

**ICAP Collaborative PMTCT and Pediatric HIV Strategic Planning Workshop
In Partnership with Tygerberg Children's Hospital, South Africa and S2S**

Title:	How to identify lost patients and bring them back into care
Country	Ethiopia
Host Name/ Title:	Dr. Tsigereda Gadisa, Director for M&ER
Session Goal:	To describe and discuss ICAP experiences implementing tracing systems to bring lost patients back into care and treatment.
Learning Objectives:	<ol style="list-style-type: none"> 1. To construct/examine criteria to define loss to follow up in the context of pediatric HIV and PMTCT services. 2. To identify common reasons children and pregnant women discontinue care and treatment in ICAP country settings. 3. To identify effective strategies to identify pediatric and PMTCT patients who have discontinued care and treatment. 4. To identify effective strategies to bring patients back into care and treatment and to support them to stay in care. 5. Describe likely barriers to implementation of the above strategies, as well as potential solutions to these barriers.
Instructional Method(s):	<ul style="list-style-type: none"> • Introductory exercise • Group brainstorming • Small group work and report back • Group discussion
Session Description :	<p>0 - 10 minutes:</p> <ul style="list-style-type: none"> • Each participant will introduce him/herself, including: <ul style="list-style-type: none"> - Name - Country office and position - One thing they have with them that says something about them (e.g. a photo of a family member, an Association membership card, a piece of jewelry given by a loved one, etc.) • The host will review the session learning objectives. <p>10 - 25 minutes:</p> <ul style="list-style-type: none"> • The host will lead the group to brainstorm common reasons that patients, especially children and pregnant women, discontinue care and treatment, based on their in-country experiences. Another participant will record the responses on flip chart. • The group will be asked to agree on the top 5 reasons that children and pregnant women specifically discontinue care and treatment. These will be circled on the flip charts. <p>25 – 60 minutes:</p> <ul style="list-style-type: none"> • The large group will be broken into 2 small groups. • Each group will be assigned one of the following topics: <ul style="list-style-type: none"> ○ How do we know which patients have discontinued care? ○ How do we find patients that have discontinued care, encourage them to return to care, and support them to stay in care? • Each small group will select a facilitator and a rapporteur. • Each small group will discuss their assigned question, practical strategies, likely

barriers to implementing these strategies, and possible solutions. Participants will keep the initial brainstorming session in mind as they answer their small group questions. Groups may want to use this template to guide their discussion and report back (using flip chart):

Group Question: _____

Strategy	Barriers	Possible Solutions

	<p>60 – 80 minutes:</p> <ul style="list-style-type: none"> • Each small group will present back a summary of their discussion, using the above template as a guide. Each group will have about 5 minutes: to present with a few minutes: for questions, clarifications, and brief discussion. Participants will be encouraged to discuss how practical these strategies would/would not be in their country settings. <p>80- 90 minutes:</p> <ul style="list-style-type: none"> • The host will ask for questions and clarifications. • The host will summarize the key points of the session.
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Session Notes and Summary

Session name: How to identify lost patients and bring them back into care

Note taker name: Asqual Getaneh

Major Discussion Points and/or Conclusions:

1. Define pMTCT LTFU:

- Timing: Did not come back for CD4 test after 3-7 days of appointment.
- Tracing or contact mechanisms are difficult
- There is a general definition for ART, maybe not relevant for pMTCT
- It is difficult to define “missed appointment”
- Consider tracing missing mothers at the immunization clinic where they usually bring their babies, because this represents not only a missed appointment but more importantly a missed opportunity.

2. Why are mothers not coming back for pMTCT?

- Poor and inadequate counselling in general
- Poor linkages within programs at the health facility (ANC, FP, immunization, OPD etc.)
- Self transfer-out to other clinics for fear of stigma after HIV testing
- Stigma: The fact that the mother becomes the first identified HIV positive member of the family might lead to accusations that she has brought disease into the family.
- Our systems are failing mothers: too many clinic visits, uncoordinated appointments, inaccessibility of the clinics due to lack of transportation and distance from their homes, separate appointments for exposed infants, separate clinical staging and CD4 count measurements, high staff turn over of HCWs which limits rapport, alternative , poor male involvement, cultural barriers, methods to confirm adherence such as pill counts in pMTCT have not been instituted.

3. How do we know mothers have not come back?

- In most cases there is no tracking system with few countries using appointment registers for pMTCT
- Mozambique programs use appointment registers
- Nigeria programs uses paediatric action groups

- Tanzania programs family support groups and peer educators
- Lesotho programs use telecommunication methods from vodacom to sms free of charge to trace mothers
- Swaziland programs use peer educators
- Ethiopia is initiating appointment registers and starting M2M groups has planned to use appointment calendars for pMTCT tracing and tracking.

4. What strategies can we place to trace missed/lost mothers?

- Establish appointment registers to track mothers
- Use cohort groups (M2M), family support groups and peer educators
- Coordinated appointments for mother and infant care.
- Strengthen PICT at all delivery points so that we will capture mothers who missed their appointments through contact at all delivery points
- Improve linkages to care and treatment services