

# Module 5

## Post-test Counselling for Infant HIV Testing



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# Module 5, Part 1: Trainer Guide



**Total Module Time: 245 minutes (4 hours, 5 minutes)**

## Overview for the Trainer

### Session 5.1: HIV-negative Test Result, Post-test Counselling Session

Activity/Method	Time
Interactive trainer presentation and large group discussion	35 minutes
Exercise 1: HIV-negative test result, post-test counselling: Role play followed by practice in pairs	70 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>110 minutes</b>

### Session 5.2: HIV-positive Test Result, Post-test Counselling Session

Activity/Method	Time
Interactive trainer presentation and large group discussion	35 minutes
Exercise 2: HIV-positive test result, post-test counselling: Role play in pairs	70 minutes
Questions and answers	5 minutes
<b>Total Session Time</b>	<b>110 minutes</b>

### Session 5.3: Infants with Confirmed HIV Infection

Activity/Method	Time
Interactive trainer presentation and large group discussion	15 minutes
Questions and answers	5 minutes
Review of key points	5 minutes
<b>Total Session Time</b>	<b>25 minutes</b>

#### Materials Needed



- Slide set for Module 5
- Flip chart and markers
- Tape or Bostik (adhesive putty)
- Ensure participants have:
  - Copies of the Participant Manual

## Special Instructions



- There are 2 exercises in this module, both are based on role plays. Review the role plays and adapt as needed to ensure they are believable and culturally relevant. Be sure that you are familiar with the cases so that you can respond to participant questions and provide answers to case studies where needed.

# Session 5.1: HIV-negative Test Result, Post-test Counselling Session

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**Total Session Time: 110 minutes (1 hour, 50 minutes)**

## Session Objective

After completing this session, participants will be able to:

- Conduct the post-test counselling session for an infant or child under 18 months of age who tests HIV-negative by NAT or a child 18 months of age or older who tests HIV-negative by RDT



## Trainer Instructions

Slides 1–6

### Step 1:

#### Session Objective

Read the session objective as listed above. Ask participants if they have any questions before moving on.

### Step 2:

#### Diagnostic Testing for HIV

Provide a very brief overview of diagnostic testing for HIV in infants and children. This session focuses on post-test counselling after **diagnostic** testing. That means that the focus is on NAT for infants/children younger than 18 months of age and RDT for children 18 months of age or older.

The use of RDT for children less than 18 months for special indications (to determine HIV exposure where mother is not available or in sick children where NAT is not available) is discussed in Module 2.

### Step 3:

#### Overview of the HIV-negative Post-test Session

Ask if any participants have delivered HIV test results to a parent or caregiver of an infant or child. Invite these participants to share their insights and lessons learned throughout this discussion.

### Step 4:

Ask participants:

- *What topics need to be discussed during the post-test session for the baby testing HIV-negative by nucleic acid testing (NAT) at the first follow-up visit?*

Record key points on flipchart paper so that by the time participants have completed brainstorming the post-test HIV-negative session, most of the points in the checklist below will have been noted on flipchart paper in front of the room.



### Make These Points

- There are 5 steps when providing an HIV-negative test result. The messages given at each of the steps are slightly different depending on type of test (antibody or virological/NAT), whether the child is breastfed or weaned more than 3 months before the test was drawn, and the child's age.
- The 5 steps are as follows:
  1. Explain test result
  2. Discuss HIV prevention plan (ensure mother is on ART and provide breastfeeding counselling and support)
  3. Review child's care plan
  4. Discuss date of next visit and future testing plan
  5. Assess caregiver's understanding of the result and plan. Address questions.



### Trainer Instructions

Slides 7–20

#### Step 5:

#### Content of the HIV-negative Post-test Session

Take about 15 minutes to review Table 5.1 in Session 5.1 Course Content. First review the column describing the post-test session for the infant who has been breastfed in the past 3 months; then review the column describing the post-test session for the infant who has not been breastfed in the past 3 months. Ask different participants to read the script on each slide to make it more interesting.

#### Step 6:

Then explain that these are the scripts used to counsel caregivers in most infant HIV testing scenarios. However, there will be many other patient scenarios when this script needs to be adapted.



### Make These Points

The 5 basic steps of the post-test counselling session can be adapted to any clinical scenario.



## Trainer Instructions

Slide 21

### Step 7:

Lead participants through Exercise 1, which provides them with an opportunity to apply their knowledge of the post-test counselling session for the infant testing HIV-negative.

## Exercise 1

### Exercise 1: HIV-negative test result, post-test counselling: Role play followed by practice in pairs

<b>Purpose</b>	To practice the post-test counselling session for infants and young children testing HIV-negative.
<b>Duration</b>	70 minutes
<b>Advance Preparation</b>	Review the case studies and suggested answers as well as Table 5.1 and <i>Appendix 4A: Listening and Learning Skills Checklist</i> . Brief your co-trainer on the script for the large group role play. If you don't have a co-trainer, identify someone else such a participant or co-worker, who has experience conducting post-test counselling sessions, who can assist you.
<b>Introduction</b>	My co-trainer and I will role play the HIV post-test session for Aisha and Baby Kiki. You might remember Aisha and Baby Kiki from Module 4, pre-test session. Once we have completed the role play and de-briefing, participants will break into groups of 2 to practise role playing the HIV post-test session using scenarios in your Participant Manuals. The scripts you will be practising are those in Table 5.1.
<b>Activities</b>	<b>Large group role play (15 minutes)</b> The trainer and co-trainer, sitting at the front of the classroom, should model the following scenario to participants (convened in the large group). The role play should take about 5 minutes and the debrief about 10 minutes.  Aisha and Baby Kiki are back for their 10-week visit. Baby Kiki was HIV tested 4 weeks ago using NAT, her test result was returned at the end of last week. The HIV NAT result for Baby Kiki is negative. Aisha has been on ART for over 2 years, well before she got pregnant. Aisha is breastfeeding exclusively. What will you say to Aisha when you provide her with Kiki's results?  The person playing the healthcare provider should start the counselling session by welcoming Aisha back to the clinic. Aisha should feel free to ask questions of the healthcare provider.

	<p>The trainers should use Table 5.1 to guide their role play. Participants should turn to <i>Appendix 4A: Listening and Learning Skills Checklist</i> and tick off the counselling skills used by the healthcare provider.</p> <p>Upon completion of the role play, ask participants:</p> <ul style="list-style-type: none"> <li>• <i>How do you think the role play went?</i></li> <li>• <i>What went well?</i></li> <li>• <i>What would you have wanted to change?</i></li> <li>• <i>Did the healthcare provider cover all of the steps in Table 5.1?</i></li> <li>• <i>Did the healthcare provider demonstrate listening and learning skills (see Appendix 4A)?</i></li> <li>• <i>Any other comments?</i></li> </ul> <p><b>Small group role play (30 minutes)</b></p> <ol style="list-style-type: none"> <li>1. Invite participants to break into pairs to practise the role plays below. There are 4 role play scenarios, 2 for NAT and 2 for rapid test. One participant should play the healthcare provider and the other the caregiver for the first role play and then swap roles for the second role play. Choose one NAT scenario and one rapid test scenario to role play.</li> <li>2. Give participants about 10–15 minutes to role play and debrief the first scenario and then another 10–15 minutes or so to role play and debrief the second scenario. When debriefing they should use the same questions that appear above.</li> </ol> <p><b>Report back and large group discussion (25 minutes)</b></p> <ol style="list-style-type: none"> <li>3. Bring the large group back together and ask the group: <ul style="list-style-type: none"> <li>• <i>What did you think of the role play?</i></li> <li>• <i>Was it easy? Or difficult?</i></li> <li>• <i>If so, why?</i></li> <li>• <i>What did you learn from the role play that you will use in your work?</i></li> </ul> </li> </ol>
<b>Debriefing</b>	<p>The post-test session follows a simple script that covers just 5 basic steps but should be adapted based on the caregiver’s understanding, the situation, and the caregiver’s questions. These basic steps can be easily memorized:</p> <ol style="list-style-type: none"> <li>1. Explain test result</li> <li>2. Discuss prevention plan</li> <li>3. Review child’s care plan</li> <li>4. Discuss date of next visit and future testing plan</li> <li>5. Assess caregiver’s understanding of the result and plan, and address any questions</li> </ol>

## Exercise 1: HIV-negative test result, post-test counselling: Role play followed by practice in pairs

### Role play 1—NAT:

You will be informing Zahara that her 10-month-old infant has a negative HIV NAT result. Zahara, who started taking ART when she was 15 weeks pregnant, is still breastfeeding her 10-month old.

### Role play 2—NAT:

Dada's baby is 6 months old, she has not breastfed since the baby was 4 weeks old. The baby was tested for HIV last month using NAT. The test result is HIV-negative. Dada has been on ART since her 22<sup>nd</sup> week of pregnancy. You, the healthcare provider, will be telling Dada that her son's NAT result is HIV-negative.

### Role play 3—RDT:

You will be counselling Vada, a 25-year-old mother, who weaned her 18 month old daughter 3 months ago. You, the healthcare provider, will be telling Vada that her daughter's RDT (which was conducted early today) came back HIV-negative.

### Role play 4—RDT:

You will be counselling Magda, an 18-year-old mother, who is still breastfeeding her 19-month old son. You, the healthcare provider, will be telling Magda that her son's RDT (which was conducted early today) came back HIV-negative.



## Trainer Instructions

### Step 9:

Allow 5 minutes for questions and answers on this session.



# Session 5.2: HIV-positive Test Result, Post-test Counselling Session

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**Total Session Time: 110 minutes (1 hour, 50 minutes)**

## Session Objective

After completing this session, participants will be able to:

- Conduct the post-test counselling session for an infant or child under 18 months of age who tests HIV-positive by NAT or a child 18 months of age or older who tests HIV-positive by RDT



## Trainer Instructions

Slides 22–36

### Step 1:

#### Session Objective

Begin by reviewing the session learning objective, listed above. Ask participants if they have any questions before moving on.

### Step 2:

#### **HIV-positive Result (by NAT in children less than 18 months of age or RDT in children 18 months of age or older)**

As you deliver this session, integrate contributions, including lessons learned, from participants who have delivered HIV-positive test results to a caregiver.

### Step 3:

Use the content in the slide set and Session 5.2 Course Content to guide a discussion about the emotional impact of a positive HIV test result and how to handle this during the post-test counselling session.

Then ask participants:

- *What topics need to be discussed during the post-test session for the client testing HIV-positive?*

### Step 4:

As with the post-test HIV-negative session, record key points on flipchart paper.

### Step 5:

Ask participants:

- *How does the post-test session for an infant/child tested by NAT differ from that of a child 18 months of age or older (tested by RDT)?* [Answer: it won't differ significantly because in both cases, you will be telling this child's parent that the child is HIV-infected. However, since RDT results are available same day, you may be able to re-test to confirm the HIV status on the same day, which

may not be possible with NAT. Also, because the child tested by RDT is older he will need different infant feeding messages.]

**Step 6:**

Then review the content in Table 5.2 in Session 5.2 Course Content, row by row.



**Make These Points**

There are 5 key steps when providing an HIV-positive test result; these are the same 5 steps for the provision of an HIV-negative test result, except that each step is adapted based on test result and client circumstances.

The 5 steps of the post-test positive session for infant and child tested by RDT who is 18 months of age or older are similar to the steps for the infant/child tested by NAT.



**Step 7:**

**Trainer Instructions**

Slides 37–41

**HIV Disclosure**

Discuss disclosure of the child’s HIV status using Session 5.2 Course Content.



**Make These Points**

Healthcare providers have a role in supporting caregivers to disclose their child’s HIV status, as appropriate, to close family members and to the child who is living with HIV.



**Step 8:**

**Trainer Instructions**

Slide 42

Lead participants through Exercise 2, which provides an opportunity to apply their knowledge of the post-test counselling session for the infant testing with an HIV-positive test result.

## Exercise 2

<b>Exercise 2: HIV-positive test result, post-test counselling: Role play in pairs</b>	
<b>Purpose</b>	To review the content of the post-test session for infants and young children with a positive HIV test result.
<b>Duration</b>	70 minutes
<b>Advance Preparation</b>	Review Tables 5.2.
<b>Introduction</b>	Like the last exercise you will be breaking into pairs to practise the HIV post-test session through role play. Let's start by pairing up with someone that you haven't yet paired up with.
<b>Activities</b>	<p><b>Small group role play (40 minutes)</b></p> <ol style="list-style-type: none"> <li>1. For the first role play, one participant should role play the healthcare provider and the other the caregiver. They should swap roles for the 2<sup>nd</sup> role play. Each pair should select one NAT role play and one RDT role play.</li> <li>2. After each role play participants should debrief by discussing the following questions (within their pairs): <ul style="list-style-type: none"> <li>• <i>How do you think the role play went?</i></li> <li>• <i>What went well?</i></li> <li>• <i>What would you have wanted to change?</i></li> <li>• <i>Did the healthcare provider cover all of the steps in Table 5.2?</i></li> <li>• <i>Did the healthcare provider demonstrate listening and learning skills (see Appendix 4A)?</i></li> <li>• <i>Any other comments?</i></li> </ul> </li> <li>3. Give participants 35–40 minutes to conduct both role plays and debrief in their pairs.</li> </ol> <p><b>Report back and large group discussion (30 minutes)</b></p> <ol style="list-style-type: none"> <li>4. Bring the large group back together and ask the group: <ul style="list-style-type: none"> <li>• <i>What did you think of the role play?</i></li> <li>• <i>Was it easy? Or difficult?</i></li> <li>• <i>If so, why?</i></li> <li>• <i>What did you learn from the role play that you will use in your work?</i></li> </ul> </li> </ol>
<b>Debriefing</b>	<p>The post-test session follows a simple script that covers 5 steps. These basic steps can be easily memorized:</p> <ol style="list-style-type: none"> <li>1. Explain <b>test result</b>, give caregiver time to consider result and cope with emotions</li> <li>2. Discuss <b>treatment plan (Antiretroviral therapy)</b></li> <li>3. Review <b>child's care plan (other aspects of care)</b> <ul style="list-style-type: none"> <li>• Cotrimoxazole</li> <li>• Infant and young child feeding</li> <li>• What to do if the child is ill</li> <li>• Disclosure</li> <li>• Support and treatment for mother and other family members</li> </ul> </li> </ol>

	<p>4. The importance of <b>attendance</b> for clinic appointments; date of next visit and future testing plan</p> <p>5. Assess <b>caregiver’s understanding</b> of the result and plan. Address <b>questions</b>.</p> <p>Key points from the RDT role play 3:</p> <ul style="list-style-type: none"> <li>• If a child is acutely ill, it is important that the child is first evaluated by a clinician and stabilized before conducting an HIV test. HIV testing can take time and is not an emergency – it is most important that the infant or child gets emergency medical care first.</li> </ul>
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## Exercise 2: HIV-positive test result, post-test counselling: Role play in pairs

### **Instructions for Role Play giving NAT results:**

The participant playing the role of healthcare provider may use Table 5.2 to guide the role play. The caregiver should feel free to ask questions of the healthcare provider.

#### **Role play 1—NAT:**

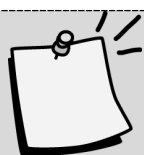
You, the health care provider, will be counselling Lesedi, an 18-year-old mother who is breastfeeding her 8-week old son. You will be telling Lesedi that her son’s NAT result is HIV-positive.

#### **Role play 2—NAT:**

You, the healthcare provider, will be counselling Chike, a 33-year-old mother of 6 children, who is breastfeeding her 10-month old daughter. You will be telling Chike that her daughter’s NAT result is HIV-positive.

#### **Role play 3—RDT:**

Ife came into the clinic today. You haven’t seen Ife in 2 ½ years, at which time she was pregnant. When you talk to her, Ife states that she stopped going to antenatal care when she was diagnosed with HIV infection because she was so angry. She came in today because her child, who is now 19 months old, has a severe respiratory infection. When you ask, Ife states that her baby has never been tested for HIV. You examine the infant, ensure that she is not in respiratory distress, and conduct a focused history and physical exam, including growth monitoring. Then you conduct an HIV RDT and the result is HIV-positive. Role play the post-test session with Ife.



### **Trainer Instructions**

**Step 9:** Allow 5 minutes for questions and answers on this session.

## Session 5.3: Infants with Confirmed HIV Infection



**Total Session Time: 25 minutes**

### Session Objective

After completing this session, participants will be able to:

- Understand the importance of linking HIV-positive infants to HIV care and treatment, including ART



### Trainer Instructions

Slides 43–50

#### Step 1:

#### Session Objective

Begin by reviewing the learning objective for this session as listed above. Ask participants if they have any questions before moving on.

#### Step 2:

#### Natural History of HIV in Untreated Children

Ask participants:

- *Has anyone here provided care for an HIV-infected infant(s)?*
- *[If so] Was that infant on ART? Was the baby symptomatic? What symptoms did he/she experience?*
- *[If not] How long do you think babies with HIV can expect to live without treatment? [Answer: without treatment, approximately 50% die before their 2<sup>nd</sup> birthday]*
- *How long might they live with treatment? [Answer: this is still unknown, but many perinatally infected children have grown up and are leading very normal lives.]*



#### Make These Points

- In the absence of an early diagnosis and appropriate management, approximately 50% of HIV-infected infants/children will not live to see their second birthday.
- ART slows and even stops or reverses disease progression, which highlights the importance of early diagnosis and immediate treatment for infants who are HIV-infected.



## Trainer Instructions

Slides 51–53

### Step 3:

#### Linking HIV-positive Infants to ART

Provide an overview of care needed by infants diagnosed with HIV infection using the slide set and Session 5.3 Course Content.

### Step 4:

Ask participants:

- *What tools and procedures are used at your facilities to ensure that caregivers of HIV-positive infants get the test results and the infants are linked to ART?*
- *What are the challenges of linking HIV-positive infants to ART?*
- *What are some ways that we can improve linkage to ART?*



### Make These Points

- Care and treatment for HIV disease, specifically ART, allows children with HIV to lead normal, healthy lives.
- It is important to ensure that HIV-infected infants and children are started on ART immediately after diagnosis. This requires the healthcare provider to ensure linkage of services between testing and ART clinic. The person or group conducting the HIV testing should actively link the infant to care and ensure that s/he is initiated on ART.



## Trainer Instructions

Slides 54–55

### Step 5:

#### Module key points

Ask participants what they think the key points of the module are. What information will they take away from this module?

Summarize the key points of the module, using participant feedback and the content below.



### Module 5: Key Points

- There are 5 steps to the post-test counselling session when providing a child's HIV test result to the caregiver. The key points for each of the 5 steps vary based on HIV test result (positive or

negative), age of child, breastfeeding status, and type of test conducted. The 5 steps are:

1. Explain test result.
  2. Discuss plan for prevention (if negative) or treatment (if positive)
  3. Review child's care plan
  4. Discuss date of next visit and future testing plan
  5. Assess caregiver's understanding of the result and plan. Address questions or concerns.
- **It is crucial to initiate infants and children with HIV on ART as soon as possible!** If untreated, HIV-infected children are at risk of rapid disease progression and death; approximately 50% of HIV-infected infants/children not on treatment die by the second year of life. In contrast, early HIV diagnosis combined with early ART dramatically reduces infant mortality and HIV progression.
  - Infants with confirmed HIV infection should also have access to co-trimoxazole prophylaxis, tuberculosis preventive therapy (TPT), safe water interventions and other routine clinical care.

**Step 6:** Ask if there are any questions or clarifications.

# Module 5, Part 2: Course Content

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## Session 5.1 Course Content: HIV-negative Test Result, Post-test Counselling Session

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### Diagnostic Testing for HIV

This module offers an overview of the post-test session for HIV diagnostic testing in infants and children who are HIV-exposed. Diagnostic testing for HIV refers to a test that is used to find out if someone has HIV or not. In infants and children under 18 months of age, the diagnostic test for HIV is NAT; for children 18 months of age or older it is RDT. RDT is not usually used in infants and children under the age of 18 months, unless it is needed to:

- Assess exposure status if the mother is not available, or
- As part of presumptive HIV diagnosis in sick children where NAT is not available.

Guidance on the post-test counselling session for infants under 18 months of age tested using RDT can be found in Appendix 5A.

### Overview of the HIV-negative Post-test Session

The post-test counselling session in the infant HIV testing setting is when the healthcare provider gives the caregiver his/her child's HIV test result. The post-test session is given as soon as possible after receipt of test results: on the same day and visit if using RDT or point-of-care NAT, or during the next visit (within 2–4 weeks) if samples were sent to an outside laboratory for testing (e.g., NAT). Regardless of scenario—whether breastfed or not, regardless of infant age, or type of test—the post-test counselling session for a negative test result follows the same steps:

1. Explain test result
2. Discuss prevention plan
  - Ensure mother is on ART
  - Provide adherence support
  - Provide breastfeeding counselling and support
3. Review child's care plan
  - Infant ARV prophylaxis
  - Cotrimoxazole
  - What to do if child is ill
  - Follow-up care
  - Support and treatment for the mother and other family members
4. Discuss date of next visit and future testing plan
5. Assess caregiver's understanding of the result and plan. Address questions.



## Content of the HIV-negative Post-test Session

Table 5.1 provides guidance on the HIV-negative post-test HIV counselling session for the caregiver of a child tested for HIV using NAT (if less than 18 months of age) or RDT (if 18 months of age or older). Table 5.1 includes sample scripts for communicating an HIV-negative result to the parent of an HIV-exposed child. There are two columns: one for children who have been breastfed within the past 3 months (of any age) and the other for children who have **not** been breastfed within in the past 3 months (of any age).

The healthcare provider should be able to adapt these scripts to any other scenario that may occur in the clinic setting.

**Table 5.1: HIV-negative diagnostic test result post-test session: infants less than 18 months tested by NAT and children 18 months and older tested by RDT**

Key point	Script/Key points	
	Breastfed in the last 3 months	Not breastfed within past 3 months
<b>1. Explain test result</b>	<ul style="list-style-type: none"> <li>Your <i>child's</i> HIV test result is negative. This means that your child was probably not infected with HIV at the time that we drew blood for the test.</li> <li>Because it can take as long as 3 months after infection for the test to become positive, there is a small possibility that he/she was actually infected when we drew blood. We will test your child again 3 months after the end of breastfeeding.</li> </ul> <p>[Adapt to national guidelines]</p>	<ul style="list-style-type: none"> <li><b>Infants and children less than 18 months of age:</b> Your child will be tested again at 18 months of age to confirm the negative result.</li> <li><b>Children 18 months of age or older:</b> Your child's test result is negative. This means that your child does not have HIV-infection.</li> </ul> <p>[Adapt to national guidelines]</p>
<b>2. Discuss prevention plan</b>	<ul style="list-style-type: none"> <li>Discuss measures to prevent mother-to-child HIV transmission: mother's ART adherence, infant antiretroviral prophylaxis if indicated, safe infant feeding practices</li> <li>Assess mother's ART adherence and provide adherence support for maternal ART and infant medications.</li> <li>Ensure mother's viral load (VL) has been taken if indicated according to national guidelines and check VL result.</li> <li>Provide infant feeding counselling and support (see Module 3): <i>As there is virus in breastmilk, your child will continue to be exposed to HIV as long as he is still breastfeeding. However, the risk of infection is extremely low as long as you are taking ART every day and have a low viral load. According to WHO guidelines, it is recommended that you breastfeed</i></li> </ul>	<p>[No special prevention messages needed because child is no longer breastfeeding; encourage mother to continue taking ART regularly for her health and to help in any future pregnancies.]</p>

	<p><i>for at least 12 months and may continue breastfeeding until 24 months of age or longer because this provides the best nutrition for your baby and prevents diarrhoea and other illnesses.</i></p> <p>[Adapt infant feeding counselling as needed to ensure consistency with national guidelines and appropriate messages for age.]</p>	
<p><b>3. Review child's care plan.</b></p> <p>[Adapt script in line with national guidelines]</p>	<p>Discuss:</p> <ul style="list-style-type: none"> <li>• Infant ARV prophylaxis (if applicable).</li> <li>• Cotrimoxazole: <i>You should start (continue) giving your child co-trimoxazole. This medicine prevents serious infections, including some types of pneumonia and malaria. You will give your child co-trimoxazole until her/his final HIV status is determined at 18 months of age or 3 months after cessation of breastfeeding (whichever is later).</i> Discuss adherence, review dosing and instructions.</li> <li>• What to do if the child is ill.</li> <li>• The importance of attendance for regularly scheduled immunizations, growth monitoring, care and follow up testing.</li> <li>• Encourage a family-based approach: promote HIV testing of the partner/ other children; provide psychosocial support to caregivers</li> </ul>	<p>Discuss:</p> <ul style="list-style-type: none"> <li>• <b>Infants and children less than 18 months of age:</b> <i>You'll need to return for follow-up care until your child is 18 months old.</i> [Adapt to national guidelines.]</li> <li>• <b>Children age 18 months or older:</b> <i>Your child is HIV-negative and does not need further care as an HIV-exposed infant.</i></li> <li>• Cotrimoxazole: <i>You should stop giving co-trimoxazole to your child.</i></li> <li>• What to do if the child is ill.</li> <li>• The importance of attendance for regularly scheduled immunizations, growth monitoring and care.</li> <li>• Importance of good nutrition.</li> <li>• Encourage a family-based approach: promote HIV testing of the partner/ other children; provide psychosocial support to caregivers.</li> </ul>
<p><b>4. Discuss date of next visit and future testing plan</b></p>	<ul style="list-style-type: none"> <li>• Date of next appointment for routine well-child follow up.</li> <li>• <b>Discuss future infant HIV testing plan:</b> Test for HIV when baby is 4–6 weeks of age, 9 months old and again at 18 months of age or 3 months after all</li> </ul>	<p>[No follow up needed for PMTCT since child is no longer HIV-exposed and has final negative HIV test]</p>

	breastfeeding has stopped (whichever is later). [Adapt as needed based on national guidelines]	
<b>5. Assess caregiver's understanding of the result &amp; plan. Address questions.</b>	<p><i>I would like to make sure I covered everything with you and explained things clearly by asking a few questions.</i></p> <ul style="list-style-type: none"> <li>• <i>Can you tell me your baby's test result? What does that mean?</i></li> <li>• <i>What medications will you give to your baby? Ask about dose/frequency.</i></li> <li>• <i>What are you going to feed your baby?</i></li> <li>• <i>When will your baby be tested next for HIV?</i></li> <li>• <i>What do you need to remember in terms of your own health? Continue to take ART and attend clinic visits; mother should know her VL result or when she is due to have VL drawn</i></li> <li>• <i>When do you need to return for your child's next follow-up visit?</i></li> <li>• <i>What questions do you have?</i></li> </ul>	<p><i>I would like to make sure I covered everything with you and explained things clearly by asking you a few questions.</i></p> <ul style="list-style-type: none"> <li>• <i>What is your child's test result? What does that mean?</i></li> <li>• <i>Where will you go if your child gets sick or for health checks?</i></li> <li>• <i>What do you need to remember in terms of your own health? Continue to take ART and attend clinic visits.</i></li> <li>• <i>What questions do you have?</i></li> </ul>

## Session 5.2 Course Content: HIV-positive Test Result, Post-test Counselling Session

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### **HIV-positive Result (by NAT in children less than 18 months of age or RDT in children 18 months of age or older)**

Learning that their infant or child is infected with HIV can be one of the most stressful events in a family's life. A diagnosis of HIV can bring up a range of issues for caregivers, including:

- Denial about their own HIV status or the infant's HIV status.
- Feeling responsible for infecting an infant (guilt, anger, hopelessness, anxiety).
- Anxiety regarding their death or the death of the infant.
- Feelings about disclosing an infant's HIV status or their HIV status to family members and other people and (eventually) to the child also.

It is important to be empathetic and patient. Listen in a non-judgmental, compassionate way. Give caregivers sufficient time to ask questions and ensure they understand the information they have received. Use simple, open, honest language—keeping in mind the caregiver's level of understanding and cultural context. Help caregivers identify their fears, encourage them to participate in support groups, and stress concrete ways they can care for their infant/child. It is critical that the caregiver understand the rationale for, and urgency of, on-going medical care and how and where they can receive it.

Caregivers are likely to be overwhelmed and unable to remember all the information they hear in the post-test session. Schedule a follow-up visit within the next week or so. Assess understanding of key points at this and future follow up visits.

The key points to be covered when telling a caregiver that his or her infant is HIV-infected are listed in Table 5.2, below. Note that information on infant care can be found in Module 3.

1. Explain test result, give caregiver time to consider result and cope with emotions
2. Discuss treatment plan
  - Initiation of ART
3. Review child's care plan
  - Cotrimoxazole
  - Infant and young child feeding
  - What to do if the child is ill
  - Disclosure support
  - The importance of attendance for clinic appointments
  - Support and treatment for the mother and other family members
4. Discuss date of next visit and future testing plan
5. Assess caregiver's understanding of the result and plan. Address questions.

**Table 5.2: HIV-positive diagnostic test result post-test session: infants less than 18 months tested by NAT and children 18 months and older tested by RDT**

Key point	Script/Key points*
<b>Explain test result</b>	<ul style="list-style-type: none"> <li>• Your <i>child's HIV test result is positive; that means that your child is HIV-infected.</i></li> <li>• <i>We will retest your child today, to confirm this test result.</i></li> <li>• <i>What questions do you have about your baby's result?</i></li> <li>• <i>How are you feeling about this?</i></li> <li>• <i>What are you most concerned about right now?</i></li> </ul>
<b>Discuss treatment plan</b>	<ul style="list-style-type: none"> <li>• <i>With treatment, your child can live a long, healthy life.</i></li> <li>• <i>Your child should start treatment as soon as possible, ideally today.</i> If child will not be started on ART in your clinic, ensure linkage to ART (patient escort or other tracking system)</li> </ul>
<p>Review child's <b>care plan.</b></p> <p>(Always adapt script in line with national guidelines.)</p>	<p>Discuss:</p> <ul style="list-style-type: none"> <li>• ART initiation: <i>It is important that we start your baby on ART (HIV treatment) as soon as possible. If your baby is currently on medication to prevent HIV, we will stop that medication and start medication that will treat HIV called ART. ART works to reduce the amount of HIV virus in the body. Taking ART every day will help your child to live a long, healthy life.</i> <ul style="list-style-type: none"> <li>• Start infant on ART as soon as possible with appropriate adherence counselling</li> <li>• If infant is on ARV prophylaxis, stop infant ARV prophylaxis once ART is initiated</li> </ul> </li> <li>• Cotrimoxazole: <i>You should continue (start) giving your child co-trimoxazole. This medicine prevents serious infections, including some types of pneumonia and malaria.</i> Discuss adherence, review dosing and instructions.</li> <li>• Infant and young child feeding (if breastfed and less than 6 months of age): <i>It is important that you continue breastfeeding. Breastfeed exclusively to 6 months of age. At 6 months introduce complementary foods while continuing to breastfeed to 2 years of age and beyond.</i> <ul style="list-style-type: none"> <li>• Complementary feeding if child is nearing 6 months of age or older.</li> <li>• Importance of good nutrition if child is 6 months of age or older</li> <li>• Provide infant feeding counselling and support appropriate to age and feeding method (see Module 3).**</li> </ul> </li> <li>• What to do if the child is ill.</li> <li>• Disclosure of the child's HIV status to others, especially the partner.</li> <li>• The importance of attendance for regularly scheduled immunizations, growth monitoring and HIV care.</li> <li>• Support and treatment for mother and other family members, including:</li> </ul>

	<ul style="list-style-type: none"> <li>• Ensure mother is on ART. If not, initiate ART (or refer for initiation) today.</li> <li>• Psychosocial support</li> <li>• Adherence support for maternal ART and infant medications. Ensure viral load (VL) is taken if indicated and check VL result.</li> <li>• HIV testing of partner and other children</li> </ul>
<b>Discuss date of next visit and future testing plan</b>	<ul style="list-style-type: none"> <li>• Date of next appointment for routine well-child follow up</li> <li>• If RDT: same day confirmatory test should be done. If NAT: provide confirmatory testing as per national guidelines. <i>We will draw a second blood sample today to confirm the test results, but we recommend starting your child on ART now. It is very rare, but if repeat tests are negative, we can always stop ART in future.</i></li> <li>• Same day linkage to ART clinic, ART initiation and follow up</li> </ul>
<b>Assess caregiver's understanding of the result &amp; plan. Address questions.</b>	<p><i>I would like to make sure I covered everything with you and explained things the right way by summarizing with a few questions for you.</i></p> <ul style="list-style-type: none"> <li>• <i>What is your baby's test result? What does that mean?</i></li> <li>• <i>What medication will you stop today? What medication will you give to your baby? Ask about dose/frequency.</i></li> <li>• <i>What are you going to feed your baby? If still exclusive breastfeeding, when will you introduce other foods and for how long will you continue breastfeeding?</i></li> <li>• <i>What do you need to remember in terms of your own health? Continue to take ART and attend clinic visits.</i></li> <li>• <i>When do you need to return for your child's next follow-up visit?</i></li> <li>• <i>What questions do you have?</i></li> </ul>
<p>* The order in which the content of the post-test counselling session flows is determined by the client's questions. Should the client not articulate any questions or concerns, follow the order above. The most important points for the initial post-test session are: (1) The child's test result is positive, (2) The child can live a long and healthy life on ART—it is important that the child start ART as soon as possible (ensure caregiver knows plan to initiate ART), (3) There is support for you (assess caregiver's support network and link her to services).</p> <p>** If child is formula fed: Provide advice about safe preparation and complementary feeding as per national guidelines. If mother wishes to breastfeed, provide/refer for breastfeeding counselling.</p>	

## HIV Disclosure

When discussing infants and children with newly diagnosed HIV infection, there are 2 types of disclosure:

- The disclosure of the child's HIV status to others, for example family members or close confidants. This type of disclosure is discussed below.
- The disclosure of the child's HIV status to the child. This type of disclosure is not discussed in this course because this training focuses on infants.

Willingness to disclose a child's HIV status is impacted by the mother's disclosure of her own HIV status to her partner, family and friends. Before disclosing her child's HIV status, she must have or be willing to disclose her own HIV status.

Lack of disclosure to male partners is an important reason for loss to follow up. Fathers and other family members can play an important role in keeping mothers and children in care and treatment.

### **The healthcare provider's role in helping the mother to disclose her own HIV status**

In most cases, it is important for a woman to disclose her HIV test result to her partner and/or a family member to get support at home and avoid secrecy when taking medications. Trusted family and friends can play a central role in supporting her to live positively with HIV. The healthcare provider should assure the mother that the provider's role is to support the mother; the provider should also reassure the mother that her HIV status and the child's HIV status will remain confidential and never be disclosed against her will. Also, assess for barriers to disclosure such as intimate partner violence or stigma in the home or community.

The role of the counsellor is to:

- Assist the client in identifying to whom to disclose to and when. (*Who do you want to disclose your HIV status to? What are your feelings about talking to your partner(s) about your test result? What are your concerns? How do you believe your partner will react?*)
- Assist the client in making the decision to disclose by identifying reasons for disclosing and possible consequences of disclosing. (*What do you hope to get out of telling the person? What are the possible negative consequences of telling the person?*)
- Assist the client on how to disclose her status, either by practising the conversation with her or by being present when she discloses. (*How do you think you would tell your partner about your test result? What would you say? It is good to practise: let's imagine that I am your partner, tell me about your results and I will respond.*)
- Assist the client to prepare for the reactions of those to whom she discloses. (*How do you think she/he will react?*)

### **The healthcare provider's role in helping parents to disclose their child's HIV status**

When the client is ready, the healthcare provider should support the mother to disclose her child's HIV status to her partner/the baby's father or other family members.

Support for disclosure may be provided during the post-test session as well as during subsequent routine visits. Counselling on disclosure to family members and friends can be broached by asking the caregiver, for example:

- *Are there any people who you might be comfortable sharing this with?*
- *What do think you might say to this person?*
- *How do you think s/he will react?*
- *What do you think s/he will say?*



## Session 5.3 Course Content: Infants with Confirmed HIV Infection

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### Natural History of HIV in Untreated Children

HIV progresses more quickly in infants and children than it does in adults. About 20% of untreated children are rapid progressors. These children present with symptoms early and progress to severe immunosuppression within the first year of life, some in the first weeks of life.

Without early diagnosis and treatment, approximately 50% of HIV-infected infants/children die by the second year of life; those who survive are at risk for developmental impairment and severe illness. However, the CHER trial showed that early HIV diagnosis and early ART reduced infant mortality by 76% and HIV progression by 75%.<sup>[1]</sup> This rapid progression without ART highlights the urgency of ensuring that HIV-exposed infants are tested early (before or at 4–6 weeks of age based on national guidelines) and those who are HIV-infected are provided with immediate care and treatment including ART. With ART, HIV-infected children can expect to survive to adulthood.

Some of the most common signs of HIV infection in children not receiving ART include:

- Failure to thrive (no weight gain or weight loss), acute malnutrition
- Loss of interest in playing, fatigue, developmental delay or loss of developmental milestones
- Oral thrush
- Generalized lymphadenopathy (enlarged lymph nodes in multiple regions)
- Lymphoid interstitial pneumonitis (leads to difficulty breathing)
- Recurrent bacterial infections/fevers
- Chronic ear infection (otitis media) with drainage
- Opportunistic infections (OIs), including *Pneumocystis jirovecii* pneumonia (PCP), herpes zoster (shingles), esophageal thrush (candidiasis)
- Tuberculosis (TB)
- Persistent diarrhoea
- Chronic rashes <sup>[2]</sup>

ART has made many of these infections uncommon, and they now occur mainly in undiagnosed children who have not yet received ART or in children who are not taking ART as prescribed. Recent studies have showed that early ART is life-saving for HIV-infected infants. These studies also show that infants who initiate ART early, before becoming symptomatic, are more likely to stay healthy than infants who initiate ART later.<sup>[3]</sup>

**It's crucial that infants infected with HIV are started on life-saving ART as early in life as possible!**

## Linking HIV-positive Infants to ART

Care and treatment of children with confirmed HIV infection includes:

- Counselling caregiver and assessing readiness to start ART.
- Initiating ART, which should be started while the results from confirmatory testing are pending (if not available same-day).
- Continuing/initiating co-trimoxazole prophylaxis.
- Providing adherence support for ART and co-trimoxazole.
- Conducting focused clinical examination including history; determining clinical stage and treating any illnesses/opportunistic infections.
- Ordering investigations and other treatments as appropriate.
- Providing access to tuberculosis preventive therapy (TPT) and malaria prevention, as per national policy.
- Providing (or linking to) other interventions such as safe water interventions, nutrition counselling and support, psycho-social counselling, etc.
- Recording baseline information in the child's HIV treatment card/medical record.
- Monitoring adherence and response to ART.
- Ongoing family-centred counselling and support.

Sometimes infants receive HIV treatment at the same facility where they received the test results; at other times, infant may need to be referred to another facility to start ART. In either case, the person receiving the test result needs to ensure that the result is given to the caregiver and that the infant is started on ART. This requires coordination between the facility where testing takes place and the facility where ART is provided. Lay providers can track caregivers and infants in the community and/or accompany them to appointments.

Registers or electronic databases should be used to track HIV-exposed infants as they progress through comprehensive care from the initial visit, each testing event (at 4–6 weeks of age, 9 months and again at 18 months of age or 3 months after breastfeeding cessation), to confirmation of negative HIV status or linkage into HIV care and treatment and the initiation of ART.

# Appendix 5A: Post-test Counselling Session for Infants Less than 18 Months Tested by RDT

Testing by RDT in infants less than 18 months of age is primarily done to assess HIV exposure status if the mother’s HIV status is not known; RDT does not accurately diagnose HIV in infants less than 18 months of age.

Key point	<i>Script/Key points, Negative HIV RDT result</i>	<i>Script/Key points, Positive HIV RDT result</i>
<p><b>Explain test result.</b></p>	<p><b>Well child less than 4 months of age:</b> <i>Your child’s HIV test result is negative. This means that the child was likely not exposed to HIV. However, if your child becomes ill, please bring him/her back right away for evaluation and testing. Your child should have another RDT to determine HIV status at 18 months of age.</i></p> <p><b>Well child 4–18 months of age:</b> <i>Your child’s HIV test result is negative. This cannot reliably tell us if the child is HIV-exposed or not – you can have a negative test even if your child was HIV exposed during pregnancy. Your child appears well, so we do not need further testing at this time, but you should bring your child back for evaluation right away if s/he becomes ill. Your child should have another RDT to determine HIV status at 18 months of age.</i></p>	<p><b>Well child less than 18 months of age:</b></p> <ul style="list-style-type: none"> <li>• <i>Your child’s test result is positive; that means that your child is HIV-exposed</i></li> <li>• <i>The test does not tell us if your child is infected. To determine your child’s HIV status, we need to test for the HIV virus, which we will do today.</i></li> <li>• <i>What questions do you have about your baby’s result?</i></li> </ul> <p><b>Sick child less than 18 months of age</b> → <i>refer to clinician for assessment for presumptive diagnosis of HIV</i></p> <ul style="list-style-type: none"> <li>• <i>Your child’s test result is positive; that means that your child is HIV-exposed.</i></li> <li>• <i>The test does not tell us for sure if your child is infected. To determine your child’s HIV status, we need to test for the HIV virus, which we will do today.</i></li> <li>• <i>If clinician makes presumptive HIV diagnosis: Because your child is very sick, we do not want to wait for the virus test result to start your child on HIV treatment. We recommend starting HIV treatment today while waiting for the final HIV test result [refer to adherence counselor for additional counselling].</i></li> </ul>

	<p><b>Sick child less than 18 months of age:</b> <i>The rapid test is negative but your child is sick, and the rapid test is not a good test for diagnosing HIV. To determine your child's HIV status, we need to test for the HIV virus, which we will do today.</i></p>	<p><b>Note:</b> All infants/children less than 18 months of age with a positive HIV rapid test result and/or appear ill, should have a clinical assessment before counselling the caregiver on results. If the child is very ill with a positive HIV rapid test result, then the child may be given a presumptive HIV diagnosis and started on ART while awaiting NAT results.</p>
<p><b>Discuss prevention/treatment plan</b></p>	<ul style="list-style-type: none"> <li>• <b>If breastfed:</b> Discuss measures to prevent mother-to-child HIV transmission: mother's ART adherence (if mother is available and HIV-infected), safe infant feeding practices</li> <li>• Provide infant feeding counselling and support (see Module 3) based on mother's situation. [Adapt infant feeding counselling as needed to ensure consistency with national guidelines and appropriate messages for age.]</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure mother is on ART (if mother is available), if not initiate ART (or refer for initiation) today.</li> <li>• Adherence support for maternal ART and infant medications. Ensure viral load (VL) is taken if indicated and check VL result.</li> <li>• Provide infant feeding counselling and support (see Module 3): <i>As there is virus in breastmilk, your child will continue to be exposed to HIV. However, the risk of infection is extremely low as long as you are taking ART every day and have a low viral load. It is recommended that you continue breastfeeding until 24 months of age or longer because this provides the best nutrition to your baby and prevents diarrhoea and other illnesses.</i></li> </ul>
<p><b>Review child's care plan.</b></p> <p>(Always adapt script in line with national guidelines.)</p>	<ul style="list-style-type: none"> <li>• What to do if the child is ill.</li> <li>• The importance of attendance for regularly scheduled immunizations, growth monitoring, care and follow up testing.</li> <li>• Encourage a family-based approach: promote HIV testing of the mother, her partner/ other children; provide psychosocial support to caregivers</li> </ul>	<p>Discuss:</p> <ul style="list-style-type: none"> <li>• Cotrimoxazole: <i>You should start (continue) giving your child cotrimoxazole. This medicine prevents serious infections, including some types of pneumonia and malaria.</i> Discuss adherence, review dosing and instructions.</li> <li>• Infant and young child feeding (follow guidelines and provide appropriate counselling based on age—See Module 3)</li> <li>• What to do if the child is ill.</li> <li>• The importance of attendance for regularly scheduled immunizations, growth monitoring and HIV care.</li> <li>• Support and treatment for mother and other family members, including:</li> </ul>

		<ul style="list-style-type: none"> <li>• Ensure mother is on ART. If not, initiate ART (or refer for initiation) today.</li> <li>• Psychosocial support</li> <li>• Adherence support for maternal ART and infant medications. Ensure viral load (VL) is taken if indicated and check VL result.</li> <li>• HIV testing of partner and other children</li> </ul>
<b>Discuss date of next visit and future testing plan</b>	<ul style="list-style-type: none"> <li>• Review date of next appointment for routine well-child follow-up.</li> <li>• Future testing plan, based on child's health and mother's willingness to be tested (if/when she is available).</li> </ul>	<ul style="list-style-type: none"> <li>• <i>We will conduct NAT now. You will need to return to the clinic in 4 weeks (or sooner if possible, based on result turn-around time) for the baby's HIV virological test/NAT result.</i></li> <li>• Infant: Date of next appointment for HIV-exposed infant care and NAT result; close follow-up if child is sick (see note below about presumptive HIV diagnosis for sick infants)</li> <li>• Mother: Same day linkage to ART clinic, ART initiation and follow up if not yet on ART.</li> </ul>
<b>Assess caregiver's understanding of the results &amp; plan. Address questions.</b>	<p><i>I would like to make sure I covered everything with you and explained things clearly by asking you a few questions.</i></p> <ul style="list-style-type: none"> <li>• <i>What is your baby's test result? What does that mean?</i></li> <li>• <i>What are you going to feed your baby?</i></li> <li>• <i>What is our plan for testing the baby's mother? (If applicable) When will your baby be tested next for HIV?</i></li> <li>• <i>When do you need to return for your child's next follow-up visit?</i></li> <li>• <i>What questions do you have?</i></li> </ul>	<p><i>I would like to make sure I covered everything with you and explained things the right way by summarizing with a few questions for you.</i></p> <ul style="list-style-type: none"> <li>• <i>What is your baby's test result? What does that mean?</i></li> <li>• <i>What medications will you give to your baby? Ask about dose/frequency.</i></li> <li>• <i>What are you going to feed your baby?</i></li> <li>• <i>What do you need to remember in terms of your own health? Continue to take ART and attend clinic visits.</i></li> <li>• <i>When do you need to return for your child's next follow-up visit?</i></li> <li>• <i>What questions do you have?</i></li> </ul>

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