



Current Practices to Improve Uptake, Retention and Adherence for Option B+ in Malawi

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mothers2mothers Malawi

mothers2mothers (m2m) works to close the gap between the increasing availability of PMTCT and health services and the lack of uptake of these services by the women and children who need them most. Since 2008, m2m has worked in Malawi to empower pregnant women and mothers to live healthier lives by educating and supporting them to access and adhere to lifesaving interventions for themselves and their babies. m2m's program model identifies and employs mothers living with HIV and with recent PMTCT experience to serve as Mentor Mothers to pregnant women and recently diagnosed HIV-positive pregnant women and new mothers. Mentor Mothers provide motivational education and psychosocial support to clients and work as fully-integrated members of the PMTCT and Reproductive, Maternal, Newborn and Child Health (RMNCH) teams in the health facilities in which they are based.

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EXECUTIVE SUMMARY

With support from the National AIDS Commission and in collaboration with the Malawi Ministry of Health, mothers2mothers reviewed current practices to support uptake, retention-in-care, adherence for Option B+ in Malawi and the region, with an emphasis on psychosocial support services. A literature review was conducted to identify practices from sub-Saharan Africa, and key informant interviews were conducted with stakeholders in Malawi to identify current practices across the country. This review identified several considerations to be explored through stakeholder dialogue.

Stakeholders continue to experience inadequate uptake of treatment and retention-in-care in the postnatal period, particularly at 12 and 24 months of age. Facility-based improvements to client flow, institution of mother-infant pair clinics, and the roll-out of point-of-care testing machines will help to address this. However, lay health workers and peer educators could be utilized more effectively within facilities. Expert clients and mentor mothers are providing vital services that are proven to help women with taking up, and remaining, in care, but their integration into facilities and the roles they play are uneven and varied. With better strategic positioning inside facilities and increased integration into health systems, these cadres can help to reduce waiting times and provide higher quality counseling, education and support, as compared to the rushed services that clients often experience in standard care.

Broad-based community outreach that includes traditional and faith-based leaders is proving to be effective in reducing stigma and discrimination, and efforts to engage couples and families are reported to be increasing male involvement in care. These approaches could be explored and lessons learned shared between stakeholders. They could also be reviewed to ensure that the best interests of women are considered in each approach, and that they do not inadvertently reinforce entrenched and unequal gender dynamics.

Many interventions remain reactive to client drop-out from care, as opposed to tackling these issues proactively to prevent them from happening in the first place. Household visits and reminder systems prior to key PMTCT events, such as early infant diagnosis at six weeks, and 12 and 24 months could be considered. It is also critical to invest resources and efforts to retain mothers in care, not just as key to identifying exposed infants, but to retain women on treatment for life for their own health and benefit.

Another gap that could be examined is the messaging that stakeholders provide to women accessing antenatal care and PMTCT. Key messages could share the benefits not only for the prevention of vertical transmission, but also clearly articulate the health promoting benefits to the woman herself and the protection provided to her partner. Stakeholders could examine, refine, and ensure alignment of these messages across programs.

The use of same-day initiation is contributing to the inadequate uptake of treatment under Option B+, which points to the need to identify alternatives or enhancements to this approach. In addition, primary prevention for HIV-negative women needs to be considered, for example through increased access to treatment as prevention and pre-exposure prophylaxis for serodiscordant couples.

To capitalize on the early successes of Option B+ and maintain momentum, it is vital that these remaining challenges hampering uptake, retention-in-care, and adherence to treatment be addressed. Now is the opportune moment for stakeholders to exchange knowledge, and identify and scale-up promising practices so that Malawi can achieve its goal of eliminating mother-to-child transmission.

This report was funded by the Malawi National AIDS Commission, Johnson and Johnson Foundation and Elton John AIDS Foundation.





ACRONYMS

A mother is not to be compared with another person - she is incomparable (African Proverb)

ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral Drugs
CAG	Community ART Group
CHW	Community Health Worker
CMM	Community Mentor Mother
CPT	Cotrimoxazole Preventive Treatment
DBS	Dry Blood Sample
DHO	District Health Office
EC	Expert Client
EGPAF	Elizabeth Glaser Pediatric AIDS Foundation
EID	Early infant diagnosis
GOOCH	Guardians of Our Children's Health
GPS	Global Positioning System
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
HSA	Health Surveillance Assistant
HTC	HIV Testing and Counseling
IEC	Information, Education and Communication
LTFU	Loss to Follow Up
MIP	Mother-Infant Pair
MIPC	Mother-Infant Pair Clinic
MM	Mentor Mother
MNCH	Maternal, Newborn and Child Health
MOH	Ministry of Health
NAC	National AIDS Commission
PCR	Polymerase Chain Reaction
PIH	Partners in Health
PLWHIV	People Living With HIV
PMTCT	Prevention of Mother-to-Child Transmission
PN	Postnatal
PNC	Postnatal Care
PPTCT	Prevention of Parent to Child Transmission
QA/QI	Quality Assurance/Quality Improvement
RMNH	Reproductive, Maternal and New born Health
SSDI	Support for Service Deliver Integration
TB	Tuberculosis
USAID	United States Agency for International Development
VHW	Village Health Worker
WASH	Water, Sanitation and Hygiene
WHO	World Health Organization



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1 INTRODUCTION AND BACKGROUND

Now that Option B+ has been implemented for three years in Malawi, the data is revealing the clear benefits of this innovative approach to prevention of mother-to-child transmission (PMTCT). The policy has vastly increased uptake and access to PMTCT with a seven-fold increase in the number of women starting antiretroviral therapy (ART) for PMTCT in its first year alone¹. Despite these successes, progress is undermined by significant challenges experienced with uptake, retention in care, and adherence to treatment.

Operational and clinical challenges are compounded by the significant personal, interpersonal, and social barriers that hamper women's ability to fully participate in PMTCT. Many women are adjusting poorly to the idea of starting treatment for life while they feel healthy and are symptom-free. High levels of stigma and discrimination continue to isolate and marginalize people living with human immunodeficiency virus (HIV) (PLWHIV) and contribute to drop-out along the PMTCT cascade. Poverty and food insecurity make it difficult to prioritize HIV treatment and care. All of these issues exist in a context where unequal gender dynamics make it difficult for women to access and adhere to HIV prevention, care and treatment².

For women and their babies to successfully navigate these challenges throughout the spectrum of PMTCT interventions, sustained education and support is vital. In Malawi's severely resource constrained environment, clinicians, nurses, and counselors are

understaffed and overburdened, and often lack the time, training and resources to provide adequate guidance. The importance of psychosocial support services is only enhanced in this context, making it a key component of PMTCT services in Malawi.

The objective of this report is to review innovative approaches and current practices in Malawi and the wider sub-Saharan African region that address uptake, retention and adherence throughout the spectrum of PMTCT services, with special attention to psychosocial support services.

With support from the National AIDS Commission (NAC) and in collaboration with the Ministry of Health (MOH) HIV/AIDS-PMTCT Program, mothers2mothers Malawi reviewed existing psychosocial support and Loss to Follow Up (LTFU) initiatives in Malawi that seek to improve the uptake and retention of pregnant women, mother-baby pairs and their partners under Option B+. It includes a review of services delivered and managed from health facilities, communities or a combination of both.

The first half of the report is a review of the evidence to date on Option B+, barriers to uptake, retention and adherence to PMTCT. The second half of the report documents current practices from the region and Malawi through a literature review and key informant interviews with PMTCT service providers. Full descriptions of PMTCT services in Malawi from the key informant interviews are also contained in the annex.

¹ Barr, B., et al. (2013). Uptake and retention in Malawi's Option B+ PMTCT program: lifelong ART for all HIV+ pregnant or lactating women. 14th Conference on Retroviruses and Opportunistic Infections, Oral Abstract. [Citation via Clayden, Uptake and retention in Malawi's Option B+ programme. HIV Treatment Bulletin 14(5/6).].

² Ghanotakis, E., Peacock, D., & Wilcher, R. (2012). The importance of addressing gender inequality in efforts to end vertical transmission of HIV. *Journal of the International AIDS Society*, 15. Retrieved from: <http://www.jiasociety.org/index.php/jias/article/view/17385>. [Hereinafter Ghanotakis, supra note 2].





...to take the findings of this report forward, identify practices that hold promise for scale-up, highlight key emerging issues and trends and opportunities to collaborate.

Regional practices and current Option B+ outcomes were identified through a literature review. Data on current practices in Malawi were collected through document review, key informant interviews and site visits. The interview tool is contained in the annex. The package of service delivery offered by various programs under review were described and compared and key considerations for the Malawian context were highlighted.

Feedback was elicited from the stakeholders interviewed and NAC and the MOH. On the 27-28th October 2014, m2m, NAC and the MOH are hosting a workshop with national stakeholders in order to take the findings of this report forward, identify practices that hold promise for scale-up, highlight key emerging issues and trends and opportunities to collaborate. The workshop will identify key recommendations, which will be added as an addendum to this report.

This report does not include an exhaustive list of stakeholders working to advance eMTCT in Malawi. Regretfully, due to resource constraints, a representative selection of organizations and programs were identified in consultation with NAC and the MOH to illustrate a sampling of the type of services currently being provided in Malawi. m2m would like to acknowledge the invaluable contribution and impact of all partners working to advance reproductive, maternal, newborn and child health (RMNCH) in Malawi.

UPTAKE

Testing and same-day initiation on treatment is a challenge to the uptake of ART under Option B+, as women are not given sufficient time or information to adjust to the idea of lifetime treatment. In Malawi, women who started ART on the day they were diagnosed were almost twice as likely to never return to the clinic than women who started Option B+ later.³

Qualitative research on client and healthcare worker perspectives on Option B+ in Malawi found that healthcare workers view clients as having difficulties in understanding immediate ART initiation.⁴ They view same-day testing and initiation on ART as “too fast” for clients to be able to process. Interviews with clients revealed that few were in any form of support group, though almost all of them said it would be a helpful component of care. All clients requested group talks and support groups, with a preference for talking to someone also on ART. Clients requested “expert mothers” to conduct supportive home visits to advise them together with their partners and to help reduce the number of clinic visits for the client themselves.

Analysis of data between October 2011 and March 2012 found that 17% of women in Malawi appeared to be lost to follow-up (LTFU) at six months after ART initiation, and that most losses occurred in the first 3 months of therapy.⁵ Women who did not start ART on the day of diagnosis and who received additional counselling had better retention than women who started treatment on the day they were diagnosed. Women who started ART during pregnancy were five times more likely to never return after their

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initial clinic visit than women who started in World Health Organization (WHO) Stage 3 or 4 or with a CD4 count of 350 or less.⁶ LTFU was highest among pregnant women who started ART at large clinics on the day they were diagnosed with HIV.

A more recent study by Lighthouse Trust followed a cohort of Option B+ women at Bwaila Hospital between September 2011 and September 2013 and found that of the women enrolled on treatment, 9.3% of women collected ART at initiation and never returned.⁷

The MOH's Integrated HIV Program Report for Quarter 1 of 2014 discusses failed ART initiation as the main reason for early LTFU of Option B+ women.⁸ The MOH report indicates that most LTFU women in the first six months never return after the first dispensing visit and many may have never actually started taking ART.

³ Tenthani L., et al. (2014). Retention in care under universal antiretroviral therapy for HIV-infected pregnant and breastfeeding women (Option B+) in Malawi. AIDS. doi: 10.1097/QAD.0000000000000143

[Hereinafter Tenthani, L. supra note 3].

⁴ Cataldo F., et al. (2013). Exploring women and health care workers' experiences in the context of PMTCT Option B+ in Malawi [Abstract]. 17th International Conference on AIDS and STIs in Africa, Cape Town, abstract ADS069.

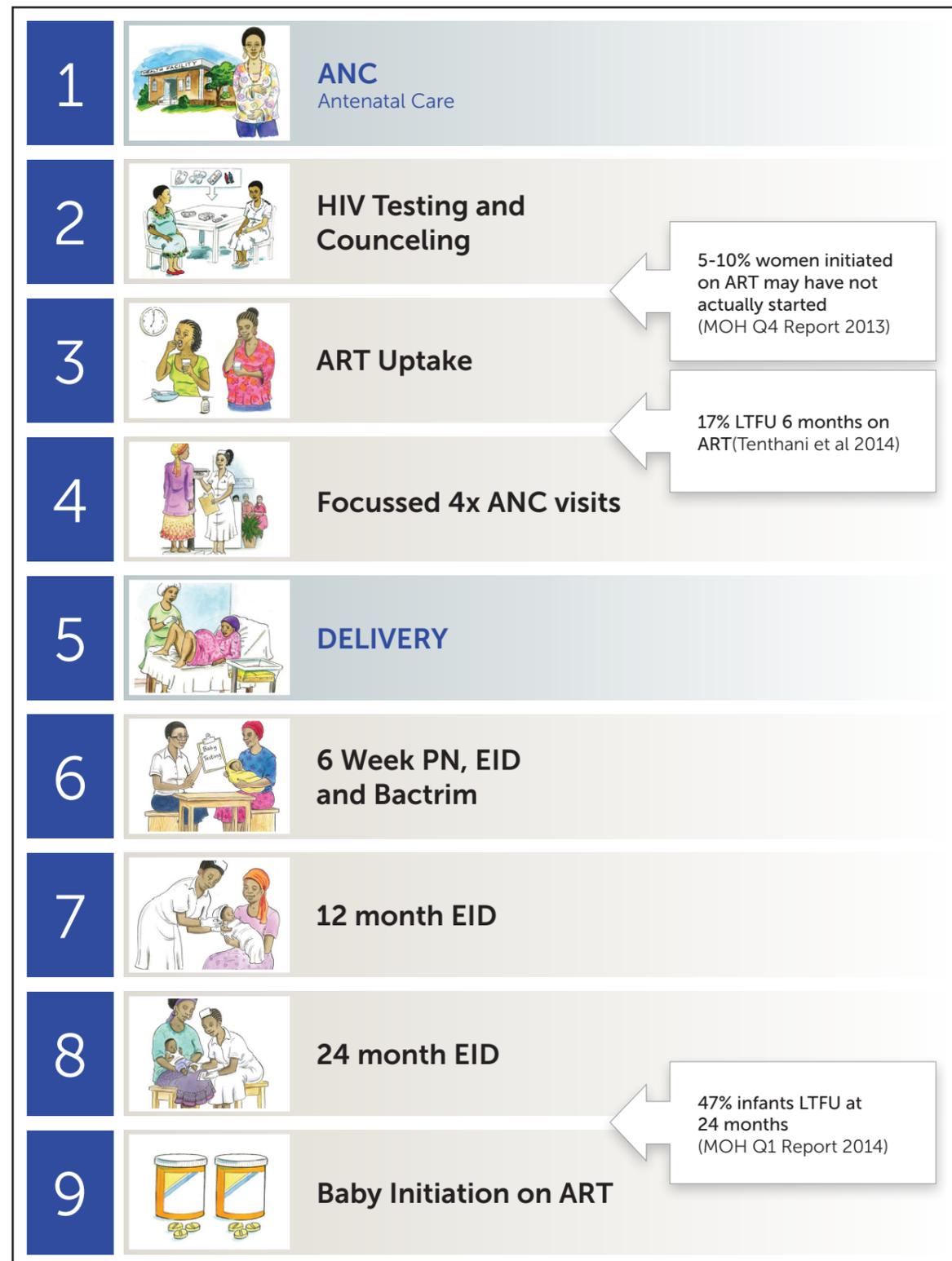
⁵⁻⁶ Tenthani, supra note 3.

⁷ Tweya H., et al. (2014). Loss to follow-up among women in Option B+ PMTCT programme in Lilongwe, Malawi: Understanding outcomes and reasons, presentation at International AIDS Society. [Hereinafter Tweya, H. supra note 7].

⁸ Malawi Ministry of Health Integrated HIV Program Report for Quarter 1 2014 [Hereinafter MOH Q1 2014, supra note 8].

RETENTION

THE OPTION B+ CASCADE IN MALAWI



The MOH tracks outcomes of three cohorts of infants – 2 months, 12 months and 24 months of age.⁹ The MOH's report for Quarter 1 of 2014 indicated that in the 2 month age cohort, just 37% of infants had received Polymerase Chain Reaction (PCR) results. In the 12-month age cohort, infection status was known for just 35% of infants, 6% of whom were confirmed to be HIV-positive. LTFU at this age was 29%. The main outcome indicator for HIV exposed child follow-up is HIV-free survival at 24 months of age. In this cohort, infection status was known for 41% of children and 47% were LTFU.

Of HIV-exposed infants discharged from maternity, 94% received nevirapine, but only 59% were enrolled in exposed child follow-up before 2 months of age.¹⁰

As nearly half of infants are LTFU at 24 months, Malawi's retention rates for HIV-exposed children present a serious challenge. Nonetheless, Malawi compares favorably to regional estimates. According to a systemic review of mostly sub-Saharan Africa countries, about one third of HIV-exposed children in standard PMTCT programs fall out of care in the three months after delivery and a further 45% stop care after their first HIV test.¹¹

Cohorts of Option B+ women retained on ART for six months, 12 months and 24 months after initiation are also tracked by the Malawian MOH. For the first quarter in 2014, 77%, 72% and 71% of women who started ART were retained on treatment at six, 12, and 24 months after initiation, respectively.¹² While this is still a significant challenge, these figures also compare favorably to regional estimates for retention. A 2012 review of 8 sub-Saharan African studies found a pooled estimate of almost half (49.08%) of pregnant women in PMTCT being LTFU between antenatal(AN) registration and delivery alone.¹³

The aforementioned Lighthouse study found that

20% (577/2930) of women missed a scheduled clinic appointment by at least 3 weeks.¹⁴ Reported retention rates were 85% at 3 months, 82% at six months, and 79% at 12 months of age. Of the 20% of women who were LTFU, 40% were successfully traced, and 66% of these were alive and not transferred to another facility for care. Unsuccessful tracing was mostly due to incorrect addresses documented in client files, likely from clients giving false addresses because of fear of stigma and discrimination.

A small study from northern rural Malawi looked at 395 women between July 2011 and January 2013, and found that of HIV-positive women not already on ART, 55% (26/47) started treatment during pregnancy.¹⁵ Five of these women (19%) stopped treatment by the time they were interviewed for the study. Forty-three percent (43%) of eligible pregnant women not on ART at the beginning of antenatal care (ANC) did not start ART during pregnancy or delivery, and at least 20% of HIV-exposed babies did not receive nevirapine.

ADHERENCE

Optimal adherence to ART is defined as an over 95%

The most common reasons for discontinuing ART were travelling; transportation costs; limited information about antiretroviral drugs (ARVs); experiencing side effects; feeling weak/sick; non-disclosure; and having conflicting religious beliefs.

adherence level, which remains the recommended goal for treatment.¹⁶ Another study conducted by Lighthouse in Malawi analyzed data between September 2011 and December 2012 using pill

⁹⁻¹⁰ MOH Q1 2014, supra note 8.

¹¹ Sibanda, E., et al. (2013). The magnitude of loss to follow-up of HIV-exposed infants along the prevention of mother-to-child HIV transmission continuum of care: a systematic review and meta-analysis. *AIDS*, 17, 2787-97. doi: 10.1097/QAD.000000000000027 [Hereinafter Sibanda, supra note 11].

¹² MOH Q1 2014, supra note 8.

¹³ Sibanda, supra note 11.

¹⁴ Tweya, supra note 7.

¹⁵ Price, A., et al. (2014). Uptake of prevention of mother-to-child transmission using Option B+ in northern rural Malawi: a retrospective cohort study. *Sexually Transmitted Infections*, 90, 309-14. doi: 10.1136/sextrans-2013-051336

¹⁶ Machtinger, E. & Bangsberg, D. (2005). Adherence to HIV Antiretroviral Therapy. Retrieved September 21, 2014 from HIV InSite Knowledge Base Chapter. Retrieved from: <http://hivinsite.ucsf.edu/InSite?page=kb-00&doc=kb-03-02-09>.

counts and found a median adherence level of 91%.¹⁷ It also found that breastfeeding women at ART initiation had an increased likelihood of having optimal adherence levels (defined in the study as between 95-100%). Women 27 years and older and on ART for at least 3 months had decreased likelihoods of optimal adherence.

In the 2013 Lighthouse study, LTFU women were traced and interviewed, and it was found that 77% of them had stopped taking ART.¹⁸ The most common reasons for discontinuing ART were travelling; transportation costs; limited information about antiretroviral drugs (ARVs); experiencing side effects; feeling weak/sick; non-disclosure; and having conflicting religious beliefs.

Seroconversion during Pregnancy and Breastfeeding

There is little information about the retention of HIV-negative women in care and they are often not considered in PMTCT programs. Effective HIV-prevention through offering repeat testing and counselling for HIV-negative women and their partners is essential in order to fulfill prong one of the Global Plan - prevention of HIV among women of reproductive age.

Attention is required on the seroconversion of pregnant and breastfeeding women because of the higher risk of vertical transmission among women who recently acquire HIV than those with chronic infections in the pregnancy and postpartum periods. A systematic review of 19 sub-Saharan African studies found the pooled vertical transmission rate among pregnant/postpartum women to be 2.9-fold higher during the postpartum period among those who had recently acquired HIV than among those with

Programs are not providing adequate assistance to women who test negative

chronic HIV infections.¹⁹ Vertical transmission was 2.3-fold higher during the pregnancy/postpartum periods combined.

A recent 957 woman cohort study from Mozambique examined the HIV incident rate and associated risk factors among postpartum women.²⁰ Researchers found HIV incidence in postpartum women to be 3.2/100 women-years, with the highest rate among 18- to 19-year olds. Of the new infections, 34% were identified during the first six months postpartum, 27% between six and 12 months, and 39% between 12 and 18 months postpartum. The vertical transmission rate was 21% among these newly infected women. Another study from Swaziland found cumulative HIV incidence of 4% among women who had arrived in maternity with unknown status or tested HIV-negative in an AN clinic.²¹ Of all HIV-positive cord blood samples taken, 15% were from women not known to be HIV-positive on arrival in maternity.

These data indicate that programs are not providing adequate assistance to women who test negative. As De Schacht, et al recommend, regular, routine, repeat HIV testing for negative postpartum women and primary prevention for HIV-negative women in AN and MCH settings is required to ensure the benefits of Option B+ for women with acute HIV infections. Primary prevention will require involvement of both partners, including partner testing, initiation on ART for the partner or pre-exposure prophylaxis for the woman.²²

¹⁷ Ng'ambi, W., Tweya, H., Speight, C., Man-Bourdon, C., Hosseinipour, M., & Phiri, S. (2013). Determinants of antiretroviral treatment adherence among women accessing PMTCT "Option B+": a retrospective cohort study at Bwaila Hospital Malawi. Presentation at International AIDS Society.

¹⁸ Tweya, supra note 7.

¹⁹ Drake, A., Wagner, A., Richardson, B., & John-Stewart, G. (2014). Incident HIV during Pregnancy and Postpartum and Risk of Mother-to-Child HIV Transmission: A Systematic Review and Meta-Analysis. PLoS Medicine. doi: 10.1371/journal.pmed.1001608

²⁰ De Schacht, C., et al. (2014) High HIV incidence in the postpartum period sustains vertical transmission in settings with generalized epidemics: a cohort study in Southern Mozambique. Journal of the International AIDS Society. [Hereinafter De Schacht, supra note 20].

²¹ Kieffer, M.P., et al. (2011) Improved Detection of Incident HIV Infection and Uptake of PMTCT Services in Labor and Delivery in a High HIV Prevalence Setting. J Acquir Immune Defic Syrn.

²² De Schacht, C., et al. supra note 20.



4 BARRIERS AND FACILITATORS

Barriers and facilitators to adherence often apply to retention in care and the uptake of PMTCT services. Some strategies that apply for adherence can have the dual purpose of promoting retention. Likewise, strategies that promote uptake can also impact

retention and adherence. Thus it is useful to think of barriers and strategies to improve uptake, retention in care and adherence together as they all impact whether clients will remain within the PMTCT cascade.

A. BARRIERS

Option B+

A qualitative study on the acceptability of Option B+ by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV/AIDS (ICW) found that one of the concerns women had about Option B+ is that if they do not need ART for their own health they will be inadequately motivated to stay in care and adhere to treatment.²³ This was a concern echoed by Tanzanian women in a qualitative study on their preferences for ARV prophylaxis, as was their fear of inadequate preparedness for lifelong treatment.²⁴ Indeed, most women in this Tanzanian study preferred Option B and Option A to Option B+. Those women who preferred Option B+ favoured this regimen because they agreed that they would eventually need ART for their own survival regardless, and (as with Option B) it also reduces stigma in their communities because they can still breastfeed.

The GNP+ and ICW study found that women were concerned by the fact that Option B+ is being presented to them as a program primarily to protect the baby with secondary benefits for the mother living with HIV. This can hinder women's motivations to stick to Option B+ between pregnancies if they do not need ART for their own health. Women expressed discomfort with the idea that their health was given less priority and felt left out by their doctors.

Women in the GNP+ and ICW study were concerned about drug supplies and treatment inequity and the tension this may cause in relationships with their partners.²⁵ That is, in concordant relationships, the women were concerned that their HIV-positive partners may suffer because of the shift in policy that prioritizes treatment of pregnant women, even when they don't require treatment for their own health, in a context when there might not be enough drugs for everyone.

Respondents under the GNP+ and ICW study expressed the need for more education and clarity around feeding guidelines as the shift to exclusive breastfeeding is causing confusion. Women were also concerned about adequate nutrition and the need for income generation in communities in order for them to stay in care, adhere to treatment, and breastfeed. Young women were especially concerned about starting treatment for life at such a young age and with a high CD4 count. Respondents also felt the need for more counselling and follow-up support.

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) studied the acceptability of Option B+ among HIV-positive pregnant and lactating women in Malawi, and found that the majority of respondents were unable to obtain adequate information from healthcare workers because they were rushed and

not given room to ask questions.²⁶ Respondents also indicated that they worry about taking treatment over a lifetime, and healthcare workers indicated that most women asked if they could stop treatment after breastfeeding. Respondents who attended ANC without their husbands struggled to decide whether to initiate treatment. All respondents indicated that same-day initiation presented a serious overload of information for them.

Poor linkages to long-term HIV care and treatment services of women diagnosed with HIV during pregnancy may be a barrier to retention of women in care under Option B+.²⁷ Without strong linkages, there is a risk that women may stop treatment between pregnancies.

Individual

Clients' low level of PMTCT knowledge is frequently cited as a barrier to retention.²⁸ Knowledge is further impeded by unequal power dynamics between health providers and clients. Women do not feel sufficiently empowered to ask questions during counselling sessions as they view healthcare professionals as authority figures.^{29,30}

Distance to facilities and frequency of visits required are cited in numerous studies as key issues affecting access to PMTCT treatment, particularly in rural areas.³¹ Traveling long distances to health centres is the largest obstacle in several studies.³² Poverty and geographic relocation (mobility) are also barriers to retention. Client mobility affects retention in care for mothers as well as infants (i.e. whose caregivers might relocate seasonally to seek work).³³

Difficulties with treatment and side effects also act as barriers to retention in ART and PMTCT.³⁴

Interpersonal and Social

Women's perceptions of their husbands' approval of HIV testing have been identified as a strong predictor of willingness to accept HIV testing and return visits. Many women do not disclose their status to their partners for fear of violence, which causes difficulties adhering to ART because they may have to hide their status and their medicines, resulting in missed doses and refill appointments.³⁵ Women in a Malawian study reported that domestic violence at the hands of their partners and the fear of such violence had a negative impact on their ability to start and continue using ARVs.³⁶

Non-disclosure to partners or not telling them about nevirapine syrup was associated with not attending the HIV clinic in a Tanzanian study, and fear of disclosure has been found to deter women from attending HIV clinics, initiating treatment and from seeking/administering infant prophylaxis.³⁷

Discrimination and stigma is well documented to hamper uptake, retention, and adherence along the entire PMTCT cascade.³⁸

A study in South Africa highlighted the particular struggles adolescents experience when participating in PMTCT services.³⁹ Client-counselor dynamics during pretest counseling were pivotal in determining uptake and participation. Other factors found to influence retention in care and adherence to treatment under PMTCT included HIV and early

²³ Global Network of People Living with HIV and International Community of Women Living with HIV/AIDS. (2013). Understanding the perspectives and/or experiences of women living with HIV regarding Option B+ in Uganda and Malawi. Retrieved from: <http://www.gnpplus.net/resources/option-b-understanding-perspectives-experiences-of-women-living-with-hiv/>. [Hereinafter GNP+ and ICW, supra note 23].

²⁴ Ngarina, M., et al. (2014). Women's preferences regarding infant or maternal antiretroviral prophylaxis for prevention of mother-to-child transmission of HIV during breastfeeding and their views on Option B+ in Dar es Salaam, Tanzania. PLoS One. doi: 10.1371/journal.pone.0085310

²⁵ GNP+ and ICW, supra note 23.

²⁶ Elizabeth Glaser Pediatric AIDS Foundation (2014). Study Report: Acceptability of Lifelong treatment (Option B+) Among HIV Positive Pregnant and Lactating Women in Selected Sites in Malawi.

²⁷ Ferguson L., et al. (2012). Linking women who test HIV-positive in pregnancy-related services to long-term HIV care and treatment services: a systematic review. Tropical Medicine & International Health. doi: 10.1111/j.1365-3156.2012.02958 [Hereinafter Ferguson, supra note 27].

²⁸ Gourlay, J., et al. Barriers and facilitating factors to the uptake of antiretroviral drugs for prevention of mother-to-child transmission of HIV in sub-Saharan Africa: a systematic review. J of Intl AIDS Soc. [Hereinafter Gourlay, supra note 28].

²⁹ Larsson, E., et al. (2012). Opt-out HIV testing during antenatal care: experiences of pregnant women in rural Uganda. Health Policy Plan, 27(1), 69-75. doi: 10.1093/heapol/czr009 [Hereinafter Larsson, supra note 29].

³⁰ Watson-Jones, D., et al. (2012). Missed opportunities: poor linkages into ongoing care for HIV-positive pregnant women in Mwanza, Tanzania. PLoS One. doi: 0.1371/journal.pone.0040091

³¹ Larsson, supra note 29.

³² Kalembo, F., & Zgambo, M. (2012). Loss to Follow-up: A major challenge to successful implementation of PMTCT of HIV-1 programs in sub-Saharan Africa. International Scholarly Research Notices AIDS. <http://dx.doi.org/10.5402/2012/589817>. [Hereinafter Kalembo & Zgambo, supra note 32].

³³ Hassan, A., et al. (2010). Dynamics and constraints of Early Infant Diagnosis of HIV infection in rural Kenya. AIDS Behavior, 16(1):5-12. doi: 10.1007/s10461-010-9877-7 [Hassan, supra note 33].

³⁴ Bupamba, M., et al. (2010). Ambassadors for Adherence: Provision of Highly Effective Defaulter Tracing by Peer Educators in Tanzania. AIDS 2010 - XVIII International AIDS Conference: Abstract no. MOAE0303 [Hereinafter Bupamba, supra note 34].

³⁵ Ghanotakis supra note 2.

³⁶ Johnson, K., Akwara, P., Rutstein, S., & Bernstein, S. (2009). Fertility preferences and the need for contraception among women living with HIV: the basis for a joint action agenda. AIDS, 23(Suppl 1) S7-17. doi: 10.1097/01.aids.0000363773.83753.27.

³⁷ Gourlay, et al, supra note 28.

³⁸ Turan, J. (2012). Stigma and discrimination: Key barriers to achieving global goals for maternal health and elimination of new child HIV infections. Working Paper Number 4, USAID.

³⁹ Varga C., & Brookes, H. (2008). Factors influencing teen mothers' enrolment and participation in prevention of mother-to-child transmission services in Limpopo Province, South Africa. Qualitative Health Research. doi: 10.1177/1049732308318449 [Hereinafter Varga & Brookes, supra note 39].

premarital pregnancy stigma, fear of a positive test result, concerns over confidentiality and poor treatment by health care providers. In this study, adolescents described elaborate strategies to avoid HIV disclosure to labor and delivery staff, despite knowing this would mean no antiretroviral therapy for their newborn infants.

Health Facility and Systems

Counselling does not always address issues client feel are pertinent to staying in care. In Malawi, women indicated that counselling was overly biomedical with insufficient attention given to psycho-social issues like poverty, transport and food insecurity.⁴⁰

Linking to long-term care may be hampered by women feeling that their health is neglected due to PMTCT services focusing almost exclusively on the infant's health. Women can feel abandoned by the healthcare system after completion of PMTCT.⁴¹

Negative staff attitudes are frequently cited as a barrier to returning to facilities, and women have experienced or fear scolding from staff for home deliveries when returning with their baby for nevirapine administration, or were otherwise stigmatized.⁴²

The poor linkage of clients to different systems of care throughout the PMTCT cascade is a systemic barrier to retention.

At facilities, shortage of space for counselling and long waiting periods for post-test counselling result in women leaving without test results, being inadequately prepared for testing and treatment, and deterred from returning.⁴³

⁴⁰ Levy, J. (2009). Women's expectations of treatment and care after an antenatal HIV diagnosis in Lilongwe, Malawi. *Reproductive Health Matter*, 17(33) 152-161. Retrieved from: <http://www.jstor.org/discover/10.2307/40647620?uid=2134&uid=2&uid=70&uid=4&sid=21104669932007>. [Hereinafter Levy, supra note 40].

⁴¹⁻⁴³ Levy, supra note 40.

⁴⁴ Rawizza, H. (2012). Toward elimination pediatric HIV infection: Improving retention in PMTCT care cascade. *Medscape*. Retrieved from: <http://www.medscape.com/viewarticle/764394>. [Hereinafter Rawizza, supra note 44].

⁴⁵⁻⁴⁶ Ferguson, supra note 27.

⁴⁷ Varga & Brookes supra note 39.

After-delivery linkage and infant follow-up is often a challenge because maternal and paediatric care is provided at distinct centres.⁴⁴ Some women have to visit multiple departments in a single day with long waiting times and have to visit the hospital on several different days.

Weak linkages between PMTCT and ART centres have also been reported as a major barrier to retention.⁴⁵ Studies have shown drastic attrition between testing and accessing care.⁴⁶

Early Infant Diagnosis (EID) and Infant Treatment & Care

Fear of stigma of having a child tested in public, fear or rejection by the family, fears regarding confidentiality, and fears regarding the potential forced disclosure of their infant's and their own status, can all impede uptake of EID.⁴⁷

Parents have also expressed fear surrounding how to disclose to the child their HIV status as a barrier to accessing follow-up services for the child.⁴⁸

EID is highly stressful and it cannot be taken for granted that all mothers (or parents, caregivers) understand that it is a pathway for treatment for the infant.⁴⁹ Not all women are aware of this service⁵⁰ and may not be guided there by health workers.⁵¹

Frequent change of caregivers also compound the challenges experienced in diagnosing HIV-exposed infants and linking infants that test positive to treatment and care.⁵²

⁴⁸ Byakika-Tusiime, J., et al. (2009). Longitudinal antiretroviral adherence in HIV+ Ugandan parents and their children initiating HAART in the MTCT-Plus family treatment model: role of depression in declining adherence over time. *AIDS Behavior*, 13 Suppl 1, 82-91. doi: 10.1007/s10461-009-9546-x.

⁴⁹ Donahue M., Dube, Q., Dow, A., Umar, E., & Van Rie, A. (2012). "They have already thrown away their chicken": barriers affecting participation by HIV-infected women in care and treatment programs for their infants in Blantyre, Malawi. *AIDS Care*, 24(10), 1233-9. doi: 10.1080/09540121.2012.656570 [Hereinafter Donahue, supra note 49].

⁵⁰ Sprague, C., Chersich M., & Black, V. (2011). Health system weaknesses constrain access to PMTCT and maternal HV services in South Africa: a qualitative enquiry. *AIDS Res Ther* 8-10. doi: 10.1186/1742-6405-8-10.

⁵¹ Hassan, supra note 33.

One qualitative study from Malawi posits that extreme poverty and high expectancy of child death is a powerful shaper of maternal thinking and practices in PMTCT.⁵³ In this study, some women were scared that should their infant test positive, they might feel that their baby's death is inevitable, which might impact whether they seek treatment for the baby.

EGPAF conducted a qualitative study on barriers and facilitators to EID and treatment services in Malawi. This study found challenges with relying on the health passport to identify HIV-exposed infants, shortages of health care workers and lack of supervision with health surveillance assistants (HSAs) all impeded EID.⁵⁴ Shortages of dry blood sample (DBS) test kits and difficulties getting blood

from infants, including because of transportation and fuel, hamper sample collecting and processing. EGPAF also found that parents and caregivers have to travel long distances and have challenges with the cost of transport and the time it consumes. If results are not available after traveling to the clinic, and if this happens more than once, parents and caregivers are unlikely to return again for results. They are also concerned about privacy at the facility. EGPAF found that healthcare workers are not as familiar with infant treatment as they are with adult treatment and neglect asking about the infant when treating women. There is also a popular belief among parents and caregivers that starting ART in young children will cause complications, which causes them to delay obtaining results or starting ART.



⁵² Hassan, supra note 33.

⁵³ Chinkonde, J., Sundby, J., & Martinson, F. (2009) The prevention of mother-to-child HIV transmission programme in Lilongwe, Malawi: why do so many women drop out. *Reproductive Health Matters*, 17(33), 143-51. doi: 10.1016/S0968-8080(09)33440-0 [Hereinafter Chinkonde, supra note 52].

⁵⁴ Phiri, M. (2013, November 22) Barriers and facilitators of Early Infant Diagnosis and Treatment (EIDT) Services in Malawi: a qualitative study in Lilongwe, Dedza and Ntcheu Districts. Elizabeth Glaser Pediatric AIDS Foundation. [Hereinafter Phiri, M. supra note 54].

B. FACILITATORS

Option B+

In the GNP+ and ICW qualitative study on the acceptability of Option B+, women in Malawi reported that they felt healthier and stronger on treatment, felt improvements in their mental health because of their hope for a healthier life, experienced less stigma because people cannot tell they are on treatment, and that they are more encouraged to attend ANC and health centres because there is certainty that treatment is available to them.⁵⁵ Women were also happy that they could become pregnant unexpectedly and still be covered by the health benefits of treatment.

The EGPAF study on the acceptability of Option B+ found that counselling is critically important for a woman to accept Option B+. Most of the respondents felt encouraged to initiate treatment when their counsellor revealed their positive sero-status to them.

Women in the GNP+ study expressed the need for guaranteed drug availability of ARVs and essential medicines, timely and thorough medical checks to prevent other diseases, income generation support, food, and clear information and educational guidelines. Women also expressed a preference and demand for linkages between ARV and AN services.

Women also reported that the simplified regimen was very convenient. All respondents highlighted the importance of their support networks for

encouragement and reminders, and indicated that their husbands were more effective support than their relatives.

Individual

The desire to prevent vertical transmission is a well-documented motivator for uptake, retention and adherence to PMTCT care.⁵⁷ Other factors have been significantly associated as PMTCT motivators in sub-Saharan Africa, including perceived benefits, easy access to the programme, and the presence of social support from a spouse.⁵⁸ Mothers who had previously attended routine postnatal (PN) care were also significantly more likely (3.6 fold) to be retained in PN PMTCT.

Factors associated with women diagnosed with HIV in pregnancy-related services registering at an HIV clinic include: having cared for someone with HIV; not having to pay for transportation to the clinic; personally knowing someone who died of AIDS, and having experienced at least one HIV-related symptom in the six months prior to enrolment.⁵⁹

Interpersonal and Social

Supportive partners, family and friends facilitate uptake and retention in treatment by women in PMTCT programs.⁶⁰

Health Facility and Systems

At a health systems level concerning EID specifically, the integration of EID with immunization services has been shown to improve the early identification of HIV-infected infants in some locations.⁶¹ Integration of HIV services to facilities providing ANC and PMTCT care has boosted enrolment. A case

study in Mozambique found that enrolment in HIV services increased from 30%-75% after integration into facilities that provided ANC/PMTCT services.⁶²⁻⁶³

Early Infant Diagnosis

The EGPAF qualitative study on barriers and facilitators to EID found that training HSAs how to identify HIV-exposed infants has facilitated EID in Malawi.⁶⁴ HSAs also meet amongst themselves to reinforce DBS training and mentor less experienced colleagues. Community health education and support from village leadership have also increased awareness about EID and treatment. Regular follow-up with the laboratory and follow-up systems at the health centre to notify women of appointments are facilitating EID and treatment. Regular Quality

Assurance / Quality Improvement (QA/QI) meetings to identify and resolve challenges were also identified as a facilitator. EGPAF identified the need to provide better counselling after DBS samples are taken and the need to honour appointments given to caregivers and parents for results. They also found that counselling and home visits make it easier to initiate children on treatment.

EGPAF is now examining the prioritization of HIV-infected infants who are at high risk of death by fast tracking positive PCR results from the labs to caregivers. While the current system for delivering results is weak, focusing on expediting positive results may help decrease turnaround times for the infants who need treatment.



⁵⁵ GNP+ and ICW, supra note 23.

⁵⁶ Elizabeth Glaser Pediatric AIDS Foundation (2014). Study Report: Acceptability of Lifelong treatment (Option B+) Among HIV Positive Pregnant and Lactating Women in Selected Sites in Malawi.

⁵⁷ Chikonde, supra note 52.

⁵⁸ Nassali, M., Nakanjako, D., Kyabayinze, D., Beyeza, J., Okoth, A., & Mutyaba, T. (2009). Access to HIV/AIDS care for mothers and children in sub-Saharan Africa: adherence to the postnatal PMTCT program. *AIDS Care*, 21(9), 1124-31. doi: 10.1080/09540120802707467 [Hereinafter Nassali, supra note 58].

⁵⁹⁻⁶⁰ Ferguson, supra note 27.

⁶¹ Goodson, J., et al. (2013). Evaluation of using routine infant immunization visits to identify and follow-up HIV-exposed infants and their mothers in Tanzania. *Journal of Acquired Immune Deficiency Syndromes*, 63(1), e9-e15. doi: 10.1097/QAI.0b013e31828a3e3f.

⁶² Pfeiffer, J., et al. (2010). Integration of HIV/AIDS services into African primary health care: lessons learned for health system strengthening in Mozambique – a case study. *Journal of the International AIDS Society*, 3:3. doi: 10.1186/1758-2652-13-3.

⁶³ Killam, W., et al. (2010). Antiretroviral therapy in antenatal care to increase treatment initiation in HIV-infected pregnant women, a stepped-wedge evaluation. *AIDS*, 24(1):85-91. doi: 10.1097/QAD.0b013e32833298be.

⁶⁴ Phiri, M. supra note 54.

5 CURRENT PRACTICES

This section documents current practices identified through a literature review of interventions in the region, and key informant interviews with stakeholders in Malawi. Interventions that aim to promote uptake,

retention and adherence were reviewed. While some evidence applies to ART more generally, PMTCT and Option B+ evidence is highlighted throughout.

A. LOSS TO FOLLOW-UP AND CLIENT TRACING PROGRAMS

i. Client Tracing

This section describes missed appointment and defaulter tracing activities. Missed appointment tracing is triggered when a client misses a scheduled appointment at the facility, such as an appointment to collect ART refills or to return for infant testing. Defaulter tracing is generally triggered when a client fails to attend the last appointment after which they will have run out of ARVs. Defaulters are defined in the 2014 MOH Guidelines as someone who has not returned to the clinic and is not known to have transferred out, stopped treatment, or died.⁶⁵ For ART cohorts, defaulters are those who have not attended scheduled appointments for 2 months after they were expected to have run out of medicines. For HIV-exposed children, it is 2 months after their last scheduled appointment visit.

PMTCT

In a defaulter tracing programme in Kenya, social workers attempted to contact clients via telephone, in-person, or both, very soon after missing their appointment.⁶⁶ Tracing activities conducted between 2008-2009 resulted in 59.4% of clients returning to the clinic, 4.5% refusing to return, and 4.5% returning to a different clinic. Fifteen percent of the clients identified for tracing could not be contacted. Overall,

LTFU among PMTCT clients decreased from 21.2% in 2006 to 11.5% in 2009.

In Uganda, a United States Agency for International Development (USAID) funded mother-baby pair tracing programme tested a comprehensive set of tracing strategies.⁶⁷ Key recommendations were to meet home visitors' transport expenses; assign tracers to specific locations; have dedicated tracing phones at the facility; provide cell phones and airtime; ensure phone numbers given by clients are correct; draw up the tracing list on a daily basis and map residences; use male expert clients to promote male attendance at AN appointments, and engage clinic staff on quality improvement activities for ongoing learning and motivation. In addition, clinic-based changes were recommended to streamline work and reduce waiting times – e.g. having mother-baby appointments on the same date and keeping their files together, having dedicated EID days, and dispensing just enough pills for the client's next visit.

In Tanzania, USAID's ASSIST Project has undertaken community health systems strengthening, mobilizing a broad cross-section of community groups (e.g. agriculture, religious, sports, education, credit and savings) to support uptake and retention of PMTCT.⁶⁸ Facility nurses serve as community QI coaches who run community QI committees. Every group is a

member of a community QI committee to which women are referred. Community QI teams would help trace clients who missed appointments. The teams also worked to improve early presentation of pregnant women to ANC. To facilitate this, and to accommodate cultural beliefs and uncertainty about viability of pregnancy, the project used anonymous client tracking cards. Community representatives developed posters with messages on early booking, exclusive breastfeeding, and follow-up of children under 5 years. The QI teams provided an effective space to link facility staff and community members to collaborate and improve care.

Médecins Sans Frontières' (MSF) defaulter tracing efforts in Lesotho and Zambia integrated tuberculosis (TB), HIV and PMTCT tracing, and extending appointment books for PMTCT.⁶⁹ However, they faced challenges with having too many registers and yet still required an additional register linking ANC and exposed infants.

ART Client Tracing

An ART client tracing program in Zambia included routine home visits, determining if the client is still alive and encouraging them to continue care.⁷⁰ They also talked to the clients about why they missed their appointments. A large portion of clients could not be traced because they had moved or were not home. Consequently, an average of 18 home visits was required before clients returned to the clinic. Reasons for missing appointments included feeling too sick, traveling away from home, being too busy, uncertainty about continuing ART, and having a surplus of medicines.

An evaluation of a defaulter tracing programme in KwaZulu-Natal observed the heavier burden of maintaining up-to-date tracking information with paper-based systems.⁷¹ In this programme, data on each client was used to estimate their risk for default. Then high risk clients were given extra counselling

and surveillance to trace as soon as they default. The main challenge they faced with defaulting was the lack of telephone numbers in their records and unclear addresses. Lack of transport was also reported as hindering tracing. This evaluation posited that intensified tracing during the first six months could have reduced discontinuation of ART significantly, as the period after treatment is assigned is the most critical to remaining on ART. The authors recommend recording global positioning system (GPS) coordinates of clients home where they have unclear addresses, which may require staff to accompany the client home to register the coordinates of their residence. Lastly, the need for intensive support to front line staff was underscored as it helps to ensure they understand the advantages of inputting data and tracking risky clients.

In Uganda, an ART missed appointment tracing program at a large hospital first attempted contact by phone, and if unsuccessful, switched to home visits, which were limited to a 20km radius.⁷² A tracking form was used to record whether the client was dead, self-transferred to another clinic, planning to return, or untraceable. A large portion of those who were untraceable or dead were on ART for less than six months, thus the author's recommendation to pay special attention to clients who just started ART. Critically, this research also found that clients were more likely to return to care if they were tracked 1 week after the missed appointment.

This same Ugandan project experienced low tracking rates due to incorrect addresses and phone numbers given by clients, and because clients often used different names at the facility and community. The implementation of a "physical address form" improved tracking; 81% of successfully tracked clients had forms completed, compared to only 59% of those unable to be tracked. These forms included information on phone contact and ownership; client disclosure status if the phone contact given is for

⁶⁵ Malawi MOH (2014). Clinical Management of HIV in Children and Adults. [Hereinafter Malawi MOH, supra note 65].

⁶⁶ Thomson, K., Cheti, E., & Reid, T. (2011). Implementation and outcomes of an active defaulter tracing system for HIV, prevention of mother to child transmission of HIV (PMTCT), and TB patients in Kibera, Nairobi, Kenya. *Trans R Soc Trop Med Hyg*, 105(6), 320-6. doi: 10.1016/j.trstmh.2011.02.011.

⁶⁷ Nsubuga-Nyombi, T., Karamagi-Nkolo, E., Draru, J., Megere, H., & Stern, Amy. (2014). Improving Retention of Mother-Baby Pairs: Tested Changes

and Guidance from Uganda. Published by the USAID Applying Science to Strengthen and Improve Systems (ASSIST) Project. Retrieved from: <https://www.usaidassist.org/resources/improving-retention-mother-baby-pairs-tested-changes-and-guidance-uganda>.

⁶⁸ Bright, R., & Hizza, R. (2013). Strengthening Community Systems to Increase Uptake and Retention in Services in Tanzania. Published by USAID ASSIST Project. Retrieved from: <http://www.emtct-iatt.org/wp-content/uploads/2014/02/Strengthening-Community-Systems-to-Increase-Uptake-and-Retention-of-PMTCT-Services-in-Tanzania.pdf>.

⁶⁹ MSF. (2012). The Leaking PMTCT Cascade Experience' from the MSF Projects in Lesotho and Zimbabwe. Retrieved from: <http://www.msf.org.za/msf-publications/leaking-pmtct-cascade-experience-msf-projects-lesotho-and-zimbabwe>.

⁷⁰ Krebs, D., et al. (2008). Community-based follow-up for late patients enrolled in a district-wide programme for antiretroviral therapy in Lusaka, Zambia. *AIDS Care*, 20(3), 311-7. doi: 10.1080/09540120701594776

⁷¹ Vella, V., et al. (2008). Evaluation of the antiretroviral therapy in KwaZulu-Natal, South Africa. Published by KZN Department of Health. Retrieved from: <http://www.kznhealth.gov.za/italian/arv.pdf>.

⁷² Nakiwogga-Muwanga, A., Musaazi, J., Katabira, E., Alamo-Talisuna, S., & Colebunders, R. (2014). Early tracking after a missed return visit reduces the proportion of untraceable patients at a large HIV clinic in Kampala, Uganda. *Journal of the International Association of Providers of AIDS Care*. doi: 10.1177/2325957414530471

someone else; client consent for phone or home visit; and location map to client's home.

A client tracing program at a clinic in South Africa reduced LTFU to 2%.⁷³ This programme regularly generated lists of clients who missed appointments and used a tracking register that captured re-entry into care. A site coordinator oversaw the process and a site data officer was responsible for overseeing data capturers who generated the lists. The staff members participated in monthly team meetings to review their progress and attempted to trace clients immediately after they missed their appointments.

A Rwandan defaulter tracing programme used data teams to develop electronic data systems to generate a missing client list based on clinic data.⁷⁴ Community teams including social workers and community volunteers were assigned to each client. The teams located clients, determined the reasons for missing appointments, and coordinated with clinicians and data teams to facilitate client re-entry into care. While an evaluation of this programme found that many clients were incorrectly documented as missing due to data entry errors, 88% of those that were defined as LTFU we re-enrolled in care.

TB Client Tracing

Defaulter tracing has been used extensively for tracking TB patients because of patients' high

risk to public health. In South Africa, a national effort involved tracking patients, finding out their issues, counselling them, and getting them back to treatment.⁷⁵ Patients who were on re-treatment and required daily injections of streptomycin were provided this at home instead of requiring them to travel to the clinic at their own cost. This intervention has reduced defaulter rates everywhere it was implemented.

Dealing with Client Mobility

In Lesotho, a project placed detailed information on each client into their folders and asked about mobility specifically. If clients were seasonal movers, staff members discussed what facilities provide ART in the area to which they're moving.⁷⁶

Documenting Return to Care

Several studies recommend that defaulter tracing activities link to client records in order to accurately measure return to care outcomes.⁷⁷ Given the workload of maintaining up to date records (with a paper based or electronic system); some studies have recommended ensuring the availability of dedicated data capturing staff. Regular supervision and involvement and buy-in from health authorities and staff have also been cited as facilitators of successful client tracing.⁷⁸



⁷³ Worley S., et al. (2007). Development of a system for identifying and tracking ART Patients to minimize losses to follow-up in Eastern Cape South Africa. Third South African AIDS Conference, Durban. Abstract 672.

⁷⁴ Umuhoza, M., Moen M., & Byicaza, O. (2008). Reducing LTFU by Integrating Clinical Data Management in Community Support Systems in AIDS Relief-support Rural health Facilities in Rwanda. 5th IAS Conference on HIV pathogenesis, Treatment and Prevention: Abstract no. TUPDD104. Retrieved from: <http://www.iasociety.org/Default.aspx?pageld=12&abstractId=200721995>.

⁷⁵ Bateman, C. (2010). The Protracted TB Struggle – South Africa Ups the Intensity. South African Medical Journal, 100(4), 207-209. doi: 10.7196/samj.4103

⁷⁶ Cohen, et al. (2009). ART treatment outcomes from a nurse-driven community-supported HIV/AIDS treatment programme in rural Lesotho: observational cohort assessment at 2 years. J Intl AIDS Soc.

⁷⁷ Bupamba, supra note 34.

⁷⁸ Davey, D., et al. (2013). Improved uptake of institutional birth and early infant HIV testing following SMS reminders among PMTCT patients in Mozambique. Presentation at International AIDS Society. Retrieved from: <http://pag.ias2013.org/Abstracts.aspx?AID=3055>. [Hereinafter Davey, supra note 78].

CURRENT PRACTICES

1. **Timing:** Tracing ART clients may be most successful when conducted within the first week of a missed appointment.
2. **Client Illiteracy:** Client literacy should be considered as they must be able to read SMS interactions.
3. **Link Tracing and Client Records:** Linking defaulter tracing activities to client records can help to more accurately measure return to care outcomes.
4. **Risk assessment:** Assessing clients' risk for default can help determine how to allocate resources and determine which clients to focus on. Risk assessment can be individualised to each client, or based on progression along the PMTCT cascade and whether clients have reached points in the PMTCT timeline that are most vulnerable to client drop-out.
5. **Changing tactics based on timing:** There are points in the ART timeline and PMTCT cascade where clients are more vulnerable to drop-out. Focus can be placed on clients within these time frames. It may also be useful to switch tracing tactics during these periods – e.g. from a reactive to a proactive response.
6. **Locator cards:** These can address challenges with clients' addresses (having the address incorrectly documented or unable to physically locate the home) and with having incorrect phone numbers documented. Locator cards can include GPS coordinates, a simple location map, list all of the client's common names, and note the client's consent and disclosure status.
7. **Alternate contact person:** For clients who have disclosed their status, it can be useful to list an alternate contact person that can be contacted if the client herself cannot be traced.
8. **Regularly update contact information:** It is widely recommended to regularly update contact information.
9. **Discuss barriers:** Several ART defaulter tracing programmes recommend discussing the reasons for missing appointments and helping clients to address their concerns. It is a logical step to take for clients who are concerned about continuing treatment or require further encouragement and education – not just reminders.
10. **Confidentiality and Anonymity:** Aside from redacting confidential information when sharing defaulter lists to client tracers, anonymous client tracking can be enabled for women in early stages of their pregnancy.
11. **Client mobility:** Programmes might benefit from incorporating client mobility as a discussion point during interactions and providing clients with information on clinics in the area to which they're moving. This can also help to more accurately assess whether a client is actually LTFU or has simply moved to a different area.
12. **Delivering treatment:** There has been success with having TB tracers provide daily injections of streptomycin to circumvent clients skipping trips to the clinic due to transport and other structural barriers. An example of "meeting clients half-way," this strategy or others to further decentralise and ease ARV distribution might be applied to PMTCT for stable clients.
13. **Electronic systems with dedicated staff:** While the literature does note the feasibility of paper-based client tracing systems, the burden required to maintain them is underscored. Electronic databases are consistently recommended to ease tracing. Some also recommend hiring dedicated staff to maintain these, as opposed to putting the onus on front line staff.
14. **Leverage community structures:** It is recommended to track clients using existing community structures like community-based support groups if they know whether the client is in care.

Client Tracing in Malawi

The Government of Malawi recommends client tracing in the 2014 Clinical Management of HIV in Children and Adults guidelines.⁷⁹

Tracing is highlighted as an important tactic for increasing retention in care, and recommends that facilities and stakeholders regularly review all client cards and keep an appointment register to identify clients who are overdue for their appointments as soon as possible.

The guidelines further recommend that clients be identified by phone or a home visit from two weeks after the missed appointment, and that the client be counselled to return to care and that client cards and the register be updated with tracing outcomes. Given that tracing is expensive and time-consuming, the guidelines suggest that clients on ART and HCC clients who are eligible for ART be prioritized.

Several stakeholders conduct client tracing programs in Malawi. The Tingathe Program, run by Baylor since 2008, deploys community health workers (CHWs) who provide client case management at the facility and community.⁸⁰ CHWs follow up clients at their household two weeks after missed appointments for PMTCT. A parallel master card system documents descriptive addresses or hand-drawn maps of where the client lives, so that they are easily located. CHWs provide counselling during these visits and then document the outcome of the tracing onto the client's master card. Tingathe CHWs are given bicycles, airtime, gum boots and rain jackets and are responsible for an 18km radius. Outside of the 18kms CHWs are supported by tracers on motorcycles.

Catholic Relief Services' (CRS) IMPACT program (Integrated HIV effect Mitigation and Positive Action for Community Transformation) which has now ended, also conducted client tracing.⁸¹ This program used a cadre of community facilitators (community-based expert clients) and HSAs to trace clients who had missed appointments for ART refills for both regular ART clients and PMTCT clients. As part of the mother-infant pair (MIP) follow up, IMPACT partnered with D-tree International to develop and pilot a mobile application to support HSAs and community facilitators with the MIP protocol. The mobile application gave HSAs step-by-step guidance as they provided follow-up to mothers and their exposed infants during antenatal, postpartum, and postnatal home visits.⁸² The application allowed HSAs to track and guide each MIP based on their individual data, and also provided appointment reminders and follow-up reminders to help community facilitators with tracing clients in the case of a missed appointment. All of the information put into the application was sent to D-tree for analysis to inform quarterly supportive supervision meetings.

The Drug Resource Enhancement against AIDS and Malnutrition (DREAM) program operated by the Comunita di Sant'Egidio also deploys a cadre of client tracers called activists. Activists are volunteers who are expert clients. DREAM is a well-resourced program and uses a computerized system to track client data, including missed appointments which are checked on a daily basis. Activists first attempt to contact clients over the phone, then attempt household visits. Activists report on their tracing activities on a monthly basis, and DREAM's software tracks return to care outcomes.

Dignitas traces clients who miss appointments by two weeks, as well as defaulters (defined as clients who have not returned to care for two months), and does this for general ART patients and Option

B+ women. ART clerks use clinic registers and client master cards to generate tracing lists which are given to HSAs for follow-up. HSAs document tracing outcomes and report back to expert clients and facility staff. MSF Belgium in Nsanje deploys a similar system that leverages HSAs for tracing and identifies missed appointments using a simple diary, in which appointments are recorded, as opposed to scanning master cards and clinic registers. For quality assurance and improvement, MSF conducts monthly supportive supervision meetings with MOH staff at the facility, and client tracing is one of the issues reviewed. Other programs such as Partners in Hope also provide support to HSAs for client tracing.

Lighthouse Trust traces defaulters in their ART cohort (which includes Option B+ women) using a cadre of full-time tracers with motorcycles in a program called Back to Care. Defaulters are defined as clients who have missed appointments by three weeks after the day they would have needed to collect refills, and are identified in Lighthouse's electronic system called Baobab. Phone calls are first attempted before home visits. When traced, clients are counselled by the tracers and the outcome of the tracing is documented. Each patient is eligible to be traced a maximum of three times, regardless of outcome.

Mentor mothers (MMs) are also used to trace clients for missed appointments by mothers2mothers Malawi, and previously also by Tearfund / Evangelical Association of Malawi (EAM) (using a cadre called Mother Buddies).⁸³ m2m traces certain missed appointments identified as priority events in the PMTCT spectrum of services. This includes the second antenatal visit and infant testing and results at six weeks, 12 months and 24 months. Clients are identified through m2m's logbooks and clinic registers, and MMs first attempt to reach clients over the phone before embarking on home visits

themselves, or referring clients for follow-up by Community Mentor Mothers (CMMs) (m2m's community-based cadre). MMs are given bicycles and are responsible for tracing clients within a 5km radius of the facility, and coordinate their efforts where HSAs or other tracers are also working. Tearfund's Mother Buddies identify missed appointments through their android phone Poimapper application, and follow the same process of calling before attempting home visits on their bicycles. Support for Service Delivery Integration (SSDI) also deploys MMs who are based at facilities and trace clients who have missed appointments.⁸⁴

The Clinton Health Access Initiative (CHAI) uses an SMS system to trace clients who miss PMTCT appointments. Nurses at mother-infant pair clinics (MIPCs) extract names of clients who miss appointments on slow days during the week, and pull these names from PMTCT appointment books which are kept at ANC and maternity wards.⁸⁵ The nurses document the names on a "Request for Follow-up Form" and share these with senior HSAs during weekly linkage meetings. The senior HSAs input the information into the Frontline short message service (SMS) hub, a computer-based SMS platform. CHWs and HSAs are then sent SMS' with information of clients to follow-up, and this tracing is meant to be done within 2 weeks of the missed appointment. CHWs and HSAs give feedback on their tracing during the weekly linkage meetings, but also have the option of giving feedback to via SMS to senior HSAs at the Frontline SMS hub.

Partners In Health (PIH) uses an electronic medical record which produces an automated report every two weeks for missed visits. Village health workers, clinic based teams, and clinicians are involved in returning patients back to care.^{86 & 87}

⁸⁰ Kim, M., et al. (2013) Low Rates of Mother-to-Child HIV Transmission in a Routine Programmatic Setting in Lilongwe, Malawi. PLOS One; also Interview with Debora Nanthuru on 2 September 2014. [Hereinafter Nanthuru, supra note 80].

⁸¹ Interview with Alinafe Chibwana on 29 August 2014. [Hereinafter Chibwana, supra note 81].

⁸² USAID IMPACT Program. (2014). There's an App for that: A job aid for community-based PMTCT care. [Hereinafter IMPACT, supra note 82].

⁸³ Interview with Clive Kasalu on 25 August 2014. [Hereinafter Kasalu, supra note 83].

⁸⁴ Interview with Hendrix Dzama on 26 August 2014. [Hereinafter Dzama, supra note 84].

⁸⁵ Interview with Emily Churchman-Kobayashi on 4 September 2014 [Hereinafter Churchman-Kobayashi, supra note 85]; see also Gonzales, M., et al. (2012).

Improving Maternal, Newborn and Child Health in High HIV-burden Areas through Mobile Technology in Malawi. Columbia School of International and Public Affairs. Prepared for UNICEF Malawi and UNICEF Innovations.

⁸⁶ Please refer to Annex 2 for more information on PIH's PMTCT activities.

⁸⁶⁻⁸⁷ Feedback via email from Emily Wroe, Partners in Health. [Hereinafter Wroe, supra note 87].

The table below provides a matrix of some of the client tracer activities currently being conducted by stakeholders in Malawi.

Implementing Entity	Appointments tracked	Methods of identifying clients to trace	Timing when follow up is initiated	Tracers	Catchment Areas	Transportation
CHAI	- Any missed PMTCT appointment	- PMTCT appointment register at ANC and maternity wards	- Within 2 weeks of missed appointment	- CHWs and HSAs	- Facility catchment area	- Bicycle
Dignitas	- ART missed appointment & refills	- MOH master cards Clinic registers	- Tracing conducted weekly	- HSAs	- Facility catchment area	- On foot
DREAM	- Any missed PMTCT appointment	- DREAM computerized system	- Tracing conducted weekly	- Volunteer activists	- Facility catchment area	- On foot
Lighthouse	- ART defaulters only (3 weeks after last scheduled appointment)	- Baobab computerized system	- Tracing list generated every 2 months	- Full-time tracers	- Facility catchment area	- Motorcycles
m2m Malawi	- 2nd ANC - Exposed infant follow-up (Infant test & results at 6 weeks, 12 & 24 months)	- m2m logbooks - Clinic registers	- 3 days after missed appointment	- Mentor Mothers - Community Mentor Mothers	- 5km radius	- Bicycles
MSF Belgium	- Any missed PMTCT appointment - ART missed appointments	- Appointment diary - Health Centre tracing register - Tracing forms	- Weekly, after 5 days after missed appointments	- HSAs trace missed appointments	- Facility catchment	- On foot
Partners In Health	- Any missed PMTCT appointment	- Electronic Medical Record - Clinic Register & Mastercards (for cross-check)	- Every two weeks	- VHWs - ART clinic staff: 4 person default tracking team	- Facility catchment area	- Motorbikes (ART team) - On foot (VHWs)
Tingathe	- Any missed PMTCT appointment	- Tingathe master cards - Clinic registers	- Within 2 weeks of missed appointment	- CHWs	- <18km bicycles - >18km motorcycles	- Bicycles - Motorcycles

CONSIDERATIONS FOR MALAWI

While electronic systems make tracking clients easier, there are challenges to effectively catching all missed appointments and defaulters using paper-based systems. In order to be able to track whether a pregnant woman or a mother-baby pair have accessed priority PMTCT services, it is necessary to check both the MOH master cards and health passports. To get around the challenges this presents, organizations using paper-based systems to track PMTCT visits (not just ART refills and infant testing

which can be tracked on the master cards), inevitably developed parallel data capturing systems. It may be useful for stakeholders to learn from one another to improve their paper-based tracing systems.

Most organizations in Malawi do not systematically review client tracing and outcomes together with MOH, though stakeholders all include this in their own internal supervision processes. A QA/QI process at regular intervals that includes MOH staff may help stakeholders to address challenges and improve the efficiency of tracking. It may also increase buy-in

and accountability for the tracing process, which in many cases is tacked on top of existing workloads.

Knowing the significant drop out that occurs in the breastfeeding period, proactive follow up of clients before key PMTCT events could be considered for scale up. Proactive follow-up will be considered in a separate section.

ii. Reminders

This section describes interventions that remind clients of scheduled appointments.⁸⁸

PMTCT

In a Johannesburg hospital, postpartum women received SMS' for 10 weeks after delivery, which resulted in higher retention for six week infant testing (from 58% to 74%).

A programme in Uganda uses SMS messaging that is automatically generated from an EID data centre to remind caregivers to pick-up infant HIV test results.⁸⁹ This strategy decreased the percentage of HIV-positive infants that were lost before initiating ART (77% to 43%).

A randomized controlled trial (RCT) on the efficacy of regular SMS reminders and educational messages on improving retention in PMTCT care among HIV-positive pregnant women was conducted in Mozambique.⁹⁰ A structured series of SMS reminders

were sent to eligible pregnant women in urban, peri-urban and rural sites. The SMS platform pulled data from an electronic client database on upcoming AN and PN appointments, then sequential SMS reminders and educational messages were sent. The intervention improved outcomes on institutional births and on early infant testing (70.9% to 77.1%, and for women who gave birth in non-study site facilities, this jumped from 38% to 75%).

ART

In Cameroon, fortnightly telephone calls were made to all ART-naïve clients, using a model to prevent LTFU.⁹¹ This improved client outcomes and reduced LTFU (14% LTFU compared to 28% in control group). Clients reported these provider-initiated calls were motivating because they showed interest and support.

In Johannesburg, a mobile technology tool was used to send clients SMS alerts for future clinic appointments and offering a free "Please Call Me" mechanism to reschedule missed appointments.⁹² A dashboard in the tool allowed administrators to flag clients who frequently miss scheduled appointments. The intervention resulted in increased scheduled appointment attendance and an increased proportion of individuals attending the clinic within a week after their schedule date (from 87 to 96%). Just over half of all "Please Call Me" messages resulted in successful rescheduling of appointments.

⁸⁸ De Tolly, Technau & Benjamin. Helping HIV+ mothers protect their babies: Improving follow-up and HIV testing rates of exposed infants through SMS, via Rawizza, supra note 40, original source could not be located.

⁸⁹ EMTCT Interagency Task Team. (2013). Final Report: Stock-taking Meeting of Focus Countries in East and Southern Africa on the Global Plan for the Elimination of Mother-to-Child Transmission of HIV and Keeping Mothers Alive. Retrieved from: http://www.emtct-iatt.org/wp-content/uploads/2013/07/EMTCT-stocktaking-report_29April2013.pdf.

⁹⁰ Davey, supra note 78.

⁹¹ Muko, K., Chingang, L., & Yenwong, M. Use of mobile phones to improve on adherence and clinical outcomes of patients on ART. 5th IAS Conference on HIV Pathogenesis, Treatment and Prevention. Abstract no. WEPEB281. Retrieved from: <http://www.iasociety.org/Abstracts/A200722946.aspx>.

⁹² Neethling, et al. Text message reminders as a strategy to improve appointment attendance at HIV treatment facilities. Presented at 5th IAS Conference on HIV Pathogenesis, Treatment and Prevention, Cape Town, South Africa, July 19-22, 2009.

EVIDENCE ON REMINDER SYSTEMS

1. **SMS platforms to improve EID test and results:** SMS platforms can enable mass automatic messaging of clients. Though seemingly impersonal, automated reminders have been shown to increase infant PCR uptake and decrease loss of HIV-positive infants before initiating ART.
2. **Give clients the option to interact and reschedule for free:** Giving clients the option to seek support or to reschedule appointments for free by sending a "please call me" SMS can improve clinic attendance.
3. **Sharing educational messages:** SMS platforms can be used to send out educational messages interspersed with appointment reminders to increase retention. Separate messages can also be sent to partners to educate them on PMTCT and their own health, too. Educational messages can prompt positive dialogue between partners.
4. **Prevention of LTFU of treatment naïve clients:** Clients who are inexperienced / unfamiliar with treatment are at risk of dropping out. Targeted calls to these clients can help retain them in care early on.

Reminder Systems in Malawi

The Tingathe Program uses CHWs to follow-up clients at home and the facility from initial diagnosis until the final confirmation testing for infants at the cessation of breastfeeding, which includes reminding clients to attend their facility appointments.⁹³ The CHWs visit HIV-positive women who are enrolled in the program each month after delivery until the child is six months old. From six months to one year, the CHW visits every three months, and from one year to two years, every six months. Tearfund / EAM's Mother Buddies also proactively follow-up clients at their households. Mother Buddies visit pregnant women three times during the antenatal period, and are required to follow-up with women 24 hours after delivery to check for obstetric warning signs, then before scheduled visits at six weeks, 12 months and 24 months to remind mothers to take their infant for testing.⁹⁴ The Poimapper android phone application automatically reminds Mother Buddies of these visits.

In Neno District, PIH VHVs visit HIV-positive patients on a daily basis, including PMTCT clients. The VHVs are informed if a patient is missing from care, and they are the first step in default tracking as described in the previous section.⁹⁵

⁹³ Nanthuru, supra note 80.

⁹⁴ Dzama, supra note 84.

CHALLENGES AND CONSIDERATIONS FOR MALAWI

Few stakeholders are proactively engaging clients before key PMTCT appointments, and instead follow-up with clients after they have already missed their appointments or defaulted.

Given the well-documented LTFU that occurs in the postnatal period and the low uptake of EID, stakeholders could consider switching to proactive approaches to prevent drop-out, especially for reminders for the six weeks, 12 and 24 month infant testing.

⁹⁵ Wroe, supra 87.

B. LAY HEALTH WORKERS AND PEER EDUCATORS

This section describes various lay health worker and peer educator cadres, including expert clients and MMs, CHWs and lay counsellors.

i. Mentor Mothers and Expert Clients

MMs are mothers living with HIV who are trained, employed and empowered to work alongside doctors and nurses in understaffed health centres as members of healthcare teams. Various mentor mother programmes have been documented to increase retention-in-care. In Zimbabwe, a mentor mother programme run by MSF was shown to increase retention, with clients being twice as likely to return for testing at 6-8 weeks and to obtain results.⁹⁶ In a qualitative study of the programme, clients and MMs reported improved retention through increasing self-efficacy and motivation, supporting clients to disclose their status, increased male partner involvement, reducing stigma and discrimination, and empowering women. Other mentor mother initiatives have also proven to be effective in increasing client knowledge on PMTCT.⁹⁷

m2m Malawi deploys MMs in 101 sites who provide one-on-one and group sessions to share health education and psychosocial support to HIV-positive pregnant women and new mothers. Their ties to the community and first-hand knowledge of HIV make them effective peer mentors that are able to earn the trust of the mothers who are their clients. Community-based CMMs identify new clients, i.e. pregnant and breastfeeding women, through door-to-door visits and referrals from HSAs. Education and support is provided at the household level to encourage uptake of ANC and PMTCT for all women.

Until recently, Tearfund/EAM used Mother Buddies that provided similar community-based follow-up services. Mother Buddies were also tasked with

reducing maternal mortality in the community. Mother Buddies were trained to identify warning signs and called for ambulatory care for women experiencing obstetric emergencies. The Poimapper application on their phones also contained information on maternal mortality, which Mother Buddies referenced as they interacted with clients. When needed, Mother Buddies also called nurses at the facility who were also given a phone with Poimapper, enabling them to instantly access client data and give guidance. SSDI also deploys a cadre of facility-based MMs who trace clients in the community; however this cadre works on a voluntary basis.

Dignitas' expert clients are trained to assist with ART clinic tasks including measurement of vital signs, anthropometry and counseling.⁹⁸

An evaluation found that the expert clients carried out shifted tasks acceptably, saved formal health staff time, and also acted as 'living testimonies' of the benefits of ART and were a means of achieving greater involvement of PLWHIV in HIV treatment programs. The increased efficiency gained at the clinic because of expert clients has the potential to increase retention due to shorter waiting times and improved client experiences at the clinic.

Paid expert clients are also used by CHAI to provide psychosocial support and health education at the

⁹⁶ Shroufi, A., Mafara, E., Saint-Sauveur, J., Taziwa, F., Vinales, M. (2013). Mother to mother (m2m) peer support for women in prevention of mother to child transmission (PMTCT) programmes: a qualitative study. PLOS One. doi: 10.1371/journal.pone.0064717

⁹⁷ Teasdale, C., & Besser, M. (2008). Enhancing PMTCT programs through psychosocial support and empowerment of women: the Mothers2Mothers model of care. Southern African Journal of HIV Medicine, 9(1), 60-64. Retrieved from: <http://www.ajol.info/index.php/sajhivm/article/view/34863>.

⁹⁸ Tenthani, L., Cataldo, F., Chan, A., Bedell, R., Martiniuk, A., & van Lettow, M. (2012). Involving expert patients in antiretroviral treatment provision in a tertiary referral hospital HIV clinic in Malawi. BMC Health Services Research, 8(12), 140. doi: 10.1186/1472-6963-12-140

facility. DREAM also deploys expert clients called activists, who work on a voluntary basis.

The CRS IMPACT program paid expert clients while community-based expert clients called community facilitators worked on a volunteer basis. Expert clients were recruited through NAPHAM support groups, and were assigned in pairs to facilities. In addition to leading group education talks and one-on-one counseling sessions, expert clients assisted with client flow in order to reduce waiting times and improve efficiency. Expert clients checked clients' weight, pulled master cards for scheduled clients and filed them after each visit, packed medications in preparation for distribution and distributed bed nets, soap and buckets to antenatal mothers. Expert clients escorted clients to various points of care within the facility. They also triaged clients in the waiting room, so that sicker clients were seen first. Pulling master cards had the added benefit of easing identification of clients who needed to be traced, as master cards belonging to clients who missed their appointments would be remaining each day. Expert clients would give clients up to three days after their missed appointment to arrive, before adding them to the tracing list for follow up by HSAs and community facilitators within 14 days.

PIH uses expert patients to improve the impact of their HIV program. Each expert patient has personal experience with PMTCT and any issues associated with being an HIV-positive pregnant woman. Expert patients visit pregnant women who default for counseling. The use of expert patients is a new addition to the existing PIH VHW program.⁹⁹

CONSIDERATIONS FOR MALAWI

Expert clients for ART and variations of the mentor mother model for PMTCT are widely deployed across programs, and share the function of providing psychosocial support to their HIV-positive peers. While expert clients and MMs all provide group health talks, not all are optimally integrated into facility-based care. For example, these lay health workers do not all systematically provide pre-test group

education and post-test counseling or psychosocial support, which may help increase uptake of services, especially in high-volume facilities where clinicians and nurses have less time to interact with clients.

Programs that use expert clients or MMs to pull and organize master cards and triage clients appear to help improve client flow. It is a desired benefit that pulling master cards on a daily basis also eases identification of clients for tracing.

While this does not address identifying clients for missed ANC visits, ART-refill appointments for Option B+ women can be tracked this way. Triage clients could also be scaled up with proper training provided to these cadres on identification of warning signs and symptoms.

Expert clients and MMs can also be used as the first and last point of contact for clients at ART clinics and/or ANC facilities. This will enable them to check which PMTCT services are required and direct clients to all of the appropriate service points. For example, if a client comes to the facility just for ART refills, the expert client and mentor mother can check to see if they are also due for an infant test, immunizations or other services.

There is an opportunity for the cadre that works in the community to focus on broader maternal health issues outside of just PMTCT. Some mentor mother cadres are trained to recognize early warning signs for clinical deterioration in order to decrease maternal mortality. This is a practice to consider for replication across other community PMTCT cadres. The scale up of smart-phones with applications such as Poimapper, in addition to systems that enable the community cadre to call nurses for assistance could also be explored for scale up.

There is variation in the scope of work of expert clients and MMs who provide only facility-based services, facility and community-based services,

and just community-based services. For cadres having responsibilities to work in both facilities and communities, it can be difficult to balance the need for their services and time to achieve their targets in both areas. There are often insufficient numbers of expert clients and MMs to saturate entire catchment areas, which means that clients are likely to fall through the cracks in receiving vital support services such as tracing and follow-up. This challenge is compounded by transportation limitations, as some cadres do not have access to bicycles or motorcycles.

Stakeholders adopt a variety of approaches to secure the services of these lay health workers. Some cadres are not compensated at all and relied upon as volunteers. Others are provided modest stipends and sometimes reimbursement for transportation costs.

While cost savings and sustainability may be motivators to rely on voluntary service, there is evidence that demonstrates that lack of compensation and low compensation contributes to high levels of attrition and interrupted care.¹⁰⁰ It can also contribute to low morale and reduced productivity, as these workers feel unrecognized for their abilities, level of responsibility and contribution.¹⁰¹

It may be useful to explore the development of national standards or guidelines for expert clients, MMs, and other lay health workers, to guide their compensation, level of responsibility and roles, as they provide critical services that support overburdened and under-resourced health systems.

Lastly, stakeholders could consider including expert clients and MMs into monthly supportive supervision and QA/QI processes. This may help to institutionalize a culture of data use to improve this cadre's performance by health facility staff. As these cadres are employed by external stakeholders, this approach may also help to integrate them into health and HIV services.

ii. Community Health Workers and Lay Counsellors

Community health workers have been used to increase facility-based delivery and skilled attendance, exclusive breastfeeding and postnatal follow-up.¹⁰² A USAID-funded project in Zambia uses community PMTCT registration and support from lay counselors to significantly reduce the loss to follow-up along the PMTCT cascade.¹⁰³ The program links and reconciles community and facility registers that contain complete information on mothers and babies, and are reconciled on a monthly basis to improve tracking. Lay counselors are based out of clinics and are each assigned zones containing between 1000-7500 people. Lay counselors track clients who miss appointments and follow-up with mothers in the community. They also transport women to the clinic if they are unable to find their own transportation, and collect medication and deliver it for women who were unable to go themselves. When not interacting with clients, lay counselors also conduct outreach and education in the community. This program resulted in 50% male involvement, 92% of women living with HIV receiving ARVs for PMTCT (compared with 62% nationally), and an infant testing rate within the first 12 months of life of over 90% in most facilities.¹⁰⁴

⁹⁹ Wroe, supra note 87...

¹⁰⁰ Nkoni, L., Clifff, J., & Sanders, D. (2011). Lay health worker attrition: important but often ignored. *Bull World Health Organ*, 89, 919-923. doi: 10.2471/BLT.11.087825 [Hereinafter Nkoni, supra note 100].

¹⁰¹ Nkoni, supra note 100.

¹⁰² Bhutta, Z., Lassi, Z., Pariyo, G., & Huicho, L. (2011). Global experience of community health workers for delivery of health related millennium development goals: a systematic review, country case studies and recommendations for integration into national health systems. Published by WHO and Global Health Workforce Alliance. Retrieved from: http://www.who.int/workforcealliance/knowledge/publications/CHW_FullReport_2010.pdf?ua=1. [Hereinafter Bhutta, supra note 102].

¹⁰³ Holmes, L. (2012). The community register project: improving access to PMTCT services in Zambia. USAID AIDSTAR-ONE. Retrieved from: http://www.aidstar-one.com/focus_areas/pmtct/resources/case_study_series/community_register_project_zambia. [Hereinafter Holmes, supra note 103].

¹⁰⁴ Male involvement is not defined in the programme's case study.

In Malawi, Tingathe CHWs follow up with clients at home and the facility from initial diagnosis until confirmation of definitive HIV-uninfected status after cessation of breastfeeding or successful ART initiation for HIV-infected infants. Clients are referred to Tingathe CHWs from ANC, and are identified at labor and delivery or after birth. CHWs also conduct client registration, conduct nutritional assessments, infant feeding counseling, pill counting and distribution of nutritional supplements. CHWs split their time between clinics (40%) and the community (60%) and follow a caseload of 50 mother-infant pairs, though this can increase up to a maximum of 100 pairs at a time. CHWs use bicycles as their mode of transportation, though supervisors are given motorcycles and are tasked with tracing clients who are furthest from the facility.

The Tearfund/EAM program trained a cadre of lay health workers called Prevention of Parent to Child Transmission of HIV (PPTCT) facilitators. Volunteer church and community members serve as PPTCT Facilitators and visit pregnant women and their families in the community to provide education on prevention, HIV testing and counseling (HTC), accessing treatment, and the importance of going to ANC. PPTCT Facilitators conduct outreach at churches to encourage couples to visit the facility together for testing and conduct community outreach talks on RMNCH issues. An important aspect of the PPTCT Facilitators work involves engaging village chiefs in order to sensitize the

community and share information surrounding safe pregnancy and PMTCT practices.

PPTCT Facilitators are trained on the Guardians of Our Children's Health (GOOCH) Toolkit which helps clients understand how HIV can be transmitted from parent to child and builds the knowledge and skills of both parents in order to reduce the risk of HIV transmission to their child. The training kit encourages men to become actively involved in the health of their families and to get tested for HIV. Issues such as stigma and discrimination are addressed, and a "Positive Living" approach is introduced within the context of the local church congregation. The GOOCH manual also uses excerpts from the Bible to underscore messaging on non-discrimination, compassion for PLWHIV, and to encourage the use of family planning methods. The soft bag toolkit contains: Activity manual including handouts, Positive Health information book, 10 picture cards, 16 activity cards, 2 packs of condoms and a condom training model.¹⁰⁵

PIH employs 820 paid village health workers (VHWs) across each village in Neno District. All HIV-positive patients are assigned a specific VHW whose job entails visiting HIV-positive patients on a daily basis, doing health education sessions within the community, and acting as a link between households and the health system. Each health center has a VHW supervisor who is responsible for the VHWs in that catchment area.¹⁰⁶



¹⁰⁵ Tearfund. Guardians of our Children's Health Toolkit. Retrieved from: https://resources.tearfund.org/tearfund_resources/public/saleproduct.jsf?catalogueCode=20071. [Hereinafter Tearfund, supra note 105].

¹⁰⁶ Wroe, supra note 87.

C. IMPROVING HEALTH SYSTEMS LINKAGES AND ACCESS TO CARE AND TREATMENT EDUCATORS

This section describes health systems strengthening interventions including integration of services, the establishment of mother-infant pair clinics, and QA/QI efforts. It also examines efforts to strengthen linkages and referrals, as well as interventions to decentralize and ease ARV distribution for clients.

i. Health Service Integration

Integration of ART into ANC

A study in Cape Town found that the integration of ART initiation into ANC is associated with higher levels of ART initiation in pregnancy.¹⁰⁷ Other studies have found increased testing and initiation on ART in integrated programmes, but there is no evidence at this point on significant improvements in ART retention or improved ART coverage eight weeks before delivery.¹⁰⁸

Integration of PMTCT and MNCH Services

The integration of PMTCT and MNCH services has been shown to improve the uptake and timely initiation of ART among treatment eligible pregnant women in public health settings.¹⁰⁹ A review of integration strategies in Malawi, Mozambique and Uganda found all models to be cost-effective.¹¹⁰

Postpartum engagement of HIV-infected mothers and HIV-exposed infants has been insufficient although alignment of visits to the childhood immunization schedule and establishment of integrated mother-infant clinics may increase retention. While there may be benefits to integration, in the context of universal provision of maternal ART during pregnancy under Option B and B+, the increased demand for services may overburden systems and negatively impact the quality of care, i.e.

high demand may lead to long waiting times, which can hinder retention.

In Neno District, PMTCT services are fully integrated into ANC clinics. This is facilitated by the MOH with support from PIH. After delivery, the baby is enrolled in the EID program which is integrated into the ART clinic. Mothers of exposed infants receive food packages three months pre-partum and six months post-partum, and the exposed infant receives food packages from six months up to 24 months after delivery. This helps ensure 24 month follow up for HIV rapid test for all exposed infants.¹¹¹

Mother-Infant Pair Clinics

Ideally, all services should be available any day of the week for mothers and infants, but due to the limited resources and staffing, this approach has not been feasible everywhere.

To ensure that mothers and babies are able to access all required services in one visit, CHAI is currently establishing and evaluating Mother-Infant Pair Clinics (MIPCs), which are one-stop shops designed to provide HIV-positive women and HIV-exposed infants with all of the services they need to protect the mother's health and prevent MTCT in one place.¹¹²

MIPCs are integrated horizontally into ANC, labor and delivery, postnatal care (PNC), ART services, routine maternal and pediatric health services, and EID. All of these services must be available in order to be certified as an MIPC. The MIPC is typically run once a week at the facility, and is the designated day for all services to be focused on PMTCT and MNCH care. A typical MIPC visit for a HIV-positive mother and her infant would consist of an education session, often with songs and interaction; a nutritional

¹⁰⁷ Stinson, K., Jennings, K., & Myer, L. (2013). Integration of antiretroviral therapy services into antenatal care increases treatment initiation during pregnancy: a cohort study. *PLoS One*, 8(5). doi: 10.1371/journal.pone.0063328.

¹⁰⁸ Tudor Car, L., et al. (2011). Integrating prevention of mother-to-child HIV transmission programs to improve uptake: a systematic review. *PLoS One*, 6(6). doi: 10.1002/14651858.CD008741.¹⁰⁹ Chi, B., Bolton-Moore, C., & Holmes, C. (2013). Prevention of mother-to-child HIV transmission with maternal, newborn, and child health services. *Curr Opin HIV AIDS*, 8(5), 498-503. doi: 10.1097/COH.0b013e328363777a

¹¹⁰ Bollinger, L., & Adesina, A. (2013). Cost-effectiveness of integrating PMTCT and MNCH services: An Application of the LIST Model for Malawi, Mozambique, and Uganda. DHS Occasional Paper No. 7. USAID. Retrieved from: <http://dhsprogram.com/publications/publication-OP7-Occasional-Papers.cfm>.

¹¹¹ Wroe, supra note 87.

¹¹² Churchman-Kobayashi, supra note 85.



assessment and under five check-up for the infant; and a supply of ART refills. Both the mother's and infant's master cards are kept together and updated when each service is provided. At any point during an MIPC day, expert clients are available to counsel or consult clients who may need assistance. SSDI is also currently in the process of scaling up the MIPC model.

In order to evaluate the effectiveness and impact of the MIPCs, CHAI is partnering with the University of Malawi, College of Medicine, and the MOH to conduct a RCT with its project, Promoting Retention among Infants and Mothers Effectively (PRIME).¹¹³ To evaluate retention throughout the PMTCT cascade of care, the PRIME Project compares the proportion of HIV positive mothers and their infants retained in PMTCT care at 12 months in health facilities implementing the standard of PMTCT care versus those assigned to two new interventions: MIPCs or MIPCs plus SMS-based tracing of mother-infant pairs who do not return for care at their scheduled appointment times. The PRIME Project aims to enroll HIV positive pregnant women attending ANC in health facilities in Mangochi and Salima, who are being followed-up through 24 months post-partum.

Creating Mother-Baby Care Points

MSF Belgium has adjusted client flow in facilities across Nsanje District to create MCH Care Points for women and their babies.¹¹⁴ These care points are where mothers' and babies' master cards are kept together, which enables pairs to be tracked. Appointment diaries are also kept at these points to enable tracking of missed appointments for client tracing. EID is also supported as nurses review master cards each time a mother and/or baby visits, and check whether the baby is due for testing.

Quality Assurance / Quality Improvement

Quality Assurance / Quality Improvement processes are an important part of health systems strengthening

for PMTCT service delivery. These processes improve M&E systems to promote and strengthen data quality and data use.¹¹⁵

Critically, QA/QI processes serve to strengthen the capacity of health care workers at facilities, districts, and higher levels to collect and analyze data, and use it to improve service delivery.

Several stakeholders in Malawi include monthly and/or quarterly supportive supervision meetings where data is reviewed together with MOH facility and district level staff. MSF Belgium provides mentorship and capacity building to facility staff and reviews facility data on a monthly basis to assess progress against key uptake and retention barriers, such as uptake of HTC, registration of babies at birth, and infant testing at six weeks, 12 and 24 months.¹¹⁶ MSF coordinators also meet with District Health Management Teams to review birth cohort data. Dignitas follows a similar process of mentorship and supportive supervision, which is provided each week until the facility is deemed "graduated". Once this occurs, Dignitas conducts supportive supervision on a monthly basis, in which mentees complete self-assessments to identify areas for further professional development.

m2m engages site staff in quarterly Let's SOAR (Strengthening Outcomes by Analyzing Results) sessions to both improve the quality of services delivered to clients and improve data quality. SOAR is a continuous QI methodology designed to build m2m staff capacity to collect, analyze and use data for evidence-informed decision making at the site level. SOAR utilizes a statistically robust sampling methodology that is simple, quick, and manual and enables site staff to review m2m logbook data about client outcomes on a quarterly basis. MOH

¹¹³ Implementation Research Platform. (2014). INSPIRE Initiative. Retrieved from: http://www.implementationresearchplatform.org/inspire#.VB_f2vmSxio.

¹¹⁴ Kasalu, supra note 83.

¹¹⁵ Mesmey, E., et al. (2013). PMTCT/MNCH: An entry point to health information systems strengthening in Cameroon. ICAP.

¹¹⁶ Kasalu, supra note 83.

facility staff members are invited to participate in this program, and are engaged in problem-solving.

EGPAF has developed a QI strategy and is beginning to identify health facility projects to improve services. This effort is prioritizing the PMTCT cascade, EID and treatment and retention. Specific projects are based on site-level data and locally identified solutions. EGPAF also does monthly data dashboards with its facilities and quarterly data reviews. Likewise, m2m Malawi conducts quarterly QA/QI meetings with facility staff where uptake, retention, family planning and infant feeding indicators are reviewed. DREAM, Lighthouse, Baylor, and others also conduct monthly and quarterly reviews with facility and district MOH staff.

ii. Improving Linkages & Referrals in PMTCT

Enhanced referrals to improve retention in EID

Two rural district level hospitals in Mozambique tested enhanced referrals to improve retention in EID.¹¹⁷ This simple intervention entailed nurses directly accompanying all postpartum HIV-infected women to the location of EID services within the hospital grounds. In a private infant testing suite, the mothers then received standard HIV-related counselling by a maternal-child health nurse. All infants who received the enhanced referral also had medical records generated prior to discharge. The enhanced referral required an additional 5-10 minutes to complete and no additional staff needed to be hired. This intervention significantly increased EID (from 25.6% to 54%), and also reduced the median time from birth to follow-up (from 59 days to 33 days).

Integrating ART services within ANC and PMTCT programme sites has also been shown to improve uptake and retention in care.¹¹⁸ Other efforts to

reduce attrition along the pathway to HIV care and treatment include the use of escorts for women between ANC and highly active antiretroviral therapy (HAART) services; allowing pregnant women to bypass queues in HAART services, and regular meetings between staff from PMTCT and HAART services to track patents and discuss their needs.¹¹⁹

In Malawi, several cadres assist with escorting clients between various points of care in facilities, including CHWs in the Tingathe Program, MMs in the m2m program, and Dignitas' expert clients. CRS IMPACT's expert clients previously also assisted with this.

iii. Improve Access to Testing and Results for EID

Increased access to point-of-care testing and results has been recommended to streamline testing and to improve women and infants' linkages to treatment and care under PMTCT.¹²⁰ While this is also recommended under ART programs, the end goal is not for 100% of all facilities to be able to conduct point-of-care testing.¹²¹

In Malawi, NAC funds an EID project in 21 facilities that is implemented by DREAM.¹²² Once a week, DREAM drivers collect specimens from various facilities and deliver them to the DREAM laboratory for testing. The following week, drivers bring the results back to facilities for notification. A logbook is used to track who submitted specimens and if the results have been received. For children who test positive, DREAM calls the facility to inform them of the positive PCR results so that they can prioritize notification for these cases. Staff must report on a monthly basis on the number of DBS results they received, the number of positive and negative, and the number reported to the parent or guardian.

Dignitas also works to strengthen uptake of EID by mentoring facility staff on the care that HIV-exposed

infants should receive. This includes an emphasis on registering HIV-exposed infants into care, provision of nevirapine and cotrimoxazole preventive treatment (CPT), conducting a DBS at six weeks, and rapid tests at 12 and 24 months. When there are no DBS supplies, Dignitas liaises with the District Health Office (DHO) to get supplies and often provides transportation in order for the supplies to reach the facilities.

CHAI is also providing mentorship to MOH staff, but focusing on the national level.¹²³ CHAI also procured SMS printers for delivery of EID results, which reduced the turnaround time for results from 45 days to 35 days. As part of its new Pediatric HIV and TB program, CHAI is working on strengthening identification of pediatric HIV and TB, including by looking for HIV-exposed children who are born to mothers with unknown status or who previously tested HIV-negative.

PIH and the MOH in Neno District have one common register for all DNA PCR tests. Once results are received, they are communicated by telephone and paper records to the appropriate facility.¹²⁴

Since 2008, UNICEF has supported the MOH to develop rapid SMS technology, procure and install printers and train health workers to support access to EID testing and results.¹²⁵ High volume facilities have been equipped with rapid SMS printers and low volume facilities access results on mobile phones. A total of 447 facilities are using this technology, which represents 71% coverage of facilities following HIV-exposed infants. UNICEF reports that this initiative has reduced turnaround times from 45 days to 20 days.

iv. Decentralizing ARV distribution and fast-tracking care for stable clients

In-clinic Fast Track ARV distribution

A programme in South Africa adjusted in-clinic care so that stable clients are only seen by a clinician every six months and pick up their ARVs at the clinic

every two months at a "fast track wing" where health workers only check vital signs and distribute drugs.¹²⁶ With this model, the clinic is able to support 1200 clients a month as services are quick and waiting times are shorter. At the beginning of the intervention, 13% of clients did not collect their ARVs, and just nine months later, this figure had dropped to 2.2%.

ART Adherence Clubs and Community ART Groups

MSF's ART-adherence clubs are community-based ARV distribution and adherence supporting clubs. They are facilitated by lay club facilitators who provide quick clinical assessments, refer to clinicians where necessary, and dispense pre-packaged ART.¹²⁷ Club members work as a support group, providing peer support for adherence to lifelong treatment. The group meets at a community venue for less than an hour every 2 months. Annual blood tests are conducted, with scheduling aligned and blood samples taken at the same session and results and new prescriptions given by the club nurse two months later at their annual clinical consultation. Group members can send a proxy "buddy" to collect their ART, but must attend every second session and cannot miss the annual clinical consultation and blood investigation.

Eligibility for the group is limited to adults who have been on the same ART regimen for more than 12 months, with two or more recent consecutive viral loads undetectable, and no medical condition requiring regular clinical consultations.¹²⁸ Members exit the group when they miss a mandatory session and fail to attend the clinic within 5 days, or become unstable.

A pilot test of the ART-adherence clubs had positive outcomes, with 97% retention in clinical care after 40 months (compared to 85% by the control), and participants were 67% less likely to experience virological rebound, indicating better adherence than in mainstream care.¹²⁹

¹¹⁷ Ciampa, P., et al. (2011). Improving retention in the Early Infant Diagnosis of HIV Program in rural Mozambique by better service integration. *J Acqui Immune Defic Syndr*, 58(1), 115-9. doi: 10.1097/QAI.0b013e31822149bf

¹¹⁸⁻¹¹⁹ Ferguson, supra note 27.

¹²⁰ Dube, Q., et al. (2012). Implementing early infant diagnosis of HIV infection at the primary care level: experiences and challenges in Malawi. *Bulletin of the World Health Organization*, 90(9),699-704. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/22984315>.

¹²¹ Holmes, C. (2012). Entry Into and Retention in Care and Antiretroviral Adherence: Considerations for Resource-Limited Countries. IAPAC Guidelines. Retrieved from: http://www.iapac.org/ias/presentations/Holmes_C.pdf.

¹²² Interview with Sangaré Hawamamary on 27 August 2014.[Hereinafter Hawamamary, supra note 122].

¹²³ Churchman-Kobayashi, supra note 85.

¹²⁴ Wroe, supra note 87.

¹²⁵ Feedback via e-mail from Judith Sherman, UNICEF Malawi.

¹²⁶ Maharaj, T., et al. Strategies to address clinic waiting time and retention in care; lessons from a large ART center in South Africa. 17th International Conference on AIDs and STIs in Africa, abstract no. ADS058.

¹²⁷ Wilkinson, L. S. (2013). ART adherence clubs: A long-term retention strategy for clinically stable patients receiving antiretroviral therapy. *Southern African Journal of HIV Medicine*. [Hereinafter Wilkinson, supra note 127].

¹²⁸ Medecins Sans Frontieres. (2012). ART Adherence Club Report and Toolkit. Johannesburg: MSF South Africa.

¹²⁹ Wilkinson, supra note 127.

This model is implemented by a club team including a part-time club manager, and at least one full-time lay club facilitator per 40 ART clubs. A facility nurse is allocated on the clinic roster for each day on which a club session takes place, though they are infrequently required to see club clients after a session aside from conducting the annual blood tests and clinical consultations. Bottle-necks at the pharmacy can be prevented by allocating an additional pharmacy assistant where there are more clubs, or by using a central dispensing service for pre-packed ART.

MSF also implements Community ART Groups (CAGs) which are self-formed groups of stable clients on ART who take turns attending clinical assessment and monitoring tests at the facility, while collecting ARVs for themselves and other members of the group.¹³⁰ As with the ART Adherence Clubs, CAGs provide a means of accessing ART while providing social support. These have been implemented in places like Mozambique, Lesotho and Zimbabwe, and been shown to increase retention and reduce workloads at facilities.¹³¹

ART Clubs or CAGs could potentially be translated to the Option B+ sphere as it is limited to clinically stable clients and addresses multiple barriers to adherence (e.g. distance and transportation funds) while including a built-in support group. Demand for this type of service may only exist in the postnatal period once fewer visits are required at the facility for maternal and child care. Otherwise, women will rather just collect ARVs at the facility as they have to attend regardless. In leveraging this model, it will be important to have strong interventions to improve adherence and retention for those clients who are not eligible for club participation.¹³²

CONSIDERATIONS FOR MALAWI

While MIPCs are currently being evaluated through the PRIME study, there are other practices to consider for replication. In smaller facilities, adjusting client flow so that there is a single point of care for

mothers and infants enables staff to more easily track mother-baby pairs, maintain client tracing diaries, and ensure clients receive all relevant services at each appointment. In larger facilities, the previously discussed positioning of expert clients and MMs to be the first and last point of contact and empowering them to triage clients could be useful tasks to shift to this cadre.

This is a critical issue to consider, as without adjusting client flow, expert clients and MMs are unable to catch all clients to ensure the provision of psychosocial supportive services.

Many stakeholders are providing periodic trainings and as well as mentorship to clinicians and nurses. Regular supportive supervision through monthly and quarterly review meetings is also being done by a wide range of stakeholders. These provide useful opportunities to review performance on uptake, retention and adherence indicators and to collectively problem-solve.

The Tingathe CHWs distribute ARVs to clients at their household when they cannot get to the clinic, but this is not a common practice across other programs in Malawi. NAPHAM reported that some of its support group organize themselves to take turns collecting ARVs for the other members. While ART Clubs and CAGs are an appealing intervention, with PMTCT women seldom have to attend the facility during the ANC and PNC to only collect ARVs. Hence the replicability of these initiatives may be limited to the later periods of breastfeeding and between pregnancies for the Option B+ cohort.

Stakeholders continue to experience inadequate retention of mother-baby pairs in the postnatal period, particularly at the 12 and 24-month periods. This is hampered by the fact that there is no national



¹³⁰ MSF. 2014. Community ART Groups lighten the load for HIV patients. Retrieved from: <http://www.msf.org/article/zimbabwe-community-art-groups-lighten-load-hiv-patients>.

¹³¹ MSF. 2014. Mozambique: not alone anymore. Retrieved from: <https://www.msf.org/za/msf-publications/mozambique-not-alone-anymore>.

¹³² Dewing, S., Mathews, C., Fatti, G., Grimwood, A., & Boule, A. (2014). Antiretroviral Adherence Interventions in Southern Africa: Implications for Using HIV Treatment as Prevention. *Curr HIV/AIDS Rep*, 11(1), 63-71. doi: 10.1007/s11904-013-0193-5. [Hereinafter Dewing, supra note 132].

sample transportation system. Riders for Health is currently working in 11 districts, and EGPAF is now in the process of increasing its support to them in four of the districts.¹³³ Facility-based improvements to client flow and institution of the MIPCs and the roll-out of point-of-care testing machines will support this. However it may still be useful to consider leveraging lay health workers to proactively remind mothers and caregivers of tests, and to report the

availability of results to clients to increase collection of results. SMS platforms might also be leveraged to notify clients to collect results. Expert clients, MMs and other lay health workers can also provide vital messaging to caregivers and parents to ensure all infants who test positive are initiated on treatment.



¹³³ Feedback over email from Nicole Buono, EGPAF.

D. REORIENTING SERVICE DELIVERY – WOMEN, PARTNER, AND FAMILY-FOCUSED SERVICES

This section describes efforts that reorient service delivery to engage male partners, couples and the wider family to increase uptake, retention and adherence for PMTCT. This includes programs that engage partners and families, as well as changes to key messaging to underscore the broader familial benefit of early initiation of treatment.

i. Male Involvement in PMTCT

There is substantial evidence that involving male partners in pregnancy care has positive associations between HIV-positive pregnant women's progression through the treatment cascade and their male partners' awareness, support and participation. However, studies are not always clear on what "male involvement" is defined as, but it is an umbrella term that can encompass couples counselling and testing, men's HIV testing, facilitation of disclosure between partners, accompaniment to clinic visits, and outreach and education of men on PMTCT and gender equality.¹³⁴

There are some excellent outcomes to male involvement that have been documented. For example, a Kenyan study that found that male AN attendance reduced risk of vertical transmission and infant mortality by up to 40%.¹³⁵ A study in Malawi found that male partner accompaniment to clinic was significantly associated with hospital delivery, completion of follow-up in the programme and condom use.¹³⁶ Couple counselling and testing has been shown to improve adherence to treatment and breastfeeding protocols,¹³⁷ and to also increase the odds of having a facility-based delivery, and less

likely to be LTFU.¹³⁸

A significant benefit of male involvement in PMTCT is that it helps to increase communication about HIV and sexual risk between partners, and it also has an association with contraceptive use.¹³⁹ Men as supportive partners can influence the family's social environment to help make it more conducive to seeking treatment, retaining in care, and adhering to medication. Men's involvement also positively impacts infant feeding practices and mortality. A Tanzanian study looking at greatest impact of partner participation found that 64% of women whose partners participated adhered to infant feeding guidelines as compared to 28% whose partners did not participate.¹⁴⁰

While there are many benefits to male involvement, it is not clear in the evidence whether efforts to promote male involvement are responsible for men's utilisation of services, or whether it is men who are already constructively involved in their partners' lives that utilise PMTCT services.¹⁴¹

Women who do not have supportive partners can experience downsides to male involvement in PMTCT programs. Negative consequences can include outcomes such as divorce, abandonment, domestic violence – particularly in discordant couples and particularly when disclosed during pregnancy.¹⁴²

¹³⁴ Ramirez-Ferrero, E. (2012). Male involvement in the prevention of mother-to-child transmission of HIV. Published by WHO. Retrieved from: <http://www.who.int/reproductivehealth/publications/rtis/9789241503679/en/>.

¹³⁵ Alusio, A., Richardwon, B., Bosire, R., John-Stewart, G., Mbori-Ngacha, D., & Farguhar, C. (2011). Male antenatal attendance and HIV testing are associated with decreased infant HIV infection and increased HIV-free survival. *J Acquir Immune Defic Syndr*, 56(1), 76-82. doi: 10.1097/QAI.0b013e3181fdb4c4

¹³⁶ Kalembo, F., Zgambo, M., Mulaga, A., Yukai, D., & Ahmed, N. (2013). Association between male partner involvement and the uptake of prevention of mother-to-child transmission of HIV interventions in Mwanza District, Malawi. *PLoS One*, 8(6). doi: 10.1371/journal.pone.0066517

¹³⁷ Farquhar, C., et al. (2004). Antenatal couple counselling increases uptake of interventions to prevent HIV-1 transmission. *J of Acquir Immune Defic Syndr*, 37(5), 1620-6. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/15577420>.

¹³⁸ Conkling, M., et al. Couples' voluntary counselling and testing and nevirapine use in antenatal clinics in two African capitals: a prospective cohort study. *Journal of the International AIDS Society*, 13(10). doi: 10.1186/1758-2652-13-10

¹³⁹ Sternberg, P., & Hubley, J. (2004). Evaluating men's involvement as a strategy in sexual and reproductive health promotion. *Health Promotion International*, 19(3), 389-396. doi: 10.1093/heapro/dah312

¹⁴⁰ Msuya, S., Mbizvo, E., Hussain, A., Uriyo, J., Sam, N., & Stray-Pedersen, B. (2008). Low male partner participation in antenatal HIV counselling and testing in northern Tanzania: implications for preventive programs. *AIDS Care*, 20(6), 700-9. doi: 10.1080/09540120701687059

¹⁴¹ Bhutta, supra note 102.

¹⁴² Brusamento, S., et al. (2012). Male involvement for increasing the effectiveness of prevention of mother-to-child HIV transmission (PMTCT) programmes. *Cochrane Database of Systematic Reviews*, (11). doi: 10.1002/14651858.CD009468

Women also do not want male participation to be a condition for receiving PMTCT

as women whose partners are unwilling or unable to attend are forced to hire men to accompany them to appointments.¹⁴³ Male involvement initiatives need to ensure they are voluntary, protect confidentiality and are implemented sensitively to respect the human rights of women.

Male Involvement in Malawi

Across the board, stakeholders highlighted the lack of male involvement as a key barrier to uptake and retention in care. Several programs implement similar interventions to promote male participation in ANC. These include the use of “love letters” to invite men to the clinic with their partners; the requirement for women to bring a letter from their chief if their male partner cannot attend ANC with them; prioritization of women who bring their partners with them to the facility; couples counseling and testing drives; and framing the prevention of vertical transmission as a parents’ issue, as opposed to only a mother’s issue.

UNICEF began implementing the Male Championship program in 2012, which mobilizes men to engage in ANC and PNC and family planning through facility and community based interventions.¹⁴⁴ The community component mobilizes men to patronize ANC and couples HTC, support their partners with their facility-based delivery and in accessing postnatal services, utilizing family planning and engaging in growth monitoring. The program trains volunteer Male Motivators who are married, have been counselled and tested for HIV, have pregnant spouses and are in good standing with the community. The Male Motivators are trained to conduct health education on reproductive health including PMTCT. They also visit two households per week to provide education to other men in the community.

Despite the existence of interventions to engage men in ANC and PMTCT, stakeholders reported that

health messaging delivered at the facility is by and large not adjusted to address men who attend ANC with their partners.

This presents a lost opportunity to share HIV treatment and prevention, family planning and PMTCT messaging directed to men.

Stakeholders shared anecdotal reports that these various tactics increase male participation in ANC meetings. However, there are questions to be asked about the impact that the prioritization of women who bring their partners has on women whose partners are either unsupportive or unavailable. This approach may have the unintended consequence of penalizing women who are already vulnerable. While the letters from chiefs can help mitigate this risk by creating a mechanism for holding male partners accountable for attending ANC, ethical questions remain around placing the burden of obtaining such letters on women. The same concerns exist for the use of penalties for failure to deliver at a facility, which have been imposed by some traditional leaders. Fear of negative reactions (e.g. divorce or intimate partner violence) is a major reason for non-disclosure among pregnant women.¹⁴⁵ This fear of disclosure is a reason for dropping out of PMTCT and avoiding facility-based deliveries. As such the imposition of penalties may exacerbate existing pressures on these women.

As Ghanotakis, et al, have highlighted, male involvement interventions may have the unintended consequences of causing interpersonal violence, reinforcing men as decision-makers, and disempowering women. For example, an intervention that promoted male involvement in PMTCT negatively impacted women’s uptake of PMTCT services and ANC in a randomized control trial in Tanzania.¹⁴⁶ Programs need to consider these possibilities when developing interventions in this area.



¹⁴³ GNP+ and ICW, supra note 23.

¹⁴⁵ Ghanotakis, supra note 2.

¹⁴⁴ Feedback via e-mail from Judith Sherman, UNICEF Malawi.

ii. MTCT-Plus and Family-focused Care

MTCT-Plus initiatives use “family-focused care” to enrol not only the pregnant women diagnosed with HIV into care and treatment, but her HIV-infected family members as well.¹⁴⁷ This includes providing at a minimum, counselling, testing, treatment and psychosocial support for women’s partners, children and other household members. It can also include reproductive health and family planning services, screening for intimate partner violence, nutrition counselling, attention to mental health issues, and attention to early childhood development.

A 5-year pilot of a PMTCT-Plus project in Uganda incorporated ART into PMTCT services and added the families of HIV-positive pregnant women to the target population.¹⁴⁸ Community-based psychosocial support groups were established, community outreach was conducted, and pregnant women enrolled in PMTCT received home-based follow-up care and support. Retention increased from 30% to 93% and an overall adherence rate of 95% was registered.

During CHW’s home visits in the Tingathe Program, all family members are engaged and offered home-based HTC.¹⁴⁹ CMMs in the m2m Malawi program also engage family members during household visits, and refer them for testing at the facility.

Tearfund/EAM’s PPTCT facilitators reflect the broader approach to prevention of vertical transmission taken by this program, with the purposeful engagement of parents, as opposed to just mothers.¹⁵⁰ PPTCT Facilitators conduct outreach at churches to encourage couples to visit the facility together for testing and conduct community outreach talks on MNCH issues. As mentioned in the previous section, PPTCT Facilitators are trained on the GOOCH Toolkit which helps clients understand how HIV

can be transmitted from parent to child and builds the knowledge and skills of both parents in order to reduce the risk of HIV transmission to their child.¹⁵¹

PPTCT facilitators encourage male involvement and focus on MTCT as an issue for both parents, not solely the mother.

Tearfund also developed a Family Planning Manual which was used by Mother Buddies and PPTCT Facilitators in churches and the community. The Family Planning Manual targets married couples and used theological approaches to various areas of family planning, such as the importance of couple testing and couples ANC visits.

CONSIDERATIONS FOR MALAWI

In Malawi, most stakeholders remain focused on mother-baby pairs, as opposed to engaging the wider family. Specific engagement of families and parents for their own health as well as for the purpose of improving PMTCT outcomes, may address multiple barriers to uptake, retention and adherence, and create more supportive family environments and increase male partner participation in reproductive health. Interventions that are implemented with a community arm bring support closer to home while also reducing stigma and discrimination. These approaches could be further examined by stakeholders in Malawi.

iii. Treatment and Infant Feeding Buddies

A treatment buddy is someone chosen by a client to provide her with ongoing support for adherence to care and treatment.¹⁵² This is usually a client’s caregiver, friend, family member or another PLWHIV who is also enrolled in care and is a trusted person to whom a client can disclose her status.

Evidence from qualitative studies indicates that programs that encourage clients to have treatment buddies improve adherence.¹⁵³ Research from South Africa found that family members, excluding spouses and partners, were more likely to be chosen as treatment partners and assist clients with decision-making on care and treatment.¹⁵⁴ Clinical support is critical, but the financial, material, instrumental and emotional support provided by family is also essential to maintenance of high adherence levels.¹⁵⁵ Even one key supportive family member helps with adherence and overall wellbeing.¹⁵⁶

In Mozambique, self-selected treatment buddies have been found to increase adherence as measured through pharmacy refill data, though not substantially more than appointed, community-based peer supporters.¹⁵⁷ In a study in rural Zambia, having a spouse who is also on ART was found to be positively associated with ART adherence.¹⁵⁸ A Nigerian project found that treatment buddies boosted the chances of achieving an undetectable viral load, though they had no durable impact on viral suppression, CD4 replenishment, or mortality.¹⁵⁹

A qualitative study from Tanzania articulated four social functions of treatment partners: (1) encouraging disclosure; (2) combating stigma; (3) restoring hope; and (4) reducing social difference.¹⁶⁰ These functions work to restore social connections and reverse the isolating effects of HIV/AIDS, and strengthen access to essential community safety nets. Treatment partners help clients restore access to

social and community resources, including concrete resources like money for transportation and food which are vital for adherence.¹⁶¹ This resulting social support, which is also promoted through community interventions and support groups, is associated with ART adherence during and after pregnancy.¹⁶²

Research from Nigeria underscores that including treatment buddies in an intervention encourages disclosure, which is significantly and positively associated with ARV adherence for prevention of vertical transmission.^{163 164} There continues to be strong evidence that disclosure of HIV sero-status to a spouse or close family member facilitates uptake of PMTCT interventions and continued HIV/AIDS care.¹⁶⁵ The facilitation of disclosure therefore continues to be recommended to increase adherence to PMTCT.¹⁶⁶

In the Eastern Cape, PATH has implemented an Infant Feeding Buddy programme based on the ART treatment buddy concept, in which a mother chooses a trusted buddy who knows her status.¹⁶⁷ This buddy attends PMTCT counselling sessions with the mother and provides support for clinic visits and recall, adherence to infant feeding choice, and practicing optimal infant and young child feeding. Buddies can also counter stigma and pressure from the family and community. Buddies chosen were 36% sisters, 21% husbands/partners, 21% boyfriends, 14% mothers, and only 1% friends. The almost complete absence of buddies who are friends and many buddies who are male partners and family

¹⁴⁶ Becker, S., Mlay, R., Schwandt, H., & Lyamuya, E. (2010). Comparing couples’ and individual voluntary counseling and testing for HIV at antenatal clinics in Tanzania: a randomized trial. *AIDS Behav*, 14(3), 558-66. doi: 10.1007/s10461-009-9607-1 [Hereinafter Becker, supra note 146].

¹⁴⁷ Becker, supra note 146.

¹⁴⁸ Buyinza, K. (2012). A strong community partnership in a PMTCT-Plus model improves client retention, medication adherence and contributes to the elimination of mother-to-child transmission of HIV in resource-limited settings. 19th International AIDS Conference, Abstract no. MOPE715.

¹⁴⁹ Nanthuru, supra note 80.

¹⁵⁰ Dzama, supra note 84.

¹⁵¹ Tearfund, supra note 105.

¹⁵² ICAP. (2011). Adolescent HIV Care and Treatment, Module 8: Supporting Adolescents Retention in and Adherence to HIV Care and Treatment. Retrieved from: http://files.icap.columbia.edu/files/uploads/Module_8_-_PM_Adolescent.pdf.

¹⁵³ Scanlon, M., & Vreeman, R. (2013). Current strategies for improving access and adherence to antiretroviral therapies in resource-limited settings. *HIV AIDS*, 5, 1-17. doi: 10.2147/HIV.S28912

¹⁵⁴ Nachega, J., et al. (2006). Treatment supporter to improve antiretroviral therapy in HIV-infected South African adults. A qualitative study. *Journal of Acquired Immune Deficiency Syndrome*, 43(1), S127-133. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/17133196>. [Hereinafter Nachega, supra note 154].

¹⁵⁵ Khamarko, K., & Myers, J. J. (2013). The Influence of Social Support on the Lives of HIV-Infected Individuals in Low- and Middle-Income Countries. *WHO/HIV/2013.51*. World Health Organization. [Hereinafter Khamarko & Myers, supra note 155].

¹⁵⁶ Scott, K., et al. (2013). In what ways do communities support optimal antiretroviral treatment in Zimbabwe? *Health Promot. Int.* Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/23503291>.

¹⁵⁷ Stubbs, B., Micek, M., Pfeiffer, J., Montoya, P., & Gloyd, S. (2009). Treatment partners and adherence to HAART in Central Mozambique. *AIDS Care*, 21(11), 1412-1419. doi: 10.1080/09540120902814395

¹⁵⁸ Sasaki, Y., et al. (2012). Adherence to antiretroviral therapy during the early months of treatment in rural Zambia: influence of demographic characteristics and social surroundings of patients. *Annals of Clinical Microbiology and Antimicrobials*, 11(34). doi:10.1186/1476-0711-11-34

¹⁵⁹ Taiwo B., et al. (2012). Assessing virologic and adherence benefits of patient-selected HIV treatment partners in a resource-limited setting. *J Acq Immune Defic Syndr*, 54(1), 85-92. doi: 10.1097/01.qai.0000371678.25873.1c.

¹⁶⁰ O’Laughlin, K., Wyatt, M., Kaaya, S., Bangsberg, D., & Ware, N. (2012). How treatment partners help: social analysis of an African adherence support intervention. *AIDS Behavior*, 16(5), 1308-1315. doi: 10.1007/s10461-011-0038-4 [Hereinafter O’Laughlin, supra note 160].

¹⁶¹ O’Laughlin, supra note 160.

¹⁶² Nachega, supra note 154.

¹⁶³ Ekama, S., et al. (2012). Patterns and Determinants of Antiretroviral Drug Adherence among Nigerian Pregnant Women. *Journal of Pregnancy*, 1-6. <http://dx.doi.org/10.1155/2012/851810>.

¹⁶⁴ Rotherman-Borus, M., et al. (2010). Benefits of family and social relationships for Thai parents living with HIV. *Prevention Science*, 11(3), 298-307. doi: 10.1007/s11121-009-0165-6

¹⁶⁵ Nachega, supra note 154.

¹⁶⁶ Israel-Ballard, K. (2011). Infant Feeding Buddies: Strategies for supporting mothers for optimal infant and young child feeding. Presentation at Core Group Spring Meeting, USAID Infant and Young Child Nutrition Project. Retrieved from: <http://ycn.wpengine.netdna-cdn.com/files/Infant-feeding-buddies-presentation.pdf>.

members is in line with research from Malawi that indicates a high level of disclosure to male partners or family, yet discomfort in disclosing to friends or non-relatives.¹⁶⁸

Treatment Buddies in Malawi

In Malawi, Lighthouse Trust requests all clients identify treatment guardians to support them throughout their care.¹⁶⁹ The treatment guardian's name and contact information is captured in Lighthouse's Baobab computerized system, and they are requested to attend scheduled visits with the client and to provide moral support to them. Close friends and family are most often selected as treatment guardians, though the clinic will provide a volunteer guardian if clients are unable to identify a candidate on their own. While treatment guardians do not undergo formal training or orientation, they learn about treatment while participating in clinic appointments. Treatment guardians also serve as a secondary contact for tracers.

The treatment guardian model is a simple intervention that could be considered for scale up in Malawi to support adherence. It contains a built-in disclosure and support mechanism, which has the added benefit of providing a secondary contact for tracing clients back into care. Where clients are unable to collect ART on their own, it may also be useful to consider allowing their treatment partner to collect it on their behalf.

iv. Key messages

Stakeholders all underscored the evidence in literature to date: HIV-positive women who are not clinically ill and lack symptoms are less receptive to the idea of starting treatment for life. While messaging may speak to the need to start treatment for life, without further motivating evidence, women may not be convinced to take up treatment. In Malawi, Dignitas provides three key messages to

women about Option B+, focusing not only on prevention of vertical transmission, but the health promoting benefits for the woman herself, as well as the protection provided to her partner.¹⁷⁰ Educating women on the benefits to her partner may also better prepare her for disclosure.

Messaging that is framed in terms of risk reduction may motivate women for prevention of vertical transmission, but it may not suffice on its own for lifelong treatment.

Emerging literature on the acceptability of and messaging related to treatment as prevention could be explored for lessons learned. For example, a qualitative study in Kenya on treatment as prevention amongst discordant heterosexual couples explored attitudes towards early initiation on ART.¹⁷¹ Most respondents expressed interest in early initiation of ART, with maintaining health and preventing HIV transmission as key benefits. The primary motivation for starting treatment early was the preservation of health, rather than reducing the risk of transmission. The study also found that the meaning of ART was a fundamental consideration as participants perceived starting therapy as emblematic of the final stages of AIDS, i.e. "nearing the grave". Starting ART triggered a profound change in identity, because psychologically it marks a transition from a normal life to a terminal illness. Committing to lifelong adherence was raised as a concern, particularly in the context of early treatment, though some respondents suggested that early initiation could help them to avoid inadvertent disclosure through opportunistic infections. The researchers argue that counselling messages regarding early initiation of ART need to be modified to clarify that it is not about disease progression. Rather, it is about protecting and preserving one's own health.

In addition to the content of messaging, the timing of messaging could be examined. Stakeholders such as MSF Belgium and DREAM highlighted the importance of providing PMTCT messaging at multiple points, and even prior to pregnancies.¹⁷² This may help women to be more receptive to messaging, give them time to adjust to the idea of

starting treatment for life and reinforce the idea that it is for health promotion, as opposed to being a marker of entering an advanced stage of HIV. As such, PMTCT B+ messaging that explains the rationale for early initiation of treatment for life could be shared in general health talks, not just those targeting women in antenatal and postnatal care.



¹⁶⁸ Donahue, supra note 49.

¹⁶⁹ Interview with Tom Chaweza on 3 September 2014. [Hereinafter Chaweza, supra note 169].

¹⁷⁰ Interview with Ruth Manyera and Gabriel Mateyu on 28 August 2014. [Hereinafter Manyera & Mateyu, supra note 170].

¹⁷¹ Curran K., et al. (2013). 'If I am given antiretrovirals I will think I am nearing the grave': Kenyan HIV serodiscordant couples' attitudes regarding early initiation of antiretroviral therapy. AIDS. doi: 10.1097/QAD.0000000000000025

¹⁷² Interview with Clive Kasalu on 26 August 2014 and interview with Sangaré Hawamamary on 27 August 2014.

E. COMMUNITY-BASED SUPPORT

This section describes interventions that focus on bringing support and outreach to the community. This includes HTC drives in communities, support groups, engaging traditional birth attendants and community leaders, the provision of incentives and enforcement of penalties, and interventions to address food insecurity.

i. Community HTC and Outreach

A program in Zambia used healthcare workers and lay providers to conduct rapid HIV testing in communities, and provide support and PMTCT services. Traditional and religious leaders were also engaged for community sensitisation and to increase partner involvement.¹⁷³ This intervention resulted in an increase of pregnant women receiving results (45%-90%) and an increase in seropositive pregnant women receiving a complete course of ARV prophylaxis (29%-66%).

Formalized links between clinics and the community can increase perceived “friendliness” of clinic services and maintain regular contact with clients through accompanying clients to health facilities and hiring “meet and greet” staff to guide clients through hospital appointments.¹⁷⁴

In Malawi, Tearfund/EAM, together with local churches, organizes HTC drives held in the community or on the church premises. HTC is conducted by nurses and other MOH HTC counselors, and church leaders encourage congregation members to be tested.¹⁷⁵ Tearfund/EAM reported that this approach increases the number of couples who get tested and the number of men who attend ANC with their partners. While some couples still prefer to go to mobile HTC facilities outside of their communities, so as to not be seen by their peers, the involvement

of church and community leaders encouraged others to access services in their own community.

In order to reach communities located far from a health facility, CRS IMPACT implemented Community Health Days to bring hard-to-reach communities a wide of array of health services, and to refer these populations into facility-based care.¹⁷⁶ The health services provided include HIV testing and counseling; hypertension and tuberculosis screening; growth monitoring, malnutrition screening and immunization updates for children under five; and other services prioritized according to the geographic area.¹⁷⁷ These “one-stop-shops” were staffed by expert clients and MOH facility staff including HTC counselors, nurses and clinicians. Individuals who tested HIV-positive or those requiring additional care were referred to the nearest health facility. Expert clients assisted by giving personal testimonies, conducting health talks, and supporting HTC by giving HIV-positive clients a copy of their referral forms, and collecting referral forms to be filed at the facility.

PIH has a broad-based community program team in Neno District. The community program team is responsible for community outreach events, liaising with community groups, and holding bimonthly large-scale support events for patients with HIV. An HTC counselor is included in many of the community events to encourage community-based testing and make it readily available to community members.¹⁷⁸

ii. Support Groups

Support groups are often part of a package of community interventions for PMTCT. These groups provide psychosocial and treatment education to women, caregivers of infants who have been exposed to HIV or are HIV-positive and to male

partners. These groups provide useful links to facilities, and can help track clients who have missed appointments. Community-based support groups can make communities more supportive environments by providing vital support closer to home, and conducting outreach to educate and sensitize communities to lessen stigma and discrimination.

The benefits of linking expert clients to support groups was studied in Mozambique, and it was found to help improve retention and adherence to ART. It was also found that group counseling may increase the efficiency and impact of expert clients.¹⁷⁹

In Malawi, support groups are run by several organizations, but the largest network of support groups are those affiliated with NAPHAM. There are currently NAPHAM support groups in all 28 districts throughout the country with over 1,500 affiliated support groups.¹⁸⁰ Support groups’ affiliation with NAPHAM is on a voluntary basis, and all support groups run on their own resources. NAPHAM has provided training and capacity building to around one third of support groups using a manual (developed in partnership with World Vision) that provides guidance on group dynamics, issues faced by PLWHIV, counseling strategies, PMTCT, and nutrition practices. Some groups have created their own or joined existing Village Savings and Loan groups.

NAPHAM encourages capacity building with Village Heads in their model, which in many areas has resulted in chiefs joining the support groups themselves. Some groups also conduct community outreach activities where they distribute condoms,

spread HIV prevention and family planning messages, and implement advocacy activities to challenge stigma and discrimination.

Around 70% of support group member are women. Male involvement is a challenge and many men are wary to join. Bridge Two Project run by John Hopkins University implemented the Hope Kit Model and Positive Prevention which both assist with outreach to men. The Hope Kit Model focuses on primary prevention for both positive and negative community members. Some support groups use “love letters” to invite men to attend and others try to plan activities such as ambush theatre and community talks, which NAPHAM finds to be more appealing to men. NAPHAM is considering the addition of economic activities within the support groups to further encourage men to participate.

NAPHAM first began working with expert clients through a partnership with CRS and its IMPACT program.¹⁸¹ Expert clients use existing NAPHAM structures to counsel clients and follow up with clients in the community. Expert clients refer clients to NAPHAM support groups, and vice versa. NAPHAM connects with HSAs, expert clients and health promoters to help trace defaulters. As support groups are well-connected in communities and are trusted by many PLWHIV, they support those doing defaulter tracing with identifying defaulted clients.

Developing and disseminating updated information, education and communication (IEC) materials to support groups or including support group leadership in trainings, for example on updated guidelines, could be considered to build knowledge and capacity to address PMTCT. Stakeholders could also consider having their MMs or expert clients participate in support groups in their community, so that they can transfer their PMTCT knowledge and experiences to the group.

¹⁷³ Torpey, K., et al. (2010). Increasing the uptake of PMTCT of HIV services in a resource-limited setting. *BMC Health Services Research*, 10(29). doi:10.1186/1472-6963-10-29

¹⁷⁴ Busza, J., et al. (2012). Community-based approaches for prevention of mother to child transmission in resource-poor settings: a social ecological review. *J Int AIDS Soc*, 15(2), 17373. doi: 10.7448/IAS.15.4.17373. [Hereinafter Busza, supra note 174].

¹⁷⁵ Dzama, supra note 84.

¹⁷⁶ Chibwana, supra note 81.

¹⁷⁷ USAID IMPACT Program. (2014). *Community Health Days: One-stop shopping for health and wellness*. [Hereinafter IMPACT, supra note 177].

¹⁷⁸ Wroe, supra note 87.

¹⁷⁹ Decroo, T., et al. (2011). Distribution of antiretroviral treatment through self-forming groups of patients in Tete province, Mozambique. *J Acquir Immune Defic Syndr*, 56(2), e39-44. doi: 10.1097/QAI.0b013e3182055138

¹⁸⁰ Interview with Master Mphande on 4 September 2014. [Hereinafter Mphande, supra note 180].

¹⁸¹ Mphande, supra note 180.

iii. Training Traditional Birth Attendants

In Cameroon, traditional birth attendants (TBAs) have been trained to provide pre and post-test counselling, rapid HIV tests, and administer nevirapine during labour and to the new born.¹⁸² They have also promoted voluntary testing and counseling to pregnant women, observed ARV ingestion during home deliveries, and referred postnatal mothers to infant HIV care,¹⁸³ although these programs have not yet been rigorously evaluated.¹⁸⁴

In Malawi, where TBAs are still active, stakeholders may consider ways to actively engage and sensitize them to strengthen referral pathways into facility-based care.

iv. Engaging Community Leaders

In Malawi, several programs sensitize and regularly engage traditional leaders and report that this is an effective tactic to reduce stigma and discrimination in the community and increase community support for PMTCT and HIV services. However, few organizations explicitly seek out and engage faith-based leaders for community outreach and mobilization for PMTCT services. This is a promising practice promoted by UNAIDS because of faith leaders' potential for influencing opinions and activating communities,¹⁸⁵ and appears to hold potential for mobilizing couples and motivating men to be involved in ANC and PMTCT.

In most stakeholders' experiences, traditional leaders are very enthusiastic about engaging with programs that promote ANC and PMTCT services, and they want a larger and more clearly defined role in supporting these efforts.¹⁸⁶ As such, stakeholders could consider regular and formal feedback sessions with traditional leaders to sustain their buy-in. Referring back to the

penalties imposed by some traditional leaders for non-facility based deliveries, stakeholders could also consider engaging with them on dialogues about unequal gender dynamics that hamper women's uptake, retention and adherence to PMTCT, so that interventions do not have unintended negative consequences for women and always seek to put women's best interests first.

v. Incentives and Penalties

Nutritional supplements and reimbursement for transportation costs have been used as incentives for giving birth with help of a skilled attendant or at the facility.¹⁸⁷

One program in Zambia worked with village chiefs to institute "bylaws" requiring men to attend ANC visits with their partners and to enforce a penalty of one goat for those who do not give birth at the facility.¹⁸⁸ While this intervention resulted in all women giving birth within a facility, considerations of voluntariness and women's rights raise questions about the scalability of this model.

Tearfund/EAM periodically provided gifts to couples who attended all recommended ANC visits, thereby providing incentives for staying in care.

vi. Food and Income Security

Food insecurity is one of the more commonly reported barriers to ARV adherence in sub-Saharan Africa, suggesting that the provision of food support may be an effective strategy for promoting adherence and retention in care.¹⁸⁹ The provision of nutritional support to food insecure individuals has led to significantly better adherence to ART. A study in Zambia found that nutritional support to food insecure individuals led to better adherence

and high medication pick-up compared to the control group.¹⁹⁰ Though this was not associated with retention in care, it is thought that it has an incentivizing effect on treatment dose adherence among those retained in care.¹⁹¹

A study in rural Uganda found that there were significant gender differences as increased severity of depression in women was associated with increased food insecurity and decreased social support, but were non-significant among men in the sample.¹⁹² This is an important finding, as depression is a barrier to adherence, and it notes the disparate impact of food insecurity on women in terms of their mental health and social support.

Recent research shows that lay health worker-led cognitive behavioral intervention and food assistance led to improvements in ARV adherence

outcomes to near optimal levels, although the follow up periods of these studies are too short to assess long-term sustainability.¹⁹³

The Tingathe Program conducts nutritional assessments and provides some nutritional supplements to its clients. Care groups in Tearfund/EAM's program provided porridge to group members, funded out of the group's own resources. In Neno District, PIH provides food packages to mothers three months pre-partum and six months postpartum and to exposed infants from six months to 24 months.

While some interventions that included microfinance support as one of several components have been studied and found positive outcomes for adherence, the findings are limited because individual components have not been studied.¹⁹⁴



¹⁸² Wanyu, B., Diom, E., Mitchell, P., Tih, M., & Meyer, D. (2007). Birth attendants trained in PMTCT provide care in rural Cameroon, Africa. *J Midwifery Women's Health*, 52(4), 334-41. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/17603955>.

¹⁸³ Msaky, H., et al. (2004). Scaling the frontier: traditional birth attendant involvement in PMTCT service delivery in Hai and Kilombero districts of Tanzania. Poster Exhibition: The XV International AIDS Conference: Abstract no. ThPeE8084. Retrieved from: <http://www.iasociety.org/Abstracts/A2171908.aspx>.

¹⁸⁴ Busza, supra note 174.

¹⁸⁵ UNAIDS. (2012). Promising practices in community engagement for the elimination of new HIV infections among children by 2015 and keeping their

mothers alive. Retrieved from: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/20120628_JC2281_PromisingPracticesCommunityEngagements_en.pdf. [Hereinafter UNAIDS, supra note 185].

¹⁸⁶ Interview with Malocho Phoso on 21 August 2014 and Interview with Alinafe Chibwana on 29 August 2014.

¹⁸⁷ Rawizza, supra note 40.

¹⁸⁸ Menda, D. (2012). Community Leadership Spearheading PMTCT Program to Improve Health Outcomes of HIV Exposed Babies, at Nangoma Hospital, Zambia. 6th IAS Conference on HIV Pathogenesis and Treatment, Abstract No. CDC044. Retrieved from: <http://iasociety.org/Abstracts/A200742251.aspx>.

¹⁸⁹ Dewing, supra note 132.

¹⁹⁰ Cantrell, R., et al. (2008). A pilot study of food supplementation to improve adherence to antiretroviral therapy among food-insecure adults in Lusaka, Zambia. *Journal of Acquired Immune Deficiency Syndromes*, 49(2), 190-195. doi: 10.1097/QAI.0b013e31818455d2

¹⁹¹ Dewing, supra note 132.

¹⁹² Tsai, A., et al. (2012). Food insecurity, depression and the modifying role of social support among people living with HIV/AIDS in rural Uganda. *Social Science and Medicine*, 74(12), 2012-2019. doi: 10.1016/j.socscimed.2012.02.033

¹⁹³ Dewing, supra note 132.

¹⁹⁴ Khamarko & Myers, supra note 155.

This review has revealed a wide array of client supportive services in Malawi that are greatly supporting the reduction of vertical transmission. Moving forward it is vital that stakeholders work towards optimal impact, which requires improved coordination of activities and identification and scale-up of promising practices. Issues for consideration are summarized below.

Stakeholders continue to experience inadequate uptake of treatment and retention-in-care in the postnatal period, particularly at 12 and 24 months of age. Facility-based improvements to client flow, institution of MIPCs, and the roll-out of point-of-care testing machines will help to address this. However, lay health workers and peer educators could be utilized more effectively within facilities. Expert clients and mentor mothers are providing vital services that are proven to help women with taking up, and remaining, in care, but their integration into facilities and the roles they play are uneven and varied. With better strategic positioning inside facilities and increased integration into health systems, these cadres can help to reduce waiting times and provide higher quality counseling and support, as compared to the rushed services that clients often experience in standard care.

Broad-based community outreach that includes traditional and faith-based leaders is proving to be effective in reducing stigma and discrimination, and efforts to engage couples and families is reported to be increasing male involvement in care. These approaches could be explored and lessons learned could be shared between stakeholders. They could also be reviewed to ensure that the best interest of the woman is considered in each approach and that they do not inadvertently reinforce entrenched and unequal gender dynamics.

Many interventions remain reactive to client drop-out from care, as opposed to tackling these issues

proactively to prevent them from happening in the first place. Household visits and reminder systems prior to key PMTCT events, such as early infant diagnosis at six weeks, and 12 and 24 months could be considered. It is also critical to invest resources and efforts to retain mothers in care, not just as key to identifying exposed infants, but to retain women on treatment for life for their own health and benefit.

Another gap that could be examined is the messaging that stakeholders provide to women accessing antenatal care and PMTCT. Key messages could share the benefits not only for the prevention of vertical transmission, but also clearly articulate the health promoting benefits to the woman herself and the protection provided to her partner. Stakeholders could examine, refine, and ensure alignment of these messages across programs.

The use of same-day initiation is contributing to the inadequate uptake of treatment under Option B+, which points to the need to identify alternatives or enhancements to this approach.

In addition, primary prevention for HIV-negative women needs to be considered, for example through increased access to treatment as prevention and pre-exposure prophylaxis for serodiscordant couples.

To capitalize on the early successes of Option B+ and maintain momentum, it is vital that these remaining challenges hampering uptake, retention-in-care, and adherence to treatment be addressed. Now is the opportune moment for stakeholders to exchange knowledge, and identify and scale-up promising practices so that Malawi can achieve its goal of eliminating mother-to-child transmission.



The purpose of this research project is to document current practices for promoting uptake and retention in care in PMTCT. The research is going to be conducted through semi-structured interviews with a cross-section of stakeholders. Formative desk research has indicated that there are generally challenges with certain issues including tracking of mother-baby pairs, early uptake of ANC and PMTCT, same-day initiation under Option B+, and large drop-offs in retention for mothers and babies during the PN period. This research seeks to hone in on stakeholders' experiences dealing with these identified challenges, and to indicate other challenges they experience and what they are doing to address them. Special attention will be given to mechanisms for implementation, and how uptake and retention services provide added value to the health system (i.e. facility-based clinical services).

Questions	Responses
Overview of PMTCT services	
<p>1. Please describe an overview of your PMTCT work:</p> <ol style="list-style-type: none"> Key program activities Years worked in the field Whether services are community or facility based Number of staff directly providing PSS support/ follow up for PMTCT clients Your targeted geographic areas (names of districts and clinics) <p>NOTE TO INTERVIEWER: <i>please probe for and describe the mechanisms being used to support uptake and retention (e.g., support groups, tracing clients, adherence clubs/buddies, counselling, case finding etc.). We want adequate descriptions of how the actual activities are conducted, what their mechanisms are, and how they link to facility service and critical factors to make them effective.</i></p>	
Uptake of services	
2. What specific strategies do you use in order to enhance uptake of PMTCT by pregnant women and PN mothers and their infants? Please describe the modalities of the service being provided.	
3. Does your program experience difficulties with same-day initiation on ART under Option B+ and how do you address this? Please describe the modalities of the service being provided.	
4. Cognizant of the challenges with acceptability of universal treatment for some women who do not need treatment for their own health face, does your program adjust its services or messaging for this group of women? (e.g. Adjusted messaging to emphasize benefit to the woman for starting lifelong treatment while healthy)	

Retention in care	
5. What kind of challenges does your program face with retention of AN women, PN women and infants?	
6. What specific strategies do you use in order to enhance retention in care of pregnant women and PN mothers and their infants?	
7. What proactive follow-up services do you provide for retention and adherence of AN women, PN women and infants? Please describe the modalities of the service being provided, and specify if there are services targeted for each type of client.	
8. What reactive services (e.g. defaulter tracing) do you provide for retention of AN women, PN women and infants? Please describe the modalities of the service being provided, and specify if there are services targeted for each type of client.	
9. How does your program deal with tracking mother-baby pairs? Please describe the modalities.	
Adding Value to the Health System	
10. How do your uptake and retention strategies integrate community and facility-based services (i.e. how does it add value to health facility/clinical services)? Please describe the activities and modalities.	
11. Describe how your program coordinates with the following (describe effective partnerships and areas of overlap, in terms of service delivery):	
<ol style="list-style-type: none"> District Health Teams Health facility staff Other local implementing partners who share the PMTCT space 	
12. How has your program addressed sustainability of the services in the MOH system	
Other	
13. Is there anything else you would like to share?	
14. Ask for copies of any literature they can share, including written program descriptions, internal evaluations, and research reports. (List documents received).	

1. Baylor – Tingathe Program

The Tingathe program, which began in 2008, provides community health worker-based client case management to increase uptake and retention in PMTCT care in Malawi.¹⁹⁵ Tingathe works hand-in-hand with the Ministry of Health to run PMTCT programs in six districts: Lilongwe, Mchinji, Kasungu, Ncheu, Dowa, and Salima. Women who visit the facility in program sites are referred to the program. Clients are also identified at labour and delivery or after the birth. The program uses CHWs as a bridge to patient care in all sites. CHWs are full time salaried employees who often have between 50-100 clients in their caseload.

CHWs work at both facility and community levels, with one facility in each area acting as a base. Each facility with Tingathe CHWs has one supervisor to oversee the CHWs in that catchment area. In the facility, CHWs liaise with nurses and other MOH staff. Their responsibilities include conducting health talks at various service delivery points, escorting clients to services in the clinic, and each morning checking the maternity ward to see how many HIV+ mothers have delivered. CHWs also conduct patient registration, nutritional assessments, infant feeding counseling, pill counting and distribution of nutritional supplements.

The CHWs follow up clients at home and the facility from initial diagnosis until confirmation of definitive HIV-uninfected status after cessation of breastfeeding or successful ART initiation for HIV-infected infants. CHWs split their time between clinics (40%) and the community (60%). In addition to these responsibilities, CHWs often make referrals to other organizations for social issues such as a

family's inability to pay to send a child to school. Some CHWs are also trained on disclosure issues and depending on a child's age, can assist with partial disclosure.

Uptake

CHWs in the community conduct house visits to deliver general health education messages and encourage uptake of PMTCT services amongst pregnant women in their community. Clients followed at the community level are identified at certain service delivery points in the facility such as the under-five clinic or ANC.

Retention

The Tingathe program includes both proactive follow up services and reactive services, i.e. client tracing, to improve retention.

Patients enrolled in the Tingathe Program are asked to sign a consent form that allows them to be followed in case of a missed appointment. CHWs ask for a descriptive address/landmarks so they can easily locate the patient. Missed appointments and defaulters are tracked based on the appointment register and appointment dates listed in the mastercards. If a client is scheduled to return and does not come, they are followed up by CHWs. A patient being traced should be followed up within two weeks of the missed appointment.

When a client is traced, the CHW conducting the tracing fills in the outcome information on the mastercard directly. With all interactions recorded, including client tracing interactions, the mastercards enable CHWs to understand which clients are experiencing the most challenges, as well as to track return to care outcomes.

CHWs conducting house visits are provided with a bicycle, airtime, rain suits, and gum boots, and are responsible for an 18km radius. If clients are located outside the 18km, CHW Supervisors, who are trained on motor bikes, will conduct the visit using a motor bike for transport. CHW Supervisors are also provided with a cell phone and airtime.

HIV-positive women who are enrolled in the program are visited by a CHW each month after delivery until the child is six months old. From six months to one year, the CHW visits every three months, and from one year to two years, every six months.

While following up with a client, the CHW will also assess if other family members have been tested. CHWs are trained to provide home-based HTC for clients and family members.

Adherence

Adherence is monitored by CHWs during home visits. CHWs ensure drugs are being taken by counting the remaining pills and comparing to the number they should have based on their last appointment date. If a client is not adhering, she will be sent to the facility and will be counseled again by the clinician.

There is not a limit to the amount of times a patient can be referred for additional counseling. In some areas, such as Area 25 and Kawale, vitamin flour is distributed to pregnant HIV+ women, lactating mothers (up to six months) and exposed infants once complementary breastfeeding starts. In these cases, the CHW will ensure that the vitamin flour is being utilized. CHWs will also collaborate with HSAs to occasionally distribute ART to clients in the community.

Male Involvement

To increase male involvement, Baylor implemented the use of "Love Letters" from the ANC nurse, inviting the husband to the facility. For couples who attend facility appointment together, they are prioritized

and do not have to wait in long lines. CHWs provide couples counseling and meet male partners during home visits and encourage them to visit the facility.

Tracking Mother-Baby Pairs

In order to easily track mother-baby pairs, the infant is seen at the clinic and the mother provided with CPT at the same time the mother comes for ARV refills. Mother and baby information is registered together in the same master card, which is a parallel system to the mastercards maintained by MOH. If the infant seroconverts, their information is transferred to the infected child register with its own mastercard.

Integration with MOH

Tingathe CHWs work as part of the MOH in facilities and are included in MOH meetings and trainings. Baylor holds monthly meetings for two Tingathe staff from each site (Site Supervisor and Assistant Supervisor). Discussions include M&E, challenges faced, administration issues, and upcoming trainings.

2. Catholic Relief Services – Integrated (HIV effect) Mitigation & Positive Action for Community Transformation

The Integrated (HIV effect) Mitigation and Positive Action for Community Transformation Program (CRS IMPACT) was a four year (2010-2014) 13 million USD PEPFAR-supported initiatives designed to improve the well-being of orphans and vulnerable children and enhance access to treatment and care for PLHIV.¹⁹⁶ As the lead agency of the IMPACT Program, CRS Malawi brought together 12 consortium partners to expand service access and relevance in partnership with the government of Malawi (site HIV Programming Comes of Age doc). This narrative focuses on the HIV treatment and care components of the program, which includes ART and PMTCT supportive services and two main components: expert client support and community outreach.

¹⁹⁵ Nanthuru, supra note 80. See also Kim, et al. The Tingathe programme: a pilot intervention using community health workers to create a continuum of care in the prevention of mother to child transmission of HIV (PMTCT) cascade of care in Malawi.

¹⁹⁶ Chibwana, supra note 81.

Uptake

Expert Clients

As part of their strategy to improve quality of HIV services and increase the uptake of HIV testing and treatment, IMPACT utilized Expert Clients (ECs) in the facility and in the community to support the continuum of HIV care. ECs deployed through IMPACT were HIV-positive men and women who used their own experiences living with HIV to help others overcome the many challenges inherent in an HIV-positive diagnosis.¹⁹⁷ ECs were all recruited through NAPHAM support groups. ECs participated in a five day training where they were trained on a manual developed by the National ART/PMTCT Working Group. Training participants were provided with handouts on each topic in the manual. Refresher trainings were conducted based on the availability of new information.

At least two ECs were assigned to each facility (four were assigned to larger facilities) and each EC typically worked three days per week. The ECs chose the busiest day each week to both work, and on other days worked alone in the facility.

Community Health Days

In order to reach communities located far from a health facility, IMPACT implemented Community Health Days to bring hard-to-reach communities a wide of array of health services, and to refer these populations into facility-based care. The health services provided include HIV testing and counseling; hypertension and tuberculosis screening; growth monitoring, malnutrition screening and immunization updates for children under five; and other services prioritized according to the geographic area.¹⁹⁸ These "one-stop-shops" were staffed by expert clients and MOH facility staff including HTC counselors, nurses and clinicians.

Individuals who tested HIV-positive or those requiring additional care were referred to the nearest health

facility. ECs assisted by giving personal testimonies, conducting health talks, and supporting HTC by giving HIV-positive clients a copy of their referral forms, and collecting referral forms to be filed at the facility.

PLHIV Support Groups

The IMPACT Program actively referred HIV-positive clients to community-based support groups, and by facilitating the formation of support groups. Working with NAPHAM, IMPACT aimed to ensure longitudinal care for HIV clients through these Support Groups. Support Group colleagues coached and mentored one another, offered advice, moral support, and coaching on how to handle relationship issues, health challenges and stigma. Group members reached out to PLHIV in their communities who were not yet members of the group and offered support such as accompaniment to the health facility. Strengthening support group management was a key component of IMPACT's approach, to ensure the meaningful engagement of PLWHIV and clear, informed leadership at all levels of operation.

Love Letters

With the introduction of Option B+, CRS noticed that some women were not returning to the facility for care, had not disclosed their status to their partner, or did not take their ART because they did not feel sick. To encourage uptake of services, the IMPACT program also introduced "love letters," (like the Tingathe Program) in which the ANC nurse requested the husband's presence at the next ANC appointment. While the primary purpose of the letter was to encourage male involvement in ANC and safe delivery, men were also encourage to be tested for HIV and attend counseling as a couple.¹⁹⁹

Women who came to the facility with their partner were prioritized so they experienced shorter waiting times. A baseline study showed that 7% of men accompanied their partners to the facility. In facilities where "love letters" were piloted, 33% of pregnant

women who delivered the letters returned to the facility with their partners. This model was adopted by the MOH in five of IMPACT's nine districts.

Retention

Client flow and reducing waiting times

In facilities, ECs assisted with client flow, which helped to reduce waiting times and improve efficiency. Each day, ECs conducted treatment education sessions for pre-ART patients; checked patient's weight; pulled master cards for expected clients and filed them after each visit; packed medications in preparation for distribution and distributed bed nets, soap, and buckets to antenatal mothers.²⁰⁰ Expert clients also escorted clients to various departments within the facility and triaged patients each morning, selecting sicker patients from the outpatient department and referring them to a clinician before others. Salaried HIV service providers reported a reduction in operating hours in ART and PMTCT clinics after expert clients began assisting with these duties.²⁰¹

Client tracing

At the facility level, ECs assisted with tracing clients who had missed an appointment. Appointments were tracked through a diary by expert clients. They identified missed ART refill appointments and then notified community facilitators, who are their community-based counterparts. Patients with high viral loads were identified by clinicians, and were also traced if an appointment was missed. Community facilitators, who are provided with bicycles, then followed up with clients in the community.

Expert clients referred clients on ART to PLHIV Support Groups and Care Groups. The use of referral forms were reported to be successful by CRS. It was indicated that many people attended support groups after being referred by ECs in the facility and in the community.

Mother-Infant Pair Follow up Using Health Surveillance Assistants (HSAs)

In many hard-to-reach areas, the MOH relies heavily on HSAa to provide information and counselling to HIV-positive mothers. Under the IMPACT Program, HSAs were trained on an MOH developed manual detailing how to follow a woman from pregnancy to when the child is two years old and has graduated the PMTCT program. HSAs conducted home visits in which they encouraged mothers to participate in a variety of services throughout their pregnancy and following delivery. Important messages included attending ANC at least three times, giving birth at the facility, visiting the facility for infant testing at six weeks, 12 months, and 24 months, and practicing exclusive and supplementary breastfeeding. HSAs provided other important health information about immunization, danger signs for infants, and deworming. HSAs were asked to visit each mother infant pair at least twice per month.

As part of the mother-infant pair follow up, IMPACT partnered with D-tree International to develop and pilot a mobile application to support HSAs with the MIP protocol.²⁰² The mobile application gave HSAs step-by-step guidance as they provided follow-up to mothers and their exposed infants during antenatal, postpartum, and postnatal home visits. The application allowed HSAs to track and guide each MIP based on their individual data, and also provided appointment reminders and follow-up reminders to help Community Facilitators with tracing clients in the case of a missed appointment. All of the information put into the application was sent to D-tree for analysis to inform quarterly supportive supervision meetings, and at the ending of the program, all data was been sent to the DHO.

While IMPACT did not conduct a baseline survey to measure retention at the beginning of the program, they compared a 10.8% default rate (provided by the MOH) at one facility in Zomba before ECs were introduced to a 2.8% default rate after ECs began

¹⁹⁷ USAID IMPACT Program. (2014). Expert Clients: Supporting the continuum of HIV care in Malawi. [Hereinafter IMPACT, supra note 197].

¹⁹⁸ IMPACT, supra note 177.

¹⁹⁹ USAID IMPACT Program. (2014). Invite them and they will come: Individualized invitations bring men to antenatal care. [Hereinafter IMPACT, supra note 199].

²⁰⁰ IMPACT, supra note 197.

²⁰¹ Chibwana, supra note 81.

working.²⁰³ Similar results were seen at another facility, where 25 people were reported as defaulters before the introduction of ECs, and zero were reported after.

Adherence

Expert clients used a checklist developed by CRS to counsel pregnant HIV-positive women on adherence to ARVs and CPT. This checklist was also given to the facility and used by other staff. Adherence was measured by pill counting which was done by a nurse at the facility. If the number was incorrect, the nurse would call an EC to do further adherence counseling for that client.

Integration with MOH

Joint supervisory visits with MOH/DHO, facility staff and expert clients were conducted on a quarterly basis. An accountability form which detailed next steps and action items from the visits was used and sent to IMPACT for follow-up.

Other

Prior to implementation of the program, IMPACT sensitized local leaders and Chiefs on the objectives of the program and stigma surrounding PLHIV, the need for testing and timely initiation of treatment. Chiefs in some communities (who were HIV positive themselves) joined the Support Groups and reduced levels of stigma in their communities. Traditional leaders were also encouraged to promote importance of male partners attending facility visits with their wives. One unintended outcome was the development of by-laws and the imposition of penalties for community members who stigmatized PLHIV. Chiefs fined community members a chicken or a goat if they reportedly discriminated against someone living with HIV. The introduction of such by-laws was especially useful in cases of intra-household discrimination between discordant couples or among the relatives of orphaned children.

3. Clinton Health Access Initiative (CHAI) – Mother Infant Pair Clinics

In June 2008, CHAI and the Malawi Ministry of Health developed a proposal to pilot a holistic PMTCT model to provide comprehensive services to women and infants in rural areas with high barriers to quality healthcare services. The CHAI Comprehensive PMTCT Model provides a long-term continuum of services for mothers and infants including: ANC, HTC, ARV/ART, facility delivery, HIV-exposed infant prophylaxis, EID, and confirmatory testing. CHAI implemented these complete PMTCT services in the highly populated, highly HIV-prevalent Machinga District in Southern Malawi.²⁰⁴

CHAI is currently focusing on testing the Mother-Infant Pair Follow-up Clinic Model (described below) in its PRIME study, and is also testing the use of SMS printers and point-of-care testing machines to improve EID testing and results.²⁰⁵

Uptake and Retention

MIP Clinics and the PRIME study

To address the lack of integration across PMTCT cascade services, the MOH and CHAI developed the Mother-Infant Pair (MIP) Follow-up Clinic model. The MIP Clinic is a “one-stop shop” designed to provide HIV-positive women and HIV-exposed infants with all of the services they need to protect the mother’s health and prevent MTCT in one place (site PMTCT Final Report). MIP clinics are integrated horizontally into ANC, labor and delivery, PNC, ART services, routine maternal and pediatric health services, and EID (site PRIME Study doc). At the beginning of the PMTCT Program, a “Project Mentor” who was a Malawian nurse, developed the training package, helped defined how an MIP Clinic would function, and visited each facility and assisted with integrating the PMTCT services. Facilities were “certified” as MIP clinics as they mastered the model.

A typical MIP Clinic visit for a HIV-positive mother and her infant would consist of an education session, often with songs and interaction; a nutritional assessment and under five check-up for the infant; and a supply of ART refills. Both the mother’s and infant’s master cards are kept together and updated when each service is provided. At any point during clinic, expert clients are available to counsel or consult patients who may need assistance.

In order to evaluate the effectiveness and impact of the MIP Clinics, CHAI is partnering with the University of Malawi, College of Medicine, and the MOH to conduct a randomized cluster trial through a project titled Promoting Retention among Infants and Mothers Effectively (PRIME). To evaluate retention throughout the PMTCT cascade of care, the PRIME Project compares the proportion of HIV positive mothers and their infants retained in PMTCT care at 12 months in health facilities implementing the standard of PMTCT care versus those assigned to two new interventions: MIP clinics or MIP clinics plus SMS-based tracing of mother-infant pairs who do not return for care at their scheduled appointment times. The SMS-based tracing is described in more detail in the next section. The PRIME Project aims to enroll nearly 1,950 HIV positive pregnant women attending ANC in 30 health facilities in Mangochi and Salima. Follow up for these MIPs should continue through 24 months post-partum.

Expert Clients Peer Support Initiative

Expert clients have been used by CHAI since 2009, in order to provide counseling, psychosocial support, and assistance navigating and accessing care, with the intention of improving referral linkages and increase the enrollment of HIV-positive pregnant women, HIV-exposed infants, and HIV-positive children in care and treatment.²⁰⁶ CHAI’s expert clients worked full-time and were provided stipends of about 50 USD per month. Expert clients were placed at different clinics (ART, under 5, MIP) depending on

the services provided each day. They also worked informally in their own communities, where they are often sought out for advice and counselling.

Intensified Patient Follow-Up Systems

At the beginning of the program in 2009, CHAI implemented a paper-based system to follow up HIV-positive patients who had missed an appointment or needed to return to the facility to receive test results. Existing CHWs were used to identify, contact, and reintegrate patients. CHWs were trained on how to use “Tracer Cards” which indicated whether the patient was found and returning, found and not returning, not found, transferred/moved, or deceased.

While the Tracer Cards introduced a functional tracking system where one did not exist before, CHAI recognized the need for a more simplified process that would not overburden CHWs and HSAs. In 2010, a revised tracing procedure using Frontline SMS software was piloted in four of the highest-volume health facilities. At the pilot sites, the follow-up person at the facility used a laptop with Frontline SMS software to send a SMS message to the CHW in the village where the patient lived. The CHW then found the patient and sent the outcome of the visit back to the facility Frontline SMS laptop via SMS text message. CHAI hypothesized that by eliminating a step in the process, turn-around times and patient outcomes would improve. In the end, the expected differences in the Tracer Cards and the Frontline SMS patient follow-up were not observed, although both achieved moderate reintegration rates, with around 40% of patients returned for care within an average of one month.

In 2013, CHAI migrated its follow-up system from Frontline SMS to Rapid SMS, which is the system being tested under the PRIME study.²⁰⁷ In similar fashion, a nurse sends a coded message to a free number which is then forwarded to a CHW associated with that client’s home area. The CHW makes the visit and

²⁰³ IMPACT, supra note 82.

²⁰⁵ Churchman-Kobayashi, supra note 85.

²⁰⁴ Clinton Health Access Initiative. (2011). Machinga District, Malawi- Prevention of Mother-to-Child Transmission of HIV: Final Programme Report. [Hereinafter CHAI, supra note 197].

²⁰⁶ CHAI, supra note 197.

²⁰⁷ Churchman-Kobayashi, supra note 85.

sends back a code that explains what is happening with the client. All text messages travel through a hub located in the Mangochi District Hospital where HMIS experts forward the messages appropriately. Tracing is done for mothers who are enrolled in the MIP clinic with a baby 10 weeks or older.

4. Comunita di Sant'Egidio – DREAM

In 2006, the Comunita di Sant'Egidio began the Drug Resource Enhancement against AIDS and Malnutrition Program (DREAM) program with funding from CHAI, Project Malawi, and Norwegian Aid.²⁰⁸ DREAM Centres were the first establishments to initiate the roll out of Option B+ in Malawi and currently have Centres in Blantyre, Machinjiri, and Chileka. In a number of other facilities, DREAM offers EID services.

The DREAM Centre in Blantyre contains a laboratory that is able to do PCR, CD4 and viral load testing. All DREAM patients undergo baseline viral load tests once per year, and for children, every six months. DREAM processes viral load testing for MOH facilities throughout Blantyre district.

Uptake

Activists

To assist with uptake of services, DREAM trains volunteers to act as expert clients called activists at the facility level and in the community. Activists based in the community come to the centre once a week and are provided with funds for transport, but are not paid a salary or stipend. Activists are trained in general MNCH issues including breastfeeding practices, infection detection, nutrition, and hygiene.

At the facility level, activists are the first ones to see patients as they enter the clinic each morning. Activists conduct group education sessions on a wide range of topics including adherence, HIV testing, hygiene, and nutrition. If a number of patients request or need counseling on a certain topic, the

activist will focus on that subject. Activists will often hold one-on-one sessions following the group education for those who need further clarification or support. During these discussions, activists may use MOH tools such as the MOH adherence chart, which helps guide discussions. After group education, each patient is seen by a clinician and then often referred to a DREAM counselor if necessary.

Clinicians provide pre- and post-test counseling to patients. As a well-resourced program, clinicians are able to spend a significant amount of time with each patient and provide in-depth information and guidance to HIV-positive patients. For newly diagnosed HIV-positive women, if the partner has not been tested, the clinician discusses different tactics the woman can use to encourage her partner to come to the clinic with her and get tested. DREAM endeavors to reinforce messaging at all points of contact with the patient. So after meeting with the clinician, the patient also meets with a counselor and has the option of interacting with activists as well. DREAM reported that there has been an increase in the number of men attending clinics with their partners for ANC. However they noted that men will often complain that messages delivered at ANC are aimed at women only, as opposed to men as fathers or as parents together.

Retention

Client tracing

DREAM uses a computerized system where patient information is gathered and stored. Clinicians and counselors collect various types of information from clients including information on their household and family context, so that individual situations and challenges are documented and used to inform guidance provided to patients. DREAM checks who came for their appointments and who did not on a daily basis.

Activists are responsible for following up on missed appointments. If the client provided a phone number, the activists will call and follow up as a first attempt. If no phone number was provided or the client was not reached via phone, activists will conduct a home visit and report back to the facility. Return to care is tracked through DREAM's computerized system.

Household visits

At the community level, activists visit patients in their homes for home care. Activists may help mothers with cooking, cleaning and other domestic support if they are feeling unwell. Each time a home care visit is made, the activist prepares a report that is given to the facility. DREAM holds monthly meetings with the activists to check in and discuss any issues or challenges. Activists also submit the data they have collected over the past month and review it against what is recorded in the database.

Dream reports a 95% retention rate at 24 months after birth, and attributes this to the high quality of care and time invested in each client.²⁰⁹

Adherence

DREAM measures adherence amongst their patients using pill counts. Each patient's adherence is tracked in the electronic system. Clinicians refer patients to one of the counselors and group sessions held by activists for additional support if they are struggling to adhere to treatment. DREAM reports a 90% adherence rate at their clinics.

EID

The National AIDS Commission funds an EID project in 21 facilities, implemented by DREAM. Once a week, a DREAM driver collects specimens from each facility and delivers them to the DREAM facility for testing. The following week, a driver brings the results to each facility. A logbook is used to track who submitted specimens and if the results have been received. For children who test positive, DREAM calls the facility to inform them of the positive PCR

result for that patient so that they can prioritize these cases. Staff must report on a monthly basis on the number of DBS results they received, the number of positive and negative, and the number reported to the parent or guardian. The logbook is a paper-based system, and DREAM has reported challenges with its staff transferring children from ART registers to the logbook for follow-up.

5. Dignitas – ART/PMTCT Program

Dignitas International's ART/PMTCT Program began operating in the Southeast Zone of Malawi in 2004.²¹⁰ Dignitas is currently working in 20 facilities and plans to scale up to 40 facilities in the near future. Many of the facilities where Dignitas works are considered "priority facilities," meaning they have a high volume of patients, are geographically hard to reach, or are short staffed and lacking adequate resources. While Dignitas provides direct care in certain sites, they focus on mentorship and systems strengthening with MOH staff in the majority of facilities where they work. In the future, Dignitas aims to address challenges associated with retention and follow up of mothers on ART.

Expert Clients

Dignitas currently has 28 expert clients in three sites: two of which are run by the MOH, and one which is run by the Christian Health Association of Malawi. In August 2014, Dignitas employed an additional 46 expert clients who formerly worked on the IMPACT Program, which ended in August. The 28 initial expert clients employed by Dignitas were recruited by the In-Charge at facilities, and are clients who have successfully completed the PMTCT program.

In the facility, expert clients support nurses by triaging waiting patients, taking their height and weight, and escorting patients from one place to another. Expert clients also conduct one-on-one education sessions with clients and assist nurses with post-test counseling. Expert clients are trained on the basics of

²⁰⁸ Hawamamary, supra note 122.

²⁰⁹ Hawamamary, supra note 122.

²¹⁰ Manyera & Mateyu, supra note 170.

HIV and PMTCT, effective communication methods, and are instructed on how to conduct group and one-on-one education sessions and counseling. Dignitas expert clients are required to work four days per week from 8:00 am to 1:00 pm, although many work more as they feel invested and want to share their knowledge.

Uptake

To promote the uptake of PMTCT care, expert clients conduct general health education sessions and HIV testing and counseling sessions. A focus is placed on reaching Option B+ women during ANC. Key messaging provided by expert clients focus on three elements: 1) prevention of vertical transmission, 2) lifelong treatment and the health promotion for the woman herself, and 3) protection from transmission for her partner.

Encouraging women to come to the clinic with their partners is another way ECs promote uptake of services. The male partners tell their friends about this prioritization and more males accompany their partner to the clinic. While "love letters" are also used by Dignitas, the program also works with local chiefs to enforce male participation in ANC. Women whose partners are unable or unwilling to attend ANC obtain a letter from their chief which they bring with them to the facility. This system is meant to create accountability to the chief for men in the community. Women with male partners or with letters from their chiefs are prioritized in the line.

Retention

Dignitas works with ART clinics and HSAs to trace missed ART appointments and defaulters, though not antenatal and postnatal appointments unrelated to ART. For missed appointments, ECs use a diary to track appointments and generate a tracing list of clients who missed appointments by two weeks. This list, which includes the name of the client, phone number (if provided) and address, is given to an HSA for tracing. Patients are considered defaulters if they have not returned to the facility for care for two months. ART clerks use clinic books and client master cards to create a list of patients who have defaulted. This list is also given to an

HSA for tracing. Each time HSAs trace clients, they document outcomes of the visit for the expert clients and facility staff. Health facility staff often follow-up with the HSAs to ensure they are tracing the missed appointments and defaulters.

Adherence

Clinicians provide adherence counseling at ANC. Clients who need additional support are referred to an expert client for additional counseling. Expert clients are trained on how to use the MOH Adherence Chart, and use this tool to guide their interactions. Clinicians monitor adherence using pill counts at the ART clinic.

Other

On a quarterly basis, MOH facility staff and expert clients meet to review and discuss various indicators that look at broad areas such as ART, PMTCT and HTC. When Dignitas initially rolls out their program in a facility, they conduct mentoring/supportive supervision once a week until the facility is "graduated." After that point, supportive supervision is done on a monthly basis. During supervision, mentees complete a self-assessment in which they document the areas they are confident in and the areas they are not. Mentors then focus on developing knowledge and skills in the areas the mentee is not as comfortable with. One challenge Dignitas faces is the high turnover of staff in facilities.

In the past, Dignitas collaborated with facility staff to setup mother-baby pair clinics in select sites. When the ART/PMTCT guidelines changed, this clinic was removed in order to adhere to the guidelines. Currently Dignitas concentrates on mentoring staff on how to conduct care for exposed infants after birth.

For EID, Dignitas mentors facility staff on the care that HIV-exposed infants should receive. This includes an emphasis on registering HIV-exposed infants into care, provision of nevirapine and CPT, conducting a DBS at six weeks, and rapid tests at 12 and 24 months. When there are no DBS supplies, Dignitas liaises with the DHO to get supplies and often provides transportation in order for the supplies to reach the facilities.

6. Lighthouse Trust

Lighthouse Trust is an organization providing HIV treatment, testing and home based care for patients at two main sites in Lilongwe, Kamuzu Hospital and Bwaila Hospital.²¹¹ Lighthouse has counselors in 25 rural health facilities in Lilongwe, and provides broader mentoring in urban health centres such as Area 18, Area 25, and Kawale Health Centres. At the Lighthouse facility itself, patients are not coming specifically for PMTCT, rather general HIV care and treatment is provided for men and women of all ages.

Uptake

Lighthouse is integrated within the maternity/family health unit at Bwaila and Kamuzu Hospitals. After implementation of Option B+, all HIV-positive women begin initiation on treatment on the day they are tested, and at that point they become part of the Lighthouse cohort which provides ART to these clients. For exposed children, after one year of care at Bwaila, they are transferred back to the Lighthouse cohort. In some government sites, while every woman attending ANC is tested, there is not a designated employee who does HTC as part of their daily job. Lighthouse fills this gap by providing counselors who do HTC every day. The messaging delivered to HIV-positive mothers focuses on the benefits of long term care for herself, not just the well-being of the infant.

Retention

Lighthouse traces women who have possibly defaulted through an intervention called, "Back to Care." Using the electronic Baobab system, the M&E team generates a list of clients who need to be traced every two months. Patients are traced 21 days after the day they would have needed more pills. If the patient consented to being followed up, their phone number and location are on file. Phone calls to the patient are made initially, and if they are not reached, Lighthouse employees called tracers conduct home visits. Tracers use motorcycles to find clients and have the capacity to do basic counseling, ask why

the client did not return for care, and ask the client to return to the facility. Lighthouse currently employs five tracers who are full time, salaried employees. Lighthouse also utilizes volunteers from their home-based program to assist with tracing clients. With 400 volunteers who convene support groups in their communities, these individuals can help trace clients who have potentially defaulted. Women who receive care at Bwaila are also traced through Back to Care. Each patient can be traced a maximum of three times, regardless of the outcome of the tracing.

Adherence

Before starting treatment, each patient goes through an ART initiation session with a nurse or HTC counselor. The MOH adherence flipchart is used during these sessions. A second ART session is conducted after the client has been in care for six months. At this point, clients can be moved to two month supply refills.

Lighthouse encourages patients to come to the clinic with a guardian for additional support. Oftentimes the guardian is a family member or close friend who can also learn about the importance of adherence and assist the client with caring for themselves properly. Lighthouse uses pill counting, and adherence rates are calculated in the Baobab system. While there are some issues of people throwing away pills or leaving them at home, Lighthouse hopes that given the quality of the counseling and education, patients will not feel the need to cheat.

7. Médecins Sans Frontières Belgium – PMTCT Option B+ Program

MSF collaborates with the Ministry of Health in improving HIV care management in the 14 Health Facilities of Nsanje District. One of its interventions is the "PMTCT B+ Program" which operates through capacity building, mentorship and supportive supervision of integrated services in each health facility. The areas of attention are ANC, PNC, Maternity, under 5 years old on ART, record keeping and documentation for EID. MSF started to conduct

²¹¹ Chaweza, supra note 169.

“PMTCT cascade analysis meetings” to address the high rate of LTFU by identifying the gaps along the cascade of care together with MOH and by developing interventions.²¹² This “cascade analysis” has been initially piloted in two health facilities, Tengani Health Centre, and Trinity Hospital, and is now scaling up to others where the rate of LTFU is high.

Uptake

MSF works hand-in-hand with MCH nurses, HTC counsellors and clinicians in the 14 facilities where they run the Option B+ Program. Nurses are mentored on how to conduct health education talks on various topics and post-test and adherence counseling for HIV-positive clients. In particular, HTC Counselors are mentored on the provision of quality HIV testing and counseling during ANC visits. MSF’s program reorganizes client flow in each facility in order to create an MCH care-point for women and their babies. The mother’s and babies’ master cards are kept together at the MCH care point, which enables pairs to be tracked. This also supports uptake of EID, as nurses check master cards at this care point each time a mother and/or infant visits, and check to see if the baby is due for HTC.

MSF reported challenges with the uptake of Option B+ due to disclosure issues, women not wanting to be started on ART for life when they do not feel sick, low uptake of exposed babies being identified and referred for DBS at six weeks, lack of male and community involvement, and cultural beliefs. In addition to improving client flow, MSF is focusing on integrating Option B+ messaging during all health talks – not just those focusing on PMTCT. The goal is to increase women’s exposure to Option B+ messaging even prior to pregnancy so that they will be more receptive and knowledgeable by the time they enter antenatal care.

Retention

MSF staff implemented the use of a diary at the MCH care point track missed appointments. Clients’ names, phone numbers, and addresses are collected and recorded on the mastercard. If a client misses an appointment, a star is put next to her name in

the diary, and a list is developed for HSAs to trace. MSF encounters various difficulties tracing missed appointments including transportation for HSAs, who do not have bicycles. In addition, many clients come from across the border in Mozambique, who are unable to be traced.

Adherence

Group counseling on adherence is conducted by MMs or nurses following testing. Adherence counseling is also offered to clients when they return to the facility for their refills every month.

Other

MSF conducts monthly supportive supervision meetings with MOH facility staff to review progress against key uptake and retention indicators, discuss challenges and plan solutions. The program coordinates with the MOH at various levels including Coordinators at the district level and monthly PMTCT meetings with District Health Management Teams. Program staff also meets with SSDI on a monthly basis. Ideally, MOH staff, most likely the District Coordinator, will take over the supportive supervision when the program ends in five years.

Challenges faced by the MSF Option B+ program include high turnover of staff, lack of training, orientation and/or motivation of facility staff, lack of B+ training for HSAs, counselors and nurses, and facility staff’s difficulty to task shift. The lack of up-to-date PMTCT IEC materials, stock ruptures, poor documentation and record keeping and partial or poor counseling at ANC visits were also identified as constraints faced by the program.

8. mothers2mothers Malawi

mothers2mothers Malawi launched in 2008, and uses the mentor mother model to provide psychosocial support and education to HIV-pregnant women and new mothers on PMTCT. MMs are mothers living with HIV who are trained, employed and empowered to work alongside doctors and nurses in understaffed health centres as paid members of the healthcare team. MMs share first-hand knowledge and experience through one-on-one and group education sessions with women at the facility. m2m

also has a community cadre of MMs who interact with clients in the community. MMs and CMMs are rigorously trained and paid stipends, with the facility cadre working full-time and community cadre working three days a week.

Uptake

MMs at facilities provide group health talks and one-on-one education to women in antenatal facilities to promote uptake of services. CMMs are deployed to communities within the catchment areas for facilities in which m2m provides services. The community cadre goes door-to-door and conducts community health talks to identify new clients, provide education and support, and link women to facility-based care. CMMs and MMs reinforce messaging to couples at the facility and within the household setting to promote the understanding of reproductive choices, family planning methods, and dual protection. m2m also refers partners and wider family members to facilities for HTC.

Retention

m2m’s traces women who miss key appointments in the PMTCT cascade and follows them through phone calls and home visits to encourage their return to care. Where a community cadre is deployed, Community MMs work hand-in-hand with MMs at the facility to identify, track and engage clients. Where there is no community cadre, MMs dedicate time each week to trace clients. Staff members are given bicycles, but given to staffing constraints, the m2m limits tracing activities to a 5km radius. To trace clients beyond this radius, m2m coordinates with HSAs and other tracing cadres. At present, m2m traces clients who have missed their 2nd antenatal visit, the six week infant visit including tests, prophylaxis and immunizations, and tests and results at 12 and 24 months.

In 2015, m2m will add ART refills to the list of appointments for tracing. Where CMMs are deployed, m2m will switch to a proactive approach to prevent client drop-out from care for the six weeks and 12

and 24 month tests and results, and to ensure infant ART initiation.

CMMs also engage traditional leaders to increase buy-in and support for PMTCT and RMNCH services, and to reduce stigma and discrimination in the community. Formal linkages are developed through orientation and sensitization workshops and periodic feedback sessions with traditional leaders. Community health talks are organized in consultation with traditional leaders as well.

Adherence

m2m Malawi currently supports adherence through group and one-on-one education and support. The organization is currently preparing to enhance its offerings to support adherence.

Other

m2m engages site staff in quarterly Let’s SOAR (Strengthening Outcomes by Analyzing Results) sessions to both improve the quality of services delivered to clients and improve data quality. SOAR is a continuous program quality improvement methodology designed to build m2m staff capacity to collect, analyze and use data for evidence-informed decision making at the site level. SOAR utilizes a statistically robust sampling methodology that is simple, quick, and manual and enables site staff to review logbook data about client outcomes on a quarterly basis. MOH facility staff members are invited to participate in this program, and are engaged in problem-solving.

m2m provides care and support over an enhanced continuum of RMNH care to HIV-positive and HIV-negative women and their families through its Enhanced Program Model. Under the Enhanced Program, MMs provide education on neonatal male circumcision and referral; tuberculosis pre-screening and education; nutrition support and mid-upper arm circumference measurement; and cervical cancer education and referral.

9. National Association for People Living with HIV and AIDS in Malawi (NAPHAM)

NAPHAM is a non-government organization in Malawi that works to promote positive living for people living with HIV, and to promote quality care and support.²¹³ NAPHAM was created in 1993 and currently operates in all 28 districts throughout the country. One of the most important aspects of NAPHAM is the support groups developed for PLWHIV. There are currently over 1,500 support groups, with over 100 in some larger districts such as Lilongwe. Support groups' affiliation with NAPHAM is on a voluntary basis.

Support groups usually meet on a weekly basis, either at the facility or in the community, as determined by the group members. Each support group has a facilitator who acts as the leader of the group. Members share knowledge and experience and provide emotional support to one another. For example, group members will share their experiences with handling disclosure or negotiating condom use for other members' benefit. Newer group members gain information and grow confidence to overcome challenges they face. Group members also encourage one another to adhere to their drug regimens, and remind each other to return to the facility for appointments and ART refills. Some support groups even organize themselves to take turns collecting refills for other each other, in order to save time they would otherwise have spent waiting in life for their medicines.

NAPHAM encourages capacity building with Village Heads in their model, which in many areas has resulted in chiefs joining the support themselves. Support groups also conduct community outreach activities where they do activities such as distributing condoms, spreading HIV prevention and family planning messages, and implement advocacy activities to challenge stigma and discrimination.

When a new support group is formed, ideally NAPHAM provides training and resources. This is often a challenge due to lack of resources. Currently,

around one third of support groups have been trained on a manual (developed in partnership with World Vision) that provides guidance on group dynamics, issues faced by PLWHIV, counseling strategies, PMTCT, and nutrition practices. Each support group uses their own resources to operate. Some groups have created their own or joined existing Village Savings and Loan groups.

Around 70% of support group member are women. Male involvement is a challenge and many men are wary to join. Bridge Two Project run by John Hopkins University implemented the Hope Kit Model and Positive Prevention which both assist with outreach to men. The Hope Kit Model focuses on primary prevention for both positive and negative community members. Some support groups use "love letters" to invite men to attend and others try to plan activities such as ambush theatre and community talks, which NAPHAM finds to be more appealing to men. NAPHAM is considering the addition of economic activities within the SGs to further encourage men to participate.

Retention

NAPHAM connects with HSAs, ECs, and health promoters to help trace defaulters. As support groups are well-connected in communities and are well-trusted by many PLWHIV, they provide those doing defaulter tracing an easy way to locate a defaulted client.

Adherence

Support groups encourage each other to take drugs, get refills each month, and eat nutritiously to stay healthy. Support group facilitators are trained on adherence and members provide ongoing support, encouragement each week, and reminders about adherence.

Other

Currently, NAPHAM support groups focus on adults living with HIV. NAPHAM recognizes the need to involve children and youth in the National response to HIV/AIDS, and wants to implement interventions to target youth.

Bridge Two Project is currently developing a tool kit to assist with pediatric case finding. The toolkit is being piloted in two districts, Chiradzulu and Thiokol. The seven modules in the toolkit provide guidance on how to follow up with parents of an HIV+ child. Once the toolkit is finalized, NAPHAM will train SG facilitators who will utilize the toolkit in their communities.

NAPHAM first began working with expert clients through a partnership with CRS and the IMPACT program. Expert clients use existing NAPHAM structures to counsel clients and follow up with patients in the community. Expert clients refer clients to NAPHAM support groups, and vice versa. NAPHAM has recently identified a gap in PMTCT at the community level and would like to begin focusing on increasing PMTCT uptake and to increase community awareness and uptake of family planning methods.

10. Partners in Health

PIH began working in partnership with Malawi's MOH in the rural Neno district in 2007.²¹⁴ PIH aims to provide comprehensive, community-based care to the 125,000 people living in Neno district. During its first three years, PIH completed construction of Neno District Hospital and a community hospital in Lisungwi, which is located in an area severely burdened by the AIDS epidemic. The project also supports 11 community health centers throughout the district. The Neno Community Support Initiative, described in more detail below, boasts more than 2,500 members and provides ongoing health education and community building for people living with HIV/AIDS. This support and sense of community is particularly important in Malawi, where HIV continues to be highly stigmatized.

Uptake

PIH uses expert patients to enhance the impact of their HIV program. Each expert patient, who has personal experience with PMTCT, is assigned to defaulted pregnant women. She visits the pregnant

women who default for counseling. The use of expert patients is an addition to the existing PIH village health worker (VHW) program.

PIH employs 820 VHWs in Neno District. VHWs are paid employees located in each village throughout the district. All HIV-positive patients are assigned to a VHW in their village. VHW job duties include visiting HIV-positive patients on a daily basis, conducting health education sessions for the community, and acting as a link between households and the health system. Each health center has a VHW supervisor responsible for the VHWs in that catchment area.

Retention

PIH uses an electronic medical record which produces an automated report every two weeks for missed visits. This is cross-checked and confirmed with a clinic register and patient mastercards. The missing clients are first visited by their assigned VHW. If the VHW is not successful in returning the patient to care, a specialized ART clinic based team then attempts to visit the patient. If this is not successful, the clinicians then become involved to help bring the patient back to care. The number of patients LTFU and those successful returned to care is discussed at biweekly meetings.

PMTCT clients are included in the VHWs daily visits to HIV-positive patients. VHWs are informed if a patient is missing from care, and act as the first step in tracking the potentially defaulted patient, as described above. In addition, PIH is implementing a new initiative which uses VHWs specifically trained in maternal health. Their job will be to accompany pregnant women (both HIV-positive and negative) to ANC, facility-based delivery, and postnatal visits. PMTCT services will be integrated into this program.

Integration

In Neno District, PMTCT services are fully integrated into ANC clinics. This is facilitated by the MOH with support from PIH. After delivery, the baby is enrolled in the EID program which is integrated into the ART clinic. Mothers to exposed infants receive food

²¹³ Mphande, supra note 180.

²¹⁴ Partners in Health. 2014. Retrieved from: <http://www.pih.org/country/malawi/about>.

packages three months pre-partum and six months postpartum. The exposed infant receives food packages from six months up to 24 months, which helps ensure 24 month follow up for HIV rapid test for all exposed infants.

PIH and the MOH have one common register for all DNA PCR tests. Once results are received, they are communicated by telephone and paper records to the appropriate facility.

Other

Neno has a broad-based community programs team responsible for community outreach events, liaising with community groups, and holding bimonthly large-scale support events for patients with HIV. Several community events are accompanied with an HTC counselor for community-based testing. In addition, there are integrated maternal health outreach clinics staffed by a community nurse-midwife for distant areas where women can attend ANC. HTC counselors are also included in the maternal health outreach clinics.²¹⁵

11. Tearfund – Improving Parent and Child Outcomes (Tearfund IMPACT)

Through the Irish Aid-funded IMPACT Program, Tearfund's PMTCT activities aim to: reduce mother to child transmission of HIV; reduce maternal and child mortality; and promote male involvement in PMTCT.²¹⁶ Beginning in November 2011, Tearfund, in collaboration with the Evangelical Association of Malawi (EAM), piloted their PMTCT program in two districts in the Southern Region of Malawi, Balaka and Chiradzulu. Tearfund works with churches, traditional leaders, the Ministry of Health (MOH), Ministry of Education (MOE), and Ministry of Local Government to prevent mother to child transmission of HIV. Tearfund's PMTCT program uses "Mother Buddies" and Prevention of Parent to Child Transmission (PPTCT) Facilitators to reach out to pregnant women in communities who may be in need of PMTCT care. With five Mother Buddies in Balaka and five in Chiradzulu, Tearfund aims to reach 3,500 and 4,000

pregnant women, respectively through their PMTCT activities under the Tearfund IMPACT Program.

As an overarching strategy, Tearfund works mainly with church-based partners. Tearfund IMPACT was implemented by two partners. In addition to EAM, which is described in this section, Tearfund also partnered with Livingstonia Synod AIDS Programme (LISAP) which worked in northern Malawi.

Uptake

Mother Buddies

Tearfund's Mother Buddies are expert clients who are trained in basic maternal health and deployed at the community level to promote uptake of PMTCT services and provide psychosocial support to HIV-positive pregnant women. Mother Buddies work five days per week, befriending the women they work with and building trust by sharing their own experiences living with HIV. On average, Mother Buddies visit their clients three times before delivery to encourage early uptake of ANC and four times after delivery (24 hours after delivery, six weeks, 12 months, and 24 months). If a male partner is present during a home visit, Mother Buddies encourage the partner to accompany his wife to appointments and emphasize the importance of partner involvement at all stages of pregnancy. Many clinics in Balaka and Chiradzulu prioritize couples who come together for care, allowing them to skip the long queues and see a clinician before women who have come by themselves.

Prevention of Parent to Child Transmission (PPTCT) Facilitators

In an effort to improve early presentation of pregnancy at the facility, Tearfund trained volunteer church and community members serve as PPTCT Facilitators. These facilitators visit pregnant women and their families in the community to provide education on prevention, HTC accessing treatment, and the importance of going to ANC early in pregnancy. PPTCT Facilitators conduct outreach at churches to encourage couples to visit the facility together for

testing and conduct community outreach talks on MNCH issues. An important aspect of the PPTCT Facilitators work involves engaging village chiefs in order to sensitize the community and share information surrounding safe pregnancy and PMTCT practices.

PPTCT Facilitators are trained on the Guardians of Our Children's Health (GOOCH) Toolkit which helps clients understand how HIV can be transmitted from parent to child and builds the knowledge and skills of both parents in order to reduce the risk of HIV transmission to their child. The training kit encourages men to become actively involved in the health of their families and to get tested for HIV. Issues such as stigma and discrimination are addressed, and a "Positive Living" approach is introduced within the context of the local church congregation. The GOOCH manual also uses excerpts from the Bible to underscore messaging on non-discrimination, compassion for PLWHIV, and to encourage the use of family planning methods. The soft bag toolkit contains: Activity manual including handouts, Positive Health information book, 10 picture cards, 16 activity cards, 2 packs of condoms and a plastic penis.²¹⁷

In addition to the GOOCH manual, Tearfund developed a Family Planning Manual which was also used by Mother Buddies and PPTCT Facilitators in churches and the community. The Family Planning Manual targets married couples and used theological approaches to various areas of family planning, such as the importance of couple testing and couples ANC visits.

Together with local churches, the program organized HTC drives held in the community or on the church premises. HTC was conducted by nurses and other MOH HTC counselors, and church leaders encouraged congregation members to be tested. EAM reported that this approach increased the number of couples who tested and the number of men who attended ANC with their partners. While some couples preferred to go to mobile HTC

facilities outside of their communities, so as to not be seen by their peers, the involvement of church and community leaders encouraged others to access services in their own community.

Retention

Mother Buddy Follow-up and Client Tracing

Each Mother Buddies uses an Android phone equipped with easily accessible maternal and child health information and an app that helps them track clients. The tracking app is provided through PoiMapper, which allows Mother Buddies to collect patient information and transfer the data to the database at the health facility. A nurse at each facility also has an Android phone with the app, so that if a mother buddy calls the nurse for assistance, the nurse is able to access the patient information in real time. PoiMapper auto populates the dates of client's next visits, and reminds Mother Buddies when a client is due to visit the facility. Each phone is password protected in order to protect client confidentiality. Using the mobile application, Mother Buddies track clients based on missed appointments. Tracing is typically done through phone calls, but for clients who do not have a phone, they can be followed up with a home visit if they consented and provided an address. Nurses with access to the mobile application at the clinic can also remind the Mother Buddies to follow up with a client, or they can call the clients themselves.

Care groups

In addition to household visits, each mother buddy creates five care groups that meet once per week with pregnant women in the community. During care group meetings, the women discuss maternal health issues, share their experiences and challenges, and talk about how they can help each other as a community. Churches in the community often provide funding for mothers to cook nutritious porridge during the care groups. Mother Buddies report how many clients they have identified through the care groups, and then reach out to clients separately for one-on-one discussions.

²¹⁵ Wroe, supra note 87.

²¹⁶ Dzama, supra note 84.

²¹⁷ Tearfund, supra note 105.

Adherence

Tearfund identified access and treatment as one of the five key result areas they aim to impact. Mother Buddies educate women on accessing ART and emphasize the importance of proper ART adherence.

Other

Tearfund works to strengthen the linkages between community churches, the MOH, DHTs, traditional leaders, and other stakeholders in the community. A critical piece of their PMTCT approach involves collaboration between all partners. Under the IMPACT Program, Mother Buddies, coordinators at catchment levels, community leaders, HSAs, and

MOH facility staff meet once a month to share challenges and successes, identify gaps, and discuss how to bridge these gaps. Monthly meetings are led by clinicians or nurses at the facility. Tearfund reports that facility staff has become invested in this process and understand the importance of providing updated information and collaborating across organizations.

With the Tearfund IMPACT program ending, Tearfund is hopeful that much of their work will continue with assistance from local churches. Certain activities, such as PPTCT facilitators and church-led mobilization, are continuing on their own. Tearfund would also like to see the MOH employ some of the Mother Buddies within their system.



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