

GUIDELINES FOR

PAEDIATRIC HIV TESTING AND COUNSELLING

MALAWI

MINISTRY OF HEALTH

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FOREWORD

Malawi has an estimated 83,000 children living with HIV/AIDS. This is an increase of 30% from the estimated 70,000 children infected with the virus in 2004. The ARV program has gained momentum by increasing the number of patients ever started on ARVs from 13,183 patients at the end of 2004 to 82,000 patients by December 2006. However, the number of children ever started on ARVs has not increased appreciably and has remained disproportionately low, constituting only 5-6% of all patients on ARVs. In an environment where children continue to be either born with HIV or infected through breastfeeding despite concerted efforts to scale up the PMTCT program, there is a critical need to increase the number of children enrolled in the ARV program.

ART has substantially changed the face of the HIV epidemic. HIV-infected infants and children are now surviving to adolescence and adulthood in settings where HIV/AIDS and ART programs have been effectively implemented. It has been observed however that one of the barriers to systematically scaling up paediatric HIV treatment programs has been a lack of systematic guidance in the counselling and testing of infants and children.

These *Guidelines on Paediatric HIV Testing and Counselling* complement the Malawi *HIV Counselling and Testing Guidelines* [Ministry of Health 2004]. They inform a procedure and set standards for HIV testing and counselling of infants and children either presenting for treatment and care in health care institutions or voluntarily seeking HIV testing at institutions licensed to provide these services. Early HIV diagnosis is a critical prerequisite and vital entry point for ART and the early treatment of opportunistic infections. These guidelines support the strong HIV/AIDS policies which are the cornerstone of effective HIV programming. Furthermore, these guidelines contribute to the achievement of targets set in the Malawi HIV/AIDS Action framework [2005-2009] and the Malawi Universal Access targets by 2010.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
CBO	Community-Based Organisation
CPT	Cotrimoxazole Preventive Therapy
DNA	Deoxyribonucleic Acid
ELISA	Enzyme-Linked Immunosorbent Assay
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
MOH	Ministry of Health
NGO	Non-Governmental Organisation
PCR	Polymerase Chain Reaction
PMTCT	Prevention of Mother-to-Child Transmission
WHO	World Health Organisation

DEFINITION OF TERMS

Infant: Any child less than 12 months of age

Young Child: Any child between the ages of 1-5 years

School-Age Child: Any child between the ages of 6-12 years

Adolescent: Any child between the ages of 13-18

Disclosure: In the context of paediatric HTC, it is the process of informing a child of his or her HIV status. Additionally, the process of telling trusted family or friends about that child's status is another aspect of disclosure that remains an important aspect of HIV management.

Infected child: A child older than 18 months of age with 2 positive HIV rapid antibody test results, or a child below 18 months of age with one positive virologic test result (e.g. DNA PCR).

Exposed child: A child born to an HIV-infected mother but without a confirmed HIV infection, or a child exposed to infected blood products without confirmed HIV infection.

In the event that a mother's HIV status is unknown, a positive rapid test in a child below 18 months of age confirms HIV exposure, but not HIV infection status.

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GUIDELINES FOR PAEDIATRIC HIV TESTING AND COUNSELLING

1. INTRODUCTION

Diagnosis of HIV in exposed children is an essential part of any national HIV care and treatment strategy. Malawi has implemented a highly effective treatment plan that has steadily increased the number of HIV-infected individuals with access to life-saving Antiretroviral Therapy (ART). The Ministry of Health, in conjunction with development partners, has managed to provide ART to more than 80,000 infected adults over the course of 3 years. Unfortunately, children have been largely overlooked by this scale-up; only 7% of the patients on treatment are children despite the fact that children represent over 14% of HIV-infected individuals in Malawi. In an effort to address this discrepancy, the government of Malawi has made a commitment to increase the number of children accessing ART to 10% and 15% of the national total by the end of 2007 and 2010, respectively. This commitment represents a great opportunity for HIV-infected children in Malawi to access care and treatment.

These guidelines seek to promote the identification of HIV-infected children before they become critically ill and provide guidance on the appropriate referral of HIVinfected children to care and treatment services. They shall help inform policy at all levels with respect to testing and counselling of children. The goal is to provide a document that policy makers as well as healthcare providers at all levels can turn to for guidance on issues relating to pediatric testing and counselling.

Malawi's current testing and counselling guidelines do not adequately address paediatric testing and counselling and its inherent challenges. It is imperative that these gaps and challenges be addressed, particularly as routine diagnostic HIV testing is becoming the standard of care in health care settings.

2. CHALLENGES

2.1. Laboratory Testing

Protocols for HIV testing and counselling in children are separated into two distinct age groups; children at 18 months of age and younger, and those older than 18 months of age. This distinction is necessary because testing children 18 months of age and younger poses a technical challenge that is not present in those older than 18 months of age.

Due to the persistence of maternal antibodies in the bloodstream of infants born to HIV-infected mothers, virologic tests must be done to confirm infection in infants younger than 18 months of age. Although these tests are becoming more widely available in Malawi, the country does not currently have the capacity to implement a nationwide testing strategy utilizing these methods. As such, the use of clinical diagnosis in conjunction with available rapid tests is extremely important in the identification of HIV-infected children below18 months of age.

Presented in this document are several algorithms for symptomatic/clinical diagnosis of HIV infection in children less than 18 months. Maternal antibodies decrease over time, and a significant number of children aged 9-18 months who are HIV *un*infected will have lost their maternal antibodies by this age. Rapid HIV antibody tests can be performed in this age group – A negative rapid antibody test in a 9-18 month-old infant who has not been breastfed in the previous 6 weeks will accurately indicate that the infant is not HIV-infected. A positive rapid antibody test in the same situation may reflect persistent maternal antibodies, and will therefore need further confirmation. This can be done either with immediate DNA PCR or with a repeated antibody test after the child reaches 18 months of age.

Children older than 18 months of age can be accurately diagnosed with HIV infection using the widely available rapid tests provided by the Ministry of Health. The challenges faced in testing these children are due to inadequate access and lack of caregiver consent, rather than suboptimal laboratory capability.

2.2. Treatment Access

Early diagnosis of children infected with HIV has many benefits for the children themselves, as well as for the health system as a whole. The obvious benefit is the opportunity for children to access life-prolonging ART. Early diagnosis and treatment initiation in HIV-infected children markedly reduces their morbidity and mortality. Most children currently receiving ART in Malawi present at a late stage of disease. By the time ART is initiated, their health has already been compromised by multiple infections, chronic disease, stunting, wasting, permanent lung disease and other conditions. Early detection and ART initiation can improve treatment response, result in better clinical outcomes, and reduce the excessive morbidity and mortality.

All HIV-exposed infants and children should receive Cotrimoxazole Preventive Therapy (CPT) until HIV infection can be ruled out. Children who are confirmed as HIV-infected should receive CPT, regardless of their disease stage. Studies from resource-constrained settings have shown that universal CPT can reduce morbidity and mortality by up to 40% in HIV infected children. Thus, early identification of HIV-infected children in conjunction with universal CPT for HIV-exposed children can significantly improve the lives of HIV infected children in Malawi.

2.3. Consent to HIV Testing

There is often tension between the rights of the child and those of the parents or guardian. According to the Convention on the Rights of the Child, all children have a right to health. From this right, it can be extrapolated that all children have a right to know their HIV status if that knowledge will improve their health. It is well established that if a child is diagnosed with HIV and accesses care, their likelihood of death or illness is markedly reduced. At the same time, the argument is often made

that a parent possesses an inalienable right to determine his/her child's fate. It is these divergent opinions that pose a challenge in paediatric HIV care and treatment.

According to Malawian law, a child less than 12 years of age can only be tested if that child's parents or guardian gives consent. Some parents/guardians of children below 12 years may refuse to give consent. In the absence of a parent or guardian, a clinician can give consent on behalf of the parent or guardian for testing children 12 years and under for the purposes of medical management.

3. PURPOSE OF THE GUIDELINES

The purpose of these guidelines is to set standards and describe the process of HIV testing and counselling for infants and children seeking:

- Medical treatment in health care institutions
- Voluntary HIV testing and counselling in either health care institutions or other institutions providing such services
- Other services within Malawi's national healthcare system

4. GUIDING PRINCIPLES

These guidelines are informed by six principles:

4.1. **Right to Testing and Care**

All children, irrespective of the status of their health, have a right to be tested for HIV either in a health care setting where diagnostic and routine testing is being offered or in non-health care settings where voluntary HIV testing and counselling is licensed.

All infected children have a right to access HIV care and treatment wherever ART services are offered.

4.2. Consent for HIV Testing

Consent for children can be a controversial issue centering on the age at which a child should be considered capable of reaching his or her own decisions regarding his/her health:

- Children aged 12 years and below need consent for HIV testing from parents or guardians/care giver.
- In the absence of a parent or guardian/caregiver, a clinician can give consent on behalf of the parent or guardian/caregiver to test children aged less than 12 years for the purposes of medical management.
- Any young person 12 years and below who is married, pregnant or engaged in risky behaviour should be considered a mature minor and be eligible to give consent for HIV testing and counselling.
- Children aged 13 years or over shall be entitled to access HIV Testing and counselling without the consent of a parent or guardian.

• These rights must be widely publicized and made these rights made known to children through the establishment of youth-friendly centres and youth-centred services.

4.3. Right to age-appropriate HIV Counselling

The process of counselling children is very different from that of adults. The crucial points regarding counselling of children are highlighted in the appropriate sections of these guidelines.

- All children considered for HIV testing have a right to age-appropriate HIV counselling.
- For young children unable to understand HIV/AIDS knowledge, the client for HIV education, pre-test counselling and post-test counselling should be the parents or guardians.
- Children able to give consent and able to cognitively comprehend HIV/AIDS knowledge should be given age-appropriate HIV knowledge, pre-test and post-test counselling on their own or in the company of their parents or guardians.

4.4. Disclosure of HIV Status to Children

Disclosure, or telling the child that he/she is HIV-positive, should be regarded as a **process**, not an **event**. Information can be provided piece by piece so as to not overwhelm the child. Disclosure is a process that should take place as early as possible in an age-appropriate manner, beginning in children as young as 6 years of age. A good indicator for starting disclosure process is when a child starts to ask questions about his/her treatment, e.g. "why do I have to take this medicine?"

4.5. Right to Confidentiality

Any information related to a patient's medical condition must be kept confidential. A child's HIV status can only be shared with that child's parents or guardian and the medical team caring for that child; With respect to any other medical information pertinent to a child, established confidentiality laws must be adhered to.

4.6. Sensitization and Training.

All personnel providing HIV testing and counselling to children in health care and non-health care settings need to receive appropriate training in the skills and techniques needed for working with children and their families.

5. PAEDIATRIC TESTING IN HEALTH CARE SETTINGS

5.1. Diagnostic HIV Testing and Counselling

Diagnostic testing and counselling is considered part of the clinical management of patients who present with HIV-related illnesses. Diagnosis of HIV in such patients allows them to receive appropriate care and treatment.

Children displaying any of the following signs or symptoms suggestive of HIV-related illness should be tested for HIV:

- Failure to thrive
- Loss of developmental milestones
- Recurrent pneumonia
- Oral thrush
- History of greater than 2 hospitalizations within 5 years
- Pulmonary tuberculosis
- Herpes zoster
- Persistent or recurrent fever
- Hepatosplenomegaly
- Chronic parotitis
- Severe bacterial infection
- Kaposi's sarcoma
- Chronic cough
- Chronic dermatitis

5.2. Routine HIV Testing and Counselling

Routine testing is one which is offered as a routine component of care in certain health care settings. Upon coming into contact with the health system in such settings, clients are informed that an HIV test is part of their routine care and will be done unless they choose to opt-out of such a test.

In order to identify as many HIV-infected children as possible and provide them with care and treatment, the following children should be **ROUTINELY OFFERED HIV TESTING**:

Any child who is:

- An inpatient in a hospital or clinic
- A victim of sexual abuse
- Accessing care at Community Therapeutic Centers (CTCs)
- Born to HIV-positive parents or whose parents have died from suspected HIV-related causes
- A sibling of an HIV-exposed child or sibling of child who has recently died from suspected HIV-related causes
- Exposed to HIV through blood transfusion
- Pregnant

The process of routine HIV testing and counselling includes the following components:

PRE-TEST COUNSELLING: Group information and education about HIV infection should be given to children (when possible) or to parents and guardians/care givers to ensure informed consent. If the volume of patients is small, similar information and education can be provided through family/couple pre-test counselling.

TESTING: The child should be offered testing following counselling. Parents, guardians or caregivers who have informed the health care staff that their child is not to be tested should have their wishes respected.

However, in cases where knowledge of a child's HIV status is necessary for the purposes of medical management and a guardian is not present, a child below 12 years of age can be tested for HIV.

POST-TEST COUNSELLING: Post-test counselling and appropriate referral to services for infected children must be made in the case of a positive test result.

TESTING OF FAMILY MEMBERS. If a child is found to be HIV-infected, their parents and siblings should be strongly encouraged to test as there is a high probability that one or more of them is also infected.

HIV-infected children should be linked to care and treatment services immediately.

When testing children, the family context should always be considered: All untested caregivers, siblings, or cousins should be offered testing.

5.3. Testing Children 18 Months of Age and Under

5.3.1. Maternal HIV Status Positive

Any infant born to an HIV-infected mother is considered HIV-exposed and is therefore at high risk for HIV infection. All exposed infants must have a clinical evaluation. This should be done at 6 weeks of age to coincide with the routine first post-natal visit. National vaccination coverage is more than 80% in the first year of life, and therefore the 6-week infant vaccination visit represents an ideal opportunity to screen children for HIV, provide guidance on feeding issues, and clinically stage those with suspected or confirmed infection. Where DNA PCR is available, exposed infants must be tested with DNA PCR at the 6-week vaccination visit, or as early as possible.

All newborn infants should receive health passports at birth. The health passport of the newborn should be stamped with a standard government-issued stamp which notes the HIV exposure status of the newborn. This stamp also includes information about Polio and BCG vaccination status, as these are vaccines given at birth. When

the exposed infant attends the under-5 clinic for his/her 6-week visit, the clinician should prescribe Cotrimoxazole Preventive Therapy (CPT) and counsel the caregiver on when to return for follow-up care.

It is critical that all HIV-exposed infants and HIV-infected children receive CPT. This lowers their likelihood of sickness and/or death, and helps delay initiation of ARV therapy as the child's health is maintained

Testing infants aged 6 weeks to 9 months

Perform a DNA PCR test where available (See Appendix I):

- If **positive**, the infant is infected.
- Stage the infant clinically, start CPT and refer to ART clinic.
- If HIV DNA PCR is **negative** and the infant is not breastfeeding (and has not done so for more than 6 weeks), the infant is HIV negative.
- Discontinue CPT.
- If HIV DNA PCR is **negative and the infant is still breastfeeding**, repeat the PCR test 6 weeks or more after breastfeeding cessation.
- If HIV DNA PCR is **indeterminate**, report as indeterminate and request a 2nd specimen for testing.

If HIV DNA PCR is not available (see Appendix II):

- Start CPT with monthly follow-up.
- See algorithm below for presumptive diagnosis of severe immunosuppression in HIV-exposed infants.
- Retest with rapid antibody test after 9 months of age.
- If **positive**, repeat antibody testing at 18 months of age or later to confirm.
- If **negative** and the infant has not breastfed in previous 6 weeks, the infant is HIV-negative. Discontinue CPT.
- If **negative and the infant is still breastfeeding**, repeat the rapid test 6 weeks or more after breastfeeding cessation.

Infant aged 9 months to 18 months (see Appendix III)

Perform a rapid HIV antibody test

- If **positive**, virologic testing should be performed for confirmation, if available.
- If HIV DNA PCR is not available, do HIV antibody testing at 18 months of age or later to confirm.
- Continue CPT until HIV infection has been ruled out.

- If **negative** and the infant has not been breastfed in the previous 6 weeks, then the patient is not infected and unless there is ongoing exposure through breast milk, the child can be assumed to be uninfected.
- Discontinue CPT.
- If **negative and the infant is still breastfeeding**, repeat the test 6 weeks or more after breastfeeding cessation.
- Continue CPT until infection has been ruled out.

Children 18 months and above (See Appendix IV)

Perform an antibody test.

- If **positive**, patient is infected
- Start CPT.
- Stage clinically, refer to ART clinic.
- If **negative** and child is no longer exposed (e.g. breastfeeding), patient can be assumed to be, patient uninfected.
- Discontinue CPT.
- If **negative and the infant is still breastfeeding**, repeat the test 6 weeks or more after breastfeeding cessation.
- Continue CPT until infection has been ruled out.

5.3.2. Maternal HIV Status Negative

We must recall that although most children become HIV-infected through vertical transmission, there are other modes of transmission. In these cases, a mother may be HIV-negative and her child may be HIV-positive.

If an HIV-negative mother presents with her child who has suspected exposure or suspected HIV disease, do the following:

- Try to identify potential source of exposure (i.e. blood transfusion, sexual assault, traditional cutting etc.)
- If source of exposure is identified and exposure has occurred within 72 hours, follow national Post-Exposure Prophylaxis (PEP) guidelines and start AZT/3TC for post-exposure prophylaxis for 30 days. Then retest 6 weeks after exposure.
- If source of exposure is not identified or exposure has happened greater than 3 days prior to presentation, do the following:

Birth to 9 months

Perform a rapid antibody test immediately.

- If **positive**, child is exposed and was likely exposed prior to exposure in question.
- Perform virologic test 6 weeks after presumed exposure if available.
- Start CPT pending results of virologic test.

- If virologic test not available, follow algorithm for exposed infants outlined above (see Appendices I & II), and repeat rapid test in six weeks.
- If **negative**, child is unexposed and virologic test should be done to confirm absence of infection.

Older than 9 months

Perform a rapid antibody test immediately.

- If **positive**, child is exposed.
- Start CPT.
- Perform virologic test to confirm determine infection.
- If virologic test not available follow algorithm for exposed children outlined above (see Appendices III & IV).
- If **negative**, child is uninfected.
- Repeat test 6 weeks later to confirm absence of infection.

5.3.3. Maternal HIV <u>Status Unknown (See Appendix V)</u>

If maternal status is unknown, an HIV antibody test should be done on the infant in order to determine exposure.

- If antibody test is **positive**, the infant is HIV-exposed and clinicians must follow same algorithm for children with known exposure.
- If antibody test is **negative**, assume mother is not HIV-infected and child is not HIV-exposed (unless there is suspicion of another mode of exposure such as history of blood transfusion.)

5.4. Testing Children Above 18 Months of Age

Children above 18 months of age can be tested using the same antibody tests and algorithms which are used to test adults.

5.5. Presumptive Clinical Diagnosis of Severe HIV Disease

For children less than 18 months of age who do not have access to virologic testing, the WHO has established a system of clinical criteria for initiation of ART in the absence of confirmed infection in HIV-exposed children (see box below). This allows severely immuno-compromised children younger than 18 months to be started on ART.

A presumptive diagnosis of severe HIV disease can be made if: An infant is confirmed HIV antibody positive and Diagnosis of any AIDS indicator (WHO Stage IV) condition can be made or 2 or more episodes of at least one the following is present: Oral thrush Sepsis Severe Pneumonia Other factors which support the diagnosis of severe HIV disease in an HIV-exposed infant are: Recent HIV-related maternal death Advanced maternal HIV-disease Infant CD4% < 20%Children meeting the above criteria should be urgently referred to the nearest ART clinic for prompt evaluation and possible initiation of ART. Confirmation of the diagnosis should be sought as soon as possible.

Special Testing Circumstances

5.5.1. Children below 6 weeks of age

Children presenting for an HIV test before 6 weeks of age should be tested with DNA PCR if available, or at minimum they should receive a rapid HIV test and have a clinical evaluation. No child should be turned away from HIV testing due to young age. If the child is deemed to be severely immuno-suppressed on clinical grounds, then that child is eligible for referral for ART. Babies presenting for screening prior to 6 weeks are usually doing so because either their families or their healthcare providers have concerns about their wellbeing.

5.5.2. When should a child who tests negative for HIV be re-tested?

Ongoing exposures

Re-testing for HIV infection should be done whenever new HIV exposure has occurred. This includes:

- Babies who are being breastfed by an HIV-positive individual (infant re-tested for the HIV virus 6 weeks after complete breastfeeding cessation).
- Individuals with other types of potential HIV exposure including:
 - Sexual contact.
 - o Tattoos, body piercing or scarification.
 - Potentially contaminated medical (including traditional medicine) exposure.
 - Sharing potentially blood-contaminated instruments (razors, syringes etc.) with HIV-positive individuals.

Illness and Failure to thrive

If a child tests negative for HIV and no other cause of illness or failure to thrive is identified in the screening clinic, the child should be referred to a paediatric specialist for further evaluation and possible re-testing.

5.5.3. Single Negative Virologic Test Result

The following provides guidance on how to interpret a negative virologic test result where such testing is available.

Due to the high sensitivity and the relatively high cost of the test, only one negative DNA PCR result is needed to rule out HIV infection – a repeat DNA PCR is not recommended. Babies with repeated exposures or with illnesses and failure to thrive may undergo repeat DNA PCR testing at the discretion of the evaluating clinician. In settings where DNA PCR is routinely available, an antibody-based test (rapid-test or ELISA) can be done for confirmation of HIV negativity at or after 18 months of age. Therefore, a follow-up visit at 18 months should be encouraged for exposed infants with a single negative DNA PCR result.

5.5.4. When should a child testing positive for HIV be re-tested?

False Positives

False positive HIV tests are rare but do sometimes occur. In the case where a clinician suspects a false positive result repeat rapid tests may be performed.

Discordant Clinical Picture

Although approximately 25% of children are long-term non-progressors, any child with long-standing HIV infection, who maintains excellent CD4 counts and remains in WHO Stage I for a period greater than 5 years, can justifiably be retested to verify HIV status.

6. PAEDIATRIC TESTING IN NON-HEALTH CARE SETTINGS

6.1. Voluntary HIV Testing and Counselling with NGOs/CBOs

Children and their parents and guardians/care givers can voluntarily seek HIV testing and counselling with NGOs or CBOs certified to provide HIV Testing and Counselling. Such provision of HIV testing for children should follow the guiding principles as mentioned in section 5. In addition to adhering to these principles, it is essential that the following be observed.

6.1.1. Child -friendly environment.

The NGO/CBO should provide a safe setting where children feel comfortable.

6.1.2. HIV testing for both parents/care giver and children.

Parents, guardians, or care givers who bring their children for testing are encouraged to be counselled and tested for HIV as well. Siblings of those children who test positive should be offered testing and counselling as well.

6.1.3. HIV testing should be in the best interests of the child.

Counsellors should carefully assess situations where parent, guardians/care givers refuse testing and insist that their children be tested. Counsellors should ensure that in such circumstances the testing for the child is in the best interests of the child.

6.1.4. Sensitization to the conventions on the rights of children

Certified counsellors providing HIV testing and counselling should be sensitized to all the rights of children as specified in the United Nations conventions on the rights of children.

6.1.5. Referral for HIV-positive children.

All HIV-positive children should be referred with immediate effect to health care institutions for clinical assessment and management.

The same rapid HIV tests and testing algorithm used for testing adults should be used for testing children above 18 months of age.

As NGOs/CBOs licensed to provide HIV testing and counselling are often accessed by voluntary clients or by clients referred from other community based organizations; counsellors in these institutions should always encourage testing for the following categories of children:

- All children of HIV-positive parents.
- All children that are siblings of an HIV-positive child.
- All children exposed to HIV through sexual activity, sexual abuse or assault.
- All children exposed to HIV through transfusion with unsafe blood or through use of un-sterilized needles.

- All children exposed to HIV through the use of contaminated traditional medical instruments (such as those used in scarification or other procedures).
- Any child who is pregnant.

7. PAEDIATRIC HIV COUNSELLING

7.1. General Counselling Protocol

7.1.1. Pre-Test Counselling

When performing an HIV test on a child who is unable to consent to testing, the index client for counselling is the parent/parents or guardian/care giver. The following should be covered during pre-test counselling:

- Explain the purpose of the session and the rationale for testing the child.
- HIV testing is a standard part of the patient's medical care.
- The clinical benefits that can be derived from knowing one's status associated with early diagnosis of HIV.
- The benefits of HIV prevention and psychosocial support for those who test positive.
- Explain confidentiality Confidentiality of the child's HIV test results must be assured.
- Assess with parents/guardians the emotional maturity of the child. This assessment should guide how much and what information can be shared with the child, or how and when the child could be involved in the counselling process.
- Assess generic knowledge of HIV/AIDS prevention and transmission. Provide information where necessary.
- Assess the risk for HIV infection.
- If the risk is through vertical transmission, establish if parents have been tested before. If parents have not been tested before, encourage parents to be tested together with the child.
- Obtain consent for HIV testing.
- Explain the testing procedure and the type of test that will be used.
- Perform the HIV test using the approved testing algorithm.

7.1.2. Post-Test Counselling

Post-test Counselling with positive results

- Disclose the results to the parents/guardians. Explain what the results mean.
- Help the clients cope with emotions arising from the test results.
- Discuss implications of the results to the family unit.

- Discuss disclosure of HIV test results.
- Advantages and disadvantages for the child to know the results.
- How the results will be disclosed to the child.
- The most appropriate age for results to be disclosed.
- Provide or refer for appropriate clinical management and care.
- Provide relevant additional information including good nutrition and use of insecticide-treated bed nets.
- Discuss risk reduction as appropriate.
- Explore and support additional HIV testing needs of other family members or siblings.
- Refer as appropriate.

Post-test Counselling with negative results

- Disclose the results to the parents/guardians. Explain what the results mean.
- Discuss window period and the need for retesting if applicable (e.g. breastfeeding).
- Discuss risk reduction as appropriate.
- Provide appropriate clinical management and care.
- Explore and support additional HIV testing needs of other family members or siblings, particularly in instances where one of the parents is known to be HIV infected.

8. SPECIFIC COUNSELLING ISSUES

8.1. Consent

8.1.1. Children 12 years of age and below

Children younger than 10 years of age must have the consent of a parent or guardian prior to being tested for HIV. This consent can be verbal.

There are two notable exceptions to this rule:

- Children who have been the victim of sexual assault
- Hospitalized children without parents or guardians

In the case of a victim of sexual abuse, since the abuser may very well be the parent or guardian, consent is not needed to conduct an HIV test. In this case, the best interest of the child and the obvious benefits of post-exposure prophylaxis are paramount. Protecting that child from their abuser must be the top priority regardless of the abusers relationship to that child.

For the hospitalized child, in the absence of a parent or guardian a clinician can make the decision to test a child if knowledge of HIV infection will significantly impact the treatment course of that child. Children 12 years of age and below can not give consent for an HIV test unless they are engaged in activities that classify them as mature minors. To classify as mature minors they must meet one of the following criteria:

- Married
- Pregnant
- Engaged in risky behavior

If they do classify as mature minors, then a clinician can conduct an HIV test without parental or guardian consent. In such cases, the procedure outlined in the next section should be adhered to.

8.1.2. Children older than 12 years

Although these guidelines state that children older than 12 years of age can be tested solely with child's consent, a health provider is obliged to thoroughly assess the reasons why a child wants to test without knowledge of a parent or guardian. While doing so, it is important to recognize the child's right to HIV testing and to remind the child on the advantages of informing his/her parents or guardians/care giver.

The health provider must:

- Obtain a thorough social history, focusing on the reasons why a child wants to be tested without knowledge of a parent or guardian. As it is the child's right to do so, so do not insist the child informs the parent or guardian.
- With respect and sensitivity, inquire as to why the child believes he/she may be infected with HIV.
- Determine whether the child understands what HIV is and how it affects his/her body.
- Determine if there is a history of sexual abuse, and then refer to appropriate counselling and legal services.
- Ask the child what he/she will do in the event that the test is positive.
- Ensure that if the child expresses any suicidal thoughts or plans, **DO NOT TEST.**
- Ask the child if there is anyone they can share the results with.

Once these questions or issues have been addressed, the clinician can test the child. The results should be revealed during post-test counselling in the same manner as they would for an adult. Whenever possible, referrals for positive test results should be made to ART sites which are caring for and treating children.

8.2. Disclosure

During the post-test counselling, if the results are positive, the counsellor should discuss with the parents or care giver **how** and **when** they would like to disclose to the child. Disclosure is a process rather than an event, **planned jointly** by the counsellor, health care team and parents or caregivers. The planning process will determine who leads the disclosure process; whoever leads the process will need support from either the health care team/counsellor or care provider.

8.3. Disclosure of HIV Status to Children

Disclosure should not be left until a very late age, as children are more likely to find out from other sources than the caregiver or healthcare provider.

The most important partner in the disclosure process is the family. Children are dependent on their parents or caregiver and other family members not only for their healthcare need but also for their social development.

Disclosing the child's status to the child and other family members has several benefits:

- Disclosure provides children with a sense of control over their lives and allows them to participate in their own health care. Children who have been told their status have shown to have greater adherence to antiretroviral therapy than children who are not disclosed to.
- The child is more likely to receive the physical and social support he/she needs.
- The most appropriate age for disclosure differs among children and is determined separately for each child through an assessment of their emotional and cognitive levels, and family support.
- While it is usually good for children to disclose their status to a few trusted family members and friends, wider disclosure to the community is not generally beneficial. Children should be counselled to talk to their caregiver before disclosing to any other individuals.

8.3.1. A General Guideline for Disclosure by Age.

Because disclosure should be considered as a process rather than as a specific event, this means there is always age-appropriate information to be provide to a child about their chronic illness.

Young children [2-5 Years old]

Young children should be given simple information in **language they understand**. They should learn the nature of their illness, and how they can care for themselves. Health care providers should focus on the **near future** aspects of their lives, and not emphasize diagnosis and prognosis.

Children should be given enough information to know that they have a chronic illness, and that they can stay healthy by taking their medicine the way the doctor tells them to. The words "HIV" and "AIDS" should not be used.

Additional advice for counselling children includes not rushing in with too much information, following the child's lead, allowing for their questions and reaction time, and taking the time to listen to them. Use questions such as "Can you tell me why you take medicines" and "what can you do to help your (caregiver) remember to give you your medicine?" to lead into discussion with a child.

School-age children [6-12 Years old]

Full disclosure to school-age children is strongly recommended.

Disclosure should be discussed and planned with the caregivers, and all healthcare providers should be included, as well as the caregivers and the child. Children's understanding should be carefully assessed so that the information provided will be more specific.

Children will also need help in developing coping responses, in learning what they can tell others, and who they can in turn disclose to.

Information to be included when disclosing to school-age children include the role of treatment, the difference between HIV and AIDS, route of transmission, and living positively.

Adolescents [13 – 18 Years old]

Adolescents are a special population, as they are making the transition from childhood to adulthood. They are undergoing physical and emotional changes, and beginning sexual exploration. In addition, peer support becomes a greater part of their lives, and can lead to both positive and negative results. At this point in a child's life, guidance on the part of caregivers and healthcare providers can lead to more positive outcomes.

Adolescents can learn to become more responsible for their own care by being trusted more with their medication adherence, by being encouraged to play an active role in their healthcare, and by discussing their concerns directly with the physician. Because adolescents are more likely to engage in risky behavior, it is important that they be educated on important issues such as safe sex and medication interactions with alcohol. They should also be counselled on disclosing their status to potential sexual partners.

All adolescents need SUPPORT and EDUCATION !!

8.3.2. What to tell the child during the disclosure process:

Over a period of time, the following information can be given to the child as they become psychologically and emotionally ready to cope with it. At each step, and at each visit, healthcare providers should continually encourage children and give positive messages.

First steps:

- Know that you take your medicines to stay healthy
- Know when you take your medicines
- Know how you take your medicines
- Know the names of your medicines
- Know that treatment is not a cure and medication must be taken for life

Second steps:

- Know that your medicines make you healthy by increasing the "soldiers of the body"
- Recognize that your health problems are less or will be less because you have more soldiers and they are stronger

• Know that as long as your soldiers are strong, you can do whatever you want in life

Final steps:

- Know that your soldiers became weak because something was attacking them ("chirombo/chibungu")
- Learn the proper names for CD4 cells & HIV
- Dispel misconceptions or myths
- Stress positive messages and positive living

It should also be emphasized that healthcare providers and caregivers should **always tell the truth** when children ask questions. The terminology used above can provide ways to express the truth in ways that the child can understand and cope with, but **the child should never be lied to**.

9. MONITORING AND EVALUATION

Monitoring and evaluation of pediatric HTC is critical for monitoring 1) the characteristics of pediatric clients and patients seeking HTC, 2) the prevalence rates among children being tested, and 3) referrals and linkages made among pediatric HTC clients. Monitoring and evaluation includes routine monitoring of HTC clients and services on an ongoing basis as well as operations research or special studies to answer specific questions of programmatic importance.

Pediatric HTC will be monitored by the Ministry of Health within the context of overall monitoring and evaluation of HTC scale-up. Rather than developing/using separate M&E tools for pediatric HTC, existing HTC monitoring tools will be used and/or modified so that critical information on pediatric HTC can be collected, aggregated, and utilized by HTC sites.

All providers of Pediatric HTC should use the recommended national standardized tools and indicators developed by MOH. The HTC register and reporting form may be modified over time to allow for better monitoring of pediatric HTC.

The following indicators will be used for routine monitoring of the pediatric component of the HTC program.

Indicators

- Number of children 0-9 months who are HIV tested and receive results
- Number of children 9-18 months who are HIV tested and receive results
- Number of children 18 months-14 years who are HIV tested and receive their results
- Number of children 0-9 months who test HIV positive
- Number of children 9-18 months who test positive
- Number of children 18 months-14 years who test HIV-positive
- Number of children testing HIV-positive who are referred for services

Monitoring Tools

As is the current practice, each HTC site will maintain its own HTC register. The HTC register includes the following information which will be used for routine monitoring:

- Age
- Sex
- Previous HIV test
- Current HIV Test Result
- Referrals made

Quarterly Reporting

Monitoring may be done manually and/or electronically. As is the case with monitoring for the overall HTC program, monitoring of pediatric HTC will be done every quarter. In the month following the end of one quarter, the monitoring forms will be completed. For example, for the quarter 1st January to 31st March, the monitoring forms will be completed in April.

A standard reporting form for HTC services developed by MOH will be used at all HTC sites. This form will contain a subsection for pediatric HTC within the overall form. The HIV counsellor in charge of the HTC site will be responsible for completion of this form. Details will be checked during supervisory visits.

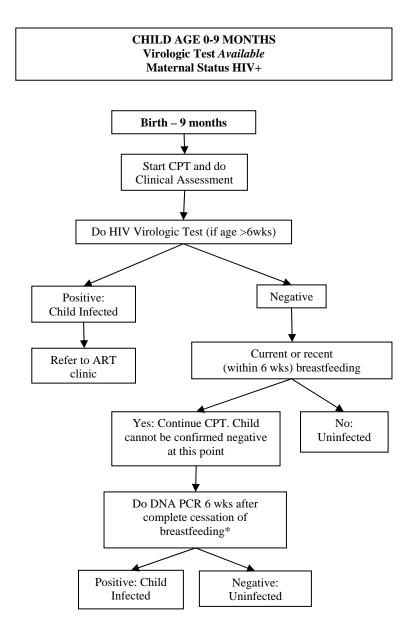
This information is used for quarterly and annual reports. It allows for site-level and national monitoring of uptake of HTC by children. It also enables the monitoring of referrals and linkages between pediatric HTC and pediatric care and treatment.

Evaluation and Operations Research

Operational research will be conducted as part of M&E activities where and when necessary to get insight on specific issues related to pediatric HTC. This may involve additional analyses on data already included in the HTC registers (e.g. further analysis of data by sex or age categories) and/or collection and analysis of additional data which cannot be collected through the clinical and administrative management process, using special studies (quality of counselling, client satisfaction, assessment of client provider interaction).

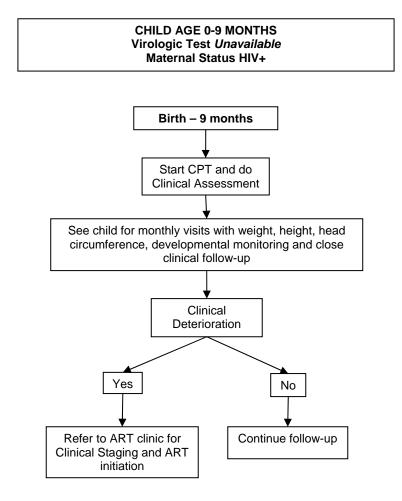
10. APPENDICES

APPENDIX I. TESTING ALGORITHM: 0-9 MONTHS, VIROLOGIC TESTING AVAILABLE

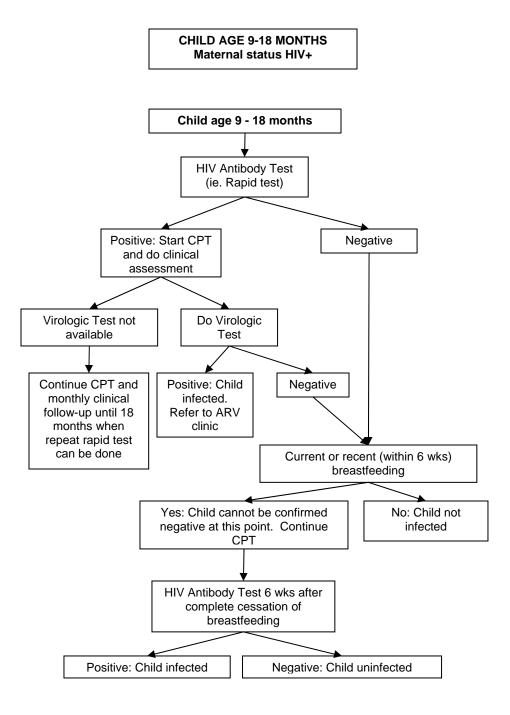


* If child is older than 9 months at weaning, use antibody test instead of DNA PCR

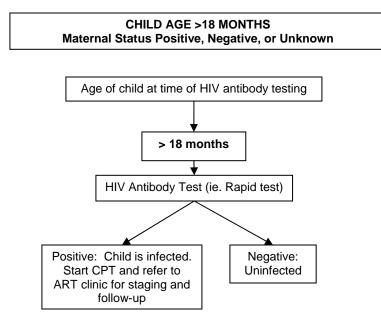
Appendix II. Testing Algorithm: 0-9 Months, Virologic Testing Unavailable



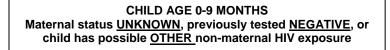
APPENDIX III. TESTING ALGORITHM: 9-18 MONTHS

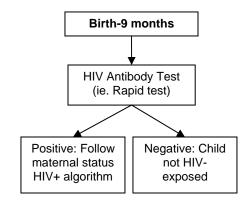


APPENDIX IV. TESTING ALGORITHM: >18 MONTHS



APPENDIX V. TESTING ALGORITHM: 0-9 MONTHS, MOTHER'S STATUS UNKNOWN





11. REFERENCES & RESOURCES

- 1. National HIV/AIDS Policy [2003]. Government of Malawi. Office of the President and Cabinet, National AIDS Commission.
- 2. Treatment of AIDS Guidelines for the Use of Antiretroviral Therapy in Malawi [2006]. Ministry of Health, Malawi.
- 3. HIV/AIDS Counselling and Testing Guidelines for Malawi [2004]. Ministry of Health, Malawi.
- 4. Malawi HIV and AIDS National Action Framework [NAF] 2005-2009 [2005]. Office of the President and Cabinet, National AIDS Commission.
- 5. HIV Testing and Counselling [HTC] The Five Year Plan To Scale Up HIV Testing and Counselling Services in Malawi 2006-2010. [2006]. Ministry of Health, Malawi.
- 6. HIV Curriculum for the Health Professional. Baylor-Abbott Children's Clinical Centre of Excellence: 01-750-877.
- 7. Pediatric CPT and ARV dosing chart (pamphlet). Baylor-Abbott Children's Clinical Centre of Excellence: 01-750-877.
