Unpacking loss to follow-up issues in a rural PMTCT programme context

Formative Research for the Eliminating Paediatric AIDS in Zimbabwe project, Study 3

DRAFT

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Fadzai N.N. Mukora-Mutseyekwa et al
This is a report of formative research conducted in 2013 as part of the Eliminating Paediatric AIDS in Zimbabwe (EPAZ) project. EPAZ is a four-year (2012-16) implementation research project under the auspices of the World Health Organisation and the Ministry of Health and Child Welfare, Zimbabwe, one of six projects in Zimbabwe, Malawi and Nigeria that are part of the INSPIRE (INtegrating and Scaling up PMTCT through Implementation Research) initiative administered by WHO with support from the Canadian International Development Agency.

Three research studies were conducted through the formative research conducted by EPAZ:

1. **Assessment of feasibility and acceptability of nurse-led initiation of anti-retroviral therapy**
2. **The design of clinic-based mother support groups to enhance retention in PMTCT programmes**
3. **Unpacking loss to follow-up issues in a rural PMTCT programme context**

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This document may be cited as follows:

Executive Summary

This exploratory research exercise was carried out as part of formative research for a larger cluster randomised control trial to test the effect of introducing point of care PCR HIV testing for infants and mother support groups on retention in the PMTCT programmes. The study aimed to describe the perceptions and experiences of key stakeholders regarding loss to follow up (LTFU) of HIV infected pregnant women and HIV exposed infants in the PMTCT programme in Mutare and Makoni districts. These findings should inform the development of experimental interventions in the main EPAZ implementation study, inform the adoption of working definitions and standard operating procedures (SOPs) for the various concepts of ‘retention’ and ‘loss to follow up’ in the larger study, as well as general interventions against PMTCT LTFU within the population of Manicaland province, Zimbabwe. A descriptive cross sectional approach was employed which made use of both qualitative and quantitative techniques with data collected as follows: A desk review of clinic PMTCT records, structured interviews with clinic and community based health workers, focus group discussions with mothers who were currently enrolled in the PMTCT programme, and in depth interviews with mothers whose clinic based records suggested they were ‘lost to follow up’.

An important finding was a general data incompleteness and poor quality observed in the registers that form the Health Information system in the investigated sites. No apparent attrition was recorded in the antenatal stages of PMTCT but at delivery a significant number of HIV infected women are not on record as having delivered at the clinics (43%) while post-natally, the number of HIV exposed infants visiting the centres for postnatal review were observed to become progressively less with the duration of follow up and less as the number of visits increased. Only about 53% of infants are on record as having undergone a DNA PCR test for HIV and 14% of guardians whose infants had blood collected for DNA PCR did not receive the result. This study showed that the figure for number of infants commenced on ART represents 30% of the number of infants who tested HIV positive.

Reported reasons and contributors to the attrition observed included environmental factors such as weather conditions and long travelling distances; economic factors such as unaffordable transport costs and competing income generation related priorities; social factors such as fear of stigma associated with disclosure, lack of partner support/negative partner interference, religious restrictions, alternative treatment options; personal factors such as denial of HIV status and ill-health; clinic based service delivery issues such as inadequate information delivery resulting in poor knowledge and understanding of the programme expectations, delays and inaccessibility of related laboratory investigations and negative health care worker attitudes; and inadequate clinic based health information record, tracking and transfer systems that are insensitive to migration, travel and transfer issues. Various recommendations directed at the main cluster randomized trials, the PMTCT programmes in general, and areas for further research were derived from the above mentioned findings and discussion.
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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>CRCT</td>
<td>Cluster Randomised Control Trial</td>
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<tr>
<td>EPAZ</td>
<td>Eliminating Paediatric AIDS in Zimbabwe</td>
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<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
</tr>
<tr>
<td>HCW</td>
<td>Health Care Worker</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>LTFU</td>
<td>Loss To Follow Up</td>
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<tr>
<td>MIP</td>
<td>Mother Infant Pair</td>
</tr>
<tr>
<td>MoHCW</td>
<td>Ministry of Health &amp; Child Welfare</td>
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<td>MSG</td>
<td>Mother Support Group</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother To Child Transmission</td>
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<tr>
<td>OI</td>
<td>Opportunistic Infection</td>
</tr>
<tr>
<td>PCC</td>
<td>Primary Care Counsellor</td>
</tr>
<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
</tr>
<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission (of HIV)</td>
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<tr>
<td>PoC</td>
<td>Point of Care</td>
</tr>
<tr>
<td>VHW</td>
<td>Village Health Worker</td>
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<tr>
<td>WHO</td>
<td>World Health Organisation</td>
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</table>

Comment [E3]: Better to use lowercase for words and capitalise diseases and organisations e.g. mother to child transmission World Health Organisation.
1. INTRODUCTION

BACKGROUND

One of the major hurdles to achieving the goals of the Prevention of Mother to Child Transmission of HIV (PMTCT) programme is the tremendous attrition rates noted throughout the stages of care in the PMTCT cascade. Loss to follow up (LTFU) of mother-infant pairs (MIPs) during the PMTCT process breaks the cascade of care, prevention and monitoring. Studies carried out in many resource poor contexts including Zambia, South Africa, Cote d’Ivoire and Zimbabwe corroborate the finding that high dropout rates are not unusual. Losses of up to 80% between HIV diagnosis and ART initiation occur, averaging 30–60% at each stage in the diagnosis-treatment chain (HIV diagnosis–CD4 staging–enrolment for HIV care – treatment initiation).

LTFU impacts negatively on the PMTCT programmes in various ways: infants do not benefit maximally from interventions prescribed under PMTCT; mothers lose out on potential support systems provided through regular follow up in service centres; and impact of PMTCT interventions becomes nearly impossible to measure without accurate records of outcome data.

Of the roughly 10 million children born in Zimbabwe between 1980 and 2005, around 504,000 (5%) were vertically infected with HIV. The MTCT rate in Zimbabwe was 21-23% in 2004-05 and remained high (26-29%) in 2008-09. These figures are ethically unacceptable where PMTCT services offered in other programmatic contexts has been proven to lower MTCT rates to below 2%.

Various strategies have been implemented or studied in an attempt to mitigate LTFU. These include the creation of support groups such as Mother2Mother in various countries in Southern Africa where women who have gone through PMTCT with successful outcomes mentor their counterparts. Other suggestions include measures to counteract the economic barriers such as elimination of ART copayments and providing

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6 http://www.m2m.org/what-we-do/where-we-work.html. Retrieved August 2013
patients with transport fares. Research has actually shown this to be a cost-effective strategy from a payer perspective.

A South African study to assess the impact of using mobile phone text messaging as a tool for reminding and encouraging adherence to follow up suggested that SMS may prove a relatively cheap (US$1.20/woman) intervention with the potential to improve infant PCR follow up rates.

**STUDY AIMS AND OBJECTIVES**

The Eliminating Paediatric AIDS in Zimbabwe (EPAZ) consortium intends to carry out implementation research in the form of a cluster randomised control trial (CRCT) that aims to test whether mother support groups (MSGs) based at health facilities with point of care (PoC) technologies increase retention of HIV-exposed infants and early infant diagnosis and treatment (EIDT) of HIV infected children in PMTCT programmes. One of the two primary outcomes of this study is ‘Retention rates of HIV-exposed infants in post-natal follow-up at 12 months’ hence the need to understand more fully the issues surrounding follow up and retention within the PMTCT programme in this context.

Within the context of a broader CRCT, this formative study aimed to offer the following outcomes;

- To come up with working definitions and indicators for the concepts of ‘follow up’ and ‘retention’ for operationalisation within the main EPAZ CRCT
- To inform the crafting of standard operating procedures (SOPs) that guide follow up and retention activities within standard of care and intervention MSG arms in the main EPAZ CRCT
- To inform the delivery of the main study interventions to the study population (i.e. MSGs and PoC PCR DNA testing for HIV exposed infants)

In addition to these achievements, there remains a void in terms of understanding the reasons for the high disappointing levels of LTFU observed in PMTCT programmes across Sub Saharan Africa. A study of this nature was also designed to aid in highlighting some of these factors specific to the research context. Specifically, with this in mind, the study objectives were;

- To provide an overview of the attrition trends of HIV infected pregnant women and HIV exposed infants in the antenatal, delivery room and postnatal stages of care along the PMTCT cascade in health centres in Mutare and Makoni districts.
- To report the challenges perceived by HIV infected mothers who are currently enrolled within the PMTCT programme in rural health institutions in Mutare and Makoni districts.

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To determine the perceptions and experiences of health care workers (HCWs) involved in PMTCT activities in the rural health centres in Mutare and Makoni regarding the factors contributing to attrition and LTFU in the PMTCT programme.

To document the reasons for disengagement from care reported by HIV infected mothers who have missed at least 3 monthly PMTCT visits in Mutare and Makoni

II METHODS

Study Design
A descriptive cross sectional design was used.

A summary of all of the information below is presented in Table 1.

Site Sampling strategies
The study was carried out in 20 clinics in Makoni and Mutare districts in Manicaland province consisting of 10 outreach clinics and one each of their adjacent satellite clinics. This sample represented 10 out of the total of 15 outreach centres that make up the study population for the main cluster randomised clinical trial. An outreach clinic is a larger clinic or rural hospital staffed by nurses, primary care counsellors (PCCs) and village health workers (VHWs) that also provides specified PMTCT services to nearby villages served by 2 to 5 satellite clinics.

The 10 outreach sites involved in this formative research were selected through prior random sampling exercises for Mutare and Makoni districts and constitute the sample for Arms 1 and 2 of the main EPAZ CRCT.

The satellite clinics used to administer tools A1 and A3 were selected through a simple random sampling exercise derived from STATA statistical package based simple random sampling software.

For tools A2 and A4, purposive sampling was carried out for the satellite clinics based on manual review of the individual site workloads for the year 2012. The satellite sites with the highest volumes were chosen in order to increase the potential of locating mothers lost to follow up who constitute the population for instrument A4 as well as to increase the chances of mobilising groups of 6 to 8 mothers currently involved in PMTCT to constitute the membership of FGDs for instrument A2.

Annex B shows the names of the centres involved for each of the four tools.

Data Collection tools
A combination of qualitative & quantitative methods of data collection were utilised. Design and content of instruments were drawn from the disciplines of public health, community psychology and sociology. The English versions of the instruments to be used are appended to this document as Appendices A1 to A4. Appropriately qualified language experts were employed in order to carry out the translation and back translation processes (to the local Shona language) required in order to maximise validity and reliability of the instruments. The data collectors and research team underwent training on a module on research ethics and then data collectors received specific training on the instruments to be utilised in this particular
study. The 4four tools were pre-tested on similar populations of PMTCT records, mothers enrolled in the PMTCT programme, defaulting LTFU mothers and nurses within rural health institutions in Mutasa district. Data collection for this formative research activity took place over a period of three months.
Table 1: Summary of methodologies

<table>
<thead>
<tr>
<th>Population</th>
<th>Sites</th>
<th>Site sample selection</th>
<th>Sample size (Target)</th>
<th>Sampling technique of individuals</th>
<th>Data collection methods</th>
<th>Data collection tools</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 PMTCT Records</td>
<td>20</td>
<td>All 10 outreach sites (Arm 1 &amp; 2) + random selection of 10 respective satellites</td>
<td>-</td>
<td>Census of all records</td>
<td>Desk review</td>
<td>Data checklist (A1)</td>
</tr>
<tr>
<td>2 HCWs</td>
<td>20</td>
<td>10 outreach sites + 10 satellite sites randomly selected</td>
<td>60</td>
<td>Convenience sampling of at least 3 cadres at each centre (1 nurse, 1 PCC, 1 VHW)</td>
<td>Interview</td>
<td>Semi-structured interview schedule (A3i and A3ii)</td>
</tr>
<tr>
<td>3 Mothers enrolled in PMTCT programme</td>
<td>10</td>
<td>5 outreach sites randomly selected from the 10 + purposive selection of 5 respective satellites (according to highest volume of PMTCT work)</td>
<td>1 FGD per centre (6-8 participants per FGD)</td>
<td>Convenience Sampling</td>
<td>Focus Group Discussion (FGD)</td>
<td>FGD schedule (A2)</td>
</tr>
<tr>
<td>4 Mothers LTFU in PMTCT programme</td>
<td>20</td>
<td>All 10 outreach sites + 10 respective satellites purposively selected (according to highest volume of PMTCT work)</td>
<td>40</td>
<td>Selection of up to the first 10 names LTFU in the register</td>
<td>In-depth interview</td>
<td>In-depth Interview schedule (A4)</td>
</tr>
</tbody>
</table>
Below is a summary of the individual populations and data collection methodologies employed in order to elicit answers for the research questions derived from specific objectives outlined in Chapter one.

2.1 What is the dropout rate of HIV infected pregnant women and HIV exposed infants in the various stages of care along the PMTCT cascade in Makoni and Mutare districts?

A census of all of the PMTCT records from the 10 outreach RHCs and one each of their satellites in Makoni and Mutare districts for the period January to December 2012 was carried out in order to answer this research question. A data checklist was used to extract information from the PMTCT records (Annex A1). Information was collected specifically from the Monthly return PMTCT reporting forms and the HIV exposed infant follow-up registers.

2.2 What challenges are faced by HIV infected mothers who are currently enrolled in the PMTCT programme within rural health institutions in Mutare and Makoni?

The population under study for this objective were the HIV infected mothers accessing PMTCT services in Mutare and Makoni districts. The study sample comprised of post-natal HIV infected mothers enrolled in PMTCT programmes at 9 sites in Mutare and Makoni districts over one month of data collection. The clinics with the largest numbers of new antenatal bookings in 2012 were purposively selected into this study. One group of 4 to 8 participants were assembled in each of the 9 sites for the purposes of Focused Group discussion (FGD). Non randomised purposive sampling was used to select participants into the FGDs. Verbal informed consenting was carried out by outreach clinic staff in order to maintain confidentiality for those members of this population not willing to participate in the study. Annex A2 shows the outline of the FGD. FGDs were conducted in Shona (most widely used language in Manicaland province) and transcribed material was translated into English. Language experts were engaged to facilitate this translation process.

Inclusion criteria into the FGDs included documentation of HIV positive test for the first time during pregnancy and documented evidence of last PMTCT follow up visit to health centre not exceeding 2 missed scheduled visits. Exclusion criteria included women who experienced obstetric complications who were referred for delivery to a secondary or tertiary health care setting elsewhere; HIV-positive women participating in other ongoing research studies at the clinics; and clients who came for ANC bookings while they were already on ART.

2.3 What are the perceptions and experiences of health workers in rural health institutions in Mutare and Makoni regarding factors that contribute to LTFU in the PMTCT programme?

The population under study to answer this question included health workers involved directly in PMTCT activities in 10 randomly selected institutions (5 outreach and 5 satellite) in Makoni and Mutare. This population includes an establishment of about 2 nurses, 1 primary care counsellor (PCC), 4 village health workers per centre totalling approximately 70. The plan was to interview at least 50% of the health care worker population (about 35 individuals) with proportionate representation of opinions from the different categories of health workers included. Convenience sampling was exercised.
found on duty at each outreach RHC on the day of data collection were enrolled into the study. Verbal informed consent was sought from health workers after which semi-structured interview schedules were used to collect data from them (Annex A3).

2.4 What reasons for disengagement from care are reported by mothers who have missed at least three monthly PMTCT visits in Makoni and Mutare districts?

The population under this objective comprised of HIV infected mothers who had been lost to follow up in the PMTCT programme (according to the definition presented below). The study was conducted from 5 purposively selected outreach sites and one each of their satellites (also purposively selected). The 10 sites were chosen on the basis of exhibiting the highest PMTCT workload during the year 2012. All of the entries in the ANC register and all the entries in the HIV exposed infants register (for the period January to December 2012) qualifying as LTFU (according to the definitions presented below) were followed up. The rural addresses listed in the registers were utilised. Physical follow up was limited to a radius encompassing the clinics’ catchment areas. Data collectors were accompanied by the local VHWs/community caregivers in order to facilitate the physical follow up exercise. A verbal informed consenting exercise was performed by the VHWs/community caregivers who went in first to talk to potential participants before the project data collectors in order to maintain confidentiality for those women not willing to participate in the study. Interview schedules were used to collect in-depth information from participants (See Annex A4). The schedule contained both open-ended and close-ended questions. These interviews were conducted in Shona (most widely used language in Manicaland province) and transcribed material translated into English. The interviews took place in as private a setting as could be accomplished at the study participant’s home. Strict confidentiality was maintained. No incentives were provided for mothers to participate in the interviews. Mothers did however receive counselling on the benefits of completion of the PMTCT process and were assured of referral back into the PMTCT and ART services if still eligible. In cases where the mothers were found to have moved or not actually to be lost to follow up this was recorded as significant findings on the relevant sections on the data collection tool.

Data Analysis
Analysis of qualitative data from interviews and FGDs was performed using the ‘thematic content analysis’ framework which consists of reading and re-reading the field notes and transcribed texts, manual coding in the margins and synthesizing and grouping data in relatively exhaustive categories.

Analysis and graphical work on quantitative data from the checklist employed on the PMTCT records was performed using Excel worksheets.

Ethics
Permission to carry out this study as part of formative research for a PMTCT implementation research project was sought from the Ministry of Health and Child Welfare. Ethical review was provided through submission of the proposal to the Medical Research Council of Zimbabwe as well as the WHO Ethics Committee.
Consenting processes were employed prior to data collection from among the different respective populations as described in sections A to D above. Verbal consent was selected over written consent for mothers involved in this study because of the confidentiality and stigma issues involved in dealing with an HIV positive population. The risk of inadvertent HIV status disclosure was noted to be a significant potential psychosocial harm to be highlighted from this study that may come to defaulting mothers followed up for study purposes at home as well as mothers participating in the FGD in the clinics. Identification with the study in any neighbourhood may become associated with being HIV infected. This implied disclosure may result in the usual social harms associated with HIV related stigma including domestic or extended family conflict resulting in domestic strife, violence or separation due to failure of the participant to obtain the consent of her partner and/or relatives for her participation in the study. The following measures were thus taken to reduce risk of social harm to participants and their family members as a result of taking part in the formative research:

i. Obtaining verbal consent from pregnant HIV-positive mothers
ii. Ensuring that the consent process is conducted over several days to ensure that family members have been consulted and have agreed to the mother participating in the study
iii. Training data collectors in issues relating to confidentiality, stigma, discrimination and Ministry of Health and Child Welfare codes of conduct regarding breaches of confidentiality

DEFINITION OF TERMS FOR THE FOLLOW UP OF MOTHERS/MIPs FOR THE FORMATIVE RESEARCH

Before this study was carried out the basic assumption was that an HIV infected pregnant woman or an HIV exposed infant who failed to show up for review within the PMTCT programme schedule before the point of discharge was viewed as having become ‘lost to follow up’. The length of the period and circumstances defining this term varies in literature. Part of the justification for carrying out this formative research was the intended realisation of a reliable, relevant and working definition for indicators of follow up and retention in the main EPAZ CRCT.

For the purposes of carrying out this formative study, the following definitions were applied:

- **LTFU during the antenatal stages of PMTCT** was defined as any HIV infected pregnant woman who did not show up for at least two consecutive scheduled visits at the time of data collection.

- **LTFU during the postnatal phase of PMTCT** was defined as any HIV exposed infant and/or their mother had not been reviewed for at least three consecutive scheduled visits within the PMTCT programme at the time of data collection.
III RESEARCH FINDINGS ON ‘LTFU’ STATISTICS & DEFINITION OF CONCEPT

A response rate of 100% was achieved in data collection with information collated from monthly return PMTCT reporting forms and HIV exposed infant follow-up registers in the 20 study sites for the period January to December 2012 using Tool A1. The analysis was however limited to data from 19 of the 20 sites. This was because of extensive disparities noted in the data collected from registers from one of the clinics. Related to this same note was the observation of general data incompleteness and inaccuracies in the various registers used to collect information for this study.

A total of nine focus group discussions (FGDs) were held instead of the planned 10 because of difficulties faced in mobilizing enough mothers to constitute an adequate ‘group’ for FGD purposes. This sample was however sufficient to assure the attainment of a finite number of issues and responses raised from the target population group of mothers currently enrolled in the PMTCT programme (Tool A2).

Responses to Tool A3 (a structured interview guide) were obtained from 20 clinic based staff (nurses and PCCs) and 19 community based health workers bringing this up to a total of 39 instead of the envisaged 60. The main contributor to this was the fact that very few of the sampled clinics actually had an established post for a primary care counsellor (PCC) as had been originally assumed. A notable finding at this stage was that some local clinics were not manned by village health workers but by a cadre known as community caregivers who is usually affiliated to a partnering non-governmental organisation (NGO) working in the local area. Since this cadre was found to be carrying out duties similar to those of the MoHCW based VHW, they were incorporated into the study.

A total of 36 mothers classified as LTFU according to the definitions set aside for this formative research paper were identified and followed up giving a response rate of 90% for Tool A4 (36/40).
3.1 Observed Retention vs Attrition of HIV infected pregnant women and HIV exposed infants in the various stages of care along the PMTCT cascade in Makoni and Mutare districts

For analysis purposes the PMTCT programme delivery was divided into antenatal, delivery and postnatal PMTCT.

3.1.1 Antenatal PMTCT

Fig. 1 shows the findings obtained from monthly return PMTCT forms with regard to antenatal PMTCT care which covers two crucial issues that is HIV testing and introduction of antiretroviral use whether full ART for eligible mothers or as prophylaxis for mothers whose CD4 count is above 350 (in line with current MoHCW Option A).

Finding (1) (Antenatal PMTCT): Inadequate initial engagement of women into the PMTCT programme

The number of women who were tested for HIV in the sampled clinics represents 94% of the total number of women who booked for ANC in the same centres.

Finding (2) (Antenatal PMTCT): Insensible statistics captured through the Health Information System

The statistics obtained from the sites suggest that more women received an HIV result than were tested and that more women were commenced on ARVs than the number that tested HIV positive (See Fig. 1).

Finding (3) (Antenatal PMTCT): No apparent declines within PMTCT at the level of Antenatal PMTCT

Fig. 1 suggests that there was no attrition observed in the PMTCT programme at the levels of HIV test result receipt and at the level of ART commencement during pregnancy over the course of the evaluated period.

Figure 1: Number of pregnant women who accessed the various antenatal stages of the PMTCT cascade in 19 clinics in Arms 1 & 2, Mutare & Makoni, January-December, 2012

* Either antiretroviral therapy or prophylaxis
3.1.2 Delivery Room PMTCT

Finding (4) Delivery PMTCT: A significant number of HIV infected women are not delivered at the clinic where they are enrolled for PMTCT and about one fifth of all deliveries in the study sites were at home.

Whilst records show that a total of 544 women were either commenced on ART or on ARV prophylaxis (MER) depending on eligibility, just 57% of that number is depicted as having been delivered in the clinics (Fig. 2).

![Diagram showing delivery PMTCT](image)

**Figure 2:** Number of HIV infected women who were commenced on ARVs during pregnancy compared to the number who went on to be delivered in the 19 clinics in Arms 1 and 2, 2012

* Either antiretroviral therapy or prophylaxis

Related to the aspect of Delivery PMTCT was also the fact that a significant proportion of the 2647 deliveries (irrespective of HIV status) recorded in the sample clinics took place at home rather than in the formal clinic settings as shown in Fig. 3.

![Diagram showing delivery settings](image)

**Figure 3:** Proportion of delivery settings observed in 19 clinics in Arms 1 & 2, Mutare & Makoni districts, January-December, 2012

A significant number of HIV infected women are not delivered at the clinic and about one fifth of all deliveries in the study sites were at home.
Finding (5) Delivery PMTCT: The incidence of HIV is higher among women tested for HIV in labour and postnatal unit than in the antenatal clinic.

Another finding worth noting within the context of delivery PMTCT is the disparity in HIV positivity rate between women tested during ANC and those undergoing HIV testing in labour ward / postnatal care unit. Whilst about 9% of women tested HIV positive in the ANC clinic, the delivery room record showed that about 15% of women tested at this late stage were HIV infected (Fig. 4).

Figure 4: Comparison of HIV positivity rate between women tested in ANC and at delivery in 19 clinics in Arms 1 and 2, Mutare & Makoni districts, January-December, 2012

PNU - Postnatal Unit
3.1.3 Postnatal PMTCT

Results for postnatal PMTCT are presented in Figure 5: Number of infants who accessed various stages of postnatal PMTCT care & ART initiation in 19 clinics in Arms 1 & 2, Mutare & Makoni districts, January-December, 2012.

Finding (6) Postnatal PMTCT: Insensible statistics captured through the Health Information System

More infants were noted to be receiving extended Nevirapine (NVP) at 6 weeks than those initiated on NVP (AT WHICH TIME PERIOD?) a number that was captured at initiation (Fig. 5). This is similar to Finding (2) above.

Finding (7) Postnatal PMTCT: Only a fraction of the HIV exposed infants proceeded to get an HIV test

The number of infants ≤2 months captured as having undergone an HIV DNA PCR test represents just 53% of the number of infants captured as having been on extended Nevirapine (NVP) whilst the percentage for a rapid HIV antibody test after 9 months is 63% (Fig. 5).

Finding (8) Postnatal PMTCT: A significant proportion of guardians did not receive their infant’s HIV DNA PCR results

14% of guardians whose infants had blood collected for DNA PCR did not receive the result (Fig. 5).

Finding (9) Postnatal PMTCT: A high rate of MTCT of HIV was recorded in the period under discussion.

Comment [E9]: Rapid test result not given in Fig 5

Comment [E10]: Not given in fig 5
Estimated MTCT rate calculated in early infancy was calculated as number of infants testing HIV positive divided by number of infants tested (using both types tests) was 9%

Finding (10) Postnatal PMTCT: A small fraction of infants testing HIV positive was initiated on ART

This study showed that the figure for number of infants commences on ART represents 30% of the number of infants who tested HIV positive (Fig. 5).

3.2 Defining the concept of ‘Loss To Follow Up’ in the PMTCT Programme

Health workers were asked to provide a definition of ‘PMTCT defaulter’ and ‘Loss to follow up in PMTCT’. Tables 2 and 3 show the different definitions provided and their frequencies among clinic based and community based health workers. Note that some health workers provided more than one definitions and others did not provide a response at all.

A general lack of differentiation between the concept of ‘defaulting from the programme’ and ‘ loss to follow up’ was shown. Even where a difference was appreciated there was much variation in the definitions provided suggesting a lack of standardized approaches to both individual issues in practice.

Table 2: Observed frequency of various definitions of ‘a defaulter in the PMTCT programme’

<table>
<thead>
<tr>
<th>Definition</th>
<th>Community based (VHWs)</th>
<th>Clinic based (Nurses &amp; PCC)</th>
<th>All HCWs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failure to show up for 3 consecutive visits/months</td>
<td>2</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Failure to show up for 2-3 consecutive visits/months</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Failure to show up for 2 consecutive visits/months</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Failure to show up for 1-2 consecutive visits</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Failure to show up for 1 visit</td>
<td>5</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Failure to show up for 1 visit &amp; followed up</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Impermanence: Stopping for a while then resuming</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Vague response</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>I do not know</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 3: Observed frequency of various definitions of ‘loss to follow up in PMTCT’

<table>
<thead>
<tr>
<th>Definition</th>
<th>Community based (VHWs)</th>
<th>Clinic based (Nurses &amp; PCC)</th>
<th>All HCWs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Client is followed up after defaulting but doesn’t come for PMTCT</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Patient has not come to the clinic for 3 months tracked but is not found</td>
<td>0</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Not found on attempt to follow up physically</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Migration from clinic catchment area</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
3.3 Actual status of mothers counted as LTFU according to clinic records upon follow up

A total of 36 mothers and/or infants who were depicted as LTFU from the clinic records of the 10 selected study sites for the period January to December 2012 were followed up and Table 4 below shows the actual status upon follow up as confirmed by their personal reports, patient held out-patients (OPD) cards or reports from neighbours and/or family members;

Table 4: Actual observed status of MIPs qualified as LTFU in the clinic based PMTCT records

<table>
<thead>
<tr>
<th>LTFU Status</th>
<th>MIPs PMTCT Follow up status upon investigation</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confirmed Dropouts</td>
<td>MIPs Confirmed no longer accessing services in the PMTCT programme</td>
<td>12</td>
<td>33%</td>
</tr>
<tr>
<td>Possible dropouts (LTFU)</td>
<td>Migration out of clinic catchment area**</td>
<td>8</td>
<td>22%</td>
</tr>
<tr>
<td></td>
<td>Fictitious address/ Not known in the documented neighbourhoods**</td>
<td>3</td>
<td>8%</td>
</tr>
<tr>
<td></td>
<td>Mothers had travelled on the dates of data collection</td>
<td>2</td>
<td>6%</td>
</tr>
<tr>
<td>Not LTFU</td>
<td>Follow up in the PMTCT programme actually up to date*</td>
<td>6</td>
<td>17%</td>
</tr>
<tr>
<td></td>
<td>MIP discharged from the PMTCT programme^^</td>
<td>5</td>
<td>14%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td>36</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Follow up in the PMTCT programme actually up to date- In all 6 cases, data collectors and project staff confirmed through review of recording on patient held OPD cards that clients had been to their registered local clinic on the prescribed review dates and had received appropriate care and treatment.

**Mother-Infant pair discharged from the PMTCT programme- In all these 5 cases the mother had been discharged from the programme following a negative HIV test result on the baby (DNA PCR or rapid antibody tests depending on the age) after ceasation of breastfeeding. This claim was also confirmed through review of OPD cards by the data collectors.
Migration out of clinic catchment area - About a fifth of clients followed up were reported to have moved from their cited residential address. Reasons reported for migration are listed in Table 5. Data collectors obtained this information from neighbours, family members and/or new tenants at the places of residence.

Fictitious address - In two of the cases none of the people living in the residential area that had been cited in the client’s clinic based records knew anyone by the names registered in the PMTCT programme. In the third instance the address itself was found not to exist upon attempt at physical follow up for the purposes of data collection.

**Table 5: Reasons reported for migration outside of original clinic catchment area**

<table>
<thead>
<tr>
<th>Reason for Migration reported</th>
<th>Frequency reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Had been visiting. Returned to stay with husband away from clinic catchment</td>
<td>2</td>
</tr>
<tr>
<td>Farm labourer employment opportunities (termination or better opportunity elsewhere, for client or partner)</td>
<td>3</td>
</tr>
<tr>
<td>Separated from partner. Returned to her own family away from clinic catchment</td>
<td>2</td>
</tr>
<tr>
<td>Widowed. Returned to her own family away from clinic catchment</td>
<td>1</td>
</tr>
</tbody>
</table>

3.4 Self reported reasons for LTFU from mothers who have been lost to follow up in PMTCT

In view of the findings presented in Table 4, the in-depth interview (IDI) was only administered to the 12 cases of MIPs who were genuinely confirmed to have dropped out from the PMTCT programme. Table 6 is a list of emerging themes for reported issues surrounding LTFU. Below the table is a list of the summarised case histories.

**Table 6: Summary of themes emerging from the case histories**

<table>
<thead>
<tr>
<th>Direct &amp; indirect issues contributing to LTFU</th>
<th>Cases affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of partner support, marital conflict, HIV discordance</td>
<td>C E F G</td>
</tr>
<tr>
<td>Inadequate understanding of the expectations of PMTCT, less than optimum counselling and education on PMTCT</td>
<td>A B D F</td>
</tr>
<tr>
<td>Women’s lack of autonomy</td>
<td>B C H</td>
</tr>
<tr>
<td>Competing time engagement priorities—work to be done, time spent at clinic too long</td>
<td>J K L</td>
</tr>
<tr>
<td>Financial constraints to cover adjunct costs</td>
<td>B E</td>
</tr>
<tr>
<td>Long walking distance to the clinic</td>
<td>H J</td>
</tr>
<tr>
<td>Inflexible programme delivery at the level of clinic not accommodating special circumstances</td>
<td>B F</td>
</tr>
<tr>
<td>Lack of disclosure of status</td>
<td>A</td>
</tr>
<tr>
<td>Travel outside of clinic catchment area</td>
<td>A</td>
</tr>
<tr>
<td>Religious restrictions</td>
<td>H</td>
</tr>
<tr>
<td>Mental instability (lack of community/family support structures)</td>
<td>I</td>
</tr>
</tbody>
</table>
Case 1 - Mrs A

Mrs A is a married woman aged between 19 and 30 with a secondary education whose family has been to date totally reliant on subsistence farming as a source of their livelihood. Her husband left to look for possible employment in South Africa before her ANC booking and at the time of the interview she was 5 months pregnant. She tested HIV positive during routine screening in ANC and she is yet to disclose her status to anyone including her husband. She says that the reason why she did not go back to the clinic to collect her monthly ARV supply was because she had to travel to Buhera which is outside the clinic’s catchment area. She feels that her inability to disclose her status to relatives contributed to her LTFU because they sent her to Buhera at the time when she was due to collect her medications and she could not tell them about her PMTCT appointment because of the lack of disclosure. She feels that in her community people generally speak bad about people with HIV and she does not know of any community based support structures for mothers in the PMTCT programme. According to her, now that she was back at her home, she intended to resume follow up in the PMTCT programme. When tasked with explaining the expectations from the mother and infant in the various stages of the PMTCT cascade, she scored 3 out of 10 and says she never received any counselling or education on PMTCT from health personnel.

Case 2 - Mrs B

Mrs B is aged < 18, is married and completed primary school. She was registered for PMTCT in the clinic that is closest to their home which is about a 4 hour walk away. Recently married, the couple only started venturing into tobacco farming this year but currently rely on subsistence farming and an income of about US$5 per month. She identifies lack of funds as the reason for her failure to continue in the PMTCT programme. After ANC booking at Mufusire clinic, Mrs B was referred to Rusape Hospital for purposes of obstetric intervention due to her underage. She had no money to travel to Rusape and so she went back to the local clinic where she says they gave her one month’s resupply of ARVs but told her that they would not see her again before her review at the referral centre. Because of this stricture she decided not to go back since she could not afford the transport costs to Rusape. She disclosed her HIV status to her husband and mother-in-law who tried to look for funds for her but did not succeed. At the time of the interview she was now breastfeeding her child, having delivered her at home because of the failure to access health care due to financial constraints. She feels that being a woman has contributed to her failure to adhere or at least resume PMTCT activities because her husband and aunt would not allow her to go and look for a job even though the husband will not go to work himself. If she had been able to get a job then she may have been able to raise the funds necessary for her to go to Rusape. Mrs B says that she never received any counselling or health education on PMTCT and this reflected in her score of 3 out of 10 when tasked to list the activities expected of participants in PMTCT. She felt that nurses generally treated them well but that they give their instructions too fast without repeating them to allow the clients to fully understand.
Case 3 - Mrs C

Mrs C, aged 31-40, is a married woman who attained secondary education. She and her husband earn their living from gardening and part-time work. When Mrs C tested HIV positive in ANC, she disclosed her status to her husband who then later informed her that he also got tested. She emphasizes the point that he went for HIV testing on his own so she just has his word for it. Her husband discouraged her from participating in the PMTCT programme. She however participated in the PMTCT programme up to the point when her daughter had a PCR DNA test done at 6 weeks whose result was negative. From then her husband forbade Mrs C from taking any more medication for ‘his’ daughter. In this regard, she feels that being a woman has played a role in her inability to follow through with PMTCT as she may not stand up to her husband.

Case 4 - Mrs D

Mrs D is a farm labourer married to another farm labourer. She is aged between 19 and 30 and went to school up to the level of primary school. She says that the reason why she never returned for further follow up in PMTCT was that the issues and expectations were never properly explained to her by the clinic staff. During pregnancy Mrs D tested HIV negative in the ANC clinic. She was only found to have sero-converted when a repeat HIV test was done post-natally and she tested positive. She says that at that stage blood for CD4 count was collected from her and DBS from the baby then the nurses noted her phone number and said that they would call her when the results were out but they never did. The infant has since passed away.

Case 5 - Ms E

Ms E, an unemployed secondary school graduate, is aged 19-30. At the time she enrolled in the PMTCT programme she was married to one man but they have since been separated and at the time of the interview she was now living with another man. Ms E tested HIV positive in the ANC clinic. She disclosed this to her husband. This ruined their marriage because the husband believed that she had been unfaithful and therefore the source of the infection. From that time he stopped giving her money to cover transport costs to go for ANC services and that affected her ability to adhere to the scheduled visits. When the two finally separated, the father took the child with him to South Africa and she stayed behind.

Case 6 - Mrs F

Mrs F is 19 to 30 years old, is married and attained a primary education. She pointed out two issues that have resulted in her failure to follow through with expected PMTCT activities. Firstly she cites her husband’s refusal for her to participate in PMTCT during pregnancy. She only managed to secretly get tested for HIV during the time of delivery at which point both she and the baby were given antiretroviral medication. Secondly, she says that she was just commenced on ARVs but not adequately counselled and educated at the hospital regarding the requirements and expectations for her as a mother.
participating in PMTCT. According to Mrs F, the nursing staff emphasized the need for her to bring her husband in order to be able to give them more comprehensive education on PMTCT as a couple. But since her husband will not even allow her to participate in PMTCT she could not even breach the subject of escorting her to the PMTCT programme with him and so in the end just decided to stay at home.

Case 7 - Mrs G

Mrs G, aged 19-30 was educated to primary school level. When she tested HIV positive in the ANC clinic she disclosed her status to her husband. Her husband agreed to get tested and he tested HIV negative. He then started to accuse her of unfaithfulness. After the delivery of the baby her husband asked her to go back to her parents because of the discordance. She ended up lying to her husband that she had been joking about her HIV positive status and this is the reason why she did not return to the clinic to find out the baby’s DBS result or to access any further follow up even for her own health.

Case 8 - Mrs H

Mrs H is a widow aged 31-40 with a primary school education. Her husband had passed away 4 months prior to the interview. The clinic is situated at a distance of about 7 kilometres from her home and she says that she found it a challenge to walk this distance regularly during pregnancy. In addition to this, Mrs H’s in-laws and her own father are members of a conservative apostolic religious sect which does not allow members to access services from formal health institutions so she can only sneak out in secret to the clinic. Because of this background, Mrs H could not disclose her HIV status to most of the people who are close to her including her husband who was also of the same faith. Again because of her religion, she was not able to adhere to advice on exclusive breastfeeding because the birth attendants from her church who delivered the baby advised her to give the baby a mixture of cooking oil and coca cola. Although personally appreciative of the benefits of PMTCT, she feels that being a woman made it more difficult for her to stand up against her family’s stance.

Case 9 - Ms I

Ms I is described by her family and the community as ‘mentally unstable’. Because of this she is always in transit and this has contributed to her failure to adhere to the PMTCT schedule.

Case 10 - Mrs J

Mrs J is a married 31-40 year old with some secondary education. Her home is situated 7 kilometres from the clinic where she was enrolled into the PMTCT programme and to get there she walks on both journeys to and fro. Mrs J had not been to the clinic during the last three months because she had to work in the fields and was planning on going to the clinic only after completion of the weeding.

Case 11 - Mrs K

Mrs K is aged between 19 and 30, married and has been to secondary school. She had already been on ART prior to booking for ANC. She is currently exclusively breastfeeding her child and the reason why
she has not followed up on DBS result is because she has been busy with field work and guarding the fields from baboons.

Case 12 -Mrs L

Mrs L is a widow aged 31 –40 and has a secondary education. At the time of enrolment into the PMTCT programme her husband was still alive. The reason why she has not been to the clinic for her scheduled PMTCT visit is that she has generally experienced very slow service at the clinic. She says that she is a very busy woman in order to try to take care of the family as a single parent. To earn a living she engages in various activities such as keeping broilers, selling fish, selling ‘freezits’ and other wares. According to her observation, staff at the clinic are overwhelmed and work slowly. Once she spent the day at the clinic, only returning home at 5.00 PM without being attended.
Recommendations stemming from the discussion in this chapter will either be directed at the main EPAZ CRCT or at the local PMTCT programme in general.

4.1 Antenatal, Delivery Room and Postnatal PMTCT Statistics

Finding (1) represents the first level of the problem in PMTCT which is failure to engage all eligible women into the programme in the first place. Although seemingly paltry, this difference of 6% represents a number of 304 women who did not get an HIV test in actual terms. The MoHCW (Ministry of Health and child welfare) PMTCT Annual report for the year 2011 actually showed that following appropriate data verification and cleaning exercises the national HIV test acceptance rate at this stage was 85%\(^9\). It becomes crucial to try and gain deeper understanding of this still significant proportion of the population of women who still refuse to agree to an HIV test or fail to access it, even after all the milestones that have been achieved in the fields of HIV awareness, HIV testing and the obvious benefits of PMTCT and ART. Finding (5) with the incidence of delivery room HIV (15%) being almost two times as high as that in ANC (9%) emphasizes the need to concentrate pressure on HIV testing in the antenatal phase. Mothers who remain with unknown HIV status up to the time of delivery apparently represent a high risk population for HIV incidence. This is in keeping with findings reported in the PMTCT programme at the national level\(^10\), where for the year 2011 an ANC positivity rate of 12% was estimated against 25% HIV prevalence among women who were tested in labour and delivery. This delay in engagement into the programme will logically be associated with higher rates of MTCT because the foetus is exposed to a high viral load for a longer period throughout gestation and even through the more risky delivery process.

Traditionally literature on MTCT has shown that in the absence of intervention, most of the MTCT of HIV occurs during labour and delivery compared to the period during pregnancy or breastfeeding\(^11\). With this in mind, various obstetric and pharmacologic interventions have been put in place to minimize the risk of MTCT at this stage. The fact that the statistics indicate that so many deliveries are taking place at home and such a high proportion of HIV infected women are not captured under deliveries in the institutions implies a major problem with PMTCT programme disengagement at this phase (Figs. 2 and 3). Firstly, there is no reassurance that clients take the medications that have been prescribed for them for the onset of labour. Secondly, there is no guarantee of delivery through the hands of cadres who have been trained to optimize conditions against MTCT. And thirdly, there is no guarantee of infants getting commenced on required ARVs within the stipulated 72 hours of delivery. Only a fraction of the HIV exposed infants proceeded to get an HIV test, a significant proportion of guardians did not receive their infant’s HIV DNA PCR results and exponential attrition levels were observed for exposed infants expected to visit the centres for review as the number of visits increased. The suggestion in Finding (3) that attrition is not a major feature in antenatal PMTCT coupled with the marked postnatal PMTCT attrition rates (demonstrated in Findings 7,8,10 and 11) concurs with current discussion suggesting that

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implementation of PMTCT coverage has been more successful perinatally rather than post-natally. It becomes logical to hypothesize that a significant proportion of the MTCT occurring within the PMTCT programmes in high burden contexts nowadays is actually originating in the postnatal period rather than antenatally. An MTCT rate of 9% remains highly unacceptable within the context of a robust PMTCT programme based on the MER option.

Based on the preceding discussions on antenatal, delivery room and postnatal PMTCT findings on attrition in the PMTCT programme, the following set of recommendations have been derived for the main EPAZ project, followed by another set designed for the local PMTCT programme;

**Recommendations for main CRCT:**

1. Community engagement efforts at the beginning of the project in all arms should include a component on emphasizing the importance of HIV testing as a gateway into the PMTCT programme to maximize the potential for achieving required numbers for enrolment into the study right from the onset
2. The design of the MSG should emphasize under ANC activities strategies to retain women in the PMTCT programme in the institutions for purposes of delivery
3. The design of the MSG to be a crafted in such a manner that there is a lot of emphasis on mechanisms to reduce attrition in the postnatal period where the greater burden of attrition and LTFU seems to be concentrated.

**General Recommendations for PMTCT Programme:**

1. More effort has to be put in place in the programme in order to increase the uptake of HIV testing early on in ANC.
   - There may be benefit in carrying out in-depth qualitative research to understand the issues associated with non-uptake of HIV test in ANC among the population of mothers who present in labour with unknown HIV status.
2. The program is recommended to work on strengthening strategies to increase retention in delivery and postnatal PMTCT

Another disappointing finding is the very low rate of ART commencement observed for those infants testing HIV positive (30%). Evidence has shown that about 35% - 40% of HIV infected infants die within their first year of life while more than 50% die before they turn two, hence the global agreement on the urgency with which ART should be commenced among infants proven to be HIV infected. The

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12 Foster G. Where is the child in campaigns to end vertical transmission? Presented at AIDS 2012 sessions on Children, Pediatrics & EMTCT: Children and HIV: Closing the Gap; Ending vertical transmission through community action. July 20th & 21st 2012, Georgetown Conference Center, Washington DC, USA


major determent to early infant treatment with ART has been the general reluctance demonstrated by a lot of clinicians (doctors and nurses alike) to initiate ART within the paediatric patient population. It has to be borne in mind that the main EPAZ CRCT is to be conducted within this same context hence the recommendation suggested below.

**General Recommendation for PMTCT programme:**

3. There is a general need for establishment of strategies to empower and support nurses so that decentralised nurse led initiation of ART especially for paediatric patients may be realised as a reality in the whole PMTCT and paediatric ART programmes

**Recommendation for main CRCT:**

4. The EPAZ CRCT project in particular will certainly have to design strategies to empower and support nurses in the study sites in order to facilitate the operationalization of the study interventions through nurse-led initiation of ART.

### 4.2 Follow up and retention in the PMTCT programme

Literature review shows that data on MIP retention through health information systems is limited with lack of any standardised definition of retention for use in PMTCT programmes. General data incompleteness, disparity and inaccuracy was observed in the various registers used to collect information for this study. In the end, the data analysis was limited to data from 19 of the 20 sites. Data collection established the presence of some insensible statistics captured through the Health Information systems (Finding (2) and Finding (6) in Section 3.1). In addition, almost a third of mothers followed up in this study were erroneously depicted as LTFU based on incomplete clinic records with 17% of the mothers whose clinic based records pointed to loss to follow up actually observed to be up to date with their PMTCT schedule and another 14% found to have been appropriately discharged from further follow up (Table 4). This is in keeping with findings from another study carried out in a similar context within the Zimbabwean setting by Mukotekwa and colleagues who noted that some cases were actually up to date with their PMTCT follow up but their clinic based records had not been updated. These observations point out the deficiencies in the quality and completeness of the data capturing mechanisms and systems currently in place within the health information systems in use in the public health delivery institutions. These findings suggest that absolute dependence on the clinic based records as an indicator for retention and attrition trends particularly in the context of the main

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18 Mukotekwa T, Chiruka S, Maruva M, Rumbanduro E, Engelsmann B. Loss to follow up in PMTCT programs - the true picture? Insights from three health centres in Buhera district, Zimbabwe. 6th IAS Conference on HIV pathogenesis, treatment and prevention, 17-20 July 2011, Rome, Italy
CRCT study in which retention will be a major study outcome may not be advisable under current conditions of practice. In light of these findings, the following recommendations are suggested for the main EPAZ CRCT:

**Recommendations for main CRCT:**

5. There is need for the project to establish strict data quality control maintenance strategies

6. Regular refresher training and mentoring of HCWs involved in data entry on the use of clinic based registers in which PMTCT data is entered so that clinic records are always kept up to date. That way registers such as the HIV exposed infant register will provide reliable information on issues such as negative HIV result and resultant programme discontinuation or capturing of all those infants who remain adherent to the follow up schedule. This is crucial in light of the fact that these reports will serve as the main source documents for the main CRCT Case Report forms.

**General Recommendation for PMTCT programme:**

4. Regular support and supervision activities is crucial in the area of Health Information systems management and Monitoring and evaluation procedures in the public health facilities so that sensible and useful data may be recovered from sites for programme planning and administrative purposes.

Responses from health workers interviewed showed a marked lack of differentiation between the concept of ‘defaulting from the programme’ and ‘loss to follow up’. Even where a difference was appreciated there was much variation in the definitions provided suggesting a lack of standardized approaches to both individual issues in practice. There is a general lack of consensus and consequently a lot of discussion has been generated over issues of establishing standard working definitions for concepts involved in follow up and retention of patients in chronic care programmes.

Analysis of the definitions suggested in Tables 2 and 3 highlights some concepts that have to be considered for setting up definitions for adoption in the main study. These are discussed below with supporting statements from the findings gathered in other areas of this study as well as from review of current literature by experts in the field.

4.2.1 Distinction between antenatal and postnatal PMTCT retention concepts

Only one of the interviewed health workers attempted to make a differentiation between antenatal and postnatal PMTCT when requested to define the concepts of ‘defaulting’ and ‘LTFU’. This finding suggests that the operational variables for measuring retention and LTFU may well be considered similarly for both periods. Indeed, clinical reviews in both cases are scheduled on a monthly basis and consequences for failing to turn up for review are equally negative for either periods. Below is the recommendation stemming from this conclusion.
Recommendation for the main CRCT:

7. The definitions of concepts on retention and follow up as well as the SOPs on the same that are employed in the study should be the same for both the antenatal and the postnatal periods. The wording should reflect this in terms of the different nature of the clientele in the two stages i.e. mothers during antenatal PMTCT and MIPs during the postnatal PMTCT period.

4.2.2 Duration of absence

The question to be answered is ‘How long should it take before the health system becomes concerned by the fact that an MIP has not showed up to access care within the PMTCT programme?’

Some HCWs interviewed were of the opinion that failure to show up for just one visit was enough for the client to be labelled defaulter (and indeed for one respondent even LTFU). In order for MTCT rates to come down to acceptable levels in the programme, the health system is obligated to establish measures that minimize the risk of MTCT. The fact of the matter is that achievement of optimum suppression of viral load to prevent HIV transmission requires strict adherence to the prescribed drug. The moment an MIP fails to attend an appointment scheduled for the purpose of collecting these said drugs, their risk of MTCT automatically increases due to the potential for non adherence. This argument then confirms the need for an immediate reaction on the part of the health system to be effected right at the time of the first missed visit. Such a strict definition will however call for the establishment of a sensitive detection method so that follow up activities may be effected during the earliest possible timeframe. Debate has been abound over the use of the word ‘defaulter’ and its undiplomatic connotations. Literature suggests the use of the word ‘non-attender’ as a more politically correct terminology which describes the exact action of the mother/ MIP without any underlying negative implications.

Recommendations for the main CRCT:

8. The main EPAZ CRCT is recommended to introduce the term ‘non-attender’ for mothers/ MIPs who miss a single scheduled PMTCT visit

9. A tracking mechanism to pick up non attenders on the day that they fail to present themselves for a scheduled appointment should be devised at the level of the local clinic facility so that the study is able to record issues pertaining to the ‘quality of retention’ indicator (See recommendation (10) for the main CRCT ) which will be crucial for analysis at the end of the study.

General Recommendation for PMTCT Programme:

5. Local Health institutions should be set up with tracking mechanism/s to pick up non attenders on the day that they fail to present themselves for a scheduled appointment so that follow up plans can be immediately instituted. Further implementation research on the feasibility of such methods would be advisable.

4.2.3 Degree of permanence of absence

One important aspect for consideration under this discussion raised by some health workers during the interviews pertained to the length of absence from follow up or the degree of permanence of the absence from follow up. In other words the definitions for terms to be used should take into consideration the fact that some mothers/MIPs miss appointments and do not present to the clinic for certain periods of time then proceed to resume follow up at a later date.

This feature was established in one of the case studies under Section 3.4 with Mrs A (Case 1) who had missed 3 clinic appointments at the time of the interview because she had travelled but expressed an intention to resume follow up at the clinic. The FGDs with mothers enrolled in the programme and the interview with HCWs also revealed a number of reasons for travel and temporary relocation which contribute to failure to turn up for scheduled appointments (See Section 3.5.1).

The point to be made is that there is evidence of delayed attendance within the programme and any follow up and tracking mechanism that is to be cost-effectively employed will have to be instated in cognisance of this finding by allowing a specified grace period before proceeding with follow up measures.

Another discussion point confirmed from the findings is the realisation that some of the mothers/MIPs who ultimately complete the PMTCT follow up and are subsequently discharged from care may not have been exposed to the maximum benefit to be incurred from participation in the programme because of tendencies to delay attendance on the scheduled dates. Depending on the timing of such delayed attendance, MIPs may be at risk of non-adherence to prescribed ARV regimens and thus lend themselves prone to MTCT. The conclusion here made is that while the main EPAZ CRCT is primarily interested in measuring ‘retention’ as one of its major outcomes, it is worthwhile introducing another indicator on quality of retention because in the long run this is the issue that may determine whether or not prevention of MTCT is actually achieved.

**Recommendations for the main CRCT:**

10. Introduce a ‘quality of retention’ indicator to complement the ‘retention’ indicator within the main EPAZ CRCT. This additional indicator will be attained through assessing the number of appointments kept as a fraction of the total number of expected PMTCT visits. Outcomes may be recorded as non retention, partial retention and full retention.

**General Recommendation for PMTCT programme:**

6. Outside of EPAZ CRCT study setting, where tracking systems are developed, allow a grace period of at least one to two weeks after identifying a mother/MIP as ‘non-attender’ before activating follow up mechanisms.


4.2.4 Follow up effort

A number of the interviewed HCWs included the issue of tracking/physical follow up in their definition of ‘LTFU’. Indeed, a mother/MIP who has missed PMTCT appointments and has not been followed up is not in the strictest of terms ‘lost to follow up’. In the current standard of care within the Zimbabwe MoHCW PMTCT programme when mothers/MIPs do not attend a scheduled visit they are supposed to be followed up through home visits carried out by community based health workers such as VHWs or NGO based community caregivers (see the introduction in Chapter 3 for notes on this latter cadre). Most of the clinics involved in the study were either covered by VHWs, community caregivers, or both. In practice however, this is not a tracking system that is necessarily operational in all of the centres where these cadres are available. Baseline formative work for the main EPAZ CRCT revealed that a few clinics do not have this cadre on board.

General Recommendation for PMTCT Programme:

7. In line with general recommendation (5) above, a suggested tracking system for further development, support and testing as implementation research could involve activation of a routine physical follow up mechanism for every mother/MIP who fail to attend a scheduled PMTCT appointment following laid down standard of care procedures i.e. making use of VHWs and community caregivers (to be collectively referred to as community based health workers)

4.2.5 Outcomes of physical follow up effort

The study demonstrated several possible outcomes that may be observed upon carrying out physical follow up activity as is presented in Table 4 in Section 3.3. Only 33% of clients followed up could be confirmed as having ceased to access care from the PMTCT programme (N=36). Discussion with health workers revealed another possible outcome in addition to those presented in Table 4 to be death (See 3.5.6). These findings are in keeping with those from other studies that have tracked clients ‘lost to follow up from different HIV care programmes’. To summarise these findings, efforts to follow up mothers/MIPs can yield the outcomes presented in Fig. 6.

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20 Maphosa T et al, 2013 (Unpublished), Assessing the feasibility of Nurse led initiation in Makoni and Mutare districts; Formative research for the EPAZ CRCT


21 Mukotekwa T, Chiruka S, Maruva M, Rumbanduro E, Engelsmann B. Loss to follow up in PMTCT programs - the true picture? Insights from three health centres in Buhera district, Zimbabwe. 6th IAS Conference on HIV pathogenesis, treatment and prevention, 17-20 July 2011, Rome, Italy
Follow Up outcomes

- Mother/MIP found
- Mother/infant deceased
- Still does not attend clinic after follow up*
- Moved to another clinic**
- Attends clinic after follow up†

Figure 6: Summary of reported & observed outcomes upon follow up of mothers/MIPs not attending scheduled PMTCT appointments

* Lost to follow up/Status not known; ** Transfer; † Delayed attenders; ‡ Disengaged from care

A 2011 report from a meeting on retention in HIV programmes convened by the WHO identified the lack of consensus in terminologies related to follow up and retention in HIV care programmes as a significant challenge. The report suggests that ‘a most useful definition of ‘loss to follow up’ should refer to patients with unknown outcomes whilst those patients who are known to have ceased access to services would be best termed ‘disengaged from care’. This differentiation is apparently crucial in terms of dictating the appropriate programmatic response where for example the LTFU indicator would be reflective of gaps in information systems whilst ‘disengagement from care’ would signify gaps in service delivery issues.

Once a physical follow up effort has been carried out, the only group of clients who can be truly labelled LTFU includes those mothers and or infants who cannot be found or traced. In this study this population is represented by the clients who were found to have migrated, those that provided fictitious physical addresses and those clients who were said to have travelled during the time of data collection. Just 12 of the 36 clients initially labelled as LTFU were ultimately confirmed to have stopped accessing PMTCT services and thus, according to the preceding discussion were actually ‘disengaged from care’.

General Recommendation for PMTCT programme:

8. Following on recommendations (5),(6) and (7) above; a tracking system developed for the purposes of following up mothers/MIPs in the PMTCT programme may take on the following terminology for the purposes of categorization of outcomes upon performance of physical follow up activity of mothers/MIPs who fail to attend the clinic on the appointed date;
   i. Mother and/or infant deceased
   ii. Mother/MIP status not known - refers to those clients who cannot be located upon implementing physical follow up. This category will convert to Mother/MIP LTFU when the mother/MIP misses the equivalent of 3 consecutive monthly reviews.
   iii. Mother/ MIP transferred - refers to clients who are still engaged in PMTCT activities but
have switched their clinic of access.

iv. **Delayed attenders** - refers to clients who, following a physical follow up visit, then resume their visits with the PMTCT clinic

v. **Mother/MIP disengaged from care** - refers to clients who, following a physical follow up visit, do not resume clinic visits for the purposes of PMTCT

**Recommendations for the main study CRCT:**

11. The main EPAZ CRCT is not recommended to institute regular follow up and tracking exercises as part of their routine operation (this would in fact translate to a third and independent intervention). It is however recommended to follow up clients who have not met the criteria for full retention (i.e. non retention and partial retention) at the end of their individual study follow up period in order to ascertain the reasons for their inability to attend an adequate number of scheduled visits. This should assist in final classification of 'quality of retention' as well as contribute to the final analysis of study outcomes
V. LTFU IN THE PMTCT SCHEDULE: PERSPECTIVES & OBSERVATIONS OF HEALTH WORKERS & WOMEN CURRENTLY ENROLLED IN THE PMTCT PROGRAMME

Findings & Discussion

The findings in this section were obtained from two samples representing two population groups; health workers directly involved in PMTCT activities through structured interview processes (as described in section 4.2) and mothers who were currently actively enrolled in the PMTCT programme through focused group discussions (FGDs). In this chapter, issues discussed will also be related to reasons provided in the case histories of mothers qualified as LTFU who were followed up and interviewed (Section 3.4).

Research findings on reasons for LTFU suggest a number of factors that may have an influence on the capacity of families to comply with PMTCT follow-up. These include lack of knowledge, lack of paternal involvement, long distance from clinics, weak referral linkages, stigma, poor services and high death rates. In this particular formative study, most of the factors established to be potentially significant causes of the attrition seen in the PMTCT programme in Mutare and Mutasa districts were found to be in tandem with findings in the literature from other settings.

Health workers were asked the following questions (summarised):

- Have you ever experienced mothers who have defaulted or qualified as LTFU in your PMTCT programme?
- If Yes, what reasons have been given for not coming back to access scheduled PMTCT services?

All of the 39 respondents reported that they had at some point come across a woman who had defaulted PMTCT services whilst 38 had experience of women qualifying as LTFU in their programmes.

Pregnant and breastfeeding women were asked for their perspectives relating to some of the issues identified as possible reasons for LTFU.

Below are some of the emerging themes of challenges noted to be contributing to non adherence and LTFU in the programme and further breakdown of the issues surrounding these challenges as noted from the interviews and discussions with study participants.

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Comment [E19]: Should this section not logically precede the last section so that report can end with recommendations
5.1 Environmental Factors

5.1.1 Weather conditions

Three health workers interviewed had come across situations where a mother had failed to adhere to appointments for review in the PMTCT programme due to heavy rains. Rivers became flooded and the clients were unable to cross certain bridges or rivers until the water levels had settled after cessation of the heavy rains.

5.1.2 Long distance to and from the clinic

Some clients have disclosed to health workers that their reason for falling away from PMTCT is the long distances that they have to travel from their home to the clinic. Interviews with the VHWs indicated ‘local’ distances of up to just under 20km e.g. Nhokwara (15km) and Mutendebvure (17km). These distances become much longer when clients are referred to secondary or tertiary centres of health care delivery. Most of the clients walk to their respective health centres. Other forms of transportation available include mini buses which cost about US$1-2 per one way trip and in times of emergency they will use ox-drawn scotch carts or hire cars.

5.2 Economic Factors

5.2.1 Financial limitations

Some clients have dropped out from the programme or missed some important reviews due to financial constraints. The biggest adjunct cost identified in the PMTCT programme is attributed to transport costs where long distances are involved especially when clients are referred to bigger clinics or hospital for more advanced care. Clients who are referred to the secondary or tertiary level centres like Mutare Provincial hospital or Rusape hospital have to pay additional costs linked to ART initiation such as baseline blood and radiological investigations. This latter point is particularly true for the male partners. From one of the quoted sites, travelling to and from Rusape would cost US$24 per person without factoring in meals or accommodation costs.

Most of the clients in the study area are either subsistence farmers or farm labourers. Some supplement their incomes through part-time jobs (maricho) as and when opportunities present themselves. Residents in some of the clinics’ catchment areas are involved in illegal mining activities where they have claimed abandoned gold mine shafts.

Direct PMTCT services are free in all the centres that took part in the study. Indirect costs vary between the individual centres depending on differences in size of catchment area, level of care delivery, centre policies on consultation fees and availability of donor support. ANC Booking fees range from no cost to US$10, while some clinics charge an additional US$10 for sundries used during delivery.
5.2.2 Competing priorities

According to health workers interviewed, some women who failed to show up for expected PMTCT visits did so because they felt that they could not afford the time to go to the clinic for PMTCT reviews particularly if there were no apparent physical complaints with the mother or the child. They chose to use the time to spend at home working in the fields or doing some other household chores such as herding cattle. This issue was also brought to light in three of the interviewed 12 genuine cases of disengagement from the PMTCT programme (Mrs J, Mrs K and Mrs L).

Attitudes such as these may result from failure to appreciate the graveness of the issues and risks involved in PMTCT. This in turn may well be a function of the thoroughness of the information giving and counselling processes that clients go through before being enrolled into the PMTCT programme.

5.3 Social Factors

5.3.1 Lack of partner support

A number of cases of inadequate PMTCT follow up witnessed by health workers are related to lack of partner support. In some cases this is linked to failure of disclosure of HIV status to the male partner because of fear of resultant conflict. Sometimes the men who are either breadwinners or in charge of the household finances refuse to provide resources for any related costs such as bus fares. In other cases, male partners have actually ordered their female partners to discontinue participation in PMTCT. This results in the women either discontinuing completely or participating secretively which tends to complicate adherence efforts.

One VHW presented the case of a woman whose marriage was broken as a result of conflict which arose during pregnancy, related to issues of HIV testing. After delivery the woman found a new partner but she then started defaulting from PMTCT activities because of the fear to disclose to the new partner.

Two of the 8 cases whose LTFU status was found to be associated with having migrated had reportedly moved away following conflict and separation from their husbands while four of the 12 interviewed ‘disengaged’ mothers cited one or more issues related to marital conflict and lack of partner support as one of their leading reasons for loss to follow up. One of them was actually divorced at the time of the interview.

These findings are in keeping with those from many other settings in sub Saharan Africa. For example, a wide scale survey carried out in Taita district in Kenya reported at the XVIII International AIDS conference in Vienna in 2010 that women’s fear of rejection and being abandoned would keep them away from participation in the PMTCT programme.25

5.3.2 Fear of stigma and disclosure

According to the health workers, some clients are afraid of being associated with the PMTCT programme because then this may lead to inadvertent disclosure of HIV status to the community.

Various reasons were given by mothers in FGDs for their fear of disclosure of HIV status;

"It (disclosure) can be bad because you will be stigmatised. People will not be free to share food with you or accept you."

"It is better to keep it a secret between you and the husband than not be accepted in the community. People will not understand your situation."

"I will not disclose because people won’t want to bath or eat with you, or share blankets with you."

"You will be laughed at, discriminated against."

"People will despise your baby."

"People will call you vana Mwari ndauyyo (God I am coming home)"

"Some don’t want to disclose to community because some mothers in law will keep it a secret but others will accuse you of infecting their son."

"That one person you tell will go on and tell many others."

Clinic based health workers reported on a number of mechanisms that have been put in place in their centres to try and minimize leakage of information on clients’ HIV status;

i. Supermarket integrated approach is used where the same consultation rooms are used for patients whether HIV infected or not. In the MCH department those on PMTCT are not separated from those who are not and all services are offered during the same time.

ii. Clients are attended to one by one in a room with closed doors-Individual treatment of all patients, including disclosure of results and dispensing of medication.

iii. Health workers are not supposed to disclose clients’ information and they reassure clients accordingly. They seek consent before they may embark on disclosure of results in case of partner HIV test. Knowledge of clients’ HIV status and participation in PMTCT must be restricted to clinic staff and not be revealed to VHWs.

iv. All registers are kept under lock and key in lockable cupboards. Only nurses have access to them.

v. All patients go away for a distance both positive and negative after results are given. Only those who are HIV positive return later to maintain confidentiality.

vi. There is a room set aside for counseling and doing PMTCT services away from others.

Some of these mechanisms are clearly in conflict with each other [(i) and (vi)], while the feasibility and effectiveness of some others is questionable as a means of maintaining confidentiality. Some of the staff from certain clinics were convinced that their system was watertight in terms of maintaining
confidentiality and most of these justified this opinion using the argument that their patients never raised complaints regarding confidentiality issues.

Clinic staff in some sites however pointed out some loopholes in their own system that may inadvertently lead to disclosure, a list of which is provided below;

i. Some staff may not maintain confidentiality and they publicize results
ii. Since rooms are few and some doors do not close properly, confidentiality may be compromised
iii. Shortage of nursing staff sometimes leads to task sharing whereby they end up delegating some duties to the nurse aide e.g. if on leave/off duty. Similarly, tasks given VHWs may automatically suggest status of mothers to these cadres e.g. request to physically follow up clients who have missed review.
iv. Most people now know the clinic set up and know the room for VCT, so if they see a pregnant mother getting into that room regularly they become suspicious
v. Some aid programmes like food distribution for ART patients may lead to inadvertent disclosure in the community

Most mothers interviewed expressed general satisfaction at the efforts made by the centres to maintain privacy. Said one participant on the issue, “Even the person who accompanies you on the day of delivery will never know that you are being served in the PMTCT programme”.

Some of the mothers taking part in the FGD felt that nurses disclose patients’s HIV status to the public but claimed that this did not affect their attendance in the PMTCT programme.

“No secret is kept because there are specific days for PMTCT and ART so people will know your HIV status.”

“People in the community are asking what is happening because even at the beer hall it is well known who is HIV positive. There is no secrecy even at the clinic. When an HIV positive mother does not come for her appointment, nurses call them by sending anybody.”

“Nurses pick up HIV positive patients on the queue in public asking if they have come to get tablets. As a result a lot of people have changed clinics and no longer use this clinic for ART/PMTCT. Others go to Mukwada or Mutare Urban.”

“Separate rooms are used for HIV positive mothers when they take their drug”

There was also a general sentiment among the mothers, when it came to the community based health workers that some of them did not respect the client’s privacy. “Some of the VHWs walk around the neighbourhood telling them every single detail about your life”.

5.3.3 Religious restrictions

Some women reportedly fail to adhere to the PMTCT schedule or become LTFU because of their religious affiliations. One nurse quoted the Marange Apostolic sect whose members are not allowed to come into contact or make use of formal health care delivery systems like PMTCT.
According to one clinic based worker, “At times the mothers want to come to the clinic for their baby’s sake, but their husbands refuse. Some of them wind up coming without telling their partners”.

One of the 12 ‘disengaged’ mothers (Mrs H) who was interviewed also cited conservative religious affiliations as the major cause of her loss to follow up status.

5.3.4 Alternative healing efforts

Some health workers knew of mothers who did not return for review in the PMTCT programme because they had gone to seek assistance from faith healers, prophets and traditional midwives who then give them advice to the contrary of expectations of PMTCT.

5.4 Clinic based service delivery factors

5.4.1 Poor knowledge, understanding and appreciation of the programme’s expectations

Several health workers testified to coming into contact with women who when asked for the reason for defaulting follow up in PMTCT, particularly after delivery, have said that they were not aware that they were supposed to return to the clinic for any further reviews.

Other health workers felt that an underlying cause to the default rates and LTFU seen in PMTCT is the lack of appreciation of the importance of follow up to prevent MTCT. This is for example manifested by a high incidence of ‘forgetfulness’ as a reported cause of non adherence to scheduled reviews.

One nurse used the word ‘negligence’ to describe the case of a mother who wound up missing some doses of ARVs during pregnancy because she left the clinic card at home when she travelled to another district and could not be served in the ART/PMTCT programme in that other centre without any documented proof of her enrolment.

Most of the centres reported similar approaches to delivery of health education on PMTCT issues. Group discussions and lectures as well as individual health education sessions for mothers testing HIV positive are delivered. Health workers also reported the use of Information, Education and Communication (IEC) materials such as posters, manuals and pamphlets. Some centres reported the use of VHWs to provide follow up education at homes and also to organise drama sessions for the general community. One centre also used testimonies from other mothers who had successfully gone through the PMTCT programmes and another reported that they played DVDs on HIV issues.

Most of the clinic based health workers felt that the health education delivery efforts were mostly successful. Whilst there were some cases of LTFU noted, these were generally felt to be few in comparison with the number of successful cases with successful outcomes. According to nurses and PCCs, in their experience, most mothers participate well and respond accurately to questions during the group and individual discussions, most mothers come for review, enrolment in PMTCT has been steadily
increasing over the years from the time of programme inception, there is more male involvement and most babies tested through DBS PCR DNA test HIV negative.

Mothers participating in the FGD generally concurred with the providers that they believed themselves to have benefitted from the health education and quality of counselling services received from the clinics. A proportion of mothers in some centres however disclosed that they had not undergone any form of counselling after receiving their HIV result or in relation to various aspects of PMTCT such as infant feeding options.

5.4.2 Frequency of scheduled PMTCT visits

There were mixed sentiments regarding the frequency of scheduled PMTCT visits. Some mothers did not feel that there was a problem with the monthly schedule required in PMTCT. Others felt that the frequency was too much.

"People may ask where you are going every time."

"When you have a baby it is easier because you can say you are going for an injection for your child."

"The number of clinic visits is too many so people end up suspecting there is something wrong. Mothers in law can be very inquisitive."

5.4.3 Issues to do with conducting PMTCT related laboratory investigations

Some centres noted the following observations associated with testing procedures for different tests which may adversely influence a mother’s decision to remain active within the PMTCT programme;

i. There is delay in the turnaround time for DBS results for infants. This can be up to 3 months.

ii. Some mothers feel that the methods used to collect blood in infants for HIV DNA PCR are not user friendly. Said one, “The way DBS sample are collected is painful. The child is pricked under the foot and sometimes it is difficult to get enough blood because many drops are needed.”

iii. In one centre mothers felt that the waiting period before a CD4 count assay was prescribed was too long. “The nurses wait for mothers to complain of weak joints before they repeat the test for CD4 count. One client is on cotrimoxazole for 2 years and has not been tested for CD4 count for those 2 years.”

iv. Some institutions do not carry out CD4 testing so they refer to places like Rusape and St Andrew’s. According to one nurse, “CD4 count is done at St Andrews hospital and its far from here, and some patients do not have money for transport to go there”

v. Where the alternative would be to send the CD4 samples to the testing centre, some clinics find this difficult because they do not have either the transport or the money for transport for someone to take the samples to a centre like Mutare.

vi. CD4 count results are taking too long to come back to the centres.

vii. After testing the mother’s CD4 count, she is advised to come back later for the result, but sometimes they do not come back again, so they should be done at the same time at the clinic
viii. CD4 count machines in use do not show percentages, yet percentages are necessary to determine if a child who is more than 2 years old is ready for ART.

ix. In one centre the nurse cited that she has too much pressure of work as there is only one nurse and no PCC, so faces challenges in doing all the work, counseling, testing and treating other ailments.

x. Two centres voiced the issue of inadequacy of testing space. In both clinics, testing is done in the labour ward which is an open space and this compromises privacy.

5.4.4 Challenges in adherence to selected feeding options

A number of the mothers interviewed reported that they did not face many challenges in attempting to adhere to their chosen feeding option which was predominantly exclusive breastfeeding for the first 6 months of life followed by mixed feeding. VHWs cited some challenges which included the following;

i. Food shortages for the breastfeeding mothers

ii. Difficulty in affording the costs involved for those who chose supplementary feeding options

iii. Insistence by relatives that child be given some other food during the period meant for exclusive breastfeeding. This is commonly a problem with grandparents, “This is a traditional belief being enforced by mother in laws/ grandmothers who are not accepting that children can only survive with breast milk only. They end up substituting breast milk with other foods like porridge or warm water.”

5.4.5 PMTCT Drugs and kit supplies

Only two clinic based respondents mentioned a delayed delivery of ARVs in September/October 2012 which forced the clinics to supply clients with ARV doses covering two weeks at a time. None of the other centres reported any experience of drug shortages. Two other respondents mentioned that HIV rapid test kits sometimes run out at their centres. The mothers in the programme did not mention any drug related issues that may compromise retention in PMTCT.

5.4.6 HCW attitudes

None of the health workers reported having ever encountered a case of a client becoming non adherent to PMTCT expectations due to poor attitudes on the part of the providers. Most of them pronounced that there was no difference between the way they handled clients in the PMTCT programme and all the other clients. Only 4 of the 20 clinic staff interviewed admitted to differential treatment where they suggested that they actually provided a more superior service to HIV infected clients because they required more care, “Because we meet HIV infected mothers more frequently and continue to help them unlike other patients who just come for services and go, a bond develops between us and them.”

While some mothers in the FGDs did not raise any negative concerns regarding the attitudes of the HCWs in handling them and their infants, others expressed varying degrees of disgruntlement.

-“It is different from person to person”.

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“Some nurses are rough but others are welcoming”.  

“Nurses harass mothers if they don’t come too get their medication in the morning, yet a mother can be tied up and forced to come to the clinic later on in the day”.  

“Nurses first serve others then those on PMTCT. They are delayed. They say things like, ‘Zvipotsa ngazvimbomire’ ”.

**5.5 Clinic Information Record Systems & Transfer Logistics**

**5.5.1 Travel & switching clinics**

A common cause identified for failure to attend the clinic on an appointed date in the PMTCT programme is that mothers will sometimes visit outside of the catchment area of their local clinics without obtaining necessary transfer documents from their local clinic, even if it is only for a temporary period.  

A related phenomenon is presented by VHWs in their interviews when they admitted to observing mothers who have been booked in the local clinic for their initial ANC and PMTCT services who wind up accessing services in other centres elsewhere as well or the opposite scenario in which mothers have been booked in other clinics for their initial ANC and PMTCT services but wind up accessing services in the local clinic.  

The following reasons were provided for this common practice;

i. **Referral to other centres for special cases**

ii. **Temporary relocation:**

   o A local cultural practice dictates that women deliver their children from their mothers’ homes (masungiro) so they move away to stay with their parents in the third trimester
   o When client change place of residence during the rainy season, “There are other who resides on the other side of the river, so if the river is full they come to our centre”
   o Mothers usually want to be near the clinic when they get closer to delivery so if they live far away from the clinic in their area they can move to stay with relatives who live close to a clinic
   o Sometimes they are defaulters who are embarrassed by the prospects of returning to their original clinics

iii. **Service preference:**

   o When peculiar programmes that benefit people are offered at certain clinic some clients switch over to such centres. Examples include donation of health related products like mosquito nets sor grocery items like soap. To quote from one VHW, “ We have a food distribution program so some patients they come so that they can get food.”
   o Some clients prefer to move to one clinic over another due to differences in charges. “It’s because other clinics are expensive so they seek services of the local clinic.”
Clients move to clinics they know or perceive to give a better quality service particularly with respect to how health workers look after clients.

5.5.2 Migration

A common cause of actual LTFU reported by clinic as well as community based interviewees is migration. Mothers move permanently to a place outside the catchment area of their original host clinic without informing the original clinic of any intention to transfer. This is only ascertained following some kind of follow up activity. In this case no one knows for certain if such MIPs are still engaged in care elsewhere or if they have totally stopped accessing services. This situation would be remedied by the establishment of more stringent information capturing systems and transfer procedures between clinics. Electronic systems have been shown to work in contexts where resources are permissive.

The following reasons were given for the high incidence of migration observed in the study catchment area among MIPs participating in PMTCT;

i. Some clinics serve catchment areas such as Odzi which are predominantly made up of commercial farms. Farms workers tend to be mobile because it’s not their permanent home area, their posts may be temporary, and they are always searching for more lucrative positions.

ii. Mothers who move out of the area permanently commonly do so following divorce and separation from their partners in which case they migrate back to their parents’ home areas or find a new partner and move on.

5.5.3 Unreported Deaths

If a client dies and the health centre is not notified of this death then this may contribute to the statistics of PMTCT programme LTFU as was experienced by one of the nurses interviewed. The information pertaining to the death was only revealed by a relative who had come to seek her own health care services at a later date.
VI CONCLUDING REMARKS & SUMMARY OF RECOMMENDATIONS

In a country like Zimbabwe, where HIV/AIDS, the single leading cause of child mortality, contributes about 21% of deaths\(^\text{26}\), the desire to achieve elimination of paediatric HIV is one of the major forces that drives all current efforts at scaling up as well as improving the quality of available PMTCT services. Whilst decentralisation of the service has been realised in most needy settings and definitely in the two districts under EPAZ focus, MTCT rates still remain at unacceptably high levels. At the national level, early infant diagnosis PCR positivity was noted at 10.6% in 2011\(^\text{27}\) which compares well with the 9% picked up in this particular piece of formative work [Finding (9), section 3.1.3]. These estimates do not capture the population of infants who are ‘LTFU’ and therefore never get the opportunity to get tested and there is a high probability that if the HIV status of these cases were to be investigated the statistic for MTCT would be significantly increased.

Findings from this study suggest that while laudable progress has been made in the area of antenatal PMTCT, more needs to be done in order to counteract the significant attrition rates noted at the level of delivery and postnatal PMTCT service access. One notable negative finding in Antenatal PMTCT is the lack of universal uptake of HIV testing with an associated higher HIV prevalence (almost double) at testing among mothers tested in the delivery room compared to counterparts tested in ANC. At the tail end of the PMTCT cascade is the issue of early infant treatment on ART for those infants who test positive. Unfortunately, findings in this paper were that only about 30% of the statistic for infants testing HIV positive is observed to have been initiated on ART.

Disparities in data capture and apparently insensible statistics were picked up from the health information system sources at the study clinics and these even affected analysis of quantitative data for this study.

The concept of Loss to follow up was seen to be appreciated in varying terms among different health care professionals involved in PMTCT care without a working standard adopted across all sites. Issues to note included duration of non-attendance, timing relative to delivery, degree of permanence of absence and need for follow up effort. Upon follow up of mothers/ mother-infant-pairs qualifying as ‘Lost to follow up’ at the different clinics a variety of outcomes were noted to have occurred with just one third of the listed names ultimately confirmed to have ‘disengaged from care’. The rest were either up to date in their follow up (hand-held clinic records showing regular service access or justly discharged from further care), or had follow up status unknown due to either migration or supply of a wrong address.

Interviews with mothers disengaged from the PMTCT programme, health workers and FGDs with mothers currently enrolled in PMTCT yielded the following as issues contributing to attrition along the PMTCT cascade: environmental factors such as weather conditions and long travelling distances;


economic factors such as unaffordable transport costs and competing income generation related priorities; social factors such as fear of stigma associated with disclosure, lack of partner support/negative partner interference, religious restrictions, alternative treatment options; personal factors such as denial of HIV status and ill-health; clinic based service delivery issues such as inadequate information delivery resulting in poor knowledge and understanding of the programme expectations, delays and inaccessibility of related laboratory investigations and negative health care worker attitudes; Inadequate clinic based health information record, tracking and transfer systems that are insensitive to migration, as well as travel and transfer issues.

The Journal of the International AIDS society recently (2013) published a systematic review of over forty qualitative and quantitative studies on barriers and facilitators of PMTCT programmes in different parts of Sub Saharan Africa conducted between January 2000 and September 2012. Quite in tandem with findings from Mutare and Makoni districts shared in the preceding chapter, the authors come up with the following conclusion:

“Long-standing health-systems issues (such as staffing and service accessibility) and community-level factors (particularly stigma, fear of disclosure and lack of partner support) have not changed over time and continue to plague PMTCT programmes more than 10 years after their introduction. The potential of PMTCT programmes to virtually eliminate vertical transmission of HIV will remain elusive unless these barriers are tackled. The prominence of community-level factors in this review points to the importance of community-driven approaches to improve uptake of PMTCT interventions, although packages of solutions addressing barriers at different levels will be important.”

The recommendations listed below emerged from the discussion of all the findings summarised above.

6.1 Recommendations for the main EPAZ Cluster Randomised Control Trial

1. Community engagement efforts at the beginning of the project in all arms should include a component on emphasizing the importance of HIV testing as a gateway into the PMTCT programme to maximize the potential for achieving required numbers for enrolment into the study right from the onset

2. The design of the MSG should emphasize under ANC activities strategies to retain women in the PMTCT programme in the institutions for purposes of delivery

3. The design of the MSG to be a crafted in such a manner that there is a lot of emphasis on mechanisms to reduce attrition in the postnatal period where the greater burden of attrition and LTU seems to be concentrated.

4. The design of the MSG should endeavour to bring in aspects related to strengthening male partner involvement and participation in the PMTCT programme.

5. The content of the MSG curriculum should be designed to cover adequately all information necessary to ensure full comprehension of PMTCT issues and expectations by participating mothers.

6. The EPAZ CRCT project will have to design strategies to empower and support nurses in the study sites in order to facilitate the operationalization of the study interventions through nurse-led initiation of ART.

7. There is need for the project to establish strict data quality control maintenance strategies.

8. Regular refresher training and mentoring of HCWs involved in data entry on the use of clinic based registers in which PMTCT data is entered so that clinic records are always kept up to date. That way registers such as the HIV exposed infant register will provide reliable information on issues such as negative HIV result and resultant programme discontinuation or capturing of all those infants who remain adherent to the follow up schedule. This is crucial in light of the fact that these reports will serve as the main source documents for the main CRCT Case Report forms.

9. The definitions of concepts on retention and follow up as well as the SOPs on the same that are employed in the study should be the same for both the antenatal and the postnatal periods. The wording should reflect this in terms of the different nature of the clientele in the two stages i.e. mothers during antenatal PMTCT and MIPs during the postnatal PMTCT period.

10. The main EPAZ CRCT is recommended to introduce the term ‘non-attender’ for mothers/MIPs who miss a single scheduled PMTCT visit.

11. A tracking mechanism to pick up non-attenders on the day that they fail to present themselves for a scheduled appointment should be devised at the level of the local clinic facility so that the study is able to record issues pertaining to the ‘quality of retention’ indicator (See recommendation (10) for the main CRCT) which will be crucial for analysis at the end of the study.

12. Introduce a ‘quality of retention’ indicator to complement the ‘retention’ indicator within the main EPAZ CRCT. This additional indicator will be attained through assessing the number of appointments kept as a fraction of the total number of expected PMTCT visits. Outcomes may be recorded as non-retention, partial retention and full retention.

13. The main EPAZ CRCT is not recommended to institute regular follow up and tracking exercises as part of their routine operation (this would in fact translate to a third and independent intervention). It is however recommended to follow up clients who have not met the criteria for full retention (i.e. non-retention and partial retention) at the end of their individual study follow up period in order to ascertain the reasons for their inability to attend an adequate number of scheduled visits. This should assist in final classification of ‘quality of retention’ as well as contribute to the final analysis of study outcomes.
6.2 Recommendations for the PMTCT programme

1. More effort has to be put in place in the programme in order to increase the uptake of HIV testing early on in ANC.

2. The program is recommended to work on strengthening strategies to increase retention in delivery and postnatal PMTCT.

3. It is essential that the MoHCW programmes develop and foster a strategy to encourage and support the involvement of male partners in issues related to reproductive health, antenatal care and PMTCT.

4. There is need for more engagement with conservative religious communities to mobilise towards participation in PMTCT activities.

5. There is need for the programme in conjunction with partners to support current efforts and develop more strategies to increase general community awareness and support for PMTCT activities at the level of local communities.

6. There is a general need for establishment of strategies to empower and support nurses so that decentralised nurse led initiation of ART especially for paediatric patients may be realised as a reality in the whole PMTCT and paediatric ART programmes.

7. Regular support and supervision activities is crucial in the area of Health Information systems management and Monitoring and evaluation procedures in the public health facilities so that sensible and useful data may be recovered from sites for programme planning and administrative purposes.

8. Local Health institutions should be set up with tracking mechanism/s to pick up non attenders on the day that they fail to present themselves for a scheduled appointment so that follow up plans can be immediately instituted.

9. In line with general recommendation (8) above, a suggested tracking system for further development, support and testing as implementation research could involve activation of a routine physical follow up mechanism for every mother/MIP who fail to attend a scheduled PMTCT appointment following laid down standard of care procedures i.e. making use of VHWs and community caregivers (to be collectively referred to as community based health workers).

10. Where tracking systems are developed, allow a grace period of at least one to two weeks after identifying a mother/MIP as 'non-attender' before activating follow up mechanisms.

11. Following on recommendations (8),(9) and (10) above; a tracking system developed for the purposes of following up mothers/MIPs in the PMTCT programme may take on the following terminology for the purposes of categorization of outcomes upon performance of physical follow up activity of mothers/MIPs who fail to attend the clinic on the appointed date;

   i. Mother and/or infant deceased
   ii. Mother/MIP status not known - refers to those clients who cannot be located upon implementing physical follow up. This category will convert to Mother/MIP LTFU when the mother/MIP misses the equivalent of 3 consecutive monthly reviews.
   iii. Mother/ MIP transferred - refers to clients who are still engaged in PMTCT activities but have switched their clinic of access.
   iv. Delayed attenders - refers to clients who, following a physical follow up visit, then
resume their visits with the PMTCT clinic

v. **Mother/MIP disengaged from care**- refers to clients who, following a physical follow up visit, do not resume clinic visits for the purposes of PMTCT

### 6.3 Recommended areas for further research

1. There may be benefit in carrying out in-depth qualitative research to understand the issues associated with non-uptake of HIV testing in ANC among the population of mothers who present in labour with unknown HIV status.
2. Further implementation research on the feasibility of setting up and running tracking mechanism(s) to pick up non-attenders in the PMTCT programme and follow them up.
3. Research is necessary to understand the issues hindering male participation in the current PMTCT and other related health programmes
4. Implementation research to test the feasibility and outcomes of establishing electronic patient databases and other more stringent paper based forms of client transfer and tracking systems between institutions in order to obtain reliable data on MIP outcomes in the PMTCT programme
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