PATIENT LINKAGE, RETENTION AND FOLLOW-UP in HIV CARE

STANDARD OPERATING PROCEDURES

February 2012

MOHSW

THE NATIONAL ART PROGRAM
Swaziland is aggressively expanding the reach of HIV testing and counseling (HTC) services by strengthening Provider-Initiated HIV testing and counseling (PIHTC) at all health facilities, and scaling up testing in communities through Home-Based HTC, Male Circumcision (MC), and numerous other testing campaigns.

Similarly, concerted efforts are being made by the Swaziland National ART Program (SNAP) to increase access to and enrollment in HIV chronic care. In 2011, a comprehensive “pre-ART care” system was formally rolled out in all facilities to ensure that all HIV-positive individuals access high quality chronic care. Access to ART initiation also dramatically increased in 2011 through the “Nurse-Led ART in Swaziland” (NARTIS) initiative.

Despite these gains in HTC uptake and HIV chronic care enrolment, linkage of patients testing HIV+ to pre-ART/ART services and retention of those patients in care remain major challenges. It is estimated that without intervention, less than 30% of people testing HIV+ will link to pre-ART care, while 6-month retention among patients on ART is ~75%, decreasing to ~35% by the fifth year in care. Anecdotally, follow-up of defaulting patients is sporadic and inconsistent at best.

These Standard Operating Procedures (SOPs), therefore, have the objective of providing a set of nationally accepted mechanism to improve rates of linkage to and retention in care. They define a series of minimum procedures which are both efficient and sustainable.

Long-term retention in care and strong adherence to therapy prevents ARV drug resistance and enables patients to live long and healthy lives. Thus, the potential contribution of this ‘linkages and retention’ SOP towards the fight against the AIDS epidemic in the country cannot be over emphasized. The Ministry of Health believes that the effective implementation of these SOPs will translate into long-term survival and good health outcomes for all Swazis living with HIV.

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SNAP HTC: Swaziland National AIDS Program, HIV Testing and Counseling
PEPFAR-Swaziland: President’s Emergency Plan for AIDS Relief
ICAP: International Centre for AIDS Care & Treatment Program
PSI: Population Services International
CHAI: Clinton Health Access Initiative
URC: University Research Council
JSI: John Snow Incorporated
EGPAF: Elizabeth Glazer Pediatric AIDS Foundation
MSF: Médecins Sans Frontières
Futures Group

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BACKGROUND

Context and Rationale:

HIV Testing and Counseling, HTC, in Swaziland has made great progress over the past few years. The home-based testing and counseling (HBHTC) program reached almost 10,000 people in Hhohho during 2010, and integration of HTC into male circumcision campaigns such as SOKA UNCOBE have successfully increased male testing. SNAP HTC has simultaneously been working closely with health facilities to increase uptake of Provider-Initiated HIV testing and counseling (PIHTC). In the coming years, the expansion and strengthening of HIV testing services in the country is likely to greatly increase the number of Swazis who access HTC services and know their HIV status.

Access to both pre-ART and ART services increased dramatically in 2011. Roll out of the pre-ART care system to all facilities enables all HIV-positive individuals to receive high quality care (i.e. not just those who are sick and need ART). Through the “Nurse-Led ART Initiation in Swaziland” (NARTIS) initiative, nurses at over 40 rural clinics have now been equipped to initiate patients on ART. Through strengthening of pre-ART care services, continued scale-up of NARTIS, and deployment of point-of-care (POC) CD4 devices, initiation of ART-eligible patients is expected to increase steadily.

Challenge:

Given the current sero-prevalence rate in the country, it is estimated that 20-25% of the people tested at Swaziland’s HTC sites will test HIV-positive. However, to-date there haven’t been strong systems in place to refer and link these HIV-positive individuals to lifelong HIV chronic care. Beyond standard post-test counseling, there are limited systems available to help HIV-positive patients accept their diagnosis, adopt risk reduction measures, overcome barriers to accessing HIV treatment services, and then remain enrolled in care.

No national statistics are currently available for linkage to HIV care, but the SNAP estimates that without intervention, less than 30% of people identified in the various HIV testing sites will link to pre-ART care. Regarding retention of ART patients, recent national statistics show 6-month retention rates of ~75%, which decrease to ~35% by the fifth year in care. There is no national data on retention in
pre-ART care, but data from Southern Africa indicates that 12-month retention in pre-ART care is less than 45%.

The anticipated scale-up of HIV testing and ART initiation only underscores the urgent need to improve linkage and retention outcomes. Effective implementation of the Linkages and Retention SOP can help the increased testing and treatment translate into improved survival outcomes for people living with HIV.

Objective and Scope of the SOP:

The goal of the Linkages and Retention SOP is to provide a nationally accepted mechanism to improve rates of linkage to and retention in HIV care. It is meant to define a series of minimum procedures which are both efficient and sustainable. The linkage, retention, and tracing procedures are to be implemented at all HIV care centers in the country.

Barriers to Linkage and Retention:

Key barriers to linkage and retention have been identified in the scientific literature and in studies and surveys that have been conducted in Swaziland.

- Lack of understanding of why it is important to enroll in care
- Fear of disclosure and possible stigmatization
- Lack of welcome/confusing organization of receiving facilities
- Long wait times at facilities
- Distance to clinic and/or lack of transportation
- Poverty

The first four of these issues can be addressed by the health system through additional counseling and administrative changes at facilities as described in this document. Transportation and economic issues are clearly crucial, and the MOH has begun to address them through the decentralization of HIV services to rural/remote clinics which is bringing services closer to the patients.
**SECTION A: TESTING & LINKAGE TO CARE**

**Summary: Responsibilities of the referring HTC site:**

1. **Test for HIV & post-test counseling**
   - Screen for TB & complete TB screening form

2. **If HIV-negative, counsel and complete Referral Form for prevention or other services**
   - Refer to a VCT for re-testing & set appt
   - If male, refer for MC services
   - Counsel on condom use and provide them

3. **If HIV-positive, Counsel and complete Referral Form for HIV care**
   - If client does not want to attend on-site HIV clinic, ask which facility he/she would prefer to attend and agree on appointment date

4. **Give white copy of Referral Form to client, and counsel to attend department or facility on appt date**
   - Counsel client to bring form to the department or facility when he/she attends

5. **Dispatch pink copy of Referral Form to receiving department or facility**
   - If on-site referral, bring pink copy of form directly to HIV clinic by the end of the day!
   - If off-site referral, send pink copy of form to receiving facility via sample transport system

**Summary: Responsibilities of the HIV Care Site**

1. **Receive forms & file by date of appt in “Expected Patients” binder**
   - Forms should arrive directly from health worker, or via Sample Transport

2. **Enter client into Appt Book**
   - Indicate referral form number in Appt Book

3. **Send SMS reminder on the day before the appointment**
   - Every day, look at the next day’s page in the appt register and send SMS reminders

4. **If patient attends, update appt book and provide pre-ART care**
   - Document attendance on form & Appt Book
   - Staple white form to pink form
   - Move form from Expected to Arrived binder

5. **If patient does not attend, follow up by phone and home visit**
   - Identify missed appt using “Appt Book”
   - Phone first, then home visit if necessary
   - Record new appt in “Appt Book”
**TESTING & LINKAGE STEP 1: COUNSEL AND TEST**
(According to HTC, TB, PMTCT, and Paediatric Guidelines)

**Location:** HIV testing site

**Personnel:** Lay counselor / Healthcare worker / Expert client (EC)

1. Greet and welcome attending individual or couple
2. Incorporate information about HIV testing in Group Education Sessions (where applicable)
3. Provide individual pre-test counseling
4. Complete TB screening form. If a patient screens positive for TB, complete a Sputum Request Form.
5. Conduct HIV rapid test
6. If HIV-exposed infant, see box below for testing and care provision steps.
7. Provide test result, post-test counseling and appropriate referral -
   a. **For HIV negative client:**
      i. Focus on risk reduction interventions
      ii. If follow-up test or additional counseling required, provide referrals for these
      iii. If testing at CIHCT, PIHCT or outreach (e.g. HBHTC) and client is male and HIV negative, counsel and refer for male circumcision (MC) services
      iv. If testing at an MC site, allow patient to continue through normal MC procedures. MC procedures comprise provision of further risk reduction messages, plus condom promotion and provision etc.
   b. **For HIV positive client:**
      i. Focus on encouraging acceptance of diagnosis; partner testing; assessing and resolving barriers to accessing care
ii. Refer to HIV care site for pre-ART enrollment, chronic HIV care and additional counseling

iii. If diagnosis is not accepted – refer for additional counseling either on site or at the receiving HIV care site

8. Complete HTC Register (or ANC Register for Pregnant Woman)

**Required tools:**
- Counseling cue cards for pre-test and post-test counseling
- Counseling job aides
- HTC register (and ANC register if PMTCT setting)
- TB screening tool
- Sputum request form
HIV-Exposed Infants: DNA PCR Test & Immediate Care

HIV-Exposed Infants are tested by DNA PCR. Consequently, the result will not be available on the same day. However, HIV-exposed infants require care as soon as identified and should be linked to the follow-up care point just like an HIV-positive client!

When an HIV-Exposed Infant is identified:
1. Provide individual pre-test counseling to the mother/guardian
2. Provide comprehensive care for the HIV-exposed infant as specified in the pediatric HIV guidelines, including:
   - Take history
   - Assess growth and development
   - Give immunizations
   - Provide prophylaxis (CTX, NVP, IPT)
   - Identify and treat opportunistic infections early
   - Screen for TB and ask about household TB contacts
   - Counsel on infant feeding and nutrition
   - Ensure that family is receiving HIV care, FP & social support

Use the Routine Care of HIV-Exposed Infants job aid to guide care provision.

3. Take DBS sample for DNA PCR test and assign a DBS barcode number. Thoroughly complete the DBS requisition form.
4. Document HIV-Exposed Infant’s DNA PCR test and care indicators in:
   a) DNA PCR Logbook
   b) Child Welfare Clinic Register
   c) Child Health Card
5. Set appointment for mother/guardian to bring back HIV-exposed infant to receive DNA PCR results, CTX/NVP/INH, and care.
6. If HIV-exposed infant will be receiving DNA PCR result and follow-up at the place of testing, document follow-up appointment in Appointment Register.
7. If HIV-exposed infant will be receiving DNA PCR result and follow-up care/prophylaxis at a different facility (or at a different unit within the facility such as Child Welfare Clinic), complete the Referral Form as with any other patient— follow Testing and Linkage Step 2.
8. Ensure that mother is linked to (or active in) HIV chronic care. If mother is not in care, complete Referral Form for HIV care. Screen mother for TB!
9. Ensure that DBS sample and accompanying Requisition Form are dispatched in a timely manner to the reference testing lab via sample transport.
Location: HIV testing site
Personnel: Lay counselor / Healthcare worker / Expert Client

1. **Decide on Referral Facility**
   
   If facility has an HIV clinic but the patient wants to attend a different facility, or if there is no on-site HIV clinic, consult referral directory and referral map to determine nearest preferred facility that can support the patient’s needs.

2. **Complete Referral Form**
   
   Consider the following criteria in referral:

   A. **For clients testing HIV-negative:**
      
      1) HIV-negative AND NOT requiring referral for other services
         
         i. Even though client does NOT require referral, still complete Referral Form as an official record of his/her HIV Test.
         
         ii. Set appointment for re-test and document in the Referral Form.
         
         iii. Give client the WHITE copy of the Referral Form to go home with – as evidence of his/her HIV test. Retain both duplicate copies (Yellow and Pink) of the Referral Form in the book.
(2) HIV-negative BUT REQUIRING referral for other services
   i. Encourage client to attend facility closest to his/her home that is also acceptable to him/her.
   ii. Refer to facility closest and acceptable to him/her which provides the service required by client.
   iii. Give client the WHITE copy of the Referral Form to bring to the receiving facility—as evidence of referral for the required service.
   iv. Set appointment for re-test and document in Referral Form

B. HIV-positive patients (not co-infected with TB)
   i. Encourage patient to attend HIV care/treatment site closest to his/her home that is also acceptable to him/her.
      a. If receiving HIV care site is at the same location as the testing point, the appointment should be set for the same day if the patient accepts, and referral made accordingly.
      b. If receiving HIV care site is not at the same location as the testing point, the appointment date should be set within 2 weeks of HIV+ test.
   ii. If patient has a condition requiring urgent attention (e.g. Cryptococcal Meningitis), ensure immediate linkage to the necessary care point for treatment of the condition.
   iii. If patient has condition(s) other than HIV that require additional management, prioritize referral according to health condition most in need of further management -
      • For example, a patient requiring referral for HIV care and STI treatment should be referred to a site that offers the HIV care preferentially. A patient with HIV and TB should be referred as indicated below (see C below).
iv. Give client the WHITE copy of the Referral Form to bring to the receiving facility— as evidence of referral for the required service.

v. Emphasize to patient that the HIV care site will be expecting him/her on the appointment date and, if permission given, will contact him/her if the appointment is not kept.

vi. Provide HTC referral pamphlet (in English and/or Si-Swati)

vii. Refer for additional counseling as available & as needed

C. TB-HIV Co-Infected Patients

For TB-HIV Co-infected patients, the TB clinic should be the first point of care— patients will receive both TB care and HIV care at a TB clinic which also initiates ART. The patient should be started on ART within 2-8 weeks after initiation of TB treatment. After completing TB treatment, the patient will be transferred to an ART clinic for long-term care/treatment.

i. If patient is already in TB care/treatment and tests HIV-positive at any entry point, individual should continue in care at the TB clinic (if it has ART initiation capability), but now receive HIV care there as well. Start ART within 2-8 weeks of TB treatment.

ii. If patient is both newly diagnosed with TB and tests HIV-positive, the individual should be referred to a TB unit (with ART initiation capability) to receive both TB treatment and HIV care. Start ART within 2-8 weeks of TB treatment.

iii. If patient is known HIV-positive, not enrolled in HIV care/treatment, and is newly diagnosed with TB, the individual should be referred to a TB unit (with ART initiation capability) where he/she will receive both TB treatment and HIV care. Start ART within 2-8 weeks of TB treatment.

iv. If patient is known HIV-positive who is already enrolled in HIV care (on ART or in ‘pre-ART care’), and is then newly diagnosed with TB, the individual should be transferred to a TB unit with ART initiation capability where he/she will receive both TB treatment and HIV care:
- Continue ART, if already initiated on ART.
- Start ART within 2-8 weeks of TB treatment if not already initiated.

After completion of TB treatment, the patient can be transferred back to their original point of HIV care, or another HIV/ARV clinic if so requested.

3. Discuss Treatment Support

For all HIV-positive individuals—with or without TB co-infection—discuss the importance of engaging a treatment supporter. Ask client if he/she has someone who could be a treatment supporter for them, and encourage him/her to seek one out. Provide IEC materials on treatment support.

4. Distribute Copies of Referral Form

   (i) Give original copy of Referral Form (WHITE COPY) to the HIV-positive individual to bring to receiving HIV care site on the day of his/her appointment.

   (ii) Dispatch the first duplicate copy of Referral Form (PINK COPY) to the receiving HIV care clinic.

   a. If receiving facility is in the same location as the point of testing/diagnosis, bring first duplicate copy directly to HIV clinic by end of the day.

   b. If receiving facility is NOT in the same location as the testing/diagnosis point, ensure that the designated person responsible for collecting all pink Referral Forms collates all forms into envelopes labeled with the relevant facilities’ names. He/she will then send these envelopes to the receiving facilities via the National Sample Transport System network.
(iii) Leave second duplicate copy of Referral Form (YELLOW COPY) in the Referral Form book as a record of the test at the HTC site.

Required tools:
- Referral Form
- IEC materials on treatment support
- Referral directory and/or referral map
- HTC Referral Pamphlet
- Counseling cue cards about referral

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**Facility Preparation for Patient Arrival**

All facilities should review the systems in place at their site to encourage linkage and retention:

i. Signage that directs patients to the HIV care center within a facility to ensure that a new patient will not have difficulty locating it (balancing need for signs with concerns over stigma).

ii. Signage noting the different sections within the HIV care center (lab, pharmacy, registration, etc.)

iii. Waiting area that is adequate in terms of space and patient flow

iv. Triage systems for new patients

v. Site staff on ground to assist needy first-time clients

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1 Such triage systems can be based on the pending referral guidelines which may prioritize referred patients. Other systems will have to be considered on a facility-by-facility basis in conjunction with regional supervisory teams (MOH or partner).
TESTING & LINKAGE STEP 3: ORGANIZE REFERRAL FORMS & FOLLOW UP REFERRED CLIENTS AT THE HIV CARE SITE

Location: HIV care site (HIV clinic)
Personnel: Expert Client / Nurse / any other designated staff

Establishing a Focal Person to Oversee Referral System

Each HIV Care Site should have a Focal Person and Back-Up Focal Person who will be responsible for overseeing and ensuring proper/timely organization of referral forms and follow up of referred clients who don’t attend.

The team at the HIV Care Site should meet to establish a system for management of referral forms and follow-up:

- One system could be that the Focal Person does all the filing of forms and follow-up when on duty, while another staff person assumes one of the Focal Person’s other duties. When the Focal Person is not present, the back-up Focal Person does the filing and follow-up.
- Another system could be a monthly rotation system, (coordinated by the Focal Person) whereby a different staff is responsible for filing forms and making the follow-up calls each month.

*Note that the Focal Person’s role is NOT to be the only person who ever files referral forms and follows up patients. Instead, the Focal Person’s job is to “coordinate”, ensuring that there is a clear system in place and that it is being implemented.*
1. Organizing the Referral Forms
As soon as received, organize Referral Forms (pink copies) for referred HIV-positive individuals who are expected to attend the HIV care site for enrolment -

   a. All duplicate copies of Referral Form (pink) will have been received by respective HIV care facilities on the same day if testing point was at the same location, or within 2 days if testing point was at a different location (via the National Sample Transport System)

   b. Put the received copies of the Referral Form (pink) in the “Expected Patients” binder (Figure 1 below). Sort the referral forms by:
      1. the date the patients are expected
      2. patient names (or referral form #) within each date

![Figure 1: Filing the referral form at the facility](image_url)

c. Immediately write the patient’s name into the facility’s Appointment Register against the date he/she is expected to arrive at the HIV care site for linkage (Figure 2 below). Record the number at the top right of the referral form as the “Patient ID number” in the Appointment Register.
2. **Client Reminder and Follow-up**

Remind referred clients by SMS and follow-up those who do not come to enroll in care. During SOP orientation, each facility will choose its standard SMS message from an MOH list, or the facility can create its own message.

i. Each day, review the Appointment Register to determine which patients are expected the following day and the type of visit reminder that is required (please see criteria for type of reminder below).

ii. One day before expected visit, contact the patient to remind him/her of appointment and document in Call Register:

1. Send an SMS using standardized message text to all expected patients and document. (Figure 3 below).

2. Call the patient if the HCW recognizes that patient will need personalized encouragement to come to care.

3. Request an RHM or HBC or Community Expert Client to visit the patient in person *if the following conditions are met:*
a. Consent (oral or written) has been obtained. Patient may have previously given consent for home visit on the Referral Form.
b. The patient is unreachable or unattainable by cell phone or the HCW recognizes that patient will need personalized encouragement to attend.

Figure 3: Reminding patients before their appointment

iii. If the HIV-positive individual does not come as expected on the appointment date, follow up the patient. (Please refer to Section C of this SOP “Defaulter Tracing” for specific follow-up steps).

Required tools:
- Facility Appointment Register
- Telephone, Airtime, and standard SMS reminder message
- Call register
TESTING & LINKAGE STEP 4: ENROLLING PATIENT INTO HIV CARE

Location: HIV care site (HIV clinic or TB clinic)
Personnel: Expert Client / Nurse / Data clerk / Receptionist

PATIENT ARRIVAL AT THE HIV CARE SITE

1. Patient comes to clinic with the original copy (white) of the Referral Form as documentation of his/her appointment date. Check facility’s Appointment Register to confirm which date patient is expected at the clinic.
   a. If patient comes earlier than expected -
      i. congratulate him/her
      ii. find date in the facility’s Appointment Register on which they were expected and document that the patient came early
      iii. find out from client reason why he/she came earlier than the appointment date—e.g. any serious clinical problem
      iv. then proceed with item #2 as below
   b. If patient comes later than expected -
      i. congratulate him/her
      ii. find date in the facility’s Appointment Register on which they were expected and document that the patient came late
      iii. find out from client reason why he/she came later than the appointment date—e.g. issues of disclosure or denial
      iv. then proceed with item #2 as below
c. If patient comes on the day they were expected -
   i. congratulate him/her
   ii. find date in facility’s Appointment Register on which they were expected and document that the patient came on time
   iii. then proceed with item #2 as below

2. Match the patient’s copy (white) of the Referral Form with the duplicate copy (pink) of his/her Referral Form that was sent to the receiving facility at the time of testing.

3. Complete the bottom portion of the form with the name of the facility where the patient is enrolled in HIV care (i.e. the name of your facility) and the date of his/her arrival.

4. Staple the two copies (white and pink) of the Referral Form and move from the “Expected Patients” file to the “Arrived Patients” file (Figure 4).

   ![Figure 4: Transferring Referral Form to the “Arrived” File](image)

   **Note:** If patient arrives without his/her white copy of the Referral Form, look for the pink duplicate copy of the Form in the “expected patients” binder and follow these steps:

   a. If pink copy of patient’s referral form is found, confirm that it belongs to the client & proceed with the usual enrolment procedures.
   b. If pink duplicate copy of patient’s Referral Form is not found, then it is necessary to re-test the patient.
PATIENT ENROLMENT INTO HIV CARE

1. Enter patient details into Pre-ART Register (and/or TB suspect register)
2. Counsel patient on basic HIV information (usually done by EC)
3. Give patient personal Appointment Card and HIV Care Number (or use his/her National ID when and where appropriate)
4. Open new HIV Chronic Care Patient File (and TB file if applicable) and enter appropriate demographic data
5. Obtain/confirm consent for home visit by an RHM / HBC / CEC or healthcare worker (and indicate it on the Patient File in the psychosocial assessment section).
6. Confirm treatment supporter contact details and that patient understands role of treatment supporter (e.g. if the patient does not come to care, the treatment supporter might be contacted).

NOTE: If patient attends a facility that is different than the one where his/her Referral Form was sent, follow these steps:

The health care workers at the new HIV care facility should:

1. Confirm that patient has changed his/her mind regarding the HIV care facility to which he/she was originally referred.
2. Notify the original HIV care facility through phone call that the expected patient has linked to a different facility. Document the call in Call Register.
3. Open a patient file at the receiving HIV care site and follow all normal procedures of enrollment into care as below.

The health care workers at the original HIV care facility should:

1. Receive the above call from the new facility
2. Document in the facility’s Appointment Register (against the patient’s name) the new HIV care site where the patient has enrolled in care.
3. Remove the copy of the Referral Form from the “expected patients” folder, document the “alternative” clinic where the patient entered care and the date they arrived, and transfer it to the “arrived patients” folder.

4. Where the National Sample Transport System route links these two HIV care sites, the original referral site should put the patient’s Referral Form (pink copy) send it to the “alternative” HIV care site where the patient is currently enrolled via Sample Transport (addressing it to the officer who called).

5. The sending officer should also call the receiving officer on the other HIV care site to inform him/her that such a patient’s Referral Form is arriving to them through the National Sample Transport System – indicating possible date of arrival.

Required tools:
- 2 Referral Form Binders: “Expected Patients” & “Arrived Patients”
- Patient Appointment Card
- Pre-ART Register
- HIV Chronic Care patient file
- TB suspect register
- Facility Appointment Register
- Phone number listing of all HIV care sites and contact people
TESTING & LINKAGE STEP 5: ADDRESS PATIENT’S MEDICAL NEEDS

Location: HIV care site

Personnel: Nurse / Physician

1. Provide comprehensive care & complete data entry into HIV patient file:
   a. History, physical examination, and WHO staging
   b. Request labs (including “spot” sputum, if indicated)
   c. Manage opportunistic infections
   d. Prescribe appropriate prophylaxis (CTX, IPT)
   e. Plan and prepare patient for prescription of ART if eligible
   f. Provide prevention messages -
      i. partner testing and risk reduction,
      ii. condoms promotion, demonstration and provision,
      iii. STI prevention and treatment,
      iv. FP needs assessment and prescription
      v. TB screening
   g. Inform the patient and treatment supporter about the care plan, including the next appointment date.

2. Write date of next appointment in 3 places:
   a. Patient Appointment Card (and ANC card if applicable)
   b. Facility Appointment Register
   c. Patient Chronic Care File (and electronic record if applicable)

Note: For TB-HIV patients who are newly started on TB treatment but not yet on ART, give the follow-up appointment date for 2 weeks later (and provide only 2 weeks of TB Rx) since that is when the patient should return to be started on ART

Required tools:
- Patient Appointment Card
- Patient Chronic Care File
- Facility Appointment Register
- TB Suspect Register
Retention is defined as a situation whereby a patient has attended healthcare clinic within the last 90 days—for medicine collection, laboratory testing, and/or clinical review—and is not documented as having transferred-out, died, or stopped treatment.

Operational definitions for appointment keeping (Figure 5 below):

- A patient is classified as having a **missed appointment** if they are more than 3 days, but less than or equal to 7 days, late to their expected appointment.
- A patient is classified as a **defaulter** if they are more than 7 days, but less than or equal to 90 days, late to their expected appointment.
- A patient is classified as **lost to follow-up** if they have not been to an HIV care center for more than 90 days since their last appointment date.

![Figure 5: Operational Definitions of Appointment Keeping](image)
RETENTION STEP 1: REGISTRATION AT FOLLOW-UP APPOINTMENTS

**Location:** HIV care site (HIV Care Clinic, Antenatal Clinic)

**Personnel:** Senior Nurse (can delegate as appropriate to Expert Client / Data clerk / Receptionist)

1. Patient comes to clinic with an appointment card as documentation of his/her appointment date.
   a. If Pre-ART/ART patient, he/she will have “Appointment Card”
   b. If HIV-Positive Pregnant Woman, she will have the “ANC Card”
2. Use the facility Appointment Register to confirm that patient is expected on this day.
   a. If patient comes on the day they were expected
      i. congratulate patient for coming
      ii. find date in Appointment Register and mark/document that they came on time
      iii. then proceed with item 3 as below
   b. If patient comes earlier than expected
      i. congratulate patient for coming
      ii. determine why patient came earlier than expected
      iii. find date in appointment register on which they were expected and indicated that the patient came early
      iv. then proceed with item 3 as below
   c. If patient comes later than expected
      i. congratulate patient for coming
      ii. find date in Appointment Register on which they were expected and mark that they came late
      iii. determine why patient came later than expected (and explore solutions with the patient to minimize recurrence)
      iv. then proceed with item 3 as below

3. Update patient’s and treatment supporter’s contacts at every clinic visit in the patient’s HIV Chronic Care File:
   a. For HIV-Positive Pregnant Women, update information in the ANC Register as well

4. Conduct a pill count, calculate and record adherence percentage at every refill visit (for CTX and/or ARVs) and advise patient and his/her treatment supporter accordingly. Document percentage adherence in Patient File.

5. Screen patients for TB at every visit and make referrals for further evaluations as needed
6. Provide patient and treatment supporter with the facility’s contact number – to be used should they have need to contact the facility for information or assistance

7. Inquire from the patient and the treatment supporter if they have any issue they would like to discuss and refer appropriately – allow them time to ask questions

8. Provide step-up counseling on ARV adherence and other issues—like drug side effects—should be provided at every clinic visit for at least 3 consecutive clinic visits following ART initiation. Treatment supporters should be present with the patient at such step-up counseling sessions

9. Refer for additional counseling to expert client as required—especially if patient came late to their appointment.

10. Educate treatment supporter on his/her role and their duties to the patient and encourage them to come with the patient for all visits especially within the first 3-6 months of ART initiation

11. Encourage disclosure to family and friends at every visit and encourage couples counseling where appropriate

12. Link patient to a support group within his/her community or where he/she lives and works

**RETENTION STEP 2: ADDRESS PATIENT’S MEDICAL NEEDS**

**Location:** HIV care site (HIV Care Clinic, Antenatal Clinic)

**Personnel:** Nurse / Physician

1. Provide comprehensive care and complete data entry into HIV patient file as required:
a. History, physical examination, functional status and WHO staging
b. Provide prevention messages -
   i. partner testing,
   ii. risk reduction messages,
   iii. condoms promotion, demonstration and provision,
   iv. STI prevention messages, assessment and treatment where appropriate
   v. FP needs assessed and provided
   vi. TB screening
c. Request lab tests (including “spot” sputum), if needed
d. Manage opportunistic infections
e. Prescribe appropriate prophylaxis (CTX, IPT)
f. Prescribe ART, if on ART or newly eligible
g. Inform the patient and treatment supporter about the care plan, including the next appointment date.

2. Write date of next appointment in 3 places -
   a. Patient Appointment Card (and ANC card if applicable)
   b. Facility Appointment Register
   c. Patient Chronic Care File (and electronic record if applicable)

**Note:** For a pre-ART patient diagnosed with TB and newly started on TB treatment, give the follow-up appointment date for **2 weeks later** (and provide only 2 weeks of TB drugs) since that is when the patient should return to be started on ART.

**Required tools:**
- Patient Appointment Card
- Patient HIV Chronic Care File
- Facility Appointment Register
- TB Suspect Register
- ANC Card and Antenatal Register (if PMTCT setting)
Retention Steps for HIV-Exposed Infants

Location: Child Welfare Clinic (CWC)

At every follow-up visit for Exposed Infants:

1. Mother/guardian brings Child Card for documentation of her infant’s appointment date.
   a. Use the facility Appointment Register to confirm that the patient is expected on this day
   b. Update treatment supporter’s contact in DNA PCR Logbook

2. If applicable, provide DNA PCR test result and post-test counseling to mother/guardian. Document date that result was received in the DNA PCR Logbook and Child Welfare Clinic Register.
   a. If result is HIV-positive, complete Referral Form and link mother/infant to the HIV clinic for initiation on ART (same day if HIV clinic is on-site). Document referral to ART in the DNA PCR Logbook and Child Welfare Clinic Register.
   b. If result is HIV-negative, proceed to next steps.

3. If exposed infant has received a prior negative DNA PCR test result and the mother breastfed, determine whether HIV-exposed infant is due for a repeat DNA PCR test (6-8 weeks after cessation of breastfeeding).
   a. Take DBS sample if due.
   b. Assign a DBS Barcode, complete DNA PCR requisition form, and record test in the DNA PCR Logbook & Child Welfare Clinic Register.

4. Provide comprehensive care for the HIV-exposed infant as specified in the pediatric guidelines, including:
   - Take history and conduct physical examination
   - Assess growth and development
   - Give immunizations as appropriate
   - Provide prophylaxis (CTX, NVP, IPT)
   - Identify and treat opportunistic infections early
   - Screen for TB and ask about household TB contacts
   - Counsel on infant feeding and nutrition
   - Ensure that family is receiving HIV care, FP & social support

Use the Routine Care of HIV-Exposed Infants job aid to guide care provision.

5. Document care indicators (Feeding Status, TB screen, NVP, CTX, etc) in the:
   a) Child Welfare Clinic Register
   b) DNA PCR Logbook (where applicable)
   c) Child Health Card

6. Set appointment for mother/guardian to bring back HIV-exposed infant to receive follow-up care & ARV/CTX refills. Record in Appointment Register.
**SECTION C: PATIENT TRACING**

**Location:** HIV care site / community

**Supervisor:** Senior Nurse

**Personnel:** Expert Client / Data clerk / Community Expert Client / RHM

**DEFINITION:** *Patient tracing* is the combination of a number of interventions embarked on by a team of healthcare providers to reach patients who dropped from care. The aim is to encourage them to return and continue on care and support for their own benefits and/or the benefit of the larger population.

<table>
<thead>
<tr>
<th>Summary of Patient Tracing Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Identify missed appts by going through last 3 pages of Appt Book</strong></td>
</tr>
<tr>
<td>• Do this at the end of every day</td>
</tr>
<tr>
<td>• All patients who have not been checked off as attending need to be followed up</td>
</tr>
<tr>
<td><strong>2. Use “Patient Number” to retrieve the patient file, referral form, or exposed infant info</strong></td>
</tr>
<tr>
<td>• If patient had actually come but was not ticked, update the appointment book</td>
</tr>
<tr>
<td><strong>3. Call patient by telephone</strong></td>
</tr>
<tr>
<td>• Document follow-up attempts in:</td>
</tr>
<tr>
<td>• Appointment Book</td>
</tr>
<tr>
<td>• Patient File</td>
</tr>
<tr>
<td>• Telephone Call Log</td>
</tr>
<tr>
<td>• Contact RHM, Community Expert Clients, or HBC organization to home visit</td>
</tr>
<tr>
<td><strong>3a. Call patient by telephone</strong></td>
</tr>
<tr>
<td><strong>3b. Call treatment supporter if can’t reach patient by phone</strong></td>
</tr>
<tr>
<td><strong>3c. Home visit if patient or supporter isn’t reached by phone</strong></td>
</tr>
<tr>
<td><strong>4. Record new appt in Appt Book</strong></td>
</tr>
<tr>
<td>• Send SMS reminder 1 day before new appt</td>
</tr>
</tbody>
</table>
Establishing a Focal Person to Oversee Patient Tracing

Each HIV Care Site should have a Focal Person and Back-Up Focal Person who will be responsible for overseeing and ensuring timely follow up of patients who have defaulted. This should be the same focal person responsible for ensuring management of the referral system (see Section A, Step 3 above).

The team at the HIV Care Site should meet to establish a system for follow-up of all patients

- One system could be that the Focal Person does the routine patient tracing when on duty, while another staff assumes one of the Focal Person’s other duties. When the Focal Person is not present, the back-up Focal Person does the patient tracing.
- Another system could be a monthly rotation system (coordinated...
TRACING STEP 1(a): IDENTIFY MISSED APPOINTMENTS using ELECTRONIC DATA SYSTEM

1. Every day, print out the list of patients who had an appointment 3 days ago. For example, on Thursday 12 February, print out the list of patients who had an appointment on Monday 9 February. If you have entered all patients who did come on that day (and entered a new appointment date for them), then this list will contain only those patients who did not keep their appointments for that day. If you cannot print out the list, print it to file, and save it as a pdf file. Save the file in a folder so that you can find it.

2. Retrieve the files of the patients who are on this list using their patient number (or National ID—when and where available)

3. Check if they actually didn’t come back. If they did come for a visit according to the file, then it means that the visit wasn’t entered. Enter the visit in the database and put the file back.

4. If the patient file indicates that the patient died or that he/she has been transferred out, it means that the information has not been entered in the database;
   a. Enter or update the information (include the date of the event, even if it is only an approximate date) in the database
   b. Put the file back

Note that the Focal Person’s role is **NOT** to be the only person who traces defaulting patients. Instead, the Focal Person’s job is to “coordinate”, ensuring that there is a clear system in place and that it is being implemented.
5. For all remaining files, the person did not keep the appointment, so they need to be contacted at least three times—at least twice telephonically—and the third contact should be a home visit which may include an RHM referral, a home visit by ECs or any other health worker—provided the patient gave consent that he/she can be visited at home.

TRACING STEP 1(b): IDENTIFY MISSED APPOINTMENTS using APPOINTMENT REGISTER

1. Every day, the data clerk, or designated staff, goes to the appointment page of last 3 days (e.g. on Thursday 12 February, he checks on the page for previous Monday 9 February). All patients who have not been ticked off should be followed-up, including HIV-Exposed Infants (EID) and HIV-Positive Pregnant Women (PMTCT).
   a. Retrieve the file of the patient to see if he/she came. If the patient did come and was not ticked, tick off the patient in the “Attended” box.
   b. If the patient did not come, try to follow up the patient for at least two times telephonically.
   c. If you are unable to reach the patient directly, call the treatment supporter whose details are on the patient file.
   d. If the person doesn’t have a phone or cannot be reached:
      a. For those facilities that have a link with a home based care organization or RHM, contact them for a home visit. Write down the date you referred to RHM or HBC for home visit. Confirm that patient gave consent for a home visit before organizing a visit.
b. For those clinics with a Community Linkages program, liaise with the Outreach Coordinator in the region or with the Community Expert Client.

e. Document the Follow-Up attempt (phone or home visit) in:
   a. Facility Appointment Register
   b. Patient Chronic Care File (“Follow-Up Attempts” page)
   c. Call Register (if phone follow-up)

f. If the patient comes back later on, record the date the patient returned in the Appointment Register in the column “Date Patient came back”

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**TRACING STEP 2(a): STRATEGIES for TRACING—TELEPHONE CALLS**

1. These calls should be conducted in a quiet room.
2. The goal is to try and speak to the patient. Only if you are not able to speak to the patient over the phone, then you will call the treatment supporter.
3. Make sure you have all the information and forms with you:
   - Patient file
   - Call register
   - Blank telephone call report forms.
4. Familiarize yourself with the patient file before you make the call, especially the date of the last visit and the purpose for the appointment e.g. collection of DBS result, ARV refill, etc.
5. Set up an appointment date for patient return to the clinic/home visit
6. Register every attempted call in the Call Register (even if there is no answer)
7. Document follow-up attempt in the Patient File (“follow-up attempts”)
8. If someone answers the telephone and you can interview him/her, use the telephone call report form. However, caller should be careful not to divulge patient’s information to unauthorized individuals (e.g. those not listed as treatment supporter to the patient).

**After every telephone call**

1. Document in the Patient File (follow-up page), & fill in the call register:
   - Date and time of call
   - Duration of call
   - Patient name and surname
   - Pre ART or ART number
   - Telephone number
   - Name of person interviewed
   - Result of call
   - Cost of call (Swazi MTN sends the call cost via SMS after every call)

2. Fill in the telephone call report form, and put the completed form in the patient file.

3. If the patient is dead, transferred out, or did not consent for home visit, then return the file to the data clerk for updating the information in the database (if there is electronic record system).

---

**TRACING STEP 2(a): STRATEGIES for TRACING—ARRANGE FOR HOME VISIT**

1. Call the RHM and ask him/her to visit the patient. Fill-in the call register – add both the name of the patient and the RHM. This is for patients who consented to a home visit by an RHM. Document in Patient File.

2. Also fill-in the telephone call report form. Keep the form in the file and keep the file aside.
3. Call the RHM back **three (3) days** after the date agreed for a home visit to learn the outcome of her visit. Again, fill-in the call register. Ask the RHM to include this in her monthly report.

4. Document home-visit attempt in the Patient File ("Follow-Up Attempts").

5. If the patient does not appear within 2 weeks after this home visit, this will mark 3 unsuccessful attempts to encourage the patient to link to care (two telephone calls and a home visit), further attempts will be made based on availability of resources, or following new information on the client e.g. travelled but has come back.

6. Update the telephone call report form and Patient File.

7. If the patient has a clear outcome (not reachable at home, dead, transferred out, stopped treatment), document these, and then return the file to the data clerk for updating the information in the database.

8. For facilities with a Community Linkages program, liaise with the Outreach Coordinator or Community Expert Client who will follow-up clients in conjunction with the RHM.

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**TRACING STEP 3: RE-ADMIT INTO CARE (WHEN PATIENT RETURNS TO HIV CARE SITE)**

1. Find out why patient missed appointment or stopped treatment and work out possible solutions.

2. Readdress need for treatment support and role/identity of treatment supporter.

3. Ensure that the patient receives additional (step-up) counseling on adherence and positive prevention. Document the date the patient returned in the patient file

4. Link patient with the counseling and clinical team for possible re-admission into HIV care.
5. Develop patient-specific management and follow-up program with the patient, the treatment supporter and the MDT of the ART site – including investigation for possible development of ARV drug resistance (for patient already on ART)

**Required tools** -

- SMS/Call register
- Standardized scripts for SMS messages
- Standardized telephone scripts
- Facility appointment register and/or Electronic Database
- Patient File
- Telephone
- Airtime
M&E will be an integral component of the SOP implementation. Indicators will need to be collected regularly to determine the effectiveness of the SOP and inform future revisions and modifications.

Wherever possible, data will be collected using routine mechanisms including:
- Pre-ART and ART reporting forms that are completed by each facility
- Standard reports produced by the APMR electronic data systems

For SOP indicators that are not captured in the current national reporting tools and reporting mechanisms, regular Quality Improvement (QI) processes undertaken by facilities—in line with the national QI framework—can be utilized to informally assess progress.

SNAP ART is developing a study protocol to comprehensively assess all aspects of the Linkage and Retention SOP. This protocol will be implemented in collaboration with the MOH Strategic Information Department.

**Core indicators to be assessed as part of SOP implementation:**

- Percent of HIV-positive individuals who enrolled in pre-ART care after being referred from the HIV testing point
- Percent of HIV-positive individuals referred from a testing point and not attending who were followed up by phone and/or home visit
- Percent of referred HIV-positive individuals and not attending who were recovered back into care after follow-up attempts
- Percent of HIV-positive patients whose next appointment was documented in an Appointment Register (paper or electronic)
- Percent of HIV-positive patients retained in HIV care, *disaggregated by patient category* (Pre-ART, ART, EID, PMTCT, TB-HIV, etc.)
- Percent of defaulting HIV-positive patients followed up by phone or home visit
- Percent of contacted HIV+ defaulters who were recovered back into care after the follow-up attempt.
Key barriers to linkage and retention have been identified in studies and surveys conducted in Swaziland, as well as in the scientific literature. The “Linkages and Retention Working Group” identified some interventions that Swaziland could consider implementing beyond this SOP to help overcome some of these barriers.

The identified barriers & potential interventions are described in the table below:

### Annex 1: Table of barriers and interventions that might enhance linkage to/retention in care.

<table>
<thead>
<tr>
<th>Additional Steps to Improve Retention beyond this SOP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key Barrier</strong></td>
</tr>
<tr>
<td>-----------------</td>
</tr>
</tbody>
</table>
| Poor understanding of why it is important to enroll & remain in care | • Establish a class on HIV treatment literacy and support basics for patients with a treatment supporter (individual that has been disclosed to and notified of the roles/responsibilities), to be attended jointly by the patient and treatment supporter.  
• For patients without a true treatment supporter, establish facility-based PLHIV support group course that will provide important information on treatment literacy and support over the course of several sessions, so as to empower that individual to identify a treatment supporter in the future.  
• Establish a patient hotline which could explain lab results, provide counseling on issues of disclosure and stigma, etc  
• Strengthen routine counseling and health education at the facility for patients on the importance of receiving chronic care |
| Distance to the Clinic & Lack of Transportation Funds | • Actively promote early down referral of HIV-positive patients to local clinics (for patients who are stable on treatment) to reduce distances traveled and increase remote accessibility  
• Provide patients who are stable on treatment with the option of having more distant appointment dates (e.g. more than just 2 months) to ease transport demands.  
• Establish system of Community Health Nurses providing ARV refills at a patient’s home for stable patients. The patients could then be scheduled for clinical review at the HIV care site every 4-6 months.  
• Establish groups of patients who live nearby each other and initiate a system whereby one patient collects all of the patients’ medicines each month (as long as each patient in the group attends the facility for clinical review every 3 months) |
<table>
<thead>
<tr>
<th>Key Barrier</th>
<th>Potential Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fear of Disclosure &amp; Stigma</td>
<td>• Provide step-up counseling for patients who have not disclosed their HIV status, so as to equip them with the necessary skills (patient specific – based on patient context)</td>
</tr>
<tr>
<td></td>
<td>• Establish a patient hotline which could explain lab results, provide counseling on issues of disclosure and stigma, etc</td>
</tr>
<tr>
<td></td>
<td>• Schedule follow-up appointments with patient and his/her partner to assist them with the disclosure process</td>
</tr>
<tr>
<td>Poverty</td>
<td>• Link patients to programs geared towards economic empowerment (i.e. agricultural economic empowerment, coops and saving organizations, support groups)</td>
</tr>
<tr>
<td>Lack of customer-friendly services and confusing organization at receiving facilities</td>
<td>• Establish a system whereby newly tested HIV-positive patients are escorted from the testing point to the HIV clinic by an health worker or expert client</td>
</tr>
<tr>
<td></td>
<td>• Place signs at facilities that instruct patients where to find HIV clinics (or TB clinics)</td>
</tr>
</tbody>
</table>
|                                                 | Improve patient flow to decrease stress of waiting, including:  
|                                                 | • Designate specific day or afternoon for new patients  
|                                                 | • Give patients with Referral Form preference in queue at all times  
|                                                 | • Improve waiting areas and seating arrangements  
|                                                 | • Develop and implement a "client satisfaction tool" in line with the national Quality Assurance framework, and use findings to improve customer-friendly service provision  
|                                                 | • Provide "customer service training" for health care workers  
|
Annex 2: Linkages and Retention Flow Chart

**PATIENT LINKAGE TO CARE and FOLLOW-UP**

**HTC Site**
- Counsel and test for HIV & provide post test counseling / support
  - If HIV-Positive
  - Prevention Package
  - If HIV negative
- Refer to HIV care clinic: counsel, complete Referral Form, & set appt date
- Give patient original copy of Referral Form & advise to take to HIV care clinic
- Send duplicate copy of Referral Form to the HIV care clinic

**HIV Care Clinic**
- Receive duplicate copy of Referral Form from HTC site:
  - File by date of appointment & enter patient into Appointment Register
- Send SMS reminder on day before the appointment for 1st visit

**1st Visit:**
- Match Referral Form with duplicate on site
- Confirm appointment in the Appointment Register
- Open Chronic Care File and issue pre-ART number
- Provide clinical care (e.g. Staging, TB screen, CD4 count)
- Conduct lab tests (e.g. HB and CD4) and provide CTX
- Counsel on importance & benefits of returning for care
- Give & document next appt in Appointment Register
- Confirm treatment supporter contact details

**Follow-up Proactively**
- Call Patient and/or Treatment Supporter
- Home visit patient (by RHM, CBV, CECs, etc)
- Enter new date in Appointment Register

**Follow-Up Visit:**
- Confirm appointment in the Appointment Register
- Provide and document all services described above
- If eligible for ART, start adherence counselling and ART
- If on ART, provide best possible treatment (e.g. FDC ARVs)
- Ensure/confirm effective treatment support
- Give & document next appt date in Appointment Register

**Patient comes on appointment day**
- Send SMS reminder on day before follow-up appointment

**Patient does NOT come on appointment day**
- Patient does NOT come on appointment day
  - Patient does NOT come on appointment day

**Follow-up Proactively**
- Call Patient and/or Treatment Supporter
- Home visit patient (by RHM, CBV, CECs, etc)
- Enter new date in Appointment Register

[Diagram of the flow chart showing the process steps.]