Ethiopia's Prevention of Mother-to-Child Transmission (PMTCT) Programs: addressing attrition and loss to follow-up

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B.A. (Health Sciences), Simon Fraser University, 2010

RESEARCH PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF PUBLIC POLICY

> in the School of Public Policy Faculty of Arts and Social Sciences

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SIMON FRASER UNIVERSITY

Spring 2012

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Abstract

Each year more than 90 percent of childhood HIV infections (>390,000 infections) occur in Sub-Saharan Africa. In Ethiopia, mother-to-child transmission accounts for over 95 percent of childhood infections. Despite PMTCT programs in Ethiopia, attrition and loss to follow-up (LTF) are high, threatening the effectiveness of PMTCT intervention. This research identifies points where women, or mother-infant pairs, become disengaged and are lost to the system. Semi-structured interviews and qualitative coding revealed four major points of LTF along the PMTCT cascade: (1) ANC uptake, (2) ARV adherence, (3) post-delivery, and (4) post-infant vaccinations. Promising interventions for increasing retention, and reducing LTF are presented for each dropout point.

Policy and programming options addressing the first point of LTF – low ANC uptake by pregnant women – are explored and evaluated within the Ethiopian context. Two simultaneous strategies are recommended for increasing ANC uptake: (1) community education sessions and (2) expansion of Ethiopia's Mother Support Group.

Keywords: HIV/AIDS; Prevention of Mother-to-Child Transmission (PMTCT); Antenatal Care (ANC); Ethiopia; Loss to Follow-up (LTF); Attrition "No man is an island, entire of itself" - John Donne

Acknowledgements

This capstone could not have been written without the willing participation of interviewees. Your collective enthusiasm and commitment to preventing mother-to-child transmission of HIV and improving the lives of women and children across the globe is contagious. Your innovation and ingenuity were vital to the research process. It is with many thanks to you, as participants, that this capstone came to fruition.

I wish to thank Olena Hankivsky, who provided support and guidance from the proposal stage through to the final stages of defense and submission. Your comments were insightful and pushed me to refine this research into something more useful. Simultaneously, I wish to thank my current and former professors, colleagues, and fellow public health enthusiasts for introducing me to public health research and action in the first place and for giving me much reason to be passionate about it.

Finally, I owe a multitude of gratitude to my family and friends. Collectively, you ensured that I did not become an island over the past two years, providing me with ample pleasant – and necessary – distraction. Your endurance, with interest or obligation, of more than anyone's fair share of public health conversation, was not lost on me.

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List of Acronyms

AMPATH	Academic Model Providing Access to Healthcare		
ANC	Antenatal Care		
ART	Antiretroviral Therapy		
ARV	Antiretroviral		
CCT	Couple Counselling and Testing		
CHAI	Clinton Health Access Initiative		
CHWs	Community Health Workers		
CIDA	Canadian International Development Agency		
DFID	Department for International Development		
DHS	Demographic and Health Survey		
DPT3	Diphtheria, Pertussis, and Tetanus Vaccine		
EID	Early Infant Diagnosis		
ELISA	Enzyme-linked Immunosorbent Assay		
eMTCT	Elimination of Mother-to-Child Transmission		
ERTA	Ethiopian Radio and Television Agency		
HCT	HIV Counselling and Testing		
HEP	Health Extension Program		
HEWs	Health Extension Workers		
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome		
HMIS	Health Management Information System		
HRH	Human Resources for Health		
HSEP	Health Service Extension Program		
ICAP	International Center for AIDS Care and Treatment Programs		
I-TECH	International Training and Education Center for Health		
LTF	Loss to Follow-up		
M&E	Monitoring and Evaluation		
MARPs	Most-at-Risk Populations		
MDGs	Millennium Development Goals		
MNCH	Maternal, Newborn, and Child Health		
MTCT	Mother-to-Child Transmission		
ODA	Official Development Assistance		

P4P	Purchase for Progress		
PCR	Polymerase Chain Reaction		
PEs	Peer Educators		
PEPFAR	President's Emergency Plan for AIDS Relief		
PIH	Partners in Health		
PMTCT	Prevention of Mother-to-Child Transmission		
RHB	Regional Health Bureau		
SRH	Sexual and Reproductive Health		
SSA	Sub-Saharan Africa		
STI	Sexually Transmitted Infection		
ТВ	Tuberculosis		
UNAIDS	Joint United Nations Programme on HIV/AIDS		
UNFPA	United Nations Population Fund		
UNICEF	United Nations Children's Fund		
USAID	United States Agency for International Development		
WFP	World Food Programme		
WHO	World Health Organization		

Executive Summary

Mother-to-child transmission of HIV is a core public health challenge for Sub-Saharan African countries. In Ethiopia, mother-to-child transmission (MTCT) accounts for 95 percent of childhood HIV infections. Despite significant financial investment and piloting evidence-based prevention of mother-to-child transmission (PMTCT) interventions, Ethiopia's PMTCT progress lags behind other Sub-Saharan Africa countries. This results in a consistently heightened mother-to-child transmission rate. High attrition and loss to follow-up appear to be major contributing factors to lower PMTCT effectiveness.

Chapters 1 and 2 provide a background to HIV infection in Ethiopia and the health sector response to this epidemic. These sections explore the problem of loss to follow-up (LTF) of mothers, and mother-infant pairs, along the PMTCT cascade – which entails critical service points along the period of HIV mother-to-child transmission vulnerability. Literature on LTF in PMTCT programs is sparse and clarity on where mothers and mother-infant pairs are lost is absent.

Chapter 3 presents the research methodology employed in this project to addressing the uncertainty surrounding where LTF occurs along the PMTCT cascade, using a case study approach to Ethiopia. The case study approach allowed for an indepth understanding of the structures and challenges that Ethiopia faces. Throughout the course of this research, the pragmatic paradigm was employed – essentially matching the methods to the purpose of the research... using a 'what works' approach. The case study was ground in a qualitative inductive methodology, allowing themes to emerge from the data. The case study utilized both qualitative and quantitative data from relevant bodies of literature, PMTCT program data from various organizations including the Ethiopian Ministry of Health, the World Health Organization, UNAIDS, and various global health research bodies. In addition, qualitative evidence was gathered through 15 semi-structured interviews with individuals working in PMTCT programming and practice in Sub-Saharan Africa, specifically Ethiopia.

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Chapter 4 presents the major research findings. Four major themes emerged from the research, highlighting where women, and their infants, are lost to follow-up along the PMTCT cascade: (1) Antenatal care uptake, (2) ARV adherence, (3) postdelivery, and (4) post-infant vaccinations. Low antenatal care (ANC) uptake was a major point of LTF as reported by interviewees. Quantitative Ministry of Health data confirmed this finding, reporting that only 27 percent of pregnant women attend at least one antenatal care visit. Participants shared that women often refrained from seeking antenatal care because of fear of care and HIV testing, cultural norms surrounding pregnancy and childbirth, lack of partner support, and finally a significant gap in community mobilization and awareness of ANC.

Antiretroviral (ARV) adherence comprises the second point of LTF along the cascade. Obtaining ART/ARVs is difficult, particularly in rural areas, of Ethiopia. Where sufficient pharmaceutical stockpiles exist, distributing the medication remains challenging. Even where mothers are able to obtain ART/ARVs, data from surround Sub-Saharan countries suggests that one-third of women who receive ARVs, never ingest them.

Poor facility delivery rates result in the third major point of loss to follow-up. Infants born outside of health facilities, typically stay outside the formal care system. The facility rate is below 10 percent in Ethiopia. Infants born outside of the health care facilities miss critical PMTCT interventions.

The final point of LTF identified through the research process was post-infant vaccinations. The vast majority of mother-infant pairs are LTF before infant vaccinations. However, most women return to care for immunizations. While vaccinations may be an opportunity to 'find' children who have previously been LTF, many critical intervention windows have already passed by the time mothers bring their children for immunization, compromising PMTCT program effectiveness.

Targeting interventions to the beginning of the cascade has the greatest potential health impact. Increasing ANC attendance is the first step in improving program effectiveness and maternal, newborn, and child health. Furthermore, sensitizing communities to the importance of ANC is vital. Simply building more health facilities is

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insufficient. A demand creation approach, at the community level is a necessary next step.

The need to focus on ANC attendance, particularly at the community level, is reflected in the proposed policy options in Chapter 5. Five policy and programming options are presented, consisting of: (1) Community education sessions, (2) Radio telenovelas, (3) Home-based antenatal care (ANC) and HIV counselling and testing (HCT), (4) Facility-based nutritional programs, and (5) the expansion of Ethiopia's mothers support group. Criteria and measures, presented in Chapter 6, are utilized to evaluate each of these policy options. The criteria include considerations of cost, efficacy, equity, community readiness, and political support. Chapter 7 provides a fulsome evaluation of each option.

The high cost to government/international donors for the Home-based ANC and HCT option and the nutritional program indicate that, although these options both have long-term potential, they are not feasible for immediate roll-out. Upon evaluation, the community education sessions, radio telenovela and the expansion of the Mothers Support Group (MSG) are recommended for immediate roll-out. These options are relatively inexpensive and are improvements on the status quo. Furthermore, these options are not overly dependent on the health sector and social infrastructure of Ethiopia, evidenced by their low human resource requirement. Ethiopia's social programs are already over-taxed and unable to fulfill current commitments. Consequently, for the recommended options to be roll-out immediately and be most effective, low system dependence is vital. The community sessions, radio telenovela, and the MSG expansion fulfill this requirement.

Chapter 8 considers that while immediate and feasible roll-out options are necessary, they are only temporary solutions. Several system-wide and systemic issues are in urgent need of attention. In the long-term, issues of system capacity, poor health sector integration, and lack of appropriate monitoring and evaluation will largely determine the success of PMTCT interventions and population health. Furthermore, research gaps exist both at the very detailed end of PMTCT research – where costeffectiveness analyses are needed – and at the other end of the spectrum of PMTCT

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research – where a need exists to place interventions in the context of larger social realities.

Situating PMTCT intervention within the context of the daily realities of Ethiopian women is necessary. This research reminds that HIV, including mother-to-child transmission, is fundamentally a social epidemic. Consequently, it requires a social system response that reaches beyond antiretroviral access and antenatal care attendance, to the systems and structures that can improve the lives, not just the health, of Ethiopia's women and children.

1. Battling Pediatric HIV in Ethiopia

HIV infection poses a significant threat to child health and survival. Each year nearly 400,000 childhood infections occur among the world's poorest populations in Sub-Saharan Africa.¹ In Ethiopia, mother-to-child transmission (MTCT) accounts for over 95 percent of childhood infections. MTCT is almost entirely preventable.^{2, 3}

UNICEF estimates that a US\$5.9 billion annual investment would be required to effectively address the requirements of women and children across the globe in reaching

universal access targets for the four 'Ps' – preventing mother-to-child transmission (see Box 1⁴), providing pediatric care and treatment, preventing infection among adolescents, and protecting and supporting children affected by HIV/AIDS.⁵ PMTCT is identified as one of the most cost-effective global health prevention interventions with a cost-effectiveness ratio of less than

Box 1: Preventing Mother-to-Child Transmission

Infants are at significant risk for acquiring HIV infection from their mothers. The period of vulnerability for MTCT spans from early pregnancy (<28 weeks) to 24 months of age. Each stage of exposure presents opportunities for intervention, across what is referred to as the PMTCT cascade.

- ² Ministry of Foreign Affairs, Norway, 2011.
- ³ WHO, 2007.
- ⁴ CHAI, 2011.
- ⁵ UNAIDS, 2009.

¹ WHO, 2010.

US\$1,000/infection averted.⁶ An aggressive approach to prevention is the only viable mechanism for realizing global HIV prevention and child health targets.⁷

The majority of PMTCT programming is supported by international development donors.⁸ In 2005 alone between US\$7.5 and US\$8.5 billion was invested in the global HIV response.⁹ Even at this level of investment¹⁰, services are highly resource-constrained and prevention activities including initiatives such as PMTCT education sessions, family planning and contraceptive use, and early HIV-case identification, receive a relatively limited proportion of HIV expenditure. Without a strong focus on prevention, reduction in HIV transmission will never be fully realized.

Ethiopia, much like other Sub-Saharan Africa (SSA) countries, is aligning with international targets to halt and reverse the spread of HIV. PMTCT programs have emerged as one component of that effort. Some advancements have been realized through these programs. However, programs aimed at operationalizing international targets in Ethiopia, and across SSA, continue to be constrained by issues of financing, health system infrastructure and capacity, population geographical dispersion, as well as social and cultural norms. Cumulatively, these issues present substantial challenges to designing and implementing successful PMTCT strategies.^{11, 12}

⁶ Bollinger & Stover, 2006.

⁷ UNICEF, 2010.

⁸ Donor funds are not ear-marked by specific project therefore, determining the exact investment in PMTCT is difficult.

⁹ Attawell, 2008.

¹⁰ Investments targeting specifically toward HIV are declining and being reallocated to broader health system issues. For example, CIDA's HIV/AIDS specific funding to recipient countries has dropped significantly since the early 2000's. Now, HIV funding is integrated in broader health and social programming. While this is likely a beneficial transition for overall health and development, HIV/AIDS programming does receive less of the international funding 'pot'.

¹¹ Osumba, 2009.

¹² WHO, 2010b.

Without intervention, the risk of HIV-infected mothers passing their infection to their children ranges from 20-45 percent.¹³ Approximately half of the infected children will not survive their second birthday. However, with evidence-based intervention the risk of MTCT can be reduced to 2-5 percent – defined as the virtual elimination of MTCT.¹⁴ Preventing mother-to-child transmission requires clinical and population health approaches to reducing the HIV transmission rate.¹⁵ Efficacious interventions have been identified by UN agencies, along with other global health actors.¹⁶ The effective roll-out of these programs has facilitated marked improvements in HIV prevalence and incidence in developing countries. Three substantial developments at the international level are worth noting here: (1) the inception of the Millennium Development Goals (MDGs), (2) the development of a 'comprehensive PMTCT' framework, and (3) the popularization of addressing the entire cascade of services necessary for preventing MTCT, referred to as the PMTCT cascade.

PMTCT efforts fall well within the broader efforts of the MDGs to address poverty, morbidity, and mortality. Relevant MDGs include MDG 3 (gender equality), MDG 4 (reduce child mortality), MDG 5 (improve maternal health), and MDG 6 (combat HIV/AIDS). PMTCT efforts close link with several MDGs illustrates its integral involvement in advancing maternal, newborn and child health initiatives and broader development issues¹⁷ (see Appendix A¹⁸). The comprehensive PMTCT framework,

¹⁷ Krebs, 2011.

¹³ CHAI, 2011.

¹⁴ Interview: Participant 1

¹⁵ USAID, 2011.

¹⁶ Notable actors include, the WHO, UNAIDS, United Nations Children's Fund (UNICEF), United Nations Population Fund (UNFPA), the World Bank, the Canadian International Development Agency (CIDA), Department for International Development (DFID), United States Agency for International Development (USAID), the Global Fund to Fight AIDS, Tuberculosis, and Malaria, the US President's Emergency Plan for AIDS Relief (PEPFAR), the Gates Foundation, in addition to a plethora of global health research and evidence-based practice organizations, such as, the International Training and Education Center for Health (I-TECH), the International Center for AIDS Care and Treatment Programs (ICAP), the Clinton Health Access Initiative (CHAI), Partners in Health (PIH), and the International Planned Parenthood Federation.

developed by the UN, builds on PMTCT's contribution to maternal, newborn, and child health (MNCH) providing guidance on the four prongs of PMTCT intervention: (1) primary prevention, (2) family planning, (3) ART/ARV interventions, and (4) care, treatment, and follow-up.

The third major development is the PMTCT cascade. The period of vulnerability for MTCT extends from conception through a minimum of 18 months post-partum.¹⁹ Throughout this period, a variety of clinical services act to reduce MTCT vulnerability. The PMTCT cascade outlines the critical elements of treatment and care for HIV+ pregnant women from conception through delivery, infant testing, and diagnosis.²⁰ Figure 1 illustrates the periods of intervention that are included in PMTCT programming.



Figure 1. PMTCT Care Spectrum²¹

¹⁸ WHO & UNAIDS, 2010.

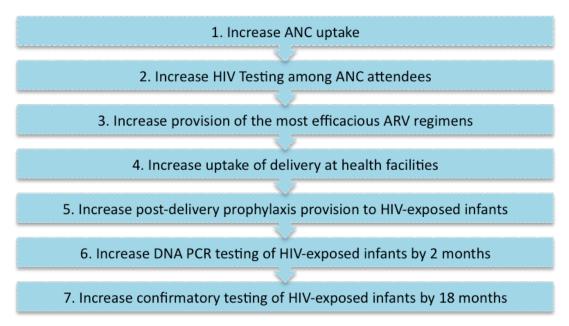
¹⁹ CHAI, 2011.

²⁰ WHO, 2011c, p. 9.

²¹ Phelps, 2011, p.3; this image was created by the University Research Co., LLC with funding from the USAID; used with permission.

While Figure 1 provides an overview of the periods of intervention, operationalizing PMTCT cascades has proven difficult for many SSA countries. In an effort to bring concreteness to the PMTCT cascade, the Clinton Health Access Initiative (CHAI) specified seven clinical points of PMTCT, which allow for easier monitoring and impact evaluation (see Figure 2). These indicators will be discussed further in the following sections where Ethiopia's current status on PMTCT indicators is presented.

Figure 2. CHAI Clinical PMTCT Indicators²²



Further discussion is necessary for the 3rd clinical indicator – ARV regimens. Knowledge of HIV treatment effectiveness is continually changing. Research institutions exploring the most cost-effective regimens and conducting combination ART trials result in updated international ARV guidelines every few years. For PMTCT, the most recent global ARV treatment revisions were made in 2010.²³ These revisions provide new recommendations of ART initiation and first line therapies, ARV prophylaxis, and infant

²² Adapted from CHAI, 2011.

²³ WHO, 2010a.

feeding practices. In October 2011, Ethiopia signed on to the 2010 guidelines.²⁴ Complying with these guidelines is now a priority for Ethiopia. However, significant procurement and distribution challenges emerge with the change in treatment guidelines. This new hurdle compounds existing access and effectiveness gaps.²⁵

The postpartum points along the cascade (CHAI's critical care points 5 through 7) are the least developed points of PMTCT intervention. Moreover, in many cases, mother-infant pairs are lost to follow-up before they reach the end of the cascade.

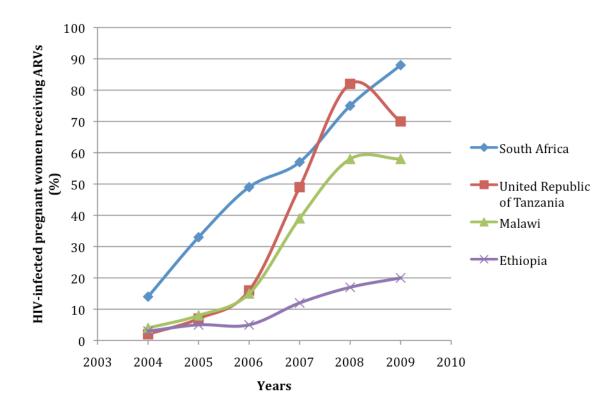
Early HIV diagnosis and timely ART/ARV treatment is a core tenet of effective PMTCT (see Figure 2). However, in 2009, 30,000 pregnant women in Ethiopia were in need of antiretrovirals (ARVs). While other SSA countries have a larger number of women in need – for example, South Africa at 210,000 – Ethiopia's progress in meeting the HIV treatment need has been slower than other Sub-Saharan countries. For example, Figure 3 illustrates that other high-prevalence²⁶ SSA countries have progressed more rapidly than Ethiopia on one of the most common PMTCT indicators – percentage of HIV-infected pregnant women receiving ARVs. The average increase of ARV coverage for pregnant women in high-prevalence countries was approximately 38 percent. Ethiopia increased its coverage by only 17 percent during the same period (2004-2009). Furthermore, Ethiopia's national government has begun operationalizing best practices from the literature, such as integrating MNCH services with PMTCT and contextualizing PMTCT within broader health systems strengthening (see Appendix D). However, the anticipated improvements have not been observed.

²⁴ Interview: Participant 8

²⁵ See Appendix B.

²⁶ High-prevalence countries were indentified by UNAIDS as countries having the highest estimated number of pregnant women living with HIV in need of antiretrovirals to prevent mother-to-child transmission. Appendix C displays the progress of 25 high-prevalence countries realized from 2004-2009.

Figure 3. Ethiopia's ARV Progress in Context, 2004-2009



Ethiopia's mother-to-child transmission (MTCT) incidence rate is 0.04, twice its 2010 international target.²⁷ Other PMTCT indicators, such as antenatal care (ANC) service uptake, demonstrate significant gaps along Ethiopia's PMTCT cascade. For example, in Ethiopia only 16 percent of pregnant women receive HIV testing and counselling – less than half of the average coverage in high-prevalence SSA countries (48 percent). No estimation is presented for the percentage of pregnant women receiving the *most efficacious* ARV treatment.²⁸ Given the current trajectory of Ethiopia's ARV coverage, the 2015 target of 90 percent of pregnant women receiving the WHO's 2010 guidelines ARV treatment is unattainable.²⁹ Under current conditions, preventable infections via mother-to-child transmission will continue. Despite strong international

²⁷ Mahy et al., 2010.

²⁸ WHO & UNAIDS, 2010.

²⁹ Interview: Participant 3

funding and significant national government commitment, Ethiopia's inability to reach set targets, represents a myriad of programming and policy problems.³⁰ Ethiopia's low antenatal care (ANC) uptake, severe human resource shortage, limited health facility equipment, unknown ARV adherence, and poor performance on the social determinants of health indicators³¹ (e.g. literacy) all appear to contribute to PMTCT challenges. Each of these issues is worthy of attention in the body of literature surrounding PMTCT. This research focuses on one portion of PMTCT intervention, namely the high attrition and loss to follow-up (see Box 2³²) experienced in PMTCT programs along the service cascade. In Ethiopia, LTF is not consistently measured at the national or regional level. However, estimates from surrounding countries suggest that up to 80 percent of women are lost between ANC and 18-month infant follow-up. This severely limits the potential

for PMTCT programming to eliminate MTCT in Ethiopia.

Through an iterative process and exploratory interviews, this research identifies major points of LTF along the PMTCT cascade. Each LTF point represents its own policy problem for effective PMTCT programming in Ethiopia. The goal of this research is to identify

Box 2: Loss to Follow-up (LTF)

Loss to follow-up refers specifically to individuals "who have dropped out of their treatment regimens and are unfindable".

major LTF points and possible interventions at each point in order to increase patient engagement, retention, and follow-up. Mechanisms for reducing LTF are identified through community-based programs in SSA countries that have demonstrated efficacy, and where possible, effectiveness. Policy and programming options for addressing the first point of LTF – low ANC uptake by pregnant women – are explored and evaluated within the Ethiopian context (Chapters 4-7) along the PMTCT cascade.

³⁰ Interview: Participant 2 and 4

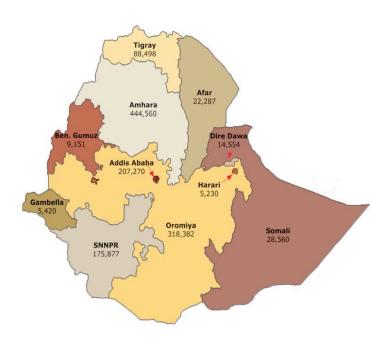
³² I-TECH Ethiopia, 2009, p.1.

³¹ WHO, 2008.

2. Ethiopia: a brief overview

Located in the North Eastern part of Africa, also known as the Horn of Africa, Ethiopia is a highly diversified geographical, climatic, and resource country.³³ Ethiopia is

the second most populous country in Africa – following Nigeria.³⁴ In 2010, Ethiopia's population was approximately 82.8 million and the country continues to experience a population growth rate of 2.7 percent per annum.³⁵ The total fertility rate in Ethiopia is 5.7 per woman, slightly higher than the WHO African Region average (5.3).³⁶ Approximately half of the population is female. Ethiopia's population is largely rurally located, with



only 17 percent of the population centralized in urban areas. However, as in most developing countries, the process of urbanization is gaining hold in Ethiopia.

³⁴ http://www.africanservices.org/index.php/African-Services-in-Ethiopia/Background-HIV/AIDSin-Ethiopia

³⁶ WHO African Regional Office, 2006.

³³ Federal Ministry of Health, 2006.

³⁵ UNFPA, 2010.

In 1994, Ethiopia adopted a new constitution, making it a federalist state, composed of nine regional states and two city administrations. The regions and city administrations are further categorized into 611 *woredas*. As a result of Ethiopia's highly decentralized population, the *woredas* are divided into 15,000 *kebeles*. The *kebeles* are organized under resident associations – peasant associations in rural communities and urban dweller associations in towns and cities.

Demographic factors and social determinants are strong predictors of health status.³⁷ The adult literacy rate in Ethiopia is 36 percent. Females have a significantly lower literacy rate of 25 percent, than males (46 percent).³⁸ Low literacy rates are linked with poorer health status through a complex pathway, including compromised access and comprehension of health information putting the population at greater risk for preventable disease, including HIV infection.³⁹ Poverty exacerbates disease risk in Ethiopia, with 47 percent of the population living below the poverty line and an estimated GDP per capita in 2008 of I\$868.⁴⁰ The per capita income is less than US\$100.⁴¹ Table 1 provides general country data for Ethiopia, and to act as a comparison, highlights some surrounding Sub-Saharan countries.

³⁷ WHO, 2008; Dennis Raphael; Sir Michael Marmot.

³⁸ UNICEF, 2009.

³⁹ Ethiopia Ministry of Health Website (accessed 2011).

⁴⁰ UNFPA, 2010. (international dollars in purchasing power parity).

⁴¹ http://www.africanservices.org/index.php/African-Services-in-Ethiopia/Background-HIV/AIDSin-Ethiopia

Country	Population (Thousands)	Urban Population (%)	GDP per capita, PPP (\$I)	Estimated no. of Pregnant Women needing ARVs
Ethiopia	82,825	17	868	30,000
Malawi	15,264	18	837	57,000
South Africa	50,110	60	10,109	210,000
Tanzania	43,739	25	1,263	84,000

 Table 1.
 Ethiopia: Country Characteristics

Ethiopia's health burden is predominantly attributable to infectious and communicable disease incidence and prevalence. Lack of universal access to sanitation facilities and clean water (particularly in rural regions), widespread malnutrition and limited access to health services all contribute to relatively low life expectancy (48 years; males: 47, females: 49), high maternal mortality (850 per 100,000 live births)⁴² and high infectious disease prevalence, including HIV, are major contributors. In 2005, HIV/AIDS alone reduced Ethiopian life expectancy by five years.⁴³

In 2006, HIV/AIDS was the leading cause of death in Ethiopia, along with lower respiratory infections.⁴⁴ HIV/AIDS was responsible for 12 percent of all deaths in all ages and 12 percent of all years of life lost. For young women and men aged 15-24, the HIV prevalence is slightly lower, at 3.5 percent.⁴⁵ Large HIV service gaps persist, particularly in pediatric HIV services and PMTCT programs.

The HIV epidemic is characterized as a generalized epidemic driven by most-atrisk populations (MARPs).⁴⁶ While the epidemic has stabilized to a large extent, the prevalence estimate provided by the Ethiopian Ministry of Health for 2007/08 is 2.1

- ⁴² WHO African Regional Office, 2006.
- ⁴³ Federal Democratic Republic of Ethiopia, 2006.
- ⁴⁴ WHO, 2010c.
- ⁴⁵ 2007 Data.
- ⁴⁶ USAID, 2010.

percent – a 0.1 percent reduction from the 2003/04 estimate. In 2010, the adult HIV prevalence fell between 1.4 percent and 2.8 percent.⁴⁷ Regional variations in the HIV epidemic are stark.⁴⁸ HIV cases (prevalence and incidence cases) are concentrated in urban areas providing reason for heightened concern as Ethiopia undergoes urbanization. In urban areas, females are 1.5 times more likely to be infected than males.⁴⁹ Co-infections with tuberculosis (HIV/AIDS accounted for 32 percent of TB cases in 2005)⁵⁰, and the burden of other infectious diseases, such as malaria, add additional complexities. High disease burdens, poor living conditions, low literacy (and associated social determinants of health), traditional cultural conceptions of health, wellness and medical treatment, as well as limited system capacity and coordination between health sector actors all contribute to the current health problems, including PMTCT.

2.1. Ethiopia's Health System

Although the Ethiopian government retains significant control in making national health policies, decision-making power has devolved significantly in Ethiopia under the federalist government structure. Health services are financed through a myriad of funding structures, including domestic revenue, taxes, private out of pocket funds, in addition to substantial donor and NGO contributions.⁵¹ National and regional levels of government share jurisdiction over health planning and service provision. While the federal government provides health services, the reliability, quality, and accessibility of services is largely dependent on government effectiveness. According to the Worldwide Governance Indicators, Ethiopia's government effectiveness – defined as "perceptions of the quality of public services, the quality of the civil service and the degree of its

⁴⁷ Ethiopian Health and Nutrition Research Institute, 2010.

⁴⁸ Federal Democratic Republic of Ethiopia, 2010.

⁴⁹ USAID, 2010.

⁵⁰ Federal Democratic Republic of Ethiopia, 2006.

⁵¹ Mekonnen, 2009.

independence from political pressure, the quality of policy formulation and implementation, and the credibility of the government's commitment to such policies"⁵² – ranks in the 40th percentile when compared with surrounding Sub-Saharan countries (see Appendix E).⁵³ Overall, government effectiveness in Ethiopia is underwhelming, with 60 percent of SSA countries scoring higher on this indicator than Ethiopia.

Within the context of HIV and PMTCT programming, the national government has been very active, moving to a decentralizing approach in 2002⁵⁴, and rolling out its first PMTCT pilot programs in 5 health facilities in 2004.⁵⁵ Despite ambitious plans on the part of the government, national coverage remains low.⁵⁶ For example, in 2010 – five years after the large scale implementation of PMTCT programming – a mere 6,990 HIV+ pregnant women were receiving ARV prophylaxis. This represents only 18.7 percent of the target coverage. While interviewees participating in this research consistently highlighted the slow progress on PMTCT indicators, one respondent specifically linked these challenges with the health system: "Ethiopia generally has a very, very, very poor health system, and the government is committed to trying to do something about it, but it's not an easy task because things [health facilities] are so spread out and the population is so spread out" (Participant 1)⁵⁷. The decentralization push has in some respects exacerbated government's inability to follow through on commitments for HIV and PMTCT programs. For example, as one participant explained, "The farther out you go, the thinner the services seem to get... there are fewer staff out there. The commodities are not necessarily on a regular basis out there. And also anything that you

⁵² Kaufmann, Kraay & Mastruzzi, 2010, p.4.

⁵³ The countries selected for the government effectiveness analysis surround Ethiopia. They include: Botswana, Burundi, Eritrea, Kenya, Malawi, Mozambique, Rwanda, South Africa, Sudan, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe.

⁵⁴ Mekonnen, 2009.

⁵⁵ Mekonnen, 2009.

⁵⁶ Nigatu & Woldegebriel, 2011.

⁵⁷ Few particiapnts made explicit links between PMTCT performance (strengths and challenges) and broader health system structures. This may be indicative of a continued siloed approach to HIV programming. Since this connection was made explicitly by Participant 1, those comments are highlighted.

need in terms of lab services, it's harder to decentralize those in terms of maintaining the quality of them" (Participant 1).

At the regional level, the Regional Health Bureau (RHB) provides public health care administration. Under the impetus of decentralized decision-making and moving health care planning 'closer to home',⁵⁸ *woredas* currently carry out the planning and political administration of health services. As of 2003, Ethiopia's total health expenditure was 5.9 percent of the GDP and with approximately 60 percent of total health expenditure originating from the public purse.⁵⁹ A large proportion of government funding is obtained from development donors. In 2006, Ethiopia was the 7th largest recipient of official development assistance (ODA) among all developing countries.⁶⁰ A substantial share of Ethiopia's ODA is directly invested in the health sector.⁶¹ Despite development funds, Ethiopia's health sector experiences fiscal austerity. PMTCT and broader MNCH initiatives are currently a priority for international donors. In 2010, the G8 made specific commitments to invest in improving MNCH through the Muskoka Initiative. Although international donor monies are often unpredictable, the Muskoka Initiative provides some stability to PMTCT planning and programming in developing countries, including Ethiopia.

Fiscal struggles are compounded by labour shortages. In the WHO's 2006 World Health Report, a critical threshold level was established for health workforce density. The threshold level was set at 2.5 health care professionals (doctors, nurses, or midwives) per 1,000 population. In the context of MNCH, the WHO estimate drops to 2.3 doctors, nurses, or midwives.⁶² Below this level, direct consequences to maternal and

 ⁵⁸ The closer to home movement has been prevalent in both developed and developing countries.
 ⁵⁹ WHO, 2006a.

⁶⁰ Federal Democratic Republic of Ethiopia, 2010.

⁶¹ For example, over 72 percent of donor resources, including ODA, financed HIV/AIDS, malaria and TB prevention, treatment, and care in 2006. (Note: The Global Fund and GAVI account for approximately 55% of these resources.)

⁶² www.who.int/hrh/workforce_mdgs/en/.

child mortality are observable. Ethiopia falling well below the threshold level (see Table 2) has been designated a human resources for health (HRH) crisis country.

Health Resources for Health	Number	Density per 1,000
Doctors	1,936	0.03
Nurses	14,893	0.21
Midwives	651	0.01
Total	17,480	0.25

 Table 2.
 Ethiopia's Health Workforce⁶³

Ethiopia's health workforce is spread unevenly, displaying a rural-urban divide.⁶⁴ As a result, the Ethiopian government is seeking to recruit, train, and retain specifically female health workers in rural areas through the pro-poor health service extension program (HSEP), introduced in 2003.^{65, 66} One of the primary goals to the HSEP and responsibilities of health extension workers (HEWs) is to improve maternal health and assist in reaching MDG 5 targets.⁶⁷ To date, over 30,000 HEWs – a mid-level cadre – have been trained and deployed, making them a pillar in the Ethiopian health system.^{68, 69} Notably, HEWs are not counted in WHO estimates of health workforce density, despite their strong presence in Ethiopia.

⁶³ WHO, 2006b. Note: Health Extension Workers are not included in these estimates.

⁶⁴ WHO, 2006b.

⁶⁵ Negusse, McAuliffe & MacLachlan, 2007.

⁶⁶ Since 2003, the HSEP has been broadened to encompass more than service delivery. As such, the program was renamed the Health Extension Program (HEP). Through the HEP, both the federal ministry of health and regional health boards, have prioritized health centre construction. Constructing and staffing new health centres is difficult in Ethiopia, but demonstrates a clear commitment from the ministry of health, regional health boards and further decentralized regions and associations to improve access to health services and advance the guality of health services.

⁶⁷ Koblinsky, Tain & Gaym et al., 2010.

⁶⁸ Interview: Participant 3

⁶⁹ Federal Democratic Republic of Ethiopia, 2010.

The introduction of HEWs provides an opportunity for some task-shifting – the delegation of tasks from one cadre to another – which holds promise for revitalizing Ethiopia's primary health care system and may be a cost-effective component in broader human resource and health reform.⁷⁰ Admassie, Abedaw, and Woldemichael's (2009)⁷¹ evaluation of the HSEP's impact on MNCH outcomes indicates that children in program villages were more likely to be vaccinated against TB, polio, measles, and DPT3. However, the effect on preventive maternal care, to date, is limited. HEWs' presence has little documented effect on the community-level uptake of prenatal or postnatal care.

2.2. Health System Response to HIV

Ethiopia established its national HIV/AIDS policy in 1998.⁷² Since then, Ethiopia has been involved both internationally and domestically to control, halt, and reverse the spread of HIV. In 2005, the Government of Ethiopia launched its free ARV/ART program, addressing major gaps in the procurement and population access to HIV treatment. In 2006, Ethiopia joined the international development community in support of the *UN General Assembly's Political Declaration on HIV/AIDS*. Actively demonstrating its commitment to universal access to HIV prevention, treatment, and care, Ethiopia has worked to harmonize efforts among stakeholders to support a comprehensive multisectoral national HIV/AIDS strategic plan, the Plan for Accelerated and Sustained Development to End Poverty (PASDEP). The Strategic Plan for Multi-Sectoral Response (SPM), now in its 2009-2014 version, focuses on "putting prevention first".⁷³ A national accelerated plan for scaling-up PMTCT has also been released as of late 2011. This document reaffirms Ethiopia's commitment to addressing ANC service access, delivery by a skilled birth attendant, and improving PMTCT indicators. This report brings to the forefront the need for male engagement in PMTCT.

⁷⁰ Lehmann, Van Damme & Barten et al., 2009.

⁷¹ Admassie, Abebaw & Woldemichael, 2009.

⁷² Federal Democratic Republic of Ethiopia, 2010.

⁷³ Federal Democratic Republic of Ethiopia, 2010.

Despite commendable efforts, the HIV prevalence among adults (ages 15-49) is 4.4 percent. The national prevalence sits at approximately 2.1 percent.⁷⁴ Rural prevalence is very low (0.9%), while urban residents experience much higher rates of infection (7.7%).⁷⁵ While other Sub-Saharan countries experience significantly higher prevalence rates than Ethiopia, Ethiopia's large population results in high absolute

infection numbers. Participant 1 commented on the challenges associated with Ethiopia's large – and dispersed – population: "The challenges of working in Ethiopia are the fact that there are so many facilities, and so your volume per facility is not actually quite... is not substantial, right? And then the actual HIV prevalence in Ethiopia is quite low. It's less... like around 2 percent of women that are infected, but it's 2 percent of a very large population. It's very

Box 3: Mothers Support Group (MSG)

In 2005, Intrahealth introduced MSGs in Ethiopia. By 2008, 84 MSG sites were identified and this initiative has continued to expand. MSGs encourage women to be tested and empower women who are HIV+ through psychosocial support, promoting economic independence, encouraging status disclosure, and adherence to treatment and care. These groups are particularly influential for pregnant women and mothers, promoting care-seeking behaviour.

PMTCT experts note that women involved in MSG groups are more likely to initiate care, attend ANC, adhere to treatment and less likely to be LTF. Performance of women in MSGs continues to improve with 98 percent uptake of desired behaviours.

similar to like China and India where you just have massive populations, and even though the HIV is low, that will equate to a very large number of people".

⁷⁴ Nigatu & Woldegebriel, 2011.
 ⁷⁵ UNICEF, 2010.

2.3. PMTCT in Ethiopia

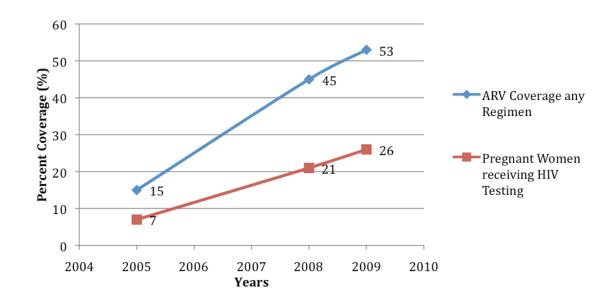
PMTCT is a recognized priority in Ethiopia. The Ministry of Health has developed a PMTCT training manual, a revised manual for the implementation of PMTCT, guidelines and a task-shifting training manual for pediatric HIV/AIDS care and treatment, and accelerated plan for implementing PMTCT programming, and a national training manual for Mothers Support Groups (MSG) in response to PMTCT needs.⁷⁶ Although the MSG concept originally emerged in South Africa (mothers-2-mothers), the peer-to-peer format has flourished in Ethiopia. MSGs are active in Ethiopia and have great potential in providing human resource capacity and opportunity for PMTCT education and patient retention (see Box 3).^{77, 78}

Furthermore, Ethiopia is integrating PMTCT and HIV testing and counselling programs. In 2005, the Demographic and Health Survey (DHS) reported that within the previous 12 months, only 1.9 percent of females who have received an HIV test knew their results. Integrating PMTCT and HIV testing and counselling may improve the current ARV and HIV testing coverage (see Figure 4).

⁷⁶ Federal Democratic Republic of Ethiopia, 2010; WHO, 2011c; Interview: Participant 3 and 6
 ⁷⁷ USAID, 2009.

⁷⁸ Interview: Participant 3





Although some progress has been made on PMTCT indicators since their largescale implementation in 2005, PMTCT activities are lagging behind. In 2009, the national PMTCT coverage was 8 percent – up 3 percentage points from 2006. The uptake of antiretroviral prophylaxis has been minimal. While only crude estimates of Ethiopia's MTCT rate exist,⁸⁰ the estimate remains at 25 percent, although transmission rates as low as 2-5 percent are feasible.⁸¹ A recent study in Addis Ababa, revealed that by 18 months, the mother-to-child transmission rate is approximately 15 percent.⁸² Malawi reports similar percentages. Of the women who do receive ARV treatment (nearly 50% of eligible population receives some form of ARV) approximately 30 percent are lost to follow-up. For infants born with HIV, few ever receive ART.⁸³

⁷⁹ UNAIDS, 2009.

- ⁸⁰ Merdekios & Adedimeji, 2011.
- ⁸¹ http://www.africanservices.org/index.php/African-Services-in-Ethiopia/Background-HIV/AIDSin-Ethiopia
- ⁸² Mekonnen, 2009.

⁸³ WHO, 2011a.

Progress on PMTCT indicators can be misleading.⁸⁴ For example, Figure 5 illustrates the significant increase in the number of health facilities providing PMTCT services since 2004. However, only 517 health facilities in Ethiopia were providing ART by the end of 2009. While this in itself is a significant achievement, it also highlights that the other 506 facilities that provide PMTCT services were missing an integral component of PMTCT service – ART/ARV prophylaxis.

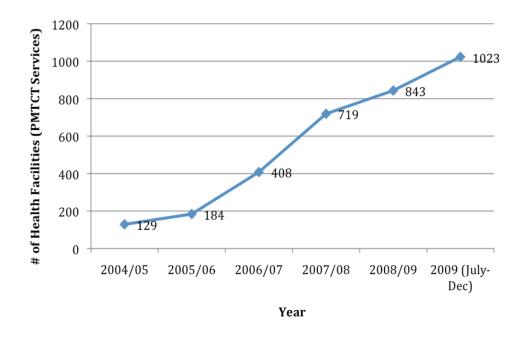


Figure 5. Number of Health Facilities Providing PMTCT Services⁸⁵

Limited service expansion, poor integration of PMTCT with ANC coverage, inadequate human resources, and low percentage of deliveries attended by skilled personnel were identified as some of the reasons participants were dissatisfied with PMTCT services and 'progress'. One participant explained: "From a PEPFAR standpoint, Ethiopia is a little interesting because they have been given significant amounts of money, but we've seen very little improvement. So they still have a really

⁸⁴ Federal Democratic Republic of Ethiopia, 2010.

⁸⁵ Federal Democratic Republic of Ethiopia, 2006.

poor facility delivery rate. They still have the same antenatal attendance rates. We haven't seen a lot of changes. But Ethiopia's unique in that their government is very involved, which is a good thing" (Participant 9). Slow uptake of PMTCT coverage expansion is documented in Table 3.

Health Services Coverage Indicator	Coverage (%)
Antenatal Care Coverage (at least one visit)	27
Antenatal Care Coverage (at least four visits)10-1287	
Births Attended by Skilled Health Personnel	6
Antiretroviral Therapy Coverage of HIV+ Pregnant Women	7-8

Table 3.	Ethiopia's PMTCT Health Service Indicators ⁸⁶
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Some progress is being made on these indictors. The preliminary 2011 DHS report indicates that 34 percent of women in the five preceding years received at least one ANC visit.⁸⁸ This represents a six-percentage point increase from the 2005 DHS. According to the DHS, health extension workers are conducting 10 percent of ANC visits. However, social inequalities cross-cut health service coverage progress. For example, in urban areas a skilled health worker attends 45 percent of births, while skilled workers attend only 3 percent of births in rural areas. Among the poorest 20 percent of the Ethiopian population only 1 percent of births are attended,⁸⁹ displaying stark social gradients in service provision and uptake. At each level, these disparities magnify MTCT vulnerability and place future generations at great risk.

⁸⁶ DHS, 2005; WHO, 2011a.

⁸⁷ WHO, 2011a. Some discrepancy exists here.

⁸⁸ DHS, 2011.

⁸⁹ WHO, 2011a.

2.4. Challenges in Advancing PMTCT

While Ethiopia has begun to employ PMTCT strategies which have achieved success in other contexts, improvement has been moderate at best. Practices such as ensuring ART/ARVs are free to patients, integrating MNCH, sexual and reproductive health, and/or broader HIV/AIDS services with PMTCT, increasing the available human resources for health, and health system strengthening have (or are currently) been rolled-out in Ethiopia. The slow, and in some circumstances lack of improvement suggests that barriers unique to Ethiopia act to hamper program effectiveness.

These barriers are poorly understood, necessitating research. Global health workers in Ethiopia are working to understand these issues. However, efforts are fragmented and 'on-the-ground' expertise and experience are infrequently translated to broader stakeholder groups. Consequently, their impact on policy and programming decisions is often sub-optimal. This research opens the door for knowledge exchange; gathering 'on-the-ground' expertise and packaging them to inform future dialogue and decisions on a primary challenge for PMTCT in Ethiopia: loss to follow-up.

2.4.1. Attrition and Loss to Follow-up (LTF)

Efficacious ARV prophylaxis is a necessary – but not sufficient – component of effective PMTCT programming. The effectiveness of ARV/ART programs, including PMTCT, is contingent on long-term patient retention. Yet, low patient adherence is a problem in Ethiopia – and consistent across Sub-Saharan Africa – posing significant challenges for controlling and reversing the HIV epidemic. PMTCT programs are not immune to these challenges. In fact, attrition is estimated to be higher in PMTCT programs than adult HIV programs.⁹⁰

⁹⁰ Phelps, 2011.

Attrition is defined as "discontinuation of ART for any reason, including death, loss to follow-up, and stopping ARV medications while remaining in care".⁹¹ Within the context of PMTCT, and this research, the definition of attrition is broadened to reflect that the critical care cascade of PMTCT includes many non-ART elements. Tracking patients who are LTF⁹², excludes patients who have died. However, monitoring and evaluation on LTF, and specifically differentiating the types of attrition, is poor and often non-existent in Ethiopia and other Sub-Saharan countries.⁹³ Poor record keeping, common 'silent transferring' of PMTCT patients to different clinics, rare electronic medical record infrastructure and availability, provide a brief sketch of some of the monitoring and evaluation (M&E) challenges that plague PMTCT care, treatment, and follow-up.

The primary focus of HIV programs – Ethiopia included – has been to increase available services.⁹⁴ While this is one core component of operationalizing HIV prevention, treatment, and care, poor patient adherence to treatment and care threatens the goals of scaling-up services. In 2007, Rosen, Fox and Gill wrote, "most studies treat patient attrition as a side issue and focus solely on describing those patients who are retained" (p. 1692). This poses significant barriers to HIV and PMTCT program success as data misrepresents program effectiveness, by failing to track the patient(s) through the care continuum or through more distant health outcomes (e.g. infant health at the end of the PMTCT cascade).

The body of literature addressing issues of, and reasons for, poor patient retention in HIV programs and high LTF has begun to grow. As Participant 1 noted, the issue of LTF is becoming central to current challenges in PMTCT programming:

⁹¹ Rosen, Fox & Gill, 2007.

⁹² Loss to follow-up (LTF) refers specifically to individuals "who have dropped out of their treatment regimens and are unfindable" (I-TECH Ethiopia, 2009, p.1).

⁹³ Interview: Participant 14

⁹⁴ For example, health facility construction and PMTCT service expansion in Ethiopia (see Chapter 4).

Now everyone is talking about the cascade and the continuum, we know that there are gaps in that, which is retention, loss to follow-up and the entire tracking of infants and ensuring that those that are infected get into treatment. Those are still large gaps that people haven't really been able to address... (Participant 1)

Piloted, typically community-based, strategies which appear to improve patient retention and mitigate LTF are poorly documented.⁹⁵ A particular absence of literature is notable for some sub-Saharan countries, including Ethiopia.

2.4.2.Loss to Follow-up (LTF) in PMTCT

Loss to follow-up is the most significant cause of patient attrition in large-scale ART programs in Africa.⁹⁶ As such, LTF is a significant threat to the effectiveness of HIV prevention and treatment programs. Even temporary LTF has significant health ramifications. Ndiaye et al. (2009) reports that even patients who return to care after a period of LTF, are at 5 times greater mortality risk than patients who were never lost to care. No universal time frame is set for the length of time clients must be off their regimented treatment plan to be considered lost to follow-up. Most recently, Chi et al. (2011) recommend, based on their analysis, adopting a 180-day cut-off. Once patients have exceeded 180-days since their last clinic visit, they are considered LTF. However, within the context of PMTCT this time frame may be overly generous and allow patients to miss important clinical interventions (e.g. ARV initiation, ANC visits, prophylaxis, and infant testing) without being identified as lost to follow-up.

In 2009, the Ethiopian Ministry of Health estimated that 25 percent of HIV+ individuals receiving ART are lost to follow-up. Within the context of PMTCT, LTF is exacerbated. National PMTCT studies in Ethiopia report than only 10 percent of women initiating PMTCT care are retained throughout the PMTCT cascade.⁹⁷ Some surrounding

⁹⁵ Interview: Participant 9

⁹⁶ Rosen, Fox & Gill, 2007.

⁹⁷ Mirkuzie, Hinderacker & Morkve, 2010.

SSA countries report that during antenatal care (ANC) 28 percent of mothers are LTF. Four months after delivery, up to 70 percent of mother-infant pairs have been lost to the system, and nearly 81 percent are lost by 6 months post-partum.^{98, 99} High LTF largely negates the progress of establishing PMTCT services and increasing the availability of ARV combination therapies.

Preventing LTF for PMTCT is arguably more complex than for other diseases as a result of its intergenerational dimension. Infants' well-being and entry into the health service structure are dependent on maternal treatment adherence and care follow-up throughout the PMTCT cascade prior to delivery. Maternal LTF for ANC and ARV prophylaxis, at 14 weeks gestation, increases risk of MTCT. Furthermore, children's lack of care initiation puts them at lifelong risk for suffering from HIV/AIDS and premature death. The loss of productivity associated with childhood exposure and/or infection is high.¹⁰⁰ Participant 4 elaborates:

We've found that a huge number of both our HIV-infected and HIVexposed children are getting lost to follow-up... Those who become lost are more likely to be severely low weight for height, severely immune suppressed, that kind of thing, so you anticipate that they're basically ill and probably have become lost because they've died... We've found that among the HIV-infected children, in fact, quite a large number of them had died as we had anticipated. The HIV-exposed children, though, most of them [were] loss to follow-up.

Attrition and LTF are significant challenges in Ethiopia's antenatal and PMTCT treatment and care. National PMTCT studies estimate that only 10 percent of HIV+ pregnant women complete the PMTCT program, following-up until infant testing.¹⁰¹ Beyond infant testing to 18 month follow-up, completion rates continue to fall. High attrition results in less effective programming. Consequently, high LTF challenges the

⁹⁸ Manzi, Zachariah & Teck et al., 2005.

⁹⁹ Painter, Diaby & Matia et al., 2004.

¹⁰⁰ UNICEF, 2009.

¹⁰¹ Mirkuzie, Hinderaker & Morkve, 2010.

current thinking which emphasizes the need to simply scale-up PMTCT programs in order to reach international targets and eliminate MTCT. Indeed, "there's leakage everywhere" along the PMTCT cascade (Participant 13).

2.4.3.Loss to Follow-up (LTF) Metrics: Puzzling Percentages

Relying on health statistics gathered in Ethiopia, particularly in studying LTF, poses numerous challenges and frustrations. One fundamental challenge is that no universal definition for LTF in the context of PMTCT is established. No standardized system to trace clients who have discontinued treatment and bring them back into care exists.¹⁰² Furthermore, without a vital statistics registry or a unique patient identification number, the data becomes very difficult to interpret.¹⁰³ Since individual patients cannot be traced, individuals are often double or triple counted.¹⁰⁴ For example, a woman attending different ANC clinics will be recorded as having many first ANC visits, inappropriately inflating the percentage of pregnant women to attend at least one ANC consultation. Consequently, "figures are very different in the DHS than they are from the service delivery data... somewhere between 40 percent and 80 percent depending on what you're counting" (Participant 5).

Consulting medical records reveals another data problem: incomplete documentation. Resulting ascertainment issues emerge. Frequently, children with a negative HIV test have outdated medical charts and appear to be LTF. HIV-exposed or infected children who are deceased are often not documented in clinic's charts or record keeping 'systems'. Participant 4 describes this issue, as follows:

...the problem is really an ascertainment issue... a lot of the loss to follow-up that we see with our HIV-exposed children are actually ascertainment issues or that the children are healthy, and so the parents don't bring them back because they've got other kids or other responsibilities and it's just not a priority.

¹⁰² Federal HIV/AIDS Prevention and Control Office (HAPCO) & I-CAP, 2008.
 ¹⁰³ Interview: Participant 5
 ¹⁰⁴ Interview: Participant 9

International statistics registries (e.g. WHO/UNAIDS) definitions for PMTCT indicators also differ from that of Ethiopia's national databases. Participant 5 cautioned: "when you look at the population data, be really sceptical about all the information". Although LTF data has many limitations, the best available data is presented here. Yet, a healthy degree of scepticism is necessary. Next steps for data availability and quality are discussed further in Chapter 8.

In 2005, Ethiopia experienced a total of 105, 675 HIV+ pregnancies, 30,338 of these resulted in HIV+ infants.¹⁰⁵ These figures have remained relatively constant since 2005.^{106, 107} Academic literature and PMTCT program data establishes that high attrition and LTF in PMTCT programs is a contributing factor to Ethiopia's inability to control and eliminate mother-to-child transmission. The data presented to this point frames the great need for research digging deeper into PMTCT loss to follow-up. This research contributes to the literature by providing a foundational understanding of where LTF occurs along the cascade in Ethiopia's PMTCT programming.

¹⁰⁵ Federal Ministry of Health, 2006.

¹⁰⁶ Interview: Participant 2

¹⁰⁷ Ethiopia is a PMTCT priority country, as identified in the *UN Global Strategy for Women's and Children's Health.*

3. Methodology

This research employs a qualitative research methodology, using a case study approach to PMTCT in Ethiopia. Drawing on Yin's approach to case studies, this research explores where expectant mothers, or mother-infant pairs, are being lost to follow-up along the pre-natal/post-natal service cascade. Three data sources comprised this research: (1) academic and grey literature, (2) PMTCT program data¹⁰⁸, and (3) semi-structured interviews (n=15) with individuals engaged in PMTCT policy and practice in SSA, specifically Ethiopia.

Methodologically, understanding Ethiopia's health sector/system, its major actors, opportunities, and challenges can be described as an in-depth case study. According to Yin (2009), case studies are well-suited to answer 'how' and 'why' research questions and allow the researcher to retain "the holistic and meaningful characteristics of real-life events".¹⁰⁹ Case studies can be exploratory, descriptive, or explanatory.¹¹⁰ Since this research focuses on the question of where and why so many women-infant pairs are lost along PMTCT service points and how Ethiopia's attrition and LTF can be minimized, an exploratory case study approach is well suited to this project.

At the outset of this research, the focus of this project was to identify potential scale-up strategies for Ethiopia's PMTCT programming. By identifying successful initiatives in case study countries (Malawi, South Africa, and Tanzania) it was hypothesized that best practices could be identified to assist Ethiopia in more effectively

¹⁰⁸ PMTCT program data was reviewed from Ethiopia's Ministry of Health as well as from interviewees respective organizations, including CHAI, AMPATH, PIH, USAIS, CIDA, WHO etc.

¹⁰⁹ Yin, 2003, p.2.

¹¹⁰ Al Qur'an, 2010.

scaling-up its PMTCT responses. However, early research and interviews revealed non scale-up issues of significant importance, particularly LTF. Furthermore, to date Ethiopia has developed a progressive *Accelerating PMTCT* document which addresses the need for scaling PMTCT programming. As such, the core research purposes shifted through an iterative process, responding to the specific LTF challenge.¹¹¹ Since high attrition and LTF interfere with the effectiveness of PMTCT, scaling-up PMTCT without addressing LTF will have limited impact on preventing mother-to-child transmission.

Yin (2009) identifies six possible data sources for case studies: documents, archival records, interviews, direct observation, participant observations, and physical artefacts. This research relies on the first three sources.¹¹² Documents and records from the Government of Ethiopia's website and specifically the Ministry of Health website provided the background to Ethiopia's health sector and system. M&E documents supplying statistical information on the burden of MTCT in Ethiopia and the response to date were obtained through Ministry contacts and global health data repositories. International donors' involvement in PMTCT efforts in Ethiopia were also explored through donor websites as well as grants and contributions documentation.¹¹³ To supplement these sources with current information on the opportunities and challenges faced by PMTCT programming and programmers, interviews were conducted with a variety of actors in Ethiopia's (and surrounding Sub-Saharan countries) PMTCT response and LTF strategies. These actors included: international agency and research organization employees, Government of Ethiopia employees, and NGO representatives. Interview interpretations were guided by a pragmatic paradigm. Following the principles

¹¹¹ The inductive qualitative methodology of this research allowed for the iterative process of 'problem identification'.

¹¹² One limitation of this research is that direct observation of PMTCT programming and the broader on-the-ground operations of health facilities in Ethiopia was outside of the scope of this project. Undoubtedly, this report would have been richer as a result of that experience.

¹¹³ Some of this data is subject to individual requests for information. The timeline of this research did not allow for some requests to be filed or for all requested data to be received.

of thematic analysis^{114, 115}, interview transcriptions were double-read to code relevant themes and identify major points of LTF as expressed by the interviewee.

Paradigm stance, which "provides a conceptual framework for seeing and making sense of the social world"¹¹⁶, is closely related to, and informs, the methodological approach.¹¹⁷ The pragmatic paradigm links the choice of methodology and research approach directly to the purpose of the research; in this case, exploring LTF in Ethiopia's PMTCT programs.¹¹⁸ As described by Armitage (2007), the pragmatic lens enables the research to embrace multiple data sources including qualitative and quantitative data – pursuing 'what works'. In the context of this project, where data is typically scarce, difficult to ascertain, and fragmented, employing a pragmatic paradigm enables the collection of meaningful data. Triangulation of data assists in constructing a comprehensive and holistic picture out of available data.

This study is unique in that it incorporates a holistic picture of LTF and attrition along the entire PMTCT cascade. Most studies addressing LTF seek to quantify the number of patients lost at an individual service point. As a result, the larger understanding of LTF and attrition along the care continuum remains absent. The interview methodology makes this approach possible as quantitative data, while valuable, is often missing or misleading (see Section 2.4.3.). The qualitative methodology employed in this study serves the 'bigger picture' well, allowing program planners, government analysts, researchers, and service providers to identify service delivery points where women, or mother-infant pairs, become disengaged and/or are lost. This study guides the targeting of interventions to minimize LTF, thereby maximizing retention and PMTCT program effectiveness.

¹¹⁴ Aronson, 1994.
 ¹¹⁵ Fereday & Muir-Cochrane, 2006.
 ¹¹⁶ Williams, 1998.
 ¹¹⁷ Armitage, 2007.

¹¹⁸ Creswell, 2003.

Chapters 4-7, highlight policy and programmatic opportunities to increase patient engagement/retention, reducing LTF and attrition. In these chapters, the experience of interviewees in Ethiopia and surrounding SSA countries, as well as documented programs, are drawn upon. Using multiple cases/country experiences is preferred in order to provide a greater robustness and more rigorous grounds for cross-case analysis, facilitating the triangulation of evidence.¹¹⁹ Triangulating evidence will assist in the construction of initiatives for reducing LTF. Notably, the challenges faced in each country context are not identical. In fact, at times they are quite divergent. This analysis does not suggest that successful programs in Rwanda, for example, are directly transferrable to the Ethiopian context. Rather, LTF initiatives are presented and their applicability to Ethiopia is explored.

3.1. Theoretical Framing¹²⁰

Public health research has traditionally been guided by an underlying empiricism. This framework typically views 'context' as "as source of potential confounders".¹²¹ The critical realist perspective, adopted in this research, conceptualizes context, and its complex interactions, as important causal agents. The aim of critical realism is to explain the relationship between experiences, events, and mechanisms.¹²² Within the context of this research, the critical realist perspective informs the exploration of relationships between pregnancy and PMTCT in Ethiopia, and the causal powers associated with LTF.

Health is intuitively understood as a personal trouble. After all, it is the individual who contracts disease, and in this case, has HIV and is at risk for passing the virus on to

¹²¹ Poland, Frohlich & Cargo, 2008.

¹¹⁹ Eisenhardt, 1989.

¹²⁰ De Maio's book *Health & Social Theory* provided an insightful and comprehensive review of the relationship between health and social theory. It contributed to this section and, more broadly, to my understanding of health as it intersects with biography, history, and society.

¹²² Jeppesen, 2005.

her child(ren). Yet, as established by the writings of Friedrich Engels (1845) and Rudolph Virchow (1848)¹²³ disease is socially patterned and as such, an expression of social, political, historical, cultural, and economic forces. These writers established that disease is largely socially determined and in the words of C. Wright Mills, 'a public issue'. Society itself plays a role in determining who is healthy and who is not, who dies prematurely and who does not. Not only is disease socially patterned, but also socially produced; favouring those who are wealthy, educated, socially connected, and autonomous.¹²⁴ Poor health is then more concentrated where these factors are absent producing a disparity, or inequity,¹²⁵ in the experience of health and illness. Society, however, is not static and theoretically, social change will result in changes in population health status.¹²⁶ This is a fundamental premise of this research.

Theorizing in health inequity is often dominated by discussions which hypothesize causal pathways from inequality to poor health. These discussions typically begin with income inequality as the fundamental cause.¹²⁷ Critiques of this perspective, particularly those of Muntaner and Coburn, utilize a critical realist perspective to, in the tradition of political economy, focus on the structural causes of inequality. Critical realism draws attention to the actuality of "income inequality as a consequence, not a determinant".¹²⁸

¹²³ Friedrich Engels' 1845 work is the classic treatise: *The Condition of the Working Cass in England* and Rudolph Virchow's 1848 work is his exploration of the typhus outbreak in Upper Silesia, highlighting the outbreaks social contagion.

¹²⁴ De Maio, 2010.

¹²⁵ While many theories make appropriate distinctions between inequity and inequality, these terms are used interchangeably for the ease of the reader and to avoid a lengthy discussion defining the boundaries of inequity and inequality. There are limitations to this approach and engaging in a broader dialogue around these concepts is likely to be beneficial. In this context, the occurrence of preventable mother-to-child transmission, and its concentration in the world's poorest countries, and among the poorest in those countries is identified as both unequal and inequitable.

¹²⁶ Leat, 2005.

¹²⁷ For further reading, see the theories and critiques presented by Wilkinson, Marmot, Turner, Muntaner, and Coburn.

¹²⁸ Coburn, 2004, p.43.

This research startles the line of mother-to-child transmission as a personal trouble and a public issue. It acknowledges that addressing the social, community, and political economy levels is essential to reversing HIV transmission trends. At the same time, the need for timely intervention at a more proximal level is recognized. Bruce Link and Jo Phelan in their influential paper on causes of disease wrote, "To be sure, a focus on mechanisms can help identify variables more proximal to health, and if such risk factors are addressed, the health of the public can be improved".¹²⁹ Cognizant of the political economy of HIV and the need for an immediate response, this research is informed by a critical realistic perspective. It focuses on PMTCT, program engagement and lost to follow-up – a proximal variable of maternal and child health – recognizing this specific problem as an expression of social structure and political economy troubles.

¹²⁹ Link & Phelan, 1995, p.88.

4. Getting Lost: Where and When

The semi-structured interviews conducted for this research project were rich with data on PMTCT practice, programming, and policy. Presenting a fulsome analysis of interviewee perspectives would require many independent works. Interviewees addressed a variety of issues including: health system strengthening, health workforce constraints, training and quality of care, cultural challenges, M&E methods, and a host of programmatic issues. However, within the first interviews, interviewees expressed the urgent need for work on LTF – a component of PMTCT programming which is beginning to be explored; an area where best practices have not been clearly identified. Consequently, interview analysis for this report focuses on LTF issues – where in the cascade mothers and mother-infant pairs are lost, how they might be engaged in the system in the first place, and retained in care. Promising programs and strategies are highlighted throughout this section situating the findings of this research with relevant on-the-ground innovations that are typically absent from the literature. Presentation of these programs also provides a pragmatic frame for motivating further discussion at the programming and policy level to minimize, if not eliminate, LTF.

The programs highlighted here focus on community-based or communityengaged programs. Community engagement is a fundamental principle of effective public health programs¹³⁰ and more recently the international development community has formalized its committed to local ownership of policies and programs.¹³¹ The majority of participants highlighted the value of community-based programming. As one example Participant 9 asserted that: "one of the best ways to improve uptake of services and

 ¹³⁰ Department of Health & Human Services, NIH, CDC, ATSDR, and CTSA, 2011.
 ¹³¹ OECD, 2009.

retention in care is to have some sort of community-based strategy". Entrenching a 'community-based' foundation in PMTCT programming is paramount to success and sustainability.¹³² Sustainability remains a core concern of developing country programming. Global financial instability has exacerbated funding issues for these programs and in some cases, severely jeopardizes their ability to work toward reducing maternal and child mortality, as well as MTCT. Community ownership and engagement has the potential to mitigate some issues of program success and sustainability¹³³ and as such, should find itself at the center of health programming in developing countries.¹³⁴ Conceptualizing community engagement broadly, national policies that entail community input and ownership do support this foundational public health tenet. This is particularly relevant for Ethiopia, which retains significant centralized power and therefore, continues to have the ability to move national programming and policies forward more readily than other Sub-Saharan countries.¹³⁵

The following section explores four themes emerging from the research identifying where¹³⁶ women are lost in the PMTCT cascade: (1) ANC uptake, (2) ARV adherence, (3) post-delivery, and (4) post-infant vaccinations. Interviewees did express that these trends cannot be analyzed at the individual program level, as program design is a primary determinant of LTF. Notably, there are other issues that result in what may

¹³⁵ Interview: Participant 9

¹³⁶ While these results focus on the 'where' of loss to follow-up, they also touch on the 'why' – why women are dropping out of care. These questions are intimately intertwined and are both fundamental to creating an evidence-base for policy and programming. A forthcoming article in the academic journal S.A.H.A.R.A qualitatively exploring the perspective of infant caregivers and the reasons for LTF of HIV-exposed infants may significantly contribute to answering the 'why' question. The decision not to seek care is context dependent and results from the interaction of a complex web of factors. From a social ecological perspective, facility, community, interpersonal, and intrapersonal level factors interact to determine care seeking behaviour. Unpacking these levels is currently a gap in understanding why women leave care.

¹³² Interview: Participant 9

¹³³ Note: appropriate and adequate financial resources are still necessary for sustainability. Community engagement is not a technique for reducing financial support but rather, making a greater impact with available resources.

¹³⁴ Newman, 2006.

be conceptualized as 'system induced' LTF. For example, insufficient human resource capacity for the women who come to ANC clinics to be seen or the inability to make the appropriate ART/ARV prophylaxis available to patients are system induced LTF. These are not uncommon occurrences in Ethiopia. In these situations, patients are displaying the necessary care seeking behaviour but structural barriers make care and follow-up impossible. System induced LTF appears to be a significant piece of the attrition puzzle. Ethiopia's weak health system and broader social infrastructure pose substantial hurdles to improving PMTCT programs. Efforts to improve individual programs, such as PMTCT, are quite dependent on system-wide improvements. In the absence of these improvements, PMTCT progress is much less secure. Data on these system barriers are scarce and feeds into the data discussion presented in Section 2.4.3 and Chapter 8.

While each point of LTF presented in this chapter represents an opportunity for policy and program intervention, the challenge of low ANC uptake in Ethiopia receives the most attention. Without engaging in ANC, HIV+ women typically remain outside of the health care system. For women who are not HIV+, initiating early ANC ensures safer pregnancy and improved maternal and child survival.¹³⁷ ANC symbolizes the first necessary step to better outcomes for pregnant women and their infants. Focusing on ANC uptake reminds program planners and policy-makers that "PMTCT shouldn't be looked at as a silo. It really should be looked at in the context of improved maternal and newborn outcomes" (Participant 1).

4.1. Antenatal Care (ANC) Uptake

"The problem, the biggest problem – and there are lots of problems – but the biggest problem is the low ANC utilization" - Participant 13

¹³⁷ Ethiopia has high infant, child and adult mortality rates.

Ethiopia, unlike some of its surrounding countries such as Tanzania¹³⁸ and South Africa¹³⁹, continues to have low ANC attendance. In 2005, only 27 percent of Ethiopian women attended ANC during pregnancy.¹⁴⁰ This percentage includes women who only have one ANC visit although the WHO recommends at least 4 ANC visits during pregnancy. Although the majority of pregnant women receive no ANC (72 percent), urban residents' attendance is higher than that of rural residents (approximately 60 percent and 45 percent respectively).¹⁴¹ Consistent with the percentages presented in Section 2.3, the 2005 DHS reports that approximately 12 percent of women attending ANC have at least 4 visits. The remaining 16 percent of women who attend ANC have less than 4 visits. Ethiopian officials advise the following visit structure:

- Visit 1: as early as possible
- Visit 2: 28-32 weeks
- Visit 3: >36 weeks
- Visit 4: before delivery date

This ANC visit structure is rarely followed. UNICEF reports that only 6 percent of women attend ANC before 4 months. Of the women that attend ANC, most have their first appointment between 4-7 months.¹⁴² In Soweto, South Africa where ANC attendance is a generalized norm, as highlighted by a key expert, "most of the mothers did go to the antenatal clinic, a lot of them went very late in their pregnancy... Some of the women said that why they didn't go earlier was because of [a] kind of fear of HIV testing" (Participant 11). This data from South Africa seems consistent with Abosse, Woldie and Ololo (2010) report from Southern Ethiopia, that 68 percent of those attending ANC, initiated care during their third trimester.¹⁴³ Only 8 percent of women attending ANC sought care during the first trimester. Several interview participants

¹³⁸ Interview: Participant 12
¹³⁹ Interview: Participant 11
¹⁴⁰ UNICEF, 2010.
¹⁴¹ UNICEF, 2010.
¹⁴² UNICEF, 2010.
¹⁴³ Abosse, Woldie & Ololo, 2010.

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highlighted these findings as an expression of the cultural element connected with early care seeking behaviour, describing the cultural norm as one that does not celebrate pregnancy – rather it celebrates child birth – contributing to later care initiation.¹⁴⁴ Late initiation results in missed treatment opportunities and a shortened window for intrapartum interventions, heightening MTCT risk.¹⁴⁵

Several participants, including Participant 9, expanded on the implications of entering PMTCT (through ANC): "PMTCT is unique in that it's sort of the entry point to care for the entire family". Consequently, late initiation has a dramatic impact on household health and care seeking behaviour. Without ANC initiation the rest of the family remains outside of care. Fear of knowing HIV status and associated discrimination¹⁴⁶ is an interpersonal and intrapersonal level barrier to attending ANC for pregnant women.¹⁴⁷ In Ethiopia, most women obtain their HIV status through ANC sites providing HIV counselling and testing (HCT), contributing to the fear and delay associated with ANC attendance. In Soweto, where most women "knew their status during pregnancy or before pregnancy [and] there's posters everywhere talking about PMTCT and HIV testing during pregnancy" (Participant 11), ANC attendance is the norm. While numerous other factors contribute to high ANC attendance in Soweto (e.g. a more densely populated area where a well managed public PEPFAR-funded hospital is located centrally) ANC and PMTCT awareness through posters and media as well as known HIV status increase the motivation to attend ANC. Since HIV status is already known, the fear associated with attending ANC is largely eliminated.

¹⁴⁴ Interview: Participant 9 and 10

¹⁴⁵ Simkhada, van Teiglingen & Porter et al., 2008.

¹⁴⁶ Stigma was mentioned by several participants as a barrier for women to attend ANC and be informed of their HIV status. However, views were dichotomous on the importance of addressing stigma particularly since HIV counselling and testing became 'opt-out'. Participants felt that universal testing normalized at least the HIV testing aspect of ANC. However, stigma associated with a positive test result was not explored extensively by interview participants. Notably, the majority of participants highlighted partner engagement (see Section 4.1.2) as a core component of addressing stigma.

¹⁴⁷ Merdekios & Adedimeji, 2011.

4.1.1.Awareness

Population awareness is a primary determinant of public engagement with available services. Awareness is typically associated with maternal education, partner education and support, availability of services, and the costs associated with service.¹⁴⁸ Community mobilization activities to increase awareness and knowledge of the benefits of ANC and PMTCT services may increase ANC uptake. In Soweto, community media contribute to high ANC attendance.¹⁴⁹ In a Tanzanian community, faith based organizations host public health discussion groups. Faith and community elders partner with community health workers (CHWs) to raise awareness of various health risks, including the need for ANC, HCT, and PMTCT.¹⁵⁰ Engaging the faith community is a vital step in these communities. Traditional medicine – which is still practiced by some Ethiopians – often excludes medical intervention and increases risk for complications throughout pregnancy and MTCT.¹⁵¹ One interview participant highlighted CHAI's innovative approach to rapid mobilization and knowledge translation:

...we call them community mobilization activities, so increasing the awareness of the importance of women who are pregnant attending ANC. And we use this method called Fast Track Initiative... We identify the problem with the country, which is women don't attend ANC; we need to increase women understanding – and men also – the importance of women going for ANC. And so in Ethiopia, they actually identified that and ran several of these Fast Track Initiatives, which were out in the community really sensitizing leaders and elders and community members about the need to go to ANC, and also to be tested for HIV. And so they were able to have almost 100 percent increase in the number of women attending ANC, and then almost 100 percent of those women getting tested for HIV. (Participant 1)

Although yet to be piloted in Ethiopia, radio dramas (e.g. telenovelas) show promise for creating greater awareness and demand for ANC services. Telenovela's

- ¹⁴⁸ Simkhada, van Teiglingen & Porter et al., 2008.
- ¹⁴⁹ Interview: Participant 11

¹⁵⁰ Interview: Participant 12

¹⁵¹ Interview: Participant 10

continue to be used for positive health messaging, becoming popular in Latin America and in developed country contexts as well, such as Colorado, USA.¹⁵² Since television ownership is low in Ethiopia and is estimated to reach less than one third of the population, other communications mediums, specifically radio which is the main source of news and information for most Ethiopians,¹⁵³ are anticipated to be more suitable.¹⁵⁴

Participants noted that for women to initiate care, ANC needs to offer patients a greater incentive. Overcoming the fear of attending health clinics where quality services are not consistently assured and women report poor treatment by personnel, and significant expense can be incurred (e.g. transportation, time etc.) requires greater incentive. Participant 13 shared that:

...the next big thing is to make ANC services at health centres and hospitals more attractive. I mean, ... they [women] don't get much ... for the traveling they have to do and the personal expense they have to go through. They don't get all that much at an ANC visit.

Chapters 5-7 focus on policy and programming options that 'give more' to the patient at ANC visits and the evidence-base for using these options in Ethiopia to engage women in ANC.

4.1.2. Partner Engagement

Partner engagement is a determinant of ANC initiation and more specifically ANC patient retention. One participant asserted:

Mothers with supportive partners are better at attending clinics for a variety of reasons. Some of it deals with [HIV status] disclosure, but some of it deals with [that] most men don't want their wives going to the clinic all the time or leaving home or those types of things. (Participant 9)

¹⁵² Andalo, 2003.

¹⁵³ Particularly in rural areas where approximately 85 percent of the population resides. ¹⁵⁴ Info as aid, 2011.

Evidence of the positive effect on partner engagement is building across Sub-Saharan Africa. Partner engagement entails knowledge of women's status enabling HIV+ women to engage in PMTCT services (e.g. HIV care) and best practices (e.g. ART/ARV treatment, modified infant feeding etc.) without having to hide these behaviours from their husbands. Lack of partner support is associated with loss from care, as well as the inability to adhere to ARV therapy and modify infant feeding practices.^{155, 156}

While women currently become aware of their status at ANC, men do not attend these visits or know their HIV status, making preventive intervention on the part of the women, including family planning measures such as condom use, difficult to enforce.¹⁵⁷ Research in Tanzania revealed that only 3 percent of women who were tested at the community ANC sites brought their male partners for testing.¹⁵⁸ Male engagement, although challenging, is vital as evidenced by the following participant excerpt:

I think [it] will create a problem when the male partners are not involved and also [in] using condoms and safe infant feeding because the mother is attending the antenatal clinic and gets knowledge but she has no power to ask, to tell, the husband about this because if it's not his knowledge and he has not obtained it himself, I don't know if he will follow it. (Participant 12)

Facilitating partner knowledge and engagement in ANC and PMTCT starts with HCT. In Nairobi, couple counselling and testing (CCT) have been piloted. Results from this trial indicate that women whose partner participated in counselling and testing were more likely to enter HIV treatment and be retained in PMTCT programs. Retention was

¹⁵⁵ Farquhar, Mbori-Ngacha & Bosire, 2001.

¹⁵⁶ Kiarie, Kreiss & Richardson, 2003.

¹⁵⁷ Nebie, Meda & Leroy, 2001.

¹⁵⁸ Interview: Participant 12

evidenced by the CCT group being five times more likely to follow modified breastfeeding practices and four times more likely to use condoms to prevent MTCT.¹⁵⁹

Intervening at the partner level presents numerous opportunities for male knowledge translation, personal testing and counselling in support of maternal and child health. One participant proposed that:

...one of the main problems was that [the] antenatal clinic, where they were asked to go for testing, was not an acceptable arena for men. They wouldn't go because they're afraid other people will laugh at them - they will be socially stigmatized. They didn't feel comfortable going there with all the women. (Participant 6)

Popularizing male testing at other facilities – for example, a male health center – may increase partner HCT uptake. Alternatively, interviewees proposed bringing males in for testing on an invitation basis from health personnel.

4.1.3. Case Finding: From Facility to Community

Seventy-two percent of pregnant women in Ethiopia never engage with ANC.¹⁶⁰ Yet, most LTF interventions and analyses to date have focused primarily on losing women who have already engaged in the ANC/PMTCT service cascade. While LTF along the cascade is high – for example, in rural Malawi, 81 percent of HIV-exposed infants and their mothers are lost by the 6 month postnatal visit¹⁶¹ - those most vulnerable to MTCT are those who are lost before they ever engage in care. The majority of case-finding in Ethiopia is done at the facility level.¹⁶² However, facility uptake is very low. Over 50 percent of the population of interest remains in the community, lost to care, treatment, and follow-up.

¹⁵⁹ Farquhar, Kiarie & Richardson et al., 2004.

¹⁶⁰ UNICEF, 2010.

¹⁶¹ Manzi & Zachariah et al., 2005.

¹⁶² Interview: Participant 3

AMPATH, in a recent home-based HIV counselling and testing initiative found that among pregnant women who have been to ANC, the average HIV prevalence falls between 2.8-3 percent. The HIV prevalence among women who have never been to ANC is up to five times higher.¹⁶³ AMPATH's home-based testing has been very successful in identifying these women, with 99 percent of households agreeing to household testing with rapid ELISA testing. "The bottom-line message is that unless the PMTCT cascade gets down to the grassroots, gets into the villages, into the households, we will never, ever manage to eliminate mother-to-child transmission" (Participant 4).

4.2. PMTCT and ARV Adherence

The vast majority of pregnant women attending ANC will not be HIV+ and therefore, will not require PMTCT services. Consequently, a disconnect emerges in the PMTCT continuum between ANC and PMTCT services. Between 2006 and 2010, 75 percent of ANC visits occurred at non-PMTCT sites. Appropriate screening/testing services were not available to HIV+ women who came to ANC.¹⁶⁴ One central challenge is sufficient health personnel to provide PMTCT services at all ANC sites.¹⁶⁵ Health extension workers' (HEWs) scope of practice – as defined by the Ministry of Health – assigns these mid-level health workers core maternal and child health responsibilities.¹⁶⁶ As originally designed, rural locations are served by HEWs at health posts, where many women receive their pre- and postnatal care. An expert on the Health Extension Programme relayed: "The big issue here, of course, is that in most areas, HEWs do not provide either testing, and certainly nowhere do they provide prophylactics. So you have... 30,000-plus HEWs providing antenatal care – and with targets for antenatal care – who do not provide testing" and treatment (Participant 2).

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¹⁶³ Interview: Participant 4

¹⁶⁴ Nigatu & Woldegebriel, 2011.

¹⁶⁵ Federal Democratic Republic of Ethiopia, 2003.

¹⁶⁶ Federal Ministry of Health, 2005.

Women testing positively at ANC are typically referred to HIV care sites where ART and/or ARV prophylaxis are provided. These clinics are significantly more difficult to access, particularly for rural patients where the expense of traveling to ART sites presents an often insurmountable barrier.¹⁶⁷ ART/ARV clinics stockpile is occasionally insufficient. Together these barriers result in ARV coverage of approximately 20 percent in Ethiopia.¹⁶⁸ Ethiopia lags far behind neighbouring countries such as Kenya at 73 percent, Tanzania at 70 percent, and Malawi at 58 percent ARV coverage.

For women who obtain ART/ARV, adherence poses the second major point of LTF. Adherence is an important part of HIV treatment success. In Zambia, Stringer et al. (2005) found that one-third of women given ARVs for the purposes of PMTCT never ingested them.¹⁶⁹ Numerous technology-focused global health research groups, including mHealth, propose information communication technologies as a solution to adherence issues in ARV ingestion and follow-up appointments. These programs using pagers, text messages, and/or emails to send reminders to patients have been piloted on various health issues including STIs and HIV/AIDS. In South Africa, short messaging service (SMS) has been successfully piloted for improving HIV patient medication adherence.¹⁷⁰ In Ethiopia, the mobile revolution has been slow to develop and the mobile penetration rate estimate ranges from 6.2-13 percent.¹⁷¹ Many rural areas have yet to receive a network signal and few own mobile handsets.¹⁷² Ethiopia, in this context, contrasts with many other developing African countries where mobile technology has

¹⁷⁰ Mukund, Bahadur & Murray, 2010.

¹⁶⁷ Interview: Participant 14

¹⁶⁸ Phelps, 2011.

¹⁶⁹ Stringer et al., 2005.

¹⁷¹ Info as aid, 2011.

¹⁷² For those who do own mobile phones, they are often shared by several people or within one household. Sending health-related messages (particularly HIV-related messages) to a shared phone presents major privacy and disclosure issues.

become mainstream for the general population. For example, in Kenya the mobile penetration rate reached 63 percent by the end of 2010.¹⁷³

Participant 7 expressed opportunity for pharmacists and CHWs to use ARV registries to enhance ARV adherence. By tracking the patients who fail to return each month for medication, CHWs – through phone calls and possible home visits – could reengage mothers and mother-infant pairs during ARV treatment stages. Ethiopia has piloted a similar program, the peer education program. Peer education is a common technique in public health to engage individuals with similar experiences and struggles to assist each other while promoting healthy behaviour and entrenching these behaviours as social norms.¹⁷⁴ This program is run by volunteers who are living with HIV/AIDS and themselves receiving treatment. In Ethiopia's pilot program, peer educators (PEs) worked within the hospital setting at four hospital sites in Ethiopia, helping patients to navigate health services, tracing patients who left care, and working to bring them back to care while acting as a source of social and psychological support for other people living with HIV. Patients were brought back to care through phone calls, home visits, and/or linkages with CHWs. Between October 2006 and December 2007, PEs conducted approximately 1,700 home visits with the purpose of bringing lost clients back to care. This program gained high levels of acceptance from hospital administration and health professionals, successfully bringing clients - and their family members - to HIV care. The four hospital facilities with PE programs observed a reduction in the number of patients' LTF.

While the Ministry of Health and ICAP recommend the expansion of this model to build capacity specific to PMTCT, recruitment may prove difficult as PE positions were not financially compensated. Interviewee 13 highlighted the importance of patient trackers and peer educators being salaried employees, saying: "You look at the countries that are actually willing to invest in these healthcare workers, compared to the countries where the precedent was set that this can be a volunteer position... that's

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¹⁷³ Info as aid, 2011.

¹⁷⁴ Federal HIV/AIDS Prevention and Control Office (HAPCO) & I-CAP, 2008.

simply not the case". In fact, this participant furthered that remuneration is central to retaining workers and making programs sustainable from an operating perspective. Participant 13 described: "You invest all this time and money in training community healthcare workers, and then they'll jump ship because this other organization is going to give them a bike in addition to a t-shirt".

4.3. Post-delivery

Only 6 percent of births are attended by skilled health personnel in Ethiopia.¹⁷⁵ Stark contrasts exist between the rural and urban populations, where 3 percent and 45 percent of births are attended, respectively. Throughout all interviews, very poor facility delivery rates were highlighted: "the delivery in the facilities is abysmal. It's less than... for the most part, we actually see less than 10 percent [of] deliveries occurring in the facilities" (Participant 1). Although Ethiopian government data estimates facility-based delivery to be between 11-19 percent, interviewees unilaterally agreed that this percentage is overestimated. Low facility deliveries result in extreme difficulties enrolling HIV-exposed infants into PMTCT follow-up.¹⁷⁶ Infant enrolment post-delivery is a major point of LTF.

In Zambezia, Mozambique only 25 percent of women enrolled in PMTCT programs prior to birth brought their infants for early infant diagnosis (EID).¹⁷⁷ In Northern Uganda, 50 percent of HIV-exposed infants are LTF before their status is known.¹⁷⁸ Similar results are mirrored in rural Malawi, where Manzi, Zachariah, and Teck et al. (2005) report that 68 percent of HIV+ pregnant women are lost to the PMTCT program at the point of delivery.¹⁷⁹ Their infants are never captured in the PMTCT

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¹⁷⁵ UNICEF, 2010.

¹⁷⁶ Interview: Participant 9

¹⁷⁷ Cook, Ciampa & Sidat et al., 2011.

¹⁷⁸ Ahoua, Ayikoru & Gnauck et al., 2010.

¹⁷⁹ Manzi, Zachariah & Teck et al., 2005.

cascade. Upon completion of a multi-country analysis, CHAI (2009) reports that 70 percent of HIV-exposed infants who complete the HIV polymerase chain reaction (PCR) test are lost before enrolling in and initiating pediatric ARV treatment.¹⁸⁰ No Ethiopia-specific data is available. Unacceptably high LTF at the point of delivery requires a new approach to connecting PMTCT and pediatrics. Exploring combined clinics – one clinician providing care to mother and infant simultaneously¹⁸¹ - as Partners in Health (PIH) is currently, holds promise for reducing LTF if facility-based delivery can be amplified.¹⁸²

Facility-based delivery is one step toward ensuring infants receive ARV prophylaxis and enter the PMTCT cascade. As explained by Participant 5:

...if they [women] are delivering in a facility, then we get into sort of national guidelines, which might be that they can go ahead and give prophylaxis to the infant as well as the mom or they can go ahead and do early infant diagnosis right there or they can do a number of things. But then, even if those things are in place, there's lack of capacity, so healthcare workers... [aren't] trained... The enrollment part of the infant is a biggie, and so unless people are assigning community healthcare workers to do follow-up back in the community, it's really, really hard to get these people in.

The theme of community engagement emerged at this LTF point as well. Ethiopia's MSGs (see Section 2.3) provide substantial support for motivating motherinfant pair retention. These groups offer not only emotional and psychosocial support, but also address very practical issues such as enrolling infants in care, administering infant AZT, and infant feeding practices.¹⁸³ USAID's (2009) evaluation of MSGs revealed that women who were involved in MSGs were more informed about HIV/AIDS and PMTCT, were more likely to be on ART and adhering to their regimen, and less likely to

¹⁸⁰ Phelps, 2011.

¹⁸¹ This type of 'combination care' can be conceptualized as one step further than current models of care integration.

¹⁸² Interview: Participant 14

¹⁸³ Laher, Cescon & Lazarus et al., 2012.

be LTF.¹⁸⁴ Increases in exclusive breastfeeding for the first 6 months were also reported. All interview participants commented on the benefits of MSGs saying, for example "we know MSGs work, and so wherever there's an MSG you get great performance" (Participant 5). Expanding MSGs to actively trace mother-infant pairs and increasing the accessibility and utility of MSGs was strongly supported as a mechanism for reducing LTF in Ethiopia.¹⁸⁵

4.4. Post-infant Vaccinations

The fourth and final major point of LTF occurs after infant's 9-month vaccinations. Few mother-infant pairs remain in PMTCT/pediatric care to this point. Rather, after leaving the PMTCT cascade, mothers re-engage with pediatric care specifically for vaccinations. According to Participant 4: "Moms will stick to the vaccination schedule, and then you kind of don't see them". Consequently, infant vaccinations represent ideal opportunities to re-engage mother-infant pairs. In the words of Participant 9: "We all know that moms are really good about the vaccinations, so in most countries even if they do bad ANC or they don't have facility-based delivery, they'll bring the kids for immunization".

Strengthening pediatric integration with maternal health services offers infant vaccinations as a prime opportunity for follow-up. Well-equipped combination clinics would allow clinicians to "test women who bring their babies... for immunization, and then test babies of women who are positive" (Participant 13). Reintegrating with PMTCT at 9-months represents a sub-optimal intervention as many critical points for preventing MTCT have passed. Promoting well-baby visits early on during infancy may offer earlier

¹⁸⁴ USAID, 2009.
¹⁸⁵ Interview: Participants 3, 7, and 12.

windows for intervention. However, these visits are currently not well attended and do not supply an established infrastructure for PMTCT/pediatric HIV care to tap into.¹⁸⁶

Tailored intervention at each major point of LTF is necessary to realize the elimination of preventable infant infections. Focusing on the initiation of care – ANC attendance – is critical. Few women attend facility-based ANC consultations. Considering this problem in the context of LTF, these women are lost to follow-up before they engage in the system. Participant 4 highlighted the gravity of this reality for MNCH, as well as its PMTCT implications:

[Many] women in the community never engage with the health facility to begin with. It's really a case of... what we see in the facility and what we experience at the facility is just the tip of the iceberg. I mean, why do we care about loss to follow-up of children? Because of sickness and death... From a PMTCT perspective, we have got to get out of the clinics and go and wallow in the mud with community members because otherwise there's just no way that we'll ever get to a mother-to-child transmission free era at all; it's not going to happen.

The greatest loss of pregnant women to care occurs at the first step of the PMTCT cascade. Concerted efforts to engage women in ANC is a core component of improving maternal, newborn, and child health outcomes. The following chapters contribute to the discussion of the first major point of LTF: antenatal care.

¹⁸⁶ Interview: Participant 3

5. Antenatal Care Uptake: Policy and Programming Options

Addressing ANC uptake requires a comprehensive policy and programmatic response. The options presented in this chapter are constructed on the basis of available literature and raw data. Moreover, these interventions targeting ANC uptake express the dialogue and knowledge exchange emerging throughout the research process, formalizing 'on-the-ground' expertise in both the public health and public policy arenas. This chapter provides brief descriptions of each option. Subsequently, evaluation criteria are introduced in Chapter 6 and the intervention options are evaluated in Chapter 7.

5.1. Community Mobilization

Community mobilization strategies have forged a prominent place for themselves in public health intervention, proving effective in multiple contexts – both in the context of HIV/AIDS intervention and resource-constrained countries. Community interventions provide residents with the opportunity to engage and take ownership of the issue and its possible solutions – addressing awareness, the appreciation/internalization of risk, and attitudes toward seeking health services.¹⁸⁷ As asserted by Edward, Jumper-Thurman and Prested et al. (2000), "successful prevention programs are 'owned' by the targeted community itself".¹⁸⁸ Community-wide strategies focus on not only society as a collection of individuals, but also on the collectivity of shared ideas and practices which influence

¹⁸⁷ Burns, Imrie & Nazroo et al., 2007.
¹⁸⁸ p. 291.

health.¹⁸⁹ In the early 17th century, John Donne wrote, "No man is an island, entire of itself". With these words, he reminded that our actions – and our health – are not solely an individual reality. Rather, they are an expression of community factors, social structures, and individual susceptibilities. As furthered in Chapter 4, engaging in PMTCT programs and leaving care is socially informed. The policy options explored here reflect this connectivity.

5.1.1. Community Education Sessions

This option employs a community mobilization framework, using community centers and religious facilities to conduct health education sessions. These sessions would address numerous health issues, with a strong emphasis on ANC, PMTCT, and more broadly HIV/AIDS and maternal, newborn, and child health (MNCH). Scheduling of the sessions would be determined at the community level, but would happen frequently (one/per week or one every other week) to ensure that participants are supported through health behaviour adoption and that a culture of healthy-living is established through frequent social interaction.

5.1.2. Radio Telenovela

This option establishes a radio-based telenovela, using education-entertainment principles to address social norms around seeking medical care, healthy pregnancy (including ANC attendance), PMTCT and HIV/AIDS, and infant care. Episodes would be aired, through the state-run Ethiopian Radio and Television Agency (ERTA), on a weekly basis. ERTA runs Ethiopia's only national radio service. For households that do not currently have a radio, this option provides a radio.

The above options employ a community mobilization strategy. Both options offer an additional advantage in that they address multiple health issues and behaviours, beyond ANC attendance. In this sense, they are less targeted toward ANC uptake but

¹⁸⁹ Rose, 1992.

may have significant spill over effects into general health or common health ailments in Ethiopia. Since interventions are desperately needed for a wide range of health conditions, a less specialized strategy may provide greater overall health benefit than a highly-targeted ANC strategy. The remaining three options are tailored more specifically toward ANC, either at the community or facility level.

5.2. Home-based Antenatal Care (ANC) and HIV Counselling and Testing (HCT)

This option addresses low ANC uptake by moving the primary initiation of care from the health facility/health post level to households. Moving care closer to women and easing access to care was explored by Participant 4 in this excerpt:

Right now it's all about getting them [women] into the clinic, but, I mean, in rural Africa, for women who have multiple children and other responsibilities... it's a big stretch for them to be coming to the clinic once a month or more. They don't have the transport funds. They don't have whatever resources are necessary. So trying to somehow bring that cascade down to the grassroots is just... it's really, really critical, and so far, as far as I can tell, nobody else is really doing it yet.

For this option, CHWs and/or HEWs would visit women in the community routinely. At the first visit women and their household would also undergo HCT. Knowing HIV status prior to pregnancy is central to seeking early PMTCT care and receiving the necessary support and treatment. Follow-up testing would likely be taken on by another organization every few years.

Communities in Ethiopia – particularly rural communities – are typically closeknit, and CHWs/HEWs are privy to intimate information (e.g. pregnancy) long before facility-based health care providers. Women would undergo initial ANC visits in their home. Follow-up visits would be conducted either in the home or at the nearest facility, based on women's preferences.

5.3. Facility-based Nutritional Program

This option offers women, and their households, an incentive for visiting local health clinics. At each health clinic, nutritional programs are instituted, in partnership with the World Food Programme (WFP).¹⁹⁰ Typically, gardens are built at each facility and maintained by a few volunteer community members to complement WFP supplied foods with fresh fruits and vegetables.¹⁹¹ Families can obtain nutritious foods from the clinic at no cost. Once at the clinic, individuals are encouraged to seek care, for women of childbearing age, family planning, HCT, and where necessary ANC would be available.¹⁹²

5.4. Mothers Support Group (MSG) Expansion

The Mothers Support Group (MSG) is very active in Ethiopia (see Chapter 2 and 4). This option proposes the expansion of MSGs to mobilize women in the community who have not engaged with MSGs and/or ANC.¹⁹³ Most MSGs are run quite informally (especially since the formal budget for Intrahealth, supporting MSG development ended). Consequently, MSGs would benefit from revitalization in leadership and funding. This option proposes equipping one peer educator (PE) per site to coordinate MSG activities and engage women throughout their pregnancy. PEs would receive some training in community engagement, healthy pregnancy, common complications, HIV/PMTCT, and infant care.

¹⁹⁰ Note: This is a component of the World Food Programme's Purchase for Progress (P4P) initiative, which has been piloted in 21 countries.

¹⁹¹ http://www.ampathkenya.org/our-programs/agriculture-nutrition/nutrition-program/

¹⁹² Federal HIV/AIDS Prevention and Control Office (HAPCO) & I-CAP, 2008.

¹⁹³ Interview: Participant 13

6. Criteria and Measures

In order to identify which options, as presented in Chapter 5, are most feasible and offer the greatest potential for increasing ANC uptake, each option is evaluated based on the following criteria and corresponding measures (see Table 4).

6.1. Cost

The cost of each option is a primary determinant of its viability. Although the Ethiopian government is committed to moving PMTCT forward and reaching international targets of reduced MTCT, maternal, and child mortality, without the domestic or donor funding to design, implement, and enforce the proposed option, it is unlikely to have an observable health impact. As donor countries continue to face their own economic hardships and debt crises, high cost and low cost-effectiveness will act as primary determinants of options potential. Two measures of cost are utilized in this analysis to capture both the cost to government (and donors), as well as the cost borne by individuals.

Cost to Government and International Donors: This criterion captures the cost, which is borne by the Ethiopian government and one of its primary sources of health financing – international donors. This is measured in USD. A note of caution is necessary here as costs for each option are not readily available and are therefore based on reasonable assumptions.

Cost to Individual(s): This criterion captures both fees levied to the individual at the point of service and the expense incurred by the individual in the process of seeking

care. Fees levied at the point of care are a significant deterrent for potential patients, particularly in low-resource settings. Moreover, point-of-care fees are contrary to Ethiopia's commitment to universal access.¹⁹⁴ Physician fees and travel expenses both embody direct costs to the individual seeking care.¹⁹⁵ Challenges and expenses associated with women going to ANC such as care of other children, work absenteeism etc. represent the indirect costs experienced by women seeking care.

6.2. Efficacy

The efficacy criterion captures whether the proposed intervention has the ability "to produce the desired beneficial effect... under ideal circumstances".¹⁹⁶ Since the literature on the efficacy of specific PMTCT interventions is often inconclusive and at times sparse, three categories are introduced to capture the evidence for each option. Options are considered efficacious if they are supported by at least two of the following: (1) current literature, (2) program evaluation data, and/or (3) evidence-based discussion¹⁹⁷ surrounding ANC and PMTCT. Foundational best practices in public health will be included under this criterion. Foundational practices include, but are not limited to, community engagement, incentives for initiating and sustaining care, partner support, and engagement.

¹⁹⁴ Souteyrand, Collard & Moatti et al., 2008.

¹⁹⁵ National Information Center on Health Services Research & Health Care Technology, 2008.

¹⁹⁶ http://medical-dictionary.thefreedictionary.com/efficacy

¹⁹⁷ Evidence-based discussion is highlighted here, rather than simply evidence, since many successful innovations in this field have not been documented and are not part of the traditional 'body of evidence'. Furthermore, innovative (and experimental) programs are needed to address current challenges. These new ideas may not qualify as 'evidence' but have their place in 'evidence-based discussion'.

6.3. Equity

This criterion captures the 'fairness' of the proposed policy/program in comparison to the status quo. Since over 70 percent of the pregnant female population is not attending ANC (the status quo), any program that would result in a reduction of this percentage improves equity (i.e. more women have access/knowledge of ANC). This criterion concerns itself with equity of access to ANC, rather than equity of outcomes (i.e. ANC attendance). Ethiopia's population is largely rural (> 80 percent). Therefore, interventions that address access of rural populations specifically are given preference. This criterion is measured on a low, medium, or high scale, measuring the degree to which knowledge and/or access of ANC is improved, relative to the current situation.

6.4. Readiness

The concept of 'community readiness' has its roots in the transtheoretical model, which identifies individual willingness and intention to change behaviour(s).¹⁹⁸ Similarly, the concept of community readiness assesses the attributes, characteristics, and resources of communities to determine their capacity and openness to change. This theoretical model is based on the premise that communities are at different stages of readiness and can be moved along the 'readiness continuum' to make programs more effective.¹⁹⁹ Community capacity to design, roll-out, and sustain any ANC/PMTCT intervention falls within the criterion of 'readiness'. Programming that compliments current activities (status quo) will require both human resource capacity and system adaptations to accommodate the intervention.

¹⁹⁸ Edwards, Jumper-Thurman & Prested, 2000.

¹⁹⁹ The Tri-Ethnic Center for Prevention Research has developed a 9 stage model of community readiness. This concept, and its application, can be explored further in their publications.

Human Resources for Health (HRH) Requirement: Ethiopia is a HRH crisis country.²⁰⁰ Severe limitations in HRH capacity mean that tasking HEWs (or other health care providers) with more ANC/PMTCT responsibilities will result in a reduction of available human resources for other health services. Participant 1 explains:

HR is just a fundamental issue - how do you increase not just the capacity of the HR, [but] the competency of the HR... you can do that by training, but most of the training mechanisms that are in place require the actual staff leaving, right, so that's just the craziest training, right? So they leave for two weeks, and now there's nobody at the facility. And... there's enough literature in the world to say that training alone does nothing. In Ethiopia, they've identified midwives as a very critical component for maternal-newborn health, for PMTCT, for all of these things that sort of serve a larger group... The government has agreed to think about how to increase the number of trained midwives that get deployed. That's a very costly endeavour...

Increasing the demand for ANC services will simultaneously require health personnel (of various cadres) to meet population needs. In this respect, any successful option presented here will require increases in human resource capacity and innovative piloting of task-shifting – particularly the use of HEWs to complete ANC visits and complete HCT at the initial ANC consultation. This itself would be a significant policy shift.²⁰¹ The Ethiopian government recognizes the necessity for more HRH and continues to invest in HRH improvements.²⁰² Since 2003, the government has trained and deployed over 30,000 HEWs. By 2010, 34,382 HEWs had been deployed – an annual average of approximately 4,900 HEWs.²⁰³ This initial investment in training and deploying HEWs is likely to slacken as these health workers work to fulfill the currently unmet population health needs. For the purposes of this analysis, human resource

²⁰⁰ WHO, 2006b.

²⁰¹ Interview: Participant 6

²⁰² Center for National Health Development in Ethiopia, 2005.

²⁰³ Note: HEWs trained for a total of one year before graduating and entering community/facility health practice.

requirements will be measured in percent ranges²⁰⁴ – estimating the additional HRH requirements of the program, beyond the current availability of health workers.

System adaptations: This criterion evaluates the degree to which the infrastructure for the policy option exists. Changes to existing systems are typically arduous and time consuming. The number of major alterations required to accommodate each option are counted numerically.

6.5. Political/Donor Support

The political feasibility criterion encompasses numerous stakeholders who influence the implementation and success of each option. International donors' willingness to support particular programs is often influenced by their respective country governments and politics. At the domestic level, the Ethiopian government determines which projects would be most politically advantageous to fund – considering both the domestic population and the ramifications at the international table. At the community level, acceptance of the intervention and engagement throughout the process is core to the success and sustainability of the project. While this criterion in actuality is likely to exist as a continuum, for simplicity sake, high, medium, and low scores are allocated based on stakeholders prior behaviours and current politics/priorities.

Criteria		Definition	Measure
Cost	Cost for Government/ Donors	The financial resources demanded of government and/or international donors.	\$ USD

Table 4. Definitions of Criteria and Measure
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²⁰⁴ Several ranges are provided to give a better estimate of the HRH requirements.

Criteria		Definition	Measure	
	Cost to Individual(s)	Money that the individual is required to pay at the point of service delivery to receive care, and/or their travel expenses and indirect costs of seeking care (e.g. productivity losses).	Direct Cost= individual is required to pay at the point of service and/or travel costs are potentially substantial Indirect Cost= individual is not required to pay at the point of services and travel costs are negligible. Other indirect costs may be incurred. No Cost= individual does not incur direct or indirect costs	
Efficacy		The intervention's ability to produce a beneficial result (increase knowledge and access to ANC) is supported by at least two of the following: current literature, program evaluation data, and/or evidence-based discussion surrounding ANC and PMTCT programming.	Yes/No	
Equity		An increase in the number of relevant populations (primarily women, but also their partners) with access to and/or knowledge of ANC services, relative to the status quo.	High= the intervention improves knowledge and/or access for all relevant populations Medium= the intervention improves knowledge and/or access for some relevant populations Low= the intervention does not improve knowledge and/or access for any relevant populations	
Readiness	Human Resource for Health (HRH) Requirement	The percentage of the average annual HEW deployment (approx. 4,900) needed to roll-out the intervention, in addition to current HRH capacity.	High= > 20% Medium/High= 16-20% Medium= 6-15% Low= 1-5% Very Low= < 1%	

Criteria		Definition	Measure	
	System Adaptations	The number of significant changes required to the existing infrastructure/system in order to accommodate the intervention.	#	
Political/ Donor Support		The degree to which the domestic Ethiopian government, Ethiopian communities, as well as international donor governments and agencies, support and/or engage with the intervention.	High= Donors have supported similar project(s) in Ethiopia and/or other ODA recipient countries and the intervention does not address a contentious political topic for Ethiopia or donor countries. Medium= Donors have not supported similar project(s) and the intervention does not address a contentious political topic for Ethiopia or donor countries. Low= Donors have not supported similar project(s) and the intervention addresses a contentious political topic in Ethiopia or in donor countries.	

7. Antenatal Care Uptake: Evaluating Policy and Programming Options

The criteria explored in the previous chapter are now utilized to evaluate each ANC uptake policy/program option. Cumulatively, these options reflect the visionary approaches of interviewees and their respective organizations to "wallow in the mud with community members".²⁰⁵ As such, only one option is situated at the facility-level. Also worth noting is that no status quo option is presented among these options. Simply put, the current situation in Ethiopia represents system failure, and maintaining this situation comes with the high cost of many lives.

Table 5 presents a summary of the options and their respective evaluations. Upon evaluation, this report recommends the roll-out of two of the five options, namely introducing community education sessions focusing on healthy pregnancy, ANC, and PMTCT and expanding Ethiopia's mother support groups. The MSG expansion formalizes the current efforts and integrates a stronger community engagement piece into MSGs' current work. Together, these initiatives have the potential to shift collective perceptions of pregnancy and motivate early care-seeking behaviour. A fulsome evaluation of each option follows in Sections 7.1 through 7.6.

²⁰⁵ Interview: Participant 4

Increasing ANC Knowledge and Service Uptake Options							
	Community Sessions	Radio Telenovela	HCT + ANC Home-visits	Nutritional Program	MSG Expansion		
Cost to Government/Donors (USD)	\$33,000/year	\$4.23 million	Year 1: \$5.7 million Year 'n': \$939,600	\$10 million/year	\$13,440/year		
Cost to Individual(s)	Indirect	None	None	Direct	Indirect		
Efficacy	Yes	Yes	Yes	No	Yes		
Equity	High	Medium	High	Medium	Medium		
HRH Requirement	Low	Very Low	High	Very Low	Very Low		
System Adaptations	0	1	1	0	1		
Political/Donor Support	High	High	Medium	High	Medium		

Table 5.Evaluation Matrix

7.1. Community Education Sessions

<u>Cost to Government/Donors</u>: The cost to government for this program is embodied in the health workers conducting the educational/health engagement sessions. HEWs earn 381 Ethiopian Birr (ETB)/month, which is equivalent to nearly US\$ 22. Salaries for nurses and technicians are slightly higher at approximately US\$ 25.²⁰⁶ For each community one additional health worker would be employed for the program (see HRH requirement), totalling an annual operational cost of US\$ 300 (25 x 12) per community. While no accurate estimate of total communities and cities in Ethiopia exists, rough

²⁰⁶ Teklehaimanot, Kitaw & G/Yohannes et al., 2007.

estimates range around 110 communities.²⁰⁷ If all communities adopt the program and each requires its own health worker (personnel do not cover more than one community), the total cost is estimated at \$33,000/year.

<u>Cost to Individual</u>: This program would entail no direct costs to the individual at the point of the education session. Additionally, since sessions are community-based no significant travel expenses are anticipated. As these sessions are offered at community centers/gathering places, small indirect costs are anticipated in urban and rural communities.

Efficacy: Education alone is rarely successful in producing behaviour change.²⁰⁸ However, Info as Aid (2011) reports that community meetings are one of the most trusted sources of information for people in Ethiopia – particularly those residing in rural areas. Furthermore, religion plays an important role in social life in Ethiopia and according to the 2007 census most Ethiopians (approx. 96 percent) attend either a Christian church (63 percent) or a Muslim mosque (33 percent). Religious endorsement for ANC has increased attendance in some pilot regions.²⁰⁹ Religious involvement supports women in respecting their religious faith (and traditional healing practices) while seeking medical care.

Community education builds strength within the community and the co-learning process is empowering; creating a social dynamic that encourages adoption of the desired behaviour and develops positive social pressure to conform to the behaviour.^{210, 211} Furthermore, investing in community capacity is a core challenge for international development. In the community education forum, opportunities to develop community health leaders and champions exist. Fostering 'community champions' is a well established best practice in public health. Community education sessions offer an

²⁰⁷ http://en.wikipedia.org/wiki/List_of_cities_and_towns_in_Ethiopia

²⁰⁸ Rose, 1992.

²⁰⁹ Interview: Participant 10

²¹⁰ Israel, Schulz & Parker et al., 1998.

²¹¹ Glasgow, Vogt & Boles, 1999.

opportunity for positive social change in relation to health and care seeking behaviour. The verbal communication of education sessions is particularly relevant for countries like Ethiopia where literacy rates remain relatively low (38 percent).²¹² Literature from developed and developing country contexts points to the efficacy of this option.

<u>Equity</u>: Attending educational sessions will improve equity as community members will become increasingly knowledgeable about ANC, as well as the available health services. The benefits experienced by women and their infant(s) as a result of seeking care will also be more fully understood. Community sessions attendance by both males and females will further encourage ANC attendance. Therefore, equity is assigned a high ranking.

<u>HRH Requirement</u>: The additional HRH capacity required for this program is low, meaning that few additional health workers are needed for this intervention. Community outreach, education, and engagement fall well within the professional scope of HEWs and community health professionals.²¹³ This intervention would fall under their leadership. Since community health professionals are over-tasked, some additional capacity would be needed. However, if 1 full-time equivalent HEW or CHW were employed for each community (approximately 110 additional workers in total), this program would comprise only a portion of their work. The time commitment is minimal (approximately 4 hours weekly or biweekly per session [including preparation time]). Multiple sessions would be run within one community as it is unlikely that the entire community could attend one session. It is anticipated that the additional workers would staff other HRH constrained health activities.

<u>System adaptations</u>: While stakeholder relationships would need to be built (e.g. with community gathering places, community elders/religious leaders), no significant system changes are necessary for the implementation of this option.

²¹² UNICEF, 2008.

²¹³ HEWs already spend nearly 75 percent of their professional time in the community; Sebhatu, 2008.

<u>Political/Donor Support</u>: The political support for this initiative is anticipated to be high. Donor countries' commitment to aid effectiveness and country ownership is likely to motivate their support of this intervention. Multiple health issues would be addressed by these sessions, making stakeholders particularly supportive. Similar projects have been piloted in Ethiopia, with success from both a government (better health outcome indicators) and community perspective (better individual health).

7.2. Radio Telenovela

<u>Cost to Government/Donors</u>: The writing, casting, and production of a radio telenovela is a costly endeavour. In Colorado, the television Telenovela *Encrucijada* required a financial investment of \$966,000 from the Colorado Health Foundation to produce and air the show.²¹⁴ This figure likely overestimates the cost of producing a radio, rather than television, telenovela. Presumably, the cost would be reduced to border on US\$500,000 per telenovela series.

In order to avert any direct costs to the individual, radios would be provided to individuals who do not already own a radio. The International Research Foundation for Open Learning estimates the cost of a radio at US\$3.²¹⁵ A possibility exists to obtain radios through donation, or external organizations. This would remove the additional cost of providing the radio for some households. The possibility of donations should be explored before ruling out this option as too fiscally demanding for Ethiopia.

Ethiopia's national radio station reaches just over 50 percent of the population. Of the population reached by the radio system, no estimates exist for the number of households that have their own radio. Assuming that 15 percent of households currently within radio wave reach require a radio, the additional cost – assuming no donations are

²¹⁴Http://web.encrucijada.tv/1/index.php?option=com_content&view=article&id=67:encrucijada&c atid=1:latest-news&Itemid=50

²¹⁵ Perraton & Crred, 2000.

secured – would be approximately \$3.73 million.²¹⁶ The total cost to government/international donors for this option is \$4.23 million.

<u>Cost to Individual</u>: This option introduces no extra cost to community members. Many individuals already own a radio (or share with neighbours) and no direct or indirect costs are associated with listening to the radio. Since this option supplies radio to those who do not have them, no direct costs are incurred by individuals purchasing radios.

Efficacy: Telenovelas have been used in numerous contexts, addressing issues of risky sexual behaviour (Tanzania), obesity and diabetes (Colorado, USA; Alabama, USA), and family planning (Ethiopia).²¹⁷ The *Yeken Kignit* radio melodrama supported by the US-based Population Media Center became very popular in Ethiopia,²¹⁸ over its 2.5 years of national broadcasting. Nearly half of the country's adult population was a regular listener. The UNFPA reports that communications between married couples regarding family planning more than doubled during that period and the demand for contraception increased by 57 percent.^{219, 220} PAHO has provided its support to this community mobilization and education-entertainment tool, commenting on its efficacy and effectiveness.²²¹

<u>Equity</u>: The equity ranking for this option is medium. The telenovela will increase the knowledge of ANC, PMTCT, other health behaviours more generally (e.g. nutrition, hygiene, addressing risk behaviours such as smoking), as well as health services. It should be noted that individuals without access to radio may be worse off under this

- ²¹⁷ UNFPA & Population Media Center, 2005.
- ²¹⁸ http://www.odemagazine.com/doc/32/can_soap_operas_save_lives/
- ²¹⁹ http://www.unfpa.org/public/News/pid/165
- ²²⁰ It is unclear how this particular outcome was measured and what confounders may be present in this analysis.

²¹⁶ Approximately 50 percent of Ethiopia's population is reached by radio (41.4 million). If 15 percent do not own a radio that equals 6,210,000 people. Assuming there are on average 5 people per household, an additional 1,242,000 radios would be required for all individuals living within radio catchement to have access to a radio in their home. If each radio costs \$3, the total additional cost of supplying radios would be \$3,726,000.

²²¹ Andalo, 2003.

option – creating (potentially greater) knowledge inequities within the population. Consequently, this option is rated as medium.

<u>HRH Requirement</u>: No additional health personnel would be required to write, produce or air the radio drama.

<u>System adaptations</u>: One significant infrastructure expansion would be required to increase the effectiveness of this intervention. Currently, the ERTA radio station has the potential to reach just over half of the population – reaching 45 million people – on medium wave. Expanding the reach of the ERTA would increase the number of potential listeners and is essential for increasing the anticipated effectiveness of this option. Additional costs are associated with expanding the radio system. However, while this program may serve as an impetus for radio expansion, the benefits would be experienced in multiple sectors. Consequently, the cost associated with infrastructure expansion is not included in the costing of this particular programmatic option.

<u>Political/Donor Support</u>: Radio and television telenovelas have been employed in many developing country contexts and in some developed countries (e.g. USA). The Ethiopian government supported the airing of the Yeken Kignit radio melodrama from 2002 through 2004 and is likely to support further healthful radio messaging.²²² High listener engagement for Yeken Kignit, confirms the community support for such projects.

7.3. Home-based Antenatal Care (ANC) and HIV Counselling and Testing (HCT)

<u>Cost to Government/Donors</u>: The cost to government would be embodied in the health professionals needed to complete HCT and ANC visits and the necessary mobile medical equipment. Currently, two HEWs are deployed to service 5,000 people. An initial survey of HIV seropositivity would be conducted in each community. If each CHW/HEW

²²² UNFPA & Population Media Center, 2005.

is assigned 5,000 people, an additional 16,000 health workers would be needed to conduct the initial testing. If each worker receives US\$300/year,²²³ the annual cost would be \$4.8 million.

Additional CHW/HEW support for home-based ANC would be required. The annual number of births in Ethiopia amounts to 3,132,000.²²⁴ If each health care worker has a caseload of 1,000 pregnant women annually, 3,132 additional permanent health care workers are required. At a US\$300 annual salary, the total cost is \$939,600.

In light of the HRH costs, additional medical equipment costs are likely to be negligible.

<u>Cost to Individual</u>: No costs are levied on the patient at the point of service. Since visits are occurring in the home environment, no travel expenses are incurred. No indirect costs are anticipated.

Efficacy: Interviewee participants were very supportive of this option – seeing great potential for the effective use of low- and mid-cadre health care workers in this manner. Home-based HCT has been embraced by AMPATH in Kenya with great success – approximately 98 percent of households agreeing to testing.²²⁵ Participant 9 highlighted that the financial investment of mobile testing and service initiatives is well warranted, saying: "You look at the countries that are actually willing to invest in these healthcare workers, compared to the countries where the precedent was set that this can be a volunteer position – that's simply not the case."

<u>Equity</u>: This population strategy ranks high for the equity criterion. In fact, of all options, this intervention promotes equity most in that care is brought directly to the individuals and services are provided in the home. Since the option allows for all households to gain

²²³ Teklehaimanot, Kitaw & G/Yohannes et al., 2007.

²²⁴ UNICEF, 2009.

²²⁵ Interview: Participant 4

knowledge of their status, and be counselled through pregnancy and ANC, the increase in ANC uptake is anticipated to be equitable under this option.

<u>HRH Requirement</u>: As noted under the government cost criterion, the HRH investment for this program is substantial. A total of 19,132 additional health workers are needed for the first year of the program, followed by a sustained additional workforce of 3,132. The HRH requirement for this project is categorized as high.

<u>System adaptations</u>: One major policy change is required for this initiative to be feasible – and to some degree contain the cost, namely, the expansion of mid-cadre health workers' (e.g. HEWs) scope of practice.²²⁶ Although HEWs are tasked with MNCH and ANC responsibilities, these services are delivered by other health professionals as well (e.g. nurses, midwives, doctors). HEWs are restricted from conducting laboratory tests and in some cases are not tasked with HCT.²²⁷ HEWs are also not able to provide ARV prophylaxis. These professional limitations severely constrain HEWs ability to provide the necessary care at the household and community outreach level. Changing scopes of practice (a.k.a. task-shifting) is integral to the successful operation of this initiative.

<u>*Political/Donor Support:*</u> Home-based visits strategies are being supported by many international donors and organizations such as, USAID, AMPATH, PIH, I-CAP etc. Communities are anticipated to be equally supportive. However, from a domestic government perspective, making professional task-shifting policies would be contentious.²²⁸ Consequently, this option is ranked medium under this criterion.

7.4. Facility-based Nutritional Program

<u>Cost to Government/Donors</u>: The cost of government/donors for this option is contained in the land needed at each facility, the necessary seeds for planting, and gardening

²²⁶ Gilks, Crowley & Ekpini et al., 2006.
²²⁷ Interview: Participant 5
²²⁸ Interview: Participant 3

equipment. The Ethiopian government owns its public health facilities and health posts. The surrounding land would be supplied by the government for a community-run farm. Worth noting here is that an opportunity cost is associated with the donation of this land. However, this analysis only looks to direct costs, further cost-benefit analysis would explore the relevant opportunity costs.

The WFP reports that the needed funding for its Purchase for Progress (P4P) strategy in Ethiopia for 2012 is above US\$ 200 million.²²⁹ Health facilities food programs are only a small fraction of P4P's activities. Assuming that health facilities comprise less than 5 percent of P4P activities, the nutritional programme would be budgeted under US\$ 10 million.

<u>Cost to Individual</u>: No fees are levied on the patient at the point of service. However, individuals are required to travel to clinics in order to receive the nutritional supplementation. Clinics, particularly in rural areas, are cumbersome to travel to. Therefore, direct costs associated with travel are anticipated.

Efficacy: This program provides individuals with an incentive to visit health clinics – whether for food, clean water, or from formal health services. In Ethiopia where all of these resources can be scarce, the incentive to frequent health facilities is substantial. In fact, AMPATH's nutritional program in Kenya has drawn individuals from neighbouring countries.²³⁰ While providing nutritional food and clean water are important steps for population health, no guarantee exists that participation in this program will increase ANC uptake. Although this option is efficacious (and effective) for improving overall health, its efficacy in increasing ANC uptake is not convincing at this point. Participant 4 conceptualizes the role of nutritional programs as central to engagement and retention in care:

We [AMPATH] also have our own farms that distribute fresh fruit and vegetables, basically, to patients who are severely malnourished, and it

²²⁹ http://documents.wfp.org/stellent/groups/public/documents/reports/wfp243264.pdf
 ²³⁰ Interview: Participant 4

would be great to be able to scale that up. And right now, we're feeding – what is it – like 30,000 people a month between the patients and the dependents... But it would be nice if we could extend this to all the [HIV] positive children, for example. I think that that would probably help a lot in terms of reducing loss to follow-up...

<u>Equity</u>: Individuals who live closer to the clinic or have the financial resources to travel easily to the clinic are more likely to take advantage of this program. Once at the facility, opportunities for ANC knowledge-acquisition and access to ANC services are present. Therefore, equity for this option is ranked as medium.

<u>HRH Requirement</u>: No additional health workers are required to implement or sustain this project. It is given a low HRH requirement ranking.

<u>System adaptations</u>: Ethiopia is currently one the 21 pilot countries for the WFP's P4P. Integrating this with health facility-based nutritional programs would require no significant changes to current policies.

<u>Political/Donor Support</u>: The P4P program has been rolled out in numerous countries, and with health facility engagement in other ODA recipient countries. The political/donor support for this option is anticipated to be high.

7.5. Mothers Support Group (MSG) Expansion

<u>Cost to Government/Donors</u>: Ethiopia's Federal HIV/AIDS Prevention and Control Office (HAPCO) in partnership with ICAP, piloted a peer education program at four hospitals providing HIV care and treatment. PE coordinators were paid 2,760 ETB for the year. This remuneration equates to nearly US\$ 160 annually. The most recent MSG evaluation reported 84 MSG sites, resulting in a total annual cost of US\$13,440.

<u>Cost to Individual</u>: There is no direct cost to the individual. An indirect cost of participating in MSGs may apply to some women.

Efficacy: MSGs have enjoyed remarkable success in Ethiopia (see Chapter 2 and 4). Their expansion is anticipated to only improve health outcomes.

<u>Equity</u>: The equity ranking for this option is medium. Since MSGs do not exist in all communities in Ethiopia, the benefits of expanding MSGs activities (not sites) will only increase knowledge and ANC uptake where MSG sites exist.

<u>HRH Requirement</u>: The additional HRH requirement for this option is very low. Some training would occur which would likely require HEWs, nurses and/or midwives to mentor peer educators. Training for PEs is anticipated to be minimal. Since MSG co-ordinators are a new level of health worker (and not currently acknowledged as health personnel), they are not counted in this section.

<u>System adaptations</u>: One system change would be required for program roll-out. Currently, peer educators are not recognized as health personnel. Acknowledging their role may be crucial to the validation of their status as MSG coordinators and for securing their salary.

<u>Political/Donor Support</u>: MSGs have become a pillar in ANC and PMTCT programs in Ethiopia and are widely acknowledged as one of the few true success stories in this field.²³¹ Donor and community support are likely to be high. However, political complexities surrounding the training and acknowledgement of PEs as health workers results in a medium ranking.

7.6. Recommendation

The recommended options, upon evaluation are two-fold: (1) community education sessions and (2) MSG expansion. The relative ease of implementation allows for a timely roll-out. Upon roll-out, it is recommended that the impact on ANC attendance is monitored, highlighting progress while ensuring that more resource intensive measures (e.g. home-based ANC and HCT) can be pursued, if warranted.

²³¹ Interview: Participant 3

The community education sessions are recommended because of their ability to mobilize the community around healthy pregnancy and ANC attendance. Furthermore, this option's low cost and lack of reliance on human resources and system adaptations, makes it feasible for immediate roll-out.

MSG expansion is recommended to couple with the community education strategy. Its low cost and minimal HRH investment indicate that this option is feasible despite constrained resources. The infrastructure and favourable reputation of MSGs in Ethiopia will provide strong assistance for community engagement. Furthermore, MSGs already have an existing client base.

Both of the recommended options do not rely heavily on Ethiopia's health and social systems. These systems are over-taxed and are struggling to fulfill basic necessities. These systems are characterized by weak infrastructure and often limits, rather than facilitates, effective programming. These options then offer a more immediate response than options that rely heavily on human resources, financial inputs, higher literacy and lower poverty. However, the recommended options would naturally benefit from a more developed and stable infrastructure. In this sense, these recommendations are still dependent on addressing systemic issues of poverty, inequity, and illness.

The radio telenovela option should also be considered as a potential future program because of its history of success in delivering health messaging in Ethiopia and other developing country contexts. The very low HRH requirement makes this option feasible for Ethiopia. However, the financial burden of this program is significant because of its radio provision and distribution functions. If radios could be secured by donation, this option would be more feasible. Furthermore, this option requires expansion of the radio system which will require time and investment. This option should be considered as the necessary structures are developed, since radio telenovelas are likely to assist in informing a social attitude/norm that is more favourable toward seeking formalized medical care, specifically in the early stages of pregnancy, and moving other poorly attended health programming such as well-baby visits, into the forefront.

The community education sessions and MSG expansion options address the individual and the collectivity of Ethiopian communities. Together, these options encompass both a less-targeted and a highly-targeted ANC uptake strategy, offering spill over health benefits while targeting the behaviour of interest. They offer immediate opportunities for increasing ANC knowledge and uptake. However, neither of the recommended options offer ANC services. Individuals are still required to actively seek ANC. Tracking the effectiveness of the education sessions and MSG expansion in increasing ANC attendance will be crucial. If these programs do not motivate sufficient improvement, home-based HCT and ANC visits are recommended. The substantial investment – both in terms of financial and human resource – makes this option less feasible at this time.

8. Discussion

Pediatric HIV infection poses a substantial threat to Ethiopia's current and future population health. Approximately 95 percent of pediatric infections result from MTCT – with an estimated transmission rate of 25 percent. Transmission rates as low as 2 percent are possible. Despite PMTCT efforts in Ethiopia, progress has been slower than expected. This research set out to explore the contribution of loss to follow-up in hampering PMTCT program effectiveness in Ethiopia. This research establishes LTF throughout pre-natal and post-natal service points as a substantial contributor to poor PMTCT progress.

This research, through a qualitative semi-structured interview process, identified four primary points of LTF: (1) ANC uptake, (2) ARV Adherence, (3) post-delivery, and (4) post-infant vaccinations. This is a substantial contribution to the literature, galvanizing 'on-the-ground' expertise and evidence to offer PMTCT programmers, policy-makers, and practitioners a holistic understanding of the areas along the cascade in urgent need of 'retention-focused' interventions. Specifically, the research presented here asserts that addressing care initiation – ANC attendance – is vital for Ethiopia, as low ANC uptake precipitates in low PMTCT uptake. Indeed, the most substantial losses occur at the first service point in the cascade. Thus the policy options attempt first to remedy low ANC uptake before tackling LTF further along the MNCH and PMTCT service cascades. The options presented in this research (Chapter 5) offer an innovative perspective to addressing social constructions around pregnancy, ANC, and PMTCT in pursuit of better MNCH outcomes.

Upon evaluation of the ANC uptake options and balancing considerations of health impact and financial investment for each option, this research supports the recommendation of a two pronged approach for increasing ANC knowledge and attendance in Ethiopia. These prongs would be rolled-out simultaneously, (1) the community education sessions and (2) the MSG expansion.

Both of these options are relatively inexpensive in comparison to other options, and have low human resource requirements. Since both financial and human resources are severely constrained in Ethiopia, low cost and HRH requirement are core tenets to successful roll-out. Community mobilization's success in developing country contexts, including Ethiopia, suggests that education sessions will successfully adjust individual behaviour and social norms, encouraging ANC attendance. MSG expansion is recommended in order to provide the social mobilization and connection needed to support pregnant women to engaging in formal health care at the early stages of pregnancy. This program already exists, offering available infrastructure which augments the ease of implementation.

These programs attend to a current gap in Ethiopia to move ANC awareness and uptake to the grass-roots, the community level. Addressing the barriers experienced by pregnant women in urban and rural contexts and providing both psychosocial support and role-modeling healthy behaviour is anticipated to increase ANC uptake and retention for HIV- and HIV+ groups.

8.1. In the Context of other Evidence

As outlined in the early chapters of this work, rigorous analysis of LTF is in its early stages. As such, this research opens the door for subsequent researchers and public health practitioners to innovate 'retention-focused' pilot programs. Work attempting to quantify the LTF at individual points along the PMTCT cascade, at specific sites or for a specific organization, provided a foundation for this research. Furthermore, the PMTCT Effectiveness in Africa: Research and Linkages to Care (PEARL) Study and CHAI's multi-country analyses advanced the importance of quantifying LTF and its impact on current estimation of PMTCT effectiveness. Cumulatively, the identification of LTF as a potential contributor to lagging PMTCT progress in this research, laid the foundation for the analysis of LTF along the cascade.

This research also encourages a shift in methodology, for a field that is predominantly preoccupied with quantitative (and results-based) analysis, to value a qualitative approach. A qualitative process facilitates knowledge exchange between

practitioners and decision-makers – a persistent challenge for research. In bridging these arenas, this research offers an opportunity for policy and practice to dialogue and develop a cohesive response.

PMTCT research in Sub-Saharan Africa is typically light on its theoretical grounding. The urgent need for intervention addressing the lived challenges of women with HIV and their 'at-risk' child(ren) often puts theoretical framing issues on the back burner, failing to fully consider the 'causes of causes'. The theoretical framing presented in Chapter 3 highlights the importance of social structures, and their resulting inequities, in addressing PMTCT and reminding policy analysts and health professionals alike of the root causes of poor health; an element that is often absent from PMTCT analyses. Simultaneously, the work presented here, which focuses on a proximal variable of health, also calls for others to further this analysis in the context of power structures, class struggles, and the sources of inequity that socially pattern and produce ill health.

8.2. Further Considerations

The options presented illustrate initiatives that the Ethiopian government could roll-out immediately, in partnership with donors and global health actors. As highlighted in Section 7.6, both of the recommended options are not heavily reliant on the health system. Throughout the course of this research, Ethiopia's limited social infrastructure, including its health system, are apparent. The success of many PMTCT initiatives (including some of the options presented in Chapter 5 such as home visits or nutritional programs) are dependent on broader system improvement, building and maintaining social and health infrastructure. Without addressing the social and cultural systems that hamper PMTCT programs, their effectiveness remains questionable. The options recommended by this research leave the responsibility of seeking care – attending the community session or joining the MSG – with the individual woman. While this is in many ways inferior to a 'passive' prevention approach, these initiatives are not overly system dependent. Consequently, the recommended options will likely have a greater immediate impact, unlike program that require health system integration, significant human resources, or established data collection methods.

These broader initiatives are necessary in the long-term. They represent important opportunities for developing Ethiopia's social structure. Several long-term initiatives exist that would have positive ramifications for addressing the data issues encountered throughout the course of analyzing LTF. They do not directly intervene on ANC attendance and therefore, were eliminated from the evaluation process. A brief discussion highlighting issues of, (1) capacity, (2) monitoring and evaluation, and (3) research gaps follows.

<u>Capacity</u>

Highlighted throughout this research are the constraints placed on efficacious and/or effective health interventions by the lack of health sector capacity. Ethiopia is not unique in this predicament. Many, if not most, Sub-Saharan countries face seemingly insurmountable hurdles in recruiting, training, and retaining enough health workers to meet population health needs. The quality of training and clinical practices embodies further complexities associated with health sector capacity. Innovative approaches to strengthening health systems through HRH expansion are desperately needed.

Implementing the recommended options is a precursor to increasing demand for ANC services. The success of the proposed policy options in increasing ANC attendance creates new challenges for health facility and human resource capacity, equipment and treatment stockpiles, including antiretroviral access. Ethiopia's progress on PMTCT facility building suggests that the physical space for increasing ANC visits is available. However, increasing health facilities alone will not result in improved ANC attendance, care, or health outcomes. The necessary personnel to complete antenatal care, treatment, and follow-up are essential. Innovating task-shifting options between health cadres – particularly increasing the use of HEWs, and potentially a minimal expansion of HEWs training curriculum to expand their scope of practice – is a vital component of addressing health resource shortages in PMTCT service delivery.²³²

²³² Banteyerga, Kidanu, Conteh et al., 2011.

Without access to the right pharmaceutical treatments, PMTCT efforts are ineffective. Access to drugs can be challenging, particularly in rural Ethiopia. However, notable progress on ARV access has been achieved through the Pharmaceutical Fund and Supply Agency. Delays in procuring essential medicines have been drastically reduced – from 360 days to 60 days.²³³ This results in reduced wastage of expired drugs, improving the sustainability of supply. However, delays in procurement, insufficient stockpiles, and distribution difficulties are still primary concerns for HIV/AIDS in Ethiopia. Delays in receiving and distributing ARVs create an opportunity for loss to follow-up, contributing to poor health outcomes.

Monitoring and Evaluation

Ethiopia has no vital statistics registry. The absence of routinely collected data and individual identification numbers poses large data collection and analysis challenges. ANC/PMTCT loss to follow-up is no exception. Investment in designing, piloting, and implementing a vital statistics registry nationally is needed to provide accurate population-level data on health conditions – prevalence, incidence, care seeking behaviour, LTF etc. Currently the absence of integrated and standardized data collection and reporting, and the necessary technological means of collecting and entering data result in a host of ascertainment issues.²³⁴ Incomplete and inaccurate data are the norm.

Linked with the efforts to establish a vital statistics registry are efforts from several global health bodies (e.g. AMPATH, PIH, and Tulane University) to reform Ethiopia's Health Management Information System (HMIS). Among the initiatives explored within the HMIS reform are re-assessing medical records – specifically, electronic medical records and mobile health initiatives.²³⁵ In the context of ANC, investing in medical records allows for the linking of "mother to baby, and that's sort of

²³³ Banteyerga, Kidanu, Conteh et al., 2011.

²³⁴ Federal Ministry of Health, 2008.

²³⁵ Interview: Participant 5

key [to changing] the way service is delivered. So instead of mom going to one place and infant going to another, they both come in and see the same clinic officer for the first six to eight months of life" (Participant 9). Core to this initiative is the establishment of a unique patient identified.

<u>Research Gaps</u>

Data limitations are inherently associated with research gaps. Indeed, research can only utilize the best available data to answer its questions. Monitoring and evaluation issues coincide with research problems. In Ethiopia, and in the context of ANC, there is a glaring absence of cost-effectiveness research. This study is also constrained by its inability to comment on the cost-effectiveness of each intervention without making several assumptions. One researcher identified a major research gap, saying: "What we need is cost effectiveness analyses to know just how cost-effective it [the intervention] is, taking into account diagnosing people earlier, getting them into care earlier and all the subsequent downstream savings of that, including fewer widows, fewer orphans, less poverty..." (Participant 4).

This research, and its recommendations, are constrained by these factors as well and would have benefited from discussion with care providers and both pregnant women deciding to seek, or not seek, antenatal care. Direct observation of the Ethiopian health care system would have informed understandings of the operational complexities, grounding the analysis in the day-to-day realities of working in Ethiopia. The insights offered from these perspectives would have further refined the data and policy/programming options presented here. However, this work is now being disseminated to interview participants and relevant global health actors to motivate a dialogue around implementing community mobilization strategies for ANC uptake and improving patient retention. In stimulating dialogue around LTF and strategies to reduce LTF, this research provides practical and feasible programs for global actors to 'pick up', while opening the door to further knowledge exchange between on-the-ground practitioners and programmers and policy-makers.

8.3. Conclusion

Preventing mother-to-child transmission of HIV continues to be a significant global health challenge. The considerable progress experienced on several PMTCT indicators in some Sub-Saharan countries is not mirrored in Ethiopia. This research establishes that high loss to follow-up along the PMTCT cascade, particularly at the initiation of antenatal care, is a major contributor to lower PMTCT effectiveness in Ethiopia. The government of Ethiopia, along with its development partners, has a unique opportunity to combine current efforts of scaling-up PMTCT with focused patientretention efforts under the common goal of reversing HIV transmission trends and improving the lives of vulnerable children.

Adopting a community mobilization approach to improving ANC attendance, and PMTCT more broadly, is essential. In Malcolm Gladwell's book *The Tipping Point*, he writes: "... the AIDS epidemic is fundamentally a social phenomenon. It spreads because of the beliefs and social structures and poverty and prejudices and personalities of a community, and sometimes getting caught up in the precise biological characteristics of a virus merely serves as a distraction".²³⁶ This research underscores the importance of understanding mother-to-child transmission as a fundamentally social phenomenon. Informed by the critical realist perspective, addressing the social structures, cultural norms, and poor material conditions is integral to changing the future of the HIV epidemic in Ethiopia. While the practical interventions presented in this research offer an immediate response to poor ANC attendance and high LTF, addressing the systemic issues that produce inequity and disease is at the core of this work. After all, these are our children.

²³⁶ Gladwell, 2002, p. 261.

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Appendices

Appendix A. PMTCT and MDGs

At the international level the WHO and UNAIDS share primary responsibility for supporting the health sector's HIV response.^{237, 238} Since the inception of the UN's Millennium Development Goals (MDGs) in 2000²³⁹, efforts to halt and reduce the spread of HIV/AIDS have become increasingly formalized. Significant developments include the production of generic ARVs, procurement advances through the Global Fund and the roll-out of ARV treatment in developing countries. In the PMTCT context, maternal health, antenatal care (ANC) services, and the attendance of a skilled health professional at delivery have each received attention. Relevant MDGs include MDG 3 (gender equality), MDG 4 (reduce child mortality), MDG 5 (improve maternal health), and MDG 6 (combat HIV/AIDS). The relevant aspects of these goals are presented below.^{240, 241}

Goal 3 Promote Gender Equality and Empower Women

Goal 4: Reduce Child Mortality

Target 4.A: Reduce by two thirds, between 1990 and 2015, the under-five mortality rate.

Goal 5: Improve Maternal Health

Target 5.A: Reduce by three quarters the maternal mortality ratio.

Target 5.B: Achieve universal access to reproductive health.

Goal 6: Combat HIV/AIDS, Malaria and Other Diseases

Target 6.A: Have halted by 2015 and begun to reverse the spread of HIV/AIDS.

Target 6.B: Achieve, by 2010, universal access to HIV/AIDS treatment for all those who need it.

²³⁷ WHO, 2009.

²³⁸ The WHO defines the health sector as, "wide ranging and encompasses organized public and private health services (including those for health promotion, disease prevention, diagnosis and care); health ministries, non-governmental organizations; community groups; and professional associations; as well as institutions which directly input into the health care system (e.g. pharmaceutical industry and teaching institutions)"; WHO, 2002.

²³⁹ http://www.undp.org/mdg/basics.shtml

²⁴⁰ UNAIDS, 2009.

²⁴¹ USAID, 2011.

Appendix B. ARV Treatment Guidelines

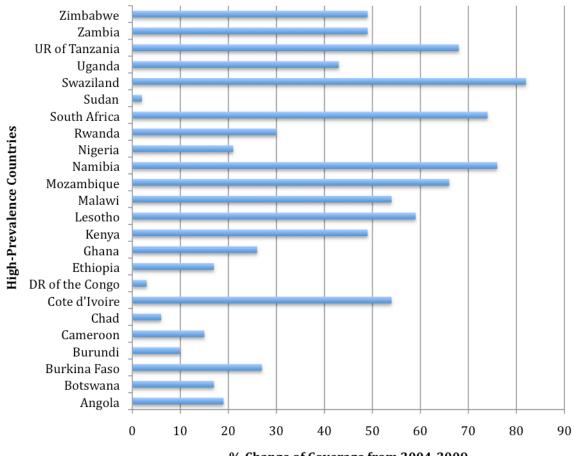
The 2010 guidelines identified four recommended first-line regimens (all combination ART options) for pregnant women. In 2006, only one recommended treatment guideline existed (AZT + 3TC + NVP). Having four treatment options provides national governments with increased flexibility to acquire first-line drugs that best meet the needs of their HIV+ populations. The 2010 guidelines also support life-long ARV treatment for HIV+ women who require it for their own health. However, for women who do not meet the eligibility standards for ART, two equally efficacious ARV prophylaxis options exist.

The two ARV prophylaxis options (Option A or Option B) are to be initiated at 14 weeks gestation, or soon after 14 weeks. Ethiopia has selected to follow Option A. Option A is as follows: "Twice daily AZT for the mother and infant prophylaxis with either AZT or NVP for six weeks after birth if the infant is not breastfeeding. If the infant is breastfeeding, daily NVP infant prophylaxis should be continued for one week after the end of the breastfeeding period."²⁴² ARVs are effective in reducing HIV transmission resulting from breastfeeding. Ethiopia, as a country that encourages exclusive breastfeeding for the first 6 months, ARVs are to be provided during that period to prevent transmission. Complementary foods are to be introduced post-weaning.

²⁴² WHO, 2010, p. 4.

Appendix C. SSA ARV Progress

Figure 1. Change in Percentage of Women Living with HIV who received ARVs for PMTCT from 2004-2009 (%)



% Change of Coverage from 2004-2009

Appendix D. Integration and Health System Strengthening

PMTCT Integration: Exploring the Options

Within the health and social services sectors, integrated approaches have a long history.²⁴³ The success of integrating HIV and TB responses for co-infections, leads to significant hope that integrating PMTCT with related health services may increase service uptake and impact.²⁴⁴ Currently, PMTCT programming is surrounded by significantly controversy as to where PMTCT services fit within the health care system, how and where these services should be delivered, and how PMTCT service expansion can work to strengthen health systems²⁴⁵. These vertical scale-up issues have financial resource implications, as well as human resource aspects. Integration – although ill-defined²⁴⁶ – is often presented as a core component of successful PMTCT programming.²⁴⁷ Furthermore, PMTCT efforts to date have largely focused on the 3rd prong of comprehensive PMTCT – ART/ARV initiatives. Increasingly, it is recognized that integration may facilitate a greater health impact.^{248, 249}

Three prominent proposals emerge with respect to PMTCT integration: (1) integrating with the larger HIV/AIDS response, (2) integrating with sexual and reproductive health (SRH), and/or (3) integrating with maternal, newborn and child health (MNCH). Proponents of integration take a 'back to basics' approach, attempting to treat women, and their infant(s), in a holistic manner acknowledging life-course disease processes and the intergenerational aspects of HIV transmission. Interview Participant 9 elaborated, saying "if you boil it down we know that integration of services helps if it means that she's [the mother] not going to have to wait in a queue that's longer than she normally would have. The whole idea with integration is that you're not going to go to four different places and wait in four different queues". Easing the mother-infant experience of initiating and maintaining care is anticipated to have favourable ramifications for patient retention – reducing LTF.

Lack of integration contributes to the slow uptake of PMTCT services and represents lost financial and human resource synergies.²⁵⁰ However, it is relevant to note that integration is usually accompanied by increased services and therefore, is unlikely to be cost-saving. Typically, PMTCT services are not offered together with SRH or MNCH services. Lack of integration may represent a missed opportunity to provide timely care and support the continuum of care – a recognized best practice for client-centred care.²⁵¹ Although HIV is a sexually transmitted infection (STI), over the course of the HIV/AIDS epidemic HIV has become largely divorced from

- ²⁴³ For example, the health and sanitation departments of government were often amalgamated. Before the development of urban planning as an independent discipline, health and city development were administered jointly as well.
- ²⁴⁴ Dickinson, Attawell & Druce, 2009.
- ²⁴⁵ Interview: Participant 9
- ²⁴⁶ Dickinson, Attawell & Druce, 2009.
- ²⁴⁷ Attawell, 2008.
- ²⁴⁸ Eyakuze, Jones & Starrs et al., 2008.
- ²⁴⁹ The global Partnership for Maternal, Newborn and Child Health (PMNCH) highlights integrated services as a necessary element of any PMTCT essential care package.
- ²⁵⁰ Lule et al., 2005.
- ²⁵¹ USAID, 2011.

broader STI efforts.²⁵² STI prevention, safer sex education, and contraception services are typically housed with SRH services. Integrating PMTCT with SRH will contribute to the construction of comprehensive PMTCT programming – addressing Prongs 1 (primary prevention) and 2 (family planning) of comprehensive PMTCT. PMTCT starts before conception. Consequently, not integrating SRH services leaves an unrealized opportunity to communicate around HIV prevention and the lack of attention to SRH exacerbates larger health system challenges (e.g. STIs, unintended pregnancies, unsafe abortions etc.).²⁵³

Historically, the intersection of maternal health with HIV has been a somewhat neglected component of comprehensive PMTCT.²⁵⁴ As the AIDS epidemic becomes increasingly feminized, integrating PMTCT with MNCH is a priority. In Sub-Saharan Africa, 61 percent of those with HIV/AIDS are female and continued disintegration is a missed opportunity to intervene on maternal mortality while providing pediatric HIV care.²⁵⁵ Failing to bring these vertical systems together has the potential to ease current access to treatment challenges for women and children. In northern Tanzania, integrating PMTCT and MNCH lowered service costs while increasing the quality of care. Transporting patients and equipment to care centres together, and unifying reporting and management tools streamlined planning and programming in northern Tanzania.²⁵⁶ Integrating PMTCT and MNCH also provides opportunity to ensure appropriate infant feeding practices. A pilot project in Swaziland demonstrated that integrating PMTCT and postnatal care resulted in a 60 percent increase in proper breastfeeding techniques.²⁵ Integration's early impact assessments indicate moving from siloed programming in maternal health. HIV and immunity, and pediatrics to integrated care continuums improves patient care. Additionally, integration has the potential to assist in increasing service uptake along the PMTCT cascade and reducing unacceptably high loss to follow-up among HIV+ pregnant women and their HIV-exposed, or infected infants.²

Health System Strengthening

Within the context of maternal, newborn, and child health (MNCH) and the 2010 G8 Muskoka Initiative, the discourse of strengthening health systems has expanded substantially at the international development table. The focus has been coupled with the aid effectiveness agenda emerging from the *Paris Declaration* (2005) and the *Accra Agenda for Action* (2008) which call for foreign aid investments to be aligned with country priorities and harmonized across donors.²⁵⁹ Taking a broader social systems approach is supported by the core messages of these international development documents.

As such, vertical approaches to health programming or a preponderance of disease specific programming is cautioned against. Much of the discussion surrounding HIV/AIDS programming in low-resource contexts has centered on the potential of vertical HIV programs – of which there have been and continue to be many – to limit the population impact and long-term sustainability of health improvement.²⁶⁰ For example, HIV-specific investment creates barriers to

- ²⁵⁴ Eyakuze, Jones & Starrs et al., 2008.
- ²⁵⁵ UNAIDS, 2010.
- ²⁵⁶ Evjen-Olsen, Evjen-Olsen & Kvale, 2009.
- ²⁵⁷ USAID, 2011.
- ²⁵⁸ Interview: Participant 1
- ²⁵⁹ OECD, 2009.
- ²⁶⁰ Chilundo & Aanestad, 2003.

²⁵² Steen, Wi & Kamali et al., 2009.

²⁵³ USAID, 2011.

comprehensive HIV programming. In Ethiopia, linking PMTCT services with the larger HIV/AIDS response continues to be relatively weak (particularly for certain sectors).²⁶¹ HIV programs typically focus on adult, adolescent or child populations, rarely pursuing a life-course approach.²⁶² Connecting HIV prevention, treatment and care presents new challenges for the continuum or care. Furthermore, connections with other health conditions and primary prevention and care are largely absent – a significant oversight to comprehensive health programming as a result of known co-infections, for example, tuberculosis. Research provides no clear guide as to whether HIV-specific investments strengthen health systems more broadly.²⁶³ In the face of limited international investment, and an inability to meet international targets as currently delineated, innovative financing often appears to threaten disease-specific investment. As a result, two opposed forces emerge – those who in order to protect their programmatic funding continue to support vertical investment and those who see an opportunity for greater long-term gain by integrating health investment. Pressure continues to mount to reorient vertical HIV funding to 'diagonal'²⁶⁴ investment, leveraging HIV funding for strengthened primary care systems.^{265, 266}

Vertical system development tends to support the fragmentation of resources – both financial and human – as well as lost opportunities for health programming synergies. Chilundo and Aanestad (2003) argue that in the context of integrating health information system in Mozambique, the structure of foreign aid investments act to facilitate vertical systems that are often not supported by domestic visions.²⁶⁷ The Government of Ethiopia reports that HIV/AIDS programming has had a positive impact on the health system.²⁶⁸ The *Paris Declaration, Accra Agenda for Action,* and the November 2011 Busan Aid Effectiveness Fourth High-Level Forum provide opportunities to reform aid to align itself with local priorities. In the context of HIV, and specifically PMTCT, integration appears to be essential for easing mothers' navigation of the PMTCT cascade, positively influencing mother-infant pair retention in PMTCT.

- ²⁶¹ Federal Democratic Republic of Ethiopia, 2010.
- ²⁶² Eyakuze, Jones & Starrs et al., 2003.
- ²⁶³ Yu, Souteyrand & Banda et al., 2008.
- ²⁶⁴ WHO, 2011b.
- ²⁶⁵ International AIDS Society, 2009.
- ²⁶⁶ http://www.acdi-cida.gc.ca/acdi-cida/ACDI-CIDA.nsf/En/JUD-111894059-K8N
- ²⁶⁷ Chilundo & Aanestad, 2003.
- ²⁶⁸ Federal Democratic Republic of Ethiopia, 2010.

Appendix E. Government Effectiveness

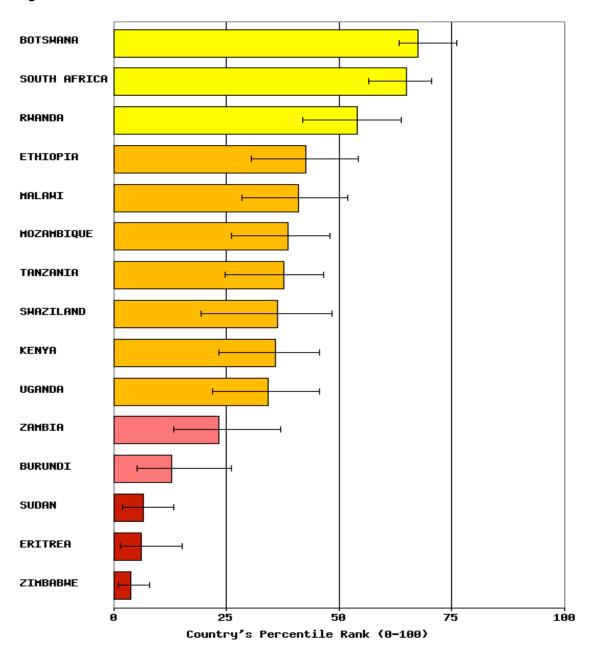


Figure 1. Government Effectiveness Indicator