**Sample Generic HIV Care Data Collection Tools (Pre ART and ART Registers) and Instructions**

The complete RHIS curriculum is available here:

[https://www.measureevaluation.org/our-work/](https://www.measureevaluation.org/our-work/routine-health-information-systems/rhis-curriculum)

[routine-health-information-systems/rhis-curriculum](https://www.measureevaluation.org/our-work/routine-health-information-systems/rhis-curriculum)

**2.2.2b**

1. **Pre-ART Register/ Page 1**

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| **Registration** | | | | | | | **Fill when applicable** | | | **Clinical stage** | | | | **PMTCT** | | | | **ART** | |
| Date enrolled  in chronic HIV care | Unique ID No. | Patient clinic ID  No. | Name in full  Upper space: surname  Lower space: given name | Sex | Age | Status at enrolment  (record TI if transfer in) | CTX  Start month/year | INH start  month/  year | TBRX  Start  month/year and TB reg No. | 1 | 2 | 3 | 4 | For each pregnancy, record EDD, ANC No. and HIV-exposed infant No. | | | | Date medically  eligible for ART | Date ART  started  (transfer to ART register) |
| Preg 1 | Preg 2 | Preg 3 | Preg 4 |
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1. **Pre-ART Register/ Page 2**

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| **Quarterly follow-up status** | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Top row**:  **Bottom row**: | | | | | | | | | | | | | | | | | | | | | | | | | |
| **Year** | | | | **Year** | | | | **Year** | | | | | **Year** | | | | | **Year** | | | | **Year** | | | |
| Q1  Jan-Mar | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec | Q1  Jan-Mar | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec | Q1  Jan-Mar | | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec | Q1  Jan-Mar | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec | | Q1  Jan-Mar | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec | Q1  Jan-Mar | Q2  Apr-Jun | Q3  Jul-Sep | Q4  Oct-Dec |
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| Total TB staus Y | | |  |  | | |  |  | | | |  |  | | |  | |  | | |  |  | | |  |
| Seen at least once in Y | | |  |  | | |  |  | | | |  |  | | |  | |  | | |  |  | | |  |
| **Top row:** record follow-up status at end of each quarter | | | | | | | | | **Bottom row:** Record TB status | | | | | | | |
| **CD4** - record last CD4 in quarter | | | | | | | | | **Y**es**/N**o - TB status completed at last visit in last quarter | | | | | | | |
| **→** - did not have visit scheduled for that quarter | | | | | | | | |  | | | | | | | |
| **LOST**- not seen in the last quarter, but scheduled for a visit | | | | | | | | |  | | | | | | | |
| **TO**- transferred out (record to where) | | | | | | | | |  | | | | | | | |
| **DEAD** - record date | | | | | | | | |  | | | | | | | |

1. **Instructions for Filling Out the Pre-ART Register**

Using the patient HIV care/ART card, enter the following data into the pre-ART register as it becomes available:

* ***First entry into the pre-ART register only***

 Facility name

 Date enrolled in chronic HIV care (sequential)

 Unique ID number

 Clinic card number

 Patient name, sex, age, and address

 Status at enrolment (**Preg**nant; **P**ost **P**artum; **TB Rx**; **Other).** If pre-ART transfer in patient, write **TI**.

* ***First entry and update when data change***:

 CTX prophylaxis -- record the month/year started

 INH prophylaxis - record month/year started at or during enrolment

 TB treatment – record month/year started and TB registration number if on TB treatment at enrolment or thereafter

 Clinical stage – check the appropriate clinical stage as the patient’s stage changes

 Date: medically eligible for ART

 ART start date.

* ***For each pregnancy during the HIV care/ART follow up:***

 EDD - record estimated due date or actual delivery date if postpartum

 ANC No. – record the woman’s ANC number

 HIV-exposed infant No. - record the exposed infant’s registration or record number if available.

* ***Quarterly follow-up status. For each quarter, record:***

 Last CD4 - last CD4 count/% available in the quarter in top row

 TB status completed at last visit – **Y**es if TB status was completed at last visit in the quarter, and **N**o if otherwise in bottom row

 a – an arrow indicating the patient did not have a visit scheduled during that quarter

 LOST - not seen during the quarter, but was scheduled for a visit (missed appointment)

 TO - transferred out to another facility, record to where

 DEAD – record date of dea

1. **ART Register/ Page 1**

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| **Cohort : Year \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Month \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_** | | | | | | | | | | | | | | | | | | | | | |
| **Registration and personal information** | | | | | | **Status at start of ART** | | | | **Fill in when applicable** | | | **PMTCT** | | | | |  | **1st -line regimen** | **2nd -line regimen** | |
| ART start date | Unique ID No. | Patient clinic ID | Name  Surname  Given name | Sex | Age | weight | WHO clinical  stage | | CD4 | CTX  Start  Month/  year | INH  Start  Month/  year | TBRX  Start  month/year  and TB reg No. | Preg 1 | Preg 2 | Preg 3 | | Preg 4 | Original  regimen | Substitution  1st: reason/date  2nd : Reason/date | Switches, substitution  1st : Reason/date  2nd : reason/date | |
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| **Reasons for regimen** | | | **Reasons for switch to 2nd -line regimen:** | | | | | **Adult 1st -line regimens** | | | **Child 1st -line regimens** | | | | | **Adult 2nd -line regimens** | | | | | **Child 2nd -line regimen** |
| 1. Toxicity/side effects | | | 8. Clinical treatment failure | | | | | 1a = d4T-3TC-NVP | | | 4a = d4T-3TC-NVP | | | | | 2a(250) = ABC - ddI(250) - LPV/r | | | | | 5a = ABC - ddI - LPV/r |
| 2. Pregnancy | | | 9. Immunologic failure | | | | | 1b = d4T-3TC-EFV | | | 4b = d4T-3TC-EFV | | | | | 2a(400) = ABC - ddI(400) - LPV/r | | | | | 5b = ABC - ddI - NFV |
| 3. Risk of pregnancy | | | 10. Virologic failure | | | | | 1C = AZT-3TC-NVP | | | 4c = AZT-3TC-NVP | | | | | 2b(250) = ABC - ddI(250) - SQV/r | | | | | 5c = ABC - ddI - SQV/r |
| 4. Due to new TB | | |  | | | | | 1d = AZT-3TC-EFV | | | 4d = AZT-3TC-EFV | | | | | 2b(400) = ABC - ddI(400) - SQV/r | | | | | 5d = …. |
| 5. New drug available | | |  | | | | | 1e = …… | | | 4e = …. | | | | | 2c(250) = TDF - ddI(250) - LPV/r | | | | | 5e = other |
| 6. Drug out of stock | | |  | | | | | 1f = …… | | | 4f = …. | | | | | 2c(400) = TDF - ddI(400) - LPV/r | | | | |  |
| 7. Other reason (specify) | | |  | | | | | 1g = other | | | 4g = other | | | | | 2d(250) = TDF - ddI(250) - SQV/r | | | | |
| 9 | | |  | | | | |  | | |  | | | | | 2d(400) = TDF - ddI(400) - SQV/r | | | | |
|  | | | | | 2e = other | | | | |

1. **ART Register/ Page 2**

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| **Write in year and month** | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| Month 0 | Month 1 | 2 | 3 | 4 | 5 | 6 | | 7 | 8 | | 9 | 10 | 11 | 12 |  | 13 | 14 | 15 | 16 | | 17 | 18 | | 19 | 20 | | 21 | 22 | 23 | 24 | |
|  | CD4 |  | CD4 |  | CD4 |  | CD4 |
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| **Top row**: Record follow-up status at end of each month | | | | | | | | | | **Bottom row:** Record TB status at last visit during the month | | | | | | | | | | **If follow-up status is ''STOP,'' then add reason (and weeks of interruption if later restarted)** | | | | | | | | | | | |
| On treatment (record current **regimen code**) | | | | | | | | | | **Y**es**/N**o - TB status completed at last visit in last quarter | | | | | | | | | | 1. Toxicity/sides effect | | | | | | 8. Other patient decision | | | | | |
| **DEAD** | | | | | | | | | |  | | | | | | | | | | 2. Pregnancy | | | | | | 9. Planned treatment interruption | | | | | |
| **STOPPED** ART (continued on other care) | | | | | | | | | |  | | | | | | | | | | 3. Treatment failure | | | | | | 10. Other | | | | | |
| **LOST** (missed drug pick-up) | | | | | | | | | |  | | | | | | | | | | 4. Poor adherence | | | | | | 11. Excluded HIV infection in infant | | | | | |
| **DROP** (lost to follow-up), not seen 3 months from last missed appointment | | | | | | | | | |  | | | | | | | | | | 5. Illness, hospitalization | | | | | |  | | | | | |
| **RESTART** | | | | | | | | | |  | | | | | | | | | | 6. Drugs out of stock | | | | | |  | | | | | |
| Transferred out (**TO**)- if TO, transferred out to where | | | | | | | | | |  | | | | | | | | | | 7. Patient lack finances | | | | | |  | | | | | |

1. **Instructions for Filling Out the ART Register**

Once the patient has started on ART, a subset of the information from the HIV care/ART card is entered into the **ART register**.

A patient is put in a cohort based on the year and month he or she started ART, regardless of where the ART 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.

The ART register includes the following:

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| *Left page for the cohort starting ART within this month*:  – Date start ART  – Unique ID number, ANC number, patient clinic number  – Patient name, sex and age (or date of birth)  – Weight, clinical stage and CD4 (if available) at start of ART  – INH prophylactic therapy - start month and year  – CTX prophylaxis - start month and year  – TB treatment - month and year started and TB registration No.  – Switch to second-line/substitutions  – Reasons for regimen change  – ARV regimen:  1st-line regimen: original, substitution with reason and date  2nd-line regimen: original, switch/substitution with reason and date  – For each pregnancy record EDD, ANC no. and HIV-exposed infant No. | *Right page:*  Month 0 to 24 - record each month:  – Current ARV regimen or  – Stop  – Lost: missed drug pick-up  – Drop or lost to follow-up (LTF): not seen for at least 90 days after last missed appointment  – Restart, Dead, or Transfer Out  – TB status completed (Y/N)  At 6, 12, 18 and 24 months:  – CD4 (if available); if infant CD4% and +/- severe |

