

## CHAPTER 6

# MONITORING SERVICES, PATIENTS AND PROGRAMMES

### INTRODUCTION

This chapter describes how to collect, manage, analyse and use routine clinical information for HIV patient management, HIV programme monitoring and reporting. The chapter assumes that the health centre will adhere to national recommendations for standardized data collection for HIV services, which may include minimum data requirements, standardized forms (cards and registers) and required reports. The text also emphasizes how health centre staff can actively integrate monitoring into service delivery to ensure local use of the information collected and to promote high quality HIV care.

Patient monitoring is the routine collection, compilation and analysis of data on patients at every visit over time, using information taken directly from paper forms or entered into a computer. Patient monitoring is often referred to as 'patient tracking'.

Patient management is clinical team action to provide care and treatment on behalf of and in consultation with an individual patient over time (assisted by written records). Patient management may also be referred to as 'clinical management' or 'clinical monitoring'.

Programme monitoring is the routine tracking of priority information about a programme, including its outputs (e.g. number of people served) and outcomes. Monitoring at the health centre level requires many types of information, including summarized patient data.

### **Monitoring a chronic disease such as HIV is different than monitoring acute illness**

Information about health status and clinical services recorded on the same patient every visit over time is known as 'longitudinal' information. Your health centre may already use this approach to monitor pregnant women and their newborn children, or to monitor people receiving TB treatment. When the information on each patient is kept in a unique folder over time, it is known as a longitudinal medical record.

Managing and monitoring HIV patients may be a new challenge for your health centre as HIV patients will receive care and treatment for life. Keeping accurate information from every visit in one longitudinal record for each patient is essential to successful HIV care and treatment.

### **Simple, standardized, but flexible**

Governments have set national standards for minimum data and tools to monitor primary health services (e.g. standardized ANC cards and registers, child health cards, TB cards and registers). There are also national standards for monitoring HIV patients and services, including:

- minimum standard data that every health centre should collect;
- recommended tools (cards and registers) the health centre should use to monitor HIV patients and services;
- standardized data tables the health centre is required to report on regularly.

The HIV monitoring system is simple and standardized. You only collect information that will be used, but you collect all the information necessary for good patient management, programme monitoring and reporting at the health centre. You adhere to the nationally recommended minimum data and use the required standard forms, registers, and reports, but you make sure to promote active use of data to review your performance and to promote higher quality services.

This Manual assumes that at most health centres, the longitudinal HIV medical record is paper-based. But, at selected health centres with more capacity, there may be a computerized database of patients. At these sites, longitudinal HIV medical information is recorded on paper, but also entered into a computer to enable quicker retrieval, analysis, monitoring, and evaluation of the care of larger patient populations. Where possible electronic record systems may make

it easier to link individual patients over time and across services, but only if health centre staff have skills to enter, analyse, retrieve and interpret data.

## 6.1 HOW TO MONITOR HIV PATIENTS AND PROGRAMMES

### **Integrate the monitoring of some HIV services into the monitoring of other health services**

Delivering HIV services works best when these services are integrated into all of the services your health centre already provides. This is also true with monitoring of HIV services. Key information about the delivery of specific HIV services such as provider-initiated testing and counselling, PMTCT interventions, and TB/HIV care has been added to the standard forms, cards, registers and reports that the health centre already uses when patients seek these other health services. For example, the standard ANC register has been modified to add columns for 'date of HIV testing' and 'HIV test result' to allow your health centre to monitor PMTCT services as part of delivering antenatal services.

In an integrated programme, early identification of HIV and prompt entry of HIV-infected people into HIV care is critical. So for example, it is important to monitor whether:

- people who receive other health services (e.g. TB, ANC, labour and delivery, Under 5' services) have HIV testing and counselling recommended and receive their results on the same day;
- people identified as HIV-infected through other health services do enrol in HIV care (and receive HIV treatment if needed).

Similarly, it will be important for patients receiving HIV services to also receive other health services as necessary, such as antenatal care with integrated PMTCT interventions, or TB treatment when appropriate.

### **Implement a specific monitoring system for HIV patients**

Separate HIV patient records, registers and reports are needed to monitor the specialized HIV prevention, care and treatment services that HIV-exposed infants and HIV-infected people receive (see Annex 5.2).

The nationally recommended specific monitoring system for HIV-exposed and HIV-infected people is essential for delivering high quality HIV prevention, care and treatment including HIV patient management, HIV programme monitoring and evaluation, and HIV reporting. Information on pregnancy, family planning, nutrition, and TB screening and treatment is included to ensure the HIV-positive client receives these services. Patient management works best when all patient health information – both HIV-related and non-HIV-related – is located in one patient medical record, chart or file.

### **Formally enrol each HIV-infected patient into HIV care**

After a patient's HIV test is confirmed as HIV-positive, on their first HIV care visit they need to be enrolled into lifelong HIV care. On this visit:

- Assign a unique HIV patient identification (ID) number that the HIV-infected patient will use for the rest of his/her life, regardless of the place where he/she receives HIV care and treatment services
- (If applicable in a national system) provide a patient-held ID card that demonstrates formal enrolment in the national HIV care and treatment programme
- Open a health centre-held longitudinal HIV medical record for this patient (this often includes a summary HIV care/ART patient card)
- Assign a row in the HIV care (pre-ART) register.

Note: A patient may have several ID numbers at the health centre (e.g. ANC number, TB number), so you need to cross-reference these with the unique HIV ID number on all patient records to ensure that all of this patient's services are linked in the record system.

### **Maintain a longitudinal medical record for each HIV-infected patient**

The next step is to update the unique longitudinal medical record during each patient visit to the health centre for HIV prevention, care and treatment services. This includes all clinical visits, as well as all counselling and support services, laboratory tests and pharmacy visits to pick up medications.

Your health centre will be using the national standardized HIV patient card, or set of standardized clinical encounter forms. This longitudinal record

documents HIV prevention, care and ART for the HIV patient over time. This includes a facility-held patient card that contains a front page that is a summary of key events and data. The second page includes information recorded at every HIV care visit, such as clinical signs and symptoms, the occurrence of opportunistic infections, medications prescribed, TB screening data, etc. The medical record also contains any clinical notes, laboratory tests ordered and results, referrals and other relevant clinical information.

The principle behind the card and any set of standardized forms (e.g. flow sheet, initial evaluation form, encounter form) is the same – to routinely collect common standard minimum data elements at every HIV patient visit to the health centre to inform and improve the quality of HIV prevention, care and treatment. This includes information collected during counselling, psychosocial support and education with a health worker.

Write clearly on the patient card so other staff can read, transcribe, abstract, or tally that information. Store records in a secure and organized location, retrieve there on the day a patient has an appointment or otherwise presents for HIV care services. Make sure you replace a record after new information has been added to it and transcribed to the pre-ART or ART register (or entered into a database, if one is used at the health centre).

### **Make appointments and actively follow up on any that are missed**

To effectively monitor HIV prevention, care and treatment services you need to set regular appointments with patients, and keep track of whether they keep them. Use an appointment log; and keep it at registration to monitor if patients come to clinic on the day of their appointments, are late for them (by a day or two), or miss their appointments altogether. Late and missed appointments signal that health centre staff need to:

- actively follow up with the patient or their treatment supporter through phone calls or home visits;
- assess the patient's ability to keep appointments in the future;
- reinforce the importance of adhering to regular HIV care and treatment appointments;
- evaluate the effectiveness of activities to promote attendance at appointments and treatment adherence.

### **Track HIV patients transferring in or out**

Good monitoring of HIV services requires a ‘transfer protocol’ that describes the expected procedures for a patient to transfer officially from one facility to another for his/her HIV prevention, care and treatment. This protocol involves moving the longitudinal medical record (or a summary of key information from the record) from one centre to another to ensure continuity of patient care. The process can be made easier with:

- a simple transfer form, the top half of which includes key summary patient information and is filled out by the referring facility and the bottom half by the receiving facility in order to promote communication between facilities;
- one national standardized patient monitoring system across all HIV care and treatment sites;
- record of patient status (e.g. ‘active’ to ‘transferred out’) in the relevant HIV record and register(s);
- adherence by both health workers and patients to the transfer protocol on the receiving and referring sides.

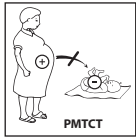
If a patient returns to the clinic after the transfer, but his transfer status has been well-documented, it is less likely that he would be mistaken for a new patient.

### **Monitor referral and linkages of HIV patients to home and community services**

Effective HIV service monitoring includes documenting the need for and referral to a wide range of home- and community-based services. To document referral and ensure services are received, you need to:

- use standardized referral forms (see Integration chapter);
- designate a staff member to do active follow-up;
- use standardized indicators and forms to monitor community-based services (based on the same data elements and indicators as health centre tools).

## **Integrate monitoring of PMTCT interventions within routine maternal and child health monitoring**



HIV-positive pregnant women require specific monitoring for both their own HIV care and treatment services, and specialized services to prevent transmission to their child, either during pregnancy or delivery or via breastfeeding. Monitoring the services they receive can be challenging as they often receive services at different health centres or other

facilities.

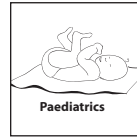
It is very important to establish longitudinal monitoring for HIV-positive pregnant women when they are first identified as being HIV-infected during pregnancy:

- Document the results of provider-initiated testing and counselling services for all women attending ANC or delivery at the health centre.
- Conduct active follow-up of HIV-infected pregnant women (and their infants) during pregnancy, labour, delivery and the postnatal period.
- Promote rapid enrolment of HIV-infected pregnant women into HIV care services, as well as rapid treatment adherence support and ART, if they are eligible.
- Track whether HIV-infected pregnant women and their newborns receive ART or ARV prophylaxis.

This is accomplished by adding HIV variables to the maternal-held pregnancy card antenatal, labour and delivery registers and records, and the 'Under 5' card (see Annex 6.4).

### **Expect specific monitoring of HIV-exposed infants**

Newborns and infants of HIV-infected mothers are special patients that need to be monitored over time. Their HIV status is unknown until confirmed by special virologic testing. Their prognosis is poor if they are HIV-infected, but not tested and placed on early ART. Mothers and their newborns are frequently lost to follow-up because mothers may not deliver the child in a facility. It can also happen because children may receive routine health care for at a different centre or location, and its staff may not know the child is HIV-exposed and needs special services.



Therefore, it is very important to establish longitudinal monitoring of mother-child pairs when a woman is first identified as HIV-positive during pregnancy. To achieve this, in addition to the monitoring described above, it is necessary to:

- Record key information listed below on the exposed infant on the mother's HIV card, and on a card started for the HIV-exposed infant, and store them together.
- Establish a special longitudinal register for HIV-exposed infants in order to monitor if the following have taken place:
  - age-appropriate HIV-testing (e.g. sending a DBS for virological testing by the time the child is two months of age);
  - receipt of HIV test results;
  - cotrimoxazole prophylaxis by two months of age, and ART if the infant is HIV-positive;
  - infant feeding practice;
- Enrol HIV-infected infants into HIV care and start ART as soon as an HIV diagnosis is confirmed.

### **Cross-monitor HIV services among TB patients, and TB services among HIV patients**

High co-morbidity between TB and HIV requires effective coordination, referral and communication between TB and HIV programmes, as well as TB/HIV co-management by clinical teams in order to ensure effective care and treatment of both diseases.

Integrated monitoring of the HIV services that TB patients receive is based on recording HIV data on the standard TB treatment card, registers and reports (see Annex 6.3) on activities that:

- ensure all TB patients receive HIV counselling and testing (with results), or otherwise know their HIV status;
- ensure that HIV-positive TB patients are enrolled in HIV care and started on ART;
- monitor TB treatment adherence and outcomes among HIV patients.

Similarly, integrated monitoring of the TB services that HIV patients receive is based on TB data elements on the standard HIV care/ART card and registers, as well as reports on activities that monitor or ensure:

- All HIV patients receive TB screening at every visit.
- All people suspected of having TB have sputum smear microscopy, and that these results are received and recorded on the patient card (see Laboratory chapter)
- INH prophylaxis is provided to HIV patients as indicated.
- patients with active TB disease receive appropriate treatment.

### **Monitor family HIV status of HIV-infected patients**

Family members, especially spouses and young children, of HIV-infected patients are vulnerable to HIV infection. Furthermore, HIV-affected families often need special preventive and supportive services that may be provided at the health centre or in the community. Therefore, you need to use the HIV care/ART card to record:

- The HIV status of family members (unknown, HIV-negative, or HIV-positive);
- Enrolment into HIV care (and the associated HIV ID number);
- If these patients need and receive preventive and supportive services.

Reviewing these data in the patient record may prompt the services to take place. For example, if a health centre staff member is checking if family members' HIV status is recorded, it may encourage them to ask each HIV patient about HIV prevention behavior, counselling and testing for their family members, and if the patient and family have received needed HIV care and support.

## **6.2 HOW TO IMPLEMENT AN INTEGRATED PATIENT MONITORING SYSTEM**

**Learn about national monitoring standards and systems (e.g. nationally standardized HIV minimum data elements, indicators, forms, registers and databases)**

Your country has adopted a set of national HIV indicators required for reporting by all health centres that deliver HIV services. Some of these indicators are derived from the national standardized HIV patient monitoring system that is used to monitor HIV-infected people receiving HIV services. Others are derived from the national MCH and TB patient monitoring systems that will have been (or are being) updated to include HIV data.

Generic illustrative forms to support these interlinked systems should be replaced by the country-adapted forms during adaptation. These are based on the updated Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT (including malaria prevention during pregnancy), and TB/HIV: standardized minimum data set and illustrative tools.

Standardized tools used in the national monitoring system are listed in the text box that follows.

In addition, some donors or supporting partner organizations may require or request additional indicators to be used. Therefore, your reporting requirements will depend on the HIV services you deliver, and may also rely in part on the donor or partner that supports your health centre. The centre team needs to know the required indicators to be reported, and the due date and recipient of the report.

**Standardized tools in three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT and TB/HIV (see 3ILPMS and annex 6 for a more detailed description of each tool)**

<p>For HIV prevention, care and treatment services:</p> <ul style="list-style-type: none"> <li>• Patient-held card if applicable</li> <li>• HIV care/ART patient card</li> <li>• Pre-ART (HIV care) register</li> <li>• ART register</li> <li>• Cross-sectional (e.g. quarterly) reporting form (HIV care, treatment, MCH/PMTCT and TB/HIV)</li> <li>• Cohort reporting form (ART only)</li> <li>• Appointment book</li> <li>• Transfer/referral form</li> </ul>	<p>For MCH PMTCT services:</p> <ul style="list-style-type: none"> <li>• Patient-held maternal health card (with HIV fields added)</li> <li>• Patient-held child health card (with HIV fields added)</li> <li>• ANC register (with HIV fields added)</li> <li>• L&amp;D register (with HIV fields added)</li> <li>• Labour record/partograph, postpartum record (with HIV fields added)</li> <li>• Summary forms</li> <li>• HIV-exposed infant register</li> </ul>	<p>TB HIV services</p> <ul style="list-style-type: none"> <li>• Facility-held TB treatment card (with HIV fields added)</li> <li>• TB suspects register (with HIV fields added)</li> <li>• TB laboratory register (with HIV fields added)</li> <li>• TB BMU register (with HIV fields added)</li> <li>• Quarterly report on TB case registration</li> <li>• Quarterly report on TB treatment outcome and TB/HIV activities</li> </ul>
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**Consider existing monitoring systems at the health centre, and assess what is needed**

Review the monitoring systems (including forms, registers, reports) already in use at your health centre, and ask:

- Does the health centre clinical team routinely review and use the information produced in those systems?
- Does the health centre send reports from the data to the district in a timely way?
- How can the systems be improved?
- Does the health centre have a strong relationship with the district health management team that provides supportive supervision of HIV monitoring?

Review the updated national standards and systems for monitoring HIV care/ ART, MCH/PMTCT and TB/HIV, and ask:

- What will you need to do to implement these monitoring standards and systems?
- How will you introduce them?

### **Consider space, file storage and other infrastructure needed for monitoring**

Adequate space and good organization of patient records, registers and reports are important. Use the 5 Ss system (see Infrastructure chapter), including the idea that:

- Monitoring HIV services integrated with MCH and TB requires little or no additional space beyond what is needed to accommodate the ANC register, the TB register, etc..
- Monitoring services for HIV-exposed infants and HIV-infected people will need additional space. This includes space to:
  - permanently store all of the longitudinal medical records in an organized and secure fashion;
  - temporarily stack/store the folders of the patients who will be seen on HIV clinic days. The location should also be secure to maintain the confidentiality of patient information;
  - allow a data clerk or other health centre staff to work on the monitoring forms, registers, and reports (e.g. to review, transcribe, and tally data from and to patient records, registers, and reports). Depending on volume of HIV services and the number of patients, this space may need to be set aside every day, or only on selected days during the week;
  - in large health centres with computerized HIV databases, space for the data clerk must include the area and security needed to store a computer, as well as other infrastructure requirements (adequate electricity, back-up power supply, protection from dust, etc.).

## Maintain confidentiality and security of patient records

PLHIV often face stigma and discrimination. Therefore, all health centre staff who handle, process, stack, and store HIV records and registers must ensure that they maintain the confidentiality of patient information. This means that patient records should be stored in a locked, secure closet or filing cabinet.

## Maintain stocks of equipment and materials

Based on the expected volume of HIV services and patient load your health centre expects to handle, you will need to order and store enough supplies to last from six to 12 months. This may include:

- folders to hold longitudinal medical records;
- folder labels;
- blank patient cards, registers, report forms (see Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT (including malaria prevention during pregnancy), and TB/HIV: standardized minimum data set and illustrative tools forms booklet);
- blank forms, such as those for referral, transfer, laboratory test requests, prescription/pharmacy, etc.;
- filing cabinets;
- desks/chairs;
- pencils/pens.

## Hire and/or train qualified staff



The health centre should expect the additional work burden associated with monitoring a full range of HIV services. This will require that:

- A key staff person – a data clerk – may need to be added to the health centre team. It is strongly recommended that every health centre delivering a range of HIV prevention, care, and treatment services needs to establish a data clerk position.

Below is a table of staff members and their suggested roles and responsibilities for HIV patient monitoring.

Staff	Roles and responsibilities for patient monitoring
Triage worker or Receptionist or Data clerk	<ul style="list-style-type: none"> <li>• Maintain appointment book and signal missed appointments</li> <li>• Start or retrieve patient records</li> <li>• Record patient data in patient record (or register, depending on the HIV service provided)</li> </ul>
ART aid or Lay counsellor or Professional counsellor	<ul style="list-style-type: none"> <li>• Record patient data in patient record (or register depending on the HIV service provided)</li> </ul>
Nurse or Clinical officer or Other clinician	<ul style="list-style-type: none"> <li>• Record patient data in patient record (or register depending on the HIV service provided)</li> <li>• Record data on patient-held card, exercise book or 'patient passport' (if used)</li> <li>• Tally data and fill in routine reports</li> <li>• Conduct patient reviews with clinical team (using longitudinal records) and discuss patient outcomes</li> <li>• Review routine HIV programme reports to track its progress</li> <li>• Review registers to assess quality of HIV services</li> <li>• Review quality of HIV patient records and registers with clinical or district supportive supervision team</li> <li>• If data clerk, secretary or other staff not available:</li> <li>• Transcribe data from patient records to registers</li> <li>• Tally data and fill in routine reports</li> </ul>
Data clerk or Secretary or Other staff	<ul style="list-style-type: none"> <li>• Organize and manage patient records and registers</li> <li>• Transcribe data from patient records to registers</li> <li>• Enter patient data into database (if used)</li> <li>• Tally data and fill in routine reports</li> <li>• Review registers to assess quality of HIV services and data</li> <li>• Review quality of HIV patient records and registers with clinical or district supportive supervision team</li> </ul>
Community workers	<ul style="list-style-type: none"> <li>• Follow up and trace lost patients</li> </ul>
External clinical mentors and supportive supervisors (e.g. from district team)	<ul style="list-style-type: none"> <li>• Review quality of HIV patient records and registers with clinical or district supportive supervision team</li> <li>• Provide supportive advice and recommendations to help improve clinical care and monitoring</li> </ul>

### **Regularly support and supervise HIV monitoring**

Supportive supervision of documentation and data management is essential for achieving quality patient monitoring. This supervision helps to:

- provide a special, regular opportunity to review the quality of HIV records;
- assist staff with analysing and compiling data for routine reporting;
- train staff on how to analyse and use information to manage patients and improve programmes;
- refresh staff on the importance of providing good data quality to achieve strong patient and programme management.

Supportive supervision of the monitoring system ensures quality of care and of data, and should be integrated with regular clinical mentoring and clinical supervision visits. Ideally, these visits will happen at least once per quarter. Depending on the size and staffing of the health centre, supportive supervision may be done by a senior staff member at the health centre, by staff from a nearby larger health centre that also provides HIV services, or by the district team (see Human resources chapter).

## **6.3 HOW TO INTEGRATE PATIENT MONITORING WITH SERVICE DELIVERY**

For each patient type, you should plan for patient flow in your health centre (see Integration chapter). For every station and staff person that a patient encounters, you need to list:

- the information that needs to be collected
- how it will be recorded (i.e. card, register, form, etc.)
- who will be responsible for recording it.

It may be helpful to create a table that summarizes this information to assist staff in understanding the responsibilities of every stage of patient monitoring, and how information from one station is needed to inform the next station. The table can also help them see how information about different services can be linked

via the patient monitoring system (e.g. clinical assessment, laboratory tests, prescription and pick-up of medications at the pharmacy, etc.), and how patient monitoring activities in an integrated system at the health centre are used.

### Example. How PITC is integrated into the first ANC visit

Cadre	Task	Documentation	Location
Peer counsellor	Sensitization, motivation, education	None	Waiting area
Patient attendant or data clerk	Issue health passport (if required), enter name, age, address, measure birth weight	Health passport	Waiting area
HIV T&C counsellor	Group pre-test information	None	Group Counselling room
Lay counsellor	Consent, rapid HIV test, syphilis test, haemoglobin test, post-test counselling	PITC register, health passport (ANC stamp)	Individual Counselling room
Lay counsellor, ANC nurse/ midwife	Post-test counselling, history, examination, vital information, WHO clinical staging Lab: CD4 draw Referral to HIV care and ART Nutritional support Counselling: family planning, infant feeding, drugs: iron, folate, sulfadoxine-pyrimethamine (SP), cotrimoxazole preventive therapy (CPT), ARV prophylaxis, other Next appointment	ANC register, health passport	Examination room

To help staff understand the flow of the patient monitoring system, it may also be useful to draw a diagram of patient flow (based for example on the information in the table above) and show the services provided in each area of the clinic, the data collection tools used for each service, and what key information is collected.

As part of patient monitoring planning and training, you will also need to consider where patient folders and registers will be permanently stored; who will retrieve them when they are needed; where they will be temporarily stored on the days they are needed, but at times when they not actually in use; who will review and process them; and who will return them to permanent storage (you also need to consider the methods staff will use to carry out these tasks).

## **6.4 HOW TO RECORD INFORMATION IN MATERNAL HEALTH SERVICES**

When PMTCT activities are integrated into maternal health services (at ANC, maternity or labour/delivery), key HIV data elements are recorded on standard maternal health data collection tools (maternal health card or health ‘passport’ kept by the patient). Data may record a single or multiple pregnancies and other health information across a woman’s lifespan. Key HIV information records for all pregnant women during maternal health service delivery will reflect the flow of PMTCT services (acceptance of HIV testing, result and receipt of test result and follow-up counselling on family planning and infant feeding). Therefore, key data elements include:

- HIV test date and result;
- Family planning (FP) counselling (and FP method if postpartum);
- Infant feeding counselling, decision, and feeding practise (exclusive breastfeeding (EBF), mixed feeding (MF) and replacement feeding (RF)).

When an HIV-positive woman receives her test result, key information to be documented reflects the sequence of events to determine her health status and eligibility for ART or ARV prophylaxis to prevent HIV transmission to the infant, provision of prophylaxis, enrolment in HIV care, and appropriate infant feeding. Therefore, key data elements to record on HIV-positive pregnant women include:

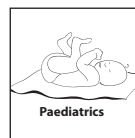
- WHO clinical stage
- CD4 count
- eligibility for ART
- ARV prophylaxis or ART, date, duration (for mother)
- ARV regimen received by or dispensed for infant and date
- cotrimoxazole, INH prophylaxis

- intermittent preventive therapy doses (as relevant)
- date enrolled in (or referred to) HIV care
- family planning counselling (and FP method if postpartum)
- infant feeding counselling, decision, and feeding practise (EBF, MF, RF).

It is a challenge, but also very critical to link key information (and ideally services) about the HIV-positive mother and her HIV-exposed infant to all service delivery sites.

## 6.5 HOW TO RECORD INFORMATION FOR HIV-EXPOSED INFANTS

An HIV-exposed infant may receive care at several different locations, including clinics that provide postpartum care, ‘Under 5’ services, immunization, and HIV care and treatment. Standard data collection tools vary by location, but at the very least, a child health card should be issued (and kept by the mother). An HIV-exposed infant register may be used to document HIV testing, test results, and follow-up services for these infants. The child should be formally linked with the mother at the HIV clinic through records and issued an HIV care/ART card (but not enrolled as HIV-positive until this is confirmed). Infant follow-up should be monitored on both the mother’s and infant’s HIV cards.



Key HIV information to record for all HIV-exposed infants reflects the flow of services needed to determine the infant’s HIV status and provide early prophylaxis and treatment. Therefore, key HIV data elements to record for HIV-exposed infants include:

- infant feeding counselling and practises;
- HIV testing, type (virological testing, antibody), date and results;
- cotrimoxazole and ART initiation and date;
- enrolment in HIV care, date, HIV ID number (if the infant is confirmed HIV-positive);
- final status.

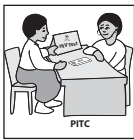
## 6.6 HOW TO RECORD INFORMATION IN TB SERVICES

When HIV services are integrated into TB service delivery, key information is based on HIV testing, the HIV test result, and the HIV-infected TB patient receiving appropriate services. Key data collection tools include the TB treatment card (for an HIV-positive patient diagnosed with TB, or a TB patient found to be HIV-positive), the patient TB register, and the 'basic management unit' or (BMU) TB register. Key HIV data elements in the TB system include:

- HIV test result and date
- ART eligibility and date assessed
- ART regimen, date started and dosage
- CTX, date started and dosage
- HIV ID numbers (e.g. pre-ART and ART register numbers)
- CD4 count.

It is crucial that health centre staff link services and information across TB and HIV service delivery points. This is made easier by documenting HIV patient ID numbers in the TB data collection system. Recording TB screening and treatment information in HIV services is described below.

## 6.7 HOW TO RECORD INFORMATION FOR TESTING AND COUNSELLING SERVICES



HIV testing and counselling may be provider-initiated (PITC) or client-initiated (CITC), and it may occur in a variety of outpatient or inpatient settings. Standardized recording on TB, maternal, and child cards and registers is described above when testing takes place in ANC, L&D, or TB settings. For

PITC in acute care or other settings and for CITC, key information to record in a PITC/CITC register includes:

- demographic and family information
- risk behaviour
- type of testing
- HIV test result and date
- receipt of test result
- referral to HIV care (if test is positive).

## 6.8 HOW TO RECORD INFORMATION FOR CARE AND TREATMENT SERVICES

For HIV care and treatment services, the patient longitudinal medical record (or card) is the foundation of all HIV data collection, analysis, and reporting activities. This is because information from the HIV patient record is:

- used to guide patient management at every clinical encounter;
- transcribed into the HIV (pre-ART or ART) register (or HIV database) where it is used to assess patient populations and health centre performance;
- summarized (via a register or database) for use at the facility and reporting to authorities at the district and national level.

After a person has been confirmed to be HIV-infected, he/she should be enrolled in HIV care. The first HIV care visit involves:

- staff assigning a unique HIV patient identification (ID) number the HIV-positive patient will use for the rest of his/her life, regardless of the place they receive HIV prevention, care and treatment services;
- if applicable, the receipt of a patient-held ID card that demonstrates his formal enrolment into the national HIV care and treatment programme;
- the opening of a facility-held longitudinal HIV medical record for this patient;
- the assignment of a row for this person on the HIV care (pre-ART) register on the date of his/her enrolment into HIV care.

Some standard minimum information should be routinely collected for every HIV patient on an HIV care or treatment visit. As a patient moves through 'stations' at the health centre, each staff member is responsible for filling out different parts of the patient record. In addition, there are special points in the continuum of HIV care and treatment that merit additional data collection; this is gathered by various staff who see the HIV patient.

On the first HIV care visit, collect basic patient identification and demographic information, including:

- name
- ID number(s)
- contact information
- sex
- age
- date of birth.

Note that much of this information will NOT change over the course of the patient's life. However, some information (contact information for patient tracking) should be verified at each visit.

On the patient's first HIV care visit on the patient's first HIV care visit, staff record the HIV status of both the patient and his family, including:

- status of patient at enrolment
  - HIV-exposed infant
  - on TB Rx
  - Pregnant or postpartum
- date and location of confirmed HIV-positive status
- HIV type (if appropriate)
- date enrolled in care
- HIV status of family members
- care of HIV-infected or HIV-exposed family members.

As noted earlier, the HIV status of an HIV patient's family should be verified at every visit, and whenever possible staff should reinforce the importance of HIV testing, prevention, care and support, and treatment for affected and infected family members. This update to family information can be done by a counsellor.

In addition, at each HIV care and treatment visit, the clinician should:

- fill in relevant fields on the patient card during the clinical assessment;
- record any additional notes from clinical assessment;
- fill out the laboratory test order form (if needed);

- fill out a prescription form (if needed);
- record the next appointment.

Key information recorded during each HIV care visit reflects the importance of monitoring the health status of PLHIV and documenting any changes since the last visit, including pregnancy (for women), immunologic status, and clinical signs and symptoms. TB screening should be done at every visit and INH prescribed as appropriate. Therefore, minimum standard data elements for each HIV care visit include:

- date of the visit
- date of next scheduled visit
- drug allergies (first visit only, then subsequent confirmation)
- height (first visit only)
- weight
- clinical stage
- TB status:
  - screened
  - referred for testing, test result
  - INH
  - TB Treatment
- pregnancy status:
  - estimated due date
  - gestation in weeks
  - PMTCT referral
  - ANC number
  - family planning method(s)
- new OIs/other problems
- cotrimoxazole:
  - dose
  - tablets dispensed

- adherence assessment
- other medication dispensed:
  - medication
  - dose
  - tablets dispensed
  - reason for discontinuation
- reason for discontinuation
- CD4 test dates and results
- other investigation test dates and results
- referral or link to other clinical or supportive care
- hospital days since last outpatient visit.
- HIV transmission prevention interventions for discordant couples, IDU, MSM, sex workers and clients of sex workers

At each HIV care visit, HIV-exposed and HIV-positive children in HIV care and treatment require special attention to growth monitoring and nutritional assessment. Therefore, there are some unique data elements to collect at each visit:

- oedema
- MUAC
- nutritional problems and support including infant feeding practise as relevant
- CD4 percentage (every 6 months).

All HIV patients are assessed for eligibility for ART. Key minimum data elements to be collected about treatment support, eligibility and ART initiation include:

- treatment supporter(s)/medication pick-up information
- treatment supporter(s) contact information

- ARV history
- date (and reason) the patient is medically eligible to start ART
- ART start date
- original first-line regimen.

Health centre staff need to pay special attention to monitoring and managing ART patients in the first three months after ART is initiated. This is to monitor responsiveness to ARV drugs and possible side-effects or toxicities. It is also to ensure a patient adheres to his appointment schedule and to the ARV drug regimen, and understands the importance of continuing to do so for life. ARV drug regimen, dose and number of days dispensed should be recorded at each visit, and adherence and reasons for non-adherence monitored.

For stable ART patients, at each monthly (or quarterly) visit, the HIV care data elements described above should be assessed and documented. In addition, staff must assess and document the patient's ART status. The key minimum data collected depends on the patient's actual ART status, but may include:

- SUBSTITUTE: date, reason, new regimen
- SWITCH: date, reason, new regimen
- STOP: date, reason
- LOST: dates
- RESTART: dates
- TRANSFER IN: facility transferred from, date initiated
- TRANSFER OUT: date, facility transferred to.
- DROP: date
- DEAD: date.

These key definitions and codes used in the three interlinked patient monitoring systems are presented in the following tables.

Term/code	Definitions of special HIV care/ART patient monitoring terms and codes
NEW	<p>Patient who starts ART at any facility in the country or system (where a system refers to a single care and treatment programme, usually a national programme).</p> <p>- NEW includes: 1) treatment-naïve patients with no prior ART; 2) patients who have received only short-course ARV prophylaxis for PMTCT; and 3) non-naïve patients with or without records who received ART from sources outside the system, and have not been counted as NEW in a system that is being monitored nationally (patient seen by private practitioner who buys drugs themselves or is sent drugs).</p> <p>- If a facility receives a non-naïve patient without records who was previously treated at a facility that reports to the national programme (and therefore reported as NEW once already), an attempt should be made to retrieve the records and confirm that the patient was previously on treatment.</p>
	<p>- In HIV care, NEW also refers to anyone who is registered in the system for the first time.</p>
START	Patient begins the first, original ART regimen in the system.
SUBSTITUTE	Substitution of drugs within first-line or second-line regimen.
SWITCH	Switch from first-line to second-line regimens (or second-line to third-line, or salvage, etc.).
STOP	Patient intentionally stops an ART regimen (usually but not always in discussion with the clinical team) through a planned interruption of ART, or following poor adherence - record the date.
RESTART	Patient who has stopped a previous ART regimen restarts ART.
LOST	<p>Patient who has missed any clinical or drug pick-up appointment. Temporarily LOST is different from DROP as defined below. Both must be clearly defined at national level.</p> <p>Temporarily LOST is also different from patient non-adherence. A patient may be non-adherent but not LOST.</p>
DROP	<p>Patient who has not responded to X number of follow-up contacts after three months from last missed appointment.</p> <p>DROP (or lost to follow-up) is different from the temporarily LOST (above) in categorizing treatment interruptions. Patients categorized as DROP are dropped from the drug supply.</p> <p>LOST and DROP are only used in the context of ART and not chronic HIV care.</p>

TRANSFER IN (TI)	When a patient who has been receiving ART at one facility in the country or system transfers to another in the same system with records. 'TRANSFER IN' is different from patients who have been receiving ART from sources outside of the system (see NEW). Patients who transfer in are not included in the number of cumulative patients ever started on ART at the facility (see definition below).
TRANSFER OUT (TO)	Patient who has been receiving ART at one facility transfers out of that facility. 'TRANSFER OUT' is not an outcome – rather, patients who transfer in and out of the facility affect the net current cohort (see below). In a national system, a transfer out patient's outcome will be captured by the receiving facility thereafter.
DEAD	Patient dies anytime after being enrolled in HIV care or ART.
ELIGIBLE BUT NOT YET STARTED ART	Patients currently enrolled in care (excluding those who have died, are lost to follow-up or transferred out), are assessed and found to be eligible for ART, but have not yet started it; they then constitute the 'waiting list'.
CUMULATIVE EVER STARTED ON ART	Number of patients who have ever started on ART as NEW at that specific facility; does not include patients who transfer in. Patients who transfer out, or are categorized as DROP, DEAD, LOST, or STOP, are not subtracted.
CURRENT ON ART	Number of patients who are currently on ART at a given facility; does include patients who transfer in. Patients who transfer out, or are categorized as DROP, DEAD, LOST, or STOP are subtracted.
COHORT	Group of patients who start ART in the same month and year, whose status is followed over time, using the ART register.
NET CURRENT COHORT (cohort analysis report)	Patients in a given cohort for whom the facility is currently responsible; consists of those who started on ART at the facility, minus those who have since transferred out, plus those who have since transferred in.

Term/code	Definitions of special TB-HIV patient monitoring terms and codes
CURE	Sputum smear microscopy positive patient who was sputum negative in the last month of treatment and on at least one previous occasion.
TREATMENT COMPLETED	Patient who has completed treatment, but who does not meet the criteria to be classified as a cure or a failure.
TREATMENT FAILURE	<p>New patient who is sputum smear microscopy positive at five months or later during treatment, or who is switched to Category IV treatment because sputum turned out to be Multi-Drug Resistant Tuberculosis (MDR-TB).</p> <p>Previously-treated patient who is sputum smear microscopy positive at the end of his re-treatment or who is switched to Category IV treatment because sputum turned out to be MDRTB.</p>
DEFAULT	Patient whose treatment was interrupted for 2 consecutive months or more.
DIED	Patient who dies from any cause during the course of treatment.
TRANSFER OUT	Patient who has been transferred to a health facility in another BMU and for whom treatment outcome is not known.
NEW	Patient who has never had treatment for TB, or who has taken antituberculosis drugs for less than one month.
RELAPSE	Patient previously treated for TB, declared cured or treatment completed, and who is diagnosed with bacteriological (+) TB (sputum smear microscopy or culture).
TREATMENT AFTER FAILURE	Patient who is started on a re-treatment regimen after having failed previous treatment.
TREATMENT AFTER DEFAULT	Patient who returns to treatment, is positive bacteriologically following interruption of treatment for two or more consecutive months.
TRANSFER IN	Patient who has been transferred from another TB register to continue treatment. This group is excluded from the Quarterly Reports on TB Case Registration and on Treatment Outcome
OTHER PREVIOUSLY TREATED	All cases that do not fit the above definitions. This group includes sputum smear microscopy positive cases with unknown history or unknown outcome of previous treatment, previously treated sputum smear microscopy negative, previously treated EP, and chronic case (i.e. a patient who is sputum smear microscopy positive at the end of re-treatment regimen).

Term/code	Definitions of special PMTCT patient monitoring terms and codes
EBF (EXCLUSIVE BREAST FEEDING)	An infant receives only breast milk and no other liquids or solids, not even water; with the exception of drops or syrups consisting of vitamins, mineral supplements or medicines.
MF (MIXED FEEDING)	Feeding both breast milk and other foods or liquids
RF (REPLACEMENT FEEDING)	The process of feeding a child who is not receiving any breast milk with a diet that provides all the nutrients the child needs until they are fully fed on family foods. During the first six months, this should be with a suitable breast-milk substitute. After six months it should be with a suitable breast-milk substitute, as well as complementary foods made from appropriately prepared and nutrient-enriched family foods.
UNKNOWN HIV STATUS	A pregnant women whose HIV status is not known during ANC or at the time of delivery, either because she has not been tested; did not receive her result; or arrived without documentation of having been tested; was tested in a previous pregnancy and tested negative; or has had exposure to HIV, but has not been tested since that exposure.
RE-TESTING	When a pregnant or postpartum woman who was previously tested is tested again due to potential HIV exposure since her initial test, or within the window period prior to the initial test.
UNKNOWN ART ELIGIBILITY	The eligibility for treatment among HIV-infected pregnant or postpartum women has not been assessed through either WHO clinical staging or CD4 count testing, and there is no previous history of eligibility for ART.
CURRENT ON ARV PROPHYLAXIS	When a pregnant women has been provided with ARV prophylaxis (any prophylactic regimen as defined in national guidelines), and continues to take the ARV prophylactic regimen (i.e. not reported to have stopped).
CURRENT ON ART	A pregnant women who is provided ART for her own health and is currently on ART (i.e. has not died, stopped, or is not considered lost to follow-up).
POSTPARTUM PERIOD	The period within two months of giving birth (some countries may define this as six months – for country adaptation).
FINAL STATUS (FOR CHILD)	<p>The final HIV status of the child based on either HIV virological testing (i.e. virological testing) or rapid antibody testing. Final status includes 'positive status' or 'negative status' and can be used for infants in the following categories:</p> <ul style="list-style-type: none"> <li>• Non-breastfeeding HIV-exposed infant six weeks or more of age (but not yet eligible for antibody testing) who tests either positive or negative using virological testing testing;</li> <li>• Breastfeeding HIV-exposed infant who tests positive using virological testing testing technology at six weeks or more of age;</li> <li>• Breastfeeding HIV-exposed infants testing positive at 18 months of age;</li> <li>• Non-breastfeeding (exclusively breastfed and weaned by 15 months of age) HIV-exposed infant testing positive or negative at 18 months.</li> </ul>

## 6.9 HOW TO USE REGISTERS TO MONITOR SERVICES AND PATIENTS

Registers are used to summarize in one place the patient information of many people. Generally, registers are set up so that each row represents a patient, and each column represents indicators of the patient's health status or health services received over time. Registers have limited space, so the columns of information are selected with great care, and the information in each column should be limited to that which is absolutely necessary and used frequently for patient management, programme monitoring or reporting.

As mentioned above, registers may be the centre's only source of patient information for some services (such as antenatal care) when there is not a complete facility-held record for a patient. For example, you may use registers to record information about pregnant women over the course of a pregnancy. Alternatively, registers may be a way to track patients and summarize patient-level information on many patients. This information may be otherwise contained in facility-held patient records, but, for various reasons, is not easily reviewed, analysed or summarized directly from those records. This is how and why HIV care (pre-ART) and the ART registers are used in HIV patient monitoring.

In longitudinal registers (that follow the same patient over time) such as the HIV care (pre-ART) and ART registers, patients are generally listed by the date of a meaningful event (such as enrolment into HIV care or initiation of ART). Each patient is entered only once in the register, and information from later visits or events is entered on the patient's row at a later date. A group of patients that begins a meaningful event around the same time (e.g. month) is called a 'cohort'. For example, you may have heard of the term 'birth cohorts', which refers to people born in the same year and followed over time. With respect to HIV services, the term 'cohort' refers to a group of people who enrol in HIV care in the same month, or people who initiate ART in the same month and year (more information is available on the country cohort report form in the Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT (including malaria prevention during pregnancy), and TB/HIV: standardized minimum data set and illustrative tools forms booklet). By aligning patients by their start dates, it is easier to locate any single patient and to analyse groups of patients (e.g. examining retention and survival at 12 months among patients who initiated HIV treatment in the same month).

In the national standardized HIV patient monitoring system, there is an HIV care (pre-ART) register and an HIV treatment (ART) register. When a HIV-infected person first enrolls in HIV care, he receives a row on the pre-ART register on the date that he enrolls. Information about his health status and HIV services are recorded in his patient record and then transcribed onto 'his' row in the appropriate columns of the HIV care (pre-ART) register.

If a patient becomes eligible for and initiates ART, they receive a row on the ART register in the month they initiate ART. Information about the patient's health status and health services are still recorded in the patient record, but this and any subsequent information is transcribed to the HIV treatment (ART) register (rather than the pre-ART register). Some sites with large patient volumes and more resources may enter the register data from the card into a computer. If they enter the full card into a computer they may forego the use of paper registers altogether, or may automatically print the registers from the electronic patient records. Registers are useful for staff to track patients and at a glance understand how they are doing.

Manually transcribing information from HIV patient records to registers needs great care. However, the task is made easier by the simple and complementary formats of the patient record and the register. Transcribing information from HIV patient records to registers can be done by a non-clinician staff member (e.g. data clerk, PLHIV) who can read numbers, shows good attention to detail and respects the confidentiality of patient information (see section - 6.2).

## **6.10 HOW TO SUMMARIZE ROUTINE INFORMATION IN ORDER TO REPORT**

### **Reporting**

If your health centre delivers HIV services, you will be required to send some information to your district, regional, and/or national authorities on a regular basis. Most countries require monthly or quarterly reporting of some information and annual reporting of other information. To achieve this, you need to:

- allow enough advance time before any deadline to tally, check, and re-tally the information;
- always perform a check of all calculations;
- keep a record of the calculations and any problems encountered;

- present and discuss the information at the health centre (see section - 6.11 and Quality Improvement chapter);
- report information to authorities on time.

### **Cross-sectional (monthly or quarterly) report**

A cross-sectional report usually refers to information about services delivered (e.g. number of tests) or coverage of people or sub-populations reached with services within a specified period of time (such as a month or quarter). This report is designed to provide information about all of the HIV-infected patients—whether they are eligible or not eligible for ART—who are enrolled in HIV care at a centre. It includes the number of people by age and sex (within the last month or quarter):

- enrolled in HIV care
- started on INH
- currently in HIV care
- started on TB Rx
- assessed for TB status at last visit
- new on ART
- currently on ART, tallied for all existing patients
- started on TB Rx
- key MCH numbers summarizing ANC, L&D and HIV-exposed infant activities

Carrying out the actual computations needed to create these summary data may be done by scanning down pages of registers, and adding results page-by-page onto a tally sheet for all services delivered in the time period (see the cross-sectional quarterly (or monthly) report form in the Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT (including malaria prevention during pregnancy), and TB/HIV: standardized minimum data set and illustrative tools. forms booklet).

### **Cohort report**

A cohort report refers to information about a group of people who are followed forward together in time from a common event. The cohort report shown in the draft Three interlinked patient monitoring systems for HIV care/ART, MCH/PMTCT (including malaria prevention during pregnancy), and TB/HIV: standardized minimum data set and illustrative tools. forms booklet). provides an overview of how patients are doing on ART at six, 12, and 24 months, such as: number and proportion of patients who are alive and on ART and

continuing on a first-line regimen; and median CD4. It assesses success of the programme. On a monthly or quarterly basis, the centre team will summarize information from the ART register on the ART cohort analysis form for those cohorts that have reached six or 12 months on ART; then for every year of completion of ART. These cohort data are verified and collected on an annual (or more frequent) visit by the district management team (see section - 6.2).

Other useful indicators that can be tallied using the registers or cards are described in the common indicators of HIV service delivery tables below. An annual (or bi-annual) patient monitoring review can be carried out to check the quality of indicators tallied from existing registers or cards. This review consists of: validating or completing the ART cohort analysis form; tallying relevant register data; and systematically sampling HIV care/ART patient cards. The annual patient monitoring review draft document (in field-testing) provides a more detailed description of how this is done.

### **Other centre reports not derived from the patient monitoring systems**

Health centre staff may also be asked to produce a report or fill out a checklist on indicators that show the policies, practises or services offered by the centre, and the availability of services or commodities during some recent period. See Supply Management chapter for how to report on drug stocks and other supplies. Laboratory reports are often aggregated counts of how many tests were conducted in a given period, sorted by the type of test conducted and the result. These can be based on counts from laboratory registers (see Laboratory chapter).

### **Common indicators of HIV service delivery derived from patient monitoring systems**

The following table provides an example of global, national and subnational 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 Universal Access, UNGASS, HIV drug resistance early warning indicators, or other national indicators. (Note: Many indicators are expressed as a percentage. The calculation of percentage is as follows: (Numerator/Denominator) \* 100.)

Indicators	Source	How to calculate the indicator
<b>PMTCT</b>		
Percentage of pregnant women who were tested for HIV and received their results	ANC/L&D registers	<p>Numerator: Number of pregnant women attending ANC and L&amp;D services who were tested for HIV and received their results; women with known HIV infection attending ANC for a new pregnancy during a selected time period.</p> <p>Denominator: Estimated number of pregnant women during a selected time period.</p>
Percentage of HIV-infected pregnant women	ANC/L&D registers	<p>Numerator: Number of pregnant women attending ANC and L&amp;D services who tested positive for HIV and received their results; women with known HIV infection attending ANC for a new pregnancy during a selected time period.</p> <p>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&amp;D during a selected time period.</p>
Percentage of HIV-infected pregnant women who received ARVs to reduce the risk of mother-to-child transmission*	ANC/L&D registers	<p>Numerator: Number of HIV-infected pregnant women who received ARVs to reduce mother-to-child transmission during a selected time period.</p> <p>Denominator: Estimated number of HIV-infected pregnant women during a selected time period.</p>
Percentage of HIV-infected eligible pregnant women who are receiving ART	HIV care/ART card - (sample of cards)	<p>Numerator: Number of HIV-infected pregnant women on ART during a selected time period.</p> <p>Denominator: Number of HIV-infected pregnant women eligible for ART during a selected time period.</p>
Percentage of infants born to HIV-infected women who received an HIV test within 12 months	HIV-exposed infant register	<p>Numerator: Number of infants born to HIV-infected women who received an HIV test within 12 months during a selected time period</p> <p>Denominator: Estimated number of HIV-infected pregnant women giving birth in the last 12 months during a selected time period.</p>

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

Percentage of infants born to HIV-infected women who received a virological testing test by two months of age	HIV-exposed infant register	<p>Numerator: Number of infants born to HIV-infected women with a DBS test sent for virological testing by two months of age during a selected time period.</p> <p>Denominator: Number of infants born to HIV-infected women who reached 2 months of age during a selected time period.</p>
Percentage of infants born to HIV-infected women initiated on cotrimoxazole prophylaxis within 2 months of birth	HIV-exposed infant register	<p>Numerator: Number of infants born to HIV-infected women started on cotrimoxazole prophylaxis within two months of birth during a selected time period.</p> <p>Denominator: Estimated number of HIV-infected pregnant women giving birth in the last 12 months during a selected time period.</p>
Percentage of HIV-exposed infants who are 3 months of age and are on: exclusive breastfeeding, replacement feeding, or mixed feeding	HIV-exposed infant register	<p>Numerator: Number of infants born to HIV-infected women who are: a) exclusive breastfeeding; b) replacement feeding; c) mixed feeding(MF) at or around 3 months during a selected time period.</p> <p>Denominator: Number of HIV-exposed infants whose feeding practise was assessed around or at three months (through the mother) during a selected time period.</p>
Percentage distribution of the final status of HIV-exposed infants at 18 months	HIV-exposed infant register	<p>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.</p> <p>Denominator: Total number of HIV-exposed infants identified.</p>
Percentage of HIV-infected women who are using a family planning method at last visit	HIV care/ART card - sample of patient cards	<p>Numerator: Number of HIV-infected women who are using a family planning method at last visit during a selected period of time</p> <p>Denominator: Total HIV-infected women in a selected time period.</p>

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

Treatment and care		
Percentage of adults and children with advanced HIV infection receiving ART*	ART register (cross-sectional report)	<p>Numerator: Number of adults and children with advanced HIV infection receiving ART during a selected time period.</p> <p>Denominator: Estimated number of adults and children with advanced HIV infection during a selected time period.</p>
Percentage of adults and children with HIV known to be on treatment 12 months after initiation of ART*	ART register (Included in cohort analysis)	<p>Numerator: Number of adults and children who are still alive and on ART at 12 months after initiating treatment.</p> <p>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.</p>
Percentage of HIV-infected children under 5 years with CD4% classification not severe at 6 or 12 months	ART register (included in cohort analysis)	<p>Numerator: Number of HIV-infected children under 5 years with last available CD4% classification not severe at 6 or 12 months after initiating treatment.</p> <p>Denominator: Total number of HIV-infected children under 5 years at 6 or 12 months after initiating treatment.</p>
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)	<p>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.</p> <p>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.</p>

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

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 7 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.

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

Percentage of adults and children enrolled in HIV care and eligible for CTX prophylaxis (according to national guidelines) and are 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 the last visit.  Denominator: Number of adults and children enrolled in HIV care who are eligible for CTX prophylaxis at the 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.
<b>TB/HIV</b>		
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.

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

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: All HIV patients on TB treatment and who were on ART during a selected time period.  Denominator: Estimated number of incident tuberculosis cases in people living with HIV during a selected time period.

\* UNGASS Indicators are reported annually

\*\* HIV Drug Resistance Early Warning Indicators

All denominators are actual numbers unless specified as 'estimated'.

## 6.11 HOW TO USE THE PATIENT MONITORING SYSTEMS TO PROMOTE QUALITY AND MONITOR PROGRAMMES

Information can be used to improve patient management and programme performance. Yet, too often staff do not have the skills or time to analyse and reflect on the information that they collect, and to discuss how the observations can improve the clinical services the health centre provides.

Review of information in the records and registers should take place regularly and should provide signals back to clinicians about patient progress, outcomes and programme performance. Special time needs to be set aside and staff assigned to do information and quality reviews. This is an indispensable part of delivering high quality HIV services (see Quality improvement chapter).

### **Review routinely collected information weekly with clinical team**

Summarize and discuss information commonly contained in registers with health centre staff to gauge how well the programme is performing.

### **Review cross-sectional and cohort reports with health centre staff**

#### **Use other methods to measure performance**



Use other methods to monitor the performance and success of your health centre's HIV services, e.g. abstract of data from a systematic sample of patient records. Examples and methods of using monitoring data to achieve quality improvement are provided in the Quality Improvement chapter.

#### **Compare trends over time**

Another way to assess programme progress and quality of care and to demonstrate scale-up, change, improvement, etc. is to make comparisons using tables or graphs to display information (on the same indicator) collected at several points over time. Trends may emerge from examining sequential cohorts over time, or from sequential quarters over time. In carrying out this comparison, some key questions to consider include:

- What is the change or trend observed?
- Does the change or trend make sense?
- Is the change or trend in the expected direction?
- What might explain the change?
- Could it be a 'real' change in the phenomenon, or could the change be due to a difference in data quality over time?

#### **Conduct periodic evaluation activities**

Occasionally, special activities to analyse available data or to collect some additional data may be warranted to evaluate programme implementation, recognize successes and identify and explain challenges. For example, combining a review of patient data with records of interviews and/or observations can highlight challenges to programme operations (e.g. why are PLHIV reluctant to have their family members take an HIV test?).

Managers of health centres with greater capacity may wish to collect information beyond the standard minimum data set to help them better understand and improve their HIV services. For example, the standard patient monitoring system will show if a health centre is struggling with large number of ART patients who are lost to follow-up, but not why. It might be prudent to train and deploy a team (e.g. PLHIVs) to track individuals lost to follow-up into the community to determine and document their vital and health status and the reason(s) they have not continued with ART. Then the health centre team can change its programme approaches to increase the chances of HIV patients remaining in their system and adhering to ART.

## 6.12 HOW TO CHECK THE QUALITY OF THE INFORMATION COLLECTED

### What is data quality?

High data quality can be achieved if information is:

- accurate (valid) – data measure what they are meant to measure;
- complete – all forms and fields are filled in every time and are legible;
- reliable – data are measured consistently over time;
- timely – data are collected, analysed, used and reported on time (if there is a deadline), or within a timeframe that feeds back usefully to clinical care;
- precise – data have sufficient detail to measure the aspect of interest.



Incomplete, illegible or lost records cannot help clinicians understand how to manage HIV patients or how to improve programmes, and will compromise patient care. Data quality can be promoted by carefully recording and transcribing information. However, everyone makes mistakes at some point, so data quality reviews are strongly recommended. Such reviews can be done routinely (e.g. incorporated into the data clerk's daily scope of work) or as a special periodic activity, for example, as part of a quarterly supportive supervisory visit by a team outside of the health centre.

There are several ways that the health centre can check the quality of the data.

### **Routine review of patient records**

A clinician or a clinical assistant should quickly scan the patient record at the end of each patient visit to ensure that all information has been filled out, is legible and is accurate. Another staff member can review the records later and note if they are incomplete, but this person would not likely be able to process missing or illegible information. The data clerk or other staff member who transcribes information from patient records needs to make note of incomplete, missing, or nonsensical information so the problems can later be discussed with clinical staff.

### **Periodic review of patient records**

A periodic review of a sample of patient records is a good way to check for data quality. This approach could be incorporated into supportive supervision visits by the district health management team.

### **Comparison of patient records to registers**

Another way to check data quality is to compare the information in the patient record with data in the register. Transcribing from the record to the register can be tedious and is prone to transcription error.

### **Comparing changes in data (and possibly data quality) over time**

Another way to check data quality is to compare information collected at one time point with information collected at another, and to assess whether both appear to be equally complete, consistent, and valid at every interval. Ideally, data quality would improve over time. But, if data quality declines, it can be difficult to analyse trends.

### **Key definitions used in the three interlinked patient monitoring systems**

One way to ensure quality is to ensure that standardized definitions of data elements and indicators are used. see definitions and codes used in the 3ILPMS forms booklet and the example on table on page 121 see definitions and codes used in the three interlinked patient monitoring systems.