Maximizing coverage of index testing for biological children of mothers living with HIV: Standard Operating Procedure (SOP)

Adapted from: PEPFAR/USAID/CDC/DOD/UNAIDS "Partner and Family-Based Index Case Testing SOP" USAID Ethiopia Facility-based Case Management Model
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SECTION 1: Intended users

The primary user of this SOP is the facility based OVC Staff (i.e. Lead Community Child Care Workers (LCCWS), OVC facility and community case workers, OVC linkage/referral coordinators, supervisors/managers) who engage with health facilities on a routine basis and may be based within the health facility. This SOP should be incorporated into any Memorandum of Understanding (MOU) that is established or updated between the health facility and the OVC implementing partner. It is vital that the clinical staff are aware of and in agreement with the procedures in this SOP and agree to the OVC Staff conducting the file reviews and sharing lists of children <19 in need of an HIV test (see clinical child index testing SOP). It is important that the criteria used to determine Index testing, HIV risk factors and HIV testing be harmonized with the recommendations from specific countries' Ministry of Health (MOH) and agreed upon between the clinical and OVC programs and be included in the MOU. The understanding of the mission of the OVC program and the clinical IP is key to creating one comprehensive care team for the child/family and the overall success of both programs and positive outcomes for children and families. Lastly it is essential that both programs understand the concept of "shared confidentiality", inform clients and obtain consent.

What is shared confidentiality? Sometimes, two organizations, such as a health facility and a community implementing partner, may share a clients' personal information in order to provide care. For example, the facility may interview a mother living with HIV to get the name of her children. The facility then shares the name of the mother and children with the community organization who conducts an OVC Needs Assessment and may go out to the patient's home and provide HIV care support. Both the facility and community partner must "share the confidentiality" of the client's information. You as the OVC staff (or program) should have a data sharing agreement which includes a description of how you both will maintain the confidentiality of client information BEFORE beginning services. It is also important to discuss this with the patient/HIV-infected mother, informing him or her that you'll be sharing this info with another partner and why you will share it and obtain informed consent to do so.

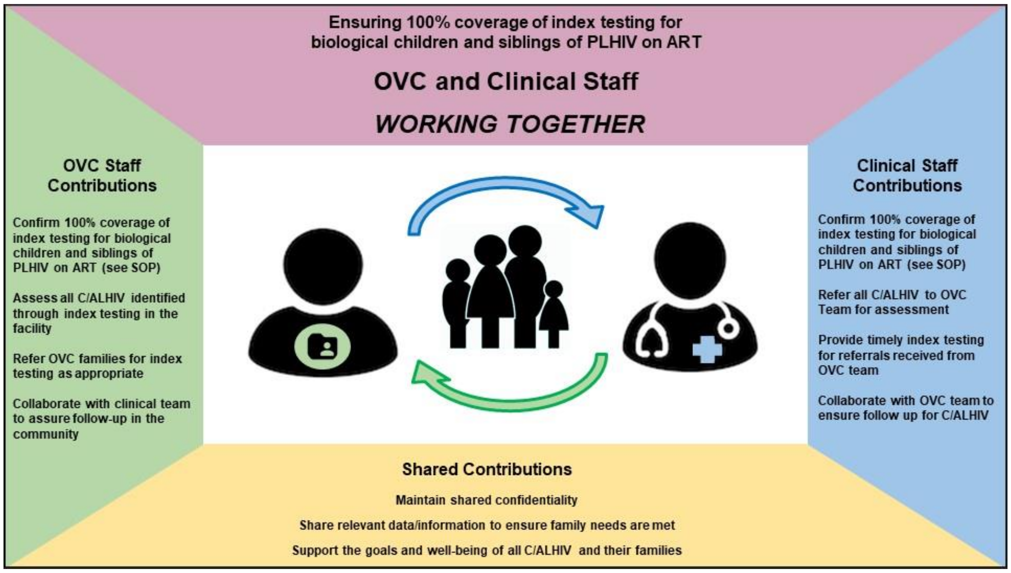
SECTION 2: Rationale

The Orphans and Vulnerable Children (OVC) Program supports infants, children, adolescents, and families across the entirety of the HIV continuum. OVC programs are well positioned to support HIV-exposed infants (HEI), to ensure they receive a documented final outcome at 18-months, and children with unknown HIV status receive testing, and ensure C/ALHIV and their caregivers living with HIV receive access to ART. In COP20, PEPFAR is prioritizing the scale-up of index testing of biological children of mothers living with HIV (and children of biological fathers living with HIV if mother's status is unknown)" and that OVC programs are requested to "employ trained case managers (social workers or para-social workers) to be stationed at highest volume clinics in high HIV burden areas." Therefore, it is expected that OVC programs are supporting this effort by identifying, in health facilities, all HIV-infected biological mothers and fathers living with HIV (if the mother's status is unknown or she is deceased) to ascertain the number of living biological children with unknown HIV status.

OVC staff working in the community also have unique access to biological children that are "well" or asymptomatic living with HIV, who remain undiagnosed, through the work with families within the community. OVC programs can help accelerate the identification of undiagnosed children and adolescents and fast-track linkage to testing and ART services as needed as they work within health facilities and in collaboration with clinical partners and in the community. OVC programs are expected to enroll an increased number of C/ALHIV in need of services through these increased testing efforts to identify C/ALHIV not already identified. OVC will also assist clinical staff in referrals for needed prevention services such as primary prevention, sexual violence prevention interventions and DREAMS for those that are deemed HIV negative but at high risk.

This SOP aims to ensure that OVC partners, in close coordination with clinical, KP and community partners, ensure that all biological children of PLHIV and biological siblings of C/ALHIV currently on ART know their HIV status. By developing efficient bi-directional referral systems between clinical IP, OVC community staff can become well equipped to refer to the health facility for HIV testing and OVC staff working in the health facility can assist in identifying children and adolescents in need of index testing to ensure they are not missed. Furthermore, as OVC staff continue to engage with clients and households in their own communities and within the health facility, OVC programs can leverage this advantage to help track clients in the community, support adherence/retention, and prevent LTFU of clients who do receive positive test results.

As required in COP20 guidance, clinical programs must work closely with OVC programs to ensure robust, bi-directional referral systems are in place for all C/ALHIV and their caregivers/parents/families. Roles and responsibilities of each program (clinical and OVC) should be well defined in mutually agreed upon MOUs to ensure strong collaboration between OVC and clinical IPs at the HF level. These efforts are key to reaching 100% coverage of index testing of biological children and for the identification of C/ALHIV previously undiagnosed.



Ensuring 100% coverage of index testing for biological children and siblings of PLHIV on ART

OVC and Clinical Staff

WORKING TOGETHER

OVC Staff Contributions

Confirm 100% coverage of index testing for biological children and siblings of PLHIV on ART (see SOP)

Assess all C/ALHIV identified through index testing in the facility

Refer OVC families for index testing as appropriate

Collaborate with clinical team to assure follow-up in the community

Clinical Staff Contributions

Confirm 100% coverage of index testing for biological children and siblings of PLHIV on ART (see SOP)

Refer all C/ALHIV to OVC Team for assessment

Provide timely index testing for referrals received from OVC team

Collaborate with OVC team to ensure follow up for C/ALHIV

Shared Contributions

Maintain shared confidentiality

Share relevant data/information to ensure family needs are met

Support the goals and well-being of all C/ALHIV and their families

This document provides a set of standard operating procedures and considerations for OVC programs to follow in their efforts to support health facilities to:

1) Identify all mothers living with HIV and biological fathers living with HIV (if mother's status is unknown or mother is deceased) to ascertain the number of living biological children with unknown status
2) Ensure that children and adolescents who have an unknown HIV status are provided with an HIV test
3) Facilitate linkage of all C/ALHIV to HIV care and treatment
4) Assure all at risk children and families are referred to HIV prevention services
5) Refer all C/ALHIV children and/or HIV affected families in need of social services, GBV, or psychosocial support to the OVC program for assessment.

SECTION 3: Operational Considerations for maximizing coverage of index testing for children and adolescents

Who are we looking for?

- Children and Adolescents (<19 years of age) of mothers living with HIV that have unknown HIV status and have not been screened for HIV testing
- Children and Adolescents of deceased mothers with HIV+ status or unknown status (likely found through their surviving HIV-infected spouse), or of fathers living with HIV where the maternal status is HIV+ or unknown, who have unknown status and have not been identified for HIV testing
- Biological siblings of C/ALHIV who have unknown status and have not been previously tested for HIV
- Adopted children whose biological parents are deceased due to chronic infection or illness

How should children in need of an HIV test be identified?

- Clinical staff should routinely ask parents living with HIV about the number and HIV status of biological children and follow the SOP for index testing
- Clinical staff should routinely ask children and adolescence living with HIV (especially if they are known to be perinatally infected) about siblings and parents' status
- OVC Staff in collaboration with the clinic staff, should engage with health facilities to systematically review clinic records and find those children and adolescents with unknown HIV status. They can also work with clinical staff to identify children in need of testing via the clinical lists of those in need of testing (see Clinical Child Index Testing SOP), including but not limited to HTS registries, index testing logs, patient files, VL testing registries. This should occur regularly and at the least on a monthly basis. Staff should complete the Index Parent Registry (See Appendix) for the following patients.

    1. Women living with HIV with biologically related children who have unknown HIV status
    2. Women living with HIV with incomplete family tree and unknown number of children
    3. Biological fathers living with HIV if mother's status is unknown to ascertain the number of living biological children with unknown status

4. Men living with HIV and family tree unknown (number of children and spouses' status not recorded)
5. C/ALHIV with biological siblings who have not been tested for HIV

When should an HIV test be offered to a child or adolescent?

Remember to develop a plan for interaction (see Appendix for examples of scripts to use during this discussion) with the parent/guardian about HIV testing or with older children/adolescents on testing options (based on country HTS guidelines).

Utilize available disclosure resources, including the New Horizons, Johnson and Johnson, and Elizabeth Glaser Pediatric AIDS Foundation materials in English and French.

After record review:

- If, after a records review, a household is found to meet the criteria above, their next appointment should be flagged for a discussion about getting the child(ren) tested; AND

- If, after a records review, a household is found to meet the criteria above, the clinic- based OVC Staff person, or a community-based OVC Case Worker, could make a home visit and discuss the importance of children getting tested with the parents.

During a clinic or community visit with family (should be done by both clinical and OVC staff)

- HIV test or testing referral should be offered to a child or adolescent when they have an unknown HIV status and meet one of more of the following:
    1. Biological mother is living with HIV
    2. Biological father is living with HIV and mother is deceased and/or status unknown
    3. Biological sibling is C/ALHIV
    4. Biological parents' status is unknown (risk assessment may be appropriate)

    - Refer for Voluntary testing (VTS) and/or community testing referrals for adolescent girls and boys seeking an HIV test (age requirements based on national HTS guidelines)

Types of HIV testing to consider when creating a plan for the child/adolescent

Facility-based testing:

PLHIV can bring their children into the ART clinic for HIV testing at any time. Providing an appointment can improve uptake and follow through if this option is selected by the family. If a child or adolescent tests positive, they can be prepared and initiated straight away. Once the child is tested, the results should be added into the index testing register by the testing provider.

Bring your children to a "be tested day."

This activity is usually done on a weekend to increase access and reduce time away from school for school aged children. Index testing is the focus of this modality and

PLHIV currently on ART are notified of the date and time and asked to bring their children and siblings in for testing on these days. Once the child is tested, the results should be added into the index testing register by the testing provider.

Provider facilitated home-based testing:

Community testing providers can come to the home of the family (by invitation of the index client or parent of C/ALHIV, ensuring consent of the parent and/or adolescent is obtained) to have their children or siblings tested. If any test positive, the child or adolescent should be escorted to the facility to initiate ART. If same day referral is not agreeable to the family, a date and time for escorting should be arranged to ensure linkages for ART initiation. All testing results should be added into the index testing register. Either the community testing provider comes to the facility and directly enters the data, or that the provider shares the index clients' names and those who were tested and their results to the facility testing provider to enter into the index register. Sharing of data between the community and facility providers should be (at a minimum) weekly.

Parent-facilitated home-based testing:

If upon discussion, the indexed client prefers to test at home, but by themselves, HIVST kits may be given to the index client (or parent of the indexed child or adolescent) for testing at home. Careful assessment for intimate partner or family violence should especially be prioritized by the health care worker prior to providing the HIVST kits. If deemed safe, the provider should give careful instructions on how to use the test kits and interpret the results and how to follow up after the testing for post-test counseling. All testing should follow national guidelines.

Community-based testing:

In some countries, there remain some targeted community-based testing locations (such as for PrEP or VMMC or other services that can be offered in the community). If the family prefers to go to one of these community testing sites, the date and time of the next testing date should be identified, and the provider should arrange to escort the family to the testing site on that date. If any test positive, the child or adolescent should be escorted to the facility to initiate ART. If same day referral is not agreeable to the family, a date and time for escorting should be arranged to ensure linkages for ART initiation.

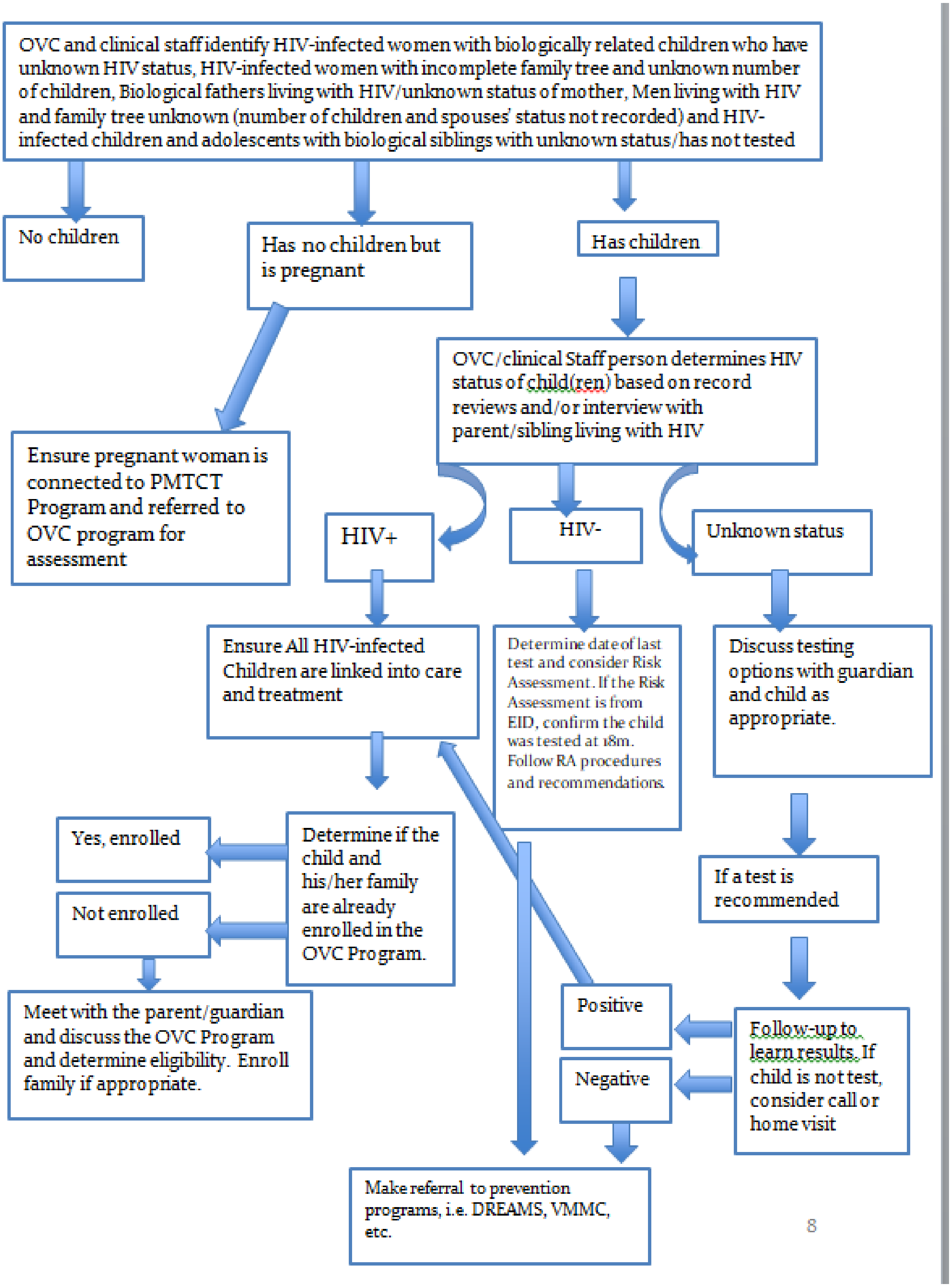
Next steps after HIV referral for testing or HIV results

- If a parent/child misses the testing appointment, OVC staff should work closely with clinical staff to assure there is prompt follow-up and a modified plan is made for testing of child/adolescence. OVC staff may schedule a home-visit and follow-up in the community.
- If the result of the test is negative assure that the following steps take place:
    1. Provide risk assessment and assess need for further testing; schedule HTS appointment
    2. Create prevention plan and provide referrals to prevention resources based on age and gender, including but not limited to DREAMS, VMMC, SRH resources, etc.

- If result of HIV test is positive assure that the following steps take place as appropriate:
    1. Depending on the age of the child, discuss disclosure or provide post-test counseling and education to the child/adolescent and/or parent(s) (See resources above)
    2. All C/ALHIV should be immediately linked for care and treatment program
    3. All C/ALHIV (and families/caregivers) should be referred to OVC program for consideration of enrollment and services
    4. All C/ALHIV should be assessed as index and followed to assure biological parents and siblings with unknown status are offered HIV testing.

Considerations for discussing HIV index testing with parents and/or children/adolescents

- It is important to comply with the country's national HTS guidelines for testing children and adolescents. Follow the country guidelines for age of consent.
- Work closely with the facility team at all stages of the process, communication is crucial for the successful implementation.
- Before making a home visit, ensure that you have the parent's permission and agreement to the visit. (by discussing it with them while they are in the clinic or by making a phone call).
- Gather as much information as you can prior to engaging the family through review of client files and engaging with service providers for the family this allows CM to be prepared with history on the family/child and create a strategy to address index testing for the child and adolescent. (mother refuses testing for child, history of GBV, history of missed appointments, etc.)
- Index testing should be discussed with an HIV-infected parent when they access the health facility, especially clients returning after a period of being LTFU.
- All information gleaned from the records review is to be kept in the strictest of confidence, this includes personally identifiable information, health status and KP status (e.g. sex worker).



OVC and clinical staff identify HIV-infected women with biologically related children who have unknown HIV status, HIV-infected women with incomplete family tree and unknown number of children, Biological fathers living with HIV/unknown status of mother, Men living with HIV and family tree unknown (number of children and spouses' status not recorded) and HIV-infected children and adolescents with biological siblings with unknown status/has not tested

No children

Has no children but is pregnant

Has children

Ensure pregnant woman is connected to PMTCT Program and referred to OVC program for assessment

OVC/clinical Staff person determines HIV status of child(ren) based on record reviews and/or interview with parent/sibling living with HIV

HIV+

HIV-

Unknown status

Ensure All HIV-infected Children are linked into care and treatment

Determine date of last test and consider Risk Assessment. If the Risk Assessment is from EID, confirm the child was tested at 18m. Follow RA procedures and recommendations.

Discuss testing options with guardian and child as appropriate.

Yes, enrolled

Not enrolled

Determine if the child and his/her family are already enrolled in the OVC Program.

If a test is recommended

Meet with the parent/guardian and discuss the OVC Program and determine eligibility. Enroll family if appropriate.

Positive

Negative

Follow-up to learn results. If child is not test, consider call or home visit

Make referral to prevention programs, i.e. DREAMS, VMMC, etc.

Appendices:

I. Issues and Concerns around Confidentiality

Confidentiality = protection of personal information.

- You need to give your client an assurance that what is said will be kept in confidence.
- It is our duty to never reveal the information that clients tell us outside of shared confidentiality with other relevant staff
- The confidentiality of all family members should be kept confidential at all times.

What Personal Identifiable Information (PII) Should Be Kept Confidential?

- Information that would allow others to identify the HIV-infected parent, child and other family members
    - Directly: name, date of birth, address, phone number, etc.
    - Indirectly: sex, geographic location, ethnic group other descriptors, their HIV testing history, HIV test results/diagnosis and treatment plan
- All information shared about during their interview and/or clinical exam, home and clinical visits

How do we maintain the confidentiality of patient and family information?

- ***Safe space:*** It is vital to ensure that the patient to be interviewed has confidence in you and the clinic. Therefore, the discussion/assessment needs to be conducted in a private space and in a low voice. When conducting a home visit assure you speak to a caregiver or child/adolescent in a confidential area. When talking with a client on the phone, please assure that no PII or medical information is discussed, and that client is in a confidential space.
- ***Physically Secure Environment:*** The OVC Needs Assessment information and data should be maintained in a physically secure environment (e.g. locked filing cabinets).
- ***Technologically Secure Environment***: Electronic OVC Needs Assessment data should be held in a technologically secure environment, with the number of data storage and persons permitted access kept to a minimum (e.g. password protected computers).
- ***Individual Responsibility:*** Individual Assessment staff authorized to access case specific information and data are responsible for protecting it (e.g. requiring staff to sign patient confidentiality agreements).

II. Establishing a Memorandum of Understanding (MOU) between the Clinical Partners/Health Facilities and OVC Program

The establishment or updating of MOUs between the OVC program and clinical partner working in the health facility is imperative to ensure that the work will be carried out collaboratively, with quality and confidentiality. An MOU for this work should include at a minimum:

- Confidentiality agreement
- Data sharing agreements to allow confirmation of index elicitation HIV testing, viral load testing and results.
- Detailed procedures for conducting clinical file reviews and other clinical registries
- OVC staff located or on rotation at health facilities and their roles and responsibilities
- Bidirectional referral protocols/pathways, case conferencing, shared confidentiality and joint case identification
- Include coordination with all clinical services (specifically ANC, peds, and adult ART clinics

Note: For detailed guidance on establishing an MOU, see the SOP on establishing an MOU

III. Scripts for use during discussions with parents and older adolescents

TO BE ADDED

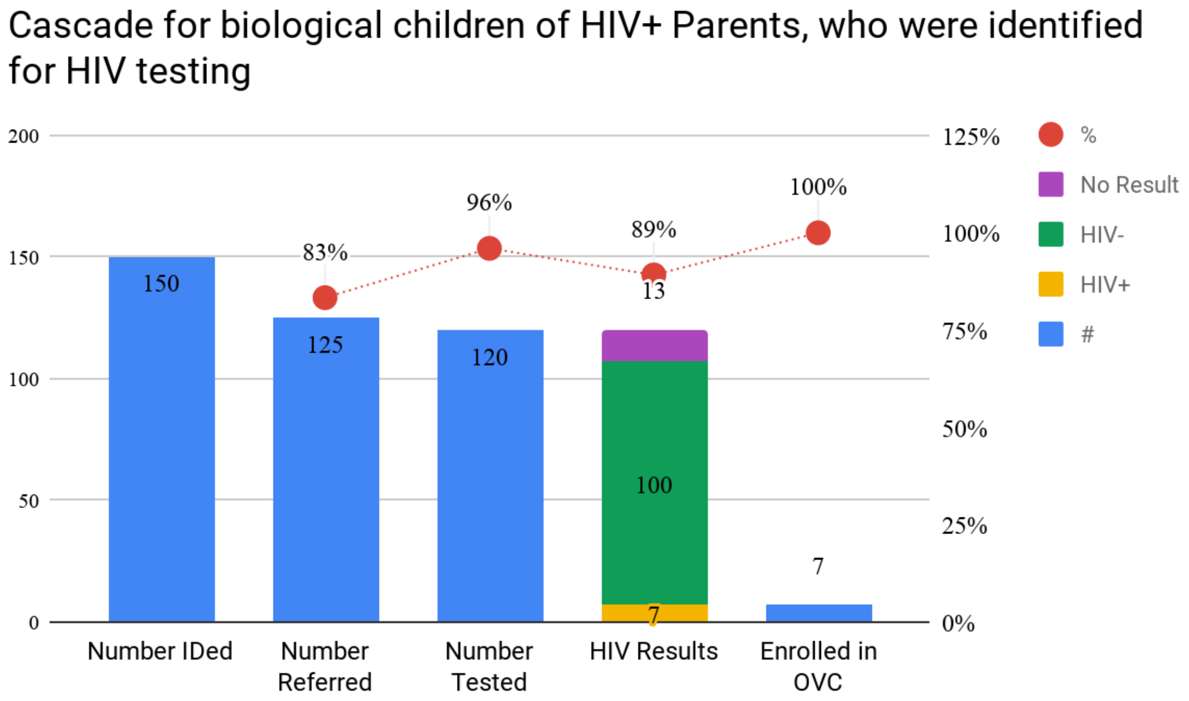
IV. Monitoring and Tracking

What data is needed to monitor this activity? In order to ensure that we are achieving objectives and the goal of this initiative, we will need to answer the following questions:

1. How many records are reviewed for each of the target criteria (HIV+ mothers, HIV+ fathers whose children's mother has died, and siblings of HIV+ children and adolescents)?
2. How many children with unknown HIV Status identified via record review, by age and sex?
3. How many children's parents were approached on the subject of an HIV test for their children?
4. How many children's parents accepted to get child tested?
5. How many children completed referred for HIV testing?
6. How many children are tested for HIV?
7. Of those tested, how many tested positive, how many negative (by age and sex)?
8. Of the total number of HIV+ children and adolescents identified in the facility, how many were enrolled in the OVC Program?

Specific indicators to report on

Indicator	**Numerator**	**Denominator**	**Disaggregates**
NUMID_<19	The number of <19 year olds identified from the records review, or clinical lists, as having an unknown HIV Status	NA	Age Sex
NUMREF_<19	Of those identified for testing, the number who were referred	NUMID_<19	Age Sex
NUMTEST_<19	Of those referred for testing, the number who actually got tested	NUMREF_<19	Age Sex
NUMPOS_<19	Of those who tested, number testing Positive	NUMTEST_<19	Age Sex
NUMNEG_<19	Of those who tested, number testing Negative	NUMTEST_<19	Age Sex
NUMENROL_<19	Of those who test HIV+, number enrolled in OVC program	NUMPOS_<19	Age Sex


Cascade for biological children of HIV+ Parents, who were identified for HIV testing

Who will be responsible for collecting the data needed to answer these questions?

All of the information needed to answer these 8 questions will be collected by the OVC Staff person working in the health facility. Questions 2-8 above, will be collected by the same OVC staff person if the parent/guardian is approached during one of their clinic visits. If, however, the discussion is held at home then the information is gathered by an OVC case care worker responsible for making home visits, which might be the same staff person who conducted the records review or it may be another staff person who is community based. In either case the OVC Staff person working in the health facility (Clinic Community Coordinator) will be responsible for following up with any community-based OVC staff person involved in the process.

The health facility OVC staff person will be responsible for reviewing records and clinic lists of those in need of testing, filling out the ”Index Parent Registry”, and following up on those families/children and adolescents, to record that the identified child/adolescent went for testing, got a result and what that result is. This will require that the in OVC health facility staff person, on a monthly basis, goes back through the files of identified families to gather the follow-up testing information on those children/adolescents referred for testing.

How will this information be gathered and reported?

In order to keep track of identified cases of children in need of an HIV test, a reporting form has been drafted as an example of what will be needed, see Index Parent Registry below. This form allows the OVC Staff person to gather all relevant information about the parent/guardian and the biologic children. It also allows the OVC staff person to centralize the actions taken as well as the results. Here is a link to the PEPFAR Index and Partner Notification Toolkit, for additional ideas.

Once the records of clients needing an HIV test are identified on item 1, the process information will be recorded on a separate tracking sheet; see the example tracking sheet, item 2, on the following pages. The data will be reported to the main office of the Implementing Partner on a monthly basis with the results data being reported on a quarterly basis. The Implementing Partner will enter and store the results in an electronic data base, or an excel spreadsheet, and will report the totals for each monitoring question above on a quarterly basis.

It is important to keep in mind that these results are not going into Datim but will be used to show how our programs are supporting the improvement of facility-based pediatric index testing. Furthermore, the beneficiaries being identified for testing through this process are more than likely to not be already enrolled in the OVC Program. Children and adolescents already enrolled in the OVC Program, with unknown HIV status, will be identified through the OVC Program Risk Assessment Form process and reported via the MER Indicator OVC_HIVSTAT. In the event that this health facility review of patient records does identify a child or adolescent of unknown status who is already enrolled in the OVC program, the linkage to testing should still be made and the facility based OVC staff person should liaise with the Community Case Worker serving that child/family.

Index Parent Registry

Parent information

Name: ____

HTS/ART Clinic Number: ____

Gender: ____**Female** ____**Male**

Number of Children <19 years old: _________________________

Date form completed (dd/mm/yyyy): _______/______/_______/
Location: _________________________
Name of OVC Staff person filling out form: _________________________
Staff person's ID number: _________________________

NAME	**Sex**		**Age**	**HIV STATUS**			**If HIV-, date of last test?**	**If status unknown: Date parent and child agree to go for test**	**Date CW verifies test?**	**If tested what was the result?**		**If HIV+, was child/family referred to OVC Program?**	
	M	F		+	-	UK	DD/MM/YYYY	DD/MM/YYYY	DD/MM/YYYY	+	-	Y	N

Tracking the process

These sheets are set up as examples of what you might want to do in order to keep a summary of who is being tracked on the “Index Parent Registry” on the previous page. They are designed to support the in-clinic OVC Staff person responsible for conducting the records review to keep a monthly and quarterly tally of how many records identify children and adolescents in need of HIV testing (as defined in this SOP), how many biologically related children (<19) of PLHIV and caregivers are identified via the clinical records review, how many of those children agree to get tested, how many children are referred, how many go for testing, and then how many get tested and obtain a result. The final sheet summarizes the test results and should be turned in on a quarterly basis. This last form may require using the “Index Parent Registration” form to go back to the records of the identified parent or sibling to find out the HIV status of the child who was referred for testing.

Tally sheet for Identifying Children <19, to be tested

Clinic Site:

Month:

Quarter:

	Week 1	Week2	Week 3	Week 4	Week 5	Monthly Total
# of Parents and siblings of children with unknown HIV status identified via record review						
HIV+ Mother						
The father of biological children of a mother who died due to HIV, or has an unknown HIV status						
HIV+ biological sibling						

# of children with unknown HIV Status identified via record review						
Female <01 yo						
Male <01 yo						
Female 1-4 yo						
Male 1-4 yo						
Female 5-9 yo						
Male 5-9 yo						
Female 10-14 yo						
Male 10-14 yo						
Female 15-17 yo						
Male 15-17 yo						
Female 18-19 yo						
Male 18-19 yo						

Tally sheet to track Children <19, who were approached, referred and received an HIV test
Site:
Month:
Quarter:

	Week 1	Week2	Week 3	Week 4	Week 5	Monthly Total
# of children/adolescents whose parents were approached and talked with about their child getting an HIV test						

Female <01 yo						
Male <01 yo						
Female 1-4 yo						
Male 1-4 yo						
Female 5-9 yo						
Male 5-9 yo						
Female 10-14 yo						
Male 10-14 yo						
Female 15-17 yo						
Male 15-17 yo						
Female 18-19 yo						
Male 18-19 yo						

# of Children/Adolescents referred for testing							
Female <01 yo							
Male <01 yo							
Female 1-4 yo							
Male 1-4 yo							
Female 5-9 yo							
Male 5-9 yo							
Female 10-14 yo							

Male 10-14 yo							
Female 15-17 yo							
Male 15-17 yo							
Female 18-19 yo							
Male 18-19 yo							
# of Children tested							
Female <01 yo							
Male <01 yo							
Female 1-4 yo							
Male 1-4 yo							
Female 5-9 yo							
Male 5-9 yo							
Female 10-14 yo							
Male 10-14 yo							
Female 15-17 yo							
Male 15-17 yo							
Female 18-19 yo							
Male 18-19 yo							

Keeping track of test results

Site:
Month:
Quarter:

Test Results			
Sex/Age	**HIV +**	**HIV-**	**No Result**
Female <01 yo			
Male <01 yo			
Female 1-4 yo			
Male 1-4 yo			
Female 5-9 yo			
Male 5-9 yo			
Female 10-14 yo			
Male 10-14 yo			
Female 15-17 yo			
Male 15-17 yo			
Female 18-19 yo			
Male 18-19 yo			

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