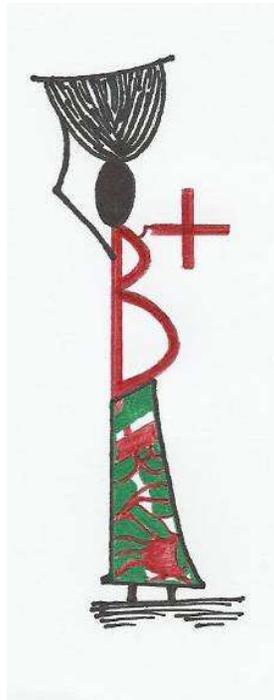




PATIENT EDUCATION & COUNSELING GUIDE FOR PMTCT B+

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1. Background and rationale

1.1. Programmatic update of WHO PMTCT guidelines: towards B & B+

In April 2012 WHO issued a programmatic update on the use of ARVs for pregnant women and PMTCT, in preparation of a full revision of the guidelines, proposing a phase out of option A and a move towards option B+ (providing lifelong ARV treatment to all HIV positive pregnant women, regardless of CD4 count). Potential benefits of B+ include programmatic simplification; no need for CD4 result to decide treatment pathway, one regimen for all, continuation of treatment into future pregnancies in settings with high fertility rates and the potential to decrease transmission in future pregnancies.

Malawi and Uganda have already rolled out PMTCT B+ at national level whilst other countries are actively discussing implementation of pilot projects. Hence in 2013 MSF will adapt to PMTCT B+ in a number of its PMTCT programmes.

1.2. Challenges of retention and adherence in PMTCT

Over the past years, low retention rates have been observed for pregnant women, causing suboptimal treatment levels: a number of studies have indicated a higher risk of loss to follow-up (LTFU) for pregnant HIV+ women than for non pregnant women or men^{1, 2}, including a substantially higher pre-treatment LTFU rate (women who do not come back for follow-up after HIV diagnosis). Moreover, research shows that adherence levels worsen after delivery³, showing the need for a continued and specific support after delivery.

1.3. Need for fast-tracking for ART initiation

Option B+ includes another important change in policy: not only are all HIV+ pregnant women put on ART irrespective of their CD4 count, women should also start their antiretroviral therapy as soon as possible after diagnosis, so as to achieve viral suppression rapidly before delivery and hence increasing the chance of having an HIV negative baby.

The current approach within MSF for ART initiation, with 2 to 3 counseling sessions to prepare the patient until he or she is proven 'ready' to start ART⁴, can be a barrier to timely ART initiation and the need for this pre therapy counseling has been questioned in some settings. One study in Uganda showed that adherence did not appear to be better with patients who underwent ART counseling before initiation, compared to patients who received adherence counseling concurrent with ARV initiation⁵. In addition there currently is no objective measurement of 'readiness' that predicts

¹ Wang B, Losina E, Stark R, Munro A, Walensky RP, Wilke M, Martin D, Lu Z, Freedberg KA, Wood R., *Loss to follow-up in a community clinic in South Africa--roles of gender, pregnancy and CD4 count.* <<http://www.ncbi.nlm.nih.gov/pubmed/21786730>> in: S Afr Med J. 2011 Apr;101(4):253-7

² Kaplan R, Orrell C, Zwane E, Bekker LG, Wood R. *Loss to follow-up and mortality among pregnant women referred to a community clinic for antiretroviral treatment.* <<http://www.ncbi.nlm.nih.gov/pubmed/18670232>> AIDS. 2008 Aug 20;22(13):1679-81

³ Nachega JB, Uthman OA, Anderson J, Peltzer K, Wampold S, Cotton MF, Mills EJ, Ho HS, Stringer JA, McIntyre JA, Mofenson L. *Adherence To Antiretroviral Therapy During and After Pregnancy in Low-Income, Middle-Income and High-Income Countries: A Systematic Review and Meta-Analysis.* AIDS 2012, 26(16) 2039-2052

⁴ Patient Education and Counselling : Handbook for HIV/TB infected adult patients. Médecins Sans Frontières, March 2012.

⁵ Siedner MJ, Lankowski A, Haberer JE, Kembabazi A, Emenyonu N, et al. (2012) *Rethinking the "Pre" in Pre-Therapy Counseling: No Benefit of Additional Visits Prior to Therapy on Adherence or Viremia in Ugandans Initiating ARVs.* PLoS ONE 7(6): e39894. doi:10.1371/journal.pone.0039894

adherence after initiation⁶. In Cape Town, it was found that ART preparation activities differ widely across clinics, with little evidence of the impact of these different approaches⁷.

To address the medical urgency of initiating pregnant mothers on treatment in order to minimize transmission, an adapted ART preparation approach needs to be implemented. This means shifting a substantial part of the counseling and education from pre- to post-initiation.

1.4. Additional strategies for retention in care

The high rate of LTFU in pregnant women, particularly after the first Antenatal Care (ANC) visit, calls for additional interventions to retain pregnant or post-partum women in care which go beyond counseling and education of patients.

Active tracing of all HIV+ pregnant women and their exposed babies coming late for appointments, should be a part of the minimal package of services. This can be done by a lay cadre or peers.

MSF's guidance on PMTCT Implementation support offers ideas on which other strategies can strengthen adherence⁸:

- The set-up of facility based or community based peer support groups or expert patient counselors
- Set up of geographical clusters of women who may attend Antenatal/ Postnatal care together
- Involvement of men (husbands, partners) in PMTCT
- Availability of Maternity Waiting Homes linked to health centres where women can stay towards the end of their pregnancy
- Involvement of traditional birth attendants for timely referrals and postnatal care
- Voucher schemes to reimburse certain costs like transport and food
- Incentive schemes (non financial only)
- Pre-packed PMTCT drugs for women who are not able to deliver in the health structure
- Set-up specific testing strategies to get partners tested such as outreach testing and oral self testing

1.5. Use of this guide

This counseling guideline aims to be a guide to health care workers involved in counseling and education of pregnant women and their exposed babies under the B or B+ treatment regimen. It suggests a standard series of counseling sessions during which certain skills are practiced. Ideally, a patient should go through the complete cycle and receive guidance throughout their pregnancy and thereafter. The patient circuit should be organized in a way that women are enabled to attend the sessions and a concise report of each counseling session needs to be included in the patient's file to allow follow-up of specific issues in future counseling sessions.

Counselors can be either trained nurses, lay cadre or peers, depending on the context of the project. More important than who is the counselor, is the quality and time dedicated to the counseling sessions. The sessions are conceived as a dialogue instead of a one-directional transfer of

⁶ Grimes Richard and Grimes Deanne, *Readiness: The State of the Science (or the Lack Thereof)*, in Curr HIV/AIDS Rep. 2010 November

⁷ Myer L, Zulliger R, Pienaar D. (2012) Diversity of patient preparation activities before initiation of antiretroviral therapy in Cape Town, South Africa. *Tropical Medicine and International Health* 17(8).

⁸ Prevention of Mother-to-Child transmission of HIV : part 2 Implementation Support. Médecins Sans Frontières. April 2011.

information. The aim is to analyze the situation of the individual patient; only when enough time is taken for this dialogue can the counseling sessions offer effective support to the patient.

Specificities of this guide:

- The counseling and education activities allow for **immediate initiation on ART**, at the day of HIV-testing. Support is provided at the start of treatment and is continued post-initiation, enabling active learning for patients while on ART.
- The guide aims at offering practical support with a **focus on problem-solving** around specific adherence barriers faced by pregnant and post-partum women and their exposed babies, making the approach patient-centered.
- The guide integrates adherence support for ART with counseling for development of other skills needed to prevent transmission to the child, thus offering a **comprehensive support** to the mothers and their babies
- Throughout the counseling sessions, there is a strong emphasis on **motivation** for taking treatment and for living a healthy life.

This guide comes with additional tools:

1. A visual aid to facilitate communication during the educational sessions;
2. A template to write down the personal adherence plan of the patient to be kept in the patient's file; if possible, a copy is given to the patient. In sites where patient files are not kept, the adherence plan can be written down in the notes part of the ANC card or a sheet can be attached to it; (see annex 1)
3. A tally sheet for monitoring purposes, where counselors keep record of the number of sessions taken, in line with the indicators that the project will monitor. (see annex 2)

2. Flow of patient education and counseling sessions

Different points for entry into the PMTCT program can be identified. Most women are tested during pregnancy, at the occasion of their first ANC visit. However, some women will already be on ART when they become pregnant, others will present and be diagnosed HIV+ during labour or breastfeeding. The counseling flow needs to be adapted to each of these cases, with the order slightly varying and some content of the sessions will need to be adapted or omitted.

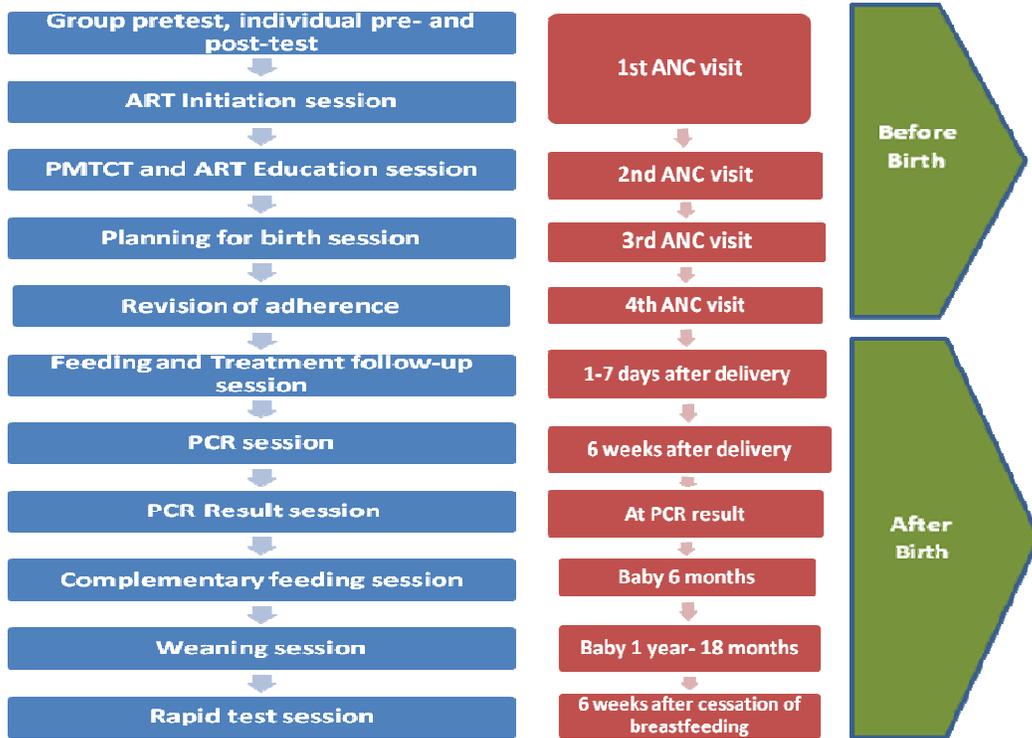
For women arriving late in pregnancy, and being unable to attend the health facility 4 times before delivery, counseling sessions should be combined.

Below are some examples of counseling flows, varying according to the moment of testing positive for HIV.

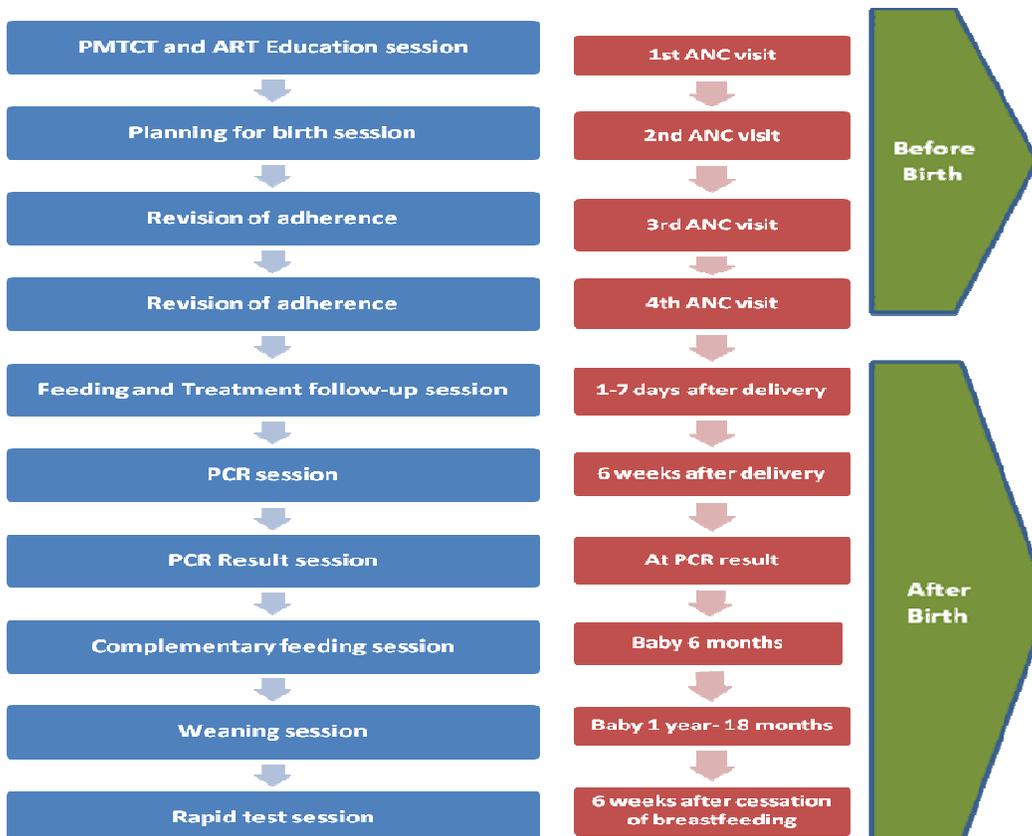
In addition to these sessions, the project should include:

- Enhanced adherence counseling in case the mother has a detectable viral load: refer to viral load protocol and enhanced adherence counseling guide of your project
- Adherence check at each and every contact with the mother and the baby

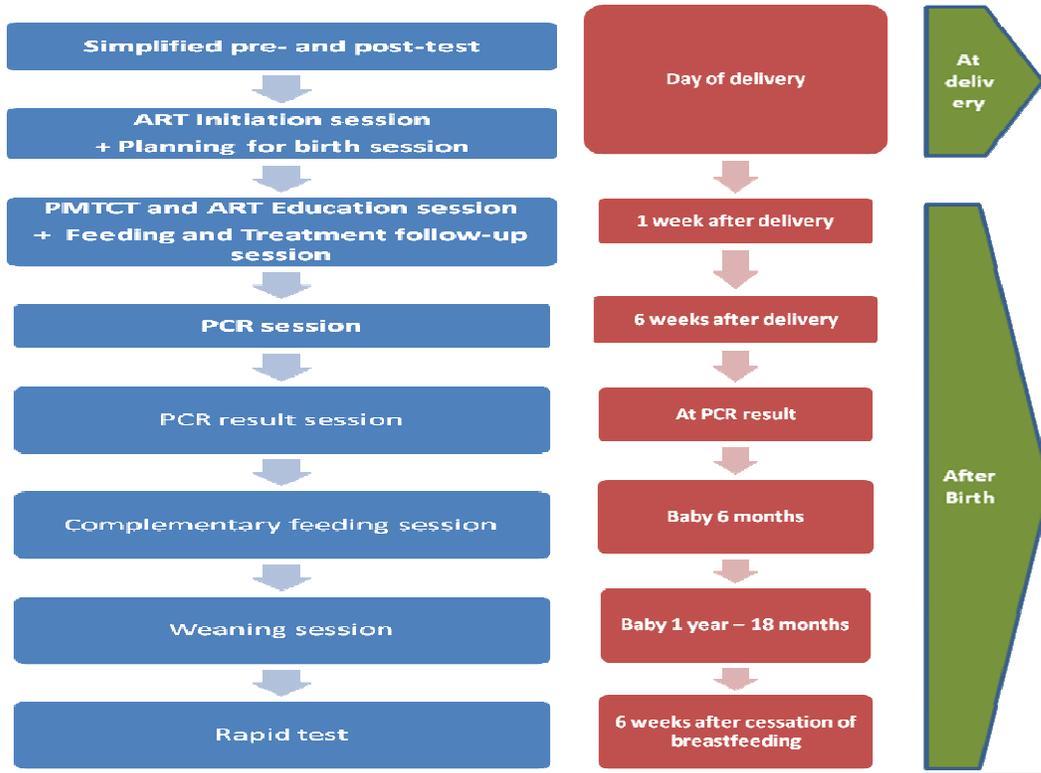
2.1. Women tested during pregnancy



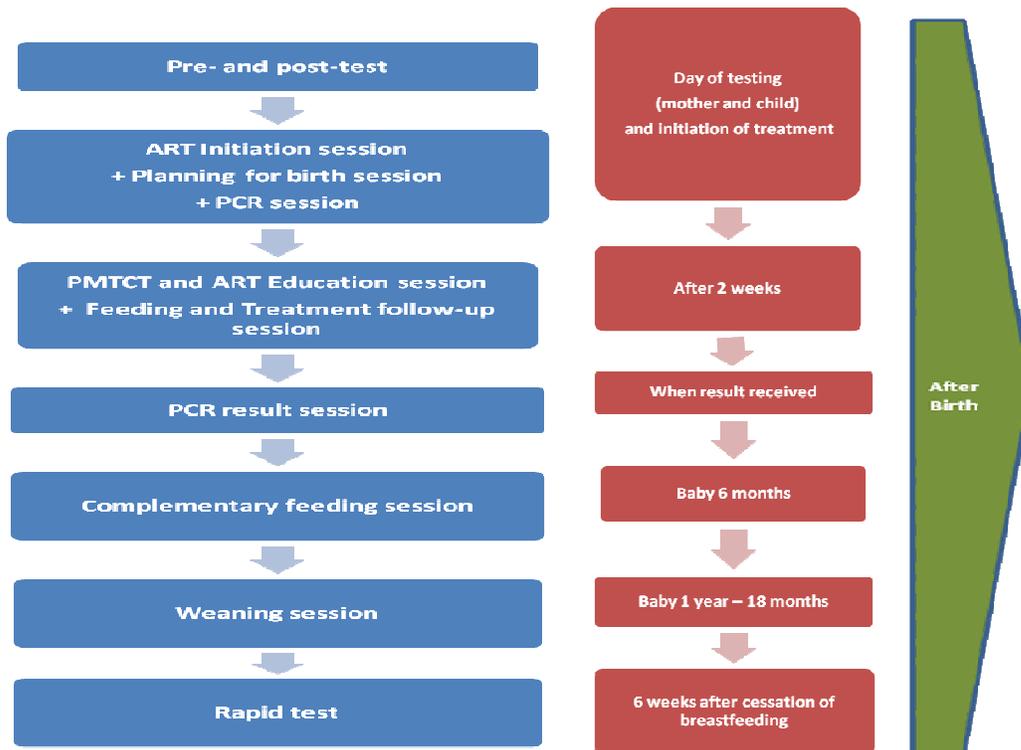
2.2. Women already on ART



2.3. Women tested during delivery



2.4. Women tested during breastfeeding



3. Monitoring and evaluation

Any patient support activity needs to be monitored to guide and improve our activities in terms of attendance of sessions by patients and to assess the work load of the counselors.

The following indicators should be measured, each linked to important key moments:

| Indicator | Numerator | Denominator | Target |
|--|--|--|--------|
| Percentage of newly diagnosed HIV positive pregnant women in the programme attending the ART initiation session | Number of newly diagnosed HIV positive pregnant or breastfeeding women attending the ART initiation session | number of newly diagnosed HIV positive pregnant or breastfeeding women | ≥ 85 % |
| Percentage of newly diagnosed HIV positive pregnant women in the programme attending the PMTCT and ART education session | Number of newly diagnosed HIV+ pregnant or breastfeeding women attending the PMTCT and ART education session | number of newly diagnosed HIV+ pregnant or breastfeeding women target | ≥ 85 % |
| Percentage of HIV positive women in the programme attending the Planning for Birth session | Number of HIV+ pregnant or breastfeeding women attending the Planning for Birth session | number of HIV+ pregnant and breastfeeding women | ≥ 85% |
| Percentage of HIV positive women in the programme attending the Baby Feeding and Treatment Follow-up session | Number of HIV+ post-partum women attending the Baby Feeding and Treatment Follow-up session | number of HIV + post partum women attending the 1st PNC | ≥ 85 % |
| Number of HIV positive women in the programme attending the Complementary Feeding session | Same | | ≥ 85 % |
| Number of HIV positive women in the programme attending the Weaning session | Same | | ≥ 85 % |

Source of verification: counselors tally sheet (see annex 2) and PMTCT register

4. Sessions

| Group Pre-test Session | | | |
|---|---|--------------|--------------------|
| Target group | Pregnant women who come for first visit ANC consultation | | |
| Objectives | To understand the basic information on HIV infection, prevention of transmission to the child and treatment | | |
| Timing | 1st ANC visit | Mode | Group |
| Duration | 20 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduction of facilitator - Explain objectives of the session <p>2. Why should you test for HIV?</p> <ul style="list-style-type: none"> - We would like to offer you an HIV test, as this is a standard proposal to all women coming for ANC/PNC - We propose an HIV test, because when you are HIV infected, there is a chance of passing HIV to your baby during pregnancy, delivery or breastfeeding. - Knowing your HIV status will allow us to give you and the baby treatment, during pregnancy, delivery and straight after birth, so that the chances of infecting your baby with HIV are very small. - Only by taking the test can you be sure of your HIV status and protect yourself and your family. <p>3. What is HIV? CARD 1</p> <ul style="list-style-type: none"> - A healthy body has an immune system that defends against all kinds of diseases that try to attack us, like TB, flu, malaria. Our 'immune system' acts like the soldiers of the body, we call them CD4. - HIV is a virus that attacks this immune system (the CD4 cells): slowly the body will become weaker. Even if you are feeling well, the virus is causing damage in your body. All kinds of diseases will be able to enter: fever, diarrhea, TB, mouth sores. Without treatment, the virus will continue to damage the immune system and eventually, an infected person will die. <p>4. How is HIV treated? CARD 2</p> <ul style="list-style-type: none"> - HIV cannot yet be cured but there is a treatment that can control HIV, called Antiretroviral Therapy (ART). - ART will fight the HIV virus and help our body to keep enough CD4 cells so that you stay strong. It will make sure the amount of HIV in your blood (viral load) stays low and it will increase the chances that your baby will be born healthy and you stay in good health. - ARV's do not kill all HIV in the body. The ART helps our body by suppressing the virus, but every day your body needs a new pill to help it fight. ART has to be taken for the rest of your life, but when you take it correctly, you can lead a good and long life with HIV. <p>5. How is HIV spread? CARD 3</p> <ul style="list-style-type: none"> - There are 3 ways of transmission of HIV: <ol style="list-style-type: none"> 1. through sexual contact | | | |

2. from a mother to her child during pregnancy, delivery or breastfeeding
 3. through contact with infected blood
- HIV is not spread through shaking hands, kissing or hugging, through sharing food or utensils, or through mosquito bites
- 6. How can you prevent transmission? CARD 4**
- Transmission from a mother to her child: A pregnant woman who is HIV+ has a high chance of having a HIV negative baby, when:
 - Starting ARV as soon as possible and taking the drugs every day at the same time.
 - Delivering at a health facility where staff can take precautions to protect the baby.
 - Exclusively breastfeeding the baby for 6 months
 - Giving the baby treatment for 6 weeks starting right after birth
 - Transmission to a partner can be prevented by practicing safe sex (using a condom)
- 7. Why to take your partner for testing?**
- If you are HIV- but your partner is HIV+, you can get infected during pregnancy with a high risk of transmission to your baby
 - If you are HIV+ and your partner isn't, you can take the appropriate measures to keep him HIV-
 - If you are both HIV+, you will both have access to treatment and support.
- 8. How does the test procedure work?**
- The test is voluntary and you are free to decide not to take it. Next time you come for ANC, we will propose it again.
 - If you do decide to take the test, be assured that the result is confidential and that a counselor is there to support you.
 - If your test is positive, it means that you are infected with the HIV virus. Even if you feel and look healthy, it is possible you are infected. You will get started on treatment in order to protect your baby from becoming infected.
 - If the test is negative it means that no trace of HIV could be found in your blood. However, we will invite you again to take the test in 3 months because it takes 3 months for any traces of the virus to become visible in your blood.
- 9. Closure of session**
- Check if clients have any further questions

| Individual Pre and Post-test Session | | | |
|---|--|---------------|------------------------------|
| Target group | Pregnant women who come for first visit ANC consultation | | |
| Objectives | To assess understanding of HIV To obtain informed consent | | |
| Duration | 20 min | Timing | After group pre-test session |
| Mode | Individual | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduction of facilitator - Explain confidentiality <p>2. Ask for Consent</p> <ul style="list-style-type: none"> - Is there still any information that is not clear after the group session? Rectify or complete the client's explanation. - Can you tell me why it is important to take an HIV test? - You are free to decide to take a test. Do you agree to take an HIV test today? <p>3. Explain test procedure</p> <p>If you agree to take the test, we will take a drop of blood from your finger. This blood is put on the rapid test. After about 10 minutes the result will appear on the test. If the test is positive we will take another test to confirm the result.</p> <p>The test taken here is confidential, we will not share the result with anyone else but you. If you turn out to be HIV positive, medical care and counseling are available to support you.</p> <p><i>While waiting for the test result counselor to perform TB screening tool as per national protocol. If positive and woman is a TB suspect, counselor to inform clinician and to follow local TB diagnostic algorithm</i></p> <p>IN CASE OF A POSITIVE RESULT</p> <p>4. Give the test result</p> <ul style="list-style-type: none"> - "The test is positive, this means you have HIV". - Give the patient a moment to consider the result, verify whether she understands the result and give emotional support ("How does this make you feel?",...). <p>5. Assessment of the patient's support system</p> <ul style="list-style-type: none"> - You will be helped and supported here at the health centre, and will receive full medical care free of cost. The test taken here is confidential, nobody will find out the results. You will decide who to tell and when, when you are ready. - "Do you have anyone at home you can talk to about your test result, a friend or family member who can support you?" <p>6. Testing of family members</p> <ul style="list-style-type: none"> - Remember that HIV is transmitted from mother to child and through sexual contact. This means | | | |

that possibly your partner and other children are infected. Ask your partner to come to this clinic to learn more about HIV testing and counseling, and bring your children for testing. All test results are kept confidential.

- “How could you convince your partner and children to come for testing?” (propose invitation letter, propose couple testing,...)

7. Risk reduction plan

- The best way to prevent your baby from getting HIV is by starting treatment today. We would like to have some time with you later today⁹ to discuss further on this.

8. Closure of session

- Check if the client has any further immediate questions and invite her for a follow-up session on treatment after she has seen the clinician or nurse.

IN CASE OF A NEGATIVE RESULT

4. Give the test result in a neutral way

- “The test is negative. This means that we did not find HIV in your blood.”
- “How does this make you feel?”

5. Retesting and testing of family members

- The first 3 months after infection, the virus is not visible in your blood. Therefore we will invite you again for testing on a 3-monthly¹⁰ basis during your pregnancy, at delivery and during breastfeeding, so as to be certain that you stay HIV negative and will not transmit HIV to your baby
- As HIV is transmitted through sexual contact, it is important to know the status of your partner too. You could tell your partner you want to talk about HIV testing so that the two of you can be closer, make decisions together, and keep your family healthy. Ask your partner to come to this clinic—or another clinic that is convenient—to learn more about HIV testing and counseling.

6. Risk reduction plan

- You can take precautions to protect yourself and the baby from HIV. Getting HIV during pregnancy or breastfeeding is a high risk for transmitting HIV to your baby. Practicing safe sex, using a condom, is the best way to stay HIV negative.
- “How could you prevent yourself from getting HIV?”

7. Closure of session

Check if the client has any further immediate questions

⁹ After visit to the clinician or nurse; the second counseling session should be done by the same counselor, if possible

¹⁰ The precise timing of the retesting should be adapted according to local guidelines. Linking a retest to a specific EPI appointment can be an effective strategy.

| Pre-test Session at delivery | | | |
|--|--|--------------|------------|
| Target group | Women who come for delivery who did not receive a test before or tested HIV negative in the past | | |
| Objectives | To obtain consent for HIV test | | |
| Timing | Before or during labour | Mode | Individual |
| Duration | 5 min | Tools | |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Facilitator introduce him/herself <p>2. Why test for HIV?</p> <ul style="list-style-type: none"> - We would like to offer you an HIV test, before you deliver, this is a standard proposal to all women who come for delivery. - We propose an HIV test, because when you are HIV infected, there is a chance of passing HIV to your baby during delivery or breastfeeding. - Knowing your HIV status will allow us to give you and the baby treatment, during delivery and straight after birth, so that the chances of infecting your baby with HIV are smaller. <p>3. Ask consent</p> <ul style="list-style-type: none"> - Can you tell me why it is important for us to take an HIV test now? - The test is voluntary and you are free to decide not to take it. The test result is confidential and we will be there to support you in case you test positive. You can choose when you would like to receive the result of the test. - Do you agree to take the test? - When would you like to receive the result? - Do you agree be given treatment during delivery in case you test positive? <p>4. Closure of session</p> <ul style="list-style-type: none"> - Check if clients have any further questions <p><i>Post test counselling can be offered after delivery</i></p> | | | |

| ART Initiation session | | | |
|--|---|--------------|--------------------|
| Target group | Women who come for ANC consultation and are found to be HIV+ | | |
| Objectives | Defining life goals and motivation for treatment Being able to take ART correctly and developing strategies for good adherence | | |
| Timing | On day women come for 1st ANC visit, after they are found to be HIV positive. | Mode | Individual |
| Duration | 30 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Explain objectives of the session - Emphasize confidentiality <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask the first concerns the woman has, now that she found out she is HIV+. Leave space for emotions. <p>3. Education in a nutshell CARD 4</p> <p>Finding out you are HIV+ is a lot to deal with today but it is important that we already speak for a moment about the health of your baby. You could have a HIV- baby if you take the right precautions:</p> <ul style="list-style-type: none"> - <i>Start ART as soon as possible:</i> HIV has no cure but there is a treatment to control HIV in your body. All pregnant women are to start this treatment as soon as possible as this gives a high chance of preventing the transmission of the virus from you to your baby. We invite you to start taking the treatment today, but it is up to you to decide if you feel ready for this. - <i>Delivery in a health facility:</i> It is safest to go to a health facility for delivery and inform the staff you are HIV positive; then the staff will be able to take all precautions to protect the baby during delivery. - <i>Correct feeding of the baby:</i> After delivery, it is important to only give breast milk for the first 6 months. After 6 months other foods can be introduced, while continuing breastfeeding until at least 12 months. - <i>Correct treatment of the baby</i> The baby will be given different protective syrups right after birth until you stop breastfeeding. <p>Through these 4 actions you will protect your baby and the chances of him or her becoming infected are very small. Today we will focus on how to take the treatment correctly. We will make a plan together to enable you to take the medication correctly.</p> | | | |

=> Fill out the adherence plan template (annex 1)

4. Adherence step 1: My motivation to start treatment

"Can you tell me 3 main reasons why you would want to stay healthy and start this treatment? Think about things that matter to you in life, or people who are important"

Write this down at the top of the adherence plan.

=> Direct the woman towards the importance of starting treatment today to prevent transmission to her baby

5. Adherence Step 2: Identify support system

- Explain adherence goal:

"It can be a big help to tell someone about your HIV status. This person could help remind you to take your drugs, be a listening ear, accompany you to the hospital, etc."

- Identify barriers:

o *"Can you think of someone you could tell about your HIV status (any family member, friend, coworker)?"*

o *"What are the reasons you feel unable to talk about your status to some people?"*

- Make a plan:

o *"Do you have a person close to you that can support you in your treatment?"*

o *"Can you think of someone who could help you in disclosing to your partner?"*

6. Adherence Step 3: Planning for future appointments

- Explain the adherence goal:

"During the coming months, you will need to come regularly for your medical check-up, to check the baby and to get a new supply of drugs."

- Identify barriers:

o *"What might cause you to miss monthly appointments?"*

- Make a plan:

o *"How will you get to your medical appointments? Could you come with someone else from your village or neighborhood?"*

o *"What could you do if something prevents you from coming to your appointment (e.g. no money for taxi, train not working, raining when you usually walk, sick child, being too sick yourself)?"*

o *Would you agree to have a Community Health Worker or a member of a peer support group visit you in case you didn't make it for your appointment in time?*

o *"How can you make sure you remember your appointments?"(e.g. mobile phone, number of pills left,...)*

7. Adherence Step 4: Creation of a medication schedule

- Review adherence goal:

"HIV treatment is one pill a day that needs to be taken every day at the same time."

- Identify barriers:

o *"Can you tell me how a regular day looks like for you (wake up time, work time, meals and bed time)?"*

o *"Do you have any rituals or routines, that could be linked to taking your medication?"*

o *"How does that day look different for week/weekends?"*

o *"What moments of the day/days of the week might be difficult to take your medication?"*

- Make a plan

o *"According to your schedule, what would be the best time for you to take your HIV treatment?"*

8. Adherence Step 5: Reminder strategies

- Explain adherence goal:
“Having reminders can help you to focus on the reasons to stay healthy, keep your baby negative and to remember when to take your HIV treatment”
- Identify barriers
 - o *What difficulties have you previously faced with remembering to take medication (like antibiotics or other)?*
 - o *How have you previously reminded yourself to take these medications?*
- Make a plan
 - o *“Can you think of an object that could help you to remember the reasons to stay healthy and alive and take treatment? Some people use stickers, a little piece of fabric or whatever they have available.”*
 - o *“These reminders can be put in your house/workplace to remind you of your reasons to stay healthy and to take your treatment. Where could you place each reminder so that you can see them at each dosing time?”*
 - o Place the sticker or piece of fabric on the patient’s adherence plan next to the 3 main reasons for staying healthy.
 - o Encourage the patient to read these reasons to stay healthy every day preferably right before they take their medication.
 - o *“What other things could you use to remind you to take your medications (set cell phone alarm, get family members to remind you)?”*

9. Adherence Step 6: Managing missed doses

- Explain adherence goal:
“As HIV treatment has to be taken every day, it is necessary you know what to do in case you miss a dose. Everybody can miss a dose, but it’s important to know what to do in case this happens”
- Identify barriers:
 - o *“In which situation could you forget (or be unable) to take your medication?”*
 - o *“What will you do if you forget to take your treatment or if you are late for a dose?”*
- Make a plan:
 - o *“Take your medication immediately when you remember, unless your dose is due within less than 8 hours. Then continue on the same (initial) medical schedule. Remember to inform your doctor or nurse of any missed doses”*

10. Adherence Step 7: Storing medication at home and keeping extra doses

- Explain adherence goal:
“It is important to identify a convenient place to store your drugs and to carry some with you in case you can’t access your treatment on time”
- Identify barriers:
 - o *“Do you worry about people seeing your medication?”*
 - o *“Where could you keep your medication at home?”*
 - o *“What type of situation could happen where you would not have access to your medication?”*
- Make a plan:
 - o *“Which safe and convenient place can you identify to store your drugs at home or at the place where you would take your drugs?”*
 - o *“Where could you carry extra doses of drugs in case you do not make it home on time for your scheduled dose (in pocket of jacket or bag that you usually take when you go*

out)?”

- “What could you keep them in (eg. envelope, little plastic bag or container, ...)?”

11. Adherence step 8: Dealing with side-effects

- Review adherence goal
 - “In the first few weeks of the treatment you might experience some light side effects such as nausea, headache, feeling fatigued or dizziness, difficulty sleeping and unusual dreams. Severe side effects are rare. Remember that if you do not feel well, you should continue your treatment and come to the clinic so the nurse/doctor can help decide what is wrong. Please don’t stop taking drugs as this will prevent the medication from working properly. The pills do not harm your baby, on the contrary, they prevent the HIV to pass from your body to the child”.
- Identify barriers
 - “What kind of side effects do you think might prevent you from taking your medication?”
 - “How could you deal with these side effects?”
- Make a plan:
 - Identify a plan on what to do when experiencing minor side effects
 - “If small side effects appear, they may just last for a few days. Remind yourself the reasons why you want to stay healthy and alive and keep taking your treatment.”
 - “If you vomit in the first hour after taking your treatment, take all of them again. If one hour or more has passed, don’t.”
 - Identify a plan on what to do when experiencing severe problems:
 - “If the side effect is bothering you so much that it may prevent you from taking your medication then **DO NOT STOP YOUR TREATMENT**. Continue to take your medication and go to the clinic as soon as possible to see your doctor/nurse.”

12. Review adherence Step 1: My motivation for treatment

- Explain the adherence goal:
 - “To ensure the health of your baby, you should start your treatment as soon as you are ready.”
 - Review patient’s 3 reasons to start treatment.
- Identify barriers:
 - “What are some of your concerns regarding starting ARV treatment?”
 - “Do you think you will be ready to start ARV’s today?”
- Make a plan:
 - “If some of your concerns haven’t been addressed in this session, we may discuss them in the coming sessions and see how to overcome them. Always feel free to express your concerns and we can discuss them”
 - In case the patient feels ready to start ARV’s as soon as possible today, refer them to clinician/pharmacy.
 - In case the patient does not feel ready to start: explore her concerns further and fix a day for a next appointment to discuss this again.
 - Explain that the first goal for her is to start treatment to ensure we do our best to prevent transmission to the baby and other steps can be dealt with at the next session.

13. Closure of session

- Check if patient has any further questions.
- Add the adherence plan to the patient's file and give a copy of the adherence plan to the patient.

| PMTCT and ART education session | | | |
|---|---|--------------|---------------------|
| Target group | Women who have initiated ART at 2 nd ANC or follow-up PMTCT visit | | |
| Objectives | <ul style="list-style-type: none"> • Understanding the way the virus works, the immune system, the action of ART and the benefits of lifelong treatment for the mother • Planning for delivery, breastfeeding and treatment of the baby | | |
| Timing | 2- 4 weeks after initiation | Mode | Group or individual |
| Duration | 20 minutes | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Congratulate for having started the treatment - Explain objectives of the session <p>2. What is HIV? CARD 1</p> <ul style="list-style-type: none"> - A healthy body has a defense against all kinds of diseases that try to attack us. This defense system is made out of CD4 cells or soldiers of the body. When a person is infected with HIV, the virus will attack the soldiers or CD4 cells. The body will become weaker and all kinds of diseases will be able to enter: fever, diarrhea, TB, mouth sores. Even if you are feeling well, the virus is causing damage in your body. You may not see this damage right now but later in life you might have a higher chance to develop heart problems or develop some cancers . <p>3. How is HIV treated? CARD 2</p> <ul style="list-style-type: none"> - HIV cannot be cured but it can be controlled. The treatment, called ART, will fight the HIV virus and make sure your defense system gets stronger again. - ART cannot kill all the HIV in your body, but makes sure the amount of HIV in your blood (viral load) stays low. The less HIV is in your blood, the less chance you can give HIV to your baby. - By starting ART early we are preventing your baby from becoming HIV positive. So even though you are feeling well it is really important you start ART early and that you take your medications regularly. <p>4. How to adhere to your treatment? CARD 5</p> <ul style="list-style-type: none"> - The ART helps our body by suppressing the virus, but every day your body needs a new pill to help it fight the virus. It is important to take the ART correctly as prescribed, to keep the amount of HIV low. - ART has to be taken for the rest of your life¹¹, so you stay in good health and can take good care of your child. - You will see that with time, taking one pill a day becomes a habit. Learning a new habit takes time and practice and we are here to help you in this. - Good adherence and taking care of your own and your baby's health also means coming to your scheduled appointments, so that the consultant can do a good follow-up of your health and that you have enough medication. | | | |

¹¹ If in line with project policy; some projects might choose to put pregnant women on ART temporarily only

5. What are the risks of not adhering to your treatment? **CARD 6**

- When we often take our pills too late, when we forget to take a dose, when we do not take all of our pills or when we stop the treatment because we are feeling better, etc. there are certain risks:
- The chance of transmitting HIV to your baby will increase. By not taking ART regularly, you will not have enough ARVs in your blood to fight the HIV. The amount of HIV in your blood will increase, increasing the chance of passing HIV to your baby.
- You may get sick, as your defense system (CD4) will be further destroyed.
- You may develop resistance. If the HIV virus encounters few ARVs in the blood, it can transform itself, and become able to resist the ARV attacks meaning that your ARVs will no longer work to kill your HIV.

6. Delivery plan **CARD 7**

One of the key moments where transmission of the virus can occur is during delivery. This is why it is best to deliver at a health facility. If you inform the health staff about your status, they will know how to handle the delivery so that the risk of transmission to the baby is as low as possible. Preparing well for delivery means:

- knowing to which hospital or health centre you will go
- knowing how you will tell the medical staff you are HIV+
- having identified someone who will take you there
- knowing how you will reach the hospital (transport)
- having prepared enough of your own medication to take with you

If you cannot deliver at your regular health facility:

- If you will travel and stay at a different house, you need to prepare enough medication for yourself and the baby: discuss this with the clinician so they can give you a transfer letter and enough drugs
- Identify a treatment site near where you will be, for the delivery, ART drug refill and for check-up and drugs for your baby.

7. Breastfeeding **CARD 8**

For the first 6 months, your baby should have only breast milk. Never give him or her cow milk or instant milk, water, tea or anything else. This is important for all babies, regardless of the HIV status of their mother. However for HIV+ mothers, mixing breast milk with other food or liquid will increase the chances of transmitting the virus.

It is only after 6 months that you may introduce some complementary foods like fruit and vegetables, rice, potatoes.

You can continue to breastfeed until the baby is 12 months old¹². After this other feeding options can be discussed.

8. Treatment for the baby **CARD 9**

- Right after birth, the baby will need to take a protective syrup for 6 weeks, called Nevirapine, this as well as the medication you are taking will protect the baby from becoming HIV positive. Six weeks later we need to change the syrup to another one, which the baby will take for the full period of breastfeeding. This syrup is called Cotrimoxazole and will protect him or her from other infections.
- If you tested positive during breastfeeding, your baby will need to be given both syrups at once.

¹² Adapt according to project

¹³ Adapt according to project

- We will show you how to administer this syrup to the baby. As with your own treatment, it is important to give this syrup every day without skipping a day.
- *Demonstrate to the group how to administer the syrup with a syringe.*

9. Testing of the baby

- The chance for your baby to become infected will be very small if you take the right precautions, but it's still possible. It is important to know as soon as possible if the baby is HIV+, so that he can start to take the treatment. This treatment will keep him strong.
- We will propose an HIV test for your baby a few times during the period of breastfeeding - the first test can be done 6 weeks after birth. We will send some blood for analysis, after xxx weeks¹³ you will receive the results. As during breastfeeding, the baby can still get infected, it is only after you stopped breastfeeding that we will take a final and conclusive test.

10. Closure of session

- If you deliver in a health facility, you stick to exclusive breastfeeding and both you and the baby take the treatment correctly, every day, the chances of transmission of the virus are very small. For now, most important is for you to continue to take your treatment to protect your baby!
- Check if there are any further questions

| Planning for birth session | | | |
|--|--|--------------|--------------------|
| Target group | Women who come for 3 rd ANC consultation or follow-up PMTCT visit | | |
| Objectives | <ul style="list-style-type: none"> • Revision of adherence plan • Making my plan for delivery • Feeding my baby • Giving treatment to my baby • Communication with the treatment team • Motivation for treatment | | |
| Timing | 4-6 weeks after initiation ¹⁴ | Mode | Individual |
| Duration | 25 minutes | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce facilitator - Explain objectives of the session <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the woman is doing, how she feels and how the treatment is going. - Congratulate her for continuing ART treatment. <p>3. Revision of adherence plan</p> <p>Go through the adherence plan that was put together during the previous session. Talk about how the woman dealt with the obstacles and if the strategy has to be revised for any of the steps.</p> <p>4. Adherence step 9: My delivery plan</p> <ul style="list-style-type: none"> - Explain adherence goal: <ul style="list-style-type: none"> <i>“As a big risk of transmission occurs during the delivery, it is best to deliver at a health facility. When this is not possible, delivery outside the health centre or at any other health centre should be well planned to take the right precautions. Wherever you deliver, it is best that you come for a check-up as soon as possible.”</i> - Identify barriers: <ul style="list-style-type: none"> ○ <i>“What could prevent you from delivering at your regular health facility?” (Explore whether there could be a problem of recognition of signs of labour, or a practical/geographical problem to get to the health facility)</i> ○ <i>“Do you have any plans to travel to another place during your pregnancy or once your baby is born?”</i> - Make a plan: <ul style="list-style-type: none"> (1) Make a plan <u>in case the patient will be staying in the area and will deliver at their regular health facility:</u> | | | |

¹⁴ Timing of this session will depend on the moment HIV was diagnosed: some women will be close to delivery - in this case, Planning Birth session should be combined with PMTCT and ART education session. In case testing is done at or after delivery, the Planning Birth session will be combined with other sessions and the delivery plan can be skipped.

- "How could you make sure you get to the health facility?"
- "Who could accompany you to the health facility?"
- "How could you make sure you have enough stock of medication with you?"
- "How could you tell the medical staff you are HIV+?"

(2) Make a plan in case the patient will be travelling to another site around the time of delivery

- *Where (to which health centre) could you go to for delivery and drug refill? "* - Identify a referral site
- Refer to clinician for a transfer letter and enough medication to cover the period of travel
- Go through other questions of plan 1

(3) Make a back-up plan in case the mother would not make it in time to the health facility.

- *"When can you come to the clinic after delivery, and how?"*
- *How can you give the syrup in the first days before you come to the clinic?*

8. Adherence step 10: Feeding the baby **CARD 8**

- Explain adherence goal:
 - "During breastfeeding, HIV can be transmitted from mother to child. But if you breastfeed correctly, the chances of transmission become very small "*
- Identify barriers:
 - *"What would prevent you from exclusively breastfeeding your baby during the first 6 months?"*
 - *"How do the people in your household think about exclusive breastfeeding?"*
 - *"How could you make sure no other family members give other liquids or food to the baby? "*
- Make a plan:
 - Make a plan on how to inform other household members on the need to exclusively breastfeed.

9. Adherence step 11: Treatment for the baby **CARD 9-10**

- Explain adherence goal:
 - "After delivery, the baby needs to be given NVP syrup for 6 weeks. The syrup needs to be given every day, without skipping any of the doses. This syrup will protect the child from getting HIV through breastfeeding"*
- Identify barriers:
 - *"What would prevent you from giving this syrup to the baby?"*
 - *"Is there anyone in your family that can help you to administer this syrup?"*
 - *"How will you remember to give this syrup, every day at the same time? "*
- Make a plan.
 - Practice administration of the syrup with the woman.
 - To administer the syrup, you need 3 devices: the syrup bottle, a syringe and a dispensing cap
 - Remove the cap from the bottle and place the dispensing cap in the bottle, so that it seals well the bottle.
 - Place the syringe on the dispensing cap.

- Turn the bottle upside down and aspirate the volume as directed by your clinician (this volume will increase as the baby 's weight increases)
- Put the bottle back in upright position and remove the syringe
- Place the dropper in the corner of the baby's mouth and slowly give the medicine. Aim for the inside of the baby's cheek instead of the back of the tongue
- *"What would help you to remember the time to give the syrup to the baby?" (e.g. time mother takes her treatment, stickers, alarm, other family members?)*

10. Adherence step 12: Communication with medical team

- Explain adherence goal
 - "It is important to discuss your medical concerns – any symptoms, medications, side effects with your nurse/doctor when you see them"*
- Identify barriers
 - *"What questions would you like to ask your doctor/nurse?"*
 - *"What might cause you not to ask your doctor the questions you have?"*
- Make a plan
 - *"How will you remember the questions you want to ask your nurse/doctor?"*
 - *"What other medical (if possible) or non-medical person (then make sure information passes to the clinician) do you trust in the clinic to help you address questions to your nurse/doctor?"*
 - *"How could you inform the medical staff in other facilities about your HIV status?"*

11. Review Adherence step 1: Motivation for treatment

- Look again at the reasons why to stay in good health and continue your treatment in the adherence plan. Review if the patient feels the reasons are still valid.
- Guide the woman towards acknowledgment of the importance of taking ART to prevent transmission to her baby through breastfeeding.

12. Closure of session

- Check if patients have any further questions and make a new appointment.

| Revision of adherence plan session | | | |
|--|---|--------------|--------------------|
| Target group | Women who come for 4th ANC visit or follow-up PMTCT visit | | |
| Objectives | Revision of adherence plan | | |
| Timing | 4 th ANC visit | Mode | Individual |
| Duration | 15 minutes | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduction of facilitator - Explain objectives of the session <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the woman is doing, how she feels and how the treatment is going. - Congratulate her for continuing her treatment <p>3. Revision of adherence plan</p> <ul style="list-style-type: none"> - Go through the adherence plan that was put together during the previous session. Talk about how the woman dealt with the obstacles and if the strategy has to be revised for any of the steps. <p>4. Review Adherence step 1: Motivation for treatment</p> <ul style="list-style-type: none"> - Look again at the reasons why to stay in good health and continue your treatment in the adherence plan. Review if the patient feels the reasons are still valid. - Guide the woman towards acknowledgment of the importance of continuing ART to prevent transmission to her baby through breastfeeding. <p>12. Closure of session</p> <ul style="list-style-type: none"> - Congratulate her for continuing ART and acknowledge that her next goal is to take the right precautions for delivery. - Check if patients have any further questions and make a new appointment. | | | |

| Feeding and treatment follow-up session | | | |
|---|--|--------------|--------------------|
| Target group | Women who come after delivery | | |
| Objectives | <ul style="list-style-type: none"> • follow-up of ART adherence of mother and child • follow-up of breastfeeding and medication administration • explanation of PCR | | |
| Timing | 1-7 days after delivery | Mode | Individual |
| Duration | 20 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the woman and her baby are doing - Review delivery plan and assess adherence during delivery period <p>3. Revision of mother's adherence plan</p> <ul style="list-style-type: none"> - Getting to appointments - Medication schedule - Reminder strategies - Managing missed doses - Storing medication at home and keeping extra doses - Breastfeeding plan - Asses how the mother has been able to implement this plan and see if any changes need to be done - Treatment for the baby - Ask the mother to show you how she gives treatment to the baby and help her where needed <p>4. PCR testing for the baby</p> <ul style="list-style-type: none"> - You have been taking many precautions to avoid transmission of HIV to your baby but there is still a small chance of having a HIV negative baby. In case your baby did get infected it is important to know as early as possible. When we detect the virus early, the baby can start treatment early - this will help him or her to stay strong. - When the baby is 6 weeks old, we can do a first test. We will take some blood for analysis, after xx time¹⁵ we will receive the results. It is important to come back to the clinic to have your baby tested. <p>5. Adherence step 13: learning from mistakes</p> <ul style="list-style-type: none"> - Revise adherence goal: <ul style="list-style-type: none"> <i>“Remember that making a change in your daily life like taking medication every day takes time and practice. Forgetting a dose or missing an appointment can happen. If that happens, it is important to get back to your adherence plan as soon as possible instead of having hopeless thoughts and giving up.”</i> | | | |

¹⁵ Adapt according to project

- Identify barriers:
 - o *“How would you feel if one day you forget to take your medication or you do not feel like taking it?”*
 - o *“What kind of thoughts do you think may keep you from restarting your treatment regimen if you missed a dose?”*
 - Make a plan:
 - o *“What can you do to pick yourself up and start where you left off before you missed a dose or experienced a difficulty”*
 - o *“What can you learn from missing a dose that will help you avoid missing others in the future?”*
 - o *“Tell yourself that you’re only human and it is normal to forget, with time it will get easier. The most important thing is to go back to your medication schedule as soon as possible”*
- 6. Revision of adherence step 1: motivation for treatment**
- *“How are you feeling now that you are under treatment for some time and the baby is born?”*
 - *“Can you remember what were the things that were worth taking this treatment for?”*
 - *“Do you feel anything has changed in your motivation to take treatment?”*
 - Guide the woman towards acknowledgment of the importance of continuing ART to prevent transmission to her baby through breastfeeding.
- 7. Closure of session**
- Congratulate the patient for continuing her treatment and that of her baby
 - Check if patients have any further questions.
 - Make an appointment for PCR when the child is 6 weeks.

| PCR session | | | |
|---|--|--------------|--------------------|
| Target group | Women with a baby of 6 weeks old | | |
| Objectives | <ul style="list-style-type: none"> • follow-up of ART adherence of mother and child • support to choose a FP method • explanation changes in medication for baby • explanation of PCR and sending of blood | | |
| Timing | When the baby is 6 weeks old | Mode | Individual |
| Duration | 25 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session - Emphasize confidentiality <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the woman is doing, how the baby is doing - Congratulate the mother for staying on treatment for herself and the baby and for coming today. <p>3. Revision of Adherence plan</p> <p>Go through the adherence plan that was put together during the previous session. Talk about how the woman dealt with the obstacles and if the strategy has to be revised for any of the steps:</p> <ol style="list-style-type: none"> 1) Support system / disclosure 2) Getting to appointments 3) Medication schedule 4) Reminder strategies 5) Managing missed doses 6) Storing medication + extra doses 7) Dealing with side effects 8) Feeding my baby <p>Identify new barriers if there were any and discuss about possible solutions.</p> <p>4. Adherence step 14: My Family Planning methods¹⁶ CARD 11</p> <ul style="list-style-type: none"> - Explain adherence goal: <ul style="list-style-type: none"> <i>“Even with HIV, it is possible to have healthy children. But it is best to plan a pregnancy so that the baby can be conceived when your health is fine (amount of HIV in our blood is low) to have the best chance to give birth to a HIV negative baby. Planning your next pregnancy will allow you the time to care for this baby, and make sure it grows healthy and with all the care you can give.</i> <i>There are easy methods to plan the next pregnancy. On top of this, HIV positive couples are advised to have protected sex to avoid re-infection. If your partner is HIV-, the only way to</i> | | | |

¹⁶ Refer to the family planning key messages and visual aid for detailed information.

protect him is by using a condom. Dual protection is the safest way"

- Identify previous barriers:
 - o *"Which FP methods do you know? "*
 - o *"Have you ever used any of them?"*
 - o *"Is it possible to discuss with your partner the use of condoms?"*
- Make a plan.
 - o *"How could you speak to your husband in order for him to accept these family planning methods?"*
 - o *"Which FP method would best suit you?"*

5. Revision of adherence step 11: Treatment for the baby - Cotrimoxazole

- Explain adherence goal:

"At 6 weeks, the baby needs to be given a different syrup or dispersible tablet. This medication will protect the child from infections and keeps his immune system strong. After you stop breastfeeding, and do a final HIV test and the baby is proven HIV negative, you will be able to stop giving this syrup"

"If you tested during breastfeeding, you will have had both syrups from the start no matter what is the age of the baby - after 6 weeks you can continue with only the Cotrimoxazole syrup.
- Identify previous barriers:
 - o *"How did you manage to give the syrup during the first 6 weeks?"*
 - o *"What would prevent you from giving this follow-up syrup to the baby?"*
 - o *"Is there anyone in your family that can help you to administer this syrup?"*
 - o *"How will you remember to give this syrup, every day? "*
- Make a plan.
 - o *"What would help you to remember: stickers, alarm, other family members?"*
 - o *Practice how to administer the syrup with the mother*

6. PCR testing for the baby CARD 12

- Women who are HIV positive can transmit the virus to their children during pregnancy, during the delivery and during breastfeeding. Even though you took a lot of precautions for the baby's health, there is still a small risk of transmission.
- Now that the baby is 6 weeks, he or she can be tested for HIV. We will take some blood from the baby's foot and send it for investigation. This investigation will take about xx weeks¹⁷.
- If the test comes back negative it means we could not detect HIV for now. But as long as you breastfeed, there is still a risk for your baby to get HIV. To prevent transmission, you will still need to take your medication correctly, and exclusively breastfeed until the baby is 6 months old. We will do another test when the baby is XX months¹⁸ and then again after you have stopped breastfeeding.
- When the test is positive, it means your baby has been infected with HIV. We will repeat the PCR to confirm the result but the baby will be started on ART as soon as possible, so that his or her body stays strong to fight the virus.
- It is very important to come back for the result of your baby, so we can give you and your baby the right care.
- If the mother agrees, perform the PCR test

7. Closure of session

- Congratulate the patient for taking the test and continuing treatment for herself and the baby

¹⁷ To adapt according to project setting

¹⁸ To adapt according to national EID algorithm

- Check if she has any further questions.
- Make an appointment for a counseling session after xx weeks to share the PCR result

| PCR result session | | | |
|--|--|-------------|------------|
| Target group | Women who agreed on PCR testing | | |
| Objectives | <ul style="list-style-type: none"> • Sharing of PCR result • Adherence follow-up | | |
| Timing | When the PCR result has come back | | |
| Duration | 20 min | Mode | Individual |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session - Emphasize confidentiality <p>2. Ask how the woman is doing, how the baby is doing</p> <p>3. The PCR result</p> <p>Ask what she remembers of the explanation you gave last time about the PCR test. Ask if she is ready to receive the result.</p> <ul style="list-style-type: none"> ▪ If “negative” <ul style="list-style-type: none"> - Your baby’s test result was negative. That means the child is not infected at the moment. This is not a final test: for as long as you breastfeed, there is still a chance of infection and we will propose other tests in the course of the coming months. After you have stopped breastfeeding the child will take a final HIV test that will give us the final result. Your next test will be at xx months of age.¹⁹ - By continuing your ART treatment during breastfeeding you can keep the chances of transmitting very low. The child will continue on Cotrimoxazole. Be sure to keep breastfeeding without mixing with other liquids, no cow milk or formula. - If you stop breastfeeding, you should bring the baby for an HIV-test 6 weeks after stopping breastfeeding. - The baby should continue with the normal immunization schedule. The clinic will aim to attend to you and all of your babies needs on the same day. - Congratulate the mother for all her efforts so far. ▪ If “positive” <ul style="list-style-type: none"> - “Your baby’s test result was positive. That means your baby is infected with HIV.” Give time for the result to sink in for the mother. When she is ready to talk, ask her how she is feeling. - Even if a lot of precautions were taken, there is always a small percentage of children that will be born with HIV. This does not mean that the child will get very sick or will soon die. When the baby starts ART, there is a good chance that he/she can grow to be an adult and can lead a good life. - The baby will have a confirmatory PCR test performed, but this should not delay the baby from being started on ART. You will see a counselor again before initiation of | | | |

¹⁹ To adapt according to national EID algorithm

treatment for the baby

- You should continue to breastfeed the baby until he or she reaches the age of 2 years. Breast milk will help to keep the child healthy.
- Congratulate the mother for all the efforts she has done and assure she will be able to continue so in the future

4. Revision of Adherence Step 1: Motivation for treatment

- If negative:
 - "How are you feeling now that you are under treatment for some time and the first test came out negative?"*
 - "Can you remember what were the things that were worth taking this treatment for?"*
 - "Do you feel anything has changed in your motivation to take treatment?"*
 - It is important for you to continue your treatment so you can take care of your child.
- If positive:
 - "The child will need a lot of your support and he/she will need you to have the strength to help him with the treatment.*
 - What could be the reasons for you to continue taking your own treatment and to take care of your child?"*

5. Closure of session

- Check if patients have any further questions.
- Make an appointment for a counseling session at 6 months for breastfeeding advice (if baby negative) or ART initiation session (if baby positive).

| Complementary feeding session | | | |
|--|--|--------------|--------------------|
| Target group | Women with 6 month old baby | | |
| Objectives | <ul style="list-style-type: none"> • Revision of adherence plan • Introduction of complementary food | | |
| Timing | Baby 6 months | Mode | Individual |
| Duration | 15 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session - Emphasize confidentiality <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the woman and the baby is doing - Congratulate her for continuing treatment for herself and the baby <p>3. Revision of adherence plan</p> <p>Address specific issues, if there are any. Review obstacles and possible solutions.</p> <p>4. Adherence step 15: Introducing complementary food CARD 8</p> <ul style="list-style-type: none"> - Explain objective: <i>“After 6 months, you can slowly start introducing complementary foods. You can continue breastfeeding, but the baby has started to need more than milk: you can give him or her rice, fruits, vegetables. You can start with semi-solid food (soft or mashed) and gradually go towards more solid food. Start with giving 2 to 3 portions of half a cup a day, with still plenty of breast milk, day and night and gradually increase the times you give other food over the coming months”</i> - Identify barriers <ul style="list-style-type: none"> ○ <i>“What type of foods do you think are good to give to the baby? What type of foods are available to you that you could start giving to your baby?”</i> ○ <i>“How could you prepare this food?”</i> ○ <i>“How can you make sure the cup and spoon are clean?”</i> - Make a plan on what type of food, how often and how to prepare <p>5. Closure of session</p> <ul style="list-style-type: none"> - Check if the patient has any further questions. | | | |

| Weaning session | | | |
|--|--|--------------|--------------------|
| Target group | Women with a baby who is at least 12 months old | | |
| Objectives | <ul style="list-style-type: none"> • Revision of adherence plan • Weaning from breastfeeding | | |
| Timing | At a follow-up visit, drug refill or HIV test for baby | Mode | Individual |
| Duration | 30 min | Tools | PMTCT B+ flipchart |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session <p>2. Ask how the woman is doing, how the baby is doing</p> <p>3. Revision of adherence plan Address specific issues, if there are any. Review obstacles and possible solutions.</p> <p>4. Adherence step 16: Weaning from breastfeeding CARD 13</p> <ul style="list-style-type: none"> - Explain objective: <ul style="list-style-type: none"> <i>"Your child is now about xx months²⁰ old. It is time to stop breastfeeding and fully switch to other food. The child does not need the breast milk anymore. Once you stopped breastfeeding, there will be no more risk of HIV transmission. Stopping breastfeeding has to be done gradually over a span of a couple of weeks or a month; you can gradually decrease the number of times you breastfeed, and increase the amount and the number of times you give other food and give more and more other food until you no longer breastfeed at all. Six weeks after you stopped breastfeeding we can take a final test to know the status of the child."</i> - Identify barriers: <ul style="list-style-type: none"> ○ <i>"How do you feel about stopping with breastfeeding?"</i> ○ <i>"What foods are available at home or can you buy and are giving now to the child?"</i> ○ <i>"How often are you giving them, in which amount?"</i> - Make a plan: <ul style="list-style-type: none"> ○ <i>When could be a good time to stop breastfeeding?</i> ○ <i>What types of food will you give?</i> ○ <i>When could you come back for a final HIV test?</i> <p>5. Closure of session</p> <ul style="list-style-type: none"> - Check if patients have any further questions. | | | |

²⁰ Adapt according to project setting

| Rapid test session | | | |
|---|--|-------------|------------|
| Target group | Women with an HIV exposed baby | | |
| Objectives | <ul style="list-style-type: none"> • Rapid test for the child • Motivation for treatment | | |
| Timing | According to local EID algorithm | Mode | Individual |
| Duration | 20 min | | |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session - Emphasize confidentiality <p>2. Ask how the woman is doing, how the child is doing</p> <p>3. Rapid test for the child</p> <ul style="list-style-type: none"> - In addition to the regular HIV testing procedure, explain the meaning of the test result: <u>Negative:</u> If the result is negative, it means that the virus could not be detected in the child's blood right now. IF you are still breastfeeding or you have stopped breastfeeding recently, we will take a test again after you have stopped breastfeeding for 6 weeks as in the meantime, infection can still happen. If the result is negative and you have stopped breastfeeding more than 6 weeks ago, it means that the child is HIV negative. <u>Positive</u> If the test is positive and your child is less than 18 months or you are still breastfeeding or have stopped only recently, we will confirm the result with a PCR test. If the baby is more than 18 months old and you stopped breastfeeding more than 6 weeks ago, it means that your child is infected with HIV. He or she should then start treatment as soon as possible. We will guide you on how to take care of your baby and how to give him or her the treatment. <p>4. Announce the result and link to motivation for treatment:</p> <ul style="list-style-type: none"> - <i>If the child is negative:</i> <ul style="list-style-type: none"> o Announce the result and explain what it means. <i>"Thanks to the good care you took of yourself and of the baby, he or she is HIV negative. Congratulations!"</i> o Go back to the adherence plan. <i>"What could be the reasons for you to continue taking the medication the same way as before? What can motivate you to stay healthy and keep coming to the clinic?"</i> => Guide the woman towards acknowledgement of the importance of her own health to continue caring for her child - If the child is positive: | | | |

- Announce the result and let it sink in. Offer emotional support.

“Even if a lot of precautions were taken, there is always a small percentage of children that will be born with HIV. This does not mean that the child will get very sick or will soon die. When he or she can take the treatment correctly, there is a good chance that he/she can grow to be an adult and can lead a good life.”

The child will need a lot of your support and he/she will need you to have the strength to help him with the treatment. We will help you to take good care of the child, and guide you the whole way if you agree. There is a lot you can do to keep the child healthy. We will talk more about this after you and your child have seen the clinician..

- Go back to the adherence plan.

“What are the reasons for you to continue taking the medication the same way as before? What can motivate you to stay healthy and keep coming to the clinic? ”

=> Guide the woman towards acknowledgement of the importance of her own health to continue caring for her child.

5. Closure of session

- Check if patients have any further questions.
- Refer for medical care and more tests if necessary

| ART initiation for HIV-infected infants | | | |
|---|---|-------------|------------|
| Target group | Mothers of HIV+ infants | | |
| Objectives | <ul style="list-style-type: none"> • Explaining the importance of lifelong ART for HIV+ children • Putting together an adherence plan for the child's treatment | | |
| Timing | Upon initiation of the infant | Mode | Individual |
| Duration | 15 min | | |
| <p>1. Introduction</p> <ul style="list-style-type: none"> - Introduce yourself - Explain objectives of the session - Emphasize confidentiality <p>2. Give emotional support</p> <ul style="list-style-type: none"> - Ask how the mother is feeling about the test result of the child and about starting ART <p>3. Adherence step 1: Motivation for treatment</p> <ul style="list-style-type: none"> - Explain adherence goal <ul style="list-style-type: none"> <i>"Your child is HIV positive. As a child's immune system is weaker than that of an adult, they are more vulnerable to disease and the HIV virus can become stronger quite fast. That is why your child should start treatment right away. But he/she will also need the same things that any other child needs: to eat, to play, to laugh, to go to school, to be in a loving environment. There are many things you can do to keep your child healthy. He/she will need your support and care.</i> - Identify obstacles <ul style="list-style-type: none"> <i>"How do you feel about starting treatment for your child?"</i> <i>"What would prevent you from starting treatment for your baby?"</i> <i>"What could motivate you to continue taking care of yourself and caring for your child?"</i> - Make a plan: <ul style="list-style-type: none"> <i>"Write down the 2 or 3 main motivations to start treatment for your baby."</i> <p>4. Adherence step 2: support in your environment</p> <ul style="list-style-type: none"> - Explain adherence goal <ul style="list-style-type: none"> <i>"Caring for yourself and caring for your child will be sometimes difficult. Your child needs safe food, to be given the medication correctly, to be taken to all medical appointments. It can be helpful to have somebody to help you with all these tasks.</i> - Identify obstacles <ul style="list-style-type: none"> <i>"Who is aware of your HIV status?"</i> <i>"What would make it difficult to disclose your/your child's status to your partner"</i> <i>"Who could help you in disclosing your/ your child's status to your partner?"</i> - Make a plan: <ul style="list-style-type: none"> <i>"Can you think of someone who you can ask for help sometimes, to take the child to the clinic,</i> | | | |

or to help with feeding or medication?"

"Could you try to join a community support group, or would you agree to have a community health worker or support group member visit you at home?"

5. Adherence step 3: Planning for future appointments

- Explain adherence goal

"You already come regularly for your own medical appointment. Now you need to come with your child as well. Especially in the first months, you might need to come regularly. It is very important to respect the appointment so that we can give the best medical care possible. "

- Identify obstacles

"What might cause you to miss the appointments?"

"What might be an obstacle for you to come here when something is wrong with the child?"

- Make a plan:

Make adaptations to original adherence step if necessary

6. Adherence step 4: Medication schedule for your baby

- Explain adherence goal

"Your child will start ART treatment today. You should make sure your child takes the treatment every day, at the same time, the correct dose. The dose will change over time, according to the weight of the child.

- Identify obstacles

"When would be a good time to give your child treatment? (ex linking it to your own time of treatment)"

- Make a plan:

"What would be the best time to give treatment to your baby?"

7. Adherence Step 5: Administrating drugs to the baby

- Explain adherence goal:

"You should give the tablet and/or syrup twice a day each and every day to your baby

- Identify barriers

"What could cause difficulties in administrating the drugs to your baby? (crying, not wanting to swallow,...)

- Make a plan

Practice the administration of the syrup with the woman / show how to crush tablets if child needs tablets

*"Do not give the medicine when the baby is crying, but try to make him/her calm first
To ensure the child takes the medicine:*

- *Talk or sing to the child to help him or her stay calm.*
- *Wrap your child in a blanket and hold him or her in the bend of your arm—this will help keep the baby still.*
- *Place the dropper in the corner of the baby's mouth and slowly give the medicine. Aim for the inside of the baby's cheek instead of the back of the tongue*
- *Blow gently into your baby's face, which should make him or her swallow.*
- *Do not give medicine when your baby is crying or by pinching his or her mouth open.*
- *If your baby vomits medicine within 30 minutes of taking it, give the dose again.*

- *If the problem persists, you should talk to your nurse. You may be able to change medications or change the form of the medication that you are giving the child.*

8. Adherence step 6: Reminder strategies

- Explain adherence goal
"As with your own treatment, it is important that your child is given the medication at the same time, every day, without skipping a day. You take only one pill but the child will need the medication twice a day"
- Identify obstacles
"How do you remind yourself about your own treatment and how could this be used to remember giving treatment to your baby?"
- Make a plan:
Refer back to stickers, or tissue to remind of reasons for taking treatment and integrate child's treatment into this"

9. Adherence step 7: Managing missed doses

- Explain adherence goal
"As HIV treatment has to be taken every day, it is necessary you know what to do in case you miss a dose. Everybody can miss a dose, but it's important to know what to do in case this happens"
- Identify barriers:
"In which situation could you forget (or be unable) to give the child the syrup?"
"What will you do if you forget to give the treatment or if you are late to give it?"
- Make a plan:
 - *"Give the medication immediately when you remember, if the next dose is within more than 6 hours. Then continue on the same (initial) medication schedule"*
 - *"Remember to inform your doctor or nurse of any missed doses"*

10. Adherence step 8: Storing medication and keeping extra doses

- Explain adherence goal
"As you know for your own medication, It is important to identify a convenient place to store your drugs and to carry some with you in case you can't access your treatment on time."
- Identify barriers:
 - *"Where do you keep your own medication at home? Can you store your child's syrup there as well?"*
 - *"Is there a cool place to keep the medication (e.g. a clay pot)?"*
 - *"Is there anyone else who knows where this medication is stored and who can give it to the baby, in case you are not at home on time?"*
 - *"What type of situation could happen where you and your baby would not have the treatment with you?"*
- Make a plan:
 - *"Which safe and convenient place can you store your baby's drugs at home or a place where you usually take your drugs?"*
 - *Where could you carry extra doses of drugs for yourself and the baby in case you do not make it home on time for your scheduled dose (in pocket of jacket or bag that you*

usually take to work or when you go out)?"

11. Adherence step 9: Dealing with side-effects

- Explain adherence goal
"The medication may cause some side effects such as diarrhea (for Lop/Rit), anaemia (for AZT) or rash and jaundice (for NVP). If your child has difficulty breathing, is very pale, he/she bruises easily, develops rash or yellow eye come immediately to the clinic. Do not stop your child's treatment, only the doctor can assess if the medication is the cause- he/she will advise what to do."

- Identify obstacles
"What kind of side effects do you think might prevent you or your child from taking your medication?"
"How will you deal with these side effects?"

- Make a plan:
Make a plan on what to do in case the child experiences some diarrhea (give plenty of water or ORS - If it doesn't subside after 3 days, or there are more than 3 stools a day, report this to the clinic
When experiencing serious side-effects, you should report back to the clinic as soon as possible.

13. Closure of session

- Check if patients have any further questions.
- Make an appointment for follow-up counseling next time she comes

Annex 1 - Adherence Plan

Name patient:

Step 1: Motivation: My reasons for taking ART treatment are

.....

ART Initiation Session Date/...../.....

Step 2: Support system

Possible obstacles to disclosure :.....
 I will disclose to.....
 The person who can help me in disclosing to my partner is:.....

Step 3: Planning for appointments

Agrees to home visit Yes No

How I will get to my appointments:.....
 Back-up plan to get to my appointments:.....
 How I will remember appointments:.....

Step 4: Creation of a medication schedule

Possible difficult moment to take treatment:
 The best time for me to take my treatment is :

Step 5: Reminder strategies

My reminder tools are:
 I will put my reminder tools at:.....

Step 6: Managing missed doses

If I miss a dose, my plan is.....

Step 7: Storing drugs at home and keeping extra doses

I will store my medication in
 I will keep extra doses in

Step 8: Managing side effects

My plan for minor side effects is
 My plan for side effects that worry me is.....

PMTCT and ART education Session Date/...../.....

Planning for Birth Session Date/...../.....

Step 9: My delivery plan

If at regular health structure

I will be accompanied to the clinic by.....
 I will get there by (transport).....

If different health structure

Referral card and medication received: yes / no

| |
|---|
| <p>I will deliver at</p> <p><u>Back up-plan when no delivery in health structure</u></p> <p>I will come on (timing)for check-up by (transport).....</p> |
| <p>Step 10: Feeding my baby</p> <p>I will keep my family from giving other food to the baby by.....</p> |
| <p>Step 11: Treatment for my baby</p> <p>I plan to give the treatment daily at (moment).....</p> <p>I will remember to give the syrup daily through.....</p> |
| <p>Step 12: Communication with the medical team</p> <p>Questions I want to ask the consultant are.....</p> <p>My contact person at the clinic is</p> |

Revision of adherence plan Date/....../.....

Feeding and treatment follow-up session Date...../....../.....

Step 13: Learning from mistakes

What can I think of to stay motivated?

PCR session Date/....../.....

Step 14: My Family Planning methods

My choice of family planning method

I will suggest it to my husband by saying.....

PCR Result session Date/....../.....

Complementary Feeding session Date/....../.....

Step 15: Introducing complementary food

These are some of the foods that are easily available that I can give.....

I will start complementary feeding on.....

Weaning Session Date/....../.....

Step 16: Weaning from breastfeeding

I will start weaning on.....

I will give following foods to my baby

Rapid test Session Date/....../.....

Annex 2: PMTCT Education and Counselling Tally sheet

Counsellor:..... Clinic:..... Month:.....

| Session | ART initiation | PMTCT & ART education | Planning for birth | Revision of adherence | Feeding and treatment follow-up | PCR | PCR result | Complementary feeding | Weaning | Rapid test |
|------------------------------------|----------------|-----------------------|--------------------|-----------------------|---------------------------------|-----|------------|-----------------------|---------|------------|
| Week .../.../... .../.../... | | | | | | | | | | |
| Week .../.../... .../.../... | | | | | | | | | | |
| Week .../.../... .../.../... | | | | | | | | | | |
| Week .../.../... .../.../... | | | | | | | | | | |
| Week .../.../... .../.../... | | | | | | | | | | |
| Totals | | | | | | | | | | |

