HIV CARE PATIENT FOLLOW-UP PROGRAMME

STANDARD OPERATING PROCEDURES

2011

MOHSW

THE NATIONAL ART PROGRAMME
SECTION A: INTRODUCTION

Objectives

The goal of the following 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 linkages procedures will first be introduced for patients who test positive during SHIMS or SOKA UNCOBE (the Male Circumcision Campaign). The retention and tracing procedures will be initiated at HIV care centers in the country simultaneously. Lessons learned from this initial rollout of the SOP will be incorporated in the subsequent extension of the concept to all testing and treatment sites in Swaziland.

Rationale

Swaziland is expanding the reach of HCT programs with SOKA UNCOBE and SHIMS

Swaziland has benefited from increasing efforts to expand access to HIV testing in both communities and facilities. Notable testing outreach activities in the community include the home based counseling and testing program that reached almost 10,000 people in Hhohho in 2010. Simultaneously, the SNAP HCT Unit has been working closely with health facilities to expand offers of provider-initiated testing into inpatient and outpatient wards.

In 2011, the upcoming Swaziland HIV Incidence Measurement Survey (SHIMS) will require testing of more than 20,000 people throughout the country at their homes and the SOKA UNCOBE will test more than 150,000 people nationwide in Male Circumcision (MC) sites. Of note, many of those expected to be tested are men ages 15-49, a particularly hard demographic to reach with counseling, testing or treatment services.

Services to keep people HIV negative are well-established within the national HTC SOP

It is expected that 75-80% of the men coming to SOKA UNCOBE sites will test negative and the MC campaign promises to be very successful in helping them stay that way. SOKA UNCOBE is expected not only to provide circumcision services to all men who test negative, but also to follow the national HTC protocols for providing individualized risk reduction information to each of them. These counseling efforts will focus on care of the surgical area, condom use, partner testing and other risk reduction activities.

For SHIMS and expanding PIHCT and CIHCT programs, such post-test counseling efforts are in place, but could use reinforcement.

Services to refer people who test HIV positive face some challenges

It is also expected that 20-25% of the people coming to SOKA UNCOBE sites or tested through other means will test positive. To date, there are only limited systems in place to refer these 25,000-35,000 individuals to care. Beyond standard post-test counseling (which is likely to be time-limited during the SOKA UNCOBE campaign), there are few systems to help them or patients tested in any other setting accept their diagnosis, adopt risk reduction measures, or overcome barriers to accessing HIV treatment services and then remain enrolled in care.
It is anticipated that the average young healthy man who comes forward for circumcision services will be very reluctant to accept a diagnosis of HIV and seek appropriate treatment. Accessing risk reduction counseling, as well as care and treatment services early will help an individual stay healthy in two ways. First, through ongoing counseling and pre-ART services, and second, if he is started on ART, the treatment will improve his immunological and clinical conditions as well as lead to a decrease in the risk of his transmitting the virus to others.

**Linkages to and retention in care are challenges currently for SNAP**

The National AIDS Program recognizes that both linkages to and retention in care are major issues in the quality of the service they are providing. Regarding linkage, no national statistics are currently available, but the national ART program estimates that without intervention, less than 30% of people identified in SHIMS, SOKA UNCOBE or other CIHCT will link to care. Regarding retention in ART care, recent draft national statistics show 6 month retention rates of ~75% which decrease to ~35% by the fifth year in care. There are no national data on retention in pre-ART care. Data from Southern Africa indicate that 12 months retention in pre-ART care is usually less than 45%.

**Key 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. These issues include:

- Lack of understanding of why it is important to enroll in care
- Fear of disclosure/stigma
- Lack of welcome/confusing organization of receiving facilities/wait time
- Distance to clinic/lack of transportation
- Poverty

The first three 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, but managing them is beyond the scope of this SOP, however, the decentralization of HIV services to rural/remote clinics by the ART Program aims at addressing these social issues by bringing services closer to the patients.

**Sources for the Details of the Linkage/Retention/Tracing SOP**

The linkage aspect of the SOP is based on experiences from the home-based testing program as well as the work of an ad hoc working group chaired by the SNAP ART Unit and including representatives of the SNAP HTC Unit, PEPFAR partners and MSF. The retention aspect of the SOP is a result of the recent efforts of the SNAP ART Unit and its partners, especially ICAP and its community linkages partners.

Given the challenges faced by the ART Program in areas of linkage to and retention in HIV care, acknowledging the mounting evidence on benefit of HIV care to both the infected and the affected, and given the need to limit emergence of preventable ARV drug resistance through high retention in care and proper adherence to therapy, the potential contribution of this patient follow-up SOP towards the fight against the AIDS epidemic in the country cannot be over emphasized. Other national projects that will immediately benefit from the SOP include SHIMS which has already started and the SOKA UNCOBE campaign that is rapidly scaling up. It is therefore essential that Swaziland adopts and implements this national linkage to care/retention in care procedures as soon as possible.


**SECTION B: TESTING & LINKAGE TO CARE**

**Scope**
The scope of this program is national as it will be conducted by all HIV diagnostic and HIV care settings. It will be initiated for the duration of SOKA UNCOBE. Continuation of this SOP beyond 2011 is dependent on SNAP approval and availability of funding.

**Operational definitions for linkage and retention**

**Linkage** is defined by the Swaziland National Comprehensive Package of Care 2010 as a first visit to HIV care following a positive HIV test result, and includes all or some of the following:

- Registration of new patient into pre-ART register
- Issuance of a patient-held appointment booklet or card
- Opening of an HIV CareFile
- Documentation of baseline clinical, laboratory and psychosocial assessment
- Provision of any clinical and/or pharmaceutical services e.g. CTX prophylaxis

**Basic principles of linkage to & retention in care**

1. All people who test negative for HIV need risk reduction counseling as defined in the Swaziland national HTC guidelines
2. All people who test positive for HIV (or screen positive for TB) should be enrolled and retained into chronic HIV care (and/or sent for sputum testing).
3. Post-test counseling should motivate the patient to attend the nearest acceptable facility that provides chronic HIV care. As part of counseling, referral providers should routinely assess readiness and barriers to enter HIV care, and as needed, help newly HIV-diagnosed clients overcome identified barriers to care.
4. Facilities offering HIV services should have appropriate mechanisms in place to facilitate linkage and retention. Such mechanisms might include signs, adequate waiting areas, trained and motivated staff.
5. Facilities offering HIV services should have mechanisms in place to trace patients who do not link to care/are not retained in care and motivate them to (re)enroll. Such mechanisms might include additional counseling by phone or face-to-face in the facility or in the patient’s home.
6. Implementation of linkage to care systems will be used to strengthen retention in care, and defaulter tracking systems. The processes will share personnel, appointment systems, registers, phone time, etc.
7. Progress in linkage to care/retention in care will be measured with appropriate monitoring and evaluation systems. These M&E systems will also inform appropriate quality improvement exercises.
TESTING & LINKAGE STEP 1: COUNSEL AND TEST  (according to HTC guidelines)

Personnel: Lay counselor/health care worker

1. Greet individual or couple coming for test
2. Provide group information
3. Provide pre-test counseling
4. Initiate HTC client form and complete all appropriate sections
5. Complete TB screening form
6. Conduct HIV test
7. Provide test result, post-test counseling and appropriate referral
   a. For HIV negative
      i. Focus on risk reduction based on risk assessment responses
      ii. If follow up test or additional counseling required, provide referral for repeat counseling and testing
      iii. If testing at CIHCT, PIHCT or SHIMS outreach and client is male and HIV negative, refer for MC
      iv. If testing at SOKA UNCOBE site, allow patient to continue through normal MC procedures. (These MC procedures include provision of further risk reduction messages)
   b. For HIV positive:
      i. Focus on encouraging acceptance of diagnosis; partner testing; assessing and resolving barriers to accessing care
      ii. If testing at CIHCT, PIHCT or SHIMS outreach, and diagnosis is not accepted, refer to HIV care site for additional counseling, care and treatment
      iii. If testing at SOKA UNCOBE site, refer patient for on-site additional counseling

Required tools:
- Counseling cue cards for pre-test and post-test counseling
- Counseling job aides
- HTC register
- HTC client form
- TB screening tool

TESTING & LINKAGE STEP 2: REFERRAL FOR FOLLOW-UP HIV CARE

Personnel: Lay counselor/health care worker

1. Based on needs identified during counseling and testing session, consult referral directory and referral map as needed to determine nearest preferred facility that can support patient needs
2. Complete remaining sections of HTC client form:
a. Referral check boxes
b. Referral site and date

iv. For all clients requiring referral:
   1. Encourage patient to attend facility closest to his/her home that is acceptable to him/her.
   2. Provide options of nearby facilities and provide reasoning for those options and guide patient to choice of one.
   3. Prioritize referral according to health condition most in need of treatment. For example:
      a. A patient requiring referral for both HIV care and STI treatment, should be referred to a site that offers the HIV care preferentially.
      b. A patient requiring referral for both HIV and TB services should be referred to a site that offers both.

v. For HIV positive patients only: (for SOKA UNCOBE, this section can be deferred and completed by the Care and Linkages Counselor—see following section)
   1. Appointment date should be set within 2 weeks of the positive test on days when the receiving clinics accept new patients.
   2. Emphasize to patient that the facility will be expecting him/her on this date and, if permission given, will contact him/her if the appointment is not kept. This permission is noted on the HTC client form.
   3. Provide HIV services referral pamphlet (in English and Siswati)
   4. Refer for additional counseling as available/required

3. Disposition of HTC client form triplicate copies at MC site
   a. Original copy of HTC client form: Counselor gives to client to bring to receiving facility as referral form.
   b. First duplicate copy of HTC client form:
      i. If client is HIV positive, provide first duplicate copy to the Care and Linkages Counselor for his/her reference.
      ii. If client is HIV negative, the first copy should be given to the client with period of validity of the result clearly indicated in the form.

4. Dispatch of HTC client form triplicate copies at CIHCT, PIHCT or SHIMS outreach
   a. Original copy of HTC client form: Counselor gives to client to bring to receiving facility as referral form.
   b. First duplicate copy of HTC client form:
      i. If client is HIV positive
         1. Provide this copy to counselor supervisor.
         2. Each day, the counselor supervisor will collate all forms into envelopes labeled with the relevant facilities’ names. He/she will then send these envelopes to the receiving facilities via the sample
transport network. With this information, the facility will know when to expect patient.

ii. If client is HIV negative, the first copy should be retained in the HTC form book, while the client is given the original copy.


Required tools:

- HTC client form (and/or HTC register)
- Referral directory and/or referral map
- Referral pamphlet that includes basic information about the positive test, HIV and why it is important to seek care
- Counseling cue cards about referral

**TESTING & LINKAGE STEP 3: ADDITIONAL COUNSELING FOR PEOPLE WHO TEST HIV POSITIVE**

Personnel: Lay counselor

All people who test HIV positive should receive a referral to HIV care and treatment services. A referral for additional counseling to overcome barriers to accessing care is also to be provided to people who have difficulties in accepting their diagnosis.

At SOKA UNCOBE sites, this service will be provided by a dedicated lay counselor known as a Care and Linkages Counselor (CLC), who will be on site at all SOKA UNCOBE facilities. A client who tests positive at the site will be referred from the first counseling interaction to a separate private space for this follow up interaction. The CLC will be given the copies of the HTC form that will be sent to the facility so that he can collate them. His/her job is to reinforce the message provided in post-test counseling, help the client accept his status and overcome barriers that might prevent him from reaching care.

When testing occurs in other settings (SHIMS, CIHTC, PIHTC), people who test positive in other settings should receive a referral for care and treatment services. Persons who indicate that they are not ready to enroll into care and treatment should also be referred for additional supportive counseling at the HIV care site to address the individual’s questions or concerns about care and treatment. Counselors at the HIV care site should continue to explain the benefits of treatment, address patient’s concerns and barriers to treatment, and assist the patient in enrolling into care and treatment when they are ready.

The Care and Linkage Counselor should also perform the following services:

1. Receive all copies of HTC client form from first HTC counselor
2. Use discussion guide and checklists to:
   a. assess patient’s readiness to initiate care and determine barriers.
b. attempt to resolve barriers as possible

c. complete individualized readiness assessment checklist

d. confirm that choice of facility and date of expected appointment noted on HTC form are acceptable to patient and correct on all 3 copies of form as necessary.

3. Reemphasize to patient that the care and treatment facility will be expecting him/her on this date and, if permission was given, will contact him/her if the appointment is not kept.

4. Ensure patient has the original copy of the HTC form

5. Staple individualized checklist to first duplicate copy of HTC form that will be sent to the facility

6. As an HTC form/checklist combination is completed, place each pair in a sealable envelope with the receiving care and treatment facility’s name on it. Using the envelope will help maintain the patient’s confidentiality.

7. At end of day, send envelopes to the facilities via sample transport system. Then, if patient does not keep his/her appointment, a follow up interaction can be focused on his/her specific issues.

Required tools:

- Discussion guide
- Individualized checklist to assess readiness and barriers
- Logbook of patient interaction

**TESTING & LINKAGE STEP 4: FACILITY PREPARATION FOR PATIENT ARRIVAL**

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

1. General:
   a. 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 these signs with concerns of stigma)
      ii. Signage noting the different sections within the HIV care center (lab, pharmacy, registration, etc.)
      iii. Waiting area 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

2. Patient specific
   a. **Only** for patients who just tested positive who have not yet enrolled:

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1Such 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).
i. All copies of HTC client forms will have been received by facilities expecting patients within 2 days via the sample transport system.

ii. At facilities, the received copies of the HTC client forms and the attached readiness’ checklist are kept in a confidential “expected patients” file sorted by
   1. the date the patients are expected
   2. patient names (or PIN code) within each date

iii. The patient’s name is written into the facility appointment register on the day he/she is expected to arrive

iv. Readiness assessment checklist is reviewed and means of contacting patient to perform visit reminder (phone call vs home visit) is determined and written in the appointment register as well.

b. For all patients—new or previously enrolled:
   i. Review of appointment register to determine which patients expected the following day and the type of visit reminder required. (Criteria for type of reminder noted below).
   ii. One day before expected visit, the facility will contact the patient to remind him/her of appointment:
      1. Send an SMS using standardized message text to all expected patients, regardless of adherence history.
      2. Call the patient if, based on readiness assessment, the HCW recognizes that patient will need personalized encouragement to come to care.
      3. Requesting an RHM/ HBC or community expert client (if available) 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 HTC client form. Also, patient may have noted if preferred visit from HBC/RHM or community expert client on the readiness assessment form.)
         b. The patient is unreachable or unattainable by cell phone or, based on readiness assessment, the HCW recognizes that patient will need personalized encouragement to come to care.

Required tools:
- Facility appointment register
- Telephone
- Air time
- Call register

**TESTING & LINKAGE STEP 5: ENROLL PATIENT INTO HIV CARE**

Location: HIV Care Site
Personnel: Expert Client/Nurse/Data clerk/Receptionist
1. Patient comes to clinic with the original copy of the HTC client form as documentation of his/her appointment date.
   a. If patient comes earlier than expected
      i. congratulate him/her
      ii. find date in appointment register on which they were expected and note that the patient came early
      iii. then proceed with item #2 as below
   b. If patient comes later than expected
      i. congratulate him/her
      ii. find date in appointment register on which they were expected and mark that they came late
      iii. 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 appointment book on which they were expected and note that the patient came on time
      iii. then proceed with item #2 as below
2. Patient’s copy of the HTC client form is matched with the copy of his/her HTC client form that was sent to the receiving facility at the time of testing.
3. The bottom portion of the form is completed with the name of the facility where the patient entered care and the date of arrival.
4. The forms are then stapled together and placed in the “expected patient” file.
5. Check facility appointment register to confirm that patient is expected on this day.

NOTE 1: If patient attends a facility other than the one where his/her HTC client form was sent, and/or no matching form can be found, follow these steps:
   a. The health care workers at the new facility should:
      i. Confirm that patient has changed his/her mind regarding the facility to which they were originally referred for care and treatment services
      ii. Notify the original facility through phone call that the expected patient has linked to a different facility within one day of the patient’s visit.
      iii. Document in call register that call to expecting facility was made: time, date, person receiving call
      iv. Open a patient file at the receiving clinic and follow all normal procedures of enrollment into care as below.
   b. The health care workers at the original facility should:
      i. Receive the above call from the new facility
      ii. Note in the appointment register (against the patient’s name) where the patient has initiated care
      iii. Remove the copy of the HTC form from the “expected patient” folder, note the clinic where the patient entered care and the date they arrived and transfer it to the “arrived patient” folder.
      iv. Where the National Sample Transport System route links these two HIV care sites, the original referral site should put the patient’s HTC form (facility copy) and the barrier assessment form in an envelope, seal it properly and address it to the offer
who called from the new site where the patient is currently enrolled into care, and
send it to the new HIV care facility through the Sample Transport System.

v. The sending officer should also call the receiving officer on the other side to inform
him/her that such a patient’s HTC form is arriving to them through the Sample
Transport System.

**NOTE 2:** If patient attends a facility without his/her HTC client form, follow these steps:

a. The health care workers at the new facility should look for their copy of the HTC form in their
files. If they cannot find it, the patient will have to be retested.

6. Enter patient details into pre-ART register (and/or TB suspect register)
7. Counsel patient on HIV basic information (usually by expert client)
8. Give patient personal appointment card/HIV Care Number
9. Open new HIV (and/or TB) patient file and enter appropriate demographic data
10. Fill in the appointment register for patient’s next appointment once date is known
11. Obtain/confirm consent for home visitation by an RHM/ HBC/CEC or healthcare worker (and
indicate it on the patient file in the psychosocial assessment section).
12. 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.)
13. Direct patient to sections of the site for other follow-up services (e.g. Lab - blood draw for
baseline tests; Doctor/Nurse – for consultation; pharmacy for CTX supply)

Required tools:

- HTC client form file
- Patient appointment booklets or cards
- Pre-ART register
- HIV patient file
- TB suspect register
- Facility appointment register
- Phone number listing of all HIV care sites and contact people

**TESTING & LINKAGE STEP 6: ADDRESS PATIENT’S MEDICAL NEEDS**

**Location:** HIV care site
**Personnel:** Nurse/Physician

1. Complete data entry into HIV (and/or TB) patient file *as required*:
   a. History, physical examination, and WHO staging
   b. Request labs (including “spot” sputum, if needed)
   c. Manage opportunistic infections
   d. Prescribe appropriate prophylaxis (CTX, IPT)
   e. Plan and prepare patient for prescription of ART if eligible
f. Prevention messaging: partner testing, risk reduction messages, condoms, STI and FP needs assessed and treated

g. Care plan, including next appointment, to be made known to patient and treatment supporter

2. Write date of next appointment in 3 places:
   a. patient appointment booklet/card
   b. facility appointment register
   c. patient file (and electronic patient record if available)

Required tools:
- Patient appointment booklets (green book)/appointment card
- HIV patient file
- TB suspect register
- Facility appointment register
SECTION C: RETENTION IN CARE

Retention is defined as a situation whereby a patient has not failed to attend clinic within 90 days since the date of their last appointment for either medicine collection, laboratory testing, or a clinical visit and has not been documented as having transferred to another clinic, died, or stopped therapy.

Operational definitions for appointment keeping:

- 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 the HIV care center for more than 90 days since their last appointment date.

RETENTION STEP 1: REGISTRATION AT FOLLOW-UP APPOINTMENTS

Location: HIV care site
Personnel: Expert Client/Nurse/Data clerk/Receptionist/Etc

1. Patient comes to clinic with the green booklet/ appointment card as documentation of his/her appointment date
2. Use the facility appointment register to confirm that patient is expected on this day.
   a. If patient comes earlier than expected
      i. determine why patient came earlier than expected
      ii. find date in appointment register on which they were expected and note that the patient came early
      iii. then proceed with item 3 as below
   b. If patient comes later than expected
      i. find date in appointment register on which they were expected and mark that they came late
      ii. determine why patient came later than expected (and explore solutions to that with patient to minimize recurrence)
      iii. then proceed with item 3 as below
   c. If patient comes on the day they were expected
      i. find date in appointment register on which they were expected and mark that they came on time
      ii. then proceed with item 3 as below
3. Update patient’s and treatment supporter’s contacts at every clinic visit
4. Conduct a pill count at every ARV refill visits and advise patient and his/her treatment supporter accordingly

5. Provide patient and treatment supporter with the facility’s contact number – to be used should they have any need to contact the facility for information or assistance

6. Inquire from the patient and the treatment supporter if they have any issue they would like to discuss with the counselor or the expert client – allow them time to ask questions

7. Referral for additional counseling by expert client as required—especially if patient came late to their appointment. 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.

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

9. 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
Personnel: Nurse/Physician

3. Complete data entry into HIV (and/or TB) patient file as required:
   a. History, physical examination and WHO staging
   b. Request labs (including “spot” sputum, if needed)
   c. Manage opportunistic infections
   d. Prescribe appropriate prophylaxis (CTX, IPT)
   e. Prescribe ART if eligible/on ART
   f. Prevention messaging: partner testing, risk reduction messages, condoms, STI and FP needs assessed and treated
   g. Care plan, including next appointment, be made known to patient and the treatment supporter

4. Write date of next appointment in 3 places:
   a. patient appointment booklet/card
   b. facility appointment register
   c. patient file (and the electronic patient file where available)

Required tools:

- Patient appointment booklets (green book)/appointment card
- HIV patient file
- TB suspect register
- Facility appointment register
POSSIBLE ADDITIONAL STEPS TO IMPROVE RETENTION: (see Annex 1 for more detail)

- Increased counseling and education for people who are enrolled in care on FAQs and positive living. People who are eligible for ART may require different curricula than people who are not eligible for ART.
- Increased education for treatment supporters, including linking them with RHMs. (Could duplicate World Vision effort of having photos of all RHMs to help people pick out the one for their community.)
- Hotline for patients and treatment supporters
- Promote early down-referral for stable patients by actively asking patients if they are interested in receiving care closer to their homes
- Open more decentralized sites/clinics that are allowed to initiate ART
- Switch to fixed-dose combinations as soon as possible (well-established practice in Swaziland).
- Provide reliable patients with an extended drug supply (2-3 months)
- Improve patient flow at HIV care sites on a facility-by-facility basis. (Also, could institute triage systems, provide numbers that show place in line, etc)
- Establish groups of patients who live nearby each other and initiate system whereby one patient collects all of the patients' medicines each month. (As long as each patient comes to be seen at least once every 3 months.)
- Provide small incentive or gift or certificate for patients who remain in care for every 6 consecutive months.
SECTION D: DEFAULTER TRACING

Location: HIV care site
Personnel: Expert Client/Nurse/Data clerk

Definition

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

TRACING STEP 1(a): For ART patients (using the APM plus system)

1. Every day, print out the list of patients who had an appointment 3 days ago. E.g. 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 come. 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
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 (s)he has been transferred out, then that 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
5. For all remaining files, the person did not come back so they need to be contacted at least 3 times (twice telephonically) within a space of at least 3 weeks 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.
6. If a person doesn’t have a phone or cannot be reached contact an RHM or HBC for a home visit
7. 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 (initial test, follow up call, repeat follow up call or follow up visit) and no further attempts will be made.
**TRACING STEP 1(b): Using the Appointment Register For Pre-ART and ART patients in facilities without APM database**

1. Every day, the data clerk, or designated staff person, goes to the appointment page of last 3 days (e.g. on Thursday 12 February, he checks on the previous Monday 9 February). All patients who have not been ticked off should be followed up:
   a. Retrieve the file of the patient to see if (s)he came. If the patient did come and was not ticked, tick off the patient in the “Attend?” box.
   b. If the patient did not come, try to follow up the patient telephonically. In the column “CALL”, write the date you called the person.
   c. If you are unable to reach the patient, 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.
      b. For those clinics with a Community Linkages program, liaise with the Outreach Coordinator in Manzini region or, in other regions, with the Community Expert Client.
   e. If the patient comes back later on, write in the column “Date Patient came back” the date the patient returned.

**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 reasons for the missed/upcoming appointment.
5. Register every attempted call in the call register (even if there is no answer)
6. 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. Fill in the call register:
   - Date of call
   - Patient name
   - Pre ART or ART number
- Telephone number
- Name of person interviewed
- Result of call
- Cost of call (Swazi MTN smses the call cost after every call)

3. If the patient needs to be called again, keep the file aside and try another time.
4. If the patient has a final outcome (not reachable, passed away, transferred out, …), then return the file to the data clerk for updating the information in the database or in the pre ART register.

**TRACING STEP 2: Arrange for Home Visit (for sites who have a follow up program e.g. with RHMs)**

1. Call the RHM and ask 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 had agreed to be visited at home by an RHM.
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 missed 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. Update the telephone call report form
5. If the patient has a final outcome (not reachable, passed away, transferred out, …), then return the file to the data clerk for updating the information in the database or in the pre ART register.
6. For clinics with a Community Linkages program, liaise with the Outreach Coordinator or Community Expert Client who will look after follow-up in conjunction with the RHM.

**TRACING STEP 3: Re-Enroll into Care (when patients returns to HIV care site)**

1. Ensure that the patient receives additional counseling on adherence and positive prevention. Team members can see that the patient has been contacted because the telephone call report form is in the file.
2. Find out why patient missed appointment and work out possible solutions using individualized checklist. Readdress need for treatment support and role/identity of treatment supporter.
3. Enter the date the patient returned on the copy of the questionnaire in the patient file
4. Link patient with the counseling and clinical team for possible re-enrollment into HIV care
5. Develop 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 (if already on ART)

Required tools for all of the above -
- Individual readiness checklist
- SMS/all register
- Standardized scripts for SMS messages
- Standardized telephone scripts
- Referral follow up register
- Facility appointment register or computer/printer
- Patient files
- Telephone
- Air time
Annex 1: Table of barriers and interventions that *might* enhance linkage to/retention in care.

The Linkages/Retention/Tracing working group identified some interventions that Swaziland could consider implementing to ensure that as many of these people as possible are linked to care. Some of these interventions will require resources beyond the minimum approach described above, but others are administrative or organizational.

They are described here in a table form that denotes the key barrier that each intervention is intended to address. The group did not determine interventions that addressed all barriers.

<table>
<thead>
<tr>
<th>Key barriers</th>
<th>Potential interventions</th>
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| • Lack of understanding of why it is important to enroll in/remain in care | • A health care worker could provide additional counseling to a person who tests positive beyond the traditional post-test counseling. (Adopted into SOP.)  
  • A hotline could be established to provide clarity on results, help with disclosure, etc  
  • Interested patients could be assigned to “Intro to HIV” classes that would follow a set curriculum for 6 classes and cover frequently asked questions and concerns. |
| • Distance to clinic/lack of transportation       | • Approve more outreach sites for facilities meeting minimum requirement for HIV care services in rural areas  
  • Down referral for HIV care services from initiating sites to local clinics for patients who are doing well on their treatment (and willing to be down-referred) to increase remote accessibility and reduce distances travelled.  
  • Distant appointment dates for patients who are stable on their treatment; longer than just 2 months.  
  • Community Health Nurses providing ARV refills at a patients home – for stable patients. The patients could then be scheduled for clinical review at the ART sites 4-6 monthly. |
| • Fear of disclosure/stigma                       | • Step-up counseling to empower patients with disclosure skills (patient specific – based on patient context)  
  • A hotline could be established to provide clarity on results, help with disclosure, etc  
  • Schedule follow-up appointment with partner to assist them with disclosure process |
| • Poverty                                         | • Linkage of patients to programs geared towards economic empowerment (i.e. agricultural economic empowerment, coops and saving organizations, support groups) |
- Lack of welcome/confusing organization of receiving facilities
- A health care worker could escort a patient from test to registration in care
- Signs at facilities that instruct patients where to find HIV (or TB) clinics (adopted into SOP)
- Improvements to patient flow to decrease stress of waiting:
  - Designate specific day or afternoon for new patients, or
  - Give patients with HTC client form preference in queue at all times
  - Improve waiting areas/seating arrangements
- Customer service training for health care workers

- Need for a psychological “push” to attend appointment at receiving facility (link to care)
- A patient could be provided with a 2 week supply of CTX at time of referral. When at runs out, a refill will be available at the initial appointment.
- Baseline labs could be drawn at the time of referral and results will be given at the initial appointment.

NB: Implement a similar program to follow -
- Linkage from positive TB screen to TB test (and from positive TB test to treatment)
- Linkage from MC referral to MC site