



# **COMMUNITY-FACILITY LINKAGES** TO SUPPORT THE SCALE UP OF LIFELONG TREATMENT FOR PREGNANT AND BREASTFEEDING WOMEN LIVING WITH HIV

A conceptual framework, compendium of promising practices  
and key operational considerations

June 2015



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## ABBREVIATIONS AND ACRONYMS

<b>AIDS</b>	Acquired immune deficiency syndrome
<b>ANC</b>	Antenatal care
<b>ART</b>	Antiretroviral therapy
<b>ARV</b>	Antiretroviral (drug)
<b>CBO</b>	Community-based organization
<b>CD4 COUNT</b>	Laboratory test measuring the number of CD4 cells in a blood sample
<b>CHW</b>	Community health worker
<b>DRC</b>	Democratic Republic of the Congo
<b>EID</b>	Early infant diagnosis
<b>EMTCT</b>	Elimination of mother-to-child transmission (of HIV)
<b>FBO</b>	Faith-based organization
<b>GIPA</b>	Greater involvement of people living with AIDS
<b>HCT</b>	HIV counselling and testing
<b>HIV</b>	Human immunodeficiency virus
<b>IAPAC</b>	International Association of Physicians in AIDS Care
<b>IAS</b>	International AIDS Society
<b>IATT</b>	Inter-Agency Task Team
<b>ICCM</b>	Integrated community case management
<b>LTFU</b>	Loss to follow-up
<b>MHEALTH</b>	Mobile health (technology)
<b>MNCH</b>	Maternal, newborn and child health
<b>MSF</b>	Médecins Sans Frontières
<b>NGO</b>	Non-governmental organization
<b>NSA</b>	Network support agent
<b>OHTA</b>	Optimising HIV Treatment Access (for pregnant and breastfeeding women)
<b>PLHIV</b>	People living with HIV
<b>PMTCT</b>	Prevention of mother-to-child transmission (of HIV)
<b>SMS</b>	Short message service
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNICEF</b>	United Nations Children's Fund
<b>USAID</b>	United States Agency for International Development
<b>WHO</b>	World Health Organization

This paper was commissioned by UNICEF through the Optimizing HIV Treatment Access (OHTA) Initiative to help strengthen community-facility linkages in support of lifelong antiretroviral therapy (ART) for pregnant and breastfeeding women living with HIV. It offers a conceptual framework and describes eleven promising practices associated with increased service uptake, adherence or retention along the continuum of care. Key operational considerations for country teams to define and roll out an effective, locally appropriate package of community-facility linkages are also recommended.

The eleven promising practices were identified through a literature review of prevention of mother-to-child transmission of HIV (PMTCT); adult ART; maternal, newborn and child health (MNCH); field visits and stakeholder consultations

The practices are grouped under four domains of support for mother-infant pairs.

**DOMAIN 1 EMPOWER CLIENTS:** individual client support, participatory women's groups and targeted food assistance are recommended.

**DOMAIN 2 PROVIDE LONGITUDINAL FOLLOW-UP OF MOTHER-INFANT PAIRS:** community case management, mHealth technology and active outreach are recommended.

**DOMAIN 3 IMPROVE THE CARE SEEKING ENVIRONMENT:** positive male involvement and the purposeful engagement of community leaders are recommended.

**DOMAIN 4 FACILITATE ACCESS:** the engagement of existing local organizations, community-based HIV counselling and testing (HCT) and community ART distribution are recommended.

The key operational considerations address planning, implementation and monitoring of a national package of community-facility linkages to support scale-up of PMTCT and broader health initiatives. Important cross-cutting recommendations include: engage all relevant stakeholders; strengthen community health cadres; build on existing community initiatives; ensure quality of community-level health communication and services; increase accountability of facilities and communities; and enhance local capacity for scale-up of community-facility linkages.

### Background

Nearly four years have passed since the June 2011 launch of the *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive*.<sup>1</sup> Since that time, admirable progress has been made in reducing the number of new HIV infections in children, especially in the 21 Global Plan priority countries in sub-Saharan Africa. However, despite the progress and momentum, rates of HIV transmission to children remain unacceptably high with considerable work ahead to achieve the elimination goals.

By 2015, the Global Plan aims to reduce the number of new HIV infections among children by 90 per cent. Between 2009 and 2013, new paediatric infections in the 21 priority countries in sub-Saharan Africa declined by 43 per cent—from 350,000 to 199,000. Of these countries, UNAIDS estimates that eight have achieved a decline of more than 50 per cent; nine have achieved a moderate decline (26-50 per cent); and the remaining four a decline of less than 25 per cent.<sup>2</sup>

In 2013, the World Health Organization (WHO) issued consolidated guidelines on the use of antiretroviral drugs (ARVs) for treating and preventing HIV infection.<sup>3</sup> This updated guidance recommends lifelong ART for all pregnant and breastfeeding women living with HIV regardless of their CD4 count.<sup>4</sup> This approach, rapidly being adopted by countries in sub-Saharan Africa and beyond, offers great promise of further progress in reducing paediatric infections and improving maternal health. However, it also presents new

challenges around service delivery as well as service uptake, adherence and retention along the continuum of care.

The [Optimising HIV Treatment Access \(OHTA\) Initiative](#) 2013-2015, funded by Sweden and Norway through the United Nations Children's Fund (UNICEF), supports the scaling-up of lifelong ART for pregnant and breastfeeding women living with HIV in four Global Plan priority countries: Côte d'Ivoire, the Democratic Republic of the Congo (DRC), Malawi and Uganda. The OHTA initiative has three main objectives:

1. To strengthen the capacity of primary health care systems to deliver lifelong HIV treatment for pregnant and breastfeeding women through the maternal, newborn and child health (MNCH) platform;
2. To increase timely uptake, adherence and retention along the PMTCT/MNCH continuum, especially through community engagement; and
3. To enhance monitoring and evaluation for timely decision-making to improve service delivery.

An additional underlying aim of the OHTA Initiative is to provide evidence-based knowledge, experience, innovation and lessons learned for all countries striving to achieve the Global Plan goals. It is within this context that UNICEF, through the OHTA Initiative, commissioned this review.

1 Referred to as the Global Plan.

2 UNAIDS, UNICEF, WHO, 2013 Global AIDS Response Progress Reporting, 2014; and UNAIDS 2013 HIV and AIDS estimates, based on 2014 Spectrum modelling, July 2014

3 Annex 2 includes a toolkit for implementing these new guidelines (IATT et al 2013)

4 WHO 2013



## Rationale and purpose

The Global Plan,<sup>5</sup> the 2013 WHO Consolidated Guidelines,<sup>6</sup> and the Option B+ Toolkit<sup>7</sup> compiled by the Inter-Agency Task Team (IATT) on the Prevention and Treatment of HIV Infection in Pregnant Women, Mothers and Children<sup>8</sup> emphasize the importance of community engagement as an integral part of the scale-up strategy. However, these documents do not provide guidance on the selection and roll out of specific community engagement strategies to support the elimination goals. The case study on community engagement for the Global Plan, released by UNAIDS in 2012, documented that meaningful community engagement can improve the supply and quality of PMTCT services; promote social and behaviour change; increase the demand for PMTCT services; and help to create a more enabling environment for the uptake of PMTCT services.<sup>9</sup> However, it also highlighted a limited scope of implementation and general lack of causal evidence on health outcomes for promising practices in community engagement.

This paper updates and further examines the literature and programme experience on community engagement for PMTCT linkages to promote successful uptake and retention of women initiating lifelong ART during pregnancy or breastfeeding. It also puts forward a conceptual framework and operational considerations to practically apply this evidence to guide programme strategy and implementation.

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5 UNAIDS 2011

6 WHO 2013

7 Annex 2-IATT, WHO, UNICEF 2013

8 [www.emtct-iatt.org](http://www.emtct-iatt.org)

9 UNAIDS 2012

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A community-facility linkage is defined as a formalized connection between a health facility and the communities it serves to support improved health outcomes.

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The scope of this paper is well defined in several important ways. First, it focuses on the community component of community-facility linkages. It does not address facility-based interventions. More broadly, this review does not consider policy, advocacy and other aspects of a comprehensive strategy for the elimination of mother-to-child transmission (eMTCT). Finally, the lens of this review along the PMTCT continuum of care begins with the first antenatal care (ANC) visit and concludes with final diagnosis and cessation of breastfeeding. Although they fall outside of the scope of this review, Prong 1 (primary HIV prevention), Prong 2 (preventing unwanted pregnancy) and Prong 4 (lifelong treatment, care and support for mothers, their children and families) of a comprehensive PMTCT programme are critical elements of the Global Plan strategy and will likely benefit from scale-up of the promising practices outlined in this document.

## Methods

The methods for this research include a literature review, stakeholder consultations and country visits.

For the literature review Internet searches were conducted using various combinations of key words and phrases (e.g., PMTCT, Option B+, community, retention, antenatal care, postnatal care, ART, early infant diagnosis, maternal, newborn and child health among others) for the

period 2011 to early 2015 on PubMed, Google Scholar and various partner websites<sup>10</sup> and conference databases<sup>11</sup>. Relevant documents were also obtained from the OHTA team at UNICEF, from IATT members, the eMTCT website<sup>12</sup> and Community of Practice.<sup>13</sup>

The literature review was guided by the following inclusion criteria: practices had to 1) demonstrate correlation between a community-facility linkage intervention and increased PMTCT, ART or MNCH service uptake or retention; and 2) this correlation should be demonstrated in more than one setting. Once a promising practice was identified, further Internet searches were conducted and, in some cases, relevant stakeholders were contacted to seek out additional evidence and gain deeper insight.

To supplement the document review and better tailor findings to the four OHTA-supported countries, the consultant reviewed PMTCT/ eMTCT plans and related documents from the four countries. Conference calls were held with the UNICEF country, regional and headquarters offices. In addition, visits were made to learn about the OHTA initiative and implementation context in Malawi and DRC. The country visits included meeting with the UNICEF team, government representatives and OHTA implementing partners, community groups, and field visits in Katanga Province, DRC.

A draft of this document was shared and feedback solicited as part of a multi-country OHTA sponsored workshop in November 2014<sup>14</sup>, through a webinar discussion hosted by the IATT in December 2014<sup>15</sup> and through individual expert review in January 2015.

## A note on the evidence base

It is useful to highlight a few observations on the evidence base for community-facility linkages in support of PMTCT, ART and MNCH.

The evidence on community engagement is more robust than that which was available for the 2012 UNAIDS case study. Although still relatively uncommon, additional randomized controlled trials have been published as well as observational and qualitative studies, before-and-after comparisons and reviews based on available programme monitoring data. Several systematic reviews and meta-analyses of community engagement strategies have also recently become available.<sup>16</sup> Such studies were of particular interest in this review because of their ability to consider results across multiple settings and discern broader trends. Despite these contributions the available evidence remains inadequate for definitive statements on causal associations, replication and scale-up for several reasons.

10 UNICEF, UNAIDS, WHO, USAID, USAID-Assist, AIDSTAR, World Vision, EGPAF, K4Health

11 20th International AIDS Conference, 17th ICASA

12 <http://www.emtct-iatt.org>

13 [http://knowledge\\_gateway.org/emtct](http://knowledge_gateway.org/emtct)

14 Optimizing HIV Treatment Access (OHTA) Initiative Multi-Country Workshop, November 17-19, Lilongwe, Malawi

15 IATT sponsored webinar: Communities driving the response for the elimination of vertical transmission of HIV, December 10th

16 Busza et al 2012, Lamb et al 2012, Scanlon and Vreeman 2013, Underwood et al 2014, Wouters et al 2012

First, the relatively recent adoption of lifelong ART for pregnant and breastfeeding women living with HIV by a growing number of countries limits the availability of evidence specific to this treatment regimen. The scope of the review was therefore expanded to consider evidence for any PMTCT programme regardless of which regimen was in use; for adult ART because its lifelong regimen is similar to that prescribed for pregnant and breastfeeding women; and for MNCH that follows a similar continuum of care from the prenatal period through child birth to postnatal and postpartum care.

Second, the available published journal articles do not capture the scope and depth of community engagement in the HIV response. For a more complete picture, this review included grey literature such as reports, conference abstracts, posters and other documents. Even so, the perspective is not a comprehensive one. This is because in many cases community-level contributions are implemented by organizations and groups that may lack the capacity, financial resources and/or access to systematically document, disseminate and publish their efforts and results.

Third, while randomised control trials remain the gold standard in clinical research and provide the best evidence on causality, they may be disruptive of the existing health care delivery environment, and their results are not necessarily replicable or scalable. A recent WHO publication on HIV implementation research advises that “a framework for understanding and describing context, as well as an adaptive approach for implementing and scaling up interventions in a context-sensitive way, are essential to advance the field of implementation science in HIV and AIDS.”<sup>17</sup>

Taking the above points into account, this inclusive review also remained focused on criteria set for defining a promising practice. As in the 2012 UNAIDS manuscript, this review calls for more research and documentation of community engagement in support of health development, especially studies that adopt a conceptual framework, draw comparisons and describe context.

## Guiding principles

From the available literature and experience to date, the following guiding principles are offered for all efforts to engage with communities in health, including community-facility linkages in support of PMTCT and lifelong ART.

**Tailor community strategies and activities to the local context.** There is no one-size-fits-all approach for what constitutes an effective community-facility linkage. The promising practices described in this document should be considered as a menu rather than a prescription. Chosen practices will require adaptation to suit the context, opportunities and challenges of the local setting.

**Align with and support national plans and frameworks.** All community-level activities should align with and support the national PMTCT/ eMTCT plan as well as national frameworks for HIV and reproductive, maternal, newborn, child and adolescent health. Beyond alignment, stakeholders can enhance the sustainability of community-facility linkages through transparent and collaborative planning, implementation, monitoring and evaluation as well as capacity development in effective community engagement.

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17 Edwards and Barker 2014

**Adopt the human rights-based approach.**

This approach prioritises equity, participation and accountability in all stages of the health programming process. It works to ensure freedom from stigma and discrimination related to health status and gender roles. This approach aims to build the capacity of individuals to claim their right to health and of health systems to respect, fulfil and protect human rights.

**Involve people living with HIV (PLHIV).** First adopted at the Paris AIDS Summit in 1994, the Greater Involvement of People Living with AIDS (GIPA) principle encourages the active and meaningful involvement of PLHIV. PLHIV have played a significant role in the HIV movement and response since the beginning of the epidemic through advocacy, working as peers, providing inputs in policy and programme development, leading support groups and networks and other areas. Meaningful engagement of PLHIV helps to ensure that programmes are relevant and responsive, while encouraging greater self-efficacy and personal development of PLHIV. A good practice guide on GIPA is listed in Annex 2.<sup>18</sup>

**Build on existing structures and resources.** All communities have existing social capital. This may be in the form of community-based organizations, women's groups, clubs, associations and credit and savings groups among others. Building on existing structures and resources, rather than creating new or parallel structures, fuels current momentum and helps to ensure local ownership and sustainability.

**Strengthen accountability for health.** All of the promising practices described in this document can contribute to improved accountability for health, a critical component of the evolving post-2015 health development agenda.

Strengthened linkages between health care systems and the communities they serve are at the heart of increased accountability. Rights-based implementation of each of the promising practices described in this document can improve the flow of information between communities and health facilities; empower mothers, families and communities to manage their own health and to expect and demand quality health services; and leverage positive social change. A first step is to ensure that communities are well informed about new health initiatives. Annex 2 includes a community guide to the WHO 2013 consolidated guidelines.<sup>19</sup>

**Encourage greater integration of health services.** Integrating HIV services with broader reproductive, maternal, newborn, child and adolescent health and community initiatives can increase service access, uptake and retention as well as improve health outcomes. Integration reduces the likelihood of missed opportunities and improves cost efficiency. Community-level health and social workers are especially well positioned to provide holistic support to mothers, their children and families, if appropriately supported.<sup>20</sup>

**Ensure quality of community-level health communication and services.** The quality of health communication and services can affect their continued use and the health outcomes achieved.<sup>21</sup> As in facilities, quality is critical for the delivery of community-level services and information. So it is essential to ensure that training, monitoring and supervision for community-level activities include systems for continuous quality improvement. Examples of community-level quality assurance initiatives are included in Annex 2.<sup>22</sup>

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18 Annex 2 - International HIV/AIDS Alliance and GNP+ 2010

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19 Annex 2 - International HIV/AIDS Alliance et al 2014

20 Wouters 2012

21 Flickinger 2014

22 Annex 2 – Pathfinder 2013

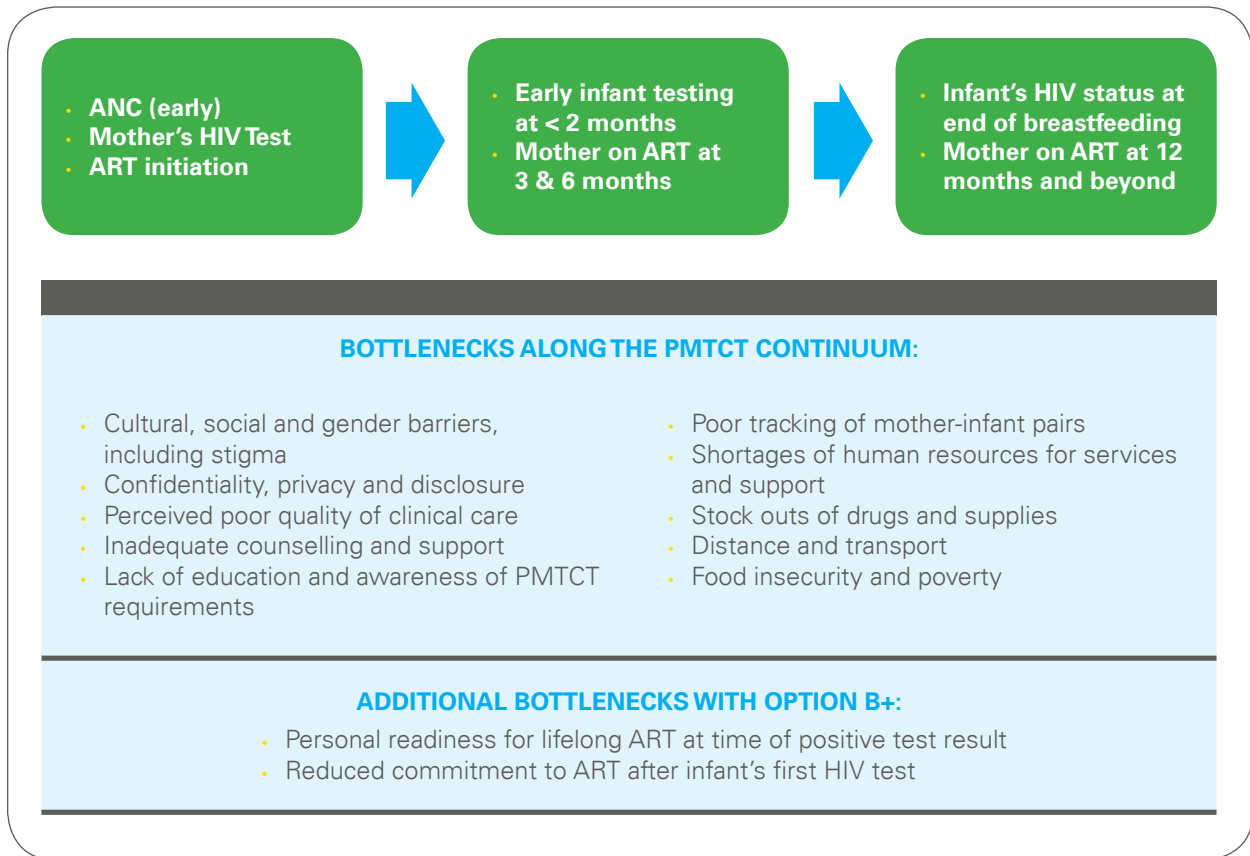
### III. THE RESEARCH FRAMEWORK

This section briefly reviews common bottlenecks along the PMTCT continuum of care and introduces the conceptual model which served as a guide and organizing framework for this research.

#### Bottlenecks along the PMTCT continuum of care

The green boxes in Figure 1 represent the PMTCT continuum of care, which highlight core monitoring indicators. The blue box lists some commonly cited bottlenecks to service uptake, adherence and retention along the continuum.<sup>23</sup>

**FIGURE 1: THE PMTCT CONTINUUM OF CARE AND COMMON BOTTLENECKS**



A notable characteristic of the bottlenecks listed above is that many extend or are generated outside the formal health care system, further emphasizing the need to establish robust community-facility linkages to help mitigate these challenges.

<sup>23</sup> Busza et al 2012, Cataldo 2013, Ferguson 2013, Gourlay et al 2013

## The conceptual model

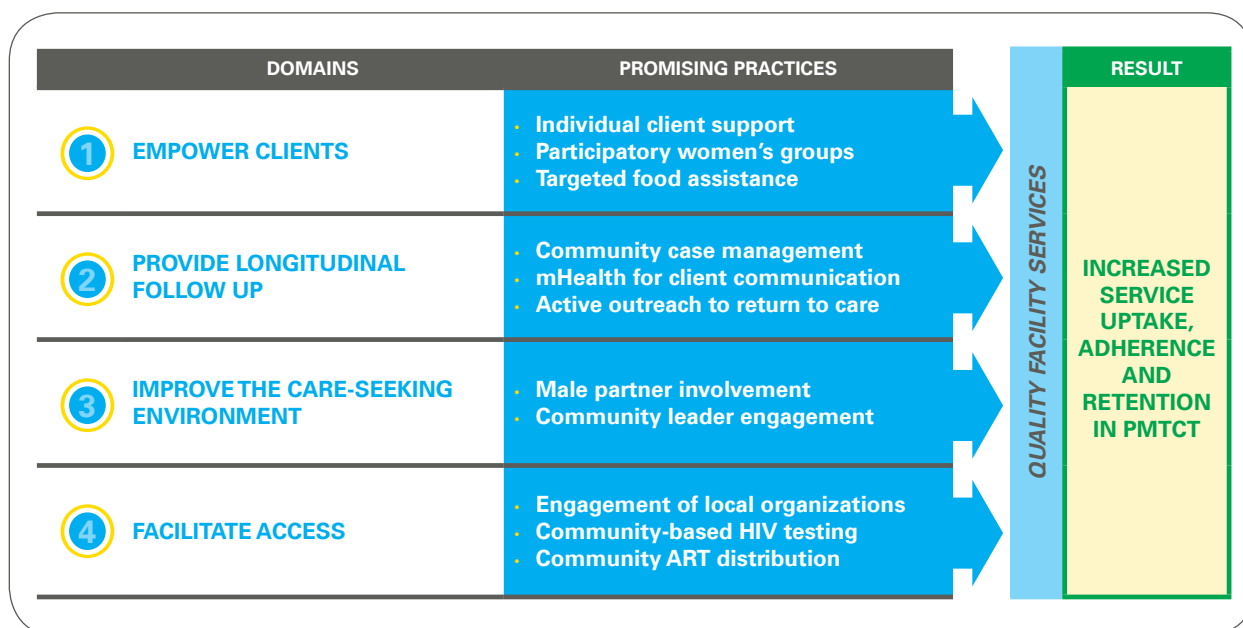
To structure the promising practices in community engagement for PMTCT the 2012 UNAIDS case study used a conceptual model based on supply, demand and enabling environment. Focusing more narrowly on community-facility linkages to support the roll out of lifelong ART for pregnant and breastfeeding women living with HIV, this review adopts a client-centred approach and asks, ‘*what do mother-infant pairs require to successfully enter and navigate PMTCT and lifelong ART?*’

Using this lens, evidence-based interventions are organized according to four domains of support for mother-infant pairs. Domains include:

1. Empower clients
2. Provide longitudinal follow-up of mother-infant pairs
3. Improve the care seeking environment
4. Facilitate access

Figure 2 highlights the four domains and eleven promising practices which have been associated with increased service uptake, adherence and/or retention along the PMTCT and/or broader HIV and MNCH continua of care. Also illustrated is the idea that community activities must be paired with quality facility services to achieve an effective community-facility linkage and the intended health benefits. Domains are not ordered by sequence or hierarchy. All domains warrant consideration when planning or reviewing programmes; however, some domains may require more emphasis than others depending on the specific context and programme bottlenecks.

**FIGURE 2: CONCEPTUAL MODEL FOR THE PROMISING PRACTICES**



## IV. THE PROMISING PRACTICES

The eleven promising practices for strengthening community-facility linkages are presented below according to the four domains. Each practice is described in terms of rationale, review findings and implementation guidance. Where available, additional resources are cited in the text and listed in Annex 1 (references) and Annex 2 (toolkits and guidance).

### Domain 1: Empower clients

This domain focuses on community-level counselling and support for PMTCT clients. Individual counselling and psychosocial support as well as the formation of support groups are longstanding practices in many PMTCT programmes. With the availability of simple, effective drug regimens and earlier treatment initiation when people are healthier, HIV infection can be managed like other chronic diseases. Increasingly, the focus of client support, whether provided one-to-one or in a group, is on empowering PLHIV for positive living and self-efficacy in HIV management. The three promising practices in this domain are individual client support, participatory women's groups and targeted food assistance.

#### Individual client support

##### *Rationale*

This promising practice focuses on education, counselling and psychosocial support provided to individual PMTCT clients by peers, community health workers (CHWs) and treatment partners. A substantial and chronic shortage of human resources is characteristic of most health systems in sub-Saharan Africa. With less restrictive eligibility criteria for ART, a rapidly increasing number of adults are initiating ART and demands on health care workers are growing. In Malawi

the number of pregnant and breastfeeding women initiating ART through PMTCT increased more than seven-fold during the first year of implementation.<sup>24</sup> The country has also observed, and is working to address, high rates of disengagement from care under the lifelong ART protocol especially after treatment initiation when some women collect the ARVs but never return, and after childbirth.<sup>25</sup> Task-shifting and intensifying support services provided by community workers and volunteers can relieve some of the burden on short-staffed health facilities while enhancing the mother's adherence, retention and self-efficacy as well as infant follow-up.

##### *Findings*

While acknowledging that there is limited systematic scientific research on the contributory role of client support provided by peers and community cadres, the findings of two broad reviews and several studies are compelling.

- A two-stage literature review published in 2012 explored the contributory role of community-based client support on HIV programme outcomes in resource-limited settings. Based on their selection criteria, the authors identified 22 different programme reports in 18 countries and found a clear association between community support and improved ART programme outcomes. Specifically they found evidence of expanded access, increased adherence and retention, improved virological and immunological outcomes and survival. The second phase of the review described the contributory role. The authors found that peers and other community supporters were able to integrate HIV services into broader primary health care systems; provide social support and counselling; empower ART clients

<sup>24</sup> White 2014

<sup>25</sup> Keehn and Karfarkis 2014

with self-management and other skills; trace defaulters and help to ameliorate human resource shortages.<sup>26</sup>

- A recent review of early experience with the scale-up of lifelong ART for pregnant and breastfeeding women in eleven countries highlights the need for enhanced counselling by lay cadres. The study showed task-shifting ART initiation to nurses created pressure on lower level cadres for counselling and follow-up. In response, the reviewers noted, several strategies were put in place, including training 600 community health assistants to provide this support in Zambia; introducing a new cadre of MNCH CHWs in Tanzania (see below); and new lay counsellors recruited in Mozambique to assist with client counselling.<sup>27</sup>

Below are two examples of CHWs engaged to provide individual client support in MNCH, ANC and PMTCT.

- A randomized controlled trial in South Africa documented improved infant feeding outcomes as a result of regular home visits by CHWs. In the intervention group, women received two home visits during pregnancy and five visits during the postnatal period. The integrated health home visit agenda used motivational interview techniques and included education, counselling and problem solving. The study found that the home visits nearly doubled the rate of exclusive breastfeeding at 12 weeks with a dose response. For every home visit made, the proportion of women exclusively breastfeeding at 12 weeks increased by 6 per cent. Additional outcomes included increased infant weight and length for age. Women in the intervention group were also more likely to make birth preparation

plans, to know the newborn danger signs and to attend postnatal clinic for mother and infant care within the first week of birth.<sup>28</sup>

- In the urban metropolis of Dar es Salaam, Tanzania, existing salaried CHWs (including 213 community home-based carers and 54 community-based outreach nurses) made quarterly home visits between January 2013 and April 2014 as part of a large-scale randomized controlled trial. In addition to raising awareness about MNCH, the researchers hypothesized home visits would inform this rapidly expanding urban population of the nearest location for ANC; serve as a reminder of the importance of ANC; and, provide a normative social influence for seeking early ANC. After 16 months a quantitative performance evaluation was conducted. Of the approximately 45,000 pregnant women identified through home visits, more than 75 per cent had not yet attended ANC. On average, each CHW identified ten pregnant women per month who had not yet attended ANC. This intervention also improved the early uptake of ANC with the average time of the first ANC visit declining from 21 weeks in January 2013 to 16 weeks in April 2014. The researchers concluded, "Such an intervention is feasible at large scale and low total cost. CHWs can be effective in identifying and counselling pregnant women in the community long before they attend ANC for the first time."<sup>29</sup>

Peer programmes involve identifying and training former PMTCT clients to support newly enrolling PMTCT clients.

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26 Wouters et al 2012

27 Kieffer et al 2014

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28 Tomlinson et al 2014

29 Lema et al 2014



- The mothers2mothers (m2m) programme is the largest example of peer support in the PMTCT field, reaching 1.2 million women to date in nine countries.<sup>30</sup> Under this model, mentor mothers who have been through the PMTCT programme are trained to support clients in facilities and communities. A 2015 evaluation in Uganda documented improved outcomes at facilities where mentor mothers provided group education sessions and individual counseling, as compared to facilities without the programme. The study found higher rates of ART retention at one year (91 vs. 64 per cent); uptake of EID at 6-8 weeks (72 vs. 46 per cent); ART initiation for infants living with HIV (61 vs. 28 per cent); exclusive breastfeeding (90 vs. 56 per cent); disclosure (82 vs. 70 per cent), and attended deliveries (87 vs. 76 per cent). Psychosocial indicators also showed improvement: 87 per cent of clients receiving m2m support were able to demonstrate coping self-efficacy compared to 65 per cent of those clients without such support.<sup>31</sup>
- A 2014 cluster randomized controlled trial in Kwa Zulu Natal, South Africa that provided an enhanced intervention of peer mentor support found PMTCT clients in the intervention arm were more likely to exclusively breastfeed for six months, had fewer underweight babies and depressive symptoms than women without peer support.<sup>32</sup>

The engagement of treatment and infant feeding partners/buddies is an alternative model in which a PMTCT client selects a family member, friend, or other trusted individual as a partner to provide her with adherence and treatment support.

- A retrospective chart review conducted in Zambia documented good adherence among 70 per cent of women who had the support of a treatment partner compared to only 53 per cent for those who did not.<sup>33</sup>
- In Tanzania, a qualitative study involving 98 interviews with patients and treatment partners found that in addition to improving adherence treatment partners contribute to encouraging disclosure; combating stigma; restoring hope; and reducing social difference.<sup>34</sup>

Annex 2 includes guidance documents on counselling and education for Option B+ and peer support.<sup>35</sup>

### **Implementation guidance**

As appropriate to the local context and resources, PMTCT programmes should ensure that every client has some form of individual treatment support from ART initiation until at least the determination of the infant's HIV status and the cessation of breastfeeding.

In light of the early performance data on lifelong ART throughout the PMTCT cascade, individual counselling and support should be intensified at the time of treatment initiation and during the postpartum and postnatal periods when the focus of support may shift to infant feeding practices and EID.

To promote greater self-efficacy individual client support should focus on skills building, problem solving and positive living.

Lay treatment supporters should be fully integrated and adequately supported as part of the health care team.

30 [www.m2m.org](http://www.m2m.org)

31 Zikusooka et al 2014

32 Rotheram-Borus et al 2014

33 Birbeck 2009

34 O'Laughlin et al

35 Annex 2 - MSF 2013(1), Okunuga 2012, USAID et al 2014

## Participatory women's groups

### Rationale

The promotion of support groups has been a common practice in the HIV response and in PMTCT programmes specifically. Support groups offer the opportunity to share information, provide social support and generate collective action for improved health and positive social change. PMTCT support groups are often facility-based and led by a health worker. Community-based models also exist and include PMTCT clients, all pregnant women and/or other family members, such as male partners or mothers-in-law.

### Findings

The 2012 UNAIDS case study on community engagement for the Global Plan noted little evaluative evidence on support groups, but cited a few examples with documented, improved health-related outcomes among support groups members compared to non-members.<sup>36</sup> A more recent study shows group membership with discussion about HIV has a positive effect on care seeking, behaviour change and HIV incidence.

- According to a World Bank Review, strong evidence was found in Zimbabwe through a quasi-experimental longitudinal study linking women's community group membership to positive behaviour change, increased service use and reduced transmission. Specifically, women who belonged to community groups that frequently discussed HIV reduced their risky behaviours, increased uptake of HIV testing and home-based care and experienced lower HIV incidence.<sup>37</sup>

Some of the strongest and most consistent evidence linking group membership and improved

health indicators comes from seven trials that assessed purpose-oriented, facilitated women's groups – that is, groups of women who meet regularly to accomplish shared objectives.<sup>38</sup> To date these groups have focused on maternal and neonatal mortality. However, a pilot with women on lifelong ART is now underway in Malawi.<sup>39</sup>

- Participatory women's groups were formed in seven trials undertaken in Bangladesh, India, Malawi and Nepal. Groups were facilitated by local literate women who had received training in MNCH and facilitation skills, were provided with locally appropriate education materials and received regular supervision. These groups undertook a facilitated cycle of problem identification, planning, implementation and assessment aimed at reducing mortality and improving maternal and newborn health. The education component of this process focused on danger signs in pregnancy, early care seeking and home care. The groups defined their own solutions and mobilised local resources to implement them. For example in Malawi, some of the common solutions included mobilising transport, establishing vegetable gardens, distribution of insecticide-treated nets and oral rehydration salts and small-scale income-generating activities.<sup>40</sup> A sub-group analysis of the seven trials including 48,333 live births, with at least 30 per cent participation of pregnant women in the groups, documented a 49 per cent reduction in maternal mortality and a 33 per cent reduction in neonatal mortality. The intervention was considered cost-effective by WHO standards.<sup>41</sup>

In 2014, WHO issued the following

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38 Rodriguez-Garcia 2013

39 personal communication with the MaiKhanda Trust

40 Rosato et al 2010

41 [Prost 2013](#)

recommendation: *implementation of community mobilisation through facilitated participatory learning and action cycles with women's groups is recommended to improve maternal and newborn health, particularly in rural settings with poor access to health services. Implementation of facilitated participatory learning and action cycles with women's groups should focus on creating a space for discussion where women are able to identify priority problems and advocate for local solutions for maternal and newborn health.*<sup>42</sup> A good practice guide on participatory women's groups is listed in Annex 2.<sup>43</sup>

### **Implementation guidance**

- Consider introducing and/or scaling-up participatory women's groups with a potential for broad coverage of pregnant women.
- To ensure locally identified solutions are successfully implemented engage community-level decision-making structures early in the participatory process.
- Ensure careful selection, training, supervision and support of group facilitators as they are key to the success of participatory women's groups.
- When feasible work with existing women's groups rather than creating new groups as this can be simpler and more effective.
- With existing PMTCT and other support groups move towards a more purposeful and problem solving approach.

## **Targeted food assistance**

### **Rationale**

One approach for reducing individual service barriers and enhancing client support is to

provide incentives, such as vouchers for services, transport or food; food rations; or cash transfers. When applied broadly these strategies can be expensive and the benefits may end when funding for incentives is no longer available. However, targeted needs-based incentives, specifically related to food and nutrition, can be helpful in improving adherence and retention in areas of food insecurity where clients fear hunger, lost wages and side-effects from taking ARVs on an empty stomach. Food security is of particular significance for pregnant women as it preserves maternal status and improves birth outcomes.<sup>44</sup>

### **Findings**

The evidence correlating food supplements to adherence and retention comes from two systematic reviews and two comparative studies in sub-Saharan Africa.

- An ecological study across ten countries with more than 230,000 clients who initiated ART between 2004 and 2008 showed "clinics with educational materials and food rations available were significantly associated with lower attrition and lower LTFU compared with clinics without these services". A sub-analysis found a marginal association with lower death rates as well.<sup>45</sup>
- A recent literature review focused on 10 randomized or non-randomized controlled trials, historical cohort studies or published evaluations of programmes "that provided some form of food assistance to vulnerable people with either tuberculosis (TB) disease or HIV infection. The authors assessed adherence to clinic appointments, medication possession, compliance to treatment and/or treatment completion" and found that

42 WHO 2014

43 Annex 2 – Badas 2013

44 Le Cuziat and Mattinen 2011

45 Lamb 2012

eight of the 10 studies documented improved adherence or treatment completion rates. Despite the intervention's positive impact the authors cautioned about the sustainability of food support given the lifelong use of ART (compared to time-bound TB treatment). They suggested providing food incentives in collaboration with other programmes that aim to create a more enabling environment for vulnerable PLHIV.<sup>46</sup>

- A cohort study from Zambia comparing clinics providing food assistance with clinics that did not and another from Niger that compared clients who received food assistance during their first year on ART with those who did not found that adherence, retention and clinical outcomes improved with food supplementation. Based on these and other findings the International Association of Physicians in AIDS Care (IAPAC) international guidelines<sup>47</sup> recommend resources to address food insecurity be provided in the context of case management.<sup>48</sup>

### **Implementation guidance**

- In areas of high food insecurity consider providing food- and nutrition-related incentives for PMTCT clients with poor access to food. Note however that sustainability is a concern and should be factored into the decision.
- Standard protocols to identify women in need of food support will be required. Collaborating with other food assistance, social welfare or protection programmes can facilitate this

46 de Pee et al 2014

47 The IAPAC guidelines created by an expert panel convened to develop evidence-based recommendations and define best practices to optimize entry into and retention in care and ART adherence and to monitor these practices. They relied on the best-published science available and highlighted areas where more research is needed.

48 Thompson 2012

process and ensure greater sustainability.

- If food assistance is provided, identify strategies to sustain these incentives and/or the improvements they generate when intervention funding decreases. This includes working with other programmes on longer-term strategies for improved access to food.

## **Domain 2: Provide longitudinal follow-up**

Retention of adult clients on ART has been a persistent challenge in the HIV response. With several counselling sessions over an extended period before starting ART many clients drop out during this pre-ART phase.<sup>49</sup> For those who do start treatment retention rates decline over time.<sup>50</sup> Similarly, loss to follow-up (LTFU) throughout the continuum of care of pregnancy, delivery and the postpartum and neonatal periods also presents a significant challenge. Early data from Malawi indicate that with same day 'test and treat' retention is a particular challenge at the time of ART initiation for pregnant women; they may be overwhelmed with the news of an HIV positive test and not personally ready to embrace lifelong treatment.<sup>51</sup> Another high-risk period for LTFU of both the mother and her infant is after childbirth and the first infant HIV test. Efforts to retain clients on ART and to return to care those who do disengage are critical and require consistent client tracking over time. Longitudinal follow-up is the focus of this domain and includes three promising practices: community case management, mobile health (mHealth) for client communication and active outreach.

49 Rosen and Fox 2011

50 Fox and Rosen 2010

51 Webb and Monteso Cullel 2013

## Community case management

### Rationale

Case management is the designation of a specific health worker (or team) to assist in the navigation and follow-up of health care services for a client (or family) with emphasis on quality and continuity of care.

### Findings

Results from two examples of comprehensive community-based case management (community-level workers are assigned a caseload of mother-infant pairs) highlight this approach as a promising practice for improved retention along the continuum of care, notably for paediatric follow-up.

- In the Tingathe trial, which took place in two large peri-urban settings in Malawi, CHWs were tasked with following up to 50 mother-infant pairs from HIV diagnosis in ANC until the final diagnosis and treatment of the infant. PMTCT clients voluntarily enrolled into the programme and were assigned a dedicated CHW. These specially trained CHWs provided non-clinical services and tracked their assigned clients at health centres and in their homes to ensure continuity of care. During 2009-2011 nearly all (94 per cent) of the women received their CD4 count results and 40 per cent initiated ART, compared to 22 per cent and 9 per cent, respectively, prior to the intervention. Over 90 per cent of newborns received infant ARVs and 81 per cent had an EID test performed. Paediatric ART was initiated for more children (77 per cent vs. 34 per cent) at an earlier age (5 months vs. 9 months) during the intervention than prior to it. The authors concluded “coordinated, longitudinal care of mother-infant pairs is possible in high-burden, resource-limited countries. Dedicated CHWs

functioning as case coordinators created a bridge between disparate clinical services and improved retention and service utilization at virtually every step within the PMTCT cascade”<sup>52</sup>

- The Community Register Project was implemented in eight districts of the Southern Province of Zambia. Based on the ‘Reach Every District’ approach used in childhood immunization programmes, this project relied on community-based registers to track every mother-infant pair in the PMTCT programme. Trained lay counsellors were assigned to each zone and were responsible for a catchment area of 1,000 to 7,500 people. The community-based registers included mother-infant pairs on the same line running across from pre-delivery on the left through 18 months post childbirth on the right. The trained volunteers followed up with women who missed their appointments according to a standard algorithm and also provided HIV and nutrition education, promoted male involvement and adherence to treatment and testing. They also worked with clients to problem solve when barriers to clinic attendance were identified. After three years of implementation (2009-2012), 92 per cent of women living with HIV were receiving ARVs and 9,230 infants received EID within the first 12 months of life, up from 442 in 2008.<sup>53</sup>

### Implementation guidance

- Work towards a tracking/monitoring system that follows mother-infant pairs together from ANC until the cessation of breastfeeding.
- Consider assigning mother-infant pairs to specific community cadres and volunteers, especially in low performance areas or with groups at high risk of LTFU.

52 Kim MH et al 2012

53 Holmes 2013

## Mobile health (mHealth) for client communication

### Rationale

Mobile phones are proving a useful tool in the health sector.<sup>54</sup> Using mobile technology to remind clients of their upcoming appointments and to offer additional information and support can help ensure that clients adhere to and remain in care and treatment.

### Findings

In an extensive literature review identifying strategies that improve ART access and adherence, mobile phone short message service (SMS) interventions were ranked among those having the strongest evidence of a correlation with improved adherence.<sup>55</sup> All of the individual studies cited below come from Kenya.

- One randomized controlled trial found that the “intervention group receiving weekly SMS reminders to take ART were significantly more likely to achieve 90 per cent adherence rates and less likely to experience treatment interruptions at 48 weeks’ follow-up compared to controls.”<sup>56</sup>
- Another randomized controlled trial documented “significant improvements in adherence and viral suppression among an intervention group that received weekly interactive SMS (inquiring about health and well-being) with follow-up calls for non-respondents after 48 hours.<sup>57</sup> At US\$0.02 per text message with an annual per client cost of US\$1.00 and US\$8.00, respectively, both interventions were deemed to be highly cost-effective.<sup>58</sup>

- A third study used an internet-based HIV infant tracking system to improve retention and care of HIV-exposed infants. Mobile phone SMS was used to notify both mothers and clinicians of necessary actions. Use of the system was associated with more than doubling the proportion of exposed infants retained in care at nine months in both urban and peri-urban areas. All HIV-infected infants (100 per cent) in both hospitals were initiated on ART.<sup>59</sup>
- A qualitative study of 45 selected PMTCT clients, male partners, CHWs and facility-based health workers was conducted in Kenya to explore the specific content and forms of mobile communication that are acceptable to support PMTCT. The perceived benefits of mobile phones for PMTCT included linking with health workers, preserving confidentiality and receiving information and reminders. Health workers emphasized that SMS systems must be coupled with face-to-face counselling, while clients stressed that messages must be relayed safely to the intended recipient. The groups’ preference was for integrated and neutral text messaging provided both before and after childbirth.<sup>60</sup>

Based on the randomized controlled trials in Kenya, the IAPAC guidelines recommend the use of reminder devices and communication technologies with an interactive component.<sup>61</sup> A planning guide on mHealth is included in Annex 2.<sup>62</sup>

### Implementation guidance

- Expand the use of mHealth technology in the scale-up of PMTCT and lifelong ART when socially acceptable and women’s access to mobile phones is readily available.

54 Thirumurthy and Lester 2012

55 Scanlon and Vreeman 2013

56 Ibid

57 Ibid

58 Thirumurthy and Lester 2012

59 Finocchario-Kessler 2014

60 Jennings et al 2013

61 Thompson et al 2012

62 Annex 2 – Duboff and Futrell 2013

- Ensure that participation in mobile phone-based systems is voluntary on the part of clients and that methods to protect their confidentiality are established and communicated to all those who participate.
- Message development should be done systematically including assessment of local context and pretesting.
- Opt for interactive text messages over one-way text messaging. Two-way communication allows for inquiries about a client's health and wellbeing and lets the client ask questions and request rescheduling of appointments if needed.

## Active outreach for return to care

### Rationale

When a mother or her infant misses a clinic appointment along the PMTCT continuum, rapid and effective follow-up is required. Outreach, especially in the form of home visits, is a promising practice in this regard.

### Findings

Findings from two meta-analyses show active outreach can have a significant impact in improving retention and that community-level workers can be especially effective in both preventing disengagement from care and returning clients to care.

An ecological study of more than 230,000 ART clients across ten African countries found that independent of other characteristics, clinics with active patient outreach (by telephone, letter and home visits) achieved significantly higher retention, especially at 12 months after ART initiation than clinics without active outreach.<sup>63</sup>

- An extensive synthetic review of relevant published work from 2003-2011 selected and analysed 30 reports from 18 resource-limited countries and found a strong positive impact of community support on a wide range of HIV-related indicators including access, coverage, retention, and biological outcomes. Defaulting from care was one of the five major challenges addressed through task-shifting to CHWs. The authors noted "out of a total of 29 studies that assessed the contribution of community support in ART outcomes, 17 (59 per cent) indicated community support providers' ability to reach out into the community and prevent LTFU or track defaulting patients". In line with promising practices cited previously in this paper the authors also noted, "that psychosocial support and regular home visits by CHWs and peer adherence counsellors have acted as powerful preventive actions against patient attrition".<sup>64</sup>

### Implementation guidance

- All PMTCT programmes should have established systems and protocols for tracking clinic appointments and active follow-up including outreach when appointments are missed. A recent review of experience in Malawi and the region more broadly offers specific implementation guidance for follow-up of clients on lifelong ART, including the need for active outreach within a week of the missed appointment.<sup>65</sup>
- Obtain client permission for active outreach and follow-up, including where and how contact is to be made, at the time of their HIV diagnosis.
- Intensify client support and active outreach for missed appointments immediately after treatment initiation and during the postnatal/

63 Lamb 2012

64 Wouters 2012

65 Keehn and Karfakis 2014

postpartum period when there is high risk of default from ART.

- Establish routine meetings of the health care team to review the status and plan follow-up for clients who have missed appointments.

### Domain 3: Improve the care-seeking environment

A key component of the shift from an emergency to a long-term response to HIV is the transition from interventions focused on individuals to a comprehensive strategy in which social/structural approaches aim to create a more enabling environment for care.<sup>66</sup> The authors of a 2012 journal article about community-based approaches for PMTCT in resource-limited settings adopted a social ecological framework and described several levels of social influence beyond the individual that can affect PMTCT uptake, retention, adherence and the psychosocial wellbeing of clients. The authors described family and peer influence, community context and socio-cultural environment in terms of the barriers they present and strategies aimed at reducing those barriers.<sup>67</sup>

This third domain focuses on the levels of family influence and community context. The identified promising practices are male partner involvement and engaging community leaders.

#### Male partner involvement

##### *Rationale*

Health care decision-making is rarely done in isolation. In the sub-Saharan African context, male partners often have significant say and financial control over health care decision-making for all

family members. Women and children in particular are influenced by the actions and opinions of male partners and fathers. The potential health benefits of positive male partner involvement have been documented in a number of settings. Despite these benefits, low rates of male participation persist in PMTCT programmes due to gender inequity and other sociocultural and economic factors, as well as characteristics of health care delivery systems.<sup>68</sup> Community-level interventions can complement facility-based efforts and further improve rates of participation in care by male partners.

##### *Findings*

The evidence of male participation improving health care use and outcomes for PMTCT is strong. There is additional emerging evidence that adding community-level strategies to engage males may have a greater impact than pursuing facility-based strategies alone.

- A WHO position paper promoting meaningful engagement of male partners in PMTCT programmes provides a succinct summary of the evidence on improved PMTCT indicators. The significant and documented health benefits of male participation in HCT, ANC and PMTCT include increased spousal communication on HIV and sexual risk; contraceptive use; uptake of HCT for both women and men; facility-based delivery; adherence to the recommended antiretroviral regimen; improved infant feeding practices; reduced LTFU; and lower rates of newborn HIV infection and mortality.<sup>69</sup>
- A recent randomized controlled trial in Kenya documented significantly higher rates (85 per cent vs. 36 per cent) of couples HCT in the

66 Auerbach et al 2011

67 Busza et al 2012

68 Dunlap et al 2014

69 Ramirez-Ferrero 2012



intervention arm that included home visits compared to the health facility giving out partner invitations. The home visit intervention also identified more HIV positive men and discordant couples.<sup>70</sup>

- In the HCT trials described under domain 4, door-to-door strategies generated the highest rates of couples HCT compared to facility-based ones. (21.6 per cent vs. between 3 and 12 per cent).<sup>71</sup>

However, there is also anecdotal<sup>72</sup> evidence that efforts to involve male partners in PMTCT may have unintended harmful consequences.

- A recent study in Malawi reported high levels of intimate partner violence experienced by women living with HIV.<sup>73</sup> A qualitative study conducted in Malawi and Uganda prior to the roll out of Option B+ involved focus group discussions with 88 young women, women living with HIV, women living with HIV in leadership positions and men living with HIV. Female participants in Malawi “confirmed that the male involvement component of Option B+ had sometimes caused conflict in the home when men did not want to join their wives at the clinic or when women start treatment”. Although they acknowledged its success in getting men tested, women leaders in Uganda were concerned that requiring pregnant women to bring their partners to ANC has led to a situation where single women are being denied ANC services and therefore have ‘hired’ men to attend ANC with them. A key recommendation from this study was that “male participation should not be a condition for women receiving care.”<sup>74</sup>

70 Osoti et al 2014

71 Menzies 2009

72 <http://www.irinnews.org/report/94652/kenya-the-downside-of-male-involvement-in-pmtct>

73 Mwanza 2012

74 Webb and Monteso-Cullel 2013

### **Implementation guidance**

- Assess the local context including family composition, dynamics and structure to inform a relevant male partner involvement strategy.
- Integrate positive male engagement into the promising practices including through community HCT, community case management, home visits and support groups.
- Avoid placing sole responsibility or conditionality on the PMTCT client for male partner involvement. This runs the risk of disadvantaging, excluding or even endangering women who may already be vulnerable.
- Closely monitor male involvement initiatives for any unintended consequences and have response strategies in place should there be increased gender-based violence or other negative incidents.

## **Community leader engagement**

### **Rationale**

Every community has groups of opinion leaders with the power to create positive social change. This promising practice involves engaging these people, including religious and traditional leaders, to help reduce harmful norms and encourage beliefs and practices that promote health. Community-level barriers to PMTCT include gender inequities and norms, stigma, discrimination and traditional beliefs and attitudes around key topics such as gender roles, when to disclose a pregnancy and infant feeding.

### **Findings**

The pathways between community-level interventions and shifts in community norms or health indicators are complex and change may occur slowly making measurement a significant challenge. No systematic reviews or meta-analyses were found. Some specific examples of

community leader engagement around PMTCT and the documented results are described below.

- A project to improve maternal and neonatal health in the predominantly Muslim North-western region of Nigeria achieved significant results by fully embracing the cultural constraints to health facility care and building on existing community systems. Before the intervention, 90 per cent of births occurred at home and 67 per cent of women had no ANC during their previous pregnancy. Women in this region are typically secluded from public life and therefore hard to reach with health services. Moreover the community had a longstanding mistrust of the health care system due to family planning concerns. The project team reached out to local religious leaders through existing community-facility co-management committees to advocate for problem solving to improve maternal and neonatal health outcomes. The committees agreed on a strategy to bring care to women at local religious leaders' homes. The sensitized leaders raised awareness with men in the community about the importance of maternal and neonatal health and the value of this new strategy. Twice a month nurses provided clinical services to pregnant women and their male partners in these "safe" venues. As trust grew, the women began attending the health facilities. During 2012 in the 79 participating facilities, 58,000 women were enrolled in ANC. Across the three Nigerian states involved, 43,000 pregnant women received HCT and the acceptance rate for ARV prophylaxis increased from 16 per cent to 93 per cent.<sup>75</sup>
- The Men Taking Action initiative in Zambia that was included in the 2012 UNAIDS case study involved training revered community leaders

(chiefs, herbalists, traditional birth attendants, etc.) as champions of PMTCT and ANC. The target community had high levels of stigma around HIV, low rates of facility delivery and widespread myths about pregnancy and HIV transmission. The leaders were trained as champions through a four-day curriculum, which was informed by a community survey. Trained champions led participatory and iterative behaviour change communication sessions targeting men and couples in the general community and at ANC clinics. A survey conducted with community leaders, beneficiaries and health providers after three years of implementation found that all three groups strongly agreed that involvement of leaders had a positive influence in changing community behaviour. At the 31 participating sites the results achieved included: ANC clients tested for HIV up from 60 per cent to 92 per cent; couples HCT up from 3 per cent to 70 per cent; acceptance of ARVs by pregnant women up from 70 per cent to 100 per cent and infant ARV uptake increased from 60 per cent to 100 per cent<sup>76</sup>.

A guidance document for the engagement of community leaders is included in Annex 2.<sup>77</sup>

### **Implementation guidance**

- Engage local opinion leaders strategically and purposefully through existing community structures to promote PMTCT, lifelong ART and male involvement, especially in areas of low coverage with strong barriers to uptake.
- Conduct participatory formative research to ensure that interventions and messages are relevant for addressing local barriers.
- There is a dose response for communication

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75 Pathfinder 2013

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76 Sinkala 2012

77 Annex 2 - SAfAIDS 2015

efforts.<sup>78</sup> Locally tailored, sustained messaging promotes early ANC, HCT, exclusive breastfeeding and other key components of PMTCT.

- Adopt a participatory approach to define indicators of success and establish monitoring systems before implementing a community leader intervention.

## Domain 4: Facilitate access

Geographic distance, transport constraints and inadequate financial support have been cited as barriers faced by some women in accessing PMTCT services.<sup>79</sup> By extending the geographic coverage of health services, such barriers can be reduced. The three promising practices identified in this domain are engaging existing local organizations to provide PMTCT-related clinical and social services, community-based HCT and community ART distribution.

### Engagement of existing local organizations and structures

#### Rationale

Throughout sub-Saharan Africa, local organizations, including community-based and faith-based organizations (CBOs and FBOs) and PLHIV networks have engaged in health care and social development. They have been an early and formidable force in all aspects of the HIV response. The PMTCT and lifelong ART scale-up effort can benefit from identifying, linking with, building on existing community structures and empowering local groups to extend clinical services and broaden social support for mother-infant pairs and their families.

Types of local organizations that may be engaged to support the roll out include mission and private health providers, women's groups, PLHIV networks, income generating associations, religious entities, community leadership groups, farming groups and childcare centres among others. Some of these entities serve especially impoverished, high risk, vulnerable and marginalized populations (e.g., families living in extreme poverty, sex workers, women who use drugs or geographically isolated populations). As a result, they have both the access and skill to extend PMTCT's reach in these populations.

#### Findings

Despite the number and range of local organizations engaged in the health sector and the HIV response across sub-Saharan Africa, there is little documented evidence linking their work to specific health outcomes. What is available is generally descriptive and found in the grey literature.

- Two extensive reviews examined FBO engagement in the HIV response, one focused on sub-Saharan Africa and the other included Southeast Asia. Both documented a wide range of clinical and non-clinical activities, including advocacy, prevention, home-based care programmes, support of PLHIV, orphans and vulnerable children, PMTCT, HCT programmes, and training of religious leaders. Both reviews cited similar advantages of working with FBOs on HIV. The authors of one review noted, "FBOs have unique reach ... and the widest network coverage on the continent; are found in all communities, are found in inaccessible and rural areas."<sup>80</sup> Both reviews concluded that FBOs are underused and could do more in the HIV response.<sup>81</sup>

78 Rodriguez-Garcia 2013

79 Ferguson 2013

80 Schmid 2008

81 Ibid and Smith and Kaybryn 2012

Three recent examples of engaging existing community groups and structures in PMTCT are described below. The first highlights local collaboration with CBOs to strengthen the continuum of care. The second illustrates the importance and value of engaging PLHIV networks and the third emphasizes the role that religious entities can play in encouraging use of health services.

- An on-going project in five districts of Malawi demonstrates that engaging local CBOs can increase community-to-facility referrals for PMTCT. An important tool in the process is a duplicate referral form that allows the CBOs to independently verify that referred clients have secured care. The CBOs, recipients of six-monthly supportive supervision and mentorship, assigned a referral point person for each facility to attend coordination meetings. During the six months prior to and after the intervention, three of the CBOs documented a six-fold increase in community-to-facility PMTCT referrals. Based on the promising early results, the referral strategy has been scaled-up to include more than 40 organizations.<sup>82</sup>
- The network support agent (NSA) example described in the 2012 UNAIDS case study on community engagement was implemented through PLHIV networks. Some 420 existing PLHIV groups organized themselves into 55 network clusters with one group identified as lead. Training was accomplished through a cascade model. At the end of the three-year project cycle, 1,302 PLHIV trained as NSAs were working with 643 health facilities and their surrounding communities, providing HIV prevention education, client tracking,

leadership for income generating activities and promotion of male involvement. During one year, the number of clients on ART reached with adherence counselling increased tenfold from 17,000 to 170,000. Referrals to facilities and CBOs increased from 5,000 to 115,000. Qualitative evidence of decreased stigma, increased disclosure, reduced client waiting times and improved tracking of client outcomes was also documented.<sup>83</sup>

- A PMTCT project in Kenya collaborated with 20 health facilities and the Kenya Council of Imams and Ulamaa, a longstanding local FBO. The project trained 25 Imams (mosque prayer leaders) and 85 Maalimat (female religious instructors) in PMTCT to address Muslim women's low use of health facilities. The Imams integrated this information into their Friday sermons and other social gatherings while the Maalimat introduced it through focus group discussions. In total, the project reached 76,000 individuals with PMTCT messages. In one year (May 2013-April 2014), the number of pregnant women tested for HIV increased more than 50 per cent from 770 to 1,183. The proportion of women who tested positive and accepted ARVs increased from 63 per cent in the first quarter to 93 per cent in the third quarter. Testing of male partners and skilled deliveries also increased during this period. Lessons learnt included the importance of integrating religious perspectives and teachings, involving men and engaging multi-sectoral community stakeholders.<sup>84</sup>
- A unique study in Zimbabwe sought to determine how local groups and structures were enabling people to achieve optimal ART access and adherence. The methodology involved 67 interviews and eight focus group

82 EGPAF Malawi, 2014 International AIDS Conference poster and personal communication

83 Kim YM et al 2012

84 Mohammed 2014

discussions with health workers, adults on ART and caregivers for children on ART as well as more than 100 hours of observation at HIV treatment sites. Indigenous groups included church groups, burial societies, rotating credit societies, farmer's groups, sport and dance clubs, youth clubs and women's groups. The study found that home-based care groups and church groups play a central role in ART access and adherence while other family and community networks also play a supportive role. The authors concluded "more attention to the community context in which HIV initiatives occur will help ensure that interventions work with and benefit from pre-existing social capital."<sup>85</sup>

### **Implementation guidance**

- Conduct a mapping exercise to identify, locate and describe all local groups and networks providing PMTCT related or supportive services in the target area as a first step towards strengthening community-facility linkages.
- Develop formal agreements between health facilities and selected community partners that define how each group operates and how they interact and support one another in the provision of PMTCT services and support.
- Provide capacity building support and sustained funding to enhance community partner performance without overwhelming or undermining their existing resources and initiative.<sup>86</sup>
- When feasible, systematically document the engagement and results achieved by local organizations in the scale-up of lifelong ART for pregnant and breastfeeding women living with HIV.

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85 Scott 2013

86 Foster 2005

## **Community-based HIV Counselling and testing (HCT)**

### **Rationale**

This promising practice involves extending HCT services into communities and homes through facility outreach, community-based health workers and volunteers or by other means. It is intended to ease physical, social and economic access. To date, HCT is the HIV-related service most commonly extended into communities. This can be done in a mass effort, often through door-to-door campaigns, or on a smaller scale through home visits to test women in hard-to-reach areas and household contacts, such as partners, children and other family members. The WHO guidance for home-based HCT is listed in Annex 2.<sup>87</sup>

### **Findings**

Three large studies in Kenya, Uganda and Malawi provide evidence on the acceptability, feasibility and effectiveness of community-based HCT.

- A study in Kenya looked at quantitative, qualitative and cost factors for a community-wide home-based HCT effort in a high prevalence rural setting. Home-based HCT was well accepted and the intervention was feasible with high uptake and relatively low cost. Just over 60 per cent of all 15-49 year olds exposed to the programme and 98 per cent of those who agreed to a counsellor's home visit consented to HCT. The adult HIV prevalence rate was 8.2 per cent with married women nearly five times as likely to be HIV-infected than never married women. Both the uptake and cost of home-based testing compared favourably with facility-based testing.<sup>88</sup>

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87 Annex 2 – WHO et al 2012

88 Negin 2009

- In Uganda, a retrospective cohort study was undertaken of 84,323 individuals who received HCT at one of four programmes (hospital, stand-alone facility, door-to-door and HCT for household contacts) during 2003-2005. The two community models, which accounted for approximately 60 per cent of all clients tested, reached the highest proportion of previously untested individuals (greater than 90 per cent of all clients tested) and identified HIV infection earlier than the facility-based testing strategies. The cost for each client reached was relatively low across all four models, ranging from US\$8.29 per client for door-to-door to US\$19.26 for stand-alone facility.<sup>89</sup>
- Investigators in Malawi added a sample of semi-structured interviews and observational data to a longitudinal household panel in Malawi to look at what contributed to higher rates of acceptance in door-to-door HCT (91 per cent in 2004) than for facility-based HCT (15 per cent of men and 13 per cent of women according to the 2004 Demographic Health Survey). The authors found that the door-to-door HCT campaign had significantly higher acceptance rates because of its convenience (physical and financial), confidentiality measures, and the credibility of the dried blood spot (DBS) method.<sup>90</sup>

### **Implementation guidance**

- Consider community-based and door-to-door HCT in high prevalence settings with low rates of prior testing and in areas or populations where gender norms or other factors may prevent women from accessing facility-based testing.
- Consider home-based contact HCT where partner and/or infant testing are low and where evident barriers to facility-based testing exist.

- Establish quality counselling, strict confidentiality measures, continuous stock of supplies and effective ART referral mechanisms for community-based HCT.
- Ensure quality HIV prevention counselling and effective referral when indicated for those who test negative.

## **Community ART distribution**

### **Rationale**

More recently, several models for extending the delivery of ART refills in communities for stable and immunosuppressed clients have also been documented. What these models all share in common is that they further decentralize ART care, lower the frequency of required clinic visits, promote self-efficacy in ART, provide adherence support and defaulter tracing and, in most cases, rely on trained community cadres.

### **Findings**

The evidence base includes an initial randomized controlled trial from Uganda that demonstrated the feasibility and acceptability of dispensing ARVs at community level and more recent programme monitoring data from Médecins sans Frontières (MSF).

- A two-year (2007-2009) randomized controlled trial in the rural and urban areas of Jinja, Uganda demonstrated home-based ART delivery matched facility-based delivery in patient survival and viral suppression. The authors concluded "This home-based HIV care strategy is as effective as is a clinic-based strategy, and therefore could enable improved and equitable access to HIV treatment, especially in areas with poor infrastructure and access to clinic care."<sup>91</sup>

<sup>89</sup> [Menzies 2009](#)

<sup>90</sup> [Angotti 2009](#)

<sup>91</sup> [Jaffar et al 2009](#)

In 2012 and 2013, MSF documented their programme experience with community ART distribution models in DRC, Malawi, Mozambique and South Africa. Pregnant women took part in the programmes in Malawi, Mozambique and South Africa.<sup>92</sup> The goal is to improve ART retention while reducing the heavy and growing client load at health care facilities. The models and their results are described below:

- In Malawi, health surveillance assistants and peer counsellors are trained to provide ART refills at rural health posts. Clients obtain refills of their ARVs every three months and visit the clinic for screening every six months. Against a country backdrop of 80 per cent, this strategy achieved 97 per cent retention at one year of follow-up.
- In Mozambique, patients join adherence groups and are trained by lay counsellors. They then take turns collecting ARVs and giving patient status updates for all members to the clinic once every six months. In this way, each client has a clinical screening and consultation every six months. The groups also provide a support network for one another. Against a national rate of 74 per cent, these groups achieved 97 per cent retention at an average follow-up time of six months. This strategy has been adopted nationwide. A pilot of the community adherence group model with PMTCT clients on lifelong ART is currently underway in Tete Province, Mozambique.
- Adherence clubs have been active in South Africa since 2007. These groups, of approximately 30 clients, meet every two months for basic health assessment by a trained counsellor. Over a period of 40 months, ART retention increased from 85 per cent to 97 per cent and viral rebound declined by half. A

toolkit for implementing community adherence groups is listed in Annex 2.<sup>93</sup>

- In DRC, community ART distribution points were established. They are run by trained PLHIV. Services offered include ART refill, adherence counselling and basic health assessment. Relative to facility service provision, this strategy cost 25 times less per visit (\$9 vs. \$230); reduced client transport costs by threefold; and reduced time spent on average by each client to secure their ARV refills from 85 minutes to 12 minutes. Nearly half (43 per cent) of ART clients chose this model and the retention rate achieved at 12 months follow-up was 89 per cent.<sup>94</sup>

These encouraging findings indicate that ARV refills can be shifted to community level and improve ART retention rates, client self-efficacy and reduce costs for both clients and the health care system. Such strategies may be especially beneficial for supporting long-term ART adherence and retention after childbirth among women living with HIV.

### **Implementation guidance**

- Consider introducing or expanding community-based ART distribution, especially in high prevalence rural areas where infrastructure and access are a challenge.
- Consider local barriers to retention, the extent of health service decentralization, task-shifting practices and any regulatory or logistical constraints when choosing an appropriate model for community ART distribution.
- Collaborate with PMTCT clients and other community stakeholders on decisions about the most appropriate community ART distribution model and the implementation details.

92 MSF and UNAIDS 2012, MSF SAMU 2013

93 Annex 2 – MSF 2013(1)

94 MSF SAMU 2013

- Ensure careful training and supervision of lay distribution agents; effective two-way referral from clinic to community; and a reliable supply of ARVs extending to community level.

## Comprehensive approaches

Separating out the promising practices, as in this review, is useful for planning and monitoring, but artificial in terms of implementation. No single intervention will address the complex array of factors involved in community-facility linkages for improving performance across the continuum of care. Comprehensive PMTCT programmes may involve multiple interventions at both the facility and community level. Both the Tingathe programme in Malawi and the network support agent effort in Uganda described earlier in this document used multiple community-level strategies to achieve their notable results.

Three additional examples of multi-pronged approaches that cover more than one domain of the framework and have achieved significant results are outlined below.

- An ART cohort study involving four sites in Lesotho, South Africa, Namibia and Botswana assessed health-related changes from 2005-2007 and correlated them with a comprehensive community support programme. Treatment eligibility criteria during this time were high and people were often unwell when they initiated ART. The package of community interventions in this study included psychosocial support through treatment buddies and support groups, treatment literacy and prevention education, food support, income generating activities and orphan care

(Domain 1), outreach for return to care (Domain 2) and outreach HCT and home-based care in remote areas (Domain 4).

At the end of the 18 months, 377 PLHIV had been followed with clinical evaluations and questionnaires. The authors found that the intervention group had more rapid and higher increases in their CD4 counts, better adherence and higher scores in cognitive functioning, emotional wellbeing and overall health-related quality of life than the control group. The association remained after controlling for age, education level, gender and baseline CD4 count. The authors recommended further research to address broader community-level impact (Domain 3) and cost-effectiveness.<sup>95</sup>

- The Zambia Prevention, Care and Treatment Partnership launched in 2005 to expand HIV services in five provinces. The project combined facility improvement and community linkage activities to increase access to and uptake of quality services. At facility level, the project invested in service integration, physical refurbishment, development of human resources and systems strengthening. At community level, community members were trained as lay counsellors, adherence support workers (ASWs) and PMTCT motivators to provide individual client support (Domain 1), ASWs conducted home visits to follow-up on missed clinic appointments (Domain 2), traditional and religious leaders were engaged to sensitize the community, reduce stigma and mobilize male involvement, while also establishing male peer groups (Domain 3) and outreach ANC and HCT were provided in geographically remote areas and CBO referral

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95 Kabore et al 2010



networks were established (Domain 4). Over 39 months of observation, acceptance of HCT doubled from 45 per cent to 90 per cent and acceptance of a full course of ARV prophylaxis by pregnant women increased from 29 per cent to 97 per cent. The authors highlighted the use of lay workers to address health worker shortages and improve service quality as well as the important role of traditional leaders in mobilizing communities to encourage uptake of HIV services, especially to increase male involvement.<sup>96</sup>

- A more recent example comes from rural Ethiopia where geographic access to skilled health providers is a major challenge. As a baseline, less than half of women receive ANC, 10 per cent have skilled delivery and only 7 per cent receive postnatal care. This project operated in three districts in two regions from 2009 to 2013 and supported a multi-faceted community strategy. As access was the most significant barrier, Domain 4 was the priority focus. Health extension workers, traditional birth attendants and community health development agents were trained in home-based lifesaving skills and provided home-based services to pregnant women (Domain 4). Family meetings were conducted to build skills and care seeking behaviour for maternal and newborn health (Domain 1). Community-based workers were made known to and followed pregnant women in the community (Domain 2). Quality improvement teams were established to identify and solve local barriers for MNCH. Team participants included local council members, priests, leaders of agricultural and women's associations and the three cadres of community health workers. Finally, culturally

appropriate behaviour change communication was promoted through various activities to increase demand for services and promote teamwork at community level (Domain 3).

The project results were assessed through a before-and-after study design. Key findings included: the mean number of safe motherhood interventions received by women increased from 18 per cent to 70 per cent in one region and from 43 per cent to 87 per cent in the other. ANC was received by 86 per cent of pregnant women and 51 per cent had received four or more visits. In one region, the proportion of first ANC visits made during the first trimester doubled (15 per cent to 30 per cent). The use of a trained provider for postnatal care increased dramatically to 77 per cent and 84 per cent in the two regions and the majority of these visits were within 48 hours of birth. Finally, the assessment showed that there was a significant increase in the number of days between perinatal deaths beginning about nine months after the roll out of the strategy. The authors concluded this "integrated model was associated with improved coverage and completeness of care and improved perinatal survival. The model is adaptable and potentially scalable."<sup>97</sup>

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96 Torpey et al 2010

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97 Sibley et al 2014

## V. KEY OPERATIONAL CONSIDERATIONS

In most countries in sub-Saharan Africa, there are numerous community activities underway to support PMTCT, ART and/or MNCH as well as other health and social development programmes. Often, several different community-facility linkages are implemented at the same time and numerous community cadres are at work with support from different programmes and partners. The job descriptions, remuneration and other support provided to these cadres may vary and contribute to high attrition with low morale among community workers. In many instances, community approaches, whether nationwide or specific to individual projects, do not have clearly defined indicators of success nor have they been consistently documented or formally evaluated. Under these circumstances, expected results may not be achieved, be short-lived or be misinterpreted.

A few countries are planning or engaging in a process to streamline and better standardize evidence-based community-facility linkages. For example, under the leadership of the Ministry of Health, partners in Malawi have catalogued facility and community PMTCT support activities to inform decisions about their PMTCT scale-up package.<sup>98</sup> In DRC, the national AIDS programme plans to review the experience of implementing different community-facility linkage activities in the six districts that piloted lifelong ART for pregnant and breastfeeding women to help in selecting an experience-based package of activities for scale-up.<sup>99</sup> By undertaking such processes and better monitoring community-facility linkages, countries can improve their programme results while realizing greater cost efficiencies and enhancing sustainability.

The tables below outline key operational considerations to support government-led country teams in streamlining, standardizing and scaling-up community-facility linkages in support of PMTCT, HIV and MNCH. The key considerations are presented in three phases: planning, implementing and monitoring.

### Planning

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<p><b>ENGAGE STAKEHOLDERS</b></p>	<p>Effective community-facility linkages require the early and meaningful engagement of a broad range of stakeholders. Depending on the mandate and capacity of current structures, an existing or a new working group can be tasked and strengthened to plan, oversee and coordinate the process of strengthening community-facility linkages. Membership will vary from country to country, but at a minimum should include:</p> <ul style="list-style-type: none"> <li>• <i>Government:</i> ministry of health and agencies or units responsible for human resources (civil service); local government and community development; women and gender.</li> <li>• <i>Civil society:</i> PLHIV networks, NGOs including CBOs, FBOs and umbrella organizations.</li> <li>• <i>Other partners:</i> UN agencies, donors, implementing partners in PMTCT, ART and MNCH.</li> </ul> <p>Ideally, this working group would be a permanent public sector unit to oversee and coordinate community-level activity in HIV and/or health.</p>

96 Keehn and Karfakis 2014

97 Personal communication

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<b>ASSESS THE POLICY AND LEGAL ENVIRONMENT</b>	<p>Policies and laws that can enable or hinder community-facility linkages should be assessed at the outset. A high priority area for review is task-shifting, especially regarding the devolution of authority for initiating ART and refilling ARVs, HCT and other PMTCT-related tasks. This will guide what can currently be accomplished at community level and what policies and laws may require revision. Global recommendations and guidelines for task-shifting in HIV and MNCH are included in Annex 2.<sup>98</sup></p>
<b>ASSESS COMMUNITY- LEVEL HUMAN RESOURCES FOR HEALTH</b>	<p>Community-facility linkages are dependent on community health cadres. However, there is wide variation across and within countries regarding these cadres. To strengthen community-facility linkages, planners should examine the job descriptions, qualifications, recruitment and retention strategies and remuneration schemes for relevant community cadres. Are they sufficient to attract and retain a qualified and motivated community-level workforce for scale-up? If not, how can these cadres be expanded, better standardized, adequately remunerated and otherwise strengthened?<sup>99</sup> Countries may consider a dedicated community cadre to support reproductive, maternal, newborn and child health, including PMTCT and ART. A toolkit for improving CHW programmes is listed in Annex 2.<sup>100</sup></p>
<b>CATALOGUE CURRENT COMMUNITY ACTIVITIES</b>	<p>Another important foundational step is to describe current community-facility linkages. This can be done through document review and stakeholder interviewing.<sup>101</sup> Once compiled, the information can be assessed in terms of resource requirements, extent of implementation, results achieved and how well current practices address the conceptual model's four domains of support for mother-infant pairs.</p>
<b>SELECT COMMUNITY-FACILITY LINKAGES TO SCALE-UP</b>	<p>An open and transparent process should be used to generate consensus for a standard package of community-facility linkages for scale-up. Factors to consider include:</p> <ul style="list-style-type: none"> <li>• programme performance including current data on the PMTCT cascade and bottlenecks</li> <li>• the policy environment</li> <li>• existing capacities and available resources</li> <li>• experience with current linkage activities</li> <li>• the conceptual model and the 11 promising practices described in this document.</li> </ul>
<b>REVIEW AND REVISE PROTOCOLS</b>	<p>Review standard protocols for referral, linkage, missed appointments and client follow-up to ensure that they are in line with clinical requirements; reflect current evidence on retention; and clearly define the roles and responsibilities at community level. Identify and plan for any needed revisions in these protocols in light of the tailored package of community-facility linkages.</p>

98 Annex 2 - WHO et al 2007, WHO 2012

99 Earth Institute 2011

100 Annex 2 – Crigler et al 2011

101 For an example from Malawi, see Keehn and Karfakis 2014

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<b>DEVELOP STANDARD MESSAGES</b>	<p>Communication is a central component of all community-facility linkages. It is important to review current communication messages; to undertake, as needed, a structured process of formative research, message development and field-testing to ensure that messages and communication tools are relevant to the scale-up activity within the social and cultural context. These national messages can be modified as appropriate for use at local level (e.g., translation into local dialects or to address specific local bottlenecks).</p>
<b>PLAN FOR SCALE-UP</b>	<p>Determine scale-up requirements, ensuring that key factors for success, including capacity development and monitoring, are adequately costed. Phasing, by location or by practice, may be a reasonable option if nationwide implementation of the full package of community-facility linkages exceeds current capacity and resource availability.</p> <p>Develop a joint costed national plan for building capacity and scaling-up the package of community-facility linkages. This plan should include timelines, persons/entities responsible, budget and funding source.</p>

## Implementing

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<b>ENGAGE LOCAL STAKEHOLDERS</b>	<p>Broad stakeholder engagement is also essential at local level, including health facility staff, local government authorities, traditional leaders and various PLHIV, community and faith-based groups and volunteers. Engaging interested groups early in the dialogue on scaling-up community-facility linkages will help to ensure that the process is successful, locally owned and sustainable. It may be possible to task and strengthen existing structures (e.g., health development committees) or it may be necessary to introduce a new structure for local level planning, coordination and oversight of community-facility linkages.</p>
<b>CONDUCT COMMUNITY MAPPING</b>	<p>All communities have existing social capital and it is important to map out the local structures and groups currently engaged in health and social development. Once mapped, relevant groups can be approached to extend or improve PMTCT-related clinical and supportive services. In particular, synergies can be created with private health initiatives, protection programmes including those that address gender-based violence, nutrition and agricultural development schemes and early childcare.</p>

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<b>FORMALIZE WORKING ARRANGEMENTS</b>	Develop clear and mutually endorsed agreements between health facilities and collaborating local partners. These agreements should specify roles and responsibilities in terms of service delivery as well as communication, reporting, oversight and mutual accountability.
<b>ENSURE ADEQUATE TRAINING AND SUPPORT FOR COMMUNITY CADRES</b>	<p>Most of the promising practices rely on qualified and motivated lay cadres. Working within national guidance:</p> <ul style="list-style-type: none"> <li>• Ensure community workers are provided with standardized, skills-based training.</li> <li>• Integrate community workers as part of the health care team through, for example, regular and supportive supervision and participation in periodic review meetings.</li> <li>• Ensure community leaders are aware of the community workers in their areas and, when possible, have a role in selecting and supporting these workers.</li> <li>• Monitor the workload of community cadres to ensure it is viable.</li> </ul>
<b>PROMOTE QUALITY COMMUNICATION ACROSS ALL COMMUNITY-FACILITY LINKAGES</b>	The quality of client communication and counselling has a direct effect on the results achieved. <sup>102</sup> Ensure messages are tailored to the local context and community workers receive practical training in communication skills and human rights. Through training and supervision, emphasize client confidentiality and the elimination of negative attitudes, judgement and stigma from all health communication.

## Monitoring

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<b>ESTABLISH A COLLABORATIVE OVERSIGHT FUNCTION FOR COMMUNITY-FACILITY LINKAGES</b>	The broadly representative committee (task force or working group) responsible for coordinating community-facility linkages at each level should also be tasked with a monitoring function. Shared accountability between facilities and the communities they serve will be essential to the success of linkage activities.
<b>IDENTIFY INDICATORS</b>	When selecting community-facility linkages for scale-up, agreement should be reached on a minimum set of meaningful indicators that will be routinely measured to ensure the programme is on track and the expected health-related results are being achieved.

102 Flickinger 2013, Lamb 2012, Kieffer et al 2014

KEY ISSUE	SUGGESTIONS FOR COUNTRY TEAMS
<p><b>DOCUMENT COMMUNITY-FACILITY LINKAGES</b></p>	<p>Information needed to measure the indicators for community-facility linkages should be integrated into existing registers and reports or, if necessary, a limited number of simple new tools introduced. All community-level tools should reflect the level of literacy of the cadres expected to use them and the stakeholders expected to review them.</p>
<p><b>SELECT AND IMPLEMENT MONITORING AND ACCOUNTABILITY METHODS</b></p>	<p>It is also necessary to agree on how the indicators will be measured and to define a monitoring process that includes periodic review and redress mechanisms. A review of experience with scorecards, quality improvement approaches and other methods is listed in Annex 1.<sup>103</sup></p> <p>At a minimum, periodic meetings at each level to jointly review the data followed by action planning to address problems identified will be needed and should be included in budget planning.</p>
<p><b>CONDUCT IMPLEMENTATION RESEARCH</b></p>	<p>As noted previously, the evidence base on community-facility linkages is limited. Additional studies that document the nature, context, results achieved and learning from existing and experimental community-facility linkages in support of PMTCT, ART and MNCH are needed.</p> <p>A few general topics recommended for further research would assess community-facility linkages:</p> <ul style="list-style-type: none"> <li>• To improve (1) early uptake of ANC, (2) ART initiation by and retention of pregnant and breastfeeding women, and (3) infant follow-up for EID, feeding practices and paediatric care and treatment.</li> <li>• To support specific key groups (e.g., women who are not in stable partnerships, young mothers).</li> <li>• For urban and peri-urban settings.</li> </ul>
<p><b>BUILD CAPACITY FOR MONITORING AND EVALUATION</b></p>	<p>Many organizations engaged in community-level support for health and social development lack the capacity and resources to develop and implement effective monitoring systems. So an essential component of scaling-up community-facility linkages is to build capacity of community partners for monitoring and evaluation.</p>

103 USAID 2014

## VI. THE LEARNING CONTINUES

This review endeavoured to summarize, package and build programming recommendations from the available evidence on community-facility linkages in PMTCT, adult ART and MNCH. As noted previously, this evidence base is not comprehensive and is challenged by the variability of context and other factors that affect implementation and scale-up.

The good news is that the evidence base is also dynamic. New programme and research initiatives are continually starting. A few current examples from formal research include:

- In Swaziland, Uganda and Zimbabwe, a large-scale three-arm intervention trial is being implemented to compare the impact of the purposeful engagement of community leaders, targeted community health dialogues, and community peer groups on PMTCT-related behavioural and operational outcomes, from early uptake of ANC through infant HIV testing at 6-8 weeks. It is estimated that this study will be completed in March 2016.<sup>104</sup>
- Several studies are being supported through the 'Integrating and Scaling up PMTCT through Implementation Research' (INSPIRE) initiative of WHO and the Canadian Government. These include research on community-based interventions such as mentor mothers (in Nigeria and Zimbabwe), peer-based facility and outreach support (Malawi) and integrated mother-child clinics and outreach follow-up (Malawi) to improve adherence and retention along the PMTCT continuum. Completion of the studies is expected in 2016.<sup>105</sup>
- Research supported through the National Institutes of Health (NIH)/President's Emergency Plan for AIDS Relief (PEPFAR) Implementation Science Alliance<sup>106</sup> includes a study to assess the effect of 'feeding buddies' on adherence to WHO PMTCT guidelines (South Africa<sup>107</sup>; conditional cash transfers to improve PMTCT uptake and retention (DRC)<sup>108</sup>; and comparing the effectiveness of congregation-based and clinic-based approaches to PMTCT (Nigeria).<sup>109</sup> The estimated completion of these studies is March 2015, October 2015 and September 2016, respectively.
- WHO and UNICEF adapted the guidelines for integrated community case management of childhood illnesses (iCCM) to incorporate HIV and TB in addition to diarrhoea, malaria and pneumonia. A pilot is now being planned to train CHWs in Zambia and Malawi for the roll out of these adapted guidelines. The goal is to expand EID and improve paediatric case finding.<sup>110</sup> The revised materials are included in Annex 2.<sup>111</sup>

With these and other formal and informal studies on the horizon, it is of great importance to ensure broad dissemination and integration of new findings within programming networks. The IATT, including its [website](#) and [community of practice](#), can play an important role in this process.

104 Woelk et al 2014, Kieffer 2014 and interpersonal communication

105 JAIDS November 1, 2014 - Volume 67 - Supplement 2

106 Sturke et al 2014

107 Israel-Ballard et al 2014

108 Yotebieng et al 2015

109 Ezeanolue et al 2013

110 Reid 2014

111 Annex 2 – WHO and UNICEF 2014

## VII. RECOMMENDED NEXT STEPS AT COUNTRY LEVEL

Community-facility linkages have a vital role in the scale-up of PMTCT, ART and MNCH and will be essential for achievement of the Global Plan targets, health-related Millennium Development and post-2015 goals. Broad recommendations to support governments, communities and their partners in creating and expanding more productive and efficient ties between health facilities and the communities they serve to improve health outcomes and quality of life for women, their children and families are offered below.

**1. Identify and scale-up a national package of community-facility linkages.** Convene relevant public sector, civil society and community stakeholders to undertake a process aimed at streamlining, redefining and expanding community-level work to address the four domains of support. The principal guidance for each domain is as follows:

- **DOMAIN 1 EMPOWER CLIENTS:** Shape client support and support group interventions to empower women and their families for greater self-efficacy in managing their HIV and overall health. Assign a treatment supporter – a peer, CHW or buddy – for every PMTCT client.
- **DOMAIN 2 PROVIDE LONGITUDINAL FOLLOW-UP OF MOTHER-INFANT PAIRS:** Establish and enforce rigorous and rapid follow-up protocols. Include outreach (home visits) for missed appointments by pregnant women, mothers and their infants.
- **DOMAIN 3 IMPROVE THE CARE SEEKING ENVIRONMENT:** Use community strategies to positively involve men in ANC and PMTCT. Avoid punitive measures and sole reliance on PMTCT clients for male participation. Purposefully engage opinion leaders to address social and gender-related barriers to care.
- **DOMAIN 4 FACILITATE ACCESS:** Build on existing social capital – including NGOs, FBOs, CBOs and informal groups – to expand PMTCT services and support. Mobilize outreach and/or community-based services in remote areas and for under-served populations.

**2. Aim to task-shift to the lowest possible level to support decentralization, help to fill the gaps created by health worker shortages and improve programme coverage.** Strengthened capacity and greater use of community cadres is an important priority for PMTCT, ART and MNCH. An up-to-date and responsive national task-shifting framework that includes plans for training, supervision and quality assurance is essential to the success of task-shifting.

**3. Build a stronger, more effective frontline workforce.** Augment government-supported community cadres for reproductive, maternal, newborn, child and adolescent health by increasing their numbers, standardizing job descriptions and providing adequate remuneration, training and supportive supervision. Implementing partners who support community cadres should align themselves with national standards and support a transitioning plan.



- 4. Increase investment in community-facility linkages.** As demonstrated through research and experience, community-facility linkages can help to fill the gaps created by health worker shortages, enhance service quality, promote client self-efficacy and improve service uptake, adherence and retention. Yet funding to support community-facility linkages is often scarce and sporadic. Governments and their partners at all levels should increase investment to support the effective scale-up of nationally defined results-based packages of community-facility linkages.
- 5. Establish and support mutual accountability mechanisms** that engage health care providers, local government and community members. Include education about health-related rights and responsibilities, agreed upon indicators, reporting tools and periodic joint review meetings at all levels to assess results and plan for improvement.
- 6. Contribute to the evidence base by systematically** documenting the roll out and results of community-facility linkages; conducting implementation research; building the capacity of community partners in monitoring and evaluation; and supporting the dissemination of relevant research findings.

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## ANNEX 2: TOOLKITS AND GUIDANCE

Some good practice guides and toolkits for the promising practices described in this report are listed below. Some are not specifically targeted to PMTCT or Option B+, but include relevant guidance that can be adapted. Additional guidelines and toolkits can be found on the IATT website ([www.emtct-iatt.org/resources-main](http://www.emtct-iatt.org/resources-main)) and USAID's K4Health website ([www.k4health.org/toolkits/all](http://www.k4health.org/toolkits/all)) among others.

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