's discussion, indicating whether the patient is approved or not approved to start ARVs, or whether their start is postponed. Also, record on this line when the medical officer has reviewed the case and approved the initiation of treatment, and has written the prescription for the ARV drugs.

During both ART adherence preparation and when ART is initiated and supported, it is important to:

- Explain the correct dose to the patient and review this at every visit and record on their card whether the patient knows when to take their medication.
- Explain when the patient needs to take their ARV drugs and record this on the card.
- Assess and educate the patient as to what can occur, how to manage common side-effects, and record this information on their card.
- Educate the patient on what to do if he/she forgets a dose, and record this on their card.
- Set up a strategy with patient on what to do when he/she travels, and record this on card.
- Monitor, emphasize, and support the patient's individualized adherence plan at every visit, and record this on their card. This may involve creating a schedule they can consult on when to take the drugs, or using aids (such as setting the mobile phone alarm to beep at the time the medication is due), or entering the times in a small diary. Record the method(s) the patient is using so that you or your colleagues can check on it/them at the next visit.
- **Treatment supporter preparation.** Help lay the groundwork for a treatment supporter or buddy to help the patient. If possible, this person should come to the clinic (see section 8.9 of the Chronic HIV care with ARV therapy and prevention module on adherence preparation). On the patient's card, record if this has been achieved. Continue to assess the success of the patient's treatment buddy plan, and record this information on their card.

- **Which doses, why doses have been missed**. Once ART begins, on every visit you will be assessing the patient's adherence to their regimen. You will record the quality of their adherence on the front of their card. If any doses have been missed, record the number and why. This can help you help the patient to solve/improve their adherence problem.
- **Link the patient to an existing ART support group and record this on their card.**
- **How to contact the clinic.** At every visit, ensure and record that the patient knows how to contact the clinic. This is particularly important with patients who are on ART.

Home-based care and support

- **Symptom management/palliative care at home.** Inform patients about the availability of symptom management and palliative care at home. This is available even if they are not on ART.
- **Caregiver booklet.** Provide the patient with the Caregiver booklet and explain its use. This describes how to provide care at home. On the patient's card, note that you have given them the booklet and when you did so.
- **Record types and dates of other home-based care provided and any liaisons with home-based care groups.** Make sure the patient knows who is providing home-based care in their community.
- **Support groups.** Connect and encourage patients and their families to join appropriate support groups, and record and review this on the card as appropriate.
- **Community support.** Connect the patient and their families with other existing community support services. Record this information and review it with the patient as appropriate.

A general principle of good chronic care:
Link the patient to community-based resources and support.

Exercise A

Completing an HIV care/ART card

In this exercise, you will read the following two scenarios and fill out the blank HIV care/ART card. (*For the purposes of the exercise, the clinic is in Veld health centre which is located in Markduk district. Dr Sam is the treating clinician*).

Scenario 1:

The patient's name is David B. He was born in July about 27 years ago. This is his first visit to the clinic (20 June 2007). He is married to Lydia and has no children. His address is the middle home in Kanut Circle. He is working and delivers mail. His telephone number is 123.456.789. He shows a written confirmation of his HIV test (Type 1) from 30 May 2007. He has had no prior ARV, but comes now on his own (self-referred) because he heard that this health centre has ART available. David has no drug allergies and his weight is 70 kg. He has no TB symptoms, but he has thrush, so his WHO clinical stage is 3. There is no CD4 available at the health centre, therefore he is medically eligible for ART. David is counselled on the availability of cotrimoxazole prophylaxis which is appropriate for him to start right away, and he is started on it.

He is also counselled on ART adherence, positive living, the concept of shared confidentiality (which is practised at the clinic) and asked to return in three days for another counselling session. His patient clinic number is 01590 and he is given a unique patient identification number at this time – DS000029. Lydia is going to be his treatment supporter and has the same address; her mobile number is 234.567.891. Lydia is also HIV-positive, but has not yet enrolled in HIV care. She is 26 years old.

Scenario 2:

Part A

The patient's name is Mary Sima. She is a 35-year-old married mother and comes to the clinic for the first time. She shows you written confirmation of her HIV test which was done on 12 January 2007 and indicates that she has Type 2 HIV. At that time, the VCT clinic recommended that she come to the health centre, but she said she felt 'fine'. She comes today (25 November 2007) because she has had a painful rash on one side of her chest for the last two days and the cream she has at home has not helped clear it up. Mary tells you that she has never been on ART before, but thinks she needs it now. On further questioning, you determine that she lives at the end of Nile Road in the roundabout in Masaka. She carries a mobile phone and her number is 078.231.456. She would like her husband Sam to be her treatment supporter. His mobile number is 078.231.323.

She tells you that she has been married to her husband for five years. They have one four-year-old son whose name is Timothy. Her husband is 40 years old, is HIV-positive and has been in HIV care for the last year. At the recommendation of the VCT counsellor, she took her son to be tested in March and found that he was HIV-positive as well. She tells you that she was shocked as he had not been sick any more than other local children. She made an appointment for her son to enter HIV care after she became sick. She and her husband would like to have more children. They use condoms occasionally. Her last menstrual period was over a month ago. She thinks she could be pregnant, but is not sure. She currently is able to do housework, but is not employed.

Mary has had no other medical problems. In fact, she tells you that this is the first time she has had any symptoms, which is why she has come today. Her weight is 54 kg. On a physical exam by the health worker, she is found to have herpes zoster which puts her at WHO clinical stage 2. Her rapid pregnancy test is positive. She has no signs of TB. She receives counselling about cotrimoxazole and is started on it. She is also prescribed acyclovir cream to help with the painful rash and is referred for PMTCT. The health worker makes a point of going over the basics of HIV transmission, positive living, the concept of shared confidentiality (which is practised at the clinic) and the importance of consistent condom use. She is to return in one week. Her patient clinic number is 01494 and at this time she is given a unique patient identification number – DS000132.

Part B

Mary returns one week later as scheduled and tells you that her rash has improved. She has no further symptoms. Her weight remains the same and her rash has visibly improved. She has been taking the cotrimoxazole every day and has not missed one dose. You look at her tablet box and agree that she has not missed any doses. She is given a one-month prescription for cotrimoxazole and you ask her to return before she runs out of it. She is still working at home and has gone to ANC/PMTCT as recommended at the last visit. Her ANC number is 001234 and her estimated delivery date (EDD) is 2 July 2008.

Part C

Mary returns earlier than her scheduled follow-up because she had developed a cough and fever during the last two weeks. She tells you that she also has night sweats and poor appetite. You suspect she has TB and take a sputum sample. Her weight is now 53 kg. She is now unable to do housework, but she can move around. She has not missed any doses of the cotrimoxazole.

Part D

Mary returns after three days for her lab results. Her sputum results are (-), (++), (++). She still has a cough and fever. Her weight is 52 kg and she is still unable to do work at home. She is started on TB treatment. Her TB registration number is 13967. The centre has no CD4 capability, so she is now medically eligible for ART. The staff provide counselling on ART adherence and she is asked to return in two weeks.

Scenario 3:

Part A

Sadiki John is a 39-year-old truck driver. He is not married and comes with his mobile phone (077 888 999). He lives at Kigogo in Ilala district but travels frequently due to his job. He comes to the clinic on 23 December 2007 on his own with the results from an HIV test done three years ago (24 September 2005). He is very sick, has lesions, is losing weight and is unable to drive at the moment. He weighs 50 kg. On examination, the physician finds Sadiki has Kaposi's sarcoma; therefore he is at clinical stage 4. There is no CD4 machine at this facility. His haemoglobin is 11gm/dl. Sadiki is sent to the counsellor for positive living information and counselling to prepare for ART. He is started on cotrimoxazole and asked to come back the next day. His patient clinic number is 01651 and he is given a unique patient identification number – DS000147.

Part B

When Sadiki returns the next day as scheduled, he is given further counselling on why complete adherence is necessary once he begins ART. He is asked to come back the next day.

Part C

When Sadiki returns a day later as scheduled, he is assessed as being 'ready' for ART. His treatment supporter will be his brother Salim John, whose telephone number is 077 444 666. Sadiki is asked to come back the next day and to bring his brother with him so his treatment can begin when the doctor makes a weekly visit to the clinic.

Part D

When Sadiki returns a day later as scheduled, he is started on AZT-3TC-NVP and is provided with ARV drugs for 32 days. The counsellor takes the time to make sure he knows how to contact the clinic if he has any questions or if any side-effects occur. His brother has also come with him and is counselled on his role as Sadiki's treatment supporter. Salim is given the *Caregiver booklet* which is available at the clinic.

Notes

3. The pre-ART register

3.1. Learning objectives

By the end of this chapter you should be able to:
- understand the purpose and usefulness of keeping chronic care registers;
- understand the purpose and usefulness of the pre-ART register;
- know where to find the information needed to fill in the pre-ART register;
- accurately transfer information from the HIV care/ART card to the pre-ART register.

3.2. Why keep registers?

The purpose of the registers is to collect in a single location (the register) the same information (a column transferred from patients' individual cards) about an entire group of patients. The information on the HIV care/ART cards allows you to monitor what is happening with each individual patient, but the information collected in the registers allows you to monitor what is happening with your *entire group of patients* and the ART programme as a whole.

You will learn how to complete the pre-ART register and the ART register. Each register consists of a number of vertical columns and horizontal rows.

Each row is one patient. Both the pre-ART and the ART registers are *chronic care* registers, as opposed to acute (or one-off) care registers. This means that each row contains the name of one patient, and every time you see him or her, you go back to that row to complete the patient's entry. You do not re-enter the patient in the same register twice. The columns contain information about the patients; one piece of information per column. As you will see, all the information entered into the registers originally comes from individual patient HIV care/ART cards.

Later in this manual you will learn how to organize certain data collected in the registers into two reports: a quarterly/monthly report form and a cohort analysis report form. The information collected in these two tools allows you to track progress at your clinic, and in the HIV care and ART programmes.

3.3. Purpose of the pre-ART register and how it will be used

The pre-ART register lists ALL patients enrolled in HIV care at your facility. Pre-ART means 'before ART'. The name is not perfect because when you first enrol a patient, you always list them in this register, even if they already started taking ART on their own or in another programme (but note that this is not a *'transfer-in with records*').

The pre-ART register is a tool for monitoring patients who are enrolled in HIV care, and for tracking their progress as they become eligible for ART. All patients who first enrol in HIV care, whether they are on ART or not, are initially listed in the pre-ART register and counted as enrolled in HIV care. This includes patients who transfer in with or without records who were previously in care at another facility, but are not yet on ART. The only patients who will NOT be entered into the pre-ART register are patients already on ART who transfer in with records. Patients who were taking ART, but do not have the records to demonstrate this, will have to be entered into the system as a new patient (with a new patient card, a new entry in the pre-ART register and a new screen for eligibility). You then continue to record data on the patient in the pre-ART register until they start ART.

Once patients begin ART, they are transferred to the ART register and tracked there. The patients are no longer tracked through the *pre-ART register* even if they STOP ART (but continue to receive care).

3.4. Where to find the information

The information required to complete the pre-ART register can be found on the patient's individual HIV care/ART card.

3.5. How to transfer the information

You have already learned how to fill out the patient HIV care/ART card. Now you will learn how to transfer information from the patient's card to the pre-ART register. In Annex 1, there is a 'key' card with numbers in balloons pointing to items on the card which are transferred to the register. The instructions below on how to fill in the register are keyed to these numbers.

Please note that the columns in the register are referred to as column 1, column 2, etc. even though they are not actually numbered on the register. Transfer the information from the card to the pre-ART register as follows:

1. **Health Unit:** Copy this information to **'Health Unit'** near the top of page of the register.

2. **Enrolled in HIV care:** Transfer this information to column 1, **'Date enrolled in chronic HIV care'**. If a patient transfers in (with records) from another facility, this is the date s/he has enrolled at YOUR facility.

3. **Unique number:** Transfer this information to **'Unique No.'**

4. **Patient clinic number:** Transfer this information to column 3, 'Patient clinic No.'.

5. **Name:** Transfer this information to column 4, **'Name'**. Write the patient's surname in the upper half of the row and first (given) name in the lower half of the row.

6. **Sex:** Transfer this information to column 5 '**Sex'**. Write **''M'** for male or **'F'** for female.

7. **Age:** Transfer to column 6, **'Age**'. Note, this is the patient's age at enrolment.

8. **Status at enrolment:** Transfer this information to column 7 **'Status at enrolment:' TB Rx** for TB treatment, **Preg** for pregnant, postpartum, or **Other**. If the patient is a pre-ART transfer-in patient write **TI.**

   If the patient is taking cotrimoxazole or INH for prophylactic purposes, is on TB treatment, or is pregnant, it will be noted on the encounter page of the HIV care/ART card. The patient's WHO clinical stage is also recorded on the encounter page. Transfer that information to the 'HIV care' section of this register.

   If a patient goes through multiple instances of cotrimoxazole, INH prophylaxis, or TB treatment, the most recent start date is the most useful to record in the register. This will require some kind of protocol decision such as filling in these columns in pencil, or allowing old dates to be crossed out.

   Use the Date column on the encounter page of the HIV care/ART card to determine the CTX, INH and TB Rx start month/year for columns 8, 9, and 10 on the pre-ART register. The start date recorded in the pre-ART register will be the date the last instance of prophylaxis or treatment that is prescribed and recorded on the encounter page. For TB Rx, transfer the TB registration number from the TB status column on the encounter page of the of the HIV care/ART card.

9. **Cotrimoxazole:** If the patient is taking this medication, transfer the start month/year from the encounter page to column 8 '**CTX**' in the pre-ART register. You may look for 'stop' (if recorded as such) in the *Cotrimoxazole* column of the encounter page to determine if there have been multiple instances of cotrimoxazole prophylaxis. If so, record the start month/year for the most recent instance.

10. **INH:** If the patient is taking isoniazid for prophylaxis purposes, transfer the start month/year from the encounter page to column 9 '**INH**' on the pre-ART register. You may look for 'stop INH' (if recorded as such) in the *INH* column of the encounter page to determine if there have been multiple instances of INH prophylaxis. If so, record the start month/year for the most recent instance.

11. **TB Treatment:** If the patient is on TB treatment, transfer the start month/year and TB registration number from the encounter page to column 10 'TB Rx' on the pre-ART register. You may look for 'stop TB Rx' (if recorded as such) in the *TB status* column of the encounter page to determine if there have been multiple instances of TB treatment. If so, record the start month/year for the most recent instance.

12. **Clinical stage:** The clinical stage of the patient is recorded at every visit on the encounter page of the patient card. On the pre-ART register, tick the appropriate clinical stage in columns 11-14 as the patient's stage changes. If the patient is a transfer-in patient, you may have past clinical staging data from their records and can fill this in accordingly.

13. **PMTCT:** For each pregnancy during the HIV care/ART follow-up period (columns 15-18), record the expected/estimated due date (EDD) and the ANC number from the *Pregnancy/RH-FP choices* column on the encounter page, and if available, the HIV-exposed infant number from the *Exposed infant follow-up* box on the first page of the HIV care/ART card.

14. **Medically eligible:** If the patient is medically eligible for ART, transfer the information from the *HIV care* box on the first page of the HIV care/ART card to column 19 **'Medically eligible for ART'.** Write the date when the patient became medically eligible for ART.

15. **ART started:** Transfer the date ART started from the *ART Care* box on the first page of the HIV care/ART card to column 20 **'Start ART first-line initial regimen'**. Once the patient starts ART, their information will be entered into the ART register.

16. **Quarterly follow-up status page:** The second page of the pre-ART register is to record the quarterly follow-up status of patients. Quarters are divided by the calendar year (i.e. quarter 1 (Q1) is January-March, Q2 is April-June, etc.). For each quarter, transfer the last CD4 count (or percentage if under 5) of the quarter from the *CD4* column on the encounter page of the HIV care/ART card to the top row under the appropriate quarter column on the quarterly follow-up status page.

    Then, check the *TB status* column of the encounter page of the HIV care/ART card and write 'Y' on the bottom row under the appropriate quarter if the TB status check was completed at the last visit of the quarter, and 'N' if the TB status check was not completed at the last visit of the quarter. Write '□' if a patient did not have a visit scheduled during that quarter, 'LOST' if a patient was scheduled for a visit, but was not seen during the quarter, 'TO' if a patient transferred to another facility during the quarter (record the name of the facility), and 'DEAD' if the patient died during the quarter (record the date of death).

Exercise D

Completing a Pre-ART register

In this exercise, your facilitator will give you blank pre-ART register.

The facilitator will give you a demonstration of how to fill in the pre-ART register using the completed HIV care/ART card for Exercise A, Scenario 1 (David) on page 2 of the *Exercise booklet*. He or she will enter the data for the first entry on the card and will do this on an enlarged register with the group. You should follow along and enter the data on the first line of your blank pre-ART register. When filling out the quarterly follow-up status for David, assume this is the last visit in quarter 2. You should feel free to ask questions at any time.

You will then enter the next entries in the pre-ART register using the completed patient card for Exercise A, Scenario 2 (Mary) and Scenario 3 (Sadiki) on pages 5-10 of the *Exercise booklet*. You should follow the steps described in Section 3.5 of this manual: 'How to transfer the information'. To fill out the quarterly follow-up status of Mary and Sadiki, assume these are their last visits in quarter 3.

Exercise E

Understanding and analysing data from a pre-ART register

For this exercise, use the sample completed pre-ART register labelled Exercise E.

Read the questions below and answer them:

1. By the end of March, how many patients had died before starting ART? _____
   a) Where did you find this information? _____
   b) What is the purpose of knowing this information? How is this information used?

2. How many patients were lost to follow-up or transferred out by the end of March?
   a) Where did you find this information? _____
   b) What is the purpose of knowing this information? How is this information used?_____

3. Of patients enrolled in January and February 2007, how many remained in pre-ART care by the end of March? _____
   a) Where did you find this information? _____
   b) What is the purpose of knowing this information? How is this information used?_____

4. Of patients enrolled in January and February 2007, how many patients are medically eligible for ART, but not yet on it by the end of March? _____
   a) Where did you find this information? _____
   b) What is the purpose of knowing this information? _____

5. What is the percentage of male and female patients who enrolled in HIV care by the end of March? Males ____% Females _____%.
   a) Where did you find this information? _____
   b) What is the purpose of knowing this information? _____

Notes

4. The ART register

4.1. Learning objectives

By the end of this chapter you should be able to:
- understand the purpose and usefulness of the ART register;
- know where to find the information needed to fill it in;
- accurately transfer information from the HIV care/ART card to the ART register.

4.2. Purpose of the ART register and how it will be used

The ART register is a tool used for patient and programme monitoring. For example, if drugs are ordered on a monthly basis, this register can be used to keep track of the distribution of ARV regimens. The ART register is also used to support cohort analyses of important variables at six months, 12 months, and then yearly thereafter.

This register is used only *after* a patient has started ART. From this point on, no further entries should be made in the pre-ART register. The ART register records information by cohort (ART start-up group) using one (or more) page(s) of the register for each cohort. A page is actually two A-3 pages that open up together and includes 24 months of follow-up (it is possible to add pages so that each cohort has room (four A-3 pages) to be followed for up to six years (or six A-3 pages for 10 years of follow-up). Each patient has a row that goes all the way across the register. See Tab 6 of this training manual for copies of the standard two-year ART register.

A patient is in a cohort based on the year and month he or she started ART, regardless of where it was started. Each page of the ART register should only be used for recording/updating information on patients in the same cohort; one row per patient.

4.3. Where to find the information

The information required to complete this register can be found on the patient's individual HIV care/ART card.

4.4. How to transfer the information

Now you will learn how to transfer information from the patient's HIV care/ART card to the ART register. In Annex 1, there is another 'key' card with numbers in balloons which point to a line item on the card. The instructions on how to fill in this register are keyed to these numbers, and numbered in the order in which you enter the information in the register.

Please note that the columns in the register are referred to as column 1, column 2, etc. even though they are not actually numbered in the register.

ART register - left-hand side (page 1)

The information for numbers 1 to 10 below is found on the summary or face page of the patient card. Transfer the information from the card to the ART register as follows:

1. **COHORT:** Transfer this information from the card to **'Cohort: Year ____ Month ____'** found near the top of the left page of the register. Write in the cohort year and month for this patient.

2. **ART started:** Transfer this information to column 1, **'ART start date'**.

3. **Unique number:** Transfer this information to column 2, **'Unique no.'**.

4. **Patient clinic number:** Transfer this information to column 3, **'Patient clinic no.'**.

5. **Name:** Transfer this information to column 4, **'Name'**. Write the patient's surname in the upper half of the row and their given name in the lower half of the row.

6. **Sex:** Transfer this information to column 5, **'Sex'**. Write **M** for male or **F** for female.

7. **Age:** Transfer this information to column 6, **'Age'**. Note that this is the age at the start of ART. It may have to be derived from the patient's age or DOB at enrolment, depending on when the patient enrolled in care.

8. At the 'start ART' line to the right - **weight:** Transfer this information to column 7, **'Wt (kg)'**.

9. At the 'start ART' line to the right - clinical **stage:** Transfer this information to column 8 **'Cl. stage'.**

10. At the 'start ART' line to the right – the **CD4 number/percentage:** Transfer this information from the encounter page of the card to column 9 **'CD4'.**

The ART register - left-hand side (page 1)

The information for numbers 11 to 15 below is found on the encounter page of the patient card. If the patient is taking cotrimoxazole or INH for prophylactic purposes, is on TB treatment or is pregnant, it will be noted on this page of the card.

If a patient goes through multiple instances of cotrimoxazole or INH prophylaxis, or TB treatment, the most recent start date will be the most useful to record in the register. This will require some kind of protocol decision, such as filling in these columns in pencil or allowing old dates to be crossed out.

There is space for up to four pregnancies in the illustrative ART register. This space can be adapted by countries if it does not seem adequate.

11. **Date:** Use this date to determine the start dates for columns 10-12. The start date will be the encounter date; that is the first instance of prophylaxis or treatment as prescribed and recorded in the appropriate column on the encounter page of the HIV care/ART card.

12. **Cotrimoxazole:** If the patient is taking cotrimoxazole (CTX), it will be noted in this column. Transfer this information to column 10 'CTX'. Enter the start month and year. The date is found in the same row in the far left column (balloon 11).You can look in the *'Cotrimoxazole'* column of the encounter page of the patient's card to determine if there have been multiple instances of cotrimoxazole prophylaxis. If so, make sure the start date for the most recent instance is the one noted in the ART register.

13. **INH:** If the patient is taking INH, it will be noted on this page. Transfer this information to column 11 'INH'. Enter the start month and year. The date is found in the same row in the far left column (balloon 11). You can look in the **'INH'** column of the encounter page of the patient's card to determine if there have been multiple instances of INH prophylaxis. If so, make sure the start date for the most recent instance is the one noted in the ART register.

14. **TB Status:** If the patient is on TB treatment, it will be noted on this page. Transfer the information to column 12 **'TB status'**. Enter the start month and year. The date is found in the same row in the far left column (balloon 11). You can look in the *'TB status'* column of the encounter page of the patient's card to determine if there have been multiple instances of TB treatment. If so, make sure the start date for the most recent instance is the one noted in the ART register. Also, transfer the patient's current TB registration number from this field of the encounter page of the HIV care/ART card to the patient's entry in the ART register.

15. **Pregnant (EDD, ANC number, HEI number):** If the patient is pregnant, transfer this information to the appropriate sub-column of column 13 **'Pregnancy/ RH-FP choices'.** There is space for up to four pregnancies in the illustrative register. Write in the estimated due date (EDD) in the upper half of the cell and the woman's ANC number in the lower half of the cell.

    If the country adopts a system of assigning numbers to HIV-exposed infants, transfer that number to the **'Pregnancy/RH-FP choices'** column. The HEI number can be added by putting a backslash - '/' - after the woman's ANC number .

    The information for numbers 16 to 18 is found on the first page of the patient card.

16. **Start ART first-line original regimen:** Transfer this information to column 14 '**Original Regimen**'. Write in the **code** for the first-line regimen which is found at the bottom of the ART register.

17. **Substitute within first-line:** If there is a first substitution within the first-line regimen, transfer this information to the upper half of the row in column 15 'Substitute within first-line'. Write in the **code** for the first substitute regimen, the reason code after a semi colon - ':' - and the date after a backslash - '/'.

    If there is a second substitution, transfer this information to the lower half of the row in column 15 by writing in the code for the second substitute regimen, the reason code after a semi colon - ':' - and the date after a backslash - '/'.

18. **Switch to second-line (or substitute within second-line):** If the patient has been switched to a second-line regimen, transfer this information to the upper half of the row in column 16 '2nd-line Regimen'. Write in the code for the new regimen, the reason code after a semi colon - ':' - and the date after a backslash - '/'.

    If there is a substitution within the second-line regimen, transfer this information to the lower half of the row in column 16 by writing in the code for the new regimen, the reason code after a semi colon - ':' - and the date after a backslash - '/'.

ART register - right-hand side (page 2)

This page of the register is used to document ARV regimens, ART outcomes, and whether or not the patient's TB status has been filled in each month for the next 24 months. Write in the year and the month of this cohort in the upper left corner (this is balloon 1 on the keyed sample patient card in Annex 1).

Under 'Month 0' enter the name of the month and the year in which the patients in this cohort started ART. This applies to all the patients on this page of the register since they are all in the same cohort, i.e. they all started in this month. Under 'Month 1' write the name of the next month and year, and continue in this manner for all 24 columns. When you reach the end of a calendar year, be sure to change the year.

For example, for the cohort of patients that started ART in September 2004:

Month 0	September 2004
Month 1	October
Month 2	November
Month 3	December 2004
Month 4	January 2005
Month 5	February
Month 6	March
Month 7	April
Month 8	May
Month 9	June
Month 10	July
Month 11	August
Month 12	September
Month 13	October
Month 14	November
Month 15	December 2005
Month 16	January 2006

Follow-up status - top row

At the end of each month, the follow-up status of the patient will be recorded in the appropriate box. This is also true for Month 0. Therefore, while a patient may have started on a certain regimen at the start of ART (1a), he or she may have returned before the end of the month to the facility and substituted to an alternative regimen (1b) due to side-effects. You will record this alternative regimen on the right-hand side of the ART register under Month 0, while the initial regimen 1a will be recorded in the column 'Original Regimen'.

If the patient picks up drugs during that month, the regimen code will be reported. In mature programmes, patients will begin to collect their drugs less frequently,

perhaps every quarter or six months. If this is the case, draw a horizontal arrow through the next two (for three months) or five (for six months) columns after writing the regimen code to denote the length of time the drugs were given.

The information for these follow-up fields on the right side of the ART register all comes from the 'ART drugs' fields on the encounter page of the HIV care/ART card.

If the patient *does not* pick up drugs during that month, one of six events must be recorded:

Transfer Out (TO). A patient has transferred out to another facility. Note the facility name.

Stopped (STOP). A patient has chosen to stop, or the clinical team has decided to interrupt treatment. Note the reason in parentheses.

Lost (LOST). A patient has missed an appointment (has not picked up their drugs).

Lost to follow-up (DROP). A patient has missed a number of appointments (enter this number) and a number of days (according to the national protocol. It is recommended that you use 90 days since the last missed appointment and that you note the attempts (enter this number) that have been made to contact this patient, but that he or she cannot be found (and is therefore dropped from the drug supply).

Died (DEAD). The facility has been notified that the patient is dead.

Restart (RESTART). A patient is restarted on ART after an interruption. Note the regimen code.

TB status completed- Bottom row

In addition to the drug regimen the patient is on, or the outcome of their ART, the patient's TB status needs to be entered at each visit in the ART follow-up fields as well. This comes from the 'TB status' column on the encounter page of the HIV care/ ART card. Record 'Y' for yes, or 'N' for no in the appropriate cell.

CD4 number/percentage at six, 12, 24, etc. months

At these specific intervals, you will see extra columns including the one for CD4 number/percentage. If CD4 values are available for the patient at these intervals, fill in these columns.

Transfer -in patients

At the end of each month, after all patients who have newly started on ART at your facility have been entered into the ART register, a prominent line (doubled or in a different colour) should be drawn underneath the last patient entered. As programmes decentralize and grow, patients will inevitably transfer into and out of facilities. ART patients who transfer in with records will be entered retrospectively into the ART register - by the date they started on ART.

For example, a patient started ART at Facility A in January 2005. An entry is made in the January 2005 ART register page. In March, 2005, the patient decides to have treatment at Facility B which is much closer to her home. 'TO Facility B' is recorded in the March 2005 (Month 2) column on the right-hand page of the January 2005 ART register at Facility A. She transfers to Facility B. An entry for this patient will now be made in Facility B's January 2005 ART register page under the line drawn after the last patient who started ART in January 2005 at Facility B (see below).

For these transfer-in patients, the first entry on the right-hand side of the ART register will be for the drug regimen picked up in that first transfer month. This is how staff at that facility will know when the patient transferred in on ART. Using the above example, the first entry for this patient would be made in Month 2 or March 2005. If a patient transfers more than six months after initiating treatment at another facility, it will also be necessary to retrospectively enter the respective six, 12, 24, etc. month outcomes for them in order to enable the clinical team to compare the cohort. You should be able to fill out most or all of the information on the left-hand side of the ART register for every transfer-in patient. This information will come from the record the patient brought with them.

Left-hand side of ART register

COHORT: Year 2005 Month January

Registration and personal Info		Status at start of ART			1st line regimen	
ART start date	Unique ART number	Weight	WHO clinical stage	CD4	Original regimen	Substitutions 1st: Reason Date 2: Reason Date
01.01.05	BA0001	52.1	150	150	1a	
08.01.05	BA0003	52.1	180	180	1a	
16.01.05	BA0006	50.0	20	20	1a	
18.01.05	BA0007	52.0	120	120	1a	
22.01.05	BA0009	46.3	20	20	1a	
10.01.05	KL0004	40.0	3	150	1a	1c: (1) 15.5.05

Transfer -in patient

Right-hand side of the ART register

Year 2005					Write in month January
Month 0 *Jan '05*	Month 1 *Feb '05*	Month 2 *Mar '05*	Month 3 *Apr '05*	Month 4 *May '05*	Month 5 *June '05*
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y
1b Y	1b Y	1b Y	1b Y	1b Y	1b Y
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y
1a Y	1a Y	1a Y	1a Y	LOST	1a Y
1a Y	1a Y	1a Y	STOP (8)		1a
		1a Y	1a Y	1c Y	1c Y

Patient transferred in March 2005

Do not enter retrospective patient ART outcome data except at six, 12, 24, etc. months

Notes

5. MCH/PMTCT Records

5.1. Learning objectives

By the end of this section you should be able to:
- recognize the importance of the MCH/PMTCT patient monitoring tools;
- fill out items of the maternal and child health cards, ANC register, labour and delivery record, labour and delivery register and the HIV- exposed infant register.

It is important to have organized ways to record patient information and to track pregnant women when they return for care at each stage during pregnancy, childbirth, and the postpartum period. In addition, patient information is passed from one point of care to the next, e.g. from the outpatient ANC clinic to the maternity ward, in order to ensure continuity of care.

There are two groups of patient records relevant for MCH/PMTCT:

Hand-held cards: Patient hand-held cards are kept by the patient and are regularly updated during their follow-up health-facility visits. Maternal and child health cards fit into this group, and in this section we will learn about the maternal card. We will learn about the HIV-sections of the child health card in section 5.12 .

Facility registers: Facility registers or cards are kept by the facility and include the ANC, labour-delivery, ART, and pre-ART registers, and HIV care/ART cards. In this section, we will review the ANC register.

5.2. Maternal health card

The maternal card is a hand-held card which assists transfer of critical patient-related information across service delivery points in the same facility or other facilities. It facilitates transfer of information from the ANC clinic to the delivery ward, and back to the outpatient postnatal service delivery point. In many settings, there are many more ANC facilities (including outreach sites) than there are delivery facilities. This often results in a pregnant woman delivering at a different facility from where she obtained her ANC services. In this case, due to the fast-paced nature of delivery services her patient-held card helps assure a continuity of care that is not possible through other means, e.g. calling the ANC facility to trace the woman's records.

Maternal health card:
1. Prepare the maternal card at the mother's first ANC visit, or at her first facility contact for maternal health services if she has not received care during pregnancy, i.e. delivery or postpartum services. The maternal card information can be extracted from the ANC and labour and delivery registers. During labour and delivery, it should be filled when the mother is discharged from the maternity ward.
2. Update the maternal health card during each facility visit, including at each ANC visit, discharge from the maternity ward, and postnatal visits.
3. Instruct the woman to bring her card during each facility visit, including when she comes for delivery. Explain to her that the card contains information that enables her care providers to give appropriate care without delay. Therefore, it is important that she keeps it safe (e.g. keeps it in a dry place, makes sure it does not get torn, etc.). Recommend to the woman that she take her card to any facility where she receives care during her pregnancy, childbirth and postpartum period, including during her visit to the HIV care clinic if she is referred there.
4. Ask the woman if she has any questions or concerns about the card, and respond clearly and accurately.

An illustrative mother's card with instructions on how to fill it in is shown to the right.

Illustrative mother's card

ANC No._____ Date enrolled in HIV care_____ Unique HIV care/ART No._____

Health facility _____

Name_____ Age_____

Address: _____ District:_____ Village_____

Marital Status_____

Gravida_____ Para_____

LMP_____ EDD _____

Contact person/next of kin _____

Preferred site of delivery_____

Mode of transportation _____

Notes _____

_____

_____

History of previous pregnancy and outcome of current pregnancy									
No.	Year	Place of delivery	Gestational age at delivery/abor-tion	History of prolonged labour (Y/N)	Mode of delivery	Birth weight	Sex	Birth outcome: Alive/Stillbirth Fresh/macerated	Serious obstetric complications
1									
2									
3									
4									
5									

Write in for antenatal, delivery and postpartum → **Antenatal (ANC)** → **Delivery (circle date)** → **Postpartum (PP)**

	1st visit	2nd visit	3rd visit	4th visit	5th visit	6th visit	7th visit	8th visit	9th visit	10th visit
Date (dd/mm/yy) of visit, current pregnancy **(21)**										
Gestation in weeks *(ANC)*/Weeks postpartum **(22)**										
Weight **(23)**										
Blood Pressure **(24)**										
Fundal ht *(ANC)* **(25)**										
Fetal Presentation *(ANC)* **(26)**										
Uterus firm *(PP)* **(27)**										
WHO clinical stage **(28)** **ART Eligible? ☐**										
CD4 (record Sent; result, result given to mother)										
Infant feeding: **C**ounselling (**Y/N**) **(29)**										
Infant feeding intention/practise: (**EBF, RF, MF**) **(30)**										
FP: **Counselling**; PP write method or **No FP (31)**										
ARV adherence counselling (**Y/N**) **(32)**										
ARV adherence (**G**ood, **F**air, **P**oor) **(33)**										
Hgb (record result) **(34)**										
Blood group and RH (record result) **(35)**										
Syphilis test result (**P**ositive, **N**egative, Unknown) **(36)**										
Syphilis treatment given/No. doses given (IM PCN 1st, 2ndor 3rd) **(37)**										
Urine protein **(38)**										
HIV test result (**P**ositive, **N**egative**, K**nown positive, **U**nknown) **(39)**										
Iron folate dispensed (**Y/N**) and No. dispensed **(40)**										
Malaria IPT (1st, 2nd, 3rd dose) **(41)**										
Slept under ITN the previous night(**Y/N**) **(42)**										
ARVs dispensed mother (**AZT**, **Triple ARVs;** or **ART**) **(43)**										
Next appointment (**dd/mm/yy**) **44)**										

Antenatal immunization	**Date (45)**
TT1	
TT2	
TT3	
TT4	
TT5	

Additional interventions	**Date**
ITN	
Cotrimoxazol started	
INH prophylaxis/ TB Rx started	
Mebendazole	
Vit A (Units)	

Labour and Delivery (transfer from labour record)

46 Infant feeding intention: ☐ EBF ☐ RF ☐ MF

47 Date of delivery _____

48 Place of delivery: ☐ Home ☐ Hospital ☐ Health Centre ☐ Other _____

50 Conducted by: ☐ Nurse/Midwife ☐ Doctor ☐ TBA ☐ Other _____

51 Condition of mother _____

53 Condition of baby _____

49 Mode of delivery (indication if operative delivery) _____

52 Postpartum complications: PPH? ☐ _____

54 ARV given during delivery: Triple ARVs ☐ AZT+3TC ☐ ART ☐ Sd NVP ☐ None ☐

ARV dispensed for the mother: AZT ☐ Triple ARVs ☐ ART ☐

55 **Postpartum- mother- outpatient visit**

56 Problem with breast feeding _____

57 Perineum _____ Lochia _____

58

59 Breasts _____

Infant feeding practice: EBF ☐ RF ☐ MF

Clinical Notes/Additional Postnatal Visits (66)

_____

_____

_____

_____

_____

_____

Referral site **(67)** _____

Reason for referral _____

61

Infant

60

Birth weight _____ Sex: ☐ Female ☐ Male

Baby Immunization: ☐ BCG ☐ OPV 0 ← 62

Vitamin K: ☐ Yes ☐ No ← 64

ARV prophylaxis: ☐ NVP ☐ AZT ☐ None ← 63

65

5.3. Filling out items on the maternal health card

1. **Health facility:** Record the name of the health facility.
2. **ANC no.:** Record the woman's ANC card number.
3. **Date enrolled in HIV care:** Record the date the woman is enrolled in HIV care. This is the date the patient first enrols in HIV care at your facility. This can be in a chronic HIV care clinic or in an integrated ANC clinic. At enrolment, open a new HIV care/ART card.
4. **Unique HIV care/ART no.:** Record the woman's HIV care/ART number.
5. **Name:** Record the name of the woman.
6. **Age:** Record the age of the woman.
7. **Marital status:** Record the marital status of the woman.
8. **Gravida:** Record the number of pregnancies the woman has had, including those that ended with an abortion.
9. **Para:** Record the number of deliveries. In some settings, women may not include stillbirths and early neonatal deaths as deliveries unless they are directly asked about them.
10. **LMP:** Record the date of the last menstrual period.
11. **EDD:** Record the expected 'Date of delivery' (as calculated from the LMP).
12. **Address:** Record the address of the woman.
13. Contact person/next of kin: Record the name and phone number of a contact person given by the woman.
14. **No:** List pregnancies in chronological order (start from the first pregnancy).
15. **Year:** Record the year of each pregnancy.
16. **Place of delivery:** Record the place of delivery of each pregnancy. Record the place of care for pregnancies that ended in an abortion.
17. **Gestational age at delivery:** Record the gestational age at delivery or at abortion.
18. **Duration of labour:** Record the duration of labour. It may be difficult to accurately obtain the history of previous deliveries.
19. **Mode of delivery:** Record the mode of delivery during past pregnancies, during ANC and in the current pregnancy at the woman's discharge from the maternity ward, or during the first postnatal visit if the woman is brought in following a home delivery.
20. **Birth weight:** Record birth weight for all newborns.
21. **Sex:** Record the sex of the baby, even if the infant was stillborn.
22. **Record outcome of delivery:** Record the outcome of the delivery as 'Alive', 'Stillbirth' (fresh or macerated).
23. **Serious complications:** Record any serious complications that occurred during each pregnancy.
24. **Record the birth plan for the current pregnancy:** Discuss with the mother and record on her birth plan her preferred site of delivery, the mode of transport to the delivery facility and any other notes.
25. **Date of visit (current pregnancy):** Record the date (dd/mm/yy) the woman comes to the facility (including for ANC, delivery, and postpartum care). Circle the date of delivery.
26. **Gestation in weeks:** Record the pregnant woman's gestational age in weeks under the corresponding date.
27. **Weight:** Record the mother's weight under the corresponding date.
28. **Blood pressure:** Record the mother's blood pressure under the corresponding date.
29. **Fundal height:** Record the fundal height under the corresponding date. This is to be recorded only during pregnancy.
30. **Presentation:** Record foetal presentation as 'Head', 'Transverse', or 'Breech' for the corresponding date. This is to be filled in only during pregnancy.
31. **Uterus firm:** Record 'Yes' if the uterus is firm or 'No' if it is not firm. This is to be filled in only for women in the postpartum period.
32. **WHO clinical stage:** Record the WHO clinical stage of an HIV-positive woman as 1, 2, 3 or 4.
    CD4: Record 'Sent' on the date the sample was taken/sent, enter the CD4 count result when it is available, and record 'Given' on the date the result is given to the mother.
    ART eligible: Tick '√' on the box if an HIV-positive woman is eligible for ART.
33. **Infant feeding counselling:** Record 'Yes' if counselling was done on this visit, and 'No' if it was not done.
34. **Infant feeding intention/practise:** Record 'EBF' if at delivery the woman intends to exclusively breastfeed; or 'RF' if she intends to do replacement feeding. During the postpartum period: Record 'EBF' if she is exclusively breastfeeding, 'RF' if she is doing replacement feeding, or 'MF' if she is doing mixed feeding.

35. **Family planning (FP)**: If there was counselling during PP, write the method; or 'No FP': Record 'C' if FP counselling was done during ANC. During the postpartum period, write in the method if the woman is using FP. If she is not using a family planning method, record 'No FP'.
36. **ARV adherence counselling**: Record 'Y' if ARV adherence counselling is done or 'N' if ARV adherence counselling is not done.
37. **ART adherence:** If the woman is on ART, record 'Good' if ≤ 3 doses are missed /month, 'Fair' if 4-8 doses are missed/month, or 'Poor' if ≥ 9 doses are missed/ month. This is based on the woman's own report.
38. **Haemoglobin**: Record the haemoglobin result in gm/dl.
39. **Blood group and RH**: Record the woman's blood group as A, B, AB, O and the RH factor as + o r -.
40. **Syphilis test result:** Record the test result: 'Positive', 'Negative', 'Unknown'. If done, record the RPR titre (e.g. 1:8).
41. **Syphilis treatment:** Record 'Y' if treatment is dispensed or 'N' if it is not given: If it is given, record the treatment given/dose (e.g. 'IM PCN/1', 'IM PCN/2', etc.).
42. **Urine protein:** Record the test result.
43. **HIV test**: Record 'Positive' if the woman tests HIV-positive or is documented to be positive from an earlier test; 'Negative' if the woman tests HIV-negative, or 'Unknown' if the HIV status of the woman is unknown, e.g. if she declines testing.
44. **Iron folate dispensed**: record 'Y' if iron folate is dispensed or 'N' if iron folate is not dispensed. Assess if iron folate is properly taken and record compliance.
45. **Malarial IPT**: Record the dose of malaria intermittent preventive therapy (IPT) - 1st, 2nd or 3rd. Ask if mother slept under an insecticide treated net (ITN) the previous night and record 'Y' for yes and 'N' for no)
46. **ARV regimen dispensed:** Record the ARV regimen dispensed (for ART or ARV prophylaxis): AZT, for AZT alone, Triple ARVs if triple ARV drugs are provided to pregnant women as prophylaxis , or the specific ART regimen if pregnant women who need ART for their own health are provided with it.
47. **Next appointment**: Record the date for next appointment in the format dd/ mm/yy.
48. **Date**: Record the date (dd/mm/yy) the woman received tetanus toxoid.
49. **Additional interventions:** Record the date (dd/mm/yy) of any additional interventions the woman received.
    ITN: Record the date an insecticide treated net was provided, or when the woman was referred to obtain it.
    CTX started: Record the date (dd/mm/yy) cotrimoxazole prophylaxis was initiated (for an HIV-positive woman).
    INH prophylaxis/TB Rx started: Record the date (dd/mm/yy) INH prophylaxis or TB Rx is initiated. Circle which one the date refers to. If there is a TB Rx, also record the TB registration number.
    Mebendazole: Record the date this was dispensed.
    Vitamin A: Record the date and number of units dispensed.
    Others: Write in any other interventions carried out and record the date(s).

Labour and delivery

50. **Infant feeding intention**: Record 'EBF' if at delivery the woman says she intends to exclusively breastfeed; RF if she says she will replacement feed; or MF if she says she will do mixed feeding.
51. **Date of delivery:** Record the date (dd/mm/yy) of delivery.
52. **Place of delivery:** Tick '√' in the appropriate box.
53. **Mode of delivery**: Record the mode of delivery, and indicate if it was an operative delivery.
54. **Conducted by:** Tick '√' in the appropriate box.
55. **Condition of mother**: Record the condition of the mother at discharge from the maternity ward (free text).
56. **Postpartum complication:** Tick '√' if the mother had a postpartum haemorrhage (PPH), record any other complications.
57. **Condition of baby**: Record the condition of the baby at discharge as 'Alive', 'Dead', or 'Stillbirth'.
58. **ARV given during labour**: Tick '√' in the appropriate boxes.
59. **ARV dispensed**: Tick '√' in the box if ARV prophylaxis is dispensed to the woman on her discharge from the maternity ward.

Postpartum outpatient visit

60. **Problem with breastfeeding:** Record any problem the mother raises about breastfeeding (free text).
61. **Breasts:** Record condition of her breasts at the corresponding date.
62. **Nipple and areola:** Record the condition of nipple and areola at the corresponding date.
63. **Lochia:** Record information about lochia.
64. **Perineum:** Record information about perineum.
65. **Infant feeding practise:**
    Record 'EBF' if the woman is exclusively breastfeeding, or
    'RF' if she is replacement feeding, or
    'MF' if she is doing mixed feeding.

Infant

66. **Birth weight:** Record the infant's weight in grams obtained within 24 hours of birth.
67. **Baby immunization:** Tick '√' in the appropriate box for any immunizations the baby received.
68. **Vitamin K:** Tick '√' in the appropriate box.
69. **ARV prophylaxis given at delivery:** Tick '√' in the appropriate box (es).
70. **ARV prophylaxis dispensed:** Tick '√' in the appropriate box.
71. Record any clinical notes in the clinical notes section.
72. Record the name of the referral site if the mother is referred, and also record the reason for the referral.

5.4. ANC register

Your ANC clinic may already have an antenatal register or special registers to record the results of HIV testing and counselling of pregnant women. When there is an ANC register for a patient, HIV-related information should be integrated into it. The facility should use both a regular HIV care/ART card *and* record the PMTCT information on the mother's card in order to easily track the pregnant woman for continued care. An example of how to integrate HIV-related information, HIV testing and results, ART eligibility or ARV prophylaxis and regimen in a longitudinal ANC-register is given on the next page, followed by instructions on filling out each column.

In a longitudinal ANC register, each pregnancy and all key data elements associated with that pregnancy are tracked in one row per patient. The facility should use both a regular HIV care/ART card *and* record the PMTCT information on the maternal and child patient-held cards. These will be used to update the ANC register's HIV-related information in settings where the ANC register is the only facility-based patient record. A pre-ART and/or ART register and an HIV-exposed infant register should be used to follow the HIV-positive woman and her HIV-exposed infant once she has enrolled in HIV care.

ANC Register – Page 1

											Syphilis test			Syphilis treatment
Date enrolled dd/mm/yy	ANC No.	ANC visit No.	Name	Age	Last menstrual period dd/mm/yy	Estimated due date dd/mm/yy	Tetanus toxoid dose	Malaria IPT dose	ITN (Y/N)	Iron supplemet (> 3 months) (Y/N)	P	N	U	(Y/N)
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						
		1 2 3 4+					1 2 3 4 5	1 2 3						

ANC Register – Page 2

HIV status at enrolment			HIV test in ANC dd/mm/yy	HIV test result				Partner testing			ART eligibility assessment				ARV prophylaxis or ART			Enrolled in HIV care
P	N	U		P	N	U	Result given	P	N	U	Assessed or Referred dd/mm/yy	WHO clinical stage	CD 4 sent dd/mm/yy Value	Result given	AZT	Triple ARVs	ART	dd/mm/yy Unique No.

5.5. Filling out the items of the ANC register

1. **Date enrolled:** Write in the date of enrolment in ANC (dd/mm/yy).
2. **ANC number:** Record the ANC number.
3. **ANC visit number:** Circle the appropriate ANC visit number (1, 2, 3, 4+).
4. **Name:** Record the full name of the woman.
5. **Age:** Record the age of the woman in years.
6. **Last menstrual period (LMP):** Record the date of the last menstrual period (dd/mm/yy).
7. **Estimated due date (EDD):** Record the expected date of delivery (dd/mm/yy).
8. **Tetanus toxoid dose (TT):** Circle the appropriate number for a tetanus toxoid dose (1, 2, 3, 4, 5).
9. **Intermittent preventive therapy (IPT):** Check the appropriate column (1st, 2nd, 3rd) for the dose of IPT given.
10. **Iron supplementation:** Check if there has been iron supplementation for ≥ three months.
11. **Syphilis test result and treatment:** Check: 'Positive', 'Negative', or 'Unknown' based on the patient's test result.
    For patients who have a positive syphilis test result, check 'Y' if treatment is given, or 'N' if no treatment is given
12. **HIV status at enrolment:** Check 'Positive', or 'Negative' if the patient's HIV status is confirmed with documentation on admission, or if there is no information, check 'Unknown'.
13. **HIV tested:** Write in the date the patient was tested for HIV (dd/mm/yy).
14. **HIV test result:** Check 'Positive' or 'Negative' in the appropriate column. Check the 'result given' column when the result has been received by the mother.
15. **Partner tested:** Check 'Positive', 'Negative', 'Unknown' (if the partner declines to be tested or did not come for testing) in the appropriate column.
16. **ART Eligibility Assessment:** Record the date (dd/mm/yy) the patient was assessed for ART eligibility. If the patient was referred to another facility for an eligibility assessment, record 'REFER' in this column. Cross check ANC registers with the pre-ART and the ART register (in an integrated setting). You need to use a referral form for information sharing across sites in non-integrated settings.

    Regardless of the setting, eligibility assessment results should come back to the ANC register so that it is the sole source of data for Indicator #4. Fill in WHO clinical stage and the CD4 count. Fill in the date the CD4 was sent above the line, and the value, once it is available, below the line. If the CD4 count and WHO stage change during a subsequent visit, cross out the earlier value and write the most recent CD4 result. Circle the value that renders the patient eligible for ART. Check the 'result given' column if the mother receives her CD4 results.
17. **ARV prophylaxis or ART:** Check 'AZT' for AZT only; 'Triple ARVs' if triple ARV drugs are provided to pregnant women as prophylaxis ; and 'ART' if pregnant women who need ART for their own health are provided with it.
18. **Enrolled in HIV care:** Write in the date the patient is enrolled in HIV care or in ART (dd/mm/yy), and the unique HIV care/ART ID.

Exercise: Filling in HIV information on the ANC register and the mother's card

Case 1: Mary

Fill in the ANC register and the mother's card for Mary

Part A: Mary's first visit

Mary Bisrat presents to the ANC clinic for her first antenatal visit on 10 May 2008. Her last menstrual period was about seven months ago, and this is her third pregnancy. She has a girl aged four and a boy aged two.

She gets tired easily these days and that is why has come to the clinic.

She has never been tested or counselled for HIV, but has heard about it.

The nurse examines her and finds that her weight is 45Kg, she has anaemia and a herpes rash. Her fundal height is around 26 weeks.

The nurse records Mary's BP which is 110/80.

She gives Mary her first dose of TT.

She advises her to have a few tests - Hb, blood group, urine and syphilis screening.

She also advises her to be tested for HIV; Mary agrees.

Mary's Hb is 8gms/dl, her blood group is A+ and urine is normal. Her syphilis test is negative.

Mary is found to be HIV-positive. There are no facilities for CD4 count at the facility, so the nurse decides that Mary is in clinical stage 2.

The nurse counsels her on diet, birth plan and danger signs, infant feeding and partner testing.

The nurse gives her a first dose of IPT and an impregnated bednet. She is also given a one-month supply of IFA and deworming tablets.

She prescribes cotrimoxazole prophylaxis and a drug for the rash. Mary is given a four-week supply of AZT, and counselled on how and when to take the doses.

She is to return for a follow-up visit in four weeks.

Mary's HIV care card number is 010004 and her ANC card number is 200056.

Fill in the relevant registers and cards

Part B: Mary's second visit

Mary returns to the ANC clinic four weeks later with her partner. The rash has subsided, but she still has poor weight gain. She is still 45 Kg. Her BP is 120/80. Her fundal height is around 28 weeks. The foetal heart rate is normal.

On this visit, Mary's haemoglobin remains at 8 g/dl. She had not taken the IFA tablets as she feels nauseated on them. However, she has taken the deworming tablet. She still has two months of cotrimoxazole left.

The nurse reviews Mary's card to see how well she has been adhering to the twice daily AZT. Mary has taken both the AZT and cotrimoxazole tablets as prescribed.

Mary is counselled on nutrition, infant feeding and family planning. She is given a second dose of IPT. The nurse reviews her birth plan and asks her about the use of bednet. She is given a second dose of TT.

Mary has decided to give birth at the facility. She is asked to take her IFA tablet after her meals and before going to bed.

She is still provided with additional adherence counselling and support, and given an additional four-week supply of AZT

She is asked to return in four weeks time.

Update the relevant sections of the appropriate registers and cards.

Part C: Mary's third visit

Mary returns in her 36th week of pregnancy. Her weight is 45.5 Kg. Her clinical examination is normal - the fundal height is around 32 weeks and the presentation is vertex. She does not have any abnormal signs.

Her haemoglobin is 8.5 g/dl. She has managed to take the IFA tablets. She is still in clinical stage 2 and she has finally disclosed her HIV status to her partner. However, he refuses to be tested, and therefore does not know his status.

She is given third dose of IPT and TT and counselled on danger signs. Her birth plan is reviewed and still she plans to deliver at the facility. She is counselled on nutrition, infant feeding and family planning, and is also supplied with IFA tablets. She is sleeping under the bednet.

Once again, Mary's adherence is good. She has not missed a dose of AZT and cotrimoxazole. The nurse gives Mary four weeks of AZT for the last four weeks of her pregnancy. She is asked to return in two weeks time, or earlier if there is a problem

Update the relevant sections of the appropriate registers and cards.

Case 2: Janet

In your spare time, fill in the ANC register and mother's card for Janet. The facilitator will provide the answers the next day.

Part A: Janet's first visit

Janet Negassa comes for her first ANC visit to your clinic on 12 September 2007. She is 30 weeks pregnant. She tested HIV-positive at a hospital eight months ago, and has documentation of her test results. At the time, she did not enrol in HIV care because she was «only visiting temporarily». However, she has disclosed her status to her partner who also tested HIV-positive.

By the time Janet comes to your clinic, she has had chronic diarrhoea for the past six weeks and has poor weight gain. The nurse decided Janet is in WHO clinical stage 3. Janet's CD4 count is 300 and her haemoglobin is 9 g/dl.

She is enrolled in HIV care and prescribed cotrimoxazole. She is given adherence counselling and told to return in one week with a treatment supporter.

Her ANC card number is 7059328, and her HIV care card number is 0178392.

Fill in the ANC register and the mother's card for Janet.

Part B: Janet's second visit

Janet returns to the ANC clinic twice in the following week with her treatment supporter (her mother) for her second and third adherence counselling sessions. At the end of her third session, she is ready to start ART. She is dispensed a two-week supply of AZT-3TC-EFV and asked to return in two weeks for follow-up. Her haemoglobin is 8 g/dl.

Update the ANC register and mother's card for Janet.

Part C: Janet's third visit

Janet returns to the clinic two weeks later as scheduled. She has taken the ARV drugs as prescribed. Her diarrhoea has stopped, but she still has poor weight gain. Her haemoglobin remains 8 g/dl. She has no other signs and symptoms. She is counselled on infant feeding options, and discusses a birth plan with the nurse.

She is given a follow-up appointment in four weeks.

Update the ANC register and mother's card.

Part D: Janet's fourth visit

Janet returns to the clinic four weeks later as planned in the 36th week of her pregnancy. She is finally gaining weight properly and feels well. Her haemoglobin is still 8 g/dl. According to her adherence table, Janet has taken all her doses of ARVs as instructed (twice daily) and is given another month's supply. She has decided to deliver at a facility near her home. Her mother will accompany her. She is instructed to give her infant the first dose of ARVs just after delivery, and is shown how to fill out her card.

She is given an appointment to return to the clinic four weeks later, but she gives birth prematurely at week 36.

Update the ANC register and maternal card.

5.6. Labour and delivery records

The labour and postpartum records, as well as the labour and delivery register, may be the only patient-level records retained at a non-integrated facility. They should therefore be adapted to be as complete as possible regarding HIV-related services. Even in integrated settings, they are valuable patient monitoring tools used during the often fast-paced course of delivery and post-partum, and are an important window of opportunity for women who deliver in a health-care setting. Therefore, the importance of including the elements of HIV care in these records cannot be underestimated.

Labour record

USE THIS RECORD FOR MONITORING DURING LABOUR, DELIVERY AND POSTPARTUM			RECORD NUMBER
NAME	AGE	PARITY	
ADDRESS			

DURING LABOUR	AT OR AFTER BIRTH - MOTHER	AT OR AFTER BIRTH – NEWBORN	PLANNED NEWBORN TREATMENT
ADMISSION DATE	BIRTH TIME	LIVEBIRTH ☐ STILLBIRTH: FRESH ☐ MACERATED ☐	
ADMISSION TIME	OXYTOCIN – TIME GIVEN	RESUSCITATION NO ☐ YES ☐	
TIME ACTIVE LABOUR STARTED	PLACENTA COMPLETE NO ☐ YES ☐	BIRTH WEIGHT:	
TIME MEMBRANES RUPTURED	TIME DELIVERED → 1	GEST. AGE _____OR PRETERM NO ☐ YES ☐	
TIME SECOND STAGE STARTS	**ESTIMATED BLOOD LOSS**	SECOND BABY	
	AZT 300MG+3TC 150MG 2X DAILY X 7 DAYS FIRST DOSE TAKEN ☐ DISPENSED ☐	INFANT FEEDING COUNSELLING **Y/N** → 2 INFANT FEEDING PRACTICE EBF ☐ RF ☐ MF ☐ → 3	
ENTRY EXAMINATION			
STAGE OF LABOUR: NOT IN ACTIVE LABOUR ☐ ACTIVE LABOUR ☐			

NOT IN ACTIVE LABOUR													PLANNED MATERNAL TREATMENT
HOURS SINCE ARRIVAL	1	2	3	4	5	6	7	8	9	10	11	12	
HOURS SINCE RUPTURED MEMBRANES													
VAGINAL BLEEDING (0 + ++)													
STRONG CONTRACTIONS IN 10 MINUTES													
FETAL HEART RATE (BEATS PERMINUTE)													
T (AXILLARY)													
PULSE (BEATS/MINUTE)													
BLOOD PRESSURE (SYSTOLIC/DIASTOLIC)													
URINE VOIDED													
CERVICAL DILATATION (CM)													
PLANNED ARV DRUG AND DOSE* → 4	5 ↗												
ARV TIME**													

PROBLEM (6 ↙)	TIME ONSET	TREATMENTS OTHER THAN NORMAL SUPPORTIVE CARE

IF MOTHER REFERRED DURING LABOUR OR DELIVERY, RECORD TIME AND EXPLAIN.

***ASK IF THE MOTHER HAS TAKEN AZT 600 MG OR SD-NVP AT ONSET OF LABOUR AT HOME, AND RECORD.**

****DURING LABOUR ADMINISTER ONLY 3TC AND ART EVERY 12 HOURS; RECORD TIME DRUG TO BE ADMINISTERED ABOVE THE LINE AND TIME ACTUALLY ADMINISTERED BELOW THE LINE.**

Labour record, partograph and postpartum record: Most facilities have a labour record that is used for follow-up of a woman during labour and childbirth. Information on ARV drug administration can be included in the labour record. The partograph is important to follow up labour, and to recognize prolonged labour early in order to achieve a timely intervention.

5.7. Filling out HIV-related information in the labour record

1. **AZT 300MG + 3TC 150MG 2X DAILY X 7 DAYS:** This is checked for women who are receiving ARV prophylaxis. Put a (√) in the box next to FIRST DOSE, 'TAKEN', if the woman took the first dose of AZT and 3TC; or check (√) 'DISPENSED' if AZT and 3TC are dispensed for 7 days (postpartum).

2. **Infant feeding counselling:** Circle 'Y' if the woman is counselled for infant feeding, or circle 'N' if the woman is not counselled for infant feeding.

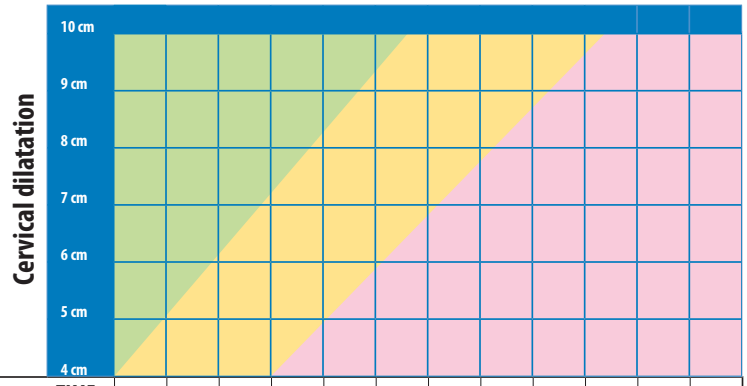
3. **Infant feeding practise:** Put a (√) in the box next to **EBF** if the newborn is exclusively breastfed; next to **RF** if the newborn is on replacement feeding; or **MF** if the newborn is on mixed feeding.

4. **Planned ARV drugs and dose:** Write the ARV drugs and dose given to the woman during labour. This applies to all women who receive ARV prophylaxis or ART.

5. & 6.**ARV time:** Record the planned time for the ARV drug to be administered above the diagonal line **(5)**, and the time the ARV drug is actually administered below this line **(6)**.

Partograph

USE THIS FORM
FOR MONITORING
ACTIVE LABOUR



FINDINGS	TIME											
HOURS IN ACTIVE LABOUR	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**
HOURS SINCE RUPTURED MEMBRANES												
RAPID ASSESSMENT												
VAGINAL BLEEDING (0 + ++)												
AMNIOTIC FLUID (MECONIUM STAINED)												
CONTRACTIONS IN 10 MINUTES												
FETAL HEART RATE (BEATS/MINUTE)												
URINE VOIDED												
T (AXILLARY)												
PULSE (BEATS/MINUTE)												
BLOOD PRESSURE (SYSTOLIC/DIASTOLIC)												
CERVICAL DILATATION (CM)												
DELIVERY OF PLACENTA (TIME)												
OXYTOCIN (TIME/GIVEN)												
PROBLEM-NOTE ONSET/DESCRIBE BELOW												

Postpartum record

Monitoring after birth	1 hour (if complications every 5-15 min)					2 hr	3 hr	4 hr	8 hr	12 hr	16 hr	20 hr	24 hr
Time													
Rapid assessment													
Bleeding (0 + ++)													
Uterus hard/round?													
Maternal: Blood pressure													
Pulse													
Urine voided													
Vulva													
Newborn: breathing													
Warmth													

6

Newborn abnormal signs (list)
Feeding observed: Feeding well ☐ difficulty ☐
Initial feeding practice: EBF ☐ RF ☐ MF ☐
Comments

7

8

Planned Treatment	Time	Treatment given
Mother		
Newborn		

If referred (mother or newborn), record time and explain:

If death (mother or newborn), date, time and cause:

ADVISE AND COUNSEL

MOTHER

- ☐ Postpartum care and hygiene
- ☐ Nutrition
- ☐ Birth spacing and family planning
- ☐ Danger signs
- ☐ Follow-up visits
- 1 → ☐ ARV adherence (mother and baby)

BABY

- 2 → ☐ Infant feeding
- ☐ Hygiene, cord care and warmth
- ☐ Special advice if low birth weight
- ☐ Danger signs
- 3 → ☐ HIV testing
- 4 → ☐ Cotrimoxazole prophylaxis
- 5 → ☐ Follow-up visits

PREVENTIVE MEASURES

For mother

- ☐ Iron folate
- ☐ Vitamin A
- ☐ Mebendazol
- ☐ Sulphadoxine-pyrimethamine
- ☐ Tetanus toxoide immunization
- ☐ RPR test result and treatment
- 9 → ☐ ARV

For Baby

- ☐ Risk of bacterial infection and treatment
- ☐ BCG, OPV -0, Hep-0
- ☐ RPR ☐ Positive ☐ Rx
- ☐ TB test result and prophylaxis
- 9 → ☐ ARV prophylaxis

Instructions for completing HIV-related information in facility postpartum record

Initial feeding practice	Check EBF ☐ or RF ☐ **or** MF ☐
Record any HIV-related treatment planned, the time it was actually given, and what was actually given for both mother and baby.	

5.8. Filling out HIV related information in the postpartum record

1. **ARV adherence**: It is important that the woman and baby adhere to the ARV drugs dispensed. Counselling and support are essential for adherence. The mother/family should be carefully instructed how to administer the ARV syrup to the newborn before discharge from the maternity ward. Put a (√) in the box if ARV advise and counselling is provided on ARV adherence.
2. **Infant feeding:** Counsel the woman on infant feeding at the most appropriate time during labour and childbirth. Put a (√) in the box if the mother is counselled on infant feeding options in the maternity ward.
3. **HIV testing:** Early diagnosis and timely treatment is critical due to the rapid progression of HIV infection in infants. Where available, HIV viral tests are recommended at six weeks of age for all HIV-exposed infants. The mother should be informed when and where to bring the baby for the HIV test before discharge from maternity ward. Put a (√) in the box if information, advice and instruction is given to the mother about HIV testing of her baby.
4. **Cotrimoxazole prophylaxis:** Cotrimoxazole prophylaxis is a life-saving intervention for HIV-infected infants. It prevents PCP which is the most common cause of death in HIV-infected infants. Cotrimoxazole prophylaxis should be started for all HIV-exposed infants at four to six weeks of age. Educate all HIV-positive women before discharge from the maternity ward on the importance of cotrimoxazole prophylaxis for their babies. Put a (√) in the box if information, advice and instruction is given to the mother on cotrimoxazole prophylaxis for her infant.
5. **Follow-up visits:** Put a (√) in the box if information, advice and instruction is provided on the newborn's follow-up visits. For all HIV-exposed infants, follow-up visits should include the facility where the infant would receive HIV care (e.g. cotrimoxazole prophylaxis, HIV testing, etc), besides routine childhood services (e.g. immunization, nutrition and growth monitoring, etc.). Service integration, coordination and linkages help the mother to continue receiving care for her baby and herself after discharge from the maternity ward.
6. **Feeding observed:** Put a (√) in the feeding well box if the newborn has no problem feeding, or write 'difficulty' if the newborn is experiencing feeding difficulty. This needs to be marked based on observation by the health worker. Whether the mother chooses exclusive breastfeeding or replacement feeding; the health worker should observe while the mother is feeding the newborn before their discharge from the maternity ward.
7. **Initial feeding practise:** Put a (√) in the appropriate box: **'EBF'** if the infant is breastfeeding exclusively, **'RF'** if replacement feeding; or **'MF'** if mixed feeding is the initial feeding practise. Mixed Feeding (MF) constitutes breastfeeding plus any other supplement provided (including water), except medications. Note that initial feeding includes all oral feeding practises including nasogastric feeding.
8. **Planned treatment, time, treatment given**: Write in any planned treatment (e.g. ART or ARV prophylaxis) for the woman and her newborn, the time it was given, and the type of treatment given in the corresponding row.
9. **ARV:** Put a (√) in the box if ARV drugs (ARV prophylaxis or ART) is given to the woman during her stay at the facility.
10. **ARV prophylaxis:** All HIV-exposed newborns should receive ARV prophylaxis as soon as possible after birth. Put a (√) in the box if ARV prophylaxis is given to the newborn while he/she is in the maternity/delivery ward.

5.9. Labour and delivery register

The labour and delivery register should be filled when the woman and her infant are discharged from the maternity ward. The labour record, partograph and the postpartum record can all be a source of information for the labour and delivery register. If the woman is tested for HIV in the labour ward, immediately enter this information without the need to record it on the labour record.

At discharge from the maternity ward, update the maternal card and prepare the child health card for the newborn. Women, who did not receive care during pregnancy should obtain their maternal card at the maternity ward for the first time. It is crucial that key information on the woman's and infant's health are transferred from labour and delivery to outpatient postpartum services to ensure continuity of care. This is very important as HIV-positive postpartum women and HIV-exposed infants need to receive continued care.

Labour and delivery register page 1

Identification				Mode of delivery	Obstetrics complications	Maternal outcome	Newborn			HIV status at admission (Check appropriate)		
Name	Age	ANC No.	Date of Delivery dd/mm/yy	1. SVD 2. Assisted vaginal 3. C/S	Y/N	1. Stable 2. Referred 3. Died	Sex	Weight in grams 1. <2,500 2. ≥2,500	1. Term 2. Preterm 3. Stillbirth	P	N	U

7	8			9	10	11				12	13		14		15	16
Previous HIV test date	**HIV Test Result** (check appropriate)			**ARV Woman Took During Pregnancy**	**Weeks Woman Took ARV During Pregnancy**	**ARV Woman Took in Labor** (Check appropriate)				**Infant Received NVP/AZT**	**ARV Infant Discharged With** (check appropriate column or if none, write **None**)		**Infant Feeding** (check appropriate or if mixed feeding, write **MF**)		**Intended family planning method chosen**	**Referred to HIV care/ ART**
(dd/mm/yy)	P	N	U	AZT Triple ARVs ART None	(≤ 4, >4)	AZT	Triple ARVs	ART	None	(check if received, if none write «none»)	AZT	NVP	EBF	RF	(Write method)	(Refer, Already in care)

Ask the woman, check hermaternal card, ANC recordor if she has otherdocumentation of HIV test result

ONLY FOR HIV-POSITIVE WOMEN AND THEIR NEWBORNS

5.10. Filling out items in the labour and delivery register

1. **Identification:** Record the identification of the woman.
   - **Name:** Record the name of the woman.
   - **Age:** Record the age of the woman.
   - **ANC No:** Record the antenatal card number of the woman. You can obtain this information from the mother's card or ANC register, or if the mother has ANC appointment card.
   - **Date of delivery:** Record the actual (not estimated) date of delivery of the current pregnancy in **dd/mm/yy.**
2. **Mode of Delivery:**
   Enter the appropriate number in the column: **1:** If it is a spontaneous vaginal delivery (SVD); **2:** If it is an assisted vaginal delivery; **3:** If it is a caesarean section (C/S). For multiple deliveries, use a digit number that corresponds to the number of births e.g. for a twin birth indicate as 11, 12, 22, the first digit represents the first baby, while the second represents the second baby. Likewise, use 3 digit numbers for triplets, and so on.
3. **Obstetric Complications:** Record **''Y''** if the woman has any obstetric complications and **''N''** if there are none.
4. **Maternal Outcome:** Record the maternal outcome at discharge, as appropriate Record the corresponding number in the column:
   1, if the woman is discharged in **Stable** condition;
   2, if the woman is **Referred** for any reason;
   3, if the woman **Died** from any reason.
5. **Newborn:** Record **'M'** for a male newborn and **'F'** for a female. Enter < 2500 if the weight of the newborn is < 2500, or > 2500 if the newborn weighs more or equal to 2500 grams. Record the outcome of delivery as **1**, if it is a term delivery; **2**, If it is a preterm delivery; or **3**, if it is a stillbirth. For multiple deliveries, indicate this by using multiple alphabets or more than one digit, e.g. 'MF' indicates an outcome of a Male (first baby) and a Female (second baby). Twin deliveries and 11 indicates that both were term deliveries.
6. **HIV status at admission:** Check '**P**ositive', '**N**egative' or '**U**nknown' in the appropriate column.
7. **Previous HIV test date:** Write down the pervious HIV test date (done before arrival for delivery) in dd/mm/yy. dd/
8. **HIV test result:** Record the HIV test result of the woman done during labour or in the immediate postpartum period before her discharge from the maternity ward. Check '**P**ositive', '**N**egative' or '**U**nknown' (if the woman declines testing) in the appropriate column. HIV testing and counselling is recommended during labour if the woman was not tested during pregnancy, or if she tested negative during pregnancy, and the health worker decides to repeat the test due to the risk of recent infection.
9. **ARVs the woman took during pregnancy:** Write down the ARV regimen the woman took during current pregnancy. **'AZT'** if she took **AZT prophylaxis, 'Triple ARVs'** or **ART** if she took **antiretroviral therapy,** or **'NONE'** if she did not take **AZT** prophylaxis or **ART.**
10. **Weeks the woman took ARVs during pregnancy:** Write down the length of time the woman took ARVs. Enter ≤ **4** if the woman took ARVs for less than or equal to four weeks; or write in **> 4** if duration was greater than four weeks. **ARV** includes ARV prophylaxis or ART.
11. **ARVs the women took in labour:**
    Write in: **'AZT'**; **'Triple ARvs'** ; **'ART'** if she received ART; **'NONE'** if none.
12. **Infant received NVP/AZT:** Check if the infant received **NVP or AZT**, if not, write down **'NONE'**.
13. **Infant feeding [practise]:** Tick **'EBF'** if the infant is exclusively breastfeeding; **'RF'** if the infant is in replacement feeding; write **'MF'** if the infant is on mixed feeding at birth.
14. **Intended family planning method chosen:** Write in **'Y'** if the woman intends to use a family planning method, or **'N'** if she does not intend to use one. After counselling, write down the chosen family planning method the woman intends to use.

15. **Referred to HIV care/ART:** Write in **'Refer'** if the woman is referred at delivery or discharge or **'Already in care'** if the woman was already in HIV care when she arrived for delivery.

Maternal card

It is very important that key information on labour and childbirth is transferred from the maternity ward to the outpatient postnatal clinic to ensure continued care of the woman and the newborn.

If the woman has a maternal card for this pregnancy because she has received ANC, update the card with key information on labour and childbirth. Remember to update the card even if the mother received ANC services, and part of the card was filled in by staff at a health facility other than yours. If the woman does not have a maternal card, for instance because she did not receive ANC, prepare a maternal card for her at discharge from the maternity ward.

5.11. Child card

Most settings use a child health card to routinely monitor child growth and immunization. If such a card is already in use in your country or at your clinic, HIV information can easily be integrated into it.

It is recommended that you fill in the child card when the newborn is discharged from the facility in order to ensure transfer of key information from the maternity ward (e.g. ARV drugs given) to outpatient services. If the infant is not born at a facility, the child health card should be prepared at the child's first contact with health care.

Proposed HIV elements to be added to existing child health cards

Date and time of birth (1)	**Date:** / / Time (2) _____
Maternal HIV status (*circle*)	☐ **P** ☐ **N** ☐ **U**
During pregnancy, mother took (*check*): ☐ **AZT** ☐ **Triple ARVs** ☐ **ART** ☐ **None** (3) Duration of ARVs or ART : ☐ **≤ 4 wks.** ☐ **> 4 wks.**	
☐ Infant feeding counselling or support at delivery (4)	Newborn feeding practice (circle) EBF RF MF
Maternal Syphilis status *(check)* ☐ **P** ☐ **N** (5) ☐ **U**	☐ **IM PCN** ☐ **Yes** ☐ **No** (6) ☐ **1st dose** ☐ **2nd dose** ☐ **3rd dose**
During labour, mother took ☐ **AZT** ☐ **Triple ARVs** ☐ **Sd- NVP** ☐ **ART** ☐ **None** (7)	
Postpartum, mother took ☐ **AZT** ☐ **Triple ARVs** ☐ **ART** ☐ **None** (8)	

ARV prophylaxis to newborn	
NVP given	**Date:** / / (11)
AZT given	**Date:** / / (12)
☐ **None**	
Adherence (*Tick*) (14)	☐ **Good** ☐ **Fair** ☐ **Poor**

Infant follow-up						
Date (15)	**Age in weeks or months**	**Infant feeding**		**HIV test**		**CTX given (√)** (21)
		Counselling Support (√)	**Practice** EBF, RF, MF (18)	**Ab** or **PCR** **DBS** sent? (√)	Result **P/ N /U** (20) Test result received? (√)	*(start at 4 - 6 weeks, stop when confirmed negative)*
/ /	(16)	☐		☐	☐	
/ /		☐		☐	☐	
/ /		☐		☐	☐	
/ /		☐		☐	☐	
/ /		☐		☐	☐	
/ /		☐		☐	☐	

Infant confirmed HIV-infected? **Y** ☐ **N** ☐ (17)	**Date infant enrolled in HIV care/ART** (10) _____ **Unique HIV care/ART No.:** (19) _____
Action(s) needed _____ (23) _____ (24)	

5.12. Filling out HIV information on the child health card

1. **Maternal HIV status.** Recording the HIV status of the mother is an important step to ensure the HIV-exposed infant continues to receive HIV care. Circle **'P'** if the mother is HIV-positive, **'N'** if she is HIV-negative, **'U'** if her HIV status is unknown because, for instance, the mother declined HIV testing, the mother has never been tested, or she is not present (e.g. the newborn is an orphan), or for any other or combination of reasons.
2. **Date and time of birth.** Record the date (dd/mm/yy) and time (hh:mm) of birth of the child.
3. **Newborn feeding practise.** The safer feeding option for infants born to HIV-positive mothers is exclusive breastfeeding or replacement feeding. The mother needs to choose the most appropriate feeding option for her situation. Infant feeding counselling helps her to make this very important decision. Circle the infant feeding practise immediately after birth: **'EBF'** (exclusive breastfeeding), **'RF'** (replacement feeding), **'MF'** (mixed feeding, breast milk and other fluids).
4. **Infant feeding counselling or support.** Infant feeding counselling and support should routinely be provided to all women at first contact with the facility; reinforced with key information and support during subsequent visits. Tick '√' the box if infant feeding counselling or support is provided to the mother at delivery.
5. **ARVs the mother took during pregnancy:** Tick '√' the appropriate box.
6. Duration ARVs were taken during pregnancy: The type of ARV regimen the mother took during pregnancy determines the ARV regimen recommended for her baby. If the woman took ARVs during pregnancy, tick '√' if ARVs were taken ≤ four weeks or > four weeks.
7. **Maternal syphilis status:** Check **'P'** if her syphilis test is positive, **'N'** if her syphilis test is negative, **'U'** if her syphilis test status is unknown because the mother is not present, (e.g. the infant is an orphan) or the mother's status is not known for another reason (she declined testing, etc.).
8. **Syphilis treatment the mother received:** Tick **'Y'** if IM penicillin was given and **'N'** if there was no treatment for syphilis, and the number of doses received (i.e. 1st, 2nd, 3rd doses).
9. **ARVs the mother took during labour:** Tick '√' the appropriate box.
10. **ARVs the mother took postpartum:** Tick '√' the appropriate box.

ARV prophylaxis for the newborn

11. **Date NVP or AZT was given:** All HIV-exposed newborns should receive ARV prophylaxis as soon as possible after birth, or within the first 72 hours if the newborn is brought in to the facility after a home delivery. Record the date (dd/mm/yy) NVP or AZT is given to the newborn.
12. **Adherence.** Assess ARV adherence at the six-week immunization visit or earlier. Record '**G**ood' if ≤ 3 doses, '**F**air' if 4-8 doses, or '**P**oor' ≥ 9 doses are missed, or as determined by the national programme of your country.

Infant follow-up

Every single row in the infant follow-up box represents a facility visit by the infant.

13. **Date.** Record the date (dd/mm/yy) of the visit.
14. **Age in weeks or months.** Write in the age of child (write 'weeks' or 'months') beside the corresponding visit.
15. **Infant feeding counselling and support.** Tick '√' if the mother was provided with infant feeding counselling and support.
16. Infant feeding practise. Write in the infant feeding practise as **'EBF'** (exclusive breastfeeding), **'RF'** (replacement feeding), **'MF'** (mixed feeding, breast milk and other fluids). Exclusive breastfeeding is applicable only until infant is six months of age.
17. **HIV test.** The appropriate HIV test for infants is age specific, and also depends on availability of viral tests. Where available, a viral test is recommended for all HIV-exposed infants at six weeks of age. Write in the type of HIV test done for the infant as **'Ab'** (if it is an antibody test) or **'PCR'** (if it is a PCR viral test). Check **'DBS'** (if it is a PCR test using a dried blood spot), and if it has been sent.

18. **HIV test result.** Some infants may need more than one HIV test before estabilishing or excluding HIV infection. Record all the HIV test results for the child. Write in 'Positive' if the HIV test result is positive, 'Negative' if it is negative, or 'Unknown' if the child is not tested for HIV.
19. **CTX (cotrimoxazole).** Recommend cotrimoxazole prophylaxis for all HIV-exposed infants at four to six weeks of age. Tick '√' if the infant was provided with CTX.
20. **Infant confirmed HIV infected?** Early diagnois of HIV infection and ART are critical interventions for HIV-infected infants. Circle **'Y'** (yes) if the infant is confirmed to be HIV-infected or **'N'** (no).
21. **Date the infant is enrolled in HIV care/ART:** If the infant is confirmed to be HIV-infected, record the date (dd/mm/yy) he or she is enrolled in HIV care/ART.
22. **Unique HIV care/ART number.** Write in the infant's unique HIV care/ART number. (Note that the infant will already have an HIV care/ART card appended to the mother's card if she is alive, but will not be enrolled or given a unique number until HIV infection is confirmed).
23. **Action(s) needed:** Write in any other action needed and recommended (regarding nutrition, adherence, immunization, etc.).

Exercise: filling out the HIV section of the labour and delivery register, labour record and mother and child health cards

Your facilitator will give you the illustrative labour record for this exercise.

A woman is admitted to the clinic at 08:00 in the first stage of labour, but not yet in active labour. She did not know her HIV status and did not receive any ARV drugs during pregnancy. You counselled her and she agreed to an HIV test; the result was positive. She agreed to take ARV prophylaxis.

She goes into active labour at 10:00, and you give her the first dose of AZT 600 mg, sd-NVP 200 mg, and 3TC 150 mg. She is due for the second dose of 3TC 12 hours later. However, there is an emergency admission around that time and you are called to assist. The actual time that you give the second dose of 3TC is 13 hours after the first dose. The third dose of 3TC is given exactly 12 hours after the second dose. She delivers at 15:00 (before the fourth dose is due).

Fill out the ARV prophylaxis section of the labour record for this mother.

Exercise: Interpret information on the mother's card

Answer the questions below based on information on Abebech's and Aselef's cards that your facilitator will hand out to the class.

1. Abebech comes to your health centre in the middle of the night. She is in active labour. When you ask her if she had ANC, she gives you her mother's card (on the next page).
   Answer the following questions from Abebech's card.
   a. What is Abebech's HIV test result, and which week of her pregnancy was the test done?
   b. What preventive interventions were provided to this woman during her ANC visits?
   c. What is Abebech's ANC number?

2. Aselef comes to your health centre in active labour. She has known that she is HIV-positive for the last two years. Her card is shown below. Answer the following questions from Aselef's card.
   a. Which ARV drugs did Aselef receive during this visit? Why and for how long?

Exercise: Filling in HIV information in labour register and the mother's card

Case 1: Mary

Mary's delivery

Mary started to have labour pains on the morning of 12 July. She came to the hospital and was given AZT and 3TC during labour.

She delivered a full-term female baby at 20:15. The baby cried immediately after birth. Mary was given 10 units of oxytocin IM. The placenta delivered within 10 minutes. The weight of the baby was 2.2 Kg. Mary had opted to breastfeed the baby, so the newborn was breastfeeding within the first hour of birth. The baby was given sd nevirapine.

Please fill in the registers and cards appropriate information.

Mary's postpartum period

Mary stayed at the hospital for 12 hours. She had a slight fever within two hours of delivery which subsided on its own. She was breastfeeding her newborn every two hours. The nurse came to examine her after two hours. Her pulse was 90 and her BP was 120/78. Her temperature was normal. Her uterus had contracted and she had normal bleeding and her vulva appeared normal. She had already passed urine. The nurse also examined her breasts and counselled her on breastfeeding. The baby was sleeping well and had no problems.

Mary wanted to go home and was discharged at 09:30 on 13 July. Before discharge she was counselled on family planning. She was also prescribed IFA and calcium tablets. She was given AZT and 3TC for one week for herself, as well as six weeks of nevirapine for the baby. She was asked to return after one month for follow-up, or earlier if she had problems. The baby was given BCG and hepatitis B vaccine before discharge.

Please fill in the registers and cards appropriate information

Follow up visit - post natal

Mary returned to the postnatal clinic after five weeks. She was examined by the nurse. Her abdomen was soft, her uterus had contracted and her vaginal bleeding was minimal. Her breasts were normal. She had given the nevirapine to the baby as prescribed. The baby's weight was 3.0 Kg and she was breastfeeding well. Mary was counselled on family planning and exclusive breastfeeding. The baby was given a second dose of hepatitis B vaccine and a first dose of DPT/OPV. The DBS of the baby was prepared. Mary's Hb was tested and it was 9 gms/dl. She was prescribed IFA and calcium tablets for another two months. She was asked to return within four weeks to collect the DBS result and to have a follow-up examination.

Please fill in the registers and cards appropriate information

Which option for ARV is recommended to Mary? What could have been the other option? In case Mary had decided not to breastfeed, what would be the ARV options for her and the baby?

Please discuss.

5.13. HIV-exposed infant register

This register is important in providing longitudinal care for HIV-exposed infants. All HIV-exposed infants enter care at different points, e.g. maternal health services, adult HIV care services, routine child health services, inpatient wards, or are referred from other facilities or community services. They need longitudinal care to ensure early diagnosis of HIV infection, a timely initiation of cotrimoxazole prophylaxis, and to ensure that they obtain access to ART as early as indicated.

An **HIV-exposed infant register** should be used at all facilities where HIV care/ART follow-up of the infant, or postpartum care of mothers is taking place. Linkages between the mother;s and the infant's care are aimed at promoting a continuum of care for both. These are reinforced through capturing the estimated due date (EDD), the ANC number, and the HIV-exposed infant's number on the woman's HIV care/ART card, and in her pre-ART and ART register entries. As well as facilitating linkages at the individual level during patient management, this allows cross-referencing of registers to maximize quality follow-up of all mother/baby pairs.

HIV Exposed Infant Register

EDD Date of delivery	HIV-exposed infant registration No.	Mother's unique HIV care/ART No.	Name	Duration ARVs during pregnancy	Infant ARV prophylaxis	Infant feeding practice within last 24 hours at DPT3 visit	Age in wks./ mos. started CTX	Test/retest				Date enrolled in HIV care, unique No.	Final status (Dead, Positive N, N/BF, Unknown)
(dd/mm/yy)								Date (dd/mm/yy)	Age in wks. /mos.	Ab or PCR	Result (P or N)		

Codes fro ARV during pregnancy	Codes for infant ARV prophylaxis	Codes for infant feeding practice
None AZT Triple ARVs ART	None AZT NVP	EBF RF MF

5.14. Filling out items in the HIV-exposed infant register

1. **Date of birth.** Write in the infant's date of birth (dd/mm/yy).
2. **HIV-exposed infant registration number.** Write in HIV-exposed infant registration number as relevant (this is different from the unique ID number given on confirmation of HIV infection and enrolment in chronic HIV care; see column 11).
3. **Mother's unique HIV care/ART number.** Write in the mother's unique HIV care/ART number if she is enrolled in HIV care or ART.
4. **Name of the infant.** Write in the first and last name of the infant.
5. **ARVs during pregnancy.** Write in **'None'** if the mother did not take any ARVs during pregnancy; **'AZT'** if she took AZT; 'Triple ARVs' if she took these; **'ART'** if she was on ART.
6. **Infant ARV prophylaxis.** Write 'None' if ARV prophylaxis was not taken; 'AZT' if the infant took it; or 'NVP' if the infant received this medication.
7. **Infant feeding practise within 24 hours of the last time seen at three months (at DPT3 visit).** Ask «what/how did you feed your baby in the last 24 hours?» Write **'EBF'** if the infant is exclusively breastfeeding; **'RF'** if the infant is replacement feeding; or **'MF'** if the infant is mixed feeding.
8. **Age the infant started CTX.** Write the age in weeks or months when cotrimoxazole prophylaxis was initiated, specify 'wks' or 'mos'.
9. **Test/Retest.** Write in information regarding the first test above the line, and information regarding the second test below the line.
   - 9.1 **Date.** Write in the date the infant was HIV tested (dd/mm/yy).
   - 9.2 **Age in weeks/months.** Write in the infant's age at the time of the test in weeks or months; specify 'wks' or 'mos'.
   - 9.3 **Ab or PCR.** Write in **'Ab'** if an antibody test was done; **'PCR'** if a PCR test was done.
   - 9.4 **Results P/N.** Write **'P'** if the test result is positive; **'N'** if the test result is negative.
10. **Date enrolled in HIV care, unique number.** If the infant is confirmed to be HIV-infected, write in the date he/she is enrolled in HIV care (dd/mm/yy) in the upper cell, and the unique HIV care/ART ID number in the lower cell. Transfer the infant's information to the pre-ART register.
11. **Final status.** Record the status of the infant at 18 months, or sooner if the infant died or was confirmed HIV-infected before the age of 18 months. Write in **'Dead'** if the infant is dead; **'P'** if the infant is confirmed to be HIV-infected; **'N'** if the infant is HIV-negative and no longer breastfeeding; **'N/BF'** if the infant is HIV-negative and still breastfeeding; or **'U'** if the infant's status is unknown. If the infant is dead, write in the date of death if it is known.

Exercise: maternal health card

1. A 36-year-old woman gave birth at Mato health centre six weeks ago. Today, she comes to the clinic for her second postpartum visit. Below is her maternal health card. Use it to answer the following questions:
   a. How many ANC visits did this woman have at Mato clinic?
   b. What laboratory tests were done for her during pregnancy? And what were the results?
   c. What treatments did she receive during her antenatal period?
   d. Did this woman receive ARV drugs during pregnancy? Explain.
   e. When and where did this woman give birth?
   f. What interventions did her baby receive at Mato clinic? Explain.

Case studies: Fill in the HIV-exposed infant register

1. Albert Makonsa is a six-week-old infant who is brought to your health centre for his first follow-up visit. His mother was told she was HIV-positive two years ago. She is enrolled in chronic HIV care, and has been taking ART (AZT-3TC-NVP) for the past year. She had regular follow-up at your MCH clinic where she also gave birth. Albert is breastfeeding exclusively based on the choice of his mother following breastfeeding counselling.
   Albert is brought today for an HIV test, as advised by the maternity ward nurse. The nurse sent a sample for the PCR test to the central hospital and started Albert on cotrimoxazole prophylaxis.
   Answer the following questions based on the maternal card that your facilitator will hand out in class:
   A. Which ARV regimen did Albert receive, and for how long?
   B. For how long didn Albert's mother take ART during pregnancy?
   C. What was the mother's infant feeding practise while in the maternity ward?

   Update the infant-follow-up section of the child card and record the information in the HIV-exposed infant register.

Notes

6. The facility-based cross-sectional report

6.1. Learning objectives

By the end of this chapter you should be able to:
- understand the differences between the cross-sectional and cohort reports;
- understand the purpose and usefulness of the facility-based, cross-sectional HIV care/ART report form;
- know where to find the information needed to fill in this form;
- accurately tally information on the form.

6.2. Cross-sectional and cohort analysis reports

There are two reports that aggregate data from the registers – a cross-sectional (monthly or quarterly) report and a cohort analysis report. The cross-sectional report is a current tally or snapshot in time of what is happening at your facility. It provides the numbers of patients newly and cumulatively enrolled in care and started on ART, and currently on ART. This report includes patients who have been on ART for different lengths of time.

The cohort analysis report allows comparison of patients who have been on ART for the same length of time. It compares baseline characteristics of ART start-up groups (monthly cohorts) with their status at six months, then yearly. It allows the clinical and district teams to monitor how well the programme is doing by for example, looking at survival and continuation on first-line regimens.

Section 7 of this manual describes how both reports can be used for programme management at all levels.

6.3. Purpose of the facility-based cross-sectional report form and how it is used

The facility-based cross-sectional report form is completed on a quarterly (or monthly) basis. It is designed to report on what has happened that is **new in the previous quarter** and is also a **cross-sectional summary of all patients currently on ART**, as of the end of the previous quarter. A copy of this facility-based report usually goes to both the district and national levels. However, a copy should always stay at the facility so the clinical team can use the information for planning purposes (see section 8 on how to use information). The report includes information on chronic HIV care and ART from a single health facility (or a single project with its own registers within a large facility). These numbers are important for monitoring programme coverage, managing the drug supply, and for assessing other inputs.

The cross-sectional report can be adapted for use at any time interval - such as monthly or quarterly, depending on a country's information needs. Whatever reporting interval is adopted, the cross-sectional report covers from the first to the last day of the reporting period. Examples of the monthly and quarterly formats of the report are in tab 6 of this training manual. For the purposes of this training session and the exercises included, the quarterly format will be used.

Tables 1 and 3 of the cross-sectional report use a very simple principle that means you only have to count once the patients who are new to HIV care and ART.

Previous reporting quarter's cumulative ever enrolled in HIV care total (from the previous reporting quarter's report column 4) (column 2)	+	New in the reporting quarter (column 3)	=	Cumulative ever enrolled in HIV care or on ART (column 4)

In each reporting period, you only have to tally the middle column. The data in the left column come from the previous reporting period. The data in the right column come from adding the left and the middle columns.

Patients make their way through the steps presented in the boxes on the next page. After testing HIV-positive, patients are newly enrolled in HIV care (boxes A and C). Some enrol in HIV care and are already eligible for ART; others are not yet eligible. All new patients are listed in the pre-ART register and tallied up as 'new in HIV care' in the middle column of Table 1. You need to tally them by age (zero (0) to 14 years, or more than 14 years) and whether they are adult men or women; or boys or girls. You only count the patients that enrolled in the reporting period, i.e. everyone is counted as new in HIV care only once.

Patients may stay for some time in box B; enrolled in HIV care, but not yet eligible for ART. Once eligible for ART, they move to:
- Box D: eligible for ART (but not yet ready and not on ART); then
- Box E: eligible and ready for ART (but not yet on it); then
- Box F: new in ART during the last reporting period.

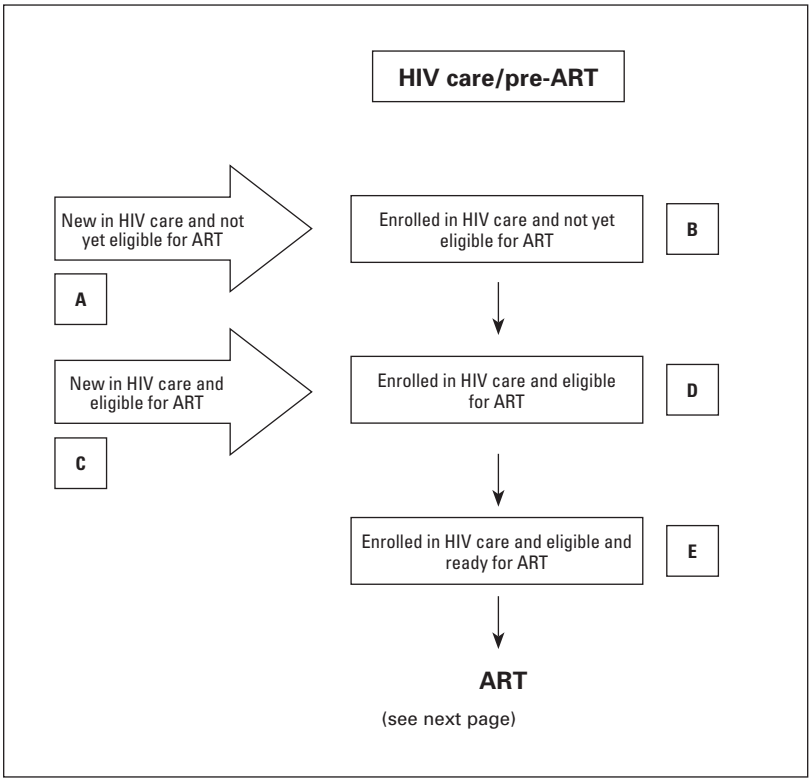
All patients who are in Box D and E will be listed in «s» (at the bottom of Table 1).

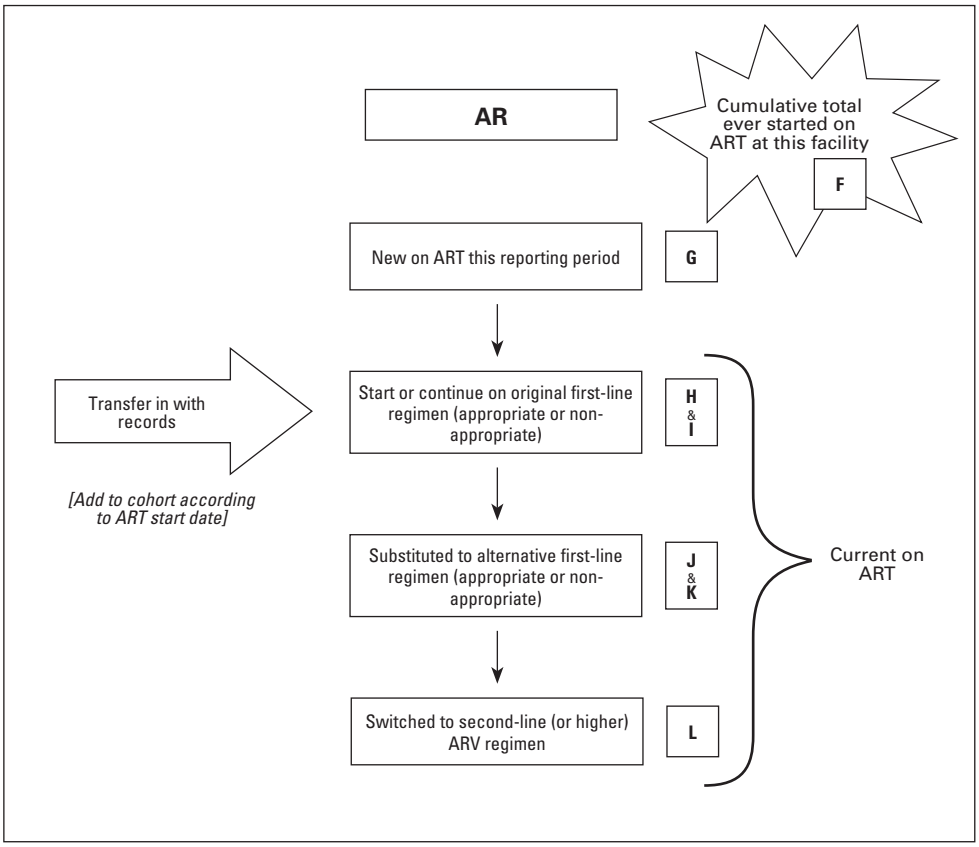
Once started on ART, the patients are also counted for that reporting period and for all subsequent reporting periods, either in:
- Box H: on the original first-line regimen;
- Box I: on an alternative first-line regimen (an ARV drug has been substituted); or
- Box J: on a second-line or higher regimen.

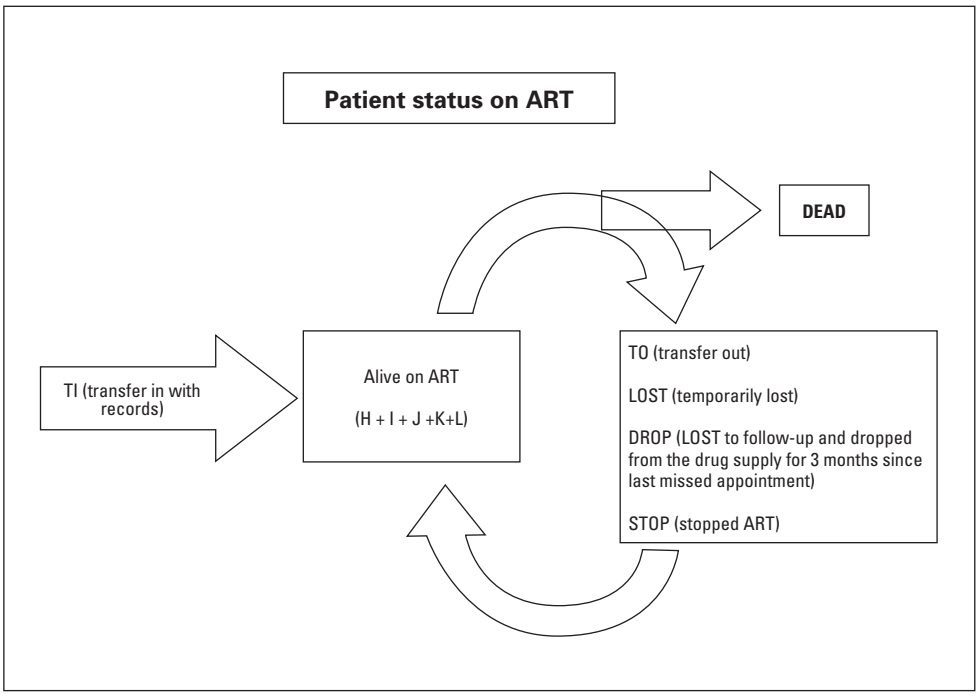
It is clearly very important that patients stay in Box H or I for as long as possible, since the original first-line regimens are the least expensive and are more available.

6.4. Where to find the information

The data for the facility-based cross-sectional report form can be compiled from the pre-ART and ART registers. In larger facilities with a separate pharmacy, some data can be collected directly from there (i.e. the ARV regimen in Table 4) in addition to the patient registration area and the clinic. Information from these various locations is linked through the unique code/number for each patient.




AR
Cumulative total ever started on ART at this facility
F
New on ART this reporting period
G
Transfer in with records
[Add to cohort according to ART start date]
Start or continue on original first-line regimen (appropriate or non-appropriate)
H & I
Substituted to alternative first-line regimen (appropriate or non-appropriate)
J & K
Switched to second-line (or higher) ARV regimen
L
Current on ART


Patient status on ART
DEAD
TI (transfer in with records)
Alive on ART
(H + I + J +K+L)
TO (transfer out)
LOST (temporarily lost)
DROP (LOST to follow-up and dropped from the drug supply for 3 months since last missed appointment)
STOP (stopped ART)

6.5. How to tally information on the cross-sectional report form

The generic cross-sectional report has 7 tables.

Using two people – one to read out the register data, and the other to record and tally them – may facilitate the counts needed disaggregated by sex, age and pregnancy status in Tables 1, 2 , 3 and 4.

Table 1. HIV care (non-ART and ART) – the new and cumulative number of persons enrolled

This table is designed to report information about all of the HIV-infected patients whether they are eligible or not eligible for ART, and who are enrolled in (registered for) HIV care at a facility.

The information in this table is broken down into categories of sex and age:
Column 2 of Table 1: **Cumulative number of persons ever enrolled in HIV care at this facility at beginning of the previous quarter**. Go back to last quarter's report to find this information. Transfer the data from Table 1, column 4, cells 'c-o', into column 2 of this month's report (cells 'a-m' of this report).

Column 3: **New persons enrolled in HIV care at this facility during the previous quarter.** The information for these cells can be found in the pre-ART register.

Go to the pre-ART register and look at the first column *'Date enrolled in chronic HIV care'.* Count the number of patients who enrolled in HIV care during the previous quarter, from the first to the last day. You should count every patient. Since they just recently enrolled, it is unlikely that they will have died, been lost to follow-up or transferred out. But even if they did, they still count as having newly enrolled in HIV care in the previous quarter. If they already started on ART, they should still be counted as newly enrolled in HIV care in the previous quarter.

You and the second person should both count the total, then tally the patients into the following categories (using an enlarged version of the quarterly report form or similar tally tool), making sure that each person is only in one category by using the age and sex :
- Male > 14 years
- Female > 14 years
- Females (< 14 years)
- Males (< 14 years).

Of patients newly enrolled in HIV care during the reporting period, count those who:
- are pregnant (p);
- started INH prophylaxis (q);
- are already enrolled in HIV care who transferred in from another facility (r).

The pre-ART register includes the patient's age, sex, pregnancy status, INH prophylaxis and status at enrolment, so you have all the information needed to do this tally. Remember that you only tally those who enrolled in the reporting quarter. You obtain the cumulative prior to the reporting quarter from the report of the last reporting quarter.

The sample pre-ART register section below shows six male adults, one non-pregnant female adult, one pregnant female adult, one male child and five non-pregnant female children as having newly enrolled in HIV care in March 2004, for a total of 14 patients newly enrolled in HIV care.

Sample pre-ART register for March 2004: selected columns

Registration				PMTCT
Date enrolled in chronic HIV care	Patient clinic ID No.	Age	Sex	For each pregnancy, record EDD, ANC No. and HIV-exposed infant No.
1.3.04	12481	11	F	
2.3.04	12482	50	M	
2.3.04	12483	2	M	
3.3.04	12485	5	F	
4.3.04	12489	18	M	
5.3.04	12658	45	F	
7.3.04	18694	24	M	
8.3.04	12968	37	M	
9.3.04	19844	23	F	12.7.04 ANC No: 00348
10.3.04	98472	67	M	
14.3.04	29106	14	F	
14.3.04	28491	6	F	
15.3.04	92849	26	M	
15.3.04	10296	13	F	

Column 4: **Cumulative number of persons ever enrolled in HIV care at this facility at the end of the previous quarter.** Add the numbers in the cells across the rows as follows:
- add cells 'a' and 'b' and write the total in cell 'c';
- add cells 'd' and 'e' and write the total in cell 'f';
- add cells 'g' and 'h' and write the total in cell 'i';
- add cells 'j' and 'k' and write the total in cell 'l'.

For the last quarter, you vertically added up cells «a» to «j»; this total is «m» which gives you the total cumulative number of persons ever enrolled up until the beginning of this quarter.

For this quarter, you vertically add up the new patients in cells «b» to «k» which gives the total number of new persons in the previous quarter, «n».

If you add this quarter's cumulative ever enrolled totals vertically from «c» to «l», you end up with «o», the current cumulative number of patients ever enrolled in HIV care at your facility.

You can check your work by making sure that if you add 'm' and 'n' (going across the row), that you also obtain the same total; 'o'.

You calculate the percentage for the cumulative number of persons, ever enrolled in HIV care at this facility at end of the current reporting period, as follows:
- Male < 14 - c/o x 100%
- Female < 14 - f/o x 100%
- Male > 14 - i/o x 100%
- Female > 14 - l/o x 100%.

Total number of persons who are enrolled and medically eligible for ART, but have not been started on it (cell «s»)

This information comes from the pre-ART register. Do not count patients who have started on ART or who have died, transferred out or been lost to follow-up before starting ART. Tally patients who are eligible and have not started, *regardless* of whether or not they are ready or selected for ART. In places with a rationed amount of ART, 's' is also known as the «waiting list'.

Sample pre-ART register for November 2004: selected columns

Date medically eligible for ART	Date ART started (transfer to ART register)	Unique ART number
2/11/04		
2/11/04	5/12/04	HED00012
5/11/04		
6/11/04		
14/11/04		

Of these five patients, four are eligible but not yet started on ART («s»). One has already started ART.

Cell 's' is an updated total based on patients who become newly eligible, and those who are no longer eligible because they started ART, or are no longer seen during the reporting period. Unlike the rest of Table 1, column 4, this is not a cumulative total of patients who become newly eligible for ART in the previous quarter. Without the help of a tallying tool, it is necessary to go through each page of the entire pre-ART register to tally patients currently enrolled and eligible.

With a simple tallying tool such as the one provided in Annex 2, you can update any patients who become newly eligible for ART during the new reporting period by tallying them in the left column (these will be additions to the previous quarter's total), as well as patients who have since started ART, died, been lost to follow-up or transferred out in the previous quarter (these will be subtractions from the total). By keeping this simple tool next to the pre-ART register, and updating it when relevant, it will be possible to add newly eligible patients (5) and subtract those who are no longer eligible (1) to the previous quarter's total (plus 4) without going through the entire pre-ART register every quarter.

Table 2. Pre-ART persons seen for HIV care during the reporting period

Old total ('s' from last reporting period's report)		Tally of persons who have become newly eligible in the reporting period (add)		Tally of persons who were eligible in the last reporting period and have since started ART, died, transferred out or been lost to follow-up (subtract)		New total
X	+	IIII \	=	I	=	X+4

This information comes from the right-hand side of the pre-ART register.
Count all patients seen in the reporting period ''a''.
Of patients seen in the reporting period, count those whose TB status was assessed and filled in at the last visit in the reporting period ''b'' (calculate the percentage as b/a X 100%).

Of patients seen in the reporting period, count those who started TB treatment during the reporting period ''c'' (calculate the percentage as c/a x 100%).

Table 3. ART care – new and cumulative number of persons started on ART

The top section of this table is designed to report information about patients who started on ART at a facility. Please note that patients who are on ART and were enrolled in the programme at another facility, i.e. the transfer-in patients below the line in each cohort in the ART register, should not be included in the 'Cumulative number of persons ever started on ART at this facility' because **they have already been counted in the programme at the other facility.**

As in Table 1, the count of patients starting on ART needs to be tallied and broken down into categories (disaggregated): sex and age.

Column 2: **Cumulative number of persons ever started on ART at this facility at beginning of the previous quarter**. Go back to last quarter's report and transfer this information (from column 4, cells 'c-o', into column 2, cells 'a-m' of this report). Do not recount.

Column 3: **New persons started on ART at this facility during the previous quarter.**

This information can be found in the ART register.

The ART register is organized by month – everyone on a large double page (two A-3 sheets, with one row per patient) was started in the same month. If more than 20 patients are started in a month, or the country decides to adapt an ART register that covers more than two years, there will be more than one double page for that month. Go to the ART register and count the number of patients who started ART during the previous quarter. Do this for cohorts who started ART during all three months of the quarter.

You should count the total, then tally (using an enlarged version of the quarterly report form or some other easy way), making sure that each person is in only one category:
- Male > 14 years
- Female > 14 years
- Children five-14 years
- Children one-4 years
- Children < one year

Put the total in cell 'q' in column 3.

The sample ART register section below shows that four male adults, three female adults and no children were newly started on ART in October 2004, for a total of seven patients newly enrolled in ART. You do not count the transfer-in patients below the double line because they have already been counted as newly started on ART at their facility of origin. Do this for the other months in the quarter – i.e. November and December 2004.

Sample ART register for October 2004: selected columns (For each pregnancy, record the EDD, the ANC number and the HIV-exposed infant number).

Year 2004 Month October

Registration and personal information			**PMTCT**
ART Start Date	Age	Sex	For each pregnancy record EDD, ANC No. HIV-exposed infant No.
01.10.04	M	40	
02.10.04	F	45	
08.10.04	M	26	
10.10.04	M	27	
15.10.04	F	28	
16.10.04	M	36	
18.10.04	F	38	
20.10.04	M	29	
22.10.04	F	30	

Column 4: **Cumulative number of persons ever started on ART at this facility at the end of the previous quarter.** Add the numbers in the cells across the rows as follows:
- add cells 'a' and 'b' and write the total in cell 'c';
- add cells 'd' and 'e' and write the total in cell 'f';
- add cells 'g' and 'h' and write the total in cell 'i';
- add cells 'j' and 'k' and write the total in cell 'l';
- add cells «m» and «n» and write total in cell «o».

For the last quarter, you vertically added up cells «a» to «m» – this total is «p» – which gives you the total cumulative number of persons ever started on ART up until the beginning of this quarter.

For this quarter, you vertically add up the new patients in cells «b» to «n»; this gives the total number of new persons in the last quarter, «q».

If you add this quarter's cumulative ever started on ART totals vertically, from «c» to «o», you end up with «r», the current cumulative number ever started on ART at your facility.

You can check your work by making sure that if you add 'p' and 'q' (going across the row), that you also finish with the same total, 'r'.

Table 4. ARV regimen at end of quarter (total current on ART)

Year 2005		**Write in month January**			
Month 0 Jan '05	Month 1 Feb '05	2 Mar '05	3 Apr '05	4 May '05	5 Jun '05
1a	1a	1a	1a	1a	1a
1a	1b	1b	1b	1b	1b
1a	1a	1a	1a	1a	1a
1a	1a	1a	1a	LOST	1a
1a	1a	1a	STOP/8		
		1a	1a	1c	1c

For the reporting quarter January-March 2005, tally the regimens in the March column. Do this for all cohorts in the ART register with data in this column.

This table includes information about the number of persons on first-line and second-line (and higher) ART regimens at the end of the previous quarter, and is sorted by age groups (adults > 14 years versus children five-14 years, one to four years and <one year), and sex. This information is found in the ART register; tally the ARV regimen listed in the column for the last or third month (end) of the quarter. For example, if the reporting period is the quarter January-March 2005, you will count the regimens picked up and recorded in the *March 2005* column on the right-hand side of the ART register.

Even if a patient switched regimens during the reporting quarter, you will still only count the regimen recorded in the last month of the quarter. You will need to tally up the regimen by sex and adult/child from all of the ART register pages using the age and sex columns.

To facilitate adding up these results from multiple ART cohorts, you can enlarge the quarterly report form to use as a tally sheet. Put the regimen (first-line or second-line) next to the drug abbreviations.

Note that first- and second-line regimens are listed in each category, followed by several blank cells. Regimens not listed can be added as needed.

After you have done the tallies, convert the tally to numbers. Then add up the totals across the rows and vertically (for example, *Adult and child Females on second-line regimens:* Add up the numbers in cells 'q-z' and enter the total in cell 'ac').

The total number of adults and children on first-line and second-line regimens will equal the 'Total current on ART' («ag»). This is the numerator for the UNGASS and National Core 7 indicators, *Percentage of people with advanced HIV infection receiving antiretroviral combination therapy.*

Subset of those current on ART

For the TB status assessed at the patient's last visit during the reporting period: count patients with TB status who were assessed and recorded in the ART register at their last visit in the reporting period ''ah''.

For TB treatment started during the reporting period: count patients who started on TB treatment or started on ART while on TB treatment in the reporting period ''ai''.

Table 5. Antenatal care

This table is designed to report information about pregnant women who are enrolled in ANC at a facility. Please note that this report is for ALL pregnant women in ANC.

New ANC patients during the reporting period (a)

Count all new clients enrolled in ANC during the reporting period.

Known HIV-positive patients at arrival during the reporting period (b)

For patients who enrolled in ANC during the reporting period, count all HIV-positive women at enrolment.

HIV tested and received their results during the reporting period (c)

Count all pregnant women who were not known to be HIV-positive at enrolment in ANC, who were tested for HIV and received their result during the reporting period.

Tested HIV-positive and received their results during the reporting period (d)

This is a subset of ''c''. Of pregnant women who were not known to be HIV-positive at enrolment in ANC and who were tested for HIV and received their results during the reporting period, count all those who were known to be HIV-positive.

Total known status (e =) b+c

This is the sum of female patients known to be HIV-positive at enrolment (b), and those who were tested for HIV and received their results in ANC during the reporting period (c).

Total HIV-positive pregnant women (f) = b+d

This is the sum of female patients who were known to be HIV-positive at enrolment (b), and those who tested positive for HIV and received their results in ANC during the reporting period (d).

Total assessed for ART eligibility by CD4 or clinical staging (g)

For HIV-positive pregnant women in ANC, count all who were assessed for ART eligibility by CD4 or clinical staging during the reporting period.

The total number of HIV-infected pregnant women who received ARV prophylaxis or ART during the reporting period (latest)

For HIV-positive pregnant women in ANC, count all who received ARV prophylaxis or ART during the reporting period (h). This count needs to be disaggregated by those who received:

- **AZT only during the reporting period (i);**
- **Triple ARVs during the reporting period (j);**
- **ART during the reporting period (k).**

For all pregnant women in ANC, count those who received:

- **IPT1 (malaria) during the reporting period (l);**
- **IPT2 (malaria) during the reporting period (m);**
- **four or more ANC visits (o);**
- **Hb test (p);**
- **the total number of women screened for syphilis at least once at any visit (q);**
- **the total number of women who were positive after a syphilis test (r);**
- **treatment for syphilis (s)**
- **iron supplements for at least three months (t).**
- **TT2 during the reporting period(u)**
- **pregnant women provided with ITN in the reporting period(v)**

Table 6. Labour and delivery

Delivered in the facility (a)

Count all mothers who delivered a newborn at the facility during the reporting period. Then count those delivered by:
- **normal vaginal delivery (b)**
- **assisted vaginal delivery (c)**
- **caesarean section (d).**

For deliveries at the facility during the reporting period, count all with a delivery outcome of a:
- **live baby (e)**
- **stillbirth (f).**

Of the live deliveries at the facility during the reporting period, count all newborns with a:
- **birth weight ≥2,500gm (g)**
- **birth weight < 2,500 gm (h).**

Count all patients who arrived at the facility due to labour and delivery (L & D) complications (i).

Count all patients whose complications were managed/referred from the facility (j).

Known HIV-positive at arrival during reporting period (k)

For all mothers delivered at the facility in the reporting period, count all with a known HIV-positive result on arrival.

Pregnant women seen in L & D with unknown HIV status who were HIV tested and received results during the reporting period

Count all pregnant women seen in L & D with unknown HIV status who were tested for HIV and received their result during the reporting period.

Tested HIV-positive and received results in L & D during the reporting period

Of pregnant women who were seen in L & D with unknown HIV status, and who were tested for HIV and received their result during the reporting period, count all of those who were HIV-positive.

Total HIV-positive pregnant women (k+m)

Count all women who were known to be HIV-positive on arrival at L & D, and those who tested positive for HIV and received their results in L & D during the reporting period.

Total number who received maternal ARV prophylaxis or ART during the reporting period (latest)
For HIV-positive pregnant women in L & D, count all who received ARV prophylaxis or ART during the reporting period, and count those who received:
- **AZT only during the reporting period;**
- **Triple ARV during the reporting period;**
- **ART during the reporting period.**

Patients who received active management during the third stage of labour

For all patients who delivered at the facility, count those who received active management of their third stage of labour.

Newborns with complications managed/referred from the facility

Table 7. HIV-exposed infants

Total number of HIV-exposed infants who turned 12 months of age in the reporting period

Count all HIV-exposed infants who turned 12 months of age in the reporting period.

Total number who received an HIV test by 12 months

For HIV-exposed infants who turned 12 months of age in the reporting period, count all who received an HIV test. Then, disaggregate this by those who received:
- **an HIV virological test by the age of two months;**
- **an initial virological test between three and 12 months;**
- **a rapid HIV antibody test before 12 months.**

Total number of HIV-exposed infant s who received DPT3

Count all HIV-exposed infants who received DPT3 during the reporting period.

Total number whose feeding practise was assessed at DPT3

For HIV-exposed infants who received DPT3 in the reporting period, count all whose feeding practise was assessed. In addition, count all who were:
- **exclusively breastfed at DPT3**
- **replacement fed at DPT3**
- **mixed fed at DPT3.**

Total number of HIV-exposed infants who turned two months of age in the reporting period

Count all HIV-exposed infants who turned two months of age in the reporting period.

Total number who started on CTX by the age of two months

For HIV-exposed infants who turned two months of age in the reporting period, count all who received CTX.

Total number of HIV-exposed infants who turned 18 months of age in the reporting period

Count all HIV-exposed infants who turned 18 months of age in the reporting period.

Total number of HIV-exposed infants confirmed HIV-positive

For HIV-exposed infants who turned 18 months of age, count all who were confirmed as being HIV-positive.

Total number of HIV-exposed infants who were HIV negative and who were breastfeeding

For HIV-exposed infants who turned 18 months of age, count all who are HIV-negative and breastfeeding.

Total number of HIV-exposed infants who were HIV-negative and no longer breastfeeding

For HIV-exposed infants who turned 18 months of age, count all who are HIV-negative and no longer breastfeeding.

Total number of HIV-exposed infants who received ARV prophylaxis in the reporting period

Received AZT
Received NVP.

Notes

7. The cohort analysis report

7.1. Learning objectives

By the end of this chapter you should be able to:
- understand the purpose and usefulness of the cohort analysis report;
- know where to find the information needed to fill it in ;
- accurately tally information on the report.

7.2. Purpose of the cohort analysis report and how it is used

The cross-sectional report is primarily useful for programme management and measuring programme coverage. The cohort analysis report is where ART programme outcomes and impact are captured.

Data from the cohort analysis report can be used for programme monitoring at the facility-level, as well as higher up in the system. It allows the facility or district team to compare in a meaningful way the success of their care of patients on ART at six and 12 months (within cohorts against the baseline), with earlier or later cohorts, and/or with other districts. The WHO publication *Patient monitoring guidelines for HIV care and ART* encourages delegating responsibility for the registers to someone on the clinical team at each ART site. It is also useful for the clinical team to fill out a cohort analysis report form (in Ethiopia, an enlarged copy is posted on the wall of health facilities). This will depend on the capacity to do so at each facility.

The outcome data covered in the cohort analysis report are critically important for programme monitoring. Therefore, it is essential for the district coordinator (or a designated person in charge of patient monitoring) to fully verify the data. This requires going back to the ART register(s) and recalculating the results for each monthly cohort. It is easier for the clinical team to update the cohort analysis report on a monthly basis, but it is not necessary to complete or transmit it this frequently (as is done with the cross-sectional report). The cohort analysis report can be reported up every six months or even yearly. This will be a national protocol decision.

When disaggregated cohort data (by sex and age) are required, the district coordinator (or a designated person in charge of patient monitoring) will be responsible for electronically transferring key data elements from the facility's ART register into a PDA or laptop during regular site visits. These data are then transferred into an electronic database at the district, regional or national level that allows more in-depth analysis of the cohort data.

7.3. Where to find the information

Data needed to fill in the cohort analysis report are found in the ART register.

Twelve months of baseline ART monthly cohorts (start-up groups) and outcome data at six, 12 and 24 months are included on one side of an A-3 piece of paper. This can be gradually filled out by someone on the clinical team, then transferred to an identical cohort analysis report form by the district monitoring person, in order to report it 'up'. The sample ART register and cohort forms you have been given show how data can be aggregated at the facility level.

7.4. How to tally information on the cohort analysis report

At the end of the month, fill out the grey baseline data column for each ART cohort (start-up group). The next column is for results at the end of six months. In a new programme, you will not be reporting cohort results until at least six months into your scale-up work.

Note that 'baseline' refers to the point in time at which the patient starts ART – **anything** that happens thereafter (transfer out, substitution or switch, stop, etc.) will be recorded in the six-month column. This means that there are several cells that will not need to be filled out and will remain blank, or have zero ('0') values at baseline including transfer-in, transfer-out, substitute, switch, stop, dead and drop.

Fill in the number of persons started on ART at this clinic – original cohort (G). This is a simple tally of the number of patients in the ART register who started ART in that month at that facility. This number does not change and can be carried over to the six-, 12- and 24-month columns for that cohort. In the example shown below, in January your clinic started 13 patients on ART. The number of patients in the original cohort will not change. In the example below, G will also be 13 at six, 12 and 24 months.

Count transfer-in (TI) patients. At the end of each month in the ART register, a line is drawn under all patients who have started ART at that facility during that month. Patients who subsequently transfer in who have previously started ART at another facility are retroactively entered into the ART register under this line according to their ART start date. For example, in the ART register below, one patient transferred in during the month of March, but her start date was in January. She is therefore entered below the line of all patients who started ART in January at that facility.

However, patient outcome data should not be entered retroactively on the second page (right-hand side) of the ART register, with the possible exception of at six, 12, 24, etc. months. The first column that should have data recorded will be for the month in which the patient transferred to the facility. In the example below, the first entry is for March for the patient who transferred in during March. This will therefore be recorded in the six-month column of the cohort analysis. You will also include this person as a transfer-in at 12 and 24 months. This will enable you to see when the patient transferred to your facility, and record this in the appropriate column in the cohort analysis form as a transfer-in.

As described above, at baseline it is too early for anyone to transfer in or out. This is why these cells are crossed out (with 'xxxxxs') at baseline. At six months and thereafter, count the number of patients below the line for each ART start-up group, and enter it in the 'Transfers-in' row. This number is cumulative which means that someone who transfers in during Month two is first reported as a transfer-in at Month six, then again at Month 12, and so on indefinitely until he or she transfers out, if that happens.

Count transfer-out (TO) patients. Patients who transfer out of the facility will be noted by a **'TO'** in the monthly follow-up status cells on the right-hand side of the ART register. Count the total number of **TO**s that have occurred during the previous six, 12 or 24 months for each ART start-up group. For example, the second patient in the ART register shown below transferred out in June. Again, this number is cumulative, so if the person transferred out during Month five, this will first be captured at Month six, then again at Month 12 and so on.

Calculate the net current cohort (N). Take the number of patients in the original cohort, add the transfer-in patients and subtract the transfer-out patients to obtain the net current cohort. At Month 0, N will always equal G because transfer-ins and outs are not possible. In the example below at Month six, there are 13 in the original cohort, one transfer in and one transfer out. Therefore, the net current cohort at month 6 = 13+1-1 = 13.

Count patients on the original appropriate first-line regimen (H): The original first-line regimen is recorded in its own column on the left-hand side of the ART register. This will be the baseline from which to compare subsequent six-, 12- and 24- month reported regimens. At six, 12 and 24 months, compare the reported regimen in the follow-up status cells with the original first-line regimen column. Record the number of patients still on the regimen noted in the original first-line regimen column. At baseline, most patients will have started ART on the original first-line regimen.

An «Appropriate first-line regimen» is one that is included in national guidelines for first-line ART, or that meets WHO recommendations for first-line ART. For patients with a regimen code that represents a standard first-line regimen, classify this as «appropriate». For regimens with a code of «other», retrieve the ART card and classify the regimen as appropriate if it meets national or WHO criteria for a first-line regimen; otherwise classify it as «not appropriate», **(original non-appropriate 1st-line regimen - I)**.

Count patients on an appropriate alternate first-line regimen (substituted) (J). Substitutions are noted in the substitutions column on the left-hand side of the ART register. They will also be recorded in the monthly follow-up status cells. Compare the regimens noted in the original first-line regimen column with the regimen recorded in the six-, 12- or 24-month follow-up status cells, and count the number of patients who have since substituted first-line regimens. For patients with a regimen code that represents a standard first-line regimen, classify it as «appropriate». For regimens with a code of «other», retrieve the ART card and classify the regimen as appropriate if it meets national or WHO criteria for a first-line regimen; otherwise classify it as «not appropriate» **(substitute/alternate non-appropriate 1st-line regimen - K)**

Count patients on a second-line regimen (switched) (L). Similar to substitutions, switches are noted in the 'switches' column on the left-hand side of the ART register, as well as in the monthly follow-up status cells. In this example, one patient switched to regimen 2a in July.

Count patients, who stopped, died or dropped. Count the number of patients who have been recorded as 'STOP', 'DEAD', or 'DROP' in the monthly follow-up status cells during the previous six-, 12- or 24-month reporting periods. At baseline, there will be no patients in these cells.

For patients recorded as **dropped** and who missed their last appointment after the ninth month of initiating ART, you will need to verify that they have not been seen ≥ 90 days To do this, you need to go back to the HIV care/ART card and confirm this. This is important, as the exact day of the missed appointment is not recorded in the ART register, yet knowing it is relevant to calculate the HIVDR EWI.

C**ount patients who were lost.** Count the number of patients who have been recorded as LOST in the monthly follow-up status cells at six, 12 or 24 months. At baseline, there will be no patients in these cells. These patients are counted to ensure comprehensive counting; however, they are not subsequently analysed.

Calculate the percent of the cohort alive and on ART (H+I+J+K+L)/N X100). This is a simple calculation using the data you have just collected in the rows above. For example, in Month six for our January cohort, there are eight patients who remain on original first-line regimen plus one patient who substituted, and one patient who switched. Therefore, 8+1+1=10 is the numerator. The denominator is N, the net current cohort which we calculated earlier to be 13 after accounting for transfers in and out. The percent of the cohort alive and on ART = 10/13*100 = **76.9%.** This is the survival percentage. At baseline, this percentage will almost always be 100%.

Calculate the number of patients on an appropriate first-line regimen (H+J).

Calculate the fraction of adult patients with a CD4 count <100 (of all adults with a CD4 value available at baseline). When CD4 values are available, this baseline fraction will help with the interpretation of later survival rates. This fraction only needs to be calculated at baseline, which is why the other cells are crossed out.

Calculate the fraction of child patients with a CD4 percentage <15% (of all children with a CD4 percentage available at baseline). When CD4 values are available, this baseline fraction will help with the interpretation of later survival rates. This fraction only needs to be calculated at baseline, which is why the other cells are crossed out.

Calculate the CD4 count median or proportion ≥ 200 (of those with an available CD4 count) (optional). CD4 counts are optional for facilities at which CD4 counts are available. At many clinics, patients are started without a baseline CD4. In this example, there are 13 CD4 counts at baseline. If the CD4 counts of the 13 patients were put in order, they would be 10, 20, 20, 25, 40, 45, 50, 100, 120, 150, 180, 180, 230. The median is 50.

Alternatively, because the median of many values can be cumbersome to calculate manually, if there are many CD4 counts available, the proportion of CD4 counts ≥ 200 can be calculated. The numerator is the number of patients with a CD4 equal to or greater than 200 at the relevant time period. The denominator is the number of patients with available CD4 counts during that same time period. In the example provided, the proportion of CD4 counts ≥ 200 = 1/13.

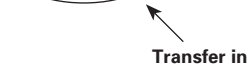
NB: If proportions are used, it is important to show both the denominator and the numerator in order for district coordinators to be able to aggregate these data later on.

In the cohort analysis report, you will be recording the most recent patient outcome that occurred over the last six, 12 or 24 months. Transfer-in and dead patients will always be counted as such across columns (cumulatively). However, transfer-out patients may return, in which case they would stop being counted as transfers-out once they do return (the most recent outcome). They will just remain in the original cohort and be included in the net current cohort. The same applies for patients who are categorized as LOST, DROP, STOP, or if they change regimens. They will be counted as such until a more recent outcome occurs.

For example, a patient who is dropped at Month four will be recorded as such in the Month six column. If, by Month eight she returns, she will be recorded as RESTART (with a regimen code) in the ART register, and will be counted in row H, I, J, K or L and no longer as a DROP. Similarly, for regimen changes, you will enter only the most recent change. For example, when reporting 12-month outcomes for a cohort, if a patient substitutes from 1a to 1b at Month seven, then switches from 1b to 2a at Month eight, you will record this as a switch to a second-line regimen, and NOT as a substitution, so as not to double count the patient.

Sample ART register for the January 2005 cohort: selected columns

Registration and personal information			**Status at start of ART**			**1st-line regimen**	
ART start date	Unique ART number	Age	Weight	*WHO clinical stage*	CD4	Original regimen	Substitutions *1st: Reason / Date* *2nd: Reason / Date*
01.01.05	BA0001	25	52	2	150	1a	
02.01.05	BA0002	23	45	4	25	1a	
08.01.05	BA0003	33	52	3	180	1a	
15.01.05	BA0005	67	44	3	50	1a	
16.01.05	BA0006	45	50	4	20	1a	
18.01.05	BA0007	50	52	4	120	1a	
22.01.05	BA0009	32	46	4	20	1a	
24.01.05	BA0010	40	65	2	180	1a	
26.01.05	BA0011	41	61	3	100	1a	
26.01.05	BA0011	43	52	4	10	1a	
26.01.05	BA0011	51	44	3	230	1a	
26.01.05	BA0011	27	58	4	40	1a	
26.01.05	BA0011	32	38	4	45	1a	
10.01.05	KL0004	45	40	3	150	1a	1c: (1) 15.5.05



Transfer in

Sample ART register for January 2005 cohort: follow-up status for Months 0-6

Patient picks up 3 months of ARVs at each visit

Year 2005							
Month							
0	**1**	**2**	**3**	**4**	**5**	**6**	**CD 4**
Jan '05	***Feb '05***	***Mar '05***	***Apr '05***	***May '05***	***Jun '05***	***Jul '05***	
1a Y	→	→	1a Y	→	→	1a Y	140
1a Y	1a Y	1a Y	1a Y	1a Y	TO		
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	125
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	2a Y	60
1a Y	1a Y	1a Y	STOP				
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	120
1a Y	1a Y	1a Y	LOST	LOST	DROP		
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	130
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	150
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	300
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	150
1a Y	1a Y	1a Y	1a Y	1a Y	1a Y	DEAD	
		1a Y	1a Y	1c Y	1c Y	1c Y	150

For the quarter January-March 2005:
14 patients are on 1a = AZT-3TC-NVP

Sample cohort analysis form with baseline (Month 0) data for the January 2005 cohort

Original cohort does not change

	For cohort starting ART by month/year: at baseline then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 05	6 mo- July05	12 mo- Jan06	24 mo- Jan07	Cohort Feb05	6 mo- Aug05	12 mo Feb06
G	Started on ART in this clinic - original cohort	13	13	13	13			
TI	Transfers-in Add +	x				x		
TO	Transfers-out Subtract -	x				x		
N	Net current cohort	13						
H	On original appropriate 1st-line regimen	13						
I	On original non-appropriate 1st-line regimen	0						
J	On alternate appropriate 1st-line regimen (substituted)	0						
K	On alternate non-appropriate 1st-line regimen (substituted)	0						
L	On 2nd-line regimen (switched)	0						
	Stopped	0						
	Died	0						
	Lost	0						
	Lost to follow-up (DROP)**	0						
	Percent of cohort alive and on ART							
	[(H + I + J + K + L) / N * 100]	13/13						
	Total on appropriate 1st-line regimen (H + J)	13						
	Fraction CD4 < 100 (of adults with available CD4 at baseline)	7/13	x	x	x		x	x
Child < 5	Fraction with CD4% < 15% (of children <5 with available CD4 at baseline)	0/0	x	x	x		x	x
	CD4 median [of those with available CD4]	50						

*Only for patients with a first-line regimen recorded in the ART register as 'other'.
**For patients who missed their last appointment after the ninth month of initiating ART. Go back to their HIV care/ART card and verify whether they have not been seen ≥ 90 days after the date of their last missed appointment day.

This same cohort reaches their «6-month ART birthday» in July. Use the following part of the register:

Year 2005								
Month		Write in month						
0	**1**	**2**	**3**	**4**	**5**	**6**	**CD 4**	**7**
Jan	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**		**Aug**

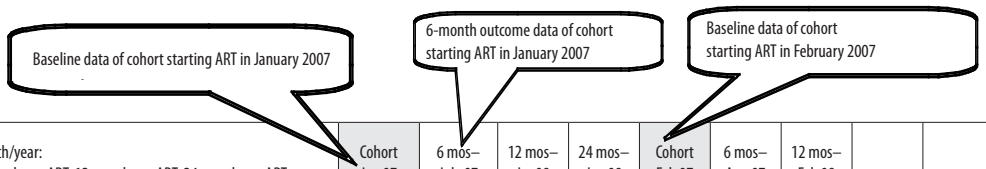
One patient who has transferred in during March started ART in another district's programme in January; she came with her records.

By July, there are nine patients for whom CD4 values are available. When calculating the median CD4 value at Month six, you include the transfer-in patient.

You will wait until early August to fill out the next column which says '6' with the word 'July' under it on the cohort analysis report for this cohort. Things are looking good, although the numbers are very small. The transfer-in patient's outcome is included in the numerator of the survival rate, and the denominator remains the net current cohort.

Once a programme is six months old, there will be six-month outcome data for one cohort each month. Once the programme is 12 months old, there will be 12-month outcome data for one cohort each month, and so on. It is up to the country to decide how often the cohort analysis data should be aggregated and sent 'up'. Most experts suggest this be done every six months or once a year.

Sample cohort analysis form with data for January 05 cohort Months 0 and 6



	For cohort starting ART by month/year: at baseline, then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 07	6 mos– July 07	12 mos– Jan08	24 mos– Jan 09	Cohort Feb 07	6 mos– Aug 07	12 mos– Feb 08			
G	**Started on ART at this clinic - original cohort**	13	13								
TI	**Transfers in** Add +	x	1			x					
TO	**Transfers out** Subtract -	x	1			x					
N	**Net current cohort**	13	13								
H	**On original appropriate 1st-line regimen**	13	8								
I	**On original non-appropriate 1st-line regimen**		1								
J	**On alternate appropriate 1st-line regimen (substituted)**										
K	**On alternate non-appropriate 1st-line regimen (substituted)**										
L	**On 2nd-line regimen (switched)**		1								
	Stopped		1								
	Died		1								
	Lost		0								
	Lost to follow-up (DROP)		1								
	Per cent of cohort alive and on ART										
	[(H + I + J) / N * 100]	100%	77%								
	Fraction with CD4% <5% (of children <5 with available CD4 – optional)										
	Fraction with CD4 <100(of adults with available CD4 at baseline)										
	CD4 median or proportion ≥200 [of those with available CD4] (optional)	50	NA								

Notes

8. Reporting and use of data from the HIV care/ART patient card and the registers

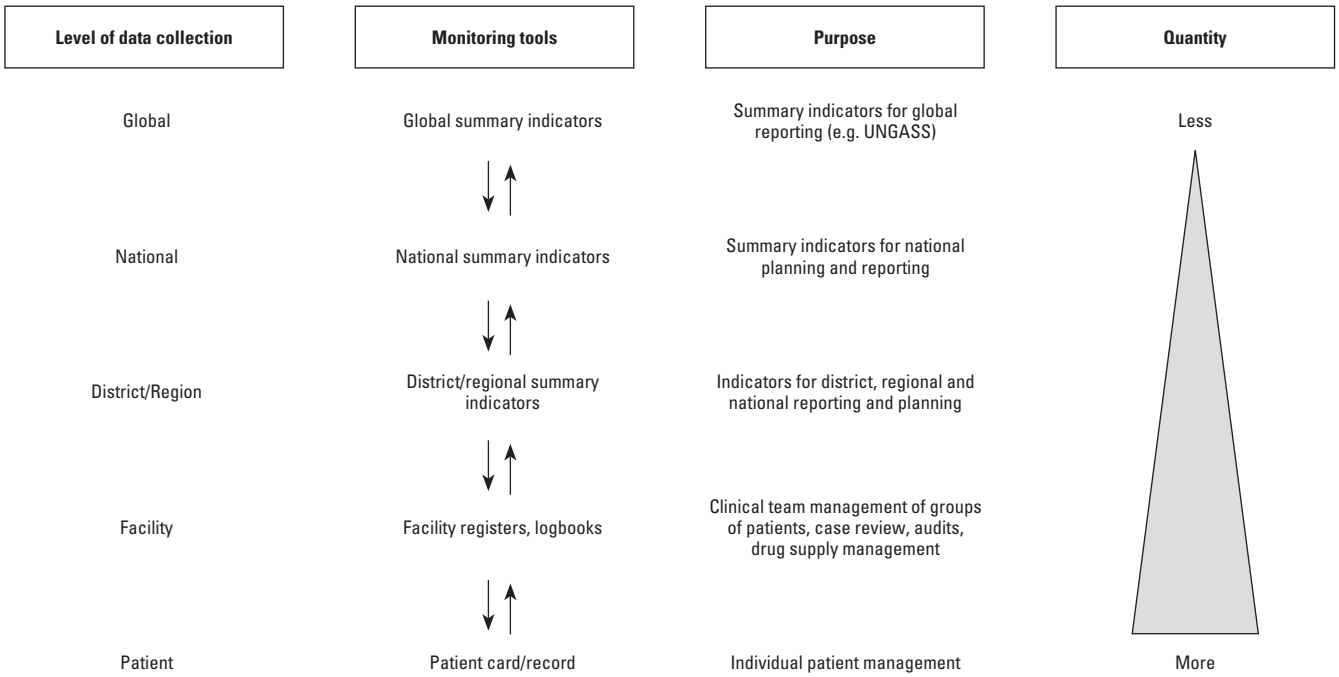
8.1. Learning objectives

By the end of this chapter you should be able to:
- understand how patient monitoring data moves through the health system and can be used at each level;
- understand the purpose and usefulness of the national ARV programme indicators, including which are available from the patient monitoring system;
- know which indicators are available from the facility-based cross-sectional report;
- know how to calculate indicators based on data summarized in the cohort analysis report;
- know how to analyse data not on the report forms, and how to review cases (other analyses by the clinical team).

8.2. HIV care/ART monitoring at different levels of the health system

The figure below shows how the patient monitoring data are used at different levels, and how only a subset move from the facility level (patient card, registers and reports) to the district or regional, national and international levels.

HIV care/ART monitoring at different levels of the health care system[1]



1 Adapted from: Health Metrics Network (HMN). *Statistics saves lives: strengthening country health information systems (Draft).* Geneva, HMN, 2005.

8.3. National indicators that measure overall progress towards universal ART treatment

By tracking and reporting key national-level indicators, all national HIV/AIDS programmes should be able to demonstrate progress in their contribution to universal access to prevention, treatment, care and support. The table below provides an example of global, national and sub-national data that can be collected and used at all levels to monitor quality of care, and to provide a basis for creating various programmes. Those in bold are UA, UNGASS, HIV drug resistance early warning indicators, or other national indicators. (Note: many indicators are expressed as a percentage that is calculated as follows: (Numerator/Denominator) X100.).

Note that most of the data collected for patient monitoring is for use by the clinical and district management teams so they can monitor how they manage groups of patients and national programme management needs, without international reporting or responding to the needs of specific projects such as PEPFAR.

Indicators	Source	How to calculate the indicator
PMTCT		
Percentage of pregnant women who were tested for HIV and received their results	ANC/L&D registers	Numerator: number of pregnant women attending ANC and L&D services who were tested for HIV and received their results; includes women with known HIV infection attending ANC for a new pregnancy during a selected time period Denominator: estimated number of pregnant women during a selected time period
Percentage of HIV-infected pregnant women	ANC/L&D registers	Numerator: number of pregnant women attending ANC and L&D services who tested positive for HIV and received their results; includes women with known HIV infection attending ANC for a new pregnancy during a selected time period Denominator: total number of pregnant women who were tested for HIV and received their results; women with known HIV infection attending ANC for a new pregnancy (with known HIV status) at least once in ANC or L&D during a selected time period
Percentage of HIV-infected pregnant women who received ARVs to reduce the risk of mother-to-child transmission*	ANC/L&D registers	Numerator: number of HIV-infected pregnant women who received ARVs to reduce mother-to-child transmission during a selected time period Denominator: estimated number of HIV-infected pregnant women during a selected time period
Percentage of HIV-infected pregnant women eligible who are receiving ART	HIV care/ART card - (sample of cards)	Numerator: number of HIV-infected pregnant women on ART during a selected time period Denominator: number of HIV-infected pregnant women eligible for ART during a selected time period
Percentage of infants born to HIV-infected women who received an HIV test within 12 months	HIV-exposed infant register	Numerator: number of infants born to HIV-infected women who received an HIV test within 12 months during a selected time period Denominator: estimated number of HIV-infected pregnant women giving birth in the last 12 months during a selected time period
Percentage of infants born to HIV-infected women who received a virological test by two months of age	HIV-exposed infant register	Numerator: number of infants born to HIV-infected women with a DBS test sent for virological test by two months of age during a selected time period Denominator: number of infants born to HIV-infected women who reached two months of age during a selected time period
Percentage of infants born to HIV-infected women initiated on cotrimoxazole prophylaxis within two months of birth	HIV-exposed infant register	Numerator: number of infants born to HIV-infected women started on cotrimoxazole prophylaxis within two months of birth during a selected time period Denominator: estimated number of HIV-infected pregnant women giving birth in the last 12 months during a selected time period
Percentage of HIV-exposed infants who are at three months of age on exclusive breastfeeding, replacement feeding, or mixed feeding	HIV-exposed infant register	Numerator: number of infants born to HIV-infected women who are: a) exclusive breastfeeding; b) replacement feeding; c) mixed feeding (MF) at or around three months during a selected time period Denominator: number of HIV-exposed infants whose feeding practise was assessed around or at three months (through the mother) during a selected time period
Percentage distribution of the final status of HIV-exposed infants at 18 months	HIV-exposed infant register	Numerator: number of HIV exposed infants whose final status at 18 months recorded as: a) positive; b) negative, still breastfeeding; c) negative no longer breastfeeding; d) dead Denominator: total number of HIV-exposed infants identified
Percentage of HIV-infected women using a family planning method at their last visit	HIV care/ART card - sample of patient cards	Numerator: number of HIV-infected women using a family planning method at their last visit during a selected period of time Denominator: total number of HIV-infected women in a selected time period

Indicators	Source	How to calculate the indicator
Percentage of HIV-infected women with an unmet need for family planning	HIV care/ART card - sample of patient cards	Numerator: number of HIV-infected women who want family planning, but are not offered or referred for it at their last visit in a selected time period Denominator: total number of HIV-infected women who want family planning at the last visit in a selected time period
Treatment and care		
Percentage of adults and children with advanced HIV infection receiving ART*	ART register (cross-sectional report)	Numerator: number of adults and children with advanced HIV infection receiving ART during a selected time period Denominator: estimated number of adults and children with advanced HIV infection during a selected time period
Percentage of adults and children with HIV known to be on treatment 12 months after initiation of ART*	ART register (included in cohort analysis)	Numerator: number of adults and children who are still alive and on ART at 12 months after initiating treatment Denominator: total number of adults and children who initiated ART who were expected to achieve a 12-month outcome, including those who have died, stopped ART and those recorded as lost to follow-up
Percentage of HIV-infected children under 5 years with CD4% < 15% at six or 12 months	ART register (included in cohort analysis)	Numerator: number of HIV-infected children under five years with last available CD4% < 15% six or 12 months after initiating treatment Denominator: total number of HIV-infected children under five years at six or 12 months after initiating treatment
Percentage of patients initiating ART at the site during a selected time period who are taking an appropriate first-line ART regimen 12 months later**	ART register (included in cohort analysis), with validation from HIV care/ART card (sample of cards)	Numerator: number of patients initiating ART at the site during a selected time period who are on an appropriate first-line ART regimen (including substitutions of one appropriate first-line regimen for another, but not substitutions of dual- or mono-therapy or an inappropriate three-drug regimen) 12 months from ART initiation Denominator: number of patients initiating ART at the site during a selected time period, excluding from this number, if available, the patients who transferred out during the 12 months after initiating ART. Patients who died, stopped ART, switched to second-line ART, or were lost to follow-up must be included in the denominator
Percentage of patients initiating ART at the site during a selected time period who are initially prescribed, or who initially pick up from the pharmacy, an appropriate first-line ART regimen**	ART register, with validation from HIV care/ ART card (sample of cards)	Numerator: number of patients initiating ART at the site who are prescribed, or who initially pick up from the pharmacy, an appropriate first-line ART regimen during a selected time period Denominator: number of patients initiating ART at the site during a selected time period
Percentage of patients initiating ART at the site in a selected time period who are lost to follow-up during the 12 months after starting ART (cohort)**	ART register (included in cohort analysis)	Numerator: number of patients initiating ART at the site in a selected time period who were not seen at the clinic, or pharmacy > 90 days after the date of their last missed appointment or last missed drug pick-up that occurred within their first 12-months of ART, and who are not known to have transferred out or died Denominator: number of patients who initiated ART during a selected time period, excluding re-starts or transfers-in
Percentage of patients initiating ART at the site during a selected time period who attend all clinic appointments on time (defined as within seven days of the scheduled appointment) during the first 12 months of ART**	HIV care/ART card - sample of cards	Numerator: number of patients who attend all appointments within seven days of the next scheduled or expected appointment date during the first 12 months of ART Denominator: number of patients who initiated ART during a selected time period, excluding re-starts or transfers-in
Percentage of patients attending clinic appointments on time after a selected month**	HIV care/ART card - sample of cards	Numerator: number of patients who attended two consecutive clinic appointments within seven days of the next scheduled or expected appointment dates after attending the clinic during a selected month Denominator: number of patients who attended a clinic appointment during a selected month
Percentage of patients initiating ART at the site during a selected time period who picked up all prescribed ARV drugs on-time during their first 12 months of ART (cohort)**	HIV care/ART card - sample of cards	Numerator: number of patients initiating ART at the site during a selected time period who picked up all their ARV drugs before their previously prescribed drugs would have been exhausted at each pick-up during the first year of ART, or until they were classified as dead, transferred out, or stopped ART Denominator: number of patients initiating ART at the site during a selected time period
Percentage of adults and children enrolled in HIV care and eligible for CTX prophylaxis (according to national guidelines) receiving CTX prophylaxis at last visit	HIV care/ART card - sample of cards	Numerator: number of adults and children receiving CTX prophylaxis among those enrolled in HIV care at their last visit Denominator: number of adults and children enrolled in HIV care who are eligible for CTX prophylaxis at their last visit
Percentage of HIV-infected persons receiving ART who experienced side-effects, OIs or other problems	HIV care/ART card - sample of cards	Numerator: number of HIV-infected persons receiving ART who experience a) side-effects; b) OIs; c) other problems Denominator: total number of HIV-infected persons receiving ART during a selected time period

Indicators	Source	How to calculate the indicator
TB/HIV		
Percentage of TB patients who had an HIV test result recorded in the TB register	BMU TB register	Numerator: number of TB patients registered during a given time period who had an HIV test result recorded in the TB register Denominator: total number of TB patients registered during a given time period
Percentage of registered TB patients who had documented HIV status recorded who are HIV-positive	BMU TB register	Numerator: number of TB patients registered over a given period of time with documented HIV-positive status Denominator: total number of TB patients registered during a given time period with documented HIV status
Percentage of HIV-positive TB patients who receive cotrimoxazole preventive therapy	BMU TB register	Numerator: number of HIV-positive TB patients, registered over a given time period, who receive at least one dose of CPT during their TB treatment Denominator: total number of HIV-positive TB patients registered over a given time period
Percentage of HIV-positive registered TB patients given ART during TB treatment	BMU TB register	Numerator: number of HIV-positive TB patients, registered over a given time period, who receive ART Denominator: number of HIV-positive TB patients registered over a given time period
Percentage of adults and children enrolled in HIV care who had TB status assessed and recorded during their last visit during the reporting period	Pre-ART and ART registers, HIV care/ART card - sample of cards	Numerator: number of adults and children enrolled in HIV care who had their TB status assessed and recorded during their last visit during the reporting period Denominator: total number of adults and children enrolled in HIV care seen at least once during the reporting period
Percentage of adults and children newly-enrolled in HIV care given isoniazid preventive therapy (IPT) for latent TB infection	Pre-ART register	Numerator: number of adults and children newly-enrolled in HIV care who start treatment of latent TB infection over a given time period Denominator: total number of adults and children newly-enrolled in HIV care over a given time period
Percentage of estimated HIV-positive incident TB cases that received treatment for TB and HIV*	ART register	Numerator: number of adults with advanced HIV infection who are currently receiving antiretroviral therapy in accordance with the nationally approved treatment protocol, and who were started on TB treatment (in accordance with national TB programme guidelines) during a selected time period Denominator: estimated number of incident tuberculosis cases in people living with HIV during a selected time period

Calculating indicators or other aggregated data

Agreed minimum essential data elements	What happens to the data	Indicators or other aggregated data
A. At baseline, six, 12 months then yearly 1. On ART and: • ALIVE • DEAD • LOST/DROP/Transfer-out 2. Current regimen • Original appropriate 1st-line • Original non-appropriate 1st line • Substituted to appropriate alternative 1st-line • Substituted to non-appropriate alternative 1st-line • 2nd-line or higher 3. CD4 test results 4. Regimen collected in last quarter	Transfer to ART register then to cohort **analysis report**	Based on cohort analysis form, at **six, 12 months** then **yearly** and compared to **baseline:** **Indicators related to success of ART** • % alive and on ART (survival on ART)* • % still on appropriate first-line regimen* • Median or mean CD4 counts (optional) **HIV drug resistance early warning indicators:** • % switched to a second-line (or higher) regimen
B. 1. When registered for HIV care 2. When medically eligible for ART 3. When ART started 4. Dead before ART 5. Lost or transfer out before ART 6. TB status completed at each visit	Transfer to pre-ART or ART register then to **quarterly report**	**Indicators related to patients who access HIV care and ART:** Disaggregated by adult, child, sex, pregnancy status: • Number enrolled in HIV care: new and cumulative ever at the facility • Number started on ART: new and cumulative ever started at the facility • Number currently on ART at the facility Not disaggregated: • Number started on INH prophylaxis • Number transferred in from another facility • Number eligible for ART but not yet started • Number/% with TB status assessed at last visit • Number/% started on TB treatment in the reporting period

Agreed minimum essential data elements	What happens to the data	Indicators or other aggregated data
C. 1. Why eligible for ART 2. Reasons for: • Substitution within first-line • Switch/substitution to or within second-line • Stop ART 3. Number and weeks of each ART treatment interruption 4. Pregnancy status 5. Start month/year of prophylaxis: • Cotrimoxazole • INH 6. TB treatment 7. Adherence on ART	Transferred to **pre-ART or ART register,** but used only by clinical team /district ART coordinator; not transferred to quarterly report or cohort analysis	**Indicators for patient and programme management at the facility/district level:** • Why eligible for ART: clinical only, CD4 or TLC • Distribution of patients not yet on ART by clinical stage • Distribution of reasons for substitute, switch, stop to investigate problems; whether substitutions and switches are appropriate (use in context reviewing medical officer log) • ART treatment interruptions: • Number/proportion of patients • Number of weeks • % pregnant patients (with EDD and ANC No. to assure linkage with PMTCT and follow up) • Number on cotrimoxazole, INH prophylaxis at end of quarter (for ordering prophylaxis drugs) • Number/% patients on both TB treatment and ART • % patients with good adherence to ART
D. 1. Date of each encounter 2. Weight (each visit; % wt gain or loss) 3. Adherence on CTX 4. Adherence on INH 5. Potential side-effects 6. New OI, other problems 7. TB status (other than treatment or prophylaxis) 8. Referred or consulted with MD 9. Number of inpatient days 10. If poor adherence on ART, reasons (coded)	**Patient card only**. Not transferred to register	**Indicators for patient management at the facility level or special studies:** • % patients referred to MD • Common side-effects, OI, other problems:** ° Patients with special problems** ° Identify patients for review at clinical team meetings** • No. or % patients hospitalized; number of days*** • Reasons for poor adherence***

* National core indicators
** These are used both for individual patient management and for medical officer or clinical mentor review on site visits. For potentially serious side-effects that result in a consultation or referral, the medical officer needs to put in a log and do further adverse event reporting.
*** Tabulations for special studies.

8.4. Indicators available from the facility-based cross-sectional report

There are three ART numbers with important differences available from the facility-based cross-sectional report:
- new on ART (in the last reporting period; not transferred in);
- cumulative ever started on ART at this facility;
- currently on ART at this facility.

'Eligible for ART but not yet started' is a very important number. These patients are enrolled in HIV care, have been assessed and found to be eligible, and are waiting for ART for various reasons. In rationed systems with insufficient ART, this number will grow. Keeping track of patients who die while waiting for ART is not included in the generic quarterly report form, but it is possible to do by using the pre-ART registers.

As previously described, the quarterly report provides a current tally or snapshot, at the end of the prior reporting period, of the ART regimens all patients in your facility are taking, divided into adults and children and by sex. This indicates how many are currently on ART and the proportion on first-line and second-line regimens. It also allows you to validate drug supply management information, and should approximate the numbers of patients picking up drugs that the pharmacy is reporting. This report mixes patients with different lengths of time on ART. In the first months of actively scaling up ART, the cross-sectional report will be dominated by patients newly on ART. This is a limitation of the cross-sectional report, and a reason it is important to also (although less often) use the cohort analysis report.

8.5. How to calculate indicators based on data summarized in the cohort analysis

The cohort analysis report compares baseline characteristics of ART start-up groups (monthly cohorts) with their status at six months, then yearly. Key indicators for the clinical and district team to see how well the programme is doing are calculated using this report. These include the proportion of patients that has survived and is still on a first-line regimen. It allows the team to meaningfully compare success at six and 12 months of ART with earlier or later cohorts, or with other districts. This report does not have to be transmitted every time it is updated at the facility; it can be reported every six months or even during a district or programme review on a yearly basis. See Row A in the table above.

Percentage of patients who initiate antiretroviral therapy at the site during a selected period who are taking an appropriate first-line regimen 12 months later	
Rationale	ART regimen options are limited and it is expected that a large majority of patients will remain on a first-line regimen as long as possible
What it measures	This indicator is part of the Early Warning Indicator for HIV Drug Resistance (EWI HDR) monitoring. It measures the continuation of a first-line regimen as a subset of indicator G3. The suggested target is ≥ 70%
Numerator	**Number of patients who initiate ART at the site during the selected time period who are on an appropriate first-line ART regimen (including substitutions* of one appropriate first-line regimen for another, but not substitutions of dual- or mono-therapy or an inappropriate three-drug regimen) 12 months from ART initiation.** See *Measurement* section below for details
Denominator	**Number of patients initiating ART at the site during a selected time period, excluding from this number, if available, the patients who transferred out during the 12 months after initiating ART. Patients who died, stopped ART, switched to second-line ART, or were lost to follow-up must be included in the denominator**
How to measure and measurement tools	Numerator and denominator: programme monitoring tools; ART register; cohort analysis forms **'Appropriate regimen'** is an ART regimen that meets one or both of the two following definitions: 1. a standard regimen listed in national ART guidelines and used in accordance with those guidelines 2. a regimen recommended in one or more sets of international ART guidelines. In each country, the international guidelines used to define 'appropriate regimens' should be selected by the national HIVDR-WG **'Initiating ART at the site'** is defined as the first prescription of ART at the site in an individual who has not previously received ART there, with the exception of ARV drugs for prevention of mother-to-child transmission (PMTCT), and who has not transferred in on ART. This definition includes: treatment of naïve patients; patients who have received ARV prophylaxis for PMTCT; and non-naïve patients who received ART from other sources and are not recorded as transferred in
Disaggregation	None requested at this stage. However if available, disaggregate by **sex and age group (<15, 15+)**
Strengths and weaknesses	This indicator needs to be interpreted in view of indicator G3 and the overall retention on ART. It measures the continuation of a 1st-line regimen, but it is dependent on the patient's survival and consequently baseline clinical-biological characteristics of the cohorts started on ART
Additional considerations	In countries where this indicator is not produced in all ART sites, but in a sub-set of facilities, interpretation should be completed with some comments on how representative it is
Data utilization	See strengths and weaknesses for interpretation
Data quality control and notes for the reporting tool	**National representativeness:** If this indicator is only produced in a sub-set of facilities, a comment should be added on the source of information and whether the information is representative of all ART sites
Other references	**Health Sector UA Framework Indicator No. 32; Early Warning Indicator for HIVDR**

Source: WHO-UNICEF-UNAIDS: A guide on indicators for monitoring and reporting on the health sector response to HIV/AIDS, January 2009.

From the cohort analysis form, the numerator will be H+J (all patients on an appropriate first-line regimen) for the cohorts at the designated duration of treatment (12, 24 months). The denominator will be **H+I +J +K** at baseline for each of the cohorts.

In the sample cohort analysis form below, this percentage would be constructed in the following way for the January 2005 cohort:

8+1 = Number of patients at 12 months who are still on an appropriate first-line regimen
= 69%
13+0 = Number of patients at baseline who started on an appropriate first-line regimen

It will be necessary to add up across all cohorts with data available for this duration of treatment (i.e. at 12 months). In the sample cohort analysis form, this calculation would be:

8+1 (January 2005 cohort) + 7+1 (February 2005 cohort) + 10+0 (March 2005 cohort) + 8+1 (April 2005 cohort)
= 69%
13+0 (January 2005 cohort) + 8+0 (February 2005 cohort) + 10+0 (March 2005 cohort) + 12+0 (April 2005 cohort)

Note that at facility level, this indicator may be slightly biased if at Month six, 12 or 24 you are also counting patients on a first-line regimen who may have transferred in and were not in the initial start-up group. When this indicator is calculated at national level, the bias should even out across facilities.

Core 8 Denominator = No. of patients who initiated a first-line

Core 8 Numerator = No. of patients who remained on a first-line regimen after 12

	For cohort starting ART by month/year: at baseline then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 05	12 mo- Jan 06	Cohort Feb 05	12 mo-	Cohort Mar 05	12 mo-	Cohort Apr 05	12 mo-
G	**Started on ART in this clinic-original cohort**	13	13	8	8	10	10	12	12
TI	**Transfers-in** Add +	x	1	x	0	x	1	x	0
TO	**Transfers-out** Subtract -	x	1	x	0	x	1	x	2
N	**Net current cohort**	13	13	8	8	10	10	12	10
H	**On original appropriate 1st-line regimen**	13	8	8	7	10	10	12	8
I	**On original non-appropriate 1st-line regimen**	0	0	0	0	0	0	0	0
J	**On alternate appropriate 1st-line regimen**	0	1	0	1	0	0	0	1
K	**On alternate non-appropriate 1st-line regimen***	0	0	0	0	0	0	0	0
L	**On 2nd-line regimen (switched)**	0	1	0	0	0	0	0	0
	Stopped	0	1	0	0	0	0	0	1
	Died	0	1	0	0	0	0	0	0
	Lost	0	0	0	0	0	0	0	0
	Lost to follow-up (DROP)	0	1	0	0	0	0	0	0
	Percent of cohort alive and on ART	13/13	10/13	8/8	8/8	10/10	10/10	12/12	9/10
	[(H + I + J+K+L) / N * 100]	100%	77%	100 %	100 %	100 %	100 %	100 %	90%

Percentage of adults and children with HIV known to be on treatment (a) 12 months, b. 24 months, c. 36 months, d. 48 months) after initiation of antiretroviral therapy	
Rationale	ART is a lifelong therapy that increases survival and reduces HIV transmission
What it measures	This indicator measures the retention on ART related to the increase in patients' survival and their willingness to continue ART. It should be produced at 12 months and then yearly after the beginning of ART. It measures the effectiveness of programme coverage
Numerator	**Number of adults and children who are still alive and on ART a) 12 months, b) 24 months, c) 36months, d) 48months, after initiating treatment**
Denominator	**Total number of adults and children who initiated ART who were expected to achieve 12-month outcomes within the reporting period,* including patients who have died since starting ART, those who have stopped ART, and those recorded as lost to follow-up at month 12. Similarly for b) - d), who were expected to achieve b) 24-, c) 36- or d) 48-month outcomes within the reporting period for the respective indicators**
How to measure and measurement tools	Numerator and denominator: programme monitoring tools; ART register; cohort analysis forms If the reporting period is 1 January to 31 December 2008, countries will calculate these indicators among: • For 12-month outcomes: all patients who started antiretroviral therapy from 1 January to 31 December 2007, by checking their outcome at 12 months during 2008. • For 24-month outcomes: all patients who started antiretroviral therapy from 1 January to 31 December 2006 by checking their outcome at 24 months during 2008. • For 36-month outcomes: all patients who started antiretroviral therapy from 1 January to 31 December 2005 by checking their outcome at 36 months during 2008. • For 48-month outcomes: all patients who started antiretroviral therapy from 1 January to 31 December 2004 by checking their outcome at 48 months during 2008
Disaggregation	As much as possible, this indicator is to be disaggregated by sex, by age (<15, 15+), by 1st-line and 2nd-line regimens at the end point
Strengths and weaknesses	The continuation of ART is mostly related to the patient's survival (but also their willingness to continue). Survival might reflect the services offered, but also depends on the baseline characteristics of the patients started on ART. Clinical, immunological and virological staging are independent predictors of survival under ART. Baseline characteristics of the cohort of patients should help in interpreting the results and, in particular, comparing ART sites
Additional considerations	For the indicator at 12 months, the numerator does not require patients to have been on antiretroviral therapy continuously for the 12-month period. Patients who may have missed one or two appointments or drug pick-ups, and temporarily stopped treatment during the 12 months since initiating treatment, but are recorded as still being on treatment at month 12, are included in the numerator. On the contrary, patients who have died, stopped treatment or been lost to follow-up at 12 months since starting treatment are not included in the numerator. This principle is similar when calculating the indicator at 24, 36 and 48 months. In countries where this indicator is not produced in all ART sites but in a sub-set of facilities, data should be interpreted keeping in mind its representativeness
Data utilization	Note any particularly low coverage, and assess the reasons behind it. Try to obtain data on the distribution of patients not on ART: dead, stopped, or lost to follow-up. If data is available, try to assess the lost to follow-up population to see if patients within it are likely to be dead, stopped, or transferred out. Compare cohorts
Data quality control and notes for the reporting tool	National representativeness: If this indicator is only produced in a subset of facilities, a comment should be added on the source of information and whether the information is representative of all ART sites
Other references	**UNGASS INDICATOR No. 24; Health Sector UA Framework Indicator No. 31**

From the cohort analysis form, the numerator for this indicator is the number of patients who are alive and on any regimen at the specified duration of treatment (12, 24, etc. months) which is **H+I+J+K+L.**

The denominator is the number of patients in the net current cohort (N) by the specified duration of treatment.

In the sample cohort analysis form above, the value for this indicator would be created in the following way for the January 2005 cohort:

8+1+1 (H+I+J) = No. of patients on ART at Month 12 **= 77%**
13 (NI) = No. of patients in net current cohort

It will be necessary to add up across all cohorts that have reached the specified duration of treatment (e.g. six months). Therefore, from the sample cohort analysis form below, this calculation would be:

8+1+1 (January 2005 cohort) + **7+1+0** (February 2005 cohort) + **10+0+0** (March 2005 cohort) + **8+1+0** (April 2005 cohort) **= 90%**
13 (January 2005 cohort) + **8** (February 2005 cohort) + **10** (March 2005 cohort) + **10** (April 2005 cohort)

Denominator =
No. of patients in net current cohort (N)

	For cohort starting ART by month/year: at baseline; then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 05	12 mo	Cohort Feb 05	12 mo-	Cohort Mar 05	12 mo-	Cohort Apr 05	12 mo-
G	**Started on ART in this clinic-original cohort**	13	13	8	8	10	10	12	12
TI	**Transfers-in** Add +	x	1	x	0	x	1	x	0
TO	**Transfers-out** Subtract -	x	1	x	0	x	1	x	2
N	**Net current cohort**	13	13	8	8	10	10	12	10
H	**On original appropriate 1st-line regimen**	13	8	8	7	10	10	12	8
I	**On original non-appropriate 1st-line regimen**	0	0	0	0	0	0	0	0
J	**On alternate appropriate 1st line regimen**	0	1	0	1	0	0	0	1
K	**On alternate non-appropriate 1st line regimen**	0	0	0	0	0	0	0	0
L	**On 2nd-line regimen (switched)**	0	1	0	0	0	0	0	0
	Stopped	0	1	0	0	0	0	0	1
	Died	0	1	0	0	0	0	0	0
	Lost	0	0	0	0	0	0	0	0
	Lost to follow-up (DROP)	0	1	0	0	0	0	0	0
	Percent of cohort alive and on ART	13/13	10/13	8/8	8/8	10/10	10/10	12/12	9/10
	[(H + I + J + K + L) / N * 100]	100%	77%	100%	100%	100%	100%	100%	90%

Numerator =
No. of patients on any regimen after 12 months on ART

8.6. How to analyse data not on the reporting forms and review cases (other analyses by the clinical team)

Many analyses are possible without electronics or a register. These can be done by simple tabulation methods such as card sorts; by stickers or flags on cards to indicate patients for review by the clinical team, etc. Patient monitoring should be used actively as a tool for quality improvement, both directly within the clinical team itself and with assistance from other teams or from the district or regional coordinators, or mentors on follow-up visits after training. Motivation is important. Patient monitoring and the simple aggregation of data need to be satisfying, possibly even fun.

Some of the most important data to help the clinical team manage their group of patients in HIV care and on ART are not included in the cross-sectional or cohort analysis reports.

- **Data transferred to the registers, but not to the reports. This includes:**
  - **the number of patients on cotrimoxazole, INH prophylaxis at the end of a month** for ordering prophylaxis drugs. This can be used to order these drugs if there is no existing method at the facility;
  - **the proportion of pregnant patients linked with PMTCT interventions** (or simply use to generate lists to assure linkage).

For example, if two counsellors provide infant feeding counselling, you can make a current list from the register and check to make sure one or the other has counselled these women. Just as ANC clinics should be referring women to your clinic, you should also be referring pregnant women to the ANC for appropriate services.

- **Distribution of reasons for substitute, switch, stop** - to investigate problems; to see whether substitutions and switches are appropriate (use in the context of reviewing the medical officer's log).

These are included in the ART register (and on the patient card). It is important that newly trained medical officers keep a log of the patients for whom they are considering an ARV drug substitution or regimen switch, and that they consult with their clinical mentor, particularly before making a switch to a second-line ART regimen.

A drug that is out of stock should raise an alarm bell. (This should have also generated an alert from the drug supply system.) It is important to document an aspect such as «patient lacks finances» since this will easily disrupt ART adherence.

Why SUBSTITUTE or SWITCH codes:	Why STOP codes:
1 Toxicity/side-effects 2 Pregnancy 3 Risk of pregnancy 4 Due to new TB 5 New drug available 6 Drug out of stock 7 Other reason (specify) Reasons for SWITCH to 2nd-line regimen only: 8 Clinical treatment failure 9 Immunologic failure 10 Virologic failure	1 Toxicity/side-effects 2 Pregnancy 3 Treatment failure 4 Poor adherence 5 Illness, hospitalization 6 Drugs out of stock 7 Patient lack finances 8 Other patient decision 9 Planned Rx interruption 10 Other (specify)

Planned treatment interruptions are not in the current guidelines for standard care. If this is marked, investigate what is happening.

- **Why is a patient eligible for ART** - clinical only, CD4 or TLC. As a programme matures, it may be desirable to see less eligibility on the basis of clinical staging only.
- **Distribution of patients not yet on ART by clinical stage.**

Both of these aspects have implications for planning clinic visits and prophylaxis. For example, if the new availability of ART caused many people to be tested who are not yet ill, there will be a higher proportion of patients with clinical stage 1 and 2. These patients will need less frequent visits, but can benefit from cotrimoxazole prophylaxis once they are stage 2.

In early scale-up, it will be common for clinics to be filled with patients mostly in stage 3 and 4, preparing for or waiting for ART.

- **ART treatment interruptions (LOST, STOP, DROP)**

The number of patients with treatment interruptions can be counted from the ART register; further details on the number of weeks and reasons for stopping are on the patient card. In a period of time such as a year, calculating the proportion of patients with a treatment interruption, for whatever reason, can provide important information.

A special study, based on reviewing the ART register, then the patient cards, and linking the number and duration of treatment interruptions with a switch to second-line would require special staff and a protocol.

- **Data available only on the patient card**

Row D in the table in section 7.3 describes summary data that can be derived directly from the patient card, for use only by the clinical team for individual patient management, or for special studies. During site visits, district coordinators or clinical mentors can also take a sample of cards to verify certain data elements are filled in correctly and completely (e.g. TB status). These data are not summarized by being transferred to the register. They can be analysed using card sorts or other methods.

Data that are only on the card (not transferred to the registers or reports) can be used in several ways:
  - during individual patient management;
  - by using a coloured paper clip (or other «tickler» system) to mark certain patients for further review the same day with a colleague, or for discussion at the weekly clinical team meeting;
  - by sorting cards into piles;
  - by having a clerk or secretary (or special research assistant) tally information by going through all or some of the patient cards.

- **Adherence**

Estimates of the percentage of adherence to ART and cotrimoxazole are recorded on the card, as well as the reasons for poor adherence (ART only), according to a code list. Adherence is so important that any patient with poor adherence should receive an immediate response to his or her problems; issues should be discussed with the treatment supporter; a home visit should be arranged, etc. and the matter also reviewed within the team to examine the reasons and the pattern, and to plan ways to improve the situation. Card sorts can be done to estimate the percentage of patients with good adherence to ART (at their last visit, consistently or for some other duration) and to summarize the reasons for poor adherence.

- **Patients with special problems**

This includes patients who need to be linked with a community-based NGO, or who need home care, or other special services.

- **Percentage of patients referred**

Periodically, it is helpful to estimate the proportion of patients who are referred to the hospital and the proportion for which a consultation with the medical officer is done. This can be carried out with card sorts or a tally sheet.

Rates of referral that are too high are challenging for both patients and providers. Knowing the rate and the cases that result in referral can help reduce this rate by:
  - assigning the most experienced clinician on the team to certain patients;
  - consulting by phone;
  - arranging for the medical officer or a specialist to visit the health centre periodically.

- **Identify patients for review at clinical team meetings**

- **Common side-effects, OIs, other problems.**

Notes

9. Analysing indicators and identifying problems

9.1. Learning objectives

By the end of this chapter you should be able to:
- calculate and analyse indicators to identify problems.

9.2. Indicators related to ART at the district level

Calculating and analysing the indicators listed in the chart below will help you to monitor your chronic HIV care and ART programme.

Indicator	Time frame for cohort	Which number or formula for calculating (numerator/denominator)[a]	Sources of data
1. Indicators related to patient *ACCESS* to HIV care and ART			
Number enrolled in HIV care	Last quarter	- New in last month - Cumulative number of persons enrolled in HIV care	Quarterly report form - Table 1
Number started on ART	Last quarter	- New in last month - Cumulative number of persons ever started on ART at this facility	Quarterly report form - Table 2
Number currently on ART	Cross-sectional - at end of last quarter	Total and disaggregated by sex, adult/child	Quarterly report form - Table 4
Number of persons who are enrolled and eligible for ART, but have not been started on it	Cross-sectional - at end of last quarter	Total number enrolled and eligible but not on ART	Quarterly report form - Table 1
Percentage of those eligible for ART in clinic who have been started on ART	Cross-sectional - at end of last quarter	Cumulative number of persons ever started on ART at this facility --- Total number enrolled and eligible, but not on ART plus cumulative number of persons ever started on ART at this facility	Quarterly report form
Percentage of people with advanced HIV infection receiving ARV combination therapy	Cross-sectional	Number currently on ART --- Denominator is an estimate based on HIV prevalence and expected proportion with AIDS (not from register data)	Quarterly report form --- Estimate, HIV prevalence data
2. Indicators related to *SUCCESS* of ART			
Core indicator Survival at 6, 12, 24, 36 months, etc. after initiation of ART	6 months on ART, 12 months on ART, 24 months, 36 months, etc. on ART	On any ARV regimen at 6 and 12 months and yearly thereafter ——————— Net current cohort (N)	Cohort analysis form --- Cohort analysis form
Core indicator Continuation of appropriate first-line ARV regimen at 6, 12 and 24 months after initiating treatment	6 months on ART, 12 months on ART, 24 months on ART	6 months on ART, 12 months on ART, 24 months, 36 months, etc. on ART --- Persons who started 1st-line ART for the first time during the time period under consideration	Cohort analysis form --- Cohort analysis form
Median CD4 (or proportion CD4 ≥ 200) at 6 and at 12 months on ART compared to baseline	6 and 12 months on ART	Median CD4 (or proportion CD4 ≥ 200)at baseline, 6 and 12 months on ART	Cohort analysis form
3. Other indicators			
Percentage of patients who started ART 6 or 12 months ago who picked up ARV medications on time 6/6 or 12/12 months	Cross-sectional - at end of last quarter	Persons who started ART 6 or 12 months ago who picked up ARV medications on time 6/6 or 12/12 months --- Persons who started ART 6 or 12 months ago and are still prescribed ART at the end of the time period	Patient card
Percentage of patients with (good) adherence to ART	Cross-sectional -- every 3-12 months	Patients with adherence estimated as good (during pre-determined period) --- Patients currently on ART	Patient card encounter form

a *The numerator is above the dashed line and the denominator below it. Formulae for the indicators can be expressed as follows:*

Numerator X 100 = percentage
Denominator

In each formula, a numerator is divided by a denominator to obtain a ratio or proportion. If you use a calculator, the result is usually expressed as a decimal fraction, for example, 0.94. You may wish to express the result as a percentage. To do this, multiply by 100 (move the decimal point two places to the right). Thus, the decimal fraction 0.94 can be expressed as 94%.

Add more indicators that will help you manage your group of patients!

Notes

10. Problem solving

10.1. Learning objectives

By the end of this chapter you should be able to:
- understand the steps to take once patient monitoring has helped reveal problems common in the management of HIV care and ART programmes.

10.2. How to solve common problems

If monitoring reveals problems, investigate the causes and try to put in place an action-oriented plan to solve them.

Monitoring will help you identify successes, but you are likely to find some problems as well. For example, you may find that the number of patients stopping ART is increasing, or that adherence is not as good as it needs to be. Or you may find that the proportion of patients with almost perfect adherence is remaining steady, rather than increasing as you had hoped. Both of these problems could have many causes. When you identify a problem, it is important to:

- **Describe the problem** in as much detail as possible. Specify when, where and with whom the problem occurred. Remember that some indicators may reveal problems that actually occurred months ago. You will need to determine if the problem is still occurring.

- **Investigate the causes** of the problem. Different causes require different solutions. Keep asking 'why' until you find the root causes of the problem. (In some cases it may be helpful to conduct or participate in a special study to investigate the causes of a problem, or to call for help from the regional or national ART scale-up team).

For specific problems in case management, it is important to review cases, both the one to which you have been alerted, but also a sample of others. Arrange discussions during the clinical team meetings. Involve the clinical mentor if possible.

- **Identify solutions appropriate to the causes** of the problem. For example, if health workers do not know how to do a task, a solution may be training. On the other hand, if the cause is a lack of equipment or supplies, a different solution is needed. Solutions should:
  - remove the cause of the problem (or reduce its effects);
  - be feasible (affordable, practical, realistic);
  - not create another problem.

If a problem has several root causes, it may be necessary to implement several solutions to address all of them. For example, if there is a lack of both equipment and training, you will need to provide both to solve the problem.

Notes

11. Validating patient monitoring data

11.1. Learning objectives

By the end of this chapter you should be able to:
- know what to look for when validating patient monitoring data, and use patient monitoring data effectively during supportive supervision.

11.2. Supervision and validation of patient monitoring data

Supervisors/managers are responsible for supervising the patient monitoring system, ensuring forms are filled in correctly and completely, and for taking the necessary action if they are not.

An important part of supervising and managing the patient monitoring system is assuring that everyone involved in it knows their role and has the capacity to carry it out.

Supportive supervision of patient monitoring activities at the facility should include the following tasks:
- Ensure that the facility has enough stock of all the appropriate tools.
- Ensure that the patient cards are stored in an orderly fashion, and that both cards and registers are kept in a secure place.
- Review at least 10 HIV care/ART cards for errors (5 pre-ART, 5 ART).
- Find these patients in the pre-ART and ART registers and check for recording errors.
- Review the quarterly report and the cohort analysis form for errors, and facilitate or support compilation if necessary.
- District coordinators should always validate the cohort analysis form by going through the relevant pages of the ART register and recalculating all the cohort data.
- Complete a summary form, noting activities carried out, results of a review and any action taken.

More information on carrying out supportive supervision can be found in module H of the IMAI training course for district HIV coordinators.

Notes

12. Aggregating patient monitoring data

12.1. Learning objectives

By the end of this chapter you should be able to:
- understand the difficulties inherent in and the importance of accurate aggregation of patient monitoring data;
- aggregate the facility-based cross-sectional reports;
- aggregate the cohort analysis reports.

12.2. Combining patient monitoring data between several sites in a district or region or projects in a facility

One of the main tasks of the district coordinator is to validate and aggregate cross-sectional and cohort analysis reports across facilities at the district level, to use this information for district-level planning, and also report up to the national level.

Combining patient monitoring data between several sites in a district or projects in a facility is a challenge, but is essential. It may be common for ART sites to be sponsored by different projects.

What if there are two projects at one facility? If there are two clinical teams and separate ARV supply and reporting requirements, one solution would be to keep separate registers; fill out a quarterly report and cohort analysis report from each project; then at the facility, add the two report forms together, then report to the district.

There are differences between countries, depending on capacity, on how data are transferred once they have been collated at the district level up to the national or international levels for programme monitoring purposes. Some countries choose to manually fill out paper-based forms up to the district level, and then transfer these data into a simple electronic database that allows aggregation and indicator generation to national and international levels. Such applications include Microsoft Access, EpiInfo, HealthMapper and a host of proprietary software. Most countries are obligated to report national programme indicators. Therefore, it is important that a suitable and feasible system be developed, standardized and maintained to meet the needs of all higher level reporting.

12.3. Aggregating cross-sectional reports

Compiling multiple cross-sectional report forms from all your facilities will be done every one to three months. Whether your report is monthly or quarterly, the method of aggregation will be the same. It may be useful to start with an enlarged, blank report form to facilitate tallying totals from each facility.

Aggregating the cross-sectional report will differ slightly depending on the reporting period (this is true for both monthly and quarterly reports). Aggregation is most straightforward if the reporting period is only one quarter (or month). In this case, you can simply add up all cells across facilities to compile the summary quarterly report for your district.

If the reporting period spans more than one period (for example it is semi-annual or annual), it will be necessary to add up across facilities AND reporting periods for some cells, and only across facilities for the remaining cells. To do this, you take the numbers for the FIRST and LAST report in the reporting period (for example, taking the January-March (first quarter) and October-December 2005 (last quarter) report when reporting for the January-December 2005 period).

The following cells can be simply added up across facilities and across reporting periods:

Table 1:
- new persons enrolled in HIV care at this facility during the previous reporting period (cells b, e, h, k, n);
- a subset of pregnant women (cell p);
- a subset of patients started in INH during the reporting period (cell q);
- number of persons already enrolled in the programme who transferred in from another facility during the reporting period (cell r).

Table 3:
- new persons started on ART at this facility during the previous reporting period (cells b, e, h, k, n, q).

The following cells will be added up across facilities, using the numbers from the FIRST report in the aggregate reporting period. For example, if the reporting period is January-December 2005, you will add up the numbers from the January-March 2005 quarterly report forms in the aggregate report.

Table 1:
- the cumulative number of persons ever enrolled in HIV care at this facility at the end of the previous reporting period (cells a, d, g, j, m).

Table 3:
- the cumulative number of persons ever started on ART at this facility at the end of previous reporting period (cells a, d, g, j, m, p).

Finally, the following cells will be added up across facilities for the LAST report in the aggregate reporting period. For example, if the reporting period is the quarter January-March 2005, all cells will be added up across facilities for that quarter. If, however, the reporting period is one year – from January-December, 2005 – then the cells will be added up across facilities for the October-December 2005 quarter (the LAST quarter in the reporting period). This includes:

Table 1:
- the cumulative number of persons ever enrolled in HIV care at this facility at end of the current reporting period (cells c, f, i, l, o);
- the total number of persons who are enrolled and eligible for ART, but have not been started on ART (cell s).

Table 3:
- the cumulative number of persons ever started on ART at this facility at end of current reporting period (cells c, f, i, l, o, r).

Table 4:
- all cells except the percentages and cells ah and aj (see below).

Percentages should always be regenerated from aggregate numbers for aggregate reports.

Data from Table 2 and cells ah and aj in Table 4 can be aggregated across facilities for the same time period by simply adding up all cells. However, aggregating across the time period is complicated by the fact that patients in these tables may be counted twice if data are simply added up across quarters over time. Conversely, if data are just taken from the last quarter in the reporting period, patients may be missing from the totals. This means that these indicators must be generated directly from the registers for aggregate reporting periods, taking care to count patients only once.

Data from Tables 5 and 6 indicators generated from the registers for the defined reporting period can be aggregated across facilities by simply adding up all cells.

Data from table 7 can be aggregated by adding up across facilities and across reporting periods.

12.4. Aggregating cohort analysis reports

Aggregation of the cohort analysis forms may be carried out in more than one way, depending on how you want to use the data. As with the aggregation of the cross-sectional report, you may want to begin with an enlarged cohort analysis form to help tally numbers and then transfer the aggregated data to a new form. To begin with, a simple aggregation, adding up all of the same columns for all facilities and entering these new totals into a blank cohort analysis form will allow you to analyse data for all facilities by cohort. It is also possible to combine all 0-month cohort totals, all six-month cohort totals and so on, to view indicators only by duration of treatment.

The former allows you to look at changes over time (over cohorts) in numbers started on ART, numbers alive and on ART and other outcomes. Hopefully, over time, outcomes will improve as the clinical team gains more experience, and patients are started earlier on treatment. The latter allows you to report on national and international indicators (survival, continuation on first-line) by giving you aggregate figures for six-, 12-, 24-, etc. month outcomes as the ART programme matures.

The sample cohort forms (showing data for four facilities and the resulting aggregate cohort form) demonstrate the simple aggregation across facilities.

There is a third tally tool in Annex 2 that facilitates the manual aggregation of multiple cohort analysis reports if an enlarged copy of the cohort analysis report is unable to provide sufficient space to do the tallies.

In the case of '**Started on ART', 'Transfers out', 'Transfers in', 'Net current cohort', 'On original appropriate, original non-appropriate, alternate appropriate, alternate non-appropriate first-line regimens', 'On second-line regimen', 'Stopped', 'Died', 'Lost', 'Drop',** the numbers can be added up simply for all these rows by cohort and by duration of treatment. In this example, 13+8+10+12 = 43 patients from all four facilities were started on ART in the original cohort.

Percent of cohort alive and on ART. This will be derived in the exact same way as it was done for one facility. Once the aggregate net current cohort has been determined for each cohort, this will become the denominator. The numerator will be the aggregated sum of **H+I+J+K +L.** In this example, the net current cohort **N** for the January 2004 cohort and month six for all facilities = 13+8+10+10 = **41.** The number of patients on first- or second-line regimens for the January 2004 Month six cohort for all facilities (H+I+J+K+L) = 33 (original appropriate first-line) + 3 (substitutions appropriate first-line) + 1 (switches) = **37.** Therefore, the aggregate percent of the cohort that is alive and on ART = 37/41 * 100 = **90%.**

CD4 median. To aggregate the median CD4 count across facilities, you may either take the mean (add up all medians and divide by the number of facilities), or take the median (place them in ascending order and take middle number). In this example, there are three CD4 medians: 50, 100, 110. The median is 100.

Proportion of CD4 ≥ 200. Add up the numerators for all facilities (by cohort and month) and divide this by the sum of all denominators.

Finally, it is important for the district coordinator to validate these numbers. For example, they must make sure that: the numerator is smaller than the denominator in the proportions; the net current cohort has been added up correctly; H+I+J+K +L, plus stopped, died and drop have been added to the net current cohort (N); and the percent of cohort alive and on ART is between 0 and 100.

Sample cohort reports for four facilities showing January 2005 cohort data at 0 and 6 months

		Facility 1		Facility 2		Facility 3		Facility 4	
	For cohort starting ART by month/year: at baseline then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 05	6 mo-July05	Cohort Jan 05	6 mo-July05	Cohort Jan 05	6 mo-July05	Cohort Jan 05	6 mo-July05
G	**Started on ART in this clinic - original cohort**	13	13	8	8	10	10	12	12
TI	**Transfers-in Add +**	x	1	x	0	x	1	x	0
TO	**Transfers-out Subtract -**	x	1	x	0	x	1	x	2
N	**Net current cohort**	13	13	8	8	10	10	12	10
H	**On original appropriate 1st-line regimen**	13	8	8	7	10	10	12	8
I	**On original non-appropriate 1st-line regimen**	0	0	0	0	0	0	0	0
J	**On alternate appropriate 1st-line regimen (substituted)**	0	1	0	1	0	0	0	1
K	**On alternate non-appropriate 1st-line regimen (substituted)**	0	0	0	0	0	0	0	0
L	**On 2nd-line regimen (switched)**	0	1	0	0	0	0	0	0
	Stopped	0	1	0	0	0	0	0	1
	Died	0	1	0	0	0	0	0	0
	Lost	0	0	0	0	0	0	0	0
	Lost to follow-up (DROP)**	0	1	0	0	0	0	0	0
	Percent of cohort alive and on ART	13/13	10/13	8/8	8/8	10/10	10/10	12/12	9/10
	[(H + I + J + K + L) / N * 100]	100%	77%	100%	100%	100%	100%	100%	90%
	Total on appropriate 1st-line regimen (H + J)	13	10	8	8	10	10	12	9
	Fraction CD4 < 100 (of adults with available CD4 at baseline)	7/13	x	3/8	x	4/10	x	7/12	x
Child < 5	**Fraction with CD4% < 15%** (of children <5 with available CD4 at baseline)	0/0	x	0/0	x	0/0	x	0/0	x
	CD4 median [of those with available CD4]	50	150	100	170	110	175	70	140

Aggregated cohort analysis report for four facilities

		All facilities	
	For the cohort starting ART by month/year: at baseline, then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 05	6 mo-July05
G	**Started on ART in this clinic- original cohort**	43	43
TI	**Transfers in Add +**	x	2
TO	**Transfers out Subtract -**	x	4
N	**Net current cohort**	43	41
H	**On original appropriate 1st-line regimen**	43	33
I	**On original non-appropriate 1st-line regimen On alternate 1st-line regimen (substituted)**	0	0
J	**On alternate appropriate 1st-line regimen (substituted)**	0	3
K	**On alternate non-appropriate 1st-line regimen (substituted)**	0	0
L	**On 2nd-line regimen (switched)**	0	1
	Stopped	0	2
	Died	0	1
	Lost to follow-up (DROP)	0	1
	Percent of cohort alive and on ART	43/43	37/41
	[(H + I + J + K + L) / N * 100]	100%	90%
	Total on appropriate 1st-line regimen (H + I + J)	43	36
	Fraction with CD4 < 100 (of adults with available CD4 at baseline)	19/43	x
	Fraction with CD4% < 15% (of children <5 with available CD4 at baseline)	0/0	x
Child < 5	CD4 median (of those with available CD4)	100	160
		50	150

Notes

13. Operationalizing the HIV care/ART patient monitoring system

13.1. Learning objectives

By the end of this chapter you should be able to:
- understand the steps necessary to operationalize and adapt an HIV care/ART patient monitoring system.

13.2. How to operationalize and adapt the HIV care/ART patient monitoring system

A patient monitoring system is a critical component of an integrated national HIV care, ART and prevention programme. The development of an effective patient monitoring system should ideally occur in conjunction with the roll-out of the programme. Setting up or improving an HIV care/ART patient monitoring system is a multi-step process. The following recommended actions do not provide a detailed methodology for improving a patient monitoring system, but they can help to adapt and operationalize one.

Note that several of these steps are iterative; that is, the process of defining indicators and developing tools to support both clinical and programme management is not linear. Indicators should be developed in light of existing reporting requirements, but also taking into account the feasibility of their collection in light of the tools. Indicators may have to be revisited once experience is gained in their collection.

More detailed guidance on adapting a generic system is currently being developed. Recommended actions to help adapt and operationalize a patient monitoring system:
- gathering key stakeholders to discuss adapting, developing, revising, or strengthening (as appropriate) the national HIV/ART patient monitoring system;
- making an inventory of current and potential patient monitoring tools and other information systems linked to HIV/ART, MCH/PMTCT and TB/HIV patient monitoring;
- obtaining a consensus on the indicators to measure and the corresponding minimum data elements to collect, as well as reviewing and standardizing definitions for each data element and indicator;
- identifying an appropriate system and tools to collect these data for each type of facility; adapting tools based on country resources and information needs (for example, data on when cotrimoxazole prophylaxis is started or stopped may be omitted from registers if this information is not required for drug supply management);
- obtaining a consensus on the patient monitoring tools from all key stakeholders;
- printing adequate copies of all patient monitoring tools, and formulating a process for disseminating tools during initial rollout and subsequently responding to facility needs;
- planning who will carry out, supervise and support patient monitoring at facility, district, regional, and national levels;
- developing (or adapting existing) training materials to prepare staff at all levels to use patient monitoring tools, then training and retraining as necessary;
- implementing training for all relevant participants – at all levels – who will be in part responsible for patient monitoring, and providing new patient monitoring tools at the same time;
- providing systematic follow-up after training and supportive supervision to ensure quality data collection and effective use of the data at facility and district level.

Experience in the field has demonstrated that it is extremely important to provide follow-up after training and supportive supervision after initial training. This supervision and follow-up may be provided by the district management team or by clinical mentors during site visits. These supervisors need to be prepared to effectively oversee, troubleshoot and solve problems. Smooth and accurate flow of data at the facility, and from facility to district to central levels requires regular facility visits by the district health information officer for data collection and analysis.

Notes

Annex 1: Key cards to pre-ART and ART registers

Pre ART register key

Status at enrolment: (8) ☐ HIV exposed Infant ☐ TB Rx ☐ Pregnancy ☐ Postpartum ☐ other

Unique No. ☐☐☐☐☐☐☐☐☐☐

District (3) _____ Health unit _____ District clinician/team _____

Name _____ Patient clinic No. _____

Sex M ☐ F ☐ Age _____ DOB _____ Marital status _____

Address _____

Telephone (whose) _____

Treatment supporter/medication pick-up if ill _____

Address _____

Telephone (whose) _____

Home based care provided by _____

Family status				
Name of family members and partners	Age	HIV P/N	HIV care Y/N	Unique No.

Exposed infant follow-up						
Exposed Infant Name/No.	DOB	Infant feeding practice at 3 mos.	CTX started by 2 mos.	HIV test type/ result	Final status	(If confirm +) Unique ID

HIV care		
	Date	
Confirmed HIV + test		HIV 1 2 Ab/virologic test Where _____
HIV enrolled (2)		☐ HIV care transfer in from_____
Medically eligible for ART (14)		Clinical stage _____ CD4 _____ ☐ Presumptive clinical diagnosis of severe HIV infection in infants

Drug allergies	Relevant medical conditions

Prior ARVs			
Y(P)	Prior ARV	Date	
	None		
	ARV/ART during pregnancy and breast feeding	_ _/_ _/_ _	Where _____ARVs _____
	Earlier ARV not transfer in	_ _/_ _/_ _	Where _____ ARVs _____

	ART	Cohort (month/year) _____/_____
	Date	
	_ / _ / _	ART transfer in from_____ ARVs _____
	_ / _ / _	Start ART 1st -line initital regimen _____
	At start ART	Wt_____ Cl.stage _____ CD4_____ Preg _____
1st - line	**Substitute within 1st-line**	
	_/_/_	New regimen _____ Why _____
	_/_/_	New regimen _____ Why _____
2nd -line	**Switch to 2nd-line (or substitution within 2nd-line)**	
	_/_/_	New regimen _____ Why _____
	_ / _ / _	New regimen _____ Why _____

ART treatment interruption - Stop or missed drug pick-up				
Stop or Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost
Date				
Why				
Date if restart				

Status		
	Date	
Dead		
Transferd out		Where _____
Lost to follow-up (drop)		

Unique No. ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **HIV care/ART card** **Name** ____________________

Date Check if scheduled. Write in alternate pick-up if ill	Follow-up date	Duration in months since first starting ART/since starting current regimen	13 Weight Ht at first visit If child record +/- Oedema	Pregnancy/ RH-FP choices If child record MUAC Write age in mos. if ≤59 mos.	11 TB status (if TBRX record month/ year started and TB reg No.)	Potential side effects	12 New OI, Other problems If child, include nutritional problems	WHO clinical stage	9 Cotrimoxazole		10 INH No. pills dispensed	Other meds dispensed (including nutritional supplements)	ARV drugs (incl. prophylaxis)		Investigations		Refer or consult or link/provide (including nutritional support and infant feeding) If hospitalized, No. of days	HIV transmission prevention for key population (Check) ☐ Discordant couple ☐ MSM ☐ IDU ☐ SW ☐ Clients of SW
									Adhere	Dose/ days			Adhere/ why	Regimen/ Dose/No. days dispensed	CD4 if <5, record CD4%	Hgb,RPR, CXR, TB sputum. Infant Ab/HIV virologic test, other		
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Status at enrolment: ☐ HIV exposed Infant ☐ TB Rx ☐ Pregnancy ☐ Postpartum ☐ other

Unique No. ☐☐☐☐☐☐☐☐☐☐

District _____ **Health unit** _____ **District clinician/team** _____

Name _____ **Patient clinic No.** _____

Sex M ☐ F ☐ **Age** _____ **DOB** _____ **Marital status** _____

Address _____

Telephone (whose) _____

Treatment supporter/medication pick-up if ill _____

Address _____

Telephone (whose) _____

Home based care provided by _____

Family status

Name of family members and partners	Age	HIV P/N	HIV care Y/N	Unique No.

Exposed infant follow-up

Exposed Infant Name/No.	DOB	Infant feeding practice at 3 mos.	CTX started by 2 mos.	HIV test type/ result	Final status	(If confirm +) Unique ID

HIV care

	Date	
Confirmed HIV + test		**HIV 1 2 Ab/virologic test** **Where** _____
HIV enrolled		☐ **HIV care transfer in from**_____
Medically eligible for ART		**Clinical stage** _____ **CD4** _____ ☐ **Presumptive clinical diagnosis of severe HIV infection in infants**

Drug allergies	Relevant medical conditions

Prior ARVs

Y(P)	Prior ARV	Date	
	None		
	ARV/ART during pregnancy and breast feeding	__/__/__	Where _____ ARVs _____
	Earlier ARV not transfer in	__/__/__	Where _____ ARVs _____

	ART	Cohort (month/year) 1 /_____
	Date	
	_/_/_	ART transfer in from_____ ARVs _____
	_/_/_	Start ART 1st -line initital regimen _____
	8	9 10
1st - line	At start ART	Wt _____ Cl.stage _____ CD4 _____ Preg _____
	Substitute within 1st t-line 17	
	_/_/_	New regimen _____ Why _____
	_/_/_	New regimen _____ Why _____
2nd -line	**Switch to 2nd-line (or substitution within 2nd-line)** 18	
	_/_/_	New regimen _____ Why _____
	_/_/_	New regimen _____ Why _____

ART treatment interruption - Stop or missed drug pick-up

Stop or Lost	Stop Lost	Stop Lost	Stop Lost	Stop Lost
Date				
Why				
Date if restart				

Status

	Date	
Dead		
Transferd out		Where _____
Lost to follow-up (drop)		

11 15 14 12 13

Unique No. ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ **HIV care/ART card** **Name** ____________________

Date Check if scheduled. Write in alternate pick-up if ill	Follow-up date	Duration in months since first starting ART/since starting current regimen	Weight Ht at first visit If child record +/- Oedema	Pregnancy/ RH-FP choices If child record MUAC Write age in mos. if ≤59 mos.	TB status (if TBRX record month/ year started and TB reg No.)	Potential side effects	New OI, Other problems If child, include nutritional problems	WHO clinical stage	Cotrimoxazole		INH No. pills dispensed	Other meds dispensed (including nutritional supplements)	ARV drugs (incl. prophylaxis)		Investigations		Refer or consult or link/provide (including nutritional support and infant feeding) If hospitalized, No. of days	HIV transmission prevention for key population (Check) ☐ Discordant couple ☐ MSM ☐ IDU ☐ SW ☐ Clients of SW
									Adhere	Dose/ days			Adhere/ why	Regimen/ Dose/No. days dispensed	CD4 if <5, record CD4%	Hgb,RPR, CXR, TB sputum. Infant Ab/HIV virologic test, other		
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Notes

Annex 2 - Tally tools

Tally tool for patients who are eligible but not yet started on ART (to be kept close to the pre-ART register and updated with each encounter

Old total ('v' from last reporting period's report)		Tally of patients who have become newly eligible in the reporting period (add)		Tally of patients who were eligible in the last reporting period and have since started ART, died, transferred out or been lost to follow-up (subtract)		New total
	+		=		=	

Tally tool for persons on ART who transferred into your facility (to be kept close to the ART register and updated with each new transfer-in patient)

Jan-06	Feb-06	Mar-06	Apr-06	May-06	Jun-06
Jul-06	**Aug-06**	**Sep-06**	**Oct-06**	**Nov-06**	**Dec-06**

Tally tool for compiling cohort analysis reports from multiple ART register pages

Cohort: Year _____ Month _____		
Baseline	Month 6 12 24 36 48 60 72 (circle appropriate month outcome)	
DATA ELEMENT		**TALLY**
(G) Started on ART at this clinic - original cohort		
(H) On original appropriate 1st-line regimen		
CD4 counts > 200		
CD4 counts available		

Cohort: Year _____ Month _____		
Baseline	Month 6 12 24 36 48 60 72 (circle appropriate month outcome)	
DATA ELEMENT		**TALLY**
(G) Started on ART in this clinic - original cohort		
(TI) Transfer in		
(TO) Transfer out		
(H) On original appropriate 1st-line regimen		
(I) On original non-appropriate 1st-line regimen		
(J) On alternate appropriate 1st-line regimen		
(K) On alternate non-appropriate 1st-line regimen		
(L) Switch		
Stopped		
Died		
Lost		
LTF (dropped)		
CD4 counts > 200		
CD4 counts available		

Notes

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HIV Department
E-mail: hiv-aids@who.int
http://www.who.int/hiv/capacity/

STOP TB Department
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Department of Maternal, Newborn, Child and Adolescents (MCA)
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IMAI — Integrated Management of Adolescent and Adult Illness
IMPAC — Integrated Management of Pregnancy and Childbirth
IMCI — Integrated Management of Childhood Illness