STANDARD PROCEDURE FOR DATA TRANSFER

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Contact: iedea-info@ispm.unibe.ch
www.iedea-sa.org / www.iedea-hiv.org

Contents

1 Introduction

1.1 General remarks

- This document provides guidance on the preparation of data tables for the transfer of data for the IeDEA Southern Africa Collaboration.
- It is requested that each clinic prepares **ten separate tables** with the new data, as described in detail below. While 6 of these tables should be submitted by all sites, tables 7 -10 will only be applicable to certain sites (see below).
- The tables can be sent in the format that is most convenient for the site, including MS Excel, MS Access, and ASCII etc. Please contact the IeDEA data manager if you have any queries.
- **It is appreciated that for some clinics it may be easier to send their data as they stand (for example in Excel) and to leave the data management and preparation of the ten tables to the data center. This is not a problem, but it is requested that a separate document be included with a list of the variables in the dataset and brief descriptions/definitions.**
- It is accepted that there will be missing data for some patients, and even entire missing tables from some sites who simply do not have that data in electronic format.
- It is requested that for security purposes, data tables be encrypted and compressed with WinZip 9 or higher using the AES encryption algorithm prior to sending. The encryption password (minimum of 10 characters long, including upper/lower case, numbers and special characters) should be communicated to the relevant data center contact person by fax or by telephone.
- Please ensure that the dataset has been stripped of personal identifying information prior to sending.
- Please include a unique anonymous identifier for each patient (PATIENT) for cross-reference with your own database. It can be the identifier you are using or a special identifier you create for IeDEA Southern Africa. This anonymization key must be maintained by the site under secure conditions.
- Sites treating children should please send the date at which they changed from using the WHO 3-stage clinical staging system to the 4-stage clinical staging system.

Thank you very much for your contribution to this collaborative project!

1.2 Inclusion criteria for patients

Please include all patients with the following characteristics:

- Documented HIV-1 infection
- Patients in care at the facility for whom the date of first visit at the facility is known exactly.

Notes:

- Where possible, it is intended that data be transferred on HIV-infected patients followed-up at the facility irrespective of whether or not they received highly active antiretroviral therapy (HAART).
- When transferring data just on patients who received HAART, it is preferable to include patients irrespective of whether or not they were exposed to anti-retroviral before the recorded HAART start date. In other words treatment-naïve and treatment-experienced patients are included.
- Sites should send all information on all patients (adults and/or children) in a single dataset. For adult patients (those whose **first visit at your facility was after their 16th birthday**) the pediatrics specific fields (highlighted in blue) do not need to be completed (i.e. enter code 88 – not applicable). Pediatric specific fields must be entered as completely as possible for all patients whose **first visit at your facility is before their 16th birthday** even if their follow-up extends beyond the age of 16 years.
- Some patients will have been in care at another facility prior to commencing care at your facility. These patients should be included in the dataset, noting against the relevant field that they have been transferred in. All treatment and opportunistic infection (OI) history prior to commencing care at the facility should be reconstructed as far as possible and entered in the appropriate tables, with unknown codes for dates of start and end date of OIs/antiretroviral drugs where necessary.

1.3 Dates

- The term baseline will not be used as this creates confusion. We will rather make use of a set of key dates that will be entered into the first table, the **PATIENT** table. These are:

Variable name	Definition of key date
FRSVIS_DMY	Date of first visit at your facility
HIVP_DMY (HIVP_Y (year) and HIVP_M (month) if exact date unknown)	Date of first positive HIV-1 test
HAART_DMY	Date of HAART initiation

- For all fields that require a date, the precise date should be entered in the format dd-mm-yyyy if it is known. If the precise date is not known, the month and year should be entered separately as far as possible in the separate dedicated fields provided for these, and the precise date field should be left blank.
- If month or both the year and month are unknown, the precise date field should be left blank and unknown codes should be entered into the year field (9999) and the month field (99) as appropriate.
- For certain date fields a precise date is obligatory e.g. date of first visit at your facility (FRSVIS_DMY) and date of HAART initiation (HAART_DMY). In patients who commenced HAART at another facility, if the precise date of start of HAART cannot be estimated

reasonably accurately, the patient should be entered as treatment experienced and the date of first visit at your facility will be regarded as the date of start of HAART.

1.4 Definitions

- HAART is defined as treatment with a combination of at least three drugs from any class or classes.
- "Treatment experienced" is defined as previous exposure to any antiretroviral drug for at least 30 days, **excluding** exposure for prevention of mother to child transmission (PMTCT) or post-exposure prophylaxis (PEP).

1.5 Standard codes

Certain codes will appear repeatedly in a number of lists for coded fields. In this instance, the same codes/coding format will be used in all fields where these codes appear as follows:

Codes	Description
0	No
1	Yes
90	Other
95	Not ascertained/Not collected at this facility
99	Unknown despite attempting ascertainment
88	Not applicable

1.6 Data tables

For each clinic, the following **five** to **ten** data tables or files should be prepared, depending on data availability.

- Tables 1 to 5 are required by all sites.
- Table 6 (LINKAGE DATA) is required only for sites that record information on families
- Table 7 (PREGNANCY) is required only for sites that record information on pregnancy electronically.
- Table 8 (PAR HEALTH) is required only for patients who commence care before their 16th birthday.
- Table 9 (TB) is required only from sites that record detailed information on episodes of tuberculosis electronically.
- Table 10 (TRIAL) is required only for sites where patients may be enrolled on clinical trials or research studies apart from cohort analyses of routinely collected data.
- In addition, a table summarizing with information on the overall cohort or "meta-data" for the transfer, should be included with all transfers.

1. **PAT (Patient data)**: A table containing socio-demographic data on patients, clinical characteristics at start of HAART in HAART-treated patients, as well as information on the

outcomes of patients. One line will correspond to one patient. In other words, each patient will appear only once in this table. We propose that this table is called PAT.

2. LAB (Laboratory data at baseline and follow-up): This is a single table containing all laboratory data: CD4, HIV viral load, and all other laboratory tests. One line will correspond to one laboratory result. In other words, most patient will have multiple records in this table. We propose that this table is called LAB.

3. ART (Antiretroviral treatments): A table with the data on all antiretroviral drugs that a patient has received or been exposed to including PMTCT (both exposure to mother as well as infant peri- or post-natal) or post-exposure prophylaxis. This includes treatment received at your facility and at other facilities. The table will contain one line for each separate drug, with different fields for the drug name (code), the prescription start dates and stop dates. Most patients will have numerous records in this table. The drug history of patients who commence care at your facility but have previously been treated at another facility should be reconstructed and entered into this table as far as possible. We propose that this table be called ART.

4. OI (Opportunistic Events): A table with the information on all opportunistic infections or incident HIV-associated diagnoses. One line will correspond to one clinical event with different fields for the event type (code), the start dates and stop dates. It is anticipated that stop dates will often not be known. In other words, some patients will have more than one record in this table and some may have no records in this table. History of opportunistic events occurring prior to commencing care at your facility should be reconstructed as far as possible. We propose that this table be called OI.

5. VIS (Visit data): A table containing information on all clinical visits (including the first visit at your facility). One line will correspond to one visit. Most patients will have more than one record in this table. We propose that this table be called VIS.

6. LINK (Linkage data): A table containing information on family members (partners, children and siblings) also receiving HIV care either within your cohort or at another site. All family members receiving HIV care should be included whether they are receiving care at an IeDEA collaborative site or at a non-IeDEA site. One line will correspond to one family member receiving HIV care. In other words, some patients will have more than one record in this table and some may have no records in this table. We propose that this table is called LINK.

7. PREG (Pregnancy data): A table containing information on all pregnancies, including spontaneous abortions/miscarriages and terminated pregnancies, and their outcomes. One line will correspond to one pregnancy. Multiple pregnancies will each have a record in the table, with the outcome of the relevant foetus recorded. Some patients will have more than one record in this table, while others (including all males and children less than 10 years) will have no records in this table. We propose that this table be called PREGNANCY.

8. PAR_HEALTH (Parental health): A table with information on parental health status. This table is only required for sites sending data on patients 15 years old and younger at their first visit to the facility. This table is linked to the visit table, so ideally there is an update on parental

health status at every visit. Alternatively, this table should be filled in at least once, either for the first visit at your facility or the date of start of HAART.

9. TUBERCULOSIS (Tuberculosis data): A table with information on all episodes of tuberculosis (TB). This table is only for sites that record detailed information on TB episodes. Sites that do not collect detailed information on TB episodes should enter the TB episodes in the OI table. One line will correspond to one TB episode. In other words, some patients will have more than one record in this table and some may have no records in this table. We propose that this table be called TB.

10. TRIAL (Enrolment in trials): A table with information on any trial or research study (apart from cohort analysis of routinely collected data) on which a patient is enrolled. This table is only for sites running trials or research studies. One line will correspond to one trial/research study on which the patient is enrolled. In other words, some patients will have more than one record in this table and some may have no records in this table. We propose that this table be called TRIAL.

11. MET (Meta-data): A table comprising key characteristics of the data that is transferred.

2 Variables to be included in core tables

2.1 Socio-demographic characteristics and outcomes (PAT table)

Table 1 below details the data that should be included in PAT table.

The patient identification variable (PATIENT) must be unique, and it cannot be missing in any of the tables. This field must contain a unique and anonymous patient identifier; the field must NOT contain their name or any other identifying information. It is up to the local collaborator to maintain the key for linking the unique patient identifier with the patient.

Table 1 – Variables to be included in PAT table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
FACILITY	Text	Text field identifying particular clinic within cohort, if more than facility within the cohort
BIRTH_DMY	DATE (dd-mm-yyyy)	Date of birth Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below.
BIRTH_Y	Numeric (for example 1960) 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	Year of birth
BIRTH_M	Numeric (for example 8) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Month of birth
GENDER	Numeric with codes: 1 = Male 2 = Female 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Sex / gender of patient
FRSVIS_DMY	DATE (dd-mm-yyyy)	Date of first visit at facility (Note: This date must be entered exactly)

ENTRY	Numeric with codes (see List 1)	Mode of entry to your facility
ENTRY_OTHER	Text	Details of other mode of entry not listed in List 1
MODE	Text with codes (see List 2)	Most probable mode of HIV transmission
HIV_TYPE	Numeric with codes (for example 1) 1 = HIV-1 2 = HIV-2 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Field to distinguish HIV-1 from HIV-2
HIVP_DMY	DATE (dd-mm-yyyy)	Date of first positive HIV test Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below.
HIVP_Y	Numeric (for example 2001) 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	Year of first positive HIV-1 test
HIVP_M	Numeric (for example 8) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Month of first positive HIV-1 test
HIV_TEST	Numeric with codes (IeDEA SA codes) 1 = Presumptive diagnosis 2 = Serology 3 = PCR 4 = P24 5 = Rapid test 90 = Other 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Type of test used for diagnosis
HAART	Numeric 0 = Never started HAART 1 = Started HAART	Conditional: If 1 then go to HAART_DMY
HAART_DMY	DATE (dd-mm-yyyy) DATE (dd-mm-yyyy)	Date of HAART initiation (minimum 3 drugs together) Note: This date must be entered exactly. If patient commenced HAART at another facility and the exact date is not known, the patient should be entered as "Treatment experienced"

		in the EXP_Y field below and the first visit at your facility will be used as the start of HAART date.
FHV_STAGE_WHO	Numeric with codes: 1 = Stage I 2 = Stage II 3 = Stage III 4 = Stage IV 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Clinical WHO stage (I to IV) at time of starting HAART (Enter 88 patients who have not commenced HAART)
FHV_SDI_1	Text (for example PCP - see List 3) 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Stage defining illness-1 at time of starting HAART. (Enter 88 patients who have not commenced HAART) Note: At least FHV_S_SDI_1 should be completed in patients commencing HAART; A maximum of 4 stage defining illness can be entered in the 4 fields provided. There is no specific ordering to the entering of stage defining illnesses.
FHV_SDI_2	Text (for example PCP - see List 3) 0 = No further stage defining illness 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Stage defining illness-2 at time of starting HAART. (Enter 88 patients who have not commenced HAART)
FHV_SDI_3	Text (for example PCP - see List 3) 0 = No further stage defining illness 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Stage defining illness-3 at time of starting HAART. (Enter 88 patients who have not commenced HAART)
FHV_SDI_4	Text (for example PCP - see List 3) 0 = No further stage defining illness 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Stage defining illness-4 at time of starting HAART. (Enter 88 patients who have not commenced HAART)
EXP_Y	Numeric with codes: 0 = No (No previous ARV experience) 1 = Yes (Treatment experienced, drug	Patient is treatment experienced prior to starting HAART (HAART_DMY) ?

	history known and recorded in ART table) 2 = Yes (Treatment experienced, drug history not known) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Experienced = Any ARV drug for at least 30 days before starting HAART (PMTCT regimen and PEP excluded) This should be entered for all patients even those who have not commenced HAART.
MTCT_Y	Numeric with codes: 0 = No (No MTCT exposure) 1 = Yes (MTCT exposed, drug history reconstructed and recorded in ART table) 2 = Yes (MTCT exposed, drug history not reconstructable) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Patient exposed to MTCT drugs (either mother during pregnancy or infant peri- or post-natally) prior to start of HAART (HAART_DMY)? This should be entered for all patients even those who have not commenced HAART.
PEP_Y	Numeric with codes: 0 = No (No PEP exposure) 1 = Yes (PEP exposed, drug history reconstructed and recorded in ART table) 2 = Yes (PEP exposed, drug history not reconstructable) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Patient exposed to post-exposure prophylaxis (PEP) drugs prior to start of HAART (HAART_DMY)? This should be entered for all patients even those who have not commenced HAART.
TB_FHV	Numeric with codes 0 = No 1 = Yes 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Patient was on treatment for TB at start of HAART (HAART_DMY) (Enter 88 patients who have not commenced HAART)
WKS_TB_FHV	Numeric (for example 8) 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Duration in weeks since start of TB treatment when HAART was commenced in patients with TB at start of HAART (Enter 88 for patients who have not commenced HAART or who did not have TB at start of HAART)
PREG_FHV	Numeric with codes 0 = No 1 = Yes 88 = Not applicable 95 = Not ascertained	Pregnant at start of HAART (Enter 88 for men and children <10 years old AND all patients who have not commenced HAART)

	99 = Unknown despite attempting ascertainment	
LAST_CONTACT_DMY	DATE (dd-mm-yyyy)	Date of last contact Note: This date must be entered exactly.
LAST_CONTACT_T	Numeric with codes (See List 4)	Type of last contact
OUTCOME	Numeric with codes (See List 5)	Outcome including death and loss to follow-up
OUTCOME_DMY	DATE (dd-mm-yyyy)	Date of outcome (Leave blank if outcome is Alive [in care] or Alive [not in care])
OUTCOME_Y	Numeric (e.g. 2004) 8888 = Not applicable or exact date of outcome entered above 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	Year of outcome Enter 8888 for patients who have not died, or if exact date of outcome entered above.
OUTCOME_M	Numeric (e.g.12) 88 = Not applicable or exact date of outcome entered above 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Enter 8888 for patients who have not died, or if exact date of outcome entered above. Month of outcome Enter 88 for patients who have not died, or if exact date of outcome entered above.
DEATH_C1	Text with codes (see List 6)	Cause of death : Enter 88 for patients who have not died
DEATH_N1	Text with following codes: I = Immediate cause U = Underlying cause/condition C = Contributing cause N = Not available	Note : There are 3 fields for 3 causes of death to be entered in no specific order. If an HIV-related cause of death is recorded, please ensure that the condition is recorded appropriately in the OI table. Nature of contribution of cause: For each cause of death, please characterise the contribution of the specific cause.
DEATH_C2	Text with codes (see List 6)	For each cause of death, please characterise the contribution of the specific cause.
DEATH_N2	Text with following codes: I = Immediate cause U = Underlying cause/condition C = Contributing cause	For each cause of death, please characterise the contribution of the specific cause.

	N = Not available	
DEATH_C3	Text with codes (see List 6)	For each cause of death, please characterise the contribution of the specific cause.
DEATH_N3	Text with following codes: I = Immediate cause U = Underlying cause/condition C = Contributing cause N = Not available	For each cause of death, please characterise the contribution of the specific cause.
DEATH_TXT	Text	?UCT
CAREG	Numeric with codes (see List 7)	Primary caregiver at start of HAART (HAART_DMY) (paediatric patients only – enter 88 for adult patients)
DISCL_CG	Numeric with codes (see List 8)	Person informed of the HIV status of the child (paediatric patients only – enter 88 for adult patients)
DISCL_CHILD	Numeric with codes 0 = No 1 = Yes 2 = In process 88 = Not applicable (adult patient) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Was the child informed of his/her status at HAART_DMY? (paediatric patients only - enter 88 for adult patients)
DELIV_M	Numeric with codes 10 = Vaginal, spontaneous 11 = Vaginal, forceps 12 = Vaginal, vacuum 20 = Caesarean section – primary/elective (before onset of labour and rupture of membranes) 21 = Caesarean section – emergency 22 = Caesarean section – type unknown 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Mode of delivery (paediatric patients only - enter 88 for adult patients)
WEIGHT_BIRTH	Numeric (e.g 3.20) 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting	Weight at birth in kg (paediatric patients only - enter 88 for adult patients)

	ascertainment	
BRSTFD	Numeric with codes 10 = breastfeeding, exclusive 11 = breast-feeding, exclusivity unknown 12 = mixed feeding 20 = Formula feeding 88 = Not applicable 95 = Not ascertained 99 = Unknown, despite attempting ascertainment	Main infant feeding option after birth (paediatric patients only - enter 88 for adult patients)
BRSTFD_ED	DATE (dd-mm-yy)	Date of cessation of breast feeding if applicable Leave blank if not applicable, child still being breastfed, date not known, or child not breastfed at all.
BRSTFD_EST_DUR	Numeric (e.g. 2) 77 = still breast-feeding, ED unknown 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Estimated duration of breastfeeding in months in children who are exclusively breastfed or mixed fed. (paediatric patients only - enter 88 for adult patients) Enter 88 if child still being breastfed or child not breastfed at all.
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

2.2 Laboratory data (LAB table)

Table 2 details the laboratory data that should be included in the LAB table. All available data from the date of first visit should be included.

Notes:

- Results of laboratory tests must be provided in the units specified
- Results of laboratory tests can be entered in one of two fields – a numeric field (LAB_V) and a coded text field (LAB_T) (for very high and/or undetectable viral loads, and for TB microscopy and culture results).
- TB microscopy and culture results should only be entered in the coded result field (LAB_T) as follows, and not in the numeric field (LAB_V):
- For viral loads, there is an additional field to indicate the lower limit of detection of the assay used. This field should be entered as not-applicable (Code = -88) for other laboratory results.
- For TB sensitivity results, there are 2 additional fields. The first (TB_DRUG) where the drug to which sensitivity testing has been done is entered, and the second (SENS), where the sensitivity is recorded using the standard yes/no format. These fields should be entered as not-applicable (Code = 88) for other laboratory results.
- Both CD4 percentage and absolute count should be included on pediatric patients until they are 16 years old.
- There is no code for unknown values of for laboratory test results as tests of which the result is unknown should not be included in the dataset.
- Only dates in the DMY format are permissible in this table

Table 2 – Variables to be included in the table LAB

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
LAB_DMY	Date (for example dd/mm/yy)	Date when specimen was taken
LAB_ID	Text (see List 9)	Code representing the measurement
LAB_V	Numeric (for example 44)	Numeric value of measurement Leave blank if result entered as code (LAB_VSRES or LAB_T)
UNIT_TXT	Text	Unit of laboratory measurement if

		different from unit in List 9
LAB_VSRES	Numeric with codes: 0 = Negative 1 = Positive 2 = Indeterminate 88 = Not applicable 99 = Unknown	Results (positive, negative, etc…) of tests
LAB_T	Text Lower than limit of detection for viral loads should be entered as "LDL" TB microscopy and culture results should be entered as follows: - Paucibacillary 1+ 2+ 3+ Unknown +	Text result eg. "> 6 000 000" or "P+++" Leave blank if result entered as number (LAB_V)
RNA_L	Numeric -88 = Not applicable -99 = Unknown	Lower limit of detection of RNA assay (Enter -88 for laboratory tests other than viral load)
TB_DRUG	Text with codes: INH_L = Isoniazid low dose INH_H = Isoniazid high dose INH_U = Isoniazid – dose unspecified PZA = Pyrazinamide RIF = Rifampicin ETN = Ethionamide ETB = Ethambutol STREP = Streptomycin QUI = Quinolone 88 = Not applicable	TB Drug against which sensitivity has been tested. (Enter 88 for laboratory tests other than viral load)
DRUG_RES	Numeric with codes: 0 = No (Sensitive) 1 = Yes (Resistant) 88 = Not applicable	Is Mycobacterium TB cultured RESISTANT to drug in TB-DRUG field? (Enter 88 for laboratory tests other than viral load)
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

	3 = no HAART	

2.3 Antiretroviral drug variables (ART table)

Table 3 details the data on antiretroviral treatment that should be included in the ART table. As previously mentioned, preferably we will receive one line per drug, each with its prescription, start and stop date.

Notes:

- All antiretroviral drugs to which a patient has been exposed (including PMTCT exposure of both pregnant women and infants peri- or postnatally) and PEP should be included with either the dates of starting and stopping the individual drugs, **OR** the number of doses **OR** the duration of treatment.
- History of exposure to antiretroviral drugs prior to commencing care at the reporting facility should be reconstructed as far as possible and included in this table, making use of appropriate drug codes for unknown regimens and date/time codes for unknown start and stop dates or unknown durations.

Table 3 – Variables to be included in ART table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
ART_ID	ATC (for example NVP – see List 10)	Type of antiretroviral drug
ART_TXT	Text	?UCT
ART_SD_DMY	Date(dd-mm-yyyy)	Date of starting each antiretroviral drug (start date). Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below.
ART_SD_Y	Numeric (e.g. 2003) 8888 = Exact start date entered in appropriate field 9999 = Unknown despite attempting ascertainment 9995 = Not ascertained	Year of starting drug
ART_SD_M	Numeric (e.g. 7) 88 = Exact start date entered in appropriate field 99 = Unknown despite attempting ascertainment 95 = Not ascertained	Month of starting drug

ART_RS	Numeric with codes (See List 11)	Reason for receiving ART
ART_FORM	Numeric with codes: 1 = Tablet/capsule 2 = Syrup/Suspension 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Type of formulation
ART_COMB	Numeric with codes: 1 = Individual drug 2 = Part of a fixed dose combination 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Is drug part of a fixed dose combination?
ART_ED_DMY	Date(dd-mm-yyyy)	Date of stopping each antiretroviral drug (end date) Enter exact date in this field if known. If unknown leave blank and enter EITHER month and year as far as possible in fields below OR number of doses OR duration in weeks in the appropriate fields.
ART_ED_Y	Numeric (e.g. 2004) 8888 = exact end date or number of doses or duration in weeks entered in appropriate fields 9999 = Unknown despite attempting ascertainment 9995 = Not ascertained	Year of stopping drug
ART_ED_M	Numeric (e.g. 7) 88 = exact end date or number of doses or duration in weeks entered in appropriate fields 99 = Unknown despite attempting ascertainment 95 = Not ascertained	Month of stopping drug
NO_DOSES	Numeric (e.g. 1) 888 = end date or duration in weeks entered in appropriate fields 999 = Unknown despite attempting ascertainment 995 = Not ascertained	Number of doses of drug e.g. 1 for single dose Nevirapine
NO_WEEKS	Numeric (e.g. 12) 888 = end date or number of doses entered in appropriate fields	Number of weeks of receiving drug e.g. 12 for AZT from 28 weeks of pregnancy delivering at term

	999 = Unknown despite attempting ascertainment 995 = Not ascertained	
ART_END_RS_TXT	Text	?UCT
ART_END_RS	Text with codes (See List 12)	Reason for stopping antiretroviral drug
ART_END_RS_REVISED	Text with codes	Reason for stopping antiretroviral drug – revised code
INFO_SOURCE	Numeric with codes 1 = Clinical records at this facility 2 = Clinical records/letter from another facility 3 = Patient/caregiver report 4 = Likely protocol in use 90 = Other 99 = Unknown	Source of information about ART
COMMENTS	Text	?UCT
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

2.4 Opportunistic events (OI table)

Table 4 below details the data on opportunistic events or HIV associated conditions diagnosed during follow up that should be included in table OI.

History of opportunistic events prior to commencing care at the reporting facility should be reconstructed as far as possible and included in this table, making use of appropriate date/time codes for unknown start and end dates. It is anticipated that the end date of OIs will frequently be unknown.

Table 4 – Variables to be included in OI table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
OI_ID	Text (for example PCP - see List 3 – Disease codes – under PAT table)	Type of opportunistic event
OI_SD_DMY	Date(dd-mm-yyyy)	Date of start of each opportunistic event. Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below.
OI_SD_Y	Numeric (e.g. 2001) 8888 = Not applicable (Exact date entered in field above) 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	Year of start of event
OI_SD_M	Numeric (e.g. 11) 88 = Not applicable (Exact date entered in field above) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Month of start of event
OI_ED_DMY	Date(dd-mm-yyyy)	Date of end of each opportunistic event. Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below If OI is ongoing (has not yet ended) leave blank and enter appropriate code in field below
OI_ED_Y	Numeric (e.g. 2001) 8885 = Ongoing 8888 = Not applicable	Year of end of event

	(Exact date entered in field above) 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	
OI_ED_M	Numeric (e.g. 11) 85 = Ongoing 88 = Not applicable (Exact date entered in field above) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Month of end of event
DIAG_METH	Numeric (see List 13)	Method of diagnosis
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

2.5 Follow-up clinic visits (VIS table)

Table 5 below details the information to be included in the **VIS table**. Please include all visits for each patient since the first visit at the reporting facility, and where possible visits at previous facilities. Weight, height and head circumference left blank will be assumed to have not been ascertained.

changed field-names with yellow background

Table 5 – Variables to be included in VIS table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
VISIT_DMY	Date (for example dd/mm/yy)	Date of visit patient
VISIT_FAC	Numeric with codes 1 = Visit at this cohort's facility 2 = Visit at another facility 99 = Site of visit unknown	Facility at which visit took place
WEIGHT	Numeric (for example 75)	Weight in kilos (kg)
HEIGHT	Numeric (for example 75)	Height in centimeters (cm)
CTX	Numeric with codes : 1 = yes 0 = No 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Cotrimoxazole status
INH_STATUS_Y	Numeric with codes : 1 = Yes 0 = No 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Isoniazid status
FLU_STATUS_Y	Numeric with codes : 1 = Yes 0 = No 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Fluconazole status
HEADC	Numeric (for example 75)	Head circumference in centimeters (cm)
SCHOOL_Y	Numeric with codes 0 = No school	Schooling for children >5 years. For adults and children less than 5 years,

	1 = At school 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	enter 88.
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

3 Variables to be included in additional tables

3.1 Family and partner linkages (LINK table)

Table 6 details the information on family members (partners, children and siblings) that should be included in the LINK table.

All family members receiving HIV care should be listed. This includes those receiving care within the reporting cohort as well as those receiving care at other sites.

The cohort-specific identifiers of family members receiving HIV care at the reporting site should be included.

Table 6 – Variables to be included in the table LINK

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
LINK_REL	Numeric with codes (See List 14)	Relationship of family member to patient
LINK_TXT	Text	?UCT
LINK_COHORT	Text with codes (See List 15)	Cohort within which family member is receiving HIV care
LINK_ID	Free (numerical or alphanumerical) -88 = Not applicable -95 = Not ascertained -99 = Unknown despite attempting ascertainment	Unique patient identifier of family member Enter -88 if family member in care at non-IeDEA site.
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

3.2 Pregnancy information (PREG table)

Table 7 details information to be included in the PREGNANCY table. This table contains information on all pregnancies since the patient was known to be HIV-infected, including spontaneous abortions/ miscarriages and terminated pregnancies, and their outcomes.

Table 7 – Variables to be included in the PREGNANCY table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
PREG_DIAG_DMY	Date (dd-mm-yyyy)	Exact date when patient first presents as pregnant
PREG_DUR_DIAG	Numeric (e.g. 12) 99 = Unknown	Estimated duration of pregnancy in weeks when patient first presents as pregnant
PREG_END_DMY	Date (dd-mm-yyyy)	Exact date of delivery, spontaneous abortion or termination Enter exact date in this field if known. If unknown leave blank and enter month and year as far as possible in fields below.
PREG_END_Y	Numeric (e.g. 2003) 8888 = Not applicable (Exact date entered in field above) 9995 = Not ascertained 9999 = Unknown despite attempting ascertainment	Year of delivery, spontaneous abortion or termination
PREG_END_M	Numeric (e.g. 9) 88 = Not applicable (Exact date entered in field above) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Month of delivery, spontaneous abortion or termination
PREG_ED	Numeric (e.g. 36) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Estimated duration of entire pregnancy in weeks
PREG_OUTCOME	Numeric with codes 1 = Live birth 2 = Still birth 3 = Termination of pregnancy 4 = Spontaneous abortion	Outcome of pregnancy

	(miscarriage) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	
INF_WT	Numeric (e.g. 2.9) 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Weight of delivered infant. If spontaneous abortion or termination, enter 88
NEONATAL_DEATH	Numeric with codes 0 = No 1 = Yes 88 = Not applicable 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Did delivered live infant die within 1 month of birth? If stillbirth, spontaneous abortion or termination, enter 88
BIRTH_DEFECT_Y	Numeric with codes 0 = No 1 = Yes 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Did fœtus or infant have any congenital malformations?
BIRTH_DEFECT_TYPE	Text	Free text description of malformations
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

3.3 Parental Health (PAR_HEALTH table)

Table 8 details variables to be included in the table PAR_HEALTH. This table contains information on parental health status.

This table is linked to the visit table, so ideally there is an update on parental health status at every visit. Alternatively, this table should be filled in at least once, either for the first visit at your facility or the date of start of HAART.

For patients over 16 years of age, no entries are required into this table (i.e. this table is not required at all for sites that have only patients over 16 years of age in their care).

While information on parental health is very valuable, it is acknowledged that many sites do not collect this information. If only information at the child's first visit or at the start of HAART is collected, this should be included with the appropriate visit date. If no information on parental health is collected, this table can be omitted.

Table 8: Variables to be included in the PAR_HEALTH table

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
VIS_DMY	Date (dd/mm/yy)	Date of parental health evaluation (probably same as clinic visit date)
MAT_DEATH	Numeric with codes 0 = No (Alive) 1 = Yes (Dead) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Maternal status: Mother deceased?
MAT_HIV	Numeric with codes 0 = Negative 1 = Positive 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Mother's HIV status if available
MAT_TTT	Numeric with codes 0 = No treatment 1 = CMX only 2 = HAART only 12 = CMX and HAART 88 = Not applicable (mother HIV negative or deceased) 95 = Not ascertained 99 = Unknown despite attempting	Mother's treatment if available

	ascertainment	
PAT_DEATH	Numeric with codes 0 = No (Alive) 1 = Yes (Dead) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Paternal status: Father deceased?
PAT_HIV	Text with codes 0 = Negative 1 = Positive 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Father's HIV status if available
PAT_TTT	Numeric with codes 0 = No treatment 1 = CMX only 2 = HAART only 12 = CMX and HAART 88 = Not applicable (father HIV negative or deceased) 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Father's treatment if available
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

3.4 Tuberculosis information (TB table)

This table is for capturing details of the TB episodes during HIV follow-up. Tests related to TB can be included in the LAB table. Where possible this data can be derived from the electronic TB register.

Table 9 – Variables to be included in the table TB

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
REG_DMY	Date (dd/mm/yy)	Date registered with TB
REGID	Text (eg. 2272007) -95 = Not ascertained -99 = Unknown despite attempting ascertainment	TB register number
RAD	Numeric with codes 0 = Not done 1 = Normal 20 = Abnormal unspecified 21 = Abnormal - not consistent with current TB 22 = Abnormal - consistent with current TB unspecified 23 = Abnormal – consistent with current TB – Cavity on right 24 = Abnormal – consistent with current TB – Cavity on left 25 = Abnormal – consistent with current TB – Bilateral cavities 26 = Abnormal – consistent with current TB - No cavities 99 = Unknown despite attempting ascertainment	Radiography findings if done
RESISTANT	Numeric with codes 0 = No 1 = MDR 2 = XDR 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Resistance data based on sensitivities Note: Exact results of sensitivities should be record in the LAB table. Code as MDR if … to more than one drug and XDR if… Categories MDR and XDR should be for the worst resistance status during the episode.
TB_START_DMY	Date (dd/mm/yy)	Date starting TB treatment

TB_END_DMY	Date (dd/mm/yy)	Date ending TB treatment or date of outcome
CAT	Numeric with codes 1 = Newly diagnosed for the first time 2 = After relapse 3 = After default 4 = After failure 95 = Not ascertained 99 = Unknown despite attempting ascertainment	TB Category
CLASS	Numeric with codes 1 = Pulmonary 2 = Extra-pulmonary 3 = Both pulmonary and extra-pulmonary 4 = Primary 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Classification of episode
SITE	Numeric with codes 1 = Bones/Joints (A18.0) 2 = Lymph nodes (A16.3) 3 = Meningitis (A17.0) 4 = Miliary (A19.9) 5 = Pleura (A16.5) 9 = Other sites (A18.8) 88 = Not applicable as pulmonary or primary only 95 = Not ascertained 99 = Unknown despite attempting ascertainment	Site of disease if extra-pulmonary component diagnosed
REGIMEN	Numeric with codes 1 = 2HRZE 4HR - Regimen 1 2 = 2HRZES 1HRZE 5HRE - Regimen 2 3 = 2HRZ 4HR - Regimen 3 4 = Other Regimen 95 = Not ascertained 99 = Unknown despite attempting ascertainment	TB treatment regimen
REG_OTHER	Text	Text field for other regimen not included in codes for REGIMEN field above
TB_OUTCOME	Numeric with codes 1 = Completed 2 = Cured 3 = Failed	Outcome of TB episode

	4 = Interrupted 5 = Defaulted 6 = Treatment ongoing 7 = Died 95 = Not ascertained 99 = Unknown despite attempting ascertainment	
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

3.5 Trial/research study enrolment information (TRIAL table)

Table 10 details the data that should be included in the TRIAL table. This table is only for sites running trials or research studies. Any trial/research study (apart from cohort analysis of routine data) on which a patient has been enrolled should be entered together with the dates of entering and leaving each trial. Sites should send an additional coding table of the trials running at their site.

Table 10 – Variables to be included in the table TRIAL

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
COHORT	Text	Text field identifying the cohort
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
TRIAL_ID	Free (numeric or text) codes (See List 16)	Name of trial on which patient is enrolled Each site to send their own List with coding and description of trial
TRIAL_START_DMY	Date (for example dd/mm/yy)	Date of enrolment onto trial
TRIAL_END_DMY	Date (for example dd/mm/yy)	Date of completion/ disenrolment Leave blank if patient is still enrolled on trial
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

4 Revised Vital Status data (Table REV_VITAL_STATUS)

This table will be an exact reflection of the information in the South African National Population Registry (NPR). The table should include ALL patients with national IDs. If patients do not have an ID number, they should NOT be included in this table.

Patients for whom there is no death date in the NPR should be coded 0. Patients with a death date in the NPR should be coded 1, and the date of death should be included as 'npr_death_dmy'.

Table 12 – Variables to be included in the table REV_VITAL_STATUS

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
PATIENT	Free (numerical or alphanumerical)	Unique, anonymous, patient identifier
COHORT	Text	Text field identifying the cohort
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent
HAART_CLASS	Numeric with codes: 1 = adults 2 = children 3 = no HAART	Class of age at start of HAART: 1 = Age at start of HAART >= 16 2 = Age at start of HAART < 16

5 Meta-data

This table contains information about the data transfer itself.

Table 11 – Variables to be included in the table META

Name	Format and definitions	Description
MERGE	Numeric	Number of merge
COHORT	Text	Text field identifying the cohort
PREVIOUS_COHORT_NAME	Text	?UCT
COUNTRY	Text	?UCT
ENROLS_DMY	Date (for example dd/mm/yy)	Date of start of enrolment
ENROLE_DMY	Date (for example dd/mm/yy)	Date of end of enrolment
FU_CLOSE_DMY	Date (for example dd/mm/yy)	Date of last possible follow-up
ASC_DMY	Date (for example dd/mm/yy)	Date of last possible outcome ascertainment
LTF_DEF	Numeric	For patients classified by the site as LTF, the number of days used to define LTF
REPORTER	Text	Name of person responsible for data transfer
TRANSFER_DMY	Date (for example dd/mm/yy)	Date extracted
EMAIL	Text	Email address of site person responsible
NOTES	Text	?UCT
valid	Numeric bit-mask	Contains the result of the data quality test Bit 0: Informed consent 0 = we have an informed consent 1 = we have not an informed consent

6 Facility-data

This table contains information about the data facilities.

Table 14 – Variables to be included in the table FACILITY_SET

Name	Format and definitions	Description
COHORT	Text	Text field identifying the cohort
FACILITY	Text	Text field identifying particular clinic within cohort, if more than facility within the cohort
PATIENT_PREFIX	Free (numerical or alphanumerical)	Prefix of the patient identifier. It includes the name of the cohort and facility and makes the patient identifier unique for the hole IeDEA-database
COHORT_old	Text	Text field identifying the cohort
FACILITY_old	Text	Text field identifying particular clinic within cohort, if more than facility within the cohort
PATIENT_PREFIX_old	Free (numerical or alphanumerical)	Prefix of the patient identifier. It includes the name of the cohort and facility and makes the patient identifier unique for the hole IeDEA-database
PATIENT_PREFIX_orig	Free (numerical or alphanumerical)	Prefix of the patient identifier. It includes the name of the cohort and facility and makes the patient identifier unique for the hole IeDEA-database
ECONOMY	Numeric with codes 1 = Urban 2 = Rural 11 = Mostly urban	Population served
LEVEL_OF_CARE	Numeric with codes (See List 17)	Level of care
ART_SD_Y	Numeric (e.g. 2003) 8888 = Exact start date entered in appropriate field 9999 = Unknown despite attempting ascertainment 9995 = Not ascertained	Year of starting drug

7 Lookup tables

List 1 - Codes for mode of entry (ENTRY)

Code source: IeDEA SA codes

Table name: LU :PAT :ENTRY

Codes	Mode of entry
1	PMTCT program
2	Diagnosis testing during hospitalization
3	Diagnosis testing during consultation
4	Orphans programs
5	Family diagnosis
6	TB program
7	General HIV service clinic
8	Self-referral with known diagnosis
90	Other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 2 - Codes for mode of infection (MODE)

*Code source: Based on HICDEP codes; new codes denoted by **

Table name: LU :PAT :MODE

Codes	Mode of infection
1	Homo/bisexual man
2	Injecting drug user
3	Homo/bisexual man + injecting drug user (1 + 2)
4	Haemophiliac
5	Transfusion, non-haemophilia related
6	Heterosexual contact
6.1	Presumed heterosexual contact
7	Heterosexual contact + Injecting drug user (6 + 2)
8	Perinatal
90	Other
95*	Not ascertained
99	Unknown despite attempting ascertainment

List 3 - Disease codes for FHV_SDI (PAT table) and OI_ID (OI table)

*Code source: Based on HICDEP codes; new codes denoted by **

Note that this is a common list of HIV-associated conditions for capturing incident opportunistic infections and HIV-associated conditions, as well as stage-defining conditions in adults and children. Where duration or recurrence is required for a condition to be stage defining, the event columns have a zero to exclude them from lookups of incident conditions. Where conditions are not stage defining, the stage-defining columns for children and adults have zeros to exclude them from lookups of stage-defining conditions.

Table name: LU :DIS

Codes	Description	WHO stage (Adult)	WHO stage (Paed)	Event (Adult)	Event (Paed)	SDI (Adult)	SDI (Paed)
ANGC	Angular cheilitis	2	2	1	1	1	1
BCGD	BCG disease – disseminated	4	4	1	1	1	1
BCGL	BCG Lymphadenitis (localised to R axilla)	88	88	1	1	0	0
BCGP	BCG Pulmonary	88	88	1	1	0	0
BCIR	Recurrent severe presumed bacterial infection (excluding pneumonia)	4	4	0	0	1	1
BCIS	Severe presumed bacterial infection – single episode (excluding pneumonia)	88	88	1	1	0	0
BCNE	Bacterial pneumonia, recurrent (>2 episodes within 1 year)	4	3	0	0	1	1
BCNS	Severe presumed bacterial pneumonia (single episode)	88	88	1	1	0	0
BLD	Unexplained anaemia (<8g/dl), and or neutropaenia (<500/mm3 – 2; <1000/mm3 - children), and or thrombocytopaenia (<50000/mm3) > 1 month	3	3	0	0	1	1
CANM	Candidiasis (oral) (outside neonatal period)	3	3	1	1	1	1
CANO	Candidiasis oesophogeal	4	4	1	1	1	1
CANT	Candidiasis (trachea, bronchi or lungs)	4	4	1	1	1	1
CLD	Chronic HIV-associated lung disease	88	3	0	1	0	1
CMO	HIV-associated cardiomyopathy	88	4	1	1	0	1
CMVO	Cytomegalovirus other location (site other than liver, spleen or lymph nodes) (onset at age>1month)	4	4	1	1	1	1
CMVR	Cytomegalovirus (CMV) chorioretinitis (onset at age>1month)	4	4	1	1	1	1
COCC	Coccidioidomycosis, disseminated or extrapulmonary						
CRCO	Cryptococcosis extrapulmonary	4	4	1	1	1	1
CRSP	Cryptosporidiosis (duration > 1 month)	4	4	0	0	1	1
CRSPS	Cryptosporidiosis	88	88	1	1	0	0
CRVC	Cervical cancer	4	88	1	1	1	0
DEM	AIDS dementia complex	4	88	1	0	1	0
DIAC	Unexplained chronic diarrhoea (> 1 month - ad; >14 days - ch)	3	3	0	0	1	1
DIAS	Diarrhoea (duration <1 month - adults; <14 days - children)	88	88	1	1	0	0
ENC	HIV encephalopathy	4	4	1	1	1	1
FBLS	Focal brain lesion	88	88	1	1	0	0

FEV	Unexplained fever (duration unknown)	88	88	1	1	1	1
FEVC	Unexplained persistent fever (> 1 month)	3	3	0	0	1	1
FNID	Fungal nail infections (fingers or toes)	88	2	0	1	0	1
FNIF	Fungal nail infections of fingers	2	88	1	0	1	0
HERP	Herpes simplex virus ulcers (duration > 1 month)	4	4	0	0	1	1
HERPS	Herpes simplex virus ulcers	88	88	1	1	0	0
HERPV	Visceral herpes simplex infection	4	4	1	1	1	1
HG	Hodgkins Lymphoma	88	88	1	1	0	0
HIST	Histoplasmosis extrapulm.	4	4	1	1	1	1
HPVE	Extensive human papilloma virus infection	88	2	1	1	0	1
HSM	Hepatosplenomegaly	88	2	0	0	0	1
HZ	Herpes zoster (not specified)	88	88	1	1	1	1
HZM	Herpes zoster (more than one dermatome)	88	88	1	1	0	0
HZS	Herpes zoster (single dermatome)	2	2	1	1	1	1
ISDI	Isosporiasis diarrhoea (duration > 1 month)	4	4	0	0	1	1
ISDS	Isosporiasis diarrhoea	88	88	1	1	0	0
KS	Kaposi Sarcoma	4	4	1	1	1	1
LEIS	Leishmaniasis visceral	4	88	1	1	1	0
LEU	Progressive multifocal leucoencephalopathy	4	4	1	1	1	1
LGE	Lineal gingival erythema	88	2	1	1	0	1
LIP	Lymphoid interstitial pneumonitis	88	3	0	1	0	1
MC	Mycobacterium avium complex (MAC) or Kanasii extrapulm.	4	4	1	1	1	1
MCDI	Microsporidosis diarrhoea (duration > 1 month)	4	4	0	0	1	1
MCDS	Microsporidosis diarrhoea	88	88	1	1	0	0
MCI	Mycobacterium Immune reconstitution syndrome	88	88	1	1	0	0
MCP	Mycobacterium tuberculosis pulmonary	3	3	1	1	1	1
MCPO	Mycobacterium pulmonary other (excluding BCG in children)	88	88	1	1	0	0
MCX	Mycobacterium tuberculosis extrapulmonary	4	4	1	1	1	1
MCXO	Mycobacterium extrapulm. other (excluding BCG in children)	4	4	1	1	1	1
MNUM	Moderate unexplained malnutrition (60-80% EWFA)	88	3	0	1	0	1
MNUS	Unexplained severe wasting or malnutrition (<60% EWFA)	88	4	0	1	0	1
MOLC	Extensive molluscum contagiosum	88	2	1	1	0	1
MYCD	Any disseminated mycosis	4	4	1	1	1	1
NHG	Non-Hodgkin Lymphoma, not specified	88	88	1	1	0	0
NHGB	Non-Hodgkin Lymphoma, Burkitt (classical or atypical)	88	88	1	1	0	0
NHGI	Non-Hodgkin Lymphoma, diffuse large B-cell lymphoma (immunoblasti or centroblastic)	4	4	1	1	1	1
NHGP	Non-Hodgkin Lymphoma primary brain lymphoma	4	4	1	1	1	1
NHGU	Non-Hodgkin Lymphoma unknown/other histology	88	88	1	1	0	0
NPO	HIV-associated nephropathy	88	4	1	1	0	1
NUS	Acute necrotising ulcerative stomatitis, gingivitis or periodontitis	3	3	1	1	1	1
OHLP	Oral hairy leukoplakia	3	3	1	1	1	1
ORUL	Recurrent oral ulcerations	2	2	0	0	1	1
PARE	Parotid enlargement	88	2	1	1	0	1
PCP	Pneumocystis carinii pneumonia	4	4	1	1	1	1

PGL	Persistent generalised lymphadenopathy	1	1	0	0	1	1
PPE	Papular pruritic eruptions	2	2	1	1	1	1
RTI	Respiratory tract infection (not specified)	88	88	1	1	1	1
RTIL	Lower respiratory tract infection (other than presumed pneumonia)	88	88	1	1	0	0
RTIR	Recurrent or chronic respiratory tract infection other than pneumonia (RTI; sinusitis; bronchitis; OM; otorrhea; pharyngitis)	2	2	0	0	1	1
RTIU	Upper respiratory tract infection	88	88	1	1	0	0
RVF	Acquired HIV-associated recto-vaginal fistula	88	4	1	1	0	1
SAM	Salmonella bacteraemia (non-typhoid) recurrent	4	88	0	0	1	0
SAME	Salmonella bacteraemia (non-typhoid) (single episode)	88	88	1	1	0	0
SEBD	Seborrheic dermatitis	2	2	1	1	1	1
TOX	Toxoplasmosis brain (outside neonatal period)	4	4	1	1	1	1
WAST	HIV Wasting Syndrome	4	88	1	0	1	0
WTLM	Moderate unexplained weight loss (<10% of body weight)	2	88	1	0	1	0
WTLS	Severe unexplained weight loss (>10% of body weight)	3	88	1	0	1	0

List 4 - Codes for last contact (LAST_CONTACT_T)

Code source: IeDEA SA codes

Table name: LU :PAT :LAST_CONTACT_T

Codes	Last contact type
1	Visit in the facility
2	Phone call
3	Home visit
4	Hospitalisation
5	Drug pick-up only
6	Visit in another facility
7	Laboratory test received
90	Other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 5 - Codes for outcome (OUTCOME)

Code source: IeDEA SA codes

Table name: LU :PAT :OUTCOME

Codes	Outcome
10	Death (HIV-related)
11	Death (HIV relationship unknown)
12	Death (not HIV-related)
20	Alive and in care at your facility
21	Known to be alive and in care at another facility
22	Known to be alive and patient is not in care

23	Known to be alive but not known whether patient is in care
30	Transfer out within the same service, vital status after transfer out unknown
31	Transfer out to a different service, vital status after transfer out unknown
40	Loss to follow-up despite active tracing attempted
41	Loss to follow-up (not actively traced)
90	Other
95	Not ascertained

List 6 - Codes for cause of death (DEATH_C1 – 3)

*Code source: HICDEP codes; new codes denoted by **

For HIV-related and Aids defining events (8.*), it is expected that the associated event will be recorded in the OI table.

Table name: LU :PAT :DEATH_C

Codes	Cause of Death
1	Myocardial Infarction
2	Stroke
3	Other cardiovascular diseases
4	Symptoms caused by mitochondrial toxicity
4.1	Lactic acidosis
5	Complications due to diabetes mellitus
6	Pancreatitis
7	Lactic acidosis
7.1	Hepatitis related
7.2	Liver failure not related to hepatitis or mitochondrial toxicity
8	HIV-related
8.1	AIDS defining event
8.2	Invasive bacterial infection
9	Renal failure
10	Bleeding (haemophilia)
20	Non AIDS defining cancer
88	Not applicable
90	Others
91	Suicide
92	Drug Overdose
93	Accident
95	Not ascertained
99	Unknown, Fatal case with no information

List 7 - Codes for primary caregiver (CAREG)

Code source: IeDEA SA codes
Table name: LU :PAT :CAREG

Codes	Primary caregiver
1	Mother
2	Father

3	Grandmother
4	Other family member
5	Institution
6	None
88	Not applicable
90	Other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 8 - Codes for person informed of the HIV status of the child (DISCL_CG)

Code source: IeDEA SA codes

Table name: LU :PAT :DISCL_CG

Codes	Disclosure to caregiver
1	Mother
2	Father
3	Grandmother
4	Other primary caregiver
12	Both parents
88	Not applicable
90	Other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 9 - Codes for measurement type (LAB_ID)

*Code source: HICDEP codes; new codes denoted by **

Table name: LU :LAB :LAB_ID

Codes	Measurement
ALB	Albumin (g/L)
ALT	Alanine-Aminotransferase (UI/L)
AMY	Amylase (IU/L)
AST	Aspartate aminotransferase (UI/L)
CD4A	CD4 absolute cell count (cells/µl)
CD4P	CD4 percentage (%)
CHOL	Cholesterol (mmol/L)
CL	Cloride ion (g/dl)
CRE	Creatinine (µmol/L)
GLUC	Glucose (mmol/L)
HAEM	Haemoglobin (g/dl)
HBSAG	Surface antigen of the hepatitis B virus (HBV)
HIV_UNK	Unknown HIV test type but result available
LACT	Lactate (mmol/L)
LYMP	Total lymphocyte count (cells/µl)
LYMPP	% lymphocytes of leukocytes
MCV	mean corpuscular volume of red blood cells (L/cells)
NEUT	Neutrophil count (x1000/mm3)

NEUTP	Neutrophil (%)
P24	P24 antigen
PCR	HIV DNA or RNA PCR
PLT	Platelets (cells/µl)
RAP	HIV rapid test
RNA	HIV-RNA measurement value (copies/ml)
SER	HIV serology (EUSA)
TBGE	TB GeneXpert
TBLP	TB Line Probe Assay
TG	Triglycerides (mmol/L)
URE	Urea (mmol/L)
WBC	White cell count (x1000/ mm3)

List 10 - Anti-retroviral drugs : (ART_ID)

Code source: ATC classification: Anatomical Therapeutic Chemical

Table name: LU :ART :ART_ID

ATC Codes	Antiretroviral treatment
J05A	ART unspecified (i.e. single drug, totally unknown)
J05A-BEV	Beviramat
J05AE	PI unspecified
J05AE01	Saquinavir (gel, not specified)
J05AE01-SQH	Saquinavir hard gel (INVIRASE)
J05AE01-SQS	Saquinavir soft gel (FORTOVASE)
J05AE02	Indinavir (CRIXIVAN)
J05AE03	Ritonavir (NORVIR)
J05AE03-H	Ritonavir high dose (NORVIR)
J05AE03-L	Ritonavir low dose (NORVIR)
J05AE04	Nelfinavir(VIRACEPT)
J05AE05	Amprenavir (141W94) (AGENERASE)
J05AE06	Lopinavir/Ritonavir (ABT-378/r, Kaletra)
J05AE07	Fosamprenavir (Telzir, Lexiva)
J05AE08	Atazanavir (Reyataz)
J05AE10	Darunavir (TMC-114, Prezista)
J05AE-ATV	Atazanavir (Reyataz)
J05AE-GW4	GW433908/VX-275 (Drug phase III) (PROGENERASE)
J05AE-TMC	Darunavir (TMC-114, Prezista)
J05AE-TPR	Tipranavir (Aptivus)
J05AF	NRTI unspecified
J05AF01	Zidovudine (AZT, RETROVIR)
J05AF02	Didanosine (ddI) (VIDEX)
J05AF03	Zalcitabine (ddC) (HIVID)
J05AF04	Stavudine (d4T) (ZERIT)
J05AF05	Lamivudine (3TC, EPIVIR)
J05AF05+J05-TRM	FDC1 (Stavudine/ Lamivudine/ Nevirapine, d4T/3TC/NVP)
J05AF06	Abacavir (1592U89) (ZIAGEN)
J05AF07	Tenofovir (TDF, VIREAD)
J05AF08	Adefovir (PREVEON)
J05AF09	Emtricitabine (FTC, EMTRIVA)

J05AF10	Entecavir
J05AF30-COM	Combivir (Zidovudine/Lamivudine, AZT/3TC)
J05AF30-COV	FDC5 (Stavudine/Lamivudine, d4T/3TC)
J05AF30-KIV	Kivexa (Lamivudine/Abacavir)
J05AF30-TRU	Truvada (Tenofovir/Emtricabine, TDF/FTC)
J05AF30-TZV	Trizivir (Zidovudine/Lamivudine/Abacavir)
J05AF-FOZ	Fozivudine tidoxi
J05AF-LDN	Lodenosine (trialdrug)
J05AG	NNRTI unspecified
J05AG01	Nevirapine (VIRAMUNE)
J05AG01-SD	Nevirapine (VIRAMUNE) single dose
J05AG02	Delavirdine (U-90152) (RESCRIPTOR)
J05AG03	Efavirenz (DMP-266) (STOCRIN, SUSTIVA)
J05AG04	Etravirine
J05AG-CPV	Capravirine
J05AG-ETV	Etravirine (TMC-125)
J05AG-LOV	Loviride
J05AG-RPV	Rilpivirine (TMC-278, Edurant)
J05AG-TMC	Etravirine (TMC-125)
J05A-PBT	Participant in Blinded Trial
J05AR	ART regimen and drug unspecified (i.e. both number and names of drugs totally unknown)
J05AR01	Combivir (zidovudine/lamivudine)
J05AR05	Douvir-N (Zidovudine/Lamivudine/Nevirapine)
J05AR06	Atripla (emtricitabine/tenofovir/efavirenz)
J05SAR10	Kaletra/Aluvia (lopinavir/ritonavir)
J05A-TRM	FDC1 (Stavudine/ Lamivudine/ Nevirapine, d4T/3TC/NVP)
J05AX07	Enfurvirtide (FUZEON, T-20/Ro 29-9800)
J05AX08	Raltegravir
J05AX09	Maraviroc
J05AX12	Dolutegravir
J05AX-EVG	Elvitegravir (Gilead)
J05AX-VIC	Vicriviroc
L01XX05	Hydroxyurea/Hydroxycarbamid (LITALIR)

List 11 - Codes for reason for receiving ART (ART_RS)

Code source: IeDEA SA codes

Table name: LU :ART :ART_RS

Codes	Reason for treatment discontinuation	AE	CI	FL	Other
1	Treatment failure (i.e. virological, immunological, and /or clinical failure)			1	
1.1	Virological failure			1	
1.2	Partial virological failure			1	
1.3	Immunological failure - CD4 drop			1	
1.4	Clinical progression			1	
2	Abnormal fat redistribution	1			

3	Concern of cardiovascular disease	1			
3.1	Dyslipidaemia	1			
3.2	Cardiovascular disease	1			
4	Hypersensitivity reaction	1			
5	Toxicity, predominantly from abdomen/G-I tract	1			
5.1	Toxicity - GI tract	1			
5.2	Toxicity - Liver	1			
5.3	Toxicity - Pancreas	1			
6	Toxicity, predominantly from nervous system	1			
6.1	Toxicity - peripheral neuropathy	1			
7	Toxicity, predominantly from kidneys	1			
8	Toxicity, predominantly from endocrine system	1			
8.1	Diabetes	1			
9	Haematological toxicity (anemia …etc.)	1			
10	Hyperlactataemie/lactic acidosis	1			
88	Death (note overlap with N/A in other lists)				1
90	Side effects - any of the above but unspecified	1			
90.1	Comorbidity		1		
91	Toxicity, not mentioned above	1			
92	Availability of more effective treatment (not specifically failure or side effect related)				1
92.1	Simplified treatment available				1
92.2	Treatment too complex				1
92.3	Drug interaction		1		
92.4	Drug interaction - commencing TB treatment		1		
92.5	Drug interaction ended - stopping TB treatment				1
93	Structured Treatment Interruption (STI)				1
93.1	Structured Treatment Interruption (STI) - at high CD4				1
94	Patient's wish/ decision, not specified above				1
94.1	Non-compliance				1
95	Physician’s decision, not specified above (note overlap with standard code				1
95.1	Contra-indication expired				1
96	Pregnancy		1		
96.1	MTCT regimen completed				1
96.2	Pregnancy ended				1
97	Study treatment				1
98	Other causes, not specified above				1

99	Unknown despite attempting ascertainment				1
99.5	Not ascertained				1

List 12 - Reason for treatment discontinuation (ART_END_RS)

*Code source: HICDEP codes; new codes denoted by **

Table name: LU :ART :ART_END_RS

Codes	Reason for treatment discontinuation	AE	CI	FL	Other
1	Treatment failure (i.e. virological, immunological, and /or clinical failure)			1	
1.1	Virological failure			1	
1.2	Partial virological failure			1	
1.3	Immunological failure - CD4 drop			1	
1.4	Clinical progression			1	
2	Abnormal fat redistribution	1			
3	Concern of cardiovascular disease	1			
3.1	Dyslipidaemia	1			
3.2	Cardiovascular disease	1			
4	Hypersensitivity reaction	1			
5	Toxicity, predominantly from abdomen/G-I tract	1			
5.1	Toxicity - GI tract	1			
5.2	Toxicity - Liver	1			
5.3	Toxicity - Pancreas	1			
6	Toxicity, predominantly from nervous system	1			
6.1	Toxicity - peripheral neuropathy	1			
6.2	Toxicity - neuropsychiatric				
6.3	Toxicity - headache				
7	Toxicity, predominantly from kidneys	1			
8	Toxicity, predominantly from endocrine system	1			
8.1	Diabetes	1			
9	Haematological toxicity (anemia …etc.)	1			
10	Hyperlactataemie/lactic acidosis	1			
88	Death (note overlap with N/A in other lists)				1
90	Side effects - any of the above but unspecified	1			
90.1	Comorbidity		1		
91	Toxicity, not mentioned above	1			
92	Availability of more effective treatment (not specifically failure or side effect related)				1

92.1	Simplified treatment available				1
92.2	Treatment too complex				1
92.3	Drug interaction		1		
92.4	Drug interaction - commencing TB treatment		1		
92.5	Drug interaction ended - stopping TB treatment				1
93	Structured Treatment Interruption (STI)				1
93.1	Structured Treatment Interruption (STI) - at high CD4				1
94	Patient's wish/ decision, not specified above				1
94.1	Non-compliance				1
95	Physician's decision, not specified above (note overlap with standard code				1
95.1	Contra-indication expired				1
96	Pregnancy		1		
96.1	Pregnancy intended				1
96.2	Pregnancy ended				1
97	Study treatment				1
97.1	Study treatment commenced				
97.2	Study treatment completed				
97.6	Drug not available				
98	Other causes, not specified above				1
99	Unknown despite attempting ascertainment				1
99.5	Not ascertained				1

List 13 - Diagnosis Method of Opportunistic Event (DIAG_METH)

Code source: IeDEA SA codes

Table name: LU :OI :DIAG_METH

Codes	Diagnosis Method
10	clinical only
11	clinical & radiology
12	clinical and endoscopy
20	microscopy for infectious agent
21	culture of infectious agent
30	blood antibody test
31	site specimen (non-blood) antibody test
40	tissue histology
90	other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 14 - Codes for relationship of family member to patient (LINK_REL)

Code source: IeDEA SA codes

Table name: LU :LINK :LINK_REL

Codes	Relationship
1	Mother
2	Father
3	Child
4	Sibling
5	Spouse/partner
90	Other
95	Not ascertained
99	Unknown despite attempting ascertainment

List 15 - Cohort where family member is receiving care (LINK_COHORT)

Code source: To be created by transferring site

Table name: LU :LINK :LINK_COHORT

Codes	Cohort
Cohort ID	Cohort description

List 16 - Example of codes for trial name (TRIAL_ID)

Code source: Site to supply own codes

Table name: LU :TRIAL :TRIAL_ID

Codes	Trial name (text field)	Short description of trial (Memo field)
INH	INH trial	Trial of thrice weekly vs daily INH prophylaxis in HIV-infected children
TB	TB treatment duration trial	Trial of 6 month vs 9 month chemotherapy in HIV-infected children

List 17 - Example of codes for level of care LEVEL_OF_CARE)

Code source: IeDEA SA codes

Table name: LU :FACILITY_SET: LEVEL_OF_CARE

CODE	LEVEL_OF_CARE
1	District clinic
2	District hospital
3	Health centre
4	Hospice
5	Ngo clinic

6	Provincial
61	Regional, provincial or univerisity
7	Regional