The Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda

Conference Report

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Report Abstract

“The Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda,” a two and a half-day conference composed of plenary sessions, interdisciplinary breakout sessions and a half-day research symposium was convened at the Harvard School of Public Health in Boston, Massachusetts from March 17th to 19th 2010. The conference brought together a multidisciplinary group from six continents engaged in HIV/AIDS and sexual and reproductive health and rights work. This conference report synthesizes current knowledge and discussions related to the four conference themes and five cross-cutting issues, identifies points of consensus and points of departure amongst participants, highlights suggestions for promoting multidisciplinary research in identified areas, and concludes with recommendations for future research.

The conference report outlines the range of factors known to influence HIV-positive women’s pregnancy intentions. The report synthesizes current knowledge and participants’ discussions in the following areas: Desired pregnancy for HIV-positive women; HIV-positive women seeking to prevent pregnancy; Safer pregnancy for HIV-positive women; and Pregnancy termination for HIV-positive women. A final section provides suggestions for areas of further research to advance the health and rights of women living with HIV.

The report concludes that women living with HIV, like all women, have the right to determine the number and spacing of their children. A stronger evidence base that brings together results from biomedical, economic, political and social science research will help provide more comprehensive information relevant to the lives of women and men living with HIV, and create demand for appropriate services and policy. Researchers, program implementers and advocacy groups are encouraged to use the findings from this report to ensure that there are adequate resources to conduct multidisciplinary research, to design studies across relevant disciplines and to translate these findings into services and programs that support HIV-positive women’s ability to stay healthy and shape their families.
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1. Introduction

The increasing feminization of the global HIV epidemic is widely recognized: while women represented just 35 percent of those infected with HIV in 1985, nearly half of the 38.6 million people living with HIV today are women. With the advent of antiretroviral therapy (ART), greater numbers of HIV-positive women are living longer healthier lives, but are also contending with myriad new and existing issues affecting their sexual and reproductive health and rights. The majority of women living with HIV are in their reproductive years, highlighting the critical need to address issues surrounding reproductive and sexual rights, including in relation to childbearing and pregnancy.

Reflecting larger social and cultural attitudes, to date the majority of research, programs and policy communities attending to the reproductive choices of HIV-positive women have generally taken as their starting point that women, upon learning their positive status, will no longer want to bear children. With the increase in access to ART and the desire of many HIV-positive women to pursue options for safer pregnancy, become pregnant and bear children, there is a clear need to bring together the many relevant disciplinary and technical perspectives to identify gaps in knowledge and create comprehensive solutions. That said, the agency to realize the desire (or not) to have children remains problematic for many women, not just HIV-positive women. Work in this area must therefore be mindful of when the needs and rights of positive women are best conceptualized with attention to their unique social pressures, vulnerabilities and biomedical concerns, and when these issues are more appropriately considered with respect to the sexual and reproductive health and rights of all women.

With the above in mind, “The Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda,” a two and a half-day conference composed of plenary sessions, interdisciplinary breakout sessions and a half-day research symposium was convened at the Harvard School of Public Health in Boston, Massachusetts, in the United States of America from March 17th to 19th 2010 (See Annex A for conference and symposium agendas). Discussion was framed around the concerns of HIV-positive women before pregnancy and after becoming pregnant, and explored issues raised by desired and undesired pregnancy. Specifically, the conference centered on the following four themes:

- Desired Pregnancy for HIV-Positive Women;
- HIV-Positive Women Seeking to Prevent Pregnancy;
- Safer Pregnancy for HIV-Positive Women; and
- Pregnancy Termination for HIV-Positive Women.

A plenary session and accompanying issue paper was dedicated to each theme. Experts from a wide range of disciplinary and experiential perspectives highlighted different aspects of each topic. Participants discussed these themes with attention to the following five cross-cutting issues:

- **Stigma and discrimination** – How they impact HIV-positive women’s sexual and reproductive intentions, choices and outcomes;
- **Knowledge and disclosure of HIV status** – How the context and the timing of HIV diagnosis
relative to pregnancy and disclosure may impact women’s pregnancy intentions;

- **Access to integrated treatment and services** – How service integration, if properly implemented, may alleviate some of the challenges to women’s decision-making and concerns for their sexual and reproductive health and rights, and for potential HIV transmission to partners or children;

- **Relationship dynamics and social context** – How sexual and reproductive choices and outcomes are influenced by complex combinations of individual and social determinants as well as factors relating to service delivery and health systems more generally; and

- **Legal and policy context** – How the legal and policy context impacts sexual and reproductive choices as well as the availability, accessibility, acceptability and quality of services. ¹

The final half-day research symposium built on discussions from the previous two days and gave specific focus to policy, methods, systems and community-level action across the four conference themes.

### 1.1 Meeting objectives

The two and a half-day conference aimed to:

- Exchange a range of disciplinary and experiential perspectives;
- Debate the larger cross-cutting issues arising from discussion;
- Discuss relevant research needs and avenues;
- Determine existing gaps and opportunities for policy, systems and community-level research with attention to different methodological approaches; and
- Determine next steps including: partnerships; meaningful social participation; strategies for dissemination of immediate and future findings; potential research collaborations; and future publications.

### 1.2 Conference participants

Conference participants included a range of individuals engaged in work at the intersection of HIV/AIDS and sexual and reproductive health, including people living with and affected by HIV/AIDS, altogether representing a wide range of disciplinary backgrounds including: advocacy, anthropology, clinical medicine, demography, epidemiology, law, public health, public policy, social science, and virology (See Annex B for participants list).

This mix of participants was purposeful, for despite recent attention to the pregnancy intentions of positive women, the challenge remains for research in this area to address relevant issues

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¹ As elaborated in 2000 by the Committee on Economic, Social and Cultural Rights, the following four elements are relevant to the delivery of health services: Availability or the sufficient quantity and provision of point of care services by trained providers; Accessibility spatially, geographically, financially and without discrimination; Acceptability on interpersonal levels with cultural and community competencies; and Quality as medically appropriate and meeting medication and treatment standards, of health services. Committee on Economic, Social and Cultural Rights (2000) The right to the highest attainable standard of health: General Comment 14. E/C.12/2000/4.
from multidisciplinary perspectives. It was anticipated that coming together in this way would result in a review of conference themes from new vantage points and facilitate collaboration, collective research and action to better address HIV-positive women’s sexual and reproductive health and rights.

1.3 Goals of this report

This report synthesizes current knowledge and discussions related to the four conference themes and five cross-cutting issues, identifies points of consensus and points of departure amongst participants, highlights suggestions for promoting multidisciplinary research in identified areas and concludes with recommendations for future research. Peer-reviewed literature and select documents from organizations represented at the conference relevant to conference themes are included in Annex F and G respectively.

2. Factors Influencing HIV and Pregnancy Intentions

With the advent of antiretroviral therapy (ART) and heightened global support of HIV/AIDS treatment, HIV-positive women are living healthier and longer lives. While research, programmatic, and policy communities have often taken as their point of departure that HIV-positive women do not wish to or should not become pregnant, HIV-positive women have long advocated for recognition and fulfillment of their sexual and reproductive rights, including the ability to decide if and when to have children.2,3,4

In all settings, a range of factors are known to influence HIV-positive women’s desire to bear children, including: age; health status; cultural significance of motherhood; number of living children; previous experience of a child’s death from HIV-related causes; the availability of HIV treatment and prevention of mother-to-child transmission (PMTCT) programs; the attitudes and influence of partners, family, and health care workers; and stigma and discrimination on the basis of HIV status especially for women coming from already marginalized populations.5 Among serodiscordant couples, the desire for pregnancy has been shown to outweigh concerns about horizontal transmission.6 Research from Brazil suggests that cultural norms are important, and in some settings HIV-positive men may be more likely to want children than HIV-positive

6 van Leeuwen, E. et al., 2008. HIV couples' anxiety and risk taking during ART. Fertility and Sterility, 90(2), 456-8.
women. At the same time, studies show women may not want to become pregnant for fear of potential HIV infection in their children or the fear that these children may be orphaned. HIV-positive women have also expressed concern that, once pregnant, they may be more vulnerable to violence and abandonment by their partners, family and community.

Spousal, family, community and cultural influences greatly shape HIV-positive women’s desire to become pregnant. Studies in India, South Africa, Taiwan and Vietnam have demonstrated the weight of culture-specific spousal and family wishes that a woman will need to consider in addition to her own desires and HIV status. Some women may also take economic factors into account, viewing children as a future resource, for example, or as a means of maintaining a relationship that provides financial security. Discussion amongst participants brought to light additional factors affecting the pregnancy intentions of HIV-positive women including the impacts of stigma and discrimination; HIV testing, disclosure and their ramifications; the influence of health care providers; and integration and broader health system factors.

2.1 Stigma and Discrimination

The specific considerations of women with HIV who are thinking about or desiring pregnancy remains tied to the stigma and discrimination they may encounter from their families, community or health system. Their access, or not, to ART will also influence this experience, and participants agreed that future research should better explore the ways in which stigma and discrimination related to all aspects of pregnancy intentions may be mitigated by the availability and accessibility of ART.

\[8\] Paiva, V. et al., 2003. The right to love: the desire for parenthood among men living with HIV. *Reproductive Health Matters*, 11(22), 91-100.
Stigma has been shown to operate differently in different contexts: studies in Zimbabwe have demonstrated that women may wish to become pregnant but do not feel safe enough to realize this decision, fearing potential backlash from the community in particular because of potential transmission of HIV to their children.\textsuperscript{18,19} Other studies in Côte d’Ivoire and South Africa have shown that some women want to become pregnant precisely to avoid the stigma associated with childlessness, predicated not only on social expectations that women should become mothers but also on the ways in which avoiding pregnancy might be interpreted as a statement of being HIV-positive.\textsuperscript{9,20} The potential impact of stigma and discrimination on reproductive decision-making in already marginalized populations such as sex workers and injecting drug users (IDUs) is a concern requiring further exploration.\textsuperscript{5,21}

Along these lines, laws criminalizing the transmission of HIV, even if originally justified as necessary to protect women from abusive partners, have recently (and paradoxically) been applied to vertical transmission.\textsuperscript{22} The impact of criminalization and other laws or penalties on the willingness of HIV-positive women to become pregnant and/or carry their pregnancies to term is an important area for investigation. Further, the limits imposed by these policies on HIV-positive women’s use of health services and thus on the safety of their pregnancies remain unknown. Scholars and advocates have been able to draw attention to the human rights violations and potential negative health effects of such laws, but substantive research in this area is needed.\textsuperscript{23}

\subsection*{2.2 HIV testing and disclosure}

Antenatal services provide an important point of entry for women to learn their HIV status, especially because women in resource-poor settings often do not encounter the health system until they become pregnant or at the time of labor and delivery. Debates over HIV testing for pregnant women have recently drawn attention to which testing strategies best support safe delivery and the health and rights of mothers.\textsuperscript{24,25} UNAIDS/WHO guidance regarding provider-initiated HIV testing and counseling in health facilities recommends testing and counseling for all women of unknown HIV status in labor.\textsuperscript{26} As a woman’s agency and ability to give truly informed consent for HIV testing may be impaired during labor for medical, pharmaceutical and/or social

\begin{thebibliography}{99}
\bibitem{22} Jurgens, R. et al., 2009. Ten reasons to oppose the criminalization of HIV exposure or transmission. \textit{Reproductive Health Matters}, 17(34), 163-72.
\end{thebibliography}
reasons, the implications for delivery outcomes and subsequent access to treatment are unclear. Approaches which focus on HIV testing during pregnancy also need to consider the ongoing risk of new HIV infection. In some high prevalence areas, pregnant women who initially tested negative later seroconverted while still pregnant or breastfeeding, even as other women have not shown any additional increased risk of transmission.

HIV-positive women's desires to bear children may also be affected by testing protocols, communication of test results and health care worker attitudes. In Vietnam, for example, if test results are delivered via a community notification system, it was observed that women may fear violation of their privacy rights and therefore be less likely to seek or receive adequate HIV counseling. Advocates have noted that both the voluntary nature of HIV testing and the ability to keep test results of pregnant women confidential are often compromised in practice, especially in settings where drugs to prevent perinatal transmission are available. Disclosure of test results may be another important deterrent for women who would otherwise choose to undergo HIV testing to inform their pregnancy intentions. Disclosure – by the woman or, at times, by her care provider – to her partner is mandated in some countries and encouraged in others. Name-based reporting of persons testing positive may not only deter testing or future interactions with the health care system, but in some cases may result in increased exposure to violence, all with unknown consequences for a positive woman’s health and pregnancy.

2.3 Health care providers

Providers’ attitudes were mentioned frequently as an obstacle to HIV-positive women getting access to correct information and appropriate services. Participants agreed that, whether HIV-positive women desire pregnancy, wish to prevent it, hope to go through pregnancy and

32 Bell, E. et al., 2007. Sexual and reproductive health services and HIV testing: Perspectives and experiences of women and men living with HIV and AIDS. Reproductive Health Matters, 15(29, Suppl), 113-35.
childbirth safely, or need to terminate a pregnancy, much remains to be done to improve provider attitudes and quality of healthcare in most countries. The fear of being stigmatized and discriminated against may prevent women from seeking services in the first place. And if women are able to seek care, they may then be confronted with hostile and discriminatory treatment.9

The way in which a health care provider approaches potential viral transmission may affect a woman's relative comfort in interacting with the broader health care system if she wishes to bear a child. In Argentina and Brazil, for example, studies showed that women living with HIV may not voice their desire to have children to their health care provider for fear of a negative reaction.37,38 And, as observed by one participant, health care workers may additionally discourage HIV-positive women from pregnancy as a result of their own misconceptions, ignorance or personal beliefs about risks to the mother and child, often inflating the risk of transmission. Advocates and programming groups have worked to develop educational materials and training curricula on HIV and pregnancy for health care workers in different contexts to address these issues, but these efforts have not yet been brought to scale.39,40 At the same time, however, participants recognized the enormous constraints faced by providers in resource-limited settings and warned against efforts which may, even inadvertently, demonize those who are doing the best possible work in difficult circumstances.

Health care providers may themselves be living with/or affected by HIV and need care. This is an area participants recognized as needing increased attention. Additionally, discussion drew attention to the global health care provider shortage. Attempts to fill the gap can result in people with little training in HIV providing care to those living with HIV. This may result, for example, in those previously trained to work in family planning now providing HIV care. Participants felt it would be important to document the extent of this phenomenon, and then shape training and inform programs and policies accordingly. It was asserted that health professionals – including midwives, school nurses, community health workers, pharmacists – can be effective drivers of changing social norms, and those playing these roles need to be supported in doing so. Examples were given from Brazil and South Africa of projects that have moved away from inculcating a prescriptive attitude in providers to a dialogue-based, human rights sensitive approach, aiming to encourage current and future professionals to think about care in a comprehensive and rights-based way. It was agreed that this is no easy task, but essential and should be replicated.

To that effect, it was suggested that medical-ethical guidelines, grounded in respect for human rights, ought to be elaborated at international and national levels to address the pregnancy desires of HIV-positive women. Then, both pre-service and in-service training could be improved and expanded to include not only HIV- specific counseling and care, including updates on contraceptive and other technologies, but also training in human rights and ethics.

37 Gogna, M.L. et al., 2009. The reproductive needs and rights of people living with HIV in Argentina: health service users' and providers' perspectives. Social Science and Medicine, 69(6), 813-20.
Participants agreed that operations research on models of care in different contexts was needed, with attention to human rights and quality of care.

Participants further noted that education and information are needed about women’s rights as patients within a health care setting, including what they should expect from providers, particularly with respect to observance of rights-based and ethical guidelines. Civil society groups should demand accountability for violations of professional ethics, and individuals should be supported and empowered to use mechanisms for redress in cases of complaint. Linked to this is a need for attention to whether the legal system is receptive to any claims for redress in the context of HIV.

2.4 Integration and broader health system factors

There is widespread recognition of the urgent need to integrate HIV and family planning services.\(^4\),\(^41\),\(^42\) Indeed, as participants agreed, compelling reasons have been put forth for integrating family planning services into (or with) HIV services and vice versa. Little consensus has emerged, however, regarding the most effective and efficient integrated models.\(^43\),\(^44\),\(^45\),\(^46\) As noted by one participant, much of the data informing integration strategies come from sub-Saharan Africa, thus key questions remain about how to extrapolate this evidence to different settings or vulnerable populations. Further, it has been suggested that programmatic decisions affecting pregnancy intentions may be influenced more by funding availability than by other factors including evidence from existing interventions or meaningful input by HIV-positive women themselves.\(^47\) Research on the ways in which different models for integrating HIV and family planning services affect HIV-positive women’s pregnancy desires and pregnancy outcomes is lacking, and solutions may call for more than an expansion of current services to fill particular gaps. As noted by participants, meaningful solutions may require a fundamental reconsideration of HIV support structures and service delivery paradigms, given that few integration strategies have paid sufficient attention to the experience and fertility goals of individual women and men.


\(^{43}\) Cooper, D. et al., 2009. Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: Implications for integrating reproductive health and HIV care services. *AIDS and Behavior*, 13(Suppl 1), 38-46.


3. HIV-Positive Women and Pregnancy Prevention

Studies have shown that as the health status of HIV-positive women improves in response to treatment, they may return to the level of sexual activity experienced before HIV diagnosis. Like for HIV-negative women, this may not indicate a desire to become pregnant or for additional children and it is therefore important from a research perspective to understand how some reasons to avoid pregnancy relate specifically to HIV status and some do not. That said, HIV treatment and PMTCT programs have documented high rates of unintended pregnancies among HIV-positive women. Of relevance, studies in Rwanda and Zambia have shown that women generally demonstrate a higher knowledge of contraception than men, but gender dynamics may prevent them acting on this knowledge. There is a general paucity of information about how best to address HIV-positive women’s contraception-related needs, including the potential barriers to acquiring and using the forms of contraception acceptable to them.

3.1 Seeking to prevent pregnancy

The discussion on preventing pregnancy highlighted ways in which the sexual and reproductive rights of HIV-positive women, including in relation to health care, family planning and delivery of contraceptives could be maximized with a particular emphasis on integrated or linked service delivery models.

In many countries, there are not a wide range of options with respect to contraceptive methods. Emergency contraception in particular is still not widely available, and as noted, this is often because emergency contraception is not registered in countries, even though it is included in the World Health Organization (WHO) List of Essential Medicines. Experience in specific settings has shown that even where female condoms are acceptable, they are often unavailable. An initiative is underway in Brazil to introduce a package including male condoms, female condoms and emergency contraception. It was agreed that this could be an interesting model to test elsewhere after evaluation.

48 Myer, L. et al., 2007. Missed opportunities to address reproductive health care needs among HIV-infected women in antiretroviral therapy programmes. Tropical Medicine & International Health, 12(12), 1484-1489.
50 Johnson, K. B. et al., 2009. Fertility preferences and the need for contraception among women living with HIV: The basis for a joint action agenda. AIDS, 23(S1), S7-17.
Researchers have indicated that women with HIV may perceive some contraceptive methods to be harmful – even if they are not. It seems clear that correct information is not always reaching women or, in some cases, providers. For instance, hormonal methods are generally safe for HIV-positive women and evidence suggests the methods do not significantly affect disease progression, even as it appears ART might decrease the efficacy of some hormonal methods.\(^5^5\) This kind of information needs to be clearly communicated to both providers and their clients.

The needs of HIV-positive adolescents were again highlighted, with attention to the additional stigma they may face in being HIV-positive and sexually active outside the context of marriage. It was further noted that the nature of adolescents’ sexual relationships – often sporadic and tentative – combined with social taboos around becoming sexually active presented additional barriers to seeking contraceptive advice and services generally. The question of how to promote dual protection was noted as particularly critical for this population.

The conversation then turned to the urgent need for attention to the needs and rights of HIV-positive women in integration of HIV care with sexual and reproductive health services, with attention to the utility of different delivery models depending on a woman’s knowledge of her HIV status. Participants described policy and program developments as having moved ahead of the evidence, and while there is evidence to show certain kinds of integrated services are appropriate in some settings, a number of major challenges remain. A key question is what models of integration or linkages are most appropriate for which setting, and which can best respond to the needs both of women who know their HIV status and those who do not. It was agreed that different options would be needed for different contexts but that different approaches needs to be carefully documented. For instance, in Cote d’Ivoire, strengthening family planning services to be able to offer some aspects of HIV services appeared to be the best option,\(^5^6\) whereas in other settings it may be easier to bring family planning into, say, voluntary counseling and testing services.

In many settings, certain aspects of sexual and reproductive health services are provided by non-governmental organizations, whereas other aspects, including maternal-child health services and some HIV services may be provided by the public sector. It was agreed that this presents a major challenge for integration, both from the financing point of view and also with respect to efforts to streamline effective policies and programs. Participants proposed that further health systems and operations research should be conducted with concrete attention to the differences for women who do and do not know their HIV status, to assess different models of integration, including whether linking services is better than integrating in particular settings.

Measuring the impact of integration or linkages was recognized as complex. In this regard it was noted that there is a lack of capacity for monitoring and evaluation of such initiatives at the country level. Integration or linkage efforts may forge ahead with insufficient attention to the range of factors influencing the use of services, including gender-related constraints such as women needing the permission of their husbands to attend certain services (e.g. family


\(^5^6\) Lafort, Y. et al., 2003. Should family planning clinics provide clinical services for sexually transmitted infections? A case study from Co’te d’Ivoire. Tropical Medicine and International Health, 8(6), 552-60.
planning). On the other hand, the move towards integration was recognized as providing an opportunity for increasing male involvement in family planning and other aspects of sexual and reproductive health. Further, it was noted that discussions on integration are often based on the assumption that all potential clients are heterosexual, adult married women (and men), thus overlooking the impact of these services for people who do not fit this pattern, including unmarried adolescents.

Finally, participants recognized the current international political climate as enabling unprecedented policy and financial support for linkages and integration between HIV and sexual and reproductive health services. Contributing to this are United States President Obama’s Global Health Initiative (GHI) and the new PEPFAR policy and field guidance encourage FP/HIV integration, which encourage integration and allow support for family planning within such funding. The Global Fund also now has a solid track record in supporting integration of HIV and sexual and reproductive health services, including paying for contraceptive technologies. It was recognized that while there is still a long way to go to ensure services adequately respond to the needs and rights of HIV-positive women, these and other initiatives have contributed to a dramatic expansion of country-based efforts to integrate services.

3.2 Hormonal contraception

Research has resolved some but not all questions about the suitability of hormonal contraception (HC) as a means for HIV-positive women to prevent pregnancy. The WHO does not classify HIV infection as a contraindication for HC in terms of its effects on HIV progression and/or transmission, even as some researchers believe that further investigation is warranted. On the other hand, medications used to treat common opportunistic and co-infections such as Rifampin are widely recognized to alter levels of circulating hormonal contraceptives with the potential to exacerbate side effects of HIV therapy including metabolic syndromes. Certain forms of ART may even have the potential to change the bioavailability of steroid hormones. For this reason, “if a woman on antiretroviral treatment decides to initiate or continue hormonal contraceptive use, the consistent use of condoms is recommended.”

Interactions between HIV, ART and other forms of HC, such as emergency contraception, have yet to be fully clarified. Another important area noted to still require investigation was the effect of hormonal contraception on the risk of cervical cancer in HIV-positive women.

3.3 Other forms of contraception

Currently, male and female condoms are the only “dual function” contraceptives that protect against both pregnancy and HIV infection. Condoms therefore remain an essential option for HIV-positive women to avoid pregnancy, protect themselves from re-infection and prevent infection in HIV-negative partners. However, power imbalances in some sexual relationships may prevent women from insisting on condom use. The most promising HIV microbicide candidates, which could also serve a dual function, have not performed well in recent clinical trials. Still, preliminary studies of newer microbicide candidates are encouraging, and other research suggests that the diaphragm in combination with an effective microbicide could be an acceptable female-initiated contraception option.

In terms of other non-hormonal forms of contraception, specific attention to long-term contraceptive methods such as intrauterine devices (IUDs) has been limited despite their proven safety and effectiveness for HIV-positive women. The contradictory impacts of permanent methods such as sterilization and vasectomy were also discussed, in particular that if handled inappropriately both raise important rights issues. However, if fully voluntary, participants highlighted the fact that, although surgery may not be advisable for those who have acute AIDS-related illnesses, they can be considered biologically safe for healthy HIV-positive women and men.

4. Safer Pregnancy for HIV-Positive Women

To date, a disproportionate amount of research on HIV and pregnancy still focuses on infant health, with insufficient attention to the health and well-being of the woman. A recent systematic review of the literature assessing the biological interactions between pregnancy and HIV indicates that researchers generally agree that pregnancy itself does not accelerate HIV disease progression. While the known benefits of taking ART during pregnancy clearly

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69 MacCarthy, S. et al., 2009. Responding to her question: a review of the influence of pregnancy on HIV disease progression in the context of expanded access to HAART in sub-Saharan Africa. AIDS and Behavior, 13(Suppl 1), 66-71.
outweigh the known risks, the relationships between pregnancy and ART are still not as well understood.

Formative research on ART use during pregnancy has found associations with pre-eclampsia, gestational diabetes, toxicity and pregnancy-induced hypertension. The reasons for this remain unclear but may relate to maternal immunologic boosts associated with pregnancy. Still, the apparent association could reflect selection bias whereby women who are healthier are more likely to become pregnant or adhere more closely to treatment during pregnancy. Information regarding physiological interactions between ART and pregnancy primarily stems from high-resource settings, and as such have unknown generalizability. The context of women’s lives, including economic, political, social and other factors such as access to health services and HIV-related stigma, may all modify physiologic interactions.

Regarding maternal treatment regimens and care, participants discussed the significant revisions made in 2009, updating the 2006 WHO PMTCT guidelines. In general, there is an increased emphasis on improving maternal health while providing maximum protection against HIV infection in the child but the extent to which donors will provide the needed financial support and practice on the ground will change remains unclear. The main revisions include: 1) A shift to promote lifelong ART for all pregnant women at a CD4 count of 350 cells/mm$^3$ or below (previous CD4 count cutoff was 200 cells/mm$^3$ or below); 2) Earlier provision of antiretroviral prophylaxis at 14 weeks instead of 28 weeks gestation; and 3) Formal recommendation to provide antiretroviral prophylaxis during breastfeeding in response to recent research suggests that maternal and/or infant antiretroviral prophylaxis during breastfeeding could reduce rates of postnatal HIV transmission. Such findings may provide additional support for and recognition of the benefits of breastfeeding.

Conference discussion further highlighted six key areas relevant to safer pregnancy for HIV-positive women: desired pregnancy, labor and safe delivery, access to ART, health during the post-partum period, breastfeeding, and the role of the community in supporting HIV-positive women through their pregnancies and childbirth.

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4.1 Desired pregnancy

Participants agreed that the desire for children takes many forms, including how many, when, how, with whom, that vary greatly from one context to another. This is independent of whether a woman is HIV-positive or not, but when a woman knows her status, the knowledge of being HIV-positive does appear to have an impact on desires and decisions about pregnancy.

While some women may make individual choices about pregnancy, many are likely to think about pregnancy in the context of their relationship with a partner. Participants agreed that research concerned with pregnancy desires of HIV-positive women must also include attention to men and their fertility desires, as they have an impact on women's desires and decisions. Men themselves may lack the information necessary to make informed decisions; for instance, information about prevention of mother-to-child transmission of HIV is rarely targeted or made available to men, and this constitutes an area of concern.

Participants agreed positive adolescent girls and boys should be the focus of much more attention and research. The population of those living with HIV from birth is growing; at the same time, this population has the prospect of living healthy lives in ways not possible before. For example, several studies conducted in Uganda demonstrate a need to strengthen health care services for the prevention of both HIV and pregnancy among adolescents. 77,78,79 Research shows that HIV-positive adolescents have specific ideas about services that would meet their needs, but there has been little evaluation of the impact of putting such services into operation. Models need to be tested, evaluated and scaled up. Participants agreed that for adolescent girls living with HIV, all the issues noted for positive women with respect to access to services are likely to be compounded, especially when it comes to pregnancy.

With regard to infertility, participants recognized that there is evidence to show that ART has a positive effect on fecundity. 80,81 While agreeing that further research in this area was not therefore a priority, participants suggested that for those on ART but still experiencing infertility, ideally assisted reproductive technologies would be an option. Access to assisted reproductive technologies, such as artificial insemination, sperm washing, in-vitro fertilization and embryonic implantation, may significantly influence HIV-positive women's desire and ability to bear children: they may also improve HIV-positive women's fertility while reducing the risk of horizontal transmission to HIV-negative male partners. Such technologies, however, are not universally available and are unevenly accessible or commonly lacking in low-income countries.

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78 Birungi, H. et al., 2009b. Preventive service needs of young people perinatally infected with HIV in Uganda. AIDS Care, 21(6), 725-31.
countries. Participants observed that in Brazil, for example, assisted reproductive technologies are offered in the private sector and therefore only available to those who can afford them. For those who are already on antiretroviral therapy, the combined expenses of ART and assisted reproductive technologies are simply out of reach. Even when available, the idea that assisted reproductive technologies could be used by women who are HIV-positive appears to be strongly opposed. This is an area where stigma and discrimination are highly manifest. There is research to show that many health care providers express the view that HIV-positive women should not have children and should certainly not have access to expensive technologies to help them do so.

“Home-based” artificial insemination and other low-technology methods for conception such as non-spermicidal microbicidal products, pre-exposure ART prophylaxis and unprotected intercourse when viral loads are low were recognized as potentially less resource-intensive strategies to minimize the risk of horizontal transmission for discordant couples or for women wishing to become pregnant on their own. However, questions of efficacy, safety and best practice remain with respect to each of these methods. Research exploring the clinical effectiveness of methods for insemination has been largely limited to resource-rich settings and has only been differentially performed in some resource-poor settings. It is unsurprising, then, that there appears to be a huge information gap among HIV-positive women and men in these settings about potentially effective methods of conception, given the limited and at times contradictory information which may be given to couples. Some NGOs globally are beginning to pressure governments to provide assisted fertility services for people living with HIV/AIDS. Adding to existing evidence in support of this effort, a recent qualitative study from Italy reported that parenthood helped serodiscordant couples “restore their sense of normalcy” and concluded that withholding such treatment was not ethically justified. Participants agreed that the availability, accessibility, acceptability and quality of assisted reproductive technologies will not be fully realized without well-informed health care providers working in strong health systems at

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85 Bujan, L. et al., 2009. Lack of clinical and scientific evidence to justify the systematic use of ICSI in HIV-serodiscordant couples wishing to conceive where the male partner is infected. *Fertility and Sterility*, 91(3), e1-2; author reply e2.
the primary health care level who can guide both women and men through their options, promoting their ability to opt for a fertility strategy that best fits their individual situation.

Adoption was raised as an important possibility for those wishing to have a child, but who are either infertile or wishing to completely avoid the risk of HIV transmission. However, its acceptability for women and their partners, families and communities in various settings remains unclear. In many countries including the United Kingdom (UK), adoption by HIV-positive parents remains difficult, and in other settings such as South Africa and Nigeria, current policies or laws have been cited as explicitly prohibiting adoption by HIV-positive individuals.91 Participants concluded that capacity for infertility management should exist and that there was need for research on alternative means to fulfill women's desires to become pregnant in low-resource settings.

Participants agreed that many questions remain concerning what can be done to support HIV-positive women's desires for pregnancy. It was suggested that communities and traditional healers may play important roles in giving women information relevant to their pregnancy intentions — some of which may be helpful and some harmful — so more should be learned about this. The situation may be quite different from one region to another even within the same country. In all settings, however, the apparent disconnect between the actual pregnancy desires of women living with HIV and the assumptions of those who design and implement ostensibly relevant programs and policies, highlights the need for this research to involve HIV-positive women, in order to, at a minimum, formulate the right research questions.

In this respect, it was noted that pregnant women are often excluded from research, due to concerns about potential harm to the fetus. However, this makes it hard to measure the impact on pregnant and breastfeeding women of drugs being developed, such as antiretroviral drugs or microbicides for prevention of sexual transmission. Results of research on the impact of ART given either as part of life-long therapy or specifically to prevent vertical transmission have remained largely focused on infant outcomes.

4.2 Labor and safe delivery

Research from high-income countries has suggested that Caesarean deliveries for HIV-positive women may reduce HIV transmission during birth,73,74 and one UK trial demonstrated healthy outcomes for HIV-positive women on ART giving birth vaginally.92 Very little data on pregnancy outcomes are available for HIV-positive women not on ART who give birth vaginally.93 Furthermore, there is limited clarity regarding best practices in low-income countries with minimal health system infrastructure, access to ART, and/or surgical capacity for Caesarean deliveries.94 Field reports from providers working in Uganda and South Africa highlighted

92 Townsend, C. L. et al., 2008. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the United Kingdom and Ireland, 2000-2006. AIDS, 22(8), 973-81.
competing clinical safety risks: while elective Caesarean deliveries may reduce HIV transmission to the child, they may increase certain types of post-operative infections in HIV-positive mothers.\textsuperscript{95,96,97} There is a range of potential challenges for women intending to carry pregnancies to term that impact their own health and that of their infants.\textsuperscript{13} In Kenya, for example, women may avoid presentation to a health care facility to deliver for fear of involuntary disclosure of their HIV status.\textsuperscript{96} Participants discussed the larger human rights and stigma issues that may impact safe delivery, and the need for examination of health care systems and delivery models, as well as the potential role of civil society organizations to better support and prepare HIV-positive women who choose to become pregnant to deliver their babies safely.

4.3 Access to antiretroviral therapy (ART)

Evidence to date highlights the role of access to ART for women with HIV to go through pregnancy and childbirth safely. Research has found that it leads to increased life expectancy, decreased morbidity, reduced risk of vertical transmission and reduced risk of transmission to discordant sexual partners. However, in many low resource settings with high incidence of HIV, only a small proportion of women in need of ART are currently obtaining it.\textsuperscript{99} Some comprehensive programs implemented in low-resource settings have reduced women’s delays in seeking care and enhanced capacity to monitor and evaluate access to HIV treatment.\textsuperscript{100,101} It was agreed this is an issue for operations research and that relevant policies and programs should be closely monitored and evaluated. Still, there was some concern expressed about the safety of ART drugs for the fetus, particularly because there are many different types, and it is unclear that the most commonly available are necessarily the safest. Participants felt that there was a need to continue research in this area, as well as to investigate the possible interactions of ART with any traditional medications that women may take during pregnancy.

The uncertainty surrounding the availability of ART, and the fact that many women find out they are HIV-positive while pregnant, almost certainly contribute to stigma as well as a host of psychological and emotional health issues including anxiety, depression and stress. Participants agreed that very little, if any, research has looked into these aspects and identified this as an urgent need so that appropriate responses can be developed. Another closely-linked issue is


that of violence. As discussed, there is some evidence to indicate that women may be subject to a greater degree of intimate partner violence during pregnancy, but also upon disclosure of their HIV status. Thus, conference participants highlighted the need to understand how risks are compounded for women who discover their HIV status during pregnancy. Such a situation will have a significant impact on their mental, physical, sexual and emotional health, with implications for their ability to get appropriate care and treatment and for safe delivery. It was suggested this is an area where already-existing interventions on dealing with violence in antenatal care settings could be tested and evaluated specifically for HIV-positive women.

4.4 Health during the post-partum period

Participants agreed there is insufficient research on the health of mother and infant in the post-partum period, and the differential standards of care which exist in different economic, political and social contexts raise a host of health and rights concerns. Perhaps the largest challenge is to effectively ensure that HIV-positive women have continued access to the treatment and care they need during and beyond the perinatal period. Based on available evidence that women’s adherence to ART often drops in the postpartum period, participants felt that this was a key area for research, particularly as evidence points to an increased risk of faster progression to disease after interrupted therapies. Beyond access to ART, little is known about the health-related concerns for HIV-positive women in the post-partum period, including access to contraception. Post-partum women need information about and access to contraception, and post-partum contraceptive counseling is still not a universal practice. Participants felt that policy and operations research could be conducted on ways to support the health of women in the post-partum period, including with respect to improving women’s adherence to ART and the barriers, if any, to sustained use of family planning after childbirth.

4.5 Breastfeeding

A woman’s decision-making process regarding whether or not to breastfeed, in light of social norms, biomedical recommendations and access to antiretrovirals, among other factors, remains highly personal and individualized. While HIV-positive women in high-resource settings are generally advised to forego the benefits of breastfeeding so as to avoid potential HIV transmission to their infants, the World Health Organization (WHO) currently recommends

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that HIV-positive women in resource-limited settings breastfeed exclusively for six months, unless they fulfill the conditions for safe replacement feeding. As noted earlier, the new recommendations call for earlier initiation of ART for adults and adolescents, the delivery of more patient-friendly antiretroviral drugs (ARVs) and prolonged use of ARVs to reduce the risk of mother-to-child transmission of HIV. And, for the first time, WHO recommends that HIV-positive mothers take ARVs while breastfeeding to prevent transmission. How and to what extent this recommendation will be put into practice in resource-limited settings remains to be seen, and developments will require close monitoring in particular the impact of repeated courses of ARVs on mothers' health over the course of multiple pregnancies. Infant feeding decisions have significant implications for women, as, to cite just one example, choosing one method over another may raise questions regarding a woman's HIV status from her partner, family and community.

Studies have highlighted contradictions between biomedically-based recommendations and local infant feeding practices that HIV-positive women must negotiate. A study in Burkina Faso, Cambodia and Cameroon showed that even when counseling options were tailored to the economic constraints that HIV-positive women face, women mostly prioritized the risk and social consequences of being stigmatized as a “bad mother” or revealed to be HIV-positive when deciding between replacement feeding or exclusive breastfeeding with early weaning. The host of rights and health concerns raised by these findings was recognized as an important area for future research.

It was agreed that there is a huge lack of consistent knowledge on the part of both positive women and health care providers. There are good examples of programs that have worked to promote breastfeeding, to support the experiences of positive women and to develop acceptable training modules and tools for healthcare workers on different forms of infant feeding. There was general agreement that these models must be brought to scale in culturally-sensitive ways. Additionally, HIV-positive women's experience in reducing the risk of HIV transmission via breast milk, such as expressing breast milk and using the “Flash Heating” method intended to kill the virus while preserving the nutritional and immunological properties of the milk, were discussed. Operations research is needed and strategies should be developed,
or further strengthened, and support provided to both women and providers on appropriate infant feeding techniques.

4.6 The role of the community

Participants discussed the fact that it is often women who are caregivers in formal health systems but also in the family and community. These caring roles may be multiplied for a woman in a household with HIV, and cause significant stress in particular when she herself may also be positive. Participants agreed that this should be an area for research, or at least the development of a policy and strategy agenda with regard to providing much greater support – emotional and financial – to women who are caregivers in their families and communities.

With respect to resource-poor settings, participants also discussed whether traditional birth attendants (TBAs) could play a greater role in supporting HIV-positive pregnant women. It was pointed out that although a decade of experience with safe motherhood programs promoting the use of TBAs found that they had not contributed to reducing maternal mortality, TBAs nonetheless remain a very important resource as elders, therefore commanding respect. Community leaders have a key role to play in creating a non-stigmatized environment (as they can also in fomenting stigma and discrimination) for HIV-positive pregnant women, yet there is little research about how communities can be strengthened as a locus of care and support. This was recognized as an important avenue to explore. It was noted that love, care and support are essential and that the family and community must be encouraged to provide this.

Finally, there was general agreement on the lack of data about the role of the community in supporting safer pregnancy for women with HIV. Participants also questioned whether any research has seriously engaged with HIV-positive women on this topic.

5. HIV-Positive Women and Pregnancy Termination

A decision to terminate pregnancy is a personal choice but reveals complex intersections of the biomedical, economic, legal, political, and social spheres, as well as donor influence both nationally and internationally. Further, the attitudes and actions of current and former sexual partners, family and community members, as well as health care providers may weigh heavily. With obvious implications for HIV-positive women, research has shown that in some African countries, including South Africa and Tanzania, the social premium placed on motherhood and the associated ramifications for women and men who fail to meet reproductive norms – including stigma and loss of social status – effectively eliminate the option to undergo abortion even if personally desired. As discussed by participants, the larger health system enables, mitigates or entirely precludes HIV-positive women’s access to safe abortion services; around the world access to abortion services is often limited by the capacity to provide surgical and/or medical abortions and limitations within the health system infrastructure more generally. Research needs relating to the decision to terminate pregnancy, the barriers to pregnancy

termination, safe pregnancy termination, HIV and unsafe abortion, and forced sterilization were discussed at length by conference participants.

### 5.1 The decision to terminate pregnancy

For all women, the ability to terminate a pregnancy is affected by the legal status of abortion in a particular country, which in turn affects the capacity of the health system to provide safe abortion services, and the existence or not of clandestine and potentially unsafe services. Yet, abortion complications are of particular concern for women living with HIV given the high rates of morbidities generally attributable to unsafe abortion. Changes in the legal status of abortion have been shown to impact the health outcomes of HIV-positive women. In Pretoria, South Africa, for example, the number of women presenting with incomplete abortions was found to decrease by half with associated reductions in case fatality rate, mortality index and maternal mortality upon legalization of abortion. Furthermore, while post-abortion care (PAC) can be life-saving to women who experience spontaneous abortions or other women who must undergo unsafe abortions, PAC may implicate an attempted or completed abortion and its provision is often significantly affected by laws that criminalize abortion. Such criminalization may further exacerbate maternal morbidity and mortality by delaying or inhibiting women from seeking PAC even where it is available. Participants agreed it is critical that PAC, which is heavily donor funded, be freely accessible in all countries, whether abortion is legal or not.

As noted at the meeting, the nuances of abortion laws in relation to HIV may not be well understood within countries, including by health practitioners responsible for delivering needed services. Notably, in jurisdictions where abortion is illegal but with permissible exceptions for women with certain health conditions, it is often not clear whether a pregnant woman’s HIV status would be recognized as a legitimate health exception, and interpreted in such a way as to promote her sexual and reproductive rights. This uncertainty among providers and the public impedes access to abortion and deepens misunderstanding and miscommunication. Participants agreed that a great deal of work is needed to bring information about abortion laws, services and experiences with abortion into the public sphere. Women must be allowed speak about their experiences of abortion without fear of condemnation or prosecution, as this can help to raise awareness.

When abortion is legal (and known by women to be legal), the ability of the health system to provide ART can further influence the decision to terminate a pregnancy, as ART offers reduced

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risk of viral transmission vertically and via breastfeeding.\textsuperscript{121} Although there is broad support for the integration of HIV care and reproductive health services across health systems, discussions of service integration continue to largely neglect the delivery of abortion services, even where it is legal.\textsuperscript{122, \textsuperscript{123}} A woman’s decision to undergo abortion may additionally be predicated on her personal financial resources and insurance coverage. Most abortion services, particularly if they are clandestine, are very expensive. Even in high-income countries such as the United States where abortion services remain legal, coverage by insurance plans is unclear, further complicating the ability of HIV-positive women to seek high quality care and services.\textsuperscript{124}

Even where abortion is available, it is likely that only a minority of health care providers have experience with abortion for women who know and are willing to disclose their HIV-positive status. The most recent literature review on this subject found no trials that assessed the effectiveness or possible side effects or complications of abortion for women with HIV. Health workers have been known to refuse to perform surgical abortions for women with HIV citing reasons ranging from stigma to the perceived risk of becoming infected while performing invasive procedures.\textsuperscript{125} At the other extreme, several studies and anecdotal reports have suggested that health care workers are known to effectively encourage or even coerce pregnant, HIV-positive women to terminate their pregnancies or undergo sterilization.\textsuperscript{9, \textsuperscript{126}} It was noted, additionally, that health care personnel who provide abortions are often marginalized and stigmatized themselves. Reports on abortion in Nepal and India published by the International Community of Women Living with HIV/AIDS (ICW) continue to highlight the ways in which an HIV diagnosis further complicates a woman’s ability to freely opt for and successfully access safe abortion.\textsuperscript{127} For these reasons, even when abortion is available, research must still consider a wide range of factors to ensure that services are in fact accessible, acceptable and of high quality for HIV positive and negative women alike.

\textsuperscript{121} Boonstra, H., 2006. Meeting the Sexual and Reproductive Health Needs of People Living with HIV. New York: Guttmacher Institute.

\textsuperscript{122} Elul, B. et al., 2009. Pregnancy desires, and contraceptive knowledge and use among prevention of mother-to-child transmission clients in Rwanda. AIDS, 23(Suppl 1), S19-26.

\textsuperscript{123} Gruskin, S. et al., 2008. HIV and pregnancy intentions: Do services adequately respond to women’s needs? American Journal of Public Health, 98(10), 1746-50.


5.2 Barriers to pregnancy termination

A large barrier to effectively addressing the issue of pregnancy termination for women with HIV is the fact that there are almost no abortion data that are disaggregated by HIV status. This is a serious handicap to understanding the dimensions of the problem, and it is linked to the difficulty of assessing an often illegal procedure, its clandestine nature and the fear of criminalization that both women and health care providers may face. Collection of data in this area was considered a priority research issue by participants.

A particular barrier for HIV-positive women seeking to terminate pregnancies in countries where it is legal is the fact that abortion services are rarely linked to HIV services. Participants agreed that efforts at integration or linking services should include safe abortion services, but recognized that this was particularly challenging in the current political and financial climate, despite governmental and donor attention to service integration generally. Nonetheless, it was recognized that counseling about family planning, pregnancy and termination of pregnancy could be included in voluntary counseling and testing services, and family planning services for women living with HIV could also include counseling and information about abortion. It was noted that future research should address how abortion care can be linked and integrated with HIV services, akin to family planning and safe motherhood, and the particular needs of adolescents in this respect were again highlighted.

In many countries, legal restrictions to abortion may also limit the available information about medical methods of abortion. It was discussed that misoprostol (a drug available for other indications in many countries) and information about its use for inducing abortion should be made generally available to women, along with information about access to back-up care services. Participants recognized an urgent need to develop context and country-specific strategies to achieve this. Discussion further highlighted the lack of evidence about the comparative advantages or disadvantages of medical methods versus surgical methods of abortion for HIV-positive women. Additional questions about potential physiologic effects of medical methods for HIV-positive women including interactions with ART, appropriate dose, and risks associated with late abortion were also recognized to constitute important areas for research.

5.3 Safe pregnancy termination

HIV-positive women can safely undergo both surgical abortion (vacuum aspiration; dilatation and curettage; and dilatation and evacuation) and medical abortion (administration of pharmaceutical agents to interfere with the continuation of pregnancy). While epidemiological abortion data is generally not disaggregated by HIV status, studies from high-income countries have recognized that many women living with HIV experience unintended pregnancies and seek abortions, and some countries have reported rates of induced abortion in HIV-positive women ranging from 25 to 63 percent. Still participants recognized there is little research that has considered the correlative and causal relationships between unintended

pregnancy, pregnancy termination decisions and HIV in other contexts. In addition, it was also noted that the HIV community, at international as well as national levels, should be encouraged to take a stand with regard to eliminating unsafe abortion and the denial of safe abortion care.

5.4 HIV and unsafe abortion

Both HIV-positive and HIV-negative women who undergo unsafe abortive procedures sought in the absence of accessible or acceptable abortion services endure a risk of complications that is several hundred times higher than that of an abortion performed by a professional under safe conditions. The WHO and The Guttmacher Institute estimate that an unchanging 20 million unsafe abortions occur annually, the majority of which occur in low-income countries where abortion laws are highly restrictive, resulting in nearly 70,000 annual female deaths worldwide. Complications of abortion are of particular concern for women living with HIV given their potentially higher rates of morbidity due to unsafe abortion, and there is evidence to suggest that there are status, vulnerability and stigma-related barriers that may compel women living with HIV to undergo unsafe abortions. Despite some initial research in this area, participants agreed this is a compelling area for further investigation and advocacy, and a gendered focus is needed to inform research and policy recommendations related to pregnancy termination.

Finally, it was noted that leading international civil society organizations and researchers have recommended policy changes that amend or rescind laws criminalizing substance use, sex work, expression of different sexual orientations and access of adolescents to sexual and reproductive health services in order to enhance the rights and health for people affected by and living with HIV. The harmful health and rights effects of criminalizing abortion are well known and could usefully be added to the concerns of those advocating for changes to harmful laws. Policies that support safe abortion care could better the health and lives of women living with HIV.

5.5 Forced sterilization

The forced sterilization of HIV-positive women has been documented in a number of countries. Forced sterilization occurs at the time women, and especially poorer women, seek other services such as abortion, Caesarean deliveries, PMTCT or cervical cancer screening, all of which are then provided only on condition that the woman be sterilized. Forced sterilization was also recognized to have the effect of driving women away from needed services, both for fear of it occurring and once it has occurred. Participants agreed that forced sterilization raises

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significant health and rights concerns, and that in addition to research, a number of actions need to be taken immediately at the policy and program levels for this practice to stop.

With respect to overall pregnancy outcomes and HIV-positive women’s future childbearing potential, a study of women in Brazil found that providers played a significant role in determining whether or not HIV-positive women were sterilized after delivery.\textsuperscript{134} In Namibia, the ICW found that 40 out of 230 HIV-positive women interviewed were either forced or coerced into sterilization. The ICW reports that women were either not asked for consent or consented under duress – at the time of labor or on their way to the operating room. Other women reported giving consent without understanding the irreversible nature of the procedure. Several women are currently seeking redress through a lawsuit brought against the Ministry of Health.\textsuperscript{133} In other countries such as Chile and Mexico, similar reports are surfacing.\textsuperscript{135,136} In 2009, the Center for Reproductive Rights and Vivo Positivo filed a complaint on the behalf of an HIV-positive woman against the Chilean Government in the Inter-American Commission on Human Rights stating that she was sterilized without her knowledge or consent immediately after delivery.\textsuperscript{135} While all forms of forced sterilization can be recognized as violations of human rights, the need for research into the extent of the practice as concerns HIV-positive women in different settings was nonetheless recognized as important.

6. HIV and Pregnancy Intentions: Moving Forward

Further research, tenets to guide the planning, conduct and translation of research into tangible results, and suggested advocacy steps including broad dissemination of conference conclusions and avenues for further work emerged as necessary to advance the health and rights of women living with HIV.

6.1 Identified research needs

A host of issues regarding the pregnancy intentions of women living with HIV and their fulfillment were identified as areas requiring future research, and attention was given to documenting areas where the research is already sufficient for advocacy, policy and programmatic action to be undertaken. Suggested key messages that identify research needs for future action, as identified through conference plenaries and break out groups, can be found in Annex C. Annex D presents key messages relating to what is already known and can be acted upon in relation to each of the conference themes. Annex E provides a matrix of research questions for different disciplines to consider.

It was agreed that, prior to or concurrent with any research efforts undertaken, a number of mapping exercises could usefully be undertaken. These could help to clarify research already underway in the areas noted above across the globe. This would be important for research but would also provide a more solid base for understanding the current structure, operation, interactions and outcomes for HIV-positive women in their contacts with the health system.

In addition to a mapping of research efforts taking place across the globe, participants expressed enthusiasm for encouraging mapping exercises that would take place within countries. For example, the vertical structures of health systems’ governance and financing could be mapped so as to identify where sexual and reproductive health and HIV appear, intersect and diverge. The horizontal structures of sexual and reproductive health and HIV service delivery in different settings could also be mapped with attention to a range of service providers including not only clinicians but also traditional birth attendants and pharmacists. These maps could then be jointly assessed, providing not only a solid base for research but the ability to develop, cost, implement and evaluate packages of integrated services for delivery in a rights-promoting way, tracing from financing all the way through to favorable health outcomes for women living with HIV.

6.2 Approaches to research

In addition to identifying specific areas for future research, the process used to carry out research pertinent to the pregnancy intentions of HIV-positive women was conceptually considered. Emphasizing the importance of multidisciplinary research that explicitly considers when and how the needs and rights of positive women are best addressed, participants discussed for example, the purpose of research, the definition and criteria for evidence and the ways in which such work can and should be actualized. Despite a common commitment to addressing issues affecting women living with HIV, ways in which differences in language, epistemological approach and research priorities (often determined by funding availability) can be reconciled, especially in light of historical tensions and points of departure between disciplinary perspectives, were also discussed. Participants agreed that to do this effectively calls for thoughtful consideration of the nature and practical translation of ‘multidisciplinary’ work, understood to be more than the addition of one discipline to the other. Participants agreed this includes explicit recognition that research conducted by investigators from different disciplines (such as biomedical, social science or legal), who may or may not explicitly work together to test one hypothesis, is nonetheless connected and situated within a larger body of knowledge and sphere of influence.

Recognizing there is no ‘one-size-fits-all’ strategy, participants concluded a truly multidisciplinary research agenda should promote context-specific and sensitive sexual and reproductive health services with attention to the overwhelming array of biomedical, economic, political, and societal forces that HIV-positive women must weigh as they simultaneously negotiate their desire for pregnancy or pregnancy prevention and concerns about HIV transmission to partners and potential children. It was repeatedly stressed that men must be actively engaged in this discussion as partners, as advocates for women’s health, and given their integral role in fertility decisions and potential to increase the safety of sexual interactions.

The apparent disconnect in many settings between the pregnancy desires of women living with HIV and the assumptions made by those who design and implement programs and policies was recognized as highlighting the need for research efforts to meaningfully involve HIV-positive women in all stages of research: planning, conducting the study, performing analyses, making
conclusions, disseminating results and informing policymakers. Participants strongly recommended that any research be done in ways that engage and empower affected communities, starting with collaborative, dialogue-based planning processes informed by understanding of the ways in which HIV-positive women have chosen to organize and network with one another. Use of the WHO Strategic Approach was mentioned as an important tool to help bring community voices to the table, but other approaches including retrospective analysis of service provision and efforts to engage existing coalitions were also recognized as important to ensure integration of HIV-positive women in research efforts.

It was suggested that operations research be used to examine ways to infuse the HIV treatment and care literacy movement with information on sexual and reproductive health services, legal support and human rights. This could help to provide more comprehensive information relevant to the lives of women and men living with HIV, and be used to create demand for appropriate service and policy changes.

Participants agreed that there is a need for greater clarity in research goals, methodologies and ultimate uses of research across disciplines. Questions as to what is recognized and valued as evidence across disciplines remain. Participants agreed that depending on its purpose, evidence can be generated in many ways from randomized-control trial to anecdotes concerning the lived or witnessed experiences of women. It was also noted that varying theoretical frameworks affect the formulation of research questions, and such frameworks may, to some extent, be driven by funders or international agencies lending a particular bias.

Participants highlighted the close connections between research and advocacy efforts that are crucial not only for fundraising, but for communicating research findings and calling for policy change. It was agreed that research in conjunction with advocacy should contribute to policymaking, relate integrally to program implementation and render decision-makers more accountable for the health and rights of women living with HIV.

The conference concluded that researchers, policy makers, program implementers and advocacy groups need to combine efforts also with respect to what is already known and to disseminate this knowledge, including to affected communities. The media could be better utilized to help disseminate research findings. International conferences and online forums were considered important venues for dialogue and to further the work initiated at the meeting.

Participants agreed that HIV and sexual and reproductive health remain highly politicized. Keeping in mind power, policy and politics, three areas were highlighted. First, efforts must be made to include cultural studies, sociology, religious studies, political science and other disciplines, to the extent possible, in such discussions going forward. Second, it was noted that time is of the essence as windows of political opportunity open and close – and that a small window appears to be opening to bring attention to the sexual and reproductive rights of women living with HIV. Participants and colleagues should therefore be prepared to seize available opportunities, even as continuing this work over the long-term. Finally, participants agreed that, given the contemporary arena of donor funding and individual priorities, as well as larger national and international health priorities, funding for innovative efforts, large and small, must be strengthened in order to further the sexual and reproductive health and rights of HIV-positive women.
7. Acknowledgements

We are very grateful to our funders for financial, substantive and technical support to help ensure the conference and this report could go from concept to reality: the World Health Organization’s Department of Reproductive Health and Research, Harvard Center for Population and Development Studies, The Program on International Health and Human Rights at the Harvard School of Public Health, The Elizabeth Glaser Pediatric AIDS Foundation, David Rockefeller Center for Latin American Studies, National Institute of Allergy and Infectious Diseases, and National Institute of Child Health and Human Development.

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Annex A: Conference Agendas

AGENDA FOR CONFERENCE 17-18 March 2010

Day 1 | INTENTIONS BEFORE PREGNANCY
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**Location:** Harvard School of Public Health (677 Huntington Avenue, Kresge Building)

**8:00 - 9:00** | Registration (Kresge Lobby)

**9:00 - 10:00** | Opening: Welcome, overview and introductions (Kresge 502)
Dean Julio Frenk, Manjula Lustri-Narasimhan and Sofia Gruskin

**10:00 - 10:30** | Tea and coffee break

**10:30 - 12:00** | Plenary session 1: Desired pregnancy for HIV-positive women (Issue Paper 1)
This session will review what is known about the desires for pregnancy among HIV-positive women, with an emphasis on issues affecting women in countries with high HIV prevalence. It will consider how the desired pregnancy of women living with HIV may be influenced by antiretroviral therapy (ART) availability, the programs and related resources including those to prevent vertical transmission of HIV, assisted reproductive technologies to improve HIV related sub-fecundity and enhance the safety of pregnancy, and integrated reproductive health and HIV/AIDS programs.

Moderator: Phyllis Kanki

Discussants: Landon Myer, Alexis Ntabona, Aluisio Segurado and Alice Welbourn

**12:00 - 1:00** | Lunch (Provided in Kresge Cafeteria)

**1:00 - 2:30** | Plenary session 2: HIV-positive women seeking to prevent pregnancy (Issue Paper 2)
This session will discuss service delivery models that can support HIV-positive women to effectively and safely meet their sexual and reproductive health needs via family planning counseling and contraception as well as HIV treatment, care and prevention. It will review the way in which the availability, accessibility, acceptability, quality, continuity and constellation of required health services may vary with women’s health status – including adjustments for improved health status conferred by ART.

Moderator: Vera Paiva

Discussants: Ian Askew, Thérèse Delvaux, Benerdette Rahab Mwaniki and Rose Wilcher

**2:40 - 4:30** | Break out groups (afternoon tea and coffee available)
(Group A - Kresge 201; Group B - Kresge 202; Group C - Kresge 203; Group D - FXB G10)

Participants will divide into groups, each representing the diversity of experience and expertise at the meeting, to discuss in more detail the issues raised in the plenary sessions. Each group will be asked to come up with concrete suggestions and recommendations to report back to the larger group.

**4:40 - 5:15** | Report back and wrap-up (Kresge 502)

**From 5:15** | Cocktail reception (Kresge Atrium)
AGENDA FOR CONFERENCE 17-18 March 2010

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<td>Location:</td>
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<tr>
<td>9:00 - 10:30</td>
<td>Plenary session 3: Safe pregnancy for HIV-positive women (Issue Paper 3)</td>
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<tr>
<td>This session will review the range of service delivery and rights issues to be addressed to ensure that pregnant women living with HIV are able to enjoy safe pregnancy and delivery. It will consider what is recognized as state-of-the-art with regard to HIV care during gestation and delivery and open discussion about other aspects of pregnancy pertinent to women living with HIV.</td>
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<tr>
<td>Moderator: Richard Parker</td>
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<tr>
<td>Discussants: Jennifer Gatsi-Mallet, Nguyen Thi Mai Huong, Angela Kaida and Lynn Matthews</td>
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<tr>
<td>10:30 - 11:00</td>
<td>Tea and coffee break</td>
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<tr>
<td>11:00 - 12:30</td>
<td>Plenary session 4: Pregnancy termination for HIV-positive women (Issue Paper 4)</td>
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<td>This session will explore pregnancy termination for women living with HIV, giving special consideration to the social, political, legal and biomedical context within which the decision and act of pregnancy termination occur. Considering a spectrum of choice, from selective to forced termination, the purpose of this session is to determine how research can better address the current gaps in policies and services to identify and meet the needs of HIV-positive women who may undergo pregnancy termination.</td>
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<tr>
<td>Moderator: Marge Berer</td>
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<tr>
<td>Discussants: Maria de Bruyn, Angel Foster, Promise Mthembu and Gilda Sedgh</td>
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<tr>
<td>12:30 - 1:30</td>
<td>Lunch (Provided in Kresge Cafeteria)</td>
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<tr>
<td>1:30 - 3:30</td>
<td>Break out groups (afternoon tea and coffee available)</td>
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<tr>
<td>(Group A - Kresge 201; Group B - Kresge 202; Group C - Kresge 203; Group D - FXB G10)</td>
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<tr>
<td>Participants will divide into groups, each representing the diversity of experience and expertise at the meeting, to discuss in more detail the issues raised in the plenary sessions. Each group will be asked to come up with concrete suggestions and recommendations to report back to the larger group.</td>
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<tr>
<td>3:40 - 5:00</td>
<td>Report back, wrap-up and closing (Kresge 502)</td>
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### AGENDA FOR RESEARCH SYMPOSIUM 19 March 2010

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>8:30 - 8:35</td>
<td>Welcome and overview</td>
<td>Harvard School of Public Health (677 Huntington Avenue, Kresge Building)</td>
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<tr>
<td>8:35 - 9:45</td>
<td>Session: Forwarding the research agenda</td>
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<td>This session will review the four conference themes--desired pregnancy,</td>
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<td>pregnancy prevention, safe pregnancy, and pregnancy termination among</td>
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<td>HIV-positive women--using the following frameworks to guide discussion:</td>
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<td>1. Policy: Policy frameworks, development and advocacy; legislation;</td>
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<td></td>
<td>human rights</td>
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<td>2. Methods: Biomedical and social science methods, tools and approaches</td>
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<td>3. Systems: Health systems capacity and enhancement</td>
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<td>4. Empowerment: Community/gender empowerment</td>
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<tr>
<td>9:45 -10:15</td>
<td>Tea and coffee break</td>
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<tr>
<td>10:15 - 11:30</td>
<td>Break out groups</td>
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<td>(Group A - Kresge 201; Group B - Kresge 202; Group C - Kresge 203; Group D - FXB G10)</td>
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<td>Four working groups will discuss the concrete research goals and agenda-</td>
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<td>setting in relation to one or several of the conference themes.</td>
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<tr>
<td>11:30 - 12:30</td>
<td>Presentations, discussion and next steps</td>
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<td>Short presentations by the four working groups will inform a discussion</td>
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<td>of substantive cross-cutting issues. The meeting will conclude with a</td>
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<td>discussion of next steps including: investigatory partnerships;</td>
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<td>meaningful social participation; strategy for dissemination of future</td>
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<td>findings; potential collaborations; future publications; and other</td>
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<td>desirable next steps.</td>
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<td>12:30</td>
<td>Closing</td>
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Annex B: Participants List

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Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda
17 – 19 March 2010

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Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda
17 – 19 March 2010

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** Group on Reproductive Health and Rights (GRHR) Member
Annex C: Suggested Key Messages – Research Needs for Future Action

This annex summarizes key areas for further research pertinent to the pregnancy intentions of HIV-positive women, as identified through conference plenaries and breakout groups. It is organized according to the topical areas identified through these discussions.

Recognizing their overlapping and connected nature, the research needs identified below are grouped according to women’s experience, and in particular with respect to contraception, testing and counseling, treatment during pregnancy and after delivery, pregnancy termination and forced sterilization. Focus then moves to research needs at the level of the health system with specific attention to the facilities and providers within that system, then to the community and finally to the larger legal and policy context.

Research Needs Regarding Contraception

- Address HIV-positive women’s contraception-related needs, including the potential barriers to acquiring and using the forms of contraception acceptable to them. Related research issues include:
  - The interactions between HIV, antiretroviral therapy (ART) and hormonal contraception including emergency contraception.
  - The effects of hormonal contraception on the risks of cervical cancer in HIV-positive women.
  - New microbicides and other female-initiated contraceptive options

Research Needs Regarding Testing and Counseling

- Consider the way in which different forms of HIV testing and counseling impact the sustained engagement of HIV-positive women with health services including on a woman’s health and the safety of her pregnancy and delivery as a result of:
  - Health care worker attitudes and the communication, reporting, and disclosure of test results.
  - HIV testing protocols in relation to testing during labor, when a women’s ability to give truly informed consent may be impaired for medical and/or social reasons.

Research Needs Regarding Treatment During Pregnancy and After Delivery

- Determine the full spectrum of physiologic interactions of ART during pregnancy, especially in low-income, low-access settings.
- Discern the safety of some antiretrovirals for fetal development, particularly in cases
where those that are available are not the safest of all existing antiretrovirals during pregnancy.

- Identify the implications of repeated use of antiretroviral prophylaxis over the course of multiple pregnancies.

- Understand the pregnancy outcomes for HIV-positive women who are not on ART and give birth vaginally.

- Establish ways to support women and providers on appropriate infant-feeding techniques in relation to ART availability, and to scale-up programs that have promoted breastfeeding while supporting positive women’s experiences and educating health care providers.

- Consider the health of mother and infant in the post-partum period and ways to effectively ensure that HIV-positive women have continued access to the treatment and care they need during and beyond the perinatal period despite different economic, political and social contexts.

**Research Needs Regarding Pregnancy Termination**

- Distinguish ways to bring information about the content and impact of abortion laws, the kinds of abortion services that are available (medical and surgical) and women’s experiences with abortion into the public sphere.

- Compare the experiences of adolescent women with HIV when accessing abortion care compared to those of adult women.

- Identify the potential physiologic effects of medical methods of abortion for HIV-positive women including interactions with ART, appropriate dose and risks associated with abortions after the first trimester.

- Clarify the correlative and causal relationships between unintended pregnancy, pregnancy termination and HIV in high-prevalence or resource-limited settings, as well as the factors that may compel women living with HIV to undergo unsafe abortions.

**Research Needs Regarding Forced Sterilization**

- Determine the extent and myriad impacts on women and on services of forced sterilization and the ways it occurs in different settings.

**Research Needs Regarding the Role of the Community**

- Explore the potential role of community, including the role of traditional birth attendants, as a locus for support and care for women living with HIV and as a link between community and clinical care locally and nationally.

- Untangle the impact of stigma, discrimination and violence on the pregnancy intentions of positive women, as perpetrated by family, community members and/or health care
providers, with special attention to:

- The potentially heightened consequences of stigma, discrimination and violence, individually and collectively, on reproductive decision-making for adolescents, with attention also to already marginalized populations such as sex workers and injecting drug users (IDUs).

- The ramifications of HIV status disclosure, pregnancy and/or termination thereof on the incidence and magnitude of intimate-partner and other types of violence.

- The ways in which stigma, discrimination and violence may be mitigated by the availability and accessibility of ART and appropriate care.

- Psychological and emotional health issues including isolation, anxiety, depression and stress among women living with HIV at the time of diagnosis, throughout pregnancy, during labor and delivery and in the post-partum period.

**Research Needs Regarding the Health System**

1. Identify the health system challenges and opportunities for improving access to quality services (including ART, contraception, assisted reproductive technologies and abortion services) including cost-effectiveness and impact assessments as well as rigorous comparative studies.

2. Establish the appropriateness of various service delivery models including those that integrate HIV care with sexual and reproductive health services, and specifically:

   - Give attention to the availability, accessibility, acceptability and quality of care individually and in relation to one another as these impact service delivery and use.

   - Examine the approaches to the service needs of populations beyond those traditionally considered by the public health community in the design of population-based service delivery models, including adolescents, sex workers, drug users and other marginalized populations.

   - Consider the ways in which information about the prevention of horizontal and vertical transmission of HIV are best targeted to or made available to men.

   - Think about the ways to promote dual contraceptive and sexually transmitted infections (STI) prevention methods.

   - Identify the effectiveness of existing assisted reproductive technologies in resource-limited settings as well as strategies to make them accessible, in conjunction with the continued development of alternative means to fulfill women’s desires to become pregnant in low-resource settings.

   - Determine the best practices related to labor in settings characterized by limited health system infrastructure, access to ART and/or surgical capacity for Cesarean deliveries.
Understand the approaches to implementation and evaluation of combined services including linking versus integrating care and the merging of services across public and private sectors.

Define the key components of dialogue-based, human rights-sensitive approaches to care, to better incorporate and address the experiences and fertility intentions of individual women and men and account for barriers to a range of services based on gender, age and other characteristics.

Identify pilot initiatives that demonstrably and effectively deliver linked and/or integrated services to HIV-positive women and then determine approaches to bringing these to scale nationally, regionally to different settings.

- Consider which mechanisms can best enhance the knowledge of providers and promote their subsequent communication of relevant information to HIV-positive women and their partners regarding:
  
  - The specific sexual and reproductive health needs and rights of adolescents, including best practices to promote contraceptive methods that prevent both pregnancy and HIV.
  
  - Contraception, including the safety and efficacy of hormonal methods and their effects on HIV progression.
  
  - Potential viral transmission before, during and after delivery.
  
  - Adherence to antiretroviral therapy and other health concerns in the post-partum period.
  
  - Assisted reproductive technologies including pre-exposure prophylaxis and sperm washing.
  
  - The impact and effectiveness of employing rights-based approaches to this work in health care settings.

Research Needs Regarding the Larger Legal and Policy Context

- Determine the larger impacts of the legal and policy context on access to information and health services for women living with HIV and partners, and their influence on pregnancy intentions, with special consideration to:
  
  - The classification of HIV and/or pregnancy as a legitimate health exception under certain laws and the impact thereof.
  
  - The content and implications of relevant laws regarding abortion in general, as well as the use of misoprostol for medical abortions.
  
  - The receptiveness of legal systems to claims for redress should a provider violate professional ethics while caring for HIV-positive women in relation to
pregnancy and childbirth.

- The impact of criminalization and other laws or penalties on HIV-positive women’s desire to become pregnant and/or carry their pregnancies to term.

- The acceptability, and in some cases legality, of adoption by women and their partners, family and communities in various settings.

- Effective application and leveraging of health and human rights frameworks in these research efforts so as to fulfill the sexual and reproductive health and rights of HIV-positive women.
Annex D: Suggested Key Messages – Current Knowledge for Action

This annex summarizes key messages related to what is already known and can be acted upon for advocacy, policy and programmatically. These messages are drawn from information presented, discussed and corroborated throughout the course of the conference proceedings, and as such, are thematically divided in line with the conference report sections. This list is intentionally and necessarily limited bringing together only those points supported by evidence generated across several settings.

Factors Influencing HIV and Pregnancy Intentions

- A decision to become pregnant as well as to terminate pregnancy is not only a personal choice but reveals complex intersections of the legal, political, social and biomedical spheres, subject to family and community pressures, stigma and discrimination, in addition to both national and donor influence. The attitudes and actions of current and former sexual partners as well as health care providers may weigh heavily on a woman’s personal desires concerning children.

- In all settings, a range of factors has been found to shape HIV-positive women’s pregnancy desires. In addition to the availability of HIV treatment and prevention of mother-to-child transmission (PMTCT) programs, these include: age; health status; cultural significance of motherhood; number of living children; previous experience of a child’s death from HIV-related causes; the attitudes and influence of partners, family, and health care workers; and stigma and discrimination on the basis of HIV status especially for already marginalized populations.

- Access to antiretroviral therapy (ART) significantly influences the desire of HIV-positive women to bear children. And in many low-resource settings, only a small proportion of women in need of ART currently receive it.

- In addition to accessing ART, the existence of assisted reproductive technologies including artificial insemination, in-vitro fertilization and embryonic implantation influence the desire and ability of HIV-positive women to bear children.

- Health care provider attitudes can inhibit HIV-positive women’s access to the correct health information and appropriate services relevant to their sexual and reproductive health and to making decisions with respect to pregnancy and childbirth.

- The attitudes of health providers, the confidentiality with which they are known to handle HIV test results, and the modalities used to communicate test results can all affect HIV-positive women’s desires with respect to pregnancy and bearing children.
**HIV-positive Women and Pregnancy Prevention**

- As their health status improves in response to treatment, HIV-positive women may return to the level of sexual activity experienced before HIV diagnosis, but this may or may not indicate a desire to become pregnant.

- In many countries a wide range of contraceptive options, and emergency contraception in particular, is still not widely available and as for other women may limit positive women’s ability to prevent pregnancy when they wish to do so.

- Power imbalances in some sexual relationships may prevent women from insisting on condom use, even though they remain the only “dual function” contraceptive method to prevent both pregnancy and HIV infection.

- Hormonal methods are generally safe for HIV-positive women and such methods do not significantly affect disease progression, even as some evidence suggests ART might decrease the efficacy of hormonal methods.

- Intra-uterine devices, sterilization and vasectomy are biologically safe for HIV-positive women and men, although surgery may not be advisable for those with acute AIDS-related illnesses.

- The need for integrated HIV and sexual and reproductive health care services is greater than ever, even as the specifics of how this is best accomplished in order to support the health and rights of HIV-positive women is known to vary by context.

**Safe Pregnancy for HIV-positive Women**

- Pregnancy itself does not accelerate HIV disease progression, and the known benefits of taking ART during pregnancy outweigh the known risks.

- Access to ART is essential for HIV-positive women to proceed safely with pregnancy, labor and delivery, breastfeeding and to maintain their own health in the post-partum period.

- ART has a positive effect on fecundity, further augmented by assisted reproductive technologies, but neither is universally available.

- Caesarean deliveries for HIV-positive women reduces the risk of HIV transmission during birth but may also increase the risks of certain types of post-operative infections in HIV-positive mothers, particularly in low-income settings.

- Women’s adherence to ART often drops in the post-partum period, and interrupted therapy may contribute to faster HIV disease progression.

- Despite biomedical recommendations and access to antiretrovirals, a woman’s decision-making process regarding whether or not to breastfeed is greatly influenced by social and
cultural factors and therefore remains highly personal and individualized.

**Pregnancy Termination for HIV-positive Women**

- HIV-positive women, similar to their HIV-negative counterparts, may experience high rates of unintended pregnancies.

- HIV-positive women can safely undergo both surgical abortion (vacuum aspiration; dilatation and curettage; and dilatation and evacuation) and medical abortion (administration of pharmaceutical agents to interfere with the continuation of pregnancy).

- HIV-positive, as well as HIV-negative women, who undergo unsafe abortion due to the absence of accessible or acceptable abortion services endure a risk of complications that is several hundred times higher than that of an abortion performed under safe conditions.

- Post-abortion care (PAC), which is heavily donor funded, can be life-saving to women who undergo unsafe abortions. Criminalization of abortion may further exacerbate maternal morbidity and mortality by delaying or inhibiting women from seeking PAC even where it is available. Complications of abortion are of particular concern for women living with HIV given their potentially higher rates of morbidity due to unsafe abortion.

- Forced and coerced sterilization of HIV-positive women has been reported in a number of countries when women seek sexual and reproductive health services including abortion, labor and delivery, and cervical cancer screenings. Many of these services are delivered in the context of PMTCT.
Annex E: Research Themes Matrix

This annex provides a matrix of some key research questions affecting the sexual and reproductive health and rights of HIV-positive women as agreed to by the conference participants. It is organized into the following four sections: policy, implementation, systems, and empowerment. Each section includes overarching questions, followed by specific questions relating to each of the four conference themes: desired pregnancy; pregnancy prevention; safe pregnancy; and pregnancy termination. The questions contained in the matrix are not exhaustive, but point to immediate areas of importance and gaps in knowledge. It is hoped that the matrix can serve to highlight some of the critical research questions for different disciplines to consider and further illustrate how these questions can be asked in a multidisciplinary fashion in order to better address the pregnancy intentions of HIV-positive women.

**POLICY - Overarching Questions**

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<td>Which policies, laws and regulations impede or improve the sexual and reproductive choices and safe practices among girls and women living with HIV?</td>
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<td>What mechanisms should be considered, tested and applied to monitor and evaluate both the intended and unintended impacts of these policies, laws and regulations?</td>
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<td>With the policy environment evolving very rapidly, how can we effectively communicate new policies to the facility and community levels as well as to professional groups outside of immediate health services (i.e. lawyers, law enforcement officers, educators)?</td>
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<td>What policy actions can be taken to determine and address the sources and manifestations of stigma and discrimination?</td>
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<td>Who influences policymaking and how can we best map out power distribution and positive and negative forces in promoting women’s ability to fulfil their sexual and reproductive rights?</td>
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<td>What kind of research on policy and politics is required to shed light on how the legal and policy environment has evolved so as to inform future efforts?</td>
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<td>How can international and donor organizations positively influence the field of sexual and reproductive (SRH) national policy?</td>
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<td>How might policy change based on the potential impact of insecurity of long-term funding for highly active antiretroviral therapy (HAART) on women’s reproductive decision-making?</td>
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<tr>
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<tbody>
<tr>
<td>Is there a need for national and/or global medical ethical guidelines for women living with HIV desiring pregnancy?</td>
<td>What are national policies, laws and regulations regarding pregnancy prevention for women living with HIV?</td>
<td>Are laws criminalizing HIV transmission being applied generally and to Mother-to-Child Transmission?</td>
<td>What are the impacts of policies, law and regulations that restrict abortion and can these impacts be examined and interpreted in a way that renders decision-makers more accountable for promoting and protecting women’s health and rights?</td>
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<td>To what extent is the importance of addressing the contraceptive needs of HIV-positive women reflected in HIV/AIDS policies, guidelines, and service delivery protocols?</td>
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<td>How can the voices and choices of women living with HIV regarding safe abortion care best be articulated so as to influence policymaking?</td>
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<td>How do laws and regulations on pregnancy termination impact on safe pregnancy termination by women living with HIV?</td>
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</tbody>
</table>
IMPLEMENTATION - Overarching Questions

- How to better integrate HIV and sexual and reproductive health research frameworks and work collaboratively across disciplines?
- What knowledge exists and what gaps remain concerning the biomedical, economic, political, social and other factors impeding access to technologies and methods needed to protect and promote sexual and reproductive health among women living with HIV?
- How do we ensure all of these methods and tools are tested, validated and applied towards the attainment of the highest standard of sexual and reproductive health, especially in low and middle-income countries and particularly among vulnerable women? Furthermore, what institutional support is necessary to ensure this is achieved?
- How can data gaps be filled by using evidence that already exists from analysis of monitoring and evaluation (M&E) data? Or which methodologies should be used in the field to fill in the gaps?

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<td>How can stigma effectively be quantified and qualified in a health care setting as women living with HIV struggle to effectively communicate and/or fulfill their desire to become pregnant?</td>
<td>What are the methodological considerations a rights perspective raises for research with regard to the timing of, and delivery sites for, contraceptive provision for women living with HIV?</td>
<td>What are the patterns of Caesarean sections and associations with sterilization among women living with HIV?</td>
<td>What methods best meet the needs of women living with HIV for voluntary pregnancy termination in varying circumstances (e.g. rural or urban homes, women taking ART or not, etc.)?</td>
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<tr>
<td></td>
<td>How best can family planning (FP) programs take into account the fact that women living with HIV have been shown to often have unintended pregnancies?</td>
<td>How is sterilization practiced (e.g. voluntary with informed consent, imposed, disclosed or not)?</td>
<td>What are adolescent women's experiences with HIV stigma when accessing abortion care, and is this different from adult women's experiences?</td>
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<td>Are special measures of sterilization decided and applied to specific sub-populations (e.g. people with mental health disorders, incarcerated populations, and/or women who are advised about hysterectomies because of abnormal pap smears)?</td>
<td>What is the range of providers’ attitudes regarding abortion for women living with HIV?</td>
</tr>
</tbody>
</table>
HEALTH SYSTEMS - Overarching Questions

- If the goal and approaches to “integration” are intended primarily to create a synergy between HIV and reproductive health work, which models of integration or linkages are most appropriate in different contexts – especially in areas with concentrated epidemics?
- Across a range of different settings, does integrating FP and HIV services result in improved health outcomes when compared to implementing these services/programs separately? Are integrated services more cost-effective?
- What specific lessons learned from sexually transmitted infections (STI)/HIV and FP/reproductive health (RH) services could inform the integration process? What are potential positive outcome and pitfalls requiring monitoring and evaluation? What indicators and methods would be best suited to monitor services and their outcomes?
- How can pre-exposure prophylaxis and counseling on approaches to safe conception be tested (akin to “harm-reduction approaches”)?
- How can the health system better reach adolescent boys and girls living with HIV to enhance their awareness, induce safer practices and increase their active participation in sexual and reproductive health matters?
- How to enhance availability, accessibility, acceptability and quality of sexual health (SH) and RH structures, goods and services for women living with HIV through a combination of public and private services? How can the health system best finance these services?
- Can a greater collaboration between formal health system and community-based health resources improve access to and quality of services for women living with HIV? How to foster greater collaboration between the formal health sector and community-based health organisations?
- How can referral systems best ensure that HIV services provide information about safe abortion and post-abortion care and that abortion care services refer women to voluntary counseling and testing (VCT) and proper support?
- What are the health system barriers to accessing safe abortion services?
- Where do structures of governance and funding, among others, for SRH and HIV intersect and diverge within a health system? How best might these be streamlined and/or collaborate?

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<tr>
<td>• How can health systems best address HIV-positive women’s desire for pregnancy, ranging from attention to safer conception to assisted reproductive technologies in resource-limited settings?</td>
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<td>• How can pre-exposure prophylaxis and counseling on approaches to safe conception be tested (akin to “harm-reduction approaches”)?</td>
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<tr>
<td>• What models of care can positively affect the accessibility, availability to and acceptability of contraceptive methods to different populations and across different settings?</td>
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<tr>
<td>• How can service delivery best be structured to ensure that women living with HIV can access the full range of services from which they could benefit during pregnancy including antenatal care, safe delivery and HIV-related services?</td>
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<tr>
<td>• How can referral systems best ensure that HIV services provide information about safe abortion and post-abortion care and that abortion care services refer women to voluntary counseling and testing (VCT) and proper support?</td>
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<td>• What are the health system barriers to accessing safe abortion services?</td>
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<tr>
<td>• What are appropriate models for integrating abortion services with HIV services?</td>
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**EMPOWERMENT - Overarching Questions**

- How to communicate the idea of risk among women living with HIV to both inform choices and minimize guilt when prevention of vertical transmission has failed?
- What social and cultural structures influence women’s sexual and reproductive choices and outcomes within communities?
- What mechanisms should be proposed, tested and advocated to ensure exchange of information and mutual support on sexual and reproductive health among women living with HIV?
- What combination of interventions can most effectively promote the sexual and reproductive health and rights of women living with HIV? Furthermore, how can partners, families, communities and providers become collaborators in this process?
- How can participation be increased to amplify the voice of women living with HIV, including in determining the research agenda?
- How can the interaction among positive networks and between these networks and policy-makers, researchers and programmers be promoted?
- What kinds of protocols are needed for community participation in the formulation of clinical, intervention and other research, including the type and duration of care provided?
- What mechanisms can women living with HIV and their partners use to increase their understanding of, and advocacy for, sexual and reproductive rights?
- How can communities be empowered and research improved by ensuring dissemination to, and feedback from, the subjects researched and community before wider dissemination?

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<tr>
<td>How is the impact of men’s fertility desires on women’s reproductive decision-making?</td>
<td>How are gender constraints to accessing and using contraception best addressed in FP/HIV integration programs?</td>
<td>How can the voices of HIV positive women be better incorporated into policies and programs designed to address safe pregnancy?</td>
<td>Who do women turn to in order to get information and to obtain an abortion, and how is this affected by their HIV status?</td>
</tr>
<tr>
<td>What social and cultural factors influence men’s fertility desires?</td>
<td>How can FP/HIV integration efforts be leveraged to increase male involvement in FP/RH?</td>
<td>Do positive and negative women experience antenatal and/or post partum support differently?</td>
<td>What kinds of information and services do women living with HIV want regarding unwanted pregnancy and their options, including safe pregnancy termination?</td>
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<td>How to get information on abortion in circumstances where it is not permitted by law to women, especially women with a stigmatized condition such as HIV?</td>
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<td>What arguments can persuade policymakers at national and international levels to speak out publicly in favor of women’s right to terminate unwanted pregnancies safely?</td>
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Annex F: Select Articles Relevant to Conference Themes

This annex brings together peer-reviewed articles referenced in conference preparatory materials and additional articles suggested by participants. Drawn from different disciplinary perspectives, these articles bring together the current state of knowledge with respect to conference themes. Due to time limitations, the articles are drawn mostly from the English language peer-reviewed literature.


Bujan, L. et al., 2009. Lack of clinical and scientific evidence to justify the systematic use of ICSI in HIV-serodiscordant couples wishing to conceive where the male partner is infected. *Fertility and Sterility*, 91(3), e1-2.


Pregnancy Intentions of HIV-Positive Women: Forwarding the Research Agenda
17 – 19 March 2010


Cooper, D. et al., 2009. Fertility intentions and reproductive health care needs of people living with HIV in Cape Town, South Africa: Implications for integrating reproductive health and HIV care services. AIDS and Behavior, 13(Suppl 1), 38-46.


Johnson, K. B. et al., 2009. Fertility preferences and the need for contraception among women living with HIV: The basis for a joint action agenda. *AIDS*, 23(Suppl 1), S7-17.


Kaida, A. et al., 2009. Antiretroviral adherence during pregnancy and post-partum among HIV-positive women enrolled in the drug treatment program in British Columbia, Canada. *18th Annual Conference of the Canadian Association for HIV Research (CAHR)*, Vancouver, BC.


Kiddugavu, M. et al., 2003. Hormonal contraceptive use and HIV-1 infection in a population-


Lafort, Y. et al., 2003. Should family planning clinics provide clinical services for sexually transmitted infections? A case study from Côte d’Ivoire. *Tropical Medicine and International Health*, 8(6), 552-60.


Paiva, V. et al., 2003. The right to love: The desire for parenthood among men living with HIV. Reproductive Health Matters, 11(22), 91-100.


Sahin-Hodoglugil, N.N. et al., 2009. Degrees of disclosure: A study of women’s covert use of the diaphragm in an HIV prevention trial in sub-Saharan Africa. Social Science and Medicine, 69(10), 1547-55.


Annex G: Select Documents Relevant to Conference Themes

This annex brings together materials, including inter-governmental, international and national nongovernmental and community-based organizational reports recommended by conference participants. Drawn from different organizational and disciplinary perspectives, these documents bring together additional information with respect to conference themes extending beyond the peer-reviewed literature.


OXFAM HIV and AIDS. Available at: http://publications.oxfam.org.uk/oxfam/display.asp?&K=9780855986032


WHO/USAID/FHI. 2009 *Strategic Considerations for Strengthening the Linkages between Family Planning and HIV/AIDS Policies, Programs, and Services.* Available at: http://www.fhi.org/en/RH/Pubs/booksReports/FP-HIV_Strategic_Considerations.htm

UK Consortium on AIDS and International Development. “How can UK stakeholders support the rapid scale up of PMTCT? Open Space Discussion – Main Recommendations”


