IATT
THE INTERAGENCY TASK TEAM
The Interagency Task Team on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children

IATT Webinar Summary and Discussion: Multi-Country PMTCT Cascade Analysis
September 17, 2015

The webinar was attended by **68 participants** representing the following countries among others: DRC, Botswana, Brazil, Ethiopia, Senegal, Tanzania, Zambia, and South Africa.

This webinar presentation was an opportunity for IATT members to learn about the multi country Prevention of Mother-to-Child-Transmission (PMTCT) cascade analysis that was done in Kenya, Malawi, Rwanda and Swaziland, as part of the USAID funded HIVCore project. The aim of the project is to improve the efficiency, effectiveness, scale, and quality of HIV related health services. In addition, it is anticipated that it will enhance effectiveness and examine new approaches for improving testing and treatment of PMTCT programmes.

Dr. Sam Kalibala representing the Population Council and Dr. Godfrey Woelk from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) gave an overview of the methodology and results of this multi-country study, with a particular focus on Rwanda. As many countries are scaling-up Option B+, the implications of this study are relevant given the emerging challenging observed with respect to retention and monitoring and evaluation.

The main points highlighted during the webinar include:

- There are different end points to measure retention, which varies across countries depending on the definition of retention used. This was the case in this multi-country study which was carried out in countries where implementation of WHO guidelines varied, including the implementation of Option A in Kenya and Swaziland, Option B in Rwanda and Option B+ in Malawi.
- The findings showed that **retention was positively** associated with health **facility characteristics** namely: **rural location and number of deliveries**. **Retention also improved after delivery** which may be due to the desire to give birth closer to home or family of origin or at a facility were the services are perceived to be of better quality. In contrast, the number of ANC clients and doctor visits were inversely associated with retention. Fewer ANC clients may reflect lower workloads which has been correlated with improved retention in South Africa. Also, fewer doctors' visits may indicate that there are an adequate number of health staff to attend to clients.
- Overall, the results of the study underscored key characteristics of health facilities are very important and **correlated with better retention: rural location, lower workloads, faith-based facilities, comprehensive services, active follow up and availability of doctors**. Therefore, it is important to start discussing how health facilities could be supported to implement these interventions.
- The presenters also highlighted that while the small number of health sites visited was a limitation of this study, these sites had the most reliable data. Nevertheless, missing data was a challenge and affected the ability to accurately assess retention.

Question & Answer Session

Q1: To facilitate comparison with other results in the literature, will the authors also report the second retention rate (i.e., after 2 months) the traditional way, with the denominator the number registered?

Answer: We estimated retention from the registration date. So the information we had was from when the mother was registered at the beginning to right at the end, and this was divided up into these overlapping segments. And then looked at these time periods from registration to 30 days after registration and then delivery and at six weeks after delivery and at 3, 6 and 12 months.

Q2: A clarification, was the OR 29 or 2.9? It was 29.
Also, the 95% confidence interval seems to be 2.0 – 4.0, is that correct?
Answer: There is an error on the slides.
Moderator: We will correct it before we share the slides.

Q3: What were the elements or modes of active follow-up in Rwanda? Did it include initiatives led by peer outreach workers or mother support groups?
Answer: As far as I am aware in terms of active follow-up, remember this an interview with the health facilities in charge, it was the community health workers that were going out and following up the mothers.
Moderator: Were community health workers the only mode used to follow-up mothers?
Answer: No, there were no other methods that were implemented that I know of.

Q4: Did you follow-up women lost if they are picking up their ARV's at other close by facilities?
Answer: No, we had no way of knowing that because this was a records review.

Q5: Do you know if family based care model was a factor positively related to retention?
Answer: No, the study didn't look at that.

Q6: Can you explain the difference in retention between the mother (67%) and infant at 12 (76%) months?
Answer: First, this is a function of quality of the data that was available. Second, we can only speculate that perhaps there is a greater attention paid to the infants by the family. The infants were analyzed separately.

Q7: What would be the recommendation of the study as to when to ultimately measure retention since there were multiple points at which retention was measured?
Answer: As you all know that is a huge debate because people come in and out of the system. For example, do you consider somebody who goes away for many months and then comes back again, to be retained in care? So as we are moving more and more to Option B+, we really want to be able to measure retention over a longer period of time. Therefore, in my view it is important look at retention at 9, 12, 18, 24 months post-delivery.

Moderator: This question also underscores the reality that it is quite common for women and infants to disengage and reengage in care – it is not exceptional. There are many ongoing discussions at the global level that will help inform what the formal definition of retention should be, but of course it will vary country by country in terms of national guidelines.

Q8: In the demographic slides, I believe you said 60% of women had known their HIV status at their first ANC visit. Is there difference in retention between women who already knew their status compared to women who newly diagnosed as HIV positive at their first ANC visit?
Answer: That is a good question, but we didn't distinguish between women who already knew their status compared to women who were recently diagnosed with HIV during first ANC.

Q9: – ***Was there a difference in outcomes based on the age of the mother, for example between young mothers and older mothers***.
Moderator: It doesn't seem like the team looked at that as a variable, but in case you did, I would like to ask the question.
Answer: No, we didn't find a difference.

Q10: Any indication as to why the retention rate is lower at the early stages of follow-up rather than later stages?
Answer: It is a speculation. I can only assume that women went somewhere else and came back later on, but other than that we don't have any further information.
Moderator: There are some other studies and evidence in the literature that gives some indication as to the reasons for early loss to follow up. Other studies suggest that this might be related to women needing time to process the diagnosis and disclose their HVI status to family and other community members who might be of support. There is wide range of reasons why there might be some loss to follow-up at early stages. In the context of Option B+, perhaps women are not feeling ill are less inclined to take medication right away.

Q11: How did you define the cohort? In your analysis did you use mother and baby pair registers that were linked or was there a separate register for each?
Answer: For the Rwanda study, there was linked data, but we also looked at other registers if they were available. There were separate registers, but the mother and infant information was combined on the patient file.

Q12: Why do married women show higher rates of retention? Is it because of couple support or perhaps it is a surrogate for income- having a higher income?
Answer: Of course, we tried to get explanation for this, but we had no means of assessing income from the records. In fact, it was the women who were living as married that weren't officially married that had better retention than women who were officially married. It seems like maybe being married involved costs and that may have been a particular subset of women.

Q 13: Any lessons learned in conducting research and implementing the study particularly to countries that might want to do a similar study in their context, especially in regards to data. How you were able to work around limited availability and quality of data? What would you do differently in the future?

Answer: Thank you for the good question. One of the lessons learned is that doing a retrospective records review is extremely difficult because of the missing data issue. It is very problematic. If one is to do such a study, it is much better to do it prospectively to ensure that the data you want will be collected. It will also requires some degree of investment in ensuring that the variables that you are interested in you will have data on. It means investment in ensuring in data quality and interventions to make sure you get what you want.

Q 14: In follow up to that - with the scale up of ART for pregnant and breastfeeding women there are a lot of discussions and investments in strengthening monitoring and evaluation systems. ***Do you have any recommendations on what are some of the key interventions to strengthen M&E systems and ensure that retention is better monitored?***
Answer: First, there is a lot of data we collect, which is probably not useful or usable so there is a burden on the individuals collecting the data. We need to really think what information we really need to monitor better retention. Secondly, some sites have clipped together the mother and baby cards and in some sites they are kept separately, which makes it very hard to link them. And in the sites with higher client volumes, there is a movement to having an electronic patient record system. This is a positive move, but we know this is not going to be possible in all the sites. And for M&E purposes, having a sentinel surveillance system with selected sites where you make significant investments to collect quality data should be seriously considered to be able to adequately monitor and evaluate monitor retention particularly.

Moderator: In summary, you are suggesting in the future, if a country wants to do a similar study to follow outcomes and also to strengthening monitoring and evaluation systems, it is important to examine the data burden that is placed on health care providers. And facilities collecting data should streamline and standardize the data that is collected, linking mother and infant pair registers, establish electronic patient record systems, particularly in larger health facilities, and set up surveillance systems to better monitor retention.

Q15: Moderator: Also, it seems like the study is pointing to the importance of having active follow up and perhaps having really strong systems where community health workers or peer outreach to actively follow up mothers who are lost to follow-up. ***And did you observe any interventions to preemptively prevent loss to follow up?***
Answer: Not that I am aware of.

Sam Kalibala:
It is important to recognize that staff in ANC clinics are overwhelmed with so many registers. A serious review of the number and need for the registers is important, especially now that the guidelines on lifelong ART for pregnant and breastfeeding women are not likely to change in the near future and that patient files will generally be maintained in ANC/MNCH until a child is 18 months old or final diagnosis is determined. It is an opportune time to streamline all of the registers.

Moderator: The point is well taken. The point about integrating registers and reducing the burden that is placed at the facility level in terms of collecting data is an important one and will go a long way to strengthening monitoring and evaluation of PMTCT outcomes. Those discussions are definitely underway. We are pleased to have both you and Godfrey with us on this webinar and this presentation will hopefully help inform future strengthening of M&E systems across countries.