Appendix B(1): E-consultation

E-consultation on PMTCT Components One and Two:

Primary Prevention of HIV and Prevention of Unintended Pregnancies

Global Network of People Living with HIV

&

International Community of Women Living with HIV

29 November – 20 December 2010

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List of Acronyms

AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ARVs	Antiretrovirals
ART	Antiretroviral therapy
AZT	Zidovudine
CBOs	Community based organizations
FGDs	Focus Group Discussions
GIPA	Greater Involvement of People Living with HIV
GMT	Greenwich Median Time
GNP+	Global Network of People Living with HIV
IATT	The Interagency Task Team
ICW	International Community of Women Living with HIV
MDGs	Millennium development goals
MTCT	Mother-to-child transmission (of HIV)
NAM	National AIDS Manual
NGO	Non-governmental organizations
PCR	Polymerase chain reaction
PIT	Provider Initiated Testing
OIs	Opportunistic infections
PITC	Provider initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission (of HIV)
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
WHO	World Health Organization

Executive Summary

This report presents a summary of key findings and recommendations emerging from the e-consultation on PMTCT components one and two held from 29 November – 20 December 2010. The International Community of Women Living with HIV (ICW) Global and the Global Network of People Living with HIV (GNP+) conducted this consultation to solicit perspectives and personal experiences from people living with HIV to inform the *Draft Strategic Framework (2010-2015) for Primary Prevention of HIV and the Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT*.

The Interagency Task Team (IATT) for Prevention of HIV Infection in Pregnant Women, Mothers, and their Children in collaboration with GNP+ and ICW (a member of the IATT) developed this strategic framework to scale-up comprehensive PMTCT, which is comprised of four components[1]: (i) Primary prevention of HIV among women of childbearing age; (ii) Preventing unintended pregnancies among women living with HIV; (ii) Preventing HIV transmission from a woman living with HIV to her infant; and (iv) Providing appropriate treatment, care and support to women living with HIV and their children and families. Unfortunately, implementation of the four components has been skewed with components three and four receiving greater emphasis and demonstrating significant progress, while components one and two have not benefited from appropriate recognition, commitment, or programming support.

Majority of key messages and recommendations emerging from the e-consultation resonated with those articulated in the Draft Framework. Participants felt, however, that a few additional recommendations should be included in the final Framework as they have the potential to significantly improve PMTCT uptake.

- Pre-conception care awareness among women (especially young women), their partners, health providers and other stakeholders should be included as a component of SRH.
- In expanding testing settings for women, appropriate timing, testing venues and supportive counseling must be assured especially among pregnant women. For example, testing a pregnant woman and disclosing an HIV positive diagnosis may have traumatic consequences for both to the woman and her child.
- Counseling support for women and their partners should be complemented with peer one-on-one counseling and group support.
- Efforts are needed to ensure PMTCT programs are viewed as interventions that balance the rights of the mother and the child.
- Revisit the choice of words in '*Prevention of Mother-to-Child Transmission* and agree on a term (s) that accurately describes HIV transmission to the child without putting blame on the mother.
- Revisit and carefully consider choice of terminology in PMTCT programming to ensure definitions are clear, not normative, clouded in ambiguity or value loaded. Use of the term 'elimination' in mother-to-child transmission should be revisited to clarify its meaning especially among people living with HIV some of who understand 'eliminate' to mean eliminating positive women in order to eliminate mother-to-child transmission.

[1] Various documents use the terms 'prongs', 'elements', and 'pillars' instead of 'components' when referring to comprehensive PMTCT.

Introduction

The IATT for Prevention of HIV Infection in Pregnant Women, Mothers, and their Children in collaboration with GNP+ and ICW (a member of the IATT) developed a strategic framework to scale-up comprehensive PMTCT, which is comprised of four components[2]:

1. Primary prevention of HIV among women of childbearing age
2. Preventing unintended pregnancies among women living with HIV
3. Preventing HIV transmission from a woman living with HIV to her infant
4. Providing appropriate treatment, care and support to women living with HIV and their children and families

Implementation of the four components has been skewed with components three and four receiving greater emphasis and demonstrating significant progress while components one and two have not benefited from appropriate recognition, commitment, or programming support.

The Draft Strategic Framework (2010-2015) on the first two components of PMTCT aims to scale-up these components by strengthening policy and programming. In addition, the Framework highlights strategies and packages of essential services that are offered through community based integrated sexual and reproductive health and HIV programs.

The Global Network of People Living with HIV and the International Community of Women Living with HIV Global conducted an e-consultation to seek perspectives from people living with HIV aimed at integrating their personal experiences into the final Strategic Framework. Contribution from the community of people living with HIV is key to the Framework development process to ensure their views are accurately captured in keeping with the principle of the Greater Involvement of People Living with HIV (GIPA).

Methodology

This e-consultation is one component of a broader effort comprising of a survey, an expert consultation, and focus group discussions to solicit contribution from people living with HIV and articulate these in the Framework.

The e-consultation was conducted with four and five open-ended questions for component one and two respectively, each linked to a package of essential services that resulted in qualitative data. The data was compiled by country, gender, and age. The analysis extracted main emerging themes categorized as; opportunities/success, challenges and recommendations highlighted under each question. The criteria for selecting participants' quotes were based on relevance to the question and articulating a balance of the rich experiences from both the developed and developing countries. The recommendations reflect the main issues of the online consultation, which were derived from participants' postings and linked to those articulated in the draft Framework where applicable.

Since majority of participants' recommendations mirrored those captured in the draft

[2] Various documents use the terms 'prongs', 'elements', and 'pillars' instead of 'components' when referring to comprehensive PMTCT.

Framework, it was logical to highlight the similarities. A few of the recommendations arising from the e-consultation were unique and provided the personal perspective that would strengthen the draft Framework to adequately addresses the sexual and reproductive health needs of people living with HIV and especially women living with HIV. The e-consultation approach was used to acquire deeper understanding from people living with HIV on PMTCT components one and two.

E-consultation Process

The e-consultation took place over a three-week period from Monday 29 November to 20 December 2010. The Consultation was hosted by NAM (formerly known as National AIDS Manual), a community based information resource organization. To launch the e-consultation, a specific website was created and incorporated into the NAM website.

An email providing a brief summary of the purpose of the e-consultation was circulated to people living with HIV highlighting the importance of their input and feedback on the Draft Framework on PMTCT component one and two. Both men and women were encouraged to participate and share their knowledge and experiences in these two areas. Using the available NAM databases and ICW Global and GNP+ list serves of networks, over 990 men and women living with HIV were invited to participate. These e-mails included the link to the e-consultation website (www.aidsmap.com/pmtct-econsultation). Participants were invited to register by completing a short user profile and were given the option to choose a user name and to upload a photo. Name, sex, organization, and country data were provided for GNP+ and ICW's internal use only.

In order to assure data confidentiality/protection of participants' information, only NAM had access to the personal information.

Feedback from participants on the draft Framework was solicited by posting four and five broadly framed questions on PMTCT component one and two respectively to initiate the discussion. The draft Framework was also available on the e-consultation website and participants were encouraged to read the document and provide their contributions. Input from people living with HIV was aimed at ensuring their perspectives were accurately captured and would inform the final version of the Strategic Framework.

A consecutive approach was used, starting with feedback on PMTCT component one (primary HIV prevention of HIV among women of child bearing age), followed by discussions on component two (prevention of unintended pregnancies among women living with HIV).

The initial start date of the E-consultation was delayed by a week while awaiting necessary clearance to post the draft Framework on the first two components of PMTCT *(i) Primary Prevention of HIV and (ii) Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT: Strategic Framework 2010-201*5.

Week 1 & 2 (20 November – 12 December): PMTCT Component One (Primary Prevention of HIV):

Discussions on component one were held from November 29th to December 12th, 2010, a week

later than planned thus coinciding with Worlds AIDS Day activities, which many advocates and activists living with HIV are usually heavily involved in.

The first component of PMTCT is the prevention of HIV among women of childbearing age. A comprehensive PMTCT package that recognizes primary prevention has enormous benefits to both mother and child and is crucial for preventing new infections. The Framework suggests as main services:

- Information and counselling to reduce the risk of sexual HIV transmission
- HIV testing and counselling for pregnant and post-partum women
- STI screening and management
- Condoms
- Blood safety to reduce blood-related transmission
- Gender-based violence prevention and impact mitigation

Based on the above services, the following four questions were asked to assess the experiences and perceptions of people living with HIV:

1. Are the services that constitute this package currently available in your country? If they are available, are they accessible?
2. In your country (or from your experience), what are the barriers that make it difficult to offer such a package of services?
3. HIV testing is often offered to women through several settings, such as antenatal care, family planning and services for sexually transmitted infections (STI). Where do women access HIV testing in your country? What rights do women have when they test for HIV?
4. What would quality counseling look like? For a woman (whether she is pregnant or not AND whether she tests HIV-positive or HIV-negative)? What would quality counseling look like for a couple?

Week 3 (13 – 20 December): PMTCT Component Two (Prevention of Unwanted Pregnancies)

Dialogue on the second component of PMTCT was held from 13 -20 December, also delayed due to reasons provided earlier for component one discussion. Component two is aimed at preventing unintended pregnancies among women living with HIV and stems from the recognition of high levels of unmet family planning needs, which is estimated globally at 38%, and at 51-90% among women living with HIV.

The package of services proposed in the framework for preventing unintended pregnancies among women living with HIV is:

- Information and counseling to reduce risk of mother-to-child transmission
- Clinical management of HIV
- Reproductive rights and family planning counseling and services
- STI screening management
- Gender-based violence prevention and impact mitigation
- Confronting stigma and discrimination

Based on the above package of services the following five questions were asked to assess the

experiences and perceptions of people living with HIV:

1. Are the services and programmes for women living with HIV that constitute this package currently available (or in place) in your country? If they are available, are they accessible?
2. In your country (or from you experience), what are the barriers that make it difficult to offer such a package of services and programmes to women living with HIV?
3. What would quality counseling and programmes look like for women living with HIV and their partners for the prevention of unintended pregnancies?
4. Considering the current PMTCT approaches in your country, is there an appropriate balance between the rights of the mother and the rights of the child?
5. Countries are discussing the 'elimination' of mother-to-child transmission. What does that mean to you?

Component one of the PMTCT discussion took place over a two-week period instead of the initially planned one-week and was closed at 12.00 GMT Sunday, December 12th, 2010. The additional week was due to low contribution for various reasons including participants' involvement in World AIDS Day activities and some technical challenges related to registration.

Component two consultations lasted a week, and contributions were closed at 12.00 GMT Monday, December 20th, 2010. Once the discussion closed, participants were unable to make new postings and revisions but had access to read previous discussions.

The Consultation was conducted in English and provided for contribution in French, Spanish, Portuguese, and Russian. A GNP+ consultant living with HIV (Naisiadet Mason) moderated these discussions through regular monitoring and contributing as needed to maintain the discussion flow while incorporating relevant information to the various topics.

Participants from Cameroon, Portugal, Mexico, and Russia participated in French, Portuguese, Spanish, and Russian respectively, while the moderator with assistance from GNP+, translated and summarized their contribution into English.

Results

Participants

Of the over 990 email invitations to participate on the e-consultation, 66 registered and 36 posted comments to the discussion (Table 1). Sixteen countries from four WHO regions contributed to the Consultation (Table 1). Twice the number of female participants compared to males registered and posted comments (Table 2).

Table 1

Regional Distribution of Participants

Region	Number of registered participants	Number of participants who registered and posted	Number of participants who registered and did NOT post
Africa Cameroon, Cote	22	14	8

D'Ivoire. Kenya, South Africa, Uganda, Zambia*			
Americas US, Canada, Mexico, Jamaica Trinidad and Tobago	16	10	6
Europe UK, Portugal, Ukraine	20	10	10
Eastern Mediterranean	0	0	0
South-East Asia	3	0	3
Western Pacific Indonesia, Thailand	5	2	3
Total	**66**	**36**	**30**

* Specific country figures were not available due to technical reasons of automatic registration and confidentiality issues.

Table 2

Distribution of Participants by Gender

Gender	Number of participants registered	Number of participants who registered and posted	Number of participants who registered and did NOT post
Female	44	28	16
Male	22	8	14
Total	**66**	**36**	**30**

A larger number of females than male participants registered and posted comments. This may be explained by the perception that PMTCT it is a domain for women and also women have a deeper awareness of its importance for their well-being and that of their child.

The least number of participants was noted in age group 20-29 with six individuals posting comments (Table 3).

Table 3

Age Distribution of Participants

Registered participants		Number of registered participants who posted	Number of registered participants who did NOT post
Age	**N**		
20-29	12	6	6
30-39	22	9	13
40-49	19	11	8
50+	13	10	3
Total	**66**	**36**	**30**

Participants came from a range of countries including Cote d'Ivoire, Indonesia, Jamaica, Kenya, Portugal, South Africa, Thailand, Trinidad and Tobago, Ukraine, and Zambia. Nearly half the participants were from the UK and the US combined. This may likely have been to due to easier internet access.

Summary of discussions

Participants were well versed on issues of PMTCT component one and two, which was demonstrated by their rich experiences and local assessment on availability and accessibility of services, as well as by their expression of sound ideas on what is required to improve access to services in their countries.

First component of PMTCT: Primary Prevention (Week 1&2; 29 November - 12 December)

Component one of PMTCT is the prevention of HIV among women of childbearing age. A comprehensive PMTCT package that recognizes primary prevention has enormous benefits to both mother and child and is crucial for preventing new infections.

- Information and counselling to reduce the risk of sexual HIV transmission
- HIV testing and counselling for pregnant and post-partum women
- STI screening and management
- Condoms
- Blood safety to reduce blood-related transmission
- Gender-based violence prevention and impact mitigation

1. Are the services that constitute this package currently available in your country? If they are available, are they accessible?
2. In your country (or from your experience), what are the barriers that make it difficult to offer such a package of services?
3. HIV testing is often offered to women through several settings, such as antenatal care, family planning and services for sexually transmitted infections (STI)?
4. What would quality counseling look like for a woman (whether she is pregnant or not AND whether she tests HIV-positive or HIV-negative)?

Fifteen individuals shared their perspectives and personal experiences during the e-consultation on the first component. Participants' echoed challenges and described strategies to increase uptake of PMTCT highlighted in the draft Framework. However, participants articulated additional socio-economic and cultural issues in the discussions, which may hinder uptake of PMTCT if appropriate interventions are not put in place.

1. Are the services that constitute this package currently available in your country? If they are available, are they accessible?

All participants shared their opinion that the essential package of services was available in their respective countries. However, access varied among countries and there was consensus that a significant number of women do not have access to these services for various reasons including affordability, uneven distribution of services (services concentrated in urban areas when

compared to rural settings), socio-cultural factors, absence of a protective legal environment, and supportive policies and economics.

Key issues included: Low levels of awareness on PMTCT including pre-conception care among women and young women, male partners, service providers, programmers, and policy makers were highlighted; gender base violence against women was mentioned as being rampant in many countries with few accessible prevention and impact mitigation programs; socio-cultural and economic barriers including: a woman's right to make decisions about her body, stigma and discrimination, prevailing gender norms, immigration uncertainties, all impact women's ability to access these services.

Based on a reflection on the proposed package of essential services recommended in the draft Framework, the following themes emerged under question one:

Availability and accessibility of the package of services for primary prevention

There was consensus among participants that PMTCT services are important and have *"huge benefits and so we don't experience pain of seeing children living with HIV"* as expressed by a female advocate from Ugandan. Although available, these services are accessible to women already in treatment and other services such as antenatal care another advocate from the UK shares.

An advocate from the UK shared*: "I was very happy with services and thankfully I have a beautiful daughter who tested HIV negative as a result of excellent interventions I received".* Unfortunately, many women are not aware of PMTCT programs and the degree to which they may be able to assert their sexual and reproductive health rights maybe be limited as a consequence. In some countries, documented cases of forced sterilization of women living with HIV have been indicated for example in four provinces of Indonesia, highlighting a gross violation of these women's sexual and reproductive rights. In Ivory Coast, PMTCT services are widely available yet there is a discrepancy between the number of women who test HIV positive and those who access PMTCT services. An advocate from Ivory Coast commented: "*Il y a en outre des déperditions importantes entre les femmes enceintes vues en CPN, testées positives, et celles qui utilisent effectivement les services de PTME. Cela révèle des insuffisances en matière de couverture et de qualité de l'offre des services PTME. Nonobstant l'existence de sites PTME dans 94% des districts sanitaires du pays, le taux de couverture des femmes enceintes recevant des services PTME en 2009 n'est que de 59%" (There is also significant loss between the pregnant women seen in antenatal consultations, tested HIV+, and those who actually use PTMCT services. This reveals weaknesses in the coverage and quality of PMTCT service provision. Despite available PMTCT sites in 94% of health districts in the country, the coverage rate of pregnant women receiving PMTCT services in 2009 is only of 59%).*

Participants strongly argued access to these services among women including those involved in sex work and/or those using drugs was also limited due various reasons including: immigration uncertainties which lead to presenting late for antenatal care; gender inequities resulting in women's inability to have sex on their own terms, poorly distributed youth friendly services; persistence of HIV-related stigma and misinformation on HIV infection and protection; uneven distribution of services with more service points in the urban when compared to rural areas; rural women having limited access to information on PMTCT in many countries, absence of a

protective legal and policy environment in many countries and lack of male friendly PMTCT services.

Testing for HIV

Participants acknowledged HIV testing as an important step in preventing mother to child transmission of HIV especially among young women, *I was infected in my 20's and the fact of being diagnosed HIV positive has deeply impacted on my reproductive choices"* shared an advocate from the UK. She further emphasized women in UK and Europe are highly sexualized and experience gender inequities, which leads to their inability to negotiate for safer sex.

Advocates observed despite many women testing for the first time during antenatal care, a large number women seroconvert after the initial screening making the case that PMTCT programs need re-examining on how often to test a pregnant woman to ensure she has appropriate information, support, and access to treatment.

Several countries stated that sex workers and women using drugs had immense challenges accessing these services due to the absence of a protective legal and policy environment. As well, people living with HIV and especially young women have been denied their sexual and reproductive health rights including access to family planning services. An advocate from Russia comments on barriers for women using drugs: *"стигма и дискриминация женщин, употребляющих наркотиков; неумение с ними работать; низкий процент женщин в программах ЗПТ; гендерное насилие" (stigma and discrimination of women using drugs; inability to work with them; low percentage of women in the programmes for substitution therapy; gender violence).* Another participant from Zambia shared: "*There are documented cases of young people living with HIV being denied of SRH".* Unfortunately, denial of this package of services to women involved in sex work, women drug users, people living with HIV, young people and especially young women can only lead to increased HIV infections among women and children.

Sexually Transmitted Infections (STIs)

Sexually Transmitted Infections screening availability and accessibility varies according to advocates' comments, with some countries having adequate access, others having limited access, and some lacking access altogether. An advocate from Uganda shared that STI screening is 100% available however access among young women is hampered due to fewer youth friendly service delivery points in rural areas when compared to the urban centers. She pointed out: *"couple counseling for STI not easily accessible leading to re-infection among partners".* This situation could be avoided if couple counseling was made more accessible to young women through increasing service points in the rural areas thus reducing transportation costs.

Condoms

Condoms' availability and accessibility varies according to participants' experience. They are available at a cost in some countries (with female condoms costing more than male condoms) putting them out of reach for many women. Despite their availability and accessibility, in some countries for example, Uganda, traditional gender roles were described as barriers both in access to and using condoms. Participants explained that women are often shy when picking the

condoms from a public place. An advocate from Uganda pointed out "*having a condom is one-thing but using it is another. In a male dominated sex game, (at least in my country a man will use a condom if its ok with him but otherwise in most cases it is usually difficult for young women to successfully negotiate condom use".*

In some countries, condoms are available through health centers while in others they are accessed during workshops and outreach programs. An advocate from Nigeria comments there is *"limited access to condoms including female condoms, which are available during workshops and outreaches"*. A participant from the US supported the argument that the cost of condoms in the US puts them out of reach for many women, "*Services (including accessing condoms) are not free so not accessible to women who do not have money".*

Gender based violence prevention and impact mitigation

Advocates advanced a strong argument on gender base violence and the importance of intensifying and scaling-up prevention and impact mitigation programs as a strategy that could significantly contribute to reducing primary prevention among women and by default mother to child transmission. An advocate from Uganda shared: *"Violence is one thing that is so common in my country. Cases are commonly reported in press for men murdering their wives because of disclosing the HIV + results after the testing, women are battered because of introducing the condom after sometime of marriage or in a relationship (of course after suspecting unfaithful husband), the continuous rapes and gang rapes, all these atrocities inflicted to young women who in most cases are economically helpless, fuel the MTCT especially among these young women".*

Another advocate in the UK argued that gender base violence has reached epidemic proportions where *" two women a week on average die as a result of gender-based violence".* She further explained, that unfortunately, these statistics have not informed any policy paper to prevent gender base violence nor to address its contribution in fueling HIV transmission among women. She further stated that, *"women in the UK are the largest group of people living with HIV, yet they have not been prioritized, as a target group with specific prevention needs"*. A participant from Portugal echoed women are not being prioritized in Portugal. She shared; *" prevenção efectuada esquece a mulher, aliás a mulher em Portugal não é prioridade, apesar das infeções terem subido" (The prevention that is carried out ignores women. In fact, women are not a priority in Portugal, in spite of the increased number of infections).*

Based on the comprehensive perspective shared by the participants, following recommendations were extracted from participants' contributions:

Recommendations

1. Increase awareness of sexual and reproductive rights including pre-conception care among women (especially young women) and their partners, service providers, policy makers and community emphasizing that benefits of family planning are key to a rights based approach to primary prevention (as part of PMTCT).
2. Greater efforts are needed to develop, implement and link gender-based violence prevention and mitigation impact programs to HIV prevention interventions. Gender base violence against women has been shown to contribute to HIV transmission and can compromise a woman's access to health, social, and legal services.

3. Design programs that address barriers related to the socio-cultural context and reduce/remove related vulnerabilities. Vulnerability caused by socio-cultural, economic, and education factors have a profound influence in women's access to HIV and SRH services.

The inclusion of pre-conception as a component of sexual and reproductive rights awareness emerged in the online discussion as innovative since it has not been articulated in the draft Framework. The other recommendations are all captured in the draft Framework and the discussions served to reinforce the appropriateness of the package of essential services from the perspective of people living with HIV.

2. In your country (or from your experience), what are the barriers that make it difficult to offer such a package of services?

In relation to the second question, all participants were unanimous that multiple barriers exist to accessing the package of services in the context of PMTCT, majority of which have already been included in the draft Framework.

Despite the call for integrated services, an advocate from the UK mentioned the following specific barriers: *"Lack of comprehensive and integrated services; services that only concentrate on the prevention of mother to child transmission and not focus on the health of the mother and baby afterwards; Judgmental healthcare providers; lack of engagement with services due to fear of stigma; gender based violence"*.

Key barriers highlighted preventing access to this package of services

Real and perceived stigma among people living with HIV, service providers, and the community at large; criminalizing of HIV transmission, sex work and drug use; perception of mandatory HIV testing in the context of PMTCT programs and socio-cultural factors including gender roles and inequity. The emerging themes from the online discussions are described in greater detail below:

Main barriers

Inadequate knowledge of PMTCT among service providers has resulted in providing women with *"mixed and conflicting messages given to mother's e.g. to breastfeed or not"* said an advocate from the UK. Affirming the lack of knowledge among health workers, an advocate from Mexico comments: *En mi pais, especificamente en el estado de Morelos, las barreras mas grandes es la falta de informacion, sobre todo al personal medico, ya que los ginecologas (la mayoria) no tienen idea, de como actuar ante el embarazo de una mujer con VIH. Las que logran ser atendidas en el proceso del embarazo se quejan de que muchas veces les niegan la cesarea" (In my country, particularly in the state of Morelos, the main barrier is the lack of information, especially among health workers; gynaecologists (most of them) don't have any idea of how to act then a VIH-positive woman is pregnant. Those who manage to be treated during pregnancy often complain that they are denied the possibility of having the baby through a Caesarea delivery).* The lack of knowledge among people living with HIV of their sexual and reproductive health rights especially those in the rural areas has led to *" failure by people living with HIV to assert their rights"* observed a participant from Zambia.

Misconception that PMTCT is a domain for the woman. Participants stated that within their communities the woman is blamed in the event a child is HIV infected due to mother-to-child transmission instead of focusing on shared responsibility of both the woman and her partner. An advocate from Zambia argued, *"I as a man view PMTCT as a primary strategy meant for women much more would have to be done to change my perception of PMTCT and my ability to see a positive role for me in the services".* Changing this perception, helping male partners understand their role and how this is beneficial to him and his family will be crucial.

Accountability when testing a woman during pregnancy: Testing a woman during pregnancy, raised a question on accountability to the woman. An advocate from the UK pointed out: "*PMTCT is a program that has a primary focus on the child raising questions on human rights violation for the woman. Studies show trauma during pregnancy impacts the development of the child. Women not positive may avoid ANC services due to fear of testing positive and the resulting stigma by health providers and community policy on testing women during pregnancy though well-intentioned in principle, is actually undermining the MDGs on maternal and child health and not just the MDG on HIV".*

Universal access to ARVs: A participant pointed out that the "*UK does not have Universal access to ARVs and failed asylum seekers, or immigrants without papers are excluded from HIV medical care".* This poses a major barrier to accessing this package of services for this sub-population.

Socio-cultural and economic factors: were highlighted as key barriers to the uptake of this package of services. For instance, gender-based violence against women who test HIV positive by their male partners has been well documented. Many women fear taking an HIV test because a positive result may expose them to violence from their partners. An advocate from the UK stated: *"Gender based violence can result in loss to care and access to the comprehensive package".*

In Western Cameroon, the social cultural practices such as wife inheritance and female genital mutilation, early marriage among under age girls contribute to the high HIV infection among children. "*Nous faisons également face à des pratiques socioculturelles illustrées par les exemples; la pratique du lévirat à l'Ouest du Cameroun qui signifie que lorsqu'un homme meurt, son frère doit prendre la veuve pour épouse et le plus souvent sans faire le test; l'excision de la femme; la jeune fille obligée par ses parents à épouser un homme…"(We also face socio-cultural practices with the following examples: levirate practice in West Cameroon meaning that when a man dies, his brother must take the widow as his wife and most often without even taking a test; female circumcision; the young girl forced to marry a man…)* hared an advocated from Cameroon.

A participant from Uganda made the case that economics also fuel infections among women. She shared when women suggest male partners use condoms (upon suspicion they are being unfaithful) this may lead to violence against the woman. This together with"*… the continuous rapes and gang rapes, all these atrocities inflicted to young women who in most cases are economically helpless, fuel the MTCT especially among these young women"*.

Non-protective legal framework and policy environment: criminalization of HIV transmission, sex work, and substance/drug abuse only serves to undermine HIV prevention efforts and increase stigma and discrimination. An advocate from the US argues: *"laws to criminalize HIV transmission are a barrier because of the legal practices towards prosecuting those who are positive, I am not sure if I would get tested at this point."* This comment points to the importance of establishing a protective legal framework and policy environment to ensure that people are in a position to voluntarily test for HIV. In addition, these laws will protect sex workers and drug users from harassment by law enforcement officers thereby ensuring their access to prevention, care and treatment services without fear of stigma and discrimination.

Recommendations:

1. Establish a protective legal framework and policy environment for people living with HIV, sex workers, and women who use drugs. Polices should be implemented and/or reviewed to ensure they uphold the principle of GIPA and respect the rights of most at risk populations (especially women in sex work and those using drugs) through monitoring and eliminating stigma and discrimination at all levels.

Several of the emerging recommendations were included under question one. All emerging recommendations derived from people living with HIV lived experiences reflected those already articulated in the draft Framework.

3. HIV testing is often offered to women through several settings, such as antenatal care, family planning, and services for sexually transmitted infections (STI). **Where do women access HIV testing in your country? What rights do women have when they test for HIV?**

Advocates from different countries commented on a variety of settings where women can access HIV testing in an attempt to increase testing and by taking service delivery to where the women are. However, some concerns were raised on some specific testing settings and how appropriate they were for testing and disclosing an HIV positive status to a pregnant woman.

Key issues highlighted: women and their partners should be offered an HIV test and should have the option to take the test when they are ready and willing; quality HIV counseling should be linked to good peer support that includes access to accurate information, one-on-one counseling, and group support; in expanding HIV testing venues, careful thought about appropriate location of testing and suitable counseling and its related implications is required (e.g. testing a pregnant woman at the Emergency Room can pose many problems in terms of confidentiality and providing appropriate psychosocial support and follow-up).

Participants cited many of the testing venues already included in the draft Framework. Testing settings mentioned included the ANC, community venues, private practice clinics, accident and emergency centers, government health facilities, NGOs/CBOS, and health fairs organized by NGOs. One of the strategies of reaching more women with testing services is taking these services to women in the community. Unfortunately, establishing new testing settings may also raise important concerns that must be addressed.

Optimizing on emerging and potential testing settings for women

An advocate from the UK expressed concern that pregnant women *"might be tested at the Accident and Emergency section of a hospital at a time when they are facing crisis and stress, and also be notified of their HIV status"*. In attempting to increase access to testing services for women, care should be taken to ensure appropriate location and counseling is available to pregnant women to support them deal with the trauma of a positive diagnosis during this vulnerable period.

An interesting observation made by an advocate from Uganda was that HIV testing is primarily targeted at pregnant women who attend ANC at government health centers and rarely in private clinics. She points out; *"for my last two children when I attended antenatal, for the two pregnancies, it was me to introduce the PMTCT topic to my doctors".*

Many women in Africa also deliver at home with assistance from a traditional birth attendant because of various reasons including poverty, judgmental attitudes of health providers, and cultural practices. This implies they do not have access to HIV testing. An advocate from Nigeria pointed out that*, "40% of women have children in hospitals yet few programs collaborate with traditional birth attendants mission homes and local midwives to provide HIV testing services".* This suggests the need to explore and optimize non-traditional testing settings to ensure pregnant women benefit from PMTCT interventions.

A number of participants expressed their concerns around what appears to be mandatory testing in PMTCT. An advocate from Nigeria points out "mandatory HIV testing for all pregnant women still exist in Nigeria yet it is a fundamental human right not to be tested against your will". Another participant from Nigeria affirms *"pregnant women do not seek HIV testing at the ANC since it is compulsory to test, and most health facilities would refuse or take on a delivery without an HIV test".* This poses a dilemma for pregnant women.

An advocate from the US argued that recently *"the right to test or not to test is losing ground and pregnant women are being mandatorily tested in the US because of PMTCT".*
Compulsory HIV testing (whether real or perceived) for pregnant women has serious implications and far reaching negative effects on mother-to-child transmission of HIV and should therefore be addressed in countries/areas where it is perceived to exist. The draft Framework emphasizes voluntary counseling as a key strategy to scaling PMTCT and is well articulated in the proposed essential package of services for primary prevention.

Recommendations:

1. Women should be offered an HIV test and should be allowed to determine whether they want to take the test, and when to take it. Programs should create awareness on human rights issues, particularly those pertaining to sexual and reproductive rights, gender base violence, the right to informed consent, confidentiality, disclosure, and freedom from coercion (e.g. HIV testing, fertility decisions etc).

2. In expanding testing settings for women, appropriate timing, testing venues and supportive counseling must be assured especially among pregnant women. For example, testing a pregnant woman and disclosing a positive diagnosis may have traumatic consequences both for the woman and her child. Efforts must be made to ensure that no further harm is caused to both the mother and child.

Although the draft Framework states "*women reproductive choices should be respected and safeguarded",* the concept of preconception care was not articulated but strongly recommended by people living with HIV as crucial to scaling-up PMTCT.

4. What would quality counseling look like? For a woman (whether she is pregnant or not AND whether she tests HIV-positive or HIV-negative)? What would quality counseling look like for a couple?

Advocates supported the essential components of quality counseling articulated in the draft Framework. However, participants also shared personal perspectives on a variety of areas that if adopted could have significant impact in supporting women and especially pregnant women deal with the trauma of an HIV positive test.

An advocate from the UK suggested that women should have access to an HIV test long before she and her partner plan to have a family. She states that*: "In my experience, counseling/support for this woman is best provided by other women/peers who have been through a similar experience, in combination with healthcare providers*. *The counseling/support should also involve partners where this is possible, so provide it for both the mothers and their partners where there are no issues of gender violence for instance".* An example of good practice based on this model is for instance the 'From Pregnancy to baby and beyond' project, which is currently being piloted at Positively UK. The model is based on Mentor Mothers'[3] experience with PMTCT to provide tailored support to other pregnant women in their peer group, and understand how to care for themselves while preventing transmission of HIV to their children.

Majority of the participants advocated for peer-to-peer counseling and group support as the most ideal approach to counseling. An advocate from the UK shared her experience when she was newly diagnosed with HIV and how she benefitted from counseling at the health facility. However, in her view, the counseling from peers in one-on-one and group setting was of greater value. She says *" my then doctor told me I had to retire from sex, unless with someone who was also HIV positive, and not get pregnant; going to support groups and meeting other positive women made me realize my doctor was not right, positive women were having sex with non-positive partners and having children, and gave me the strength to challenge my doctor and eventually change to a more enlightened consultant"*

Participants advanced a strong argument for the role of people living with HIV in peer counseling in HIV settings including PMTCT. A question arising in the discussion was the level of training and support peer counselors should receive to provide effective counseling, since training is considered an essential component of quality counseling. Providing counseling to newly diagnosed clients can be stressful and participants commented they had often observed peer counselors struggle because they are under-resourced and lack a supportive environment.

There were divergent views on whether disclosure of HIV status should be done simultaneously or individually in a couple situations. One advocate from Nigeria argued that: *"joint couple counseling and testing should be provided so that they both discover their status together and the burden of going home to tell a violent or ignorant partner is reduced".* Another advocate also

[3] www.positivelyuk.org. Positively UK, Mentor Mother Program

from Nigeria stated that *'test result should first be given individually (counselor can then assist couples to share their test result with each other, after disclosure post test counseling can then take place".*

As suggested by the draft Framework, individual assessment of the couple's situation is the best approach counselors should use in disclosing of HIV results.

Recommendations:

1. Counseling support for women and their partners must provide accurate, non-judgmental information in accessible format and should be complemented with peer one-on-one support and group support. People living with HIV are a valuable resource in services provision, for example providing peer-to-peer support as demonstrated by experiences from many countries at the service delivery level.
2. Appropriate training (including training in cultural competency) and providing a supportive environment with adequate resources are essential components of quality counseling. People living with HIV should be provided with appropriate training and resources to deliver quality peer-to-peer counseling. Additionally, health care providers should be culturally competent, and have the capacity to address stigma and discrimination.
3. Develop strategies to promote male participation in couple counseling especially in the context of PMTCT. Participants' experience suggests couple counseling at the level of ANC may help in disclosure of their HIV status. Men tested in the context of PMTCT are more knowledgeable and have greater investment in averting transmission to their child and vested interest in the welfare of his child may provide motivation to disclose.

All the recommendations distilled from the discussion are captured in the Draft Framework, however, particular emphasis was put on the importance of peer-to-peer counseling by positive women which was highlighted as vital especially in the context of PMTCT.

Week 3 (December 13th -20th) PMTCT Component Two (Prevention of Unintended Pregnancies):

The package of services proposed in the draft Framework for preventing unintended pregnancies among women living with HIV consists of:

- Information and counseling to reduce risk of mother-to-child transmission
- Clinical management of HIV
- Reproductive rights and family planning counseling and services
- STI screening management
- Gender-based violence prevention and impact mitigation
- Confronting stigma and discrimination

This discussion solicited the perspectives of people living with HIV on availability and even more importantly the accessibility of this package of services. The draft Framework emphasizes that "*PMTCT programmes need to respect the fertility desires of women living with HIV, and offer counselling and services in a non-judgmental manner, with the full range of options and accurate information provided".* Experiences shared by participants provided insight on the current situation with respect to unintended pregnancies and what more needs to be done to assure

access to the proposed package of essential services.

According to participants' comments the 'integrated package of services' is not available as proposed. However, in most countries, stand-alone services, which are not linked/integrated, are available. Major barriers in addition to those already mentioned under component one include; inadequate of knowledge on PMTCT among women living with HIV and health care providers, stigma and gender base violence. These two barriers have led to violation of positive women's sexual and reproductive rights, for example, the documented forced sterilization of women living with HIV in four provinces of Indonesia.

There was consensus among the participants that the current PMTCT program has a primary focus on preventing HIV infection to the child with no real benefits for the woman. Participants' felt that 'elimination' of mother-to-child transmission places the blame of HIV transmission on women when it should be a shared responsibility with her partner. While a different term would be preferred, it was felt that elimination of MTCT is feasible albeit a major challenge in developing countries.

Participants again discussed five questions related to the list in the draft Framework and were encouraged to share both their country perspectives and personal experiences.

1. Are the services and programmes for women living with HIV that constitute this package currently available (or in place) in your country? If they are available, are they accessible?

Emerging key issues: the' integrated package of services' is not available but services are available individually in many countries. Where available, accessibility is limited due to major barriers; weak access to clinical management of HIV by women and their partners was highlighted; and women living with HIV are not adequately empowered to demand their sexual and reproductive health rights.

Clinical Management

Weak clinical management of HIV and potentially underlying stigma were highlighted as hindering access to listed services. A female advocate from Kenya shared: *"PMTCT programs are available in most hospitals and clinical settings in the country. But the health care providers / services are slack. My son who is now 15 months was not given the full prophylaxis, i.e. the AZT syrup for six weeks. I had an agonizing wait for his PCR results, which were thankfully negative. When I tried to take it up later, I was informed that the nurses in the ward must have "forgotten" to give me the syrup when I was discharged probably because it was a weekend!"* This lax approach in managing HIV and may be a reflection of the attitudes of some health care providers towards people living with HIV.

Making the case for primary prevention based on her personal experience, a participant from Uganda reports, "*having missed out on the PMTCT services 17 years ago and consequently having a beautiful 17 year old girl growing with HIV (of course because of ARVs), I strongly feel stopping the transition to new born babies is worth an effort bearing in mind the pain the children have for not seeing a life without HIV".* Although ARVs were not available seventeen years ago to prevent mother-to-child transmission of HIV, access to these life saving drugs to manage HIV has made it possible for this participant's daughter to live a near normal life.

A male advocate from Cameroon shared his experience with trying to access needed care, treatment, and support in their quest for a second child; "*my wife and I need a second child but sorry her ill health is a hindrance" (*unfortunately her ill health is a barrier*). "Both families keep asking why we have to wait for this long to have a second child. My wife is just too scared to go for a second child, fearing it will run her system down".* The draft Framework provides a list of services including treatment and counseling that would support a couple living with HIV to have children. However, the Framework does not provide guidance to assisting in the safe conception for couples in which both partners are living with HIV or for sero-discordant couples.

A participant from Indonesia highlighted that access to ARVs including prophylaxis drugs for adults and children was a challenge. Antiretroviral dosages for children are not available in her country necessitating using half the dose for adults. She said: *"PMTCT Prong 3 & 4 only available. Prophylaxis ARVs are not yet available in Indonesia, antiretrovirals for children are provided with half the dose of adults. This becomes a big problem for women living with HIV in Indonesia, current advocacy efforts have been made by Indonesian Women Positive Network (IPPI) but no positive results that can ensure the availability of ARV Prophylaxis".* Consistent drug supply for management of HIV is critical to ensure good PMTCT outcomes.

Reproductive rights and family planning counseling and services

When discussing reproductive choices among positive women, we need to think critically about whether people living with HIV have sufficient information and the necessary tools to inform these choices. A participant from the UK suggested: *"we also need to be clear about why pregnancies are considered unintended and what decisions positive women decide to make once they realize they are pregnant".* She affirms that in the UK women have successfully had HIV free babies due to good clinical management and support of pregnant women living with HIV. In developing countries, women may fear the possibility of transmitting HIV to their child because similar quality of clinical management and support for women living with HIV is not available. Despite this fear, women living with HIV continue to have children. The participant commented; *"There certainly seem to be a lot of reports of women being told they mustn't even have sex, let alone babies - so my question here is "who is deciding that these pregnancies are unintended - and if it is indeed the women, are they having access to fully informed consent? There are of course other important issues here, if that IS the case - namely are they receiving good access to contraceptive services or are these dependent upon them being) married or be having their husband's consent?? And if there is still a pregnancy despite contraceptives, are they being given access to safe, legal totally un-coerced abortions if they want them"?*

In Cameroon, only a few NGOs have begun to address sexual and reproductive health for people living with HIV. A participant from Cameroun commented: *"Au Cameroun jusqu'à nos jour seulement quelques ONG comme CAMNAFAW développent les campagnes sur l'utilisation des service de SSR pour les PVVIH. Ceci reste au niveau des conseils. Les services proprement de procréation assisté n'existe pas. la prise en charge en PTME est possible quand au traitement de bithérapie. l'offre de service ne constitue pas un paquet intégré comprenant prise en charge VIH et santé serxuelle. il faut utiliser 2 services distinctes. ce qui n'est pas un avantage pour le patient" (In Cameroon, to date, only a few NGOs like CAMNAFAW develop campaigns on SRH service use for PLWHAs. And this only at the level of counseling. Actual assisted reproductive services are not available. PMTCT care is available in terms of dual therapy. Service provision*

doesn't constitute a comprehensive package including HIV and sexual health care. One must use 2 separate services, which is not in the interest of the patient).

Lack of services to assist women living with HIV to conceive safely may contribute significantly HIV infections among children.

Recommendations:

1. Provide a *comprehensive* package of services (modified/localized to fit different cultural contexts) linked to other prevention efforts at the community level including; broader sexual and reproductive health education, social services, gender violence prevention and mitigation programs, stigma and discrimination, and economic empowerment as the needs for women living with HIV cannot be addressed in isolation.
2. Sexual and reproductive health education should start at a young age and should for example be included in every school curriculum. The curriculum should have defined criteria that have been demonstrated to have impact on behavior, skills, and knowledge.
3. Strengthen SRH and clinical management of HIV among women and their partners. Research shows optimizing maternal HIV health status can lead to improved maternal and child health outcomes.
4. Access to preconception care including contraceptive, contraceptive counselling, and safe abortion should be among the key services provided to HIV positive women and their partners echoing one of the key message in the draft Framework; " *women's (including women living with HIV) reproductive choices should be safeguarded*".

2. In your country (or from you experience), what are the barriers that make it difficult to offer such a package of services and programmes to women living with HIV?

Main barriers:
A participant from Cameroon shared that confidentially is non-existent and it is not unusual for health care providers to have the attitude that women living with HIV want to receive special treatment. Women treated this way by health personnel will avoid returning for care. He says: *"It is common to hear that why do women living with HIV want to be treated specially? This of course scares them away and they will only come back during delivery".* She also highlighted that women seeking PMTCT without the involvement and support of their partners is a huge barrier since partner involvement is key to providing her with needed support.

An advocate from the UK indicated many of the barriers were similar to those listed in component of this discussion. However, she shared the following additional barriers: "*fragmentation of services resulting in women living with HIV traveling long distances to access the different services needed; lack of a robust national sexual health and HIV strategy to ensure that linkages at policy and program level are in place thus easing service delivery; inadequate localized prison and detention HIV policies; women in this environment live with multiple identities for example; HIV positive, asylum seeker, offender, IDU, and require centralized service; lack of funding for developing integrated HIV and SRH programs; services that are not tailored to hard to reach/hard to engage women such as sex workers; IDU; asylum seekers will further marginalize these groups; weak HIV mainstreaming in other health services; and gender based violence".*

Another advocate from the UK suggested a report entitled "*At Risk: Rights Violations of HIV-*

positive Women in Kenyan Health Facilities"[4] as a useful tool for understanding the different barriers women living with HIV experience globally in the context of PMTCT.

Recommendations:

1. Develop and implement a national strategy linking HIV and SRH that articulates actions at the policy, systems, and service delivery levels to improve coordination of PMTCT at all decentralized levels.

3. What would quality counseling and programmes look like for women living with HIV and their partners for the prevention of unintended pregnancies?

Participants shared components of quality counseling were similar to those provided under PMTCT component one. An advocate from Cameroon stated that in the African context children are not only a source of pride, but they define who we are and as such; *"Counseling should be geared more towards how to bring up their children in a good condition."*

In addition to what was articulated in component one of this e-consultation, an advocate from Jamaica added that the following would be needed to assure quality counseling:
"Couples that are HIV positive would receive counseling together to ensure both understand the shared responsibility to prevent unintended pregnancies and to have a HIV negative child; discordant couples would need added information on available options to protect partner, prevent unintended pregnancies, and protect the child; family planning and counseling would be the norm in HIV Treatment package; provide information on the contraindication and effectiveness of the morning after pill with anti-retrovirals and other medications the woman may be taking".

It should be noted that WHO has provided the state of the art of effective contraceptive methods for women living with HIV, including potential contraindications of using antiretrovirals and certain types of hormonal contraceptives in terms of their effectiveness.[5] However, most contraceptive methods are considered safe and effective for HIV positive women, both with asymptomatic HIV and AIDS.

Participants from the UK emphasized the importance of developing programs that work for both men and women where appropriate. In addition, initiation of comprehensive sexual education should commence at an early age and programs that promote prevention in the context of Positive Health, Dignity and Prevention (PHDP)[6] within communities, should be developed and implemented, to address sexual and reproductive health rights for people living with HIV and discordant couples. Positive Health, Dignity and Prevention focuses on improving and maintaining the dignity of the individual living with HIV, which has a positive impact on that individual's physical, mental, emotional and sexual health, and which, in turn, creates an enabling environment that will reduce the likelihood of new HIV infections.

[4] http://reproductiverights.org/en/document/at-risk-rights-violations-of-hiv-positive-women-in-kenyan-health-facilities
[5] World Health Organisation (2004): Medical Eligibility Criteria for Contraceptive Use. Third Edition, Reproductive Health and Research, WHO, Geneva
[6] http://www.steppingstonesfeedback.org/index.php/About/Stepping_Stones_Plus/en

Recommendations:

1. Develop programs promoting prevention in the context of Positive Health, Dignity and Prevention within communities. The Positive Health, Dignity and Prevention Framework places positive people at the center of the responses that impact their lives. Meaningful involvement of people living with HIV demands consistent investment in the development of their organizations and groups.

4. Considering the current PMTCT approaches in your country, is there an appropriate balance between the rights of the mother and the rights of the child?

Participants reported strong arguments that the current PMTCT programs have a primary focus on the child and not the mother, making the case that more needs to be done to ensure that PMTCT is viewed as a program that also has health benefits for the mother.

A participant from Cameroon shared: *"PMTCT is primarily aimed at breaking the chain of contamination from mother to child; "there is little balance between mother and child as the child has a sharp edge over the mother. PMTCT programmes are tailored in such a way that only the child benefits from what so ever".* This highlights the prevailing perception that in promoting the current PMTCT program the rights of the mother are secondary to those of the child.

According to participants' comments, *"widespread deprivation of the right of women to have a child. Forced sterilization occurs in women living with HIV while giving birth without the informed consent and counseling",* exist said an advocate from Indonesia. Another advocate from Canada shared, *"the current balance in my country does not benefit the woman at all. There is little education and information on PMTCT and the woman is almost coerced to abort or not to have any children at all because it 'encourages' onwards transmission. It's almost like there is awareness but the healthcare professionals want to relieve of themselves the burden of having to look after an HIV positive mother and her child. So the rights are not recognized".* Her sentiments further reinforce the argument that PMTCT is not perceived as a strategy aimed at improving positive women's health. The sexual and reproductive health rights of women living with HIV continue to be violated despite the good intentions of PMTCT programs.

A participant argued that parents are the best caretaker and advocate for the child. To assure the health of the child, it is imperative to assure the health of the parents. To effectively address the current PMTCT perception and rights of the woman versus the child, an advocate from the UK proposed: *"it is crucial that we start making it clear that in order to best preserve the child's rights we need to uphold the woman's rights - that the two are entirely interwoven and that the psycho-social issues affecting a woman are every bit as crucial to her well-being and her ability to look after her child well as her physical health".* If the rights of the woman are respected and she has access to treatment, care and support she requires, then by default, the health of child will be assured.

Recommendations

1. Efforts to change the perception of PMTCT programs, as interventions that balance the rights of the mother and the child are urgently needed. In keeping with the call for sexual and reproductive and human rights of all people including women living with HIV, developing messages that equally articulate benefits to the mother are urgently needed.

5. Countries are discussing the 'elimination' of mother-to-child transmission. What does that mean to you?

Participants shared divergent understanding of 'elimination ' of mother to child transmission. Some raised concerns about this term taken to mean it is "'positive women' who need to be eliminated' in order to achieve elimination of MTCT of HIV, while others understood it as no more HIV transmission from mother to the child.

Key Issues centered on perception, definition and terminology used in PMTCT programs as well as potentially contentious language. An advocate from Cameroon provided the following summary: *"Global PMTCT focus is on the health of the mother solely during pregnancy with the prime intention of prevention vertical transmission. Once, the baby is delivered, the health and health sustainability of the mother is ignored and unaddressed in country level AIDS responses that often make medication available to pregnant women and people who have an AIDS diagnosis"*.

Participants believed that zero transmission from mother to child was possible if there was political commitment and *"in settings where elimination of vertical transmission is a component of comprehensive preconception, pre-natal and post-natal and well child care is not only novel, it is doable"* said a participant from the UK. As well, effective pre-conception care was further described as an approach that is reliant on trained competent clinicians and social service workers on issues of women living with HIV, those engaged in sex work, drug users, at high risk of pregnancy and economically disenfranchised.

On the other hand achieving 'elimination' was felt impossible in the developing world, *"because they can't even provide the simplest measures of preventing transmission like first line medication, education on condom use etc and if they are, it's only the elite and high profiled individuals who can access that and the poor don't. So they shouldn't even be talking about elimination when they haven't started on the minimizing aspect"*, shared an advocate from Cameroon.

To attain the goal of 'elimination' of mother to child transmission, an advocate from the UK re-affirmed the need for robust programs with *"…proactive involvement of stakeholders to secure enabling environment for delivery of and access to maternal and child health services".* It was felt that, access to well-funded treatment and relevant interventions for pregnant mothers should be available and accessible globally. Greater political will and commitment was emphasized as key to achieving this goal.

Understanding of the term 'Elimination' of MTCT of HIV

Majority of participants expressed that the term PMTCT places the burden of responsibility of preventing HIV transmission to the child on the mother. Advocates from the UK argued *"…as long as we continue to refer to it as 'mother to child transmission', there will always be that onus and perceived responsibility/blame etc for transmission solely placed on the mother and we are all aware of what implications that can have on the lives of some HIV positive women".* Alternative terms suggested by an advocate from the UK included for example: *"…'inter-generational transmission' perhaps - or 'transmission to our children'"* and she added*, "perhaps this would be a way of engaging men in the process more effectively".*

An advocate from Cameroon viewed 'elimination as having *"significant ties to denial of SRHR rights for women living with HIV. In some setting elimination is used as a catalyst for forced sterilization, denial of family planning services or absence of pre-conception care".* Trained providers who are culturally competent and familiar with the various categories of women who provide effective preconception care can make a significant contribution to attaining the goal of 'elimination' of mother-to-child and transmission of HIV and achieve the broader Universal Access goal.

Another concern voiced referred to the emotive nature of the term 'elimination'. An advocate from the UK commented: *"I can easily see many who are against the whole idea of us as positive women even having sex, let alone children, thinking that it is "positive women" who need to be eliminated... I think this is a very slippery slope and I am worried about the use of such emotive language in such a highly complex context. We are *not* just talking here about a "simple" vaccine to eliminate smallpox - we are talking about highly complex gender inequities and power imbalances".* She advanced the argument: *"We don't talk about 'elimination' of Malaria, but instead we use the term Roll Back Malaria, which is far more realistic"*. It is in this context that some participants have misinterpreted the term 'elimination' used in "elimination of mother-to-child transmission of HIV".

Recommendations:

1. Revisit the choice of words in '*Prevention of Mother-to-Child Transmission* and agree on a term (s) that more accurately describe(s) HIV transmission to the child without placing sole responsibility or blame on the mother. Recognizing that HIV prevention is a shared responsibility of everyone irrespective of HIV status should be reflected in the terminology used for averting vertical transmission among children.

2. Revisit and carefully consider the choice of terminology in PMTCT programming to ensure definitions are clear, not normative, clouded in ambiguity or value loaded. Use of 'elimination' in mother-to-child transmission should be revisited to clarify its meaning among people living with HIV to avoid a situation where there is a perception that the aim is to eliminate positive women in order to eliminate mother-to-child transmission.

Limitations

Several methodological limitations apply to this e-consultation. They refer to the timing, some technical issues, and self-selection of participation. The results of the e-consultation clearly should not be seen as representative for all people living with HIV, but they provide a deeper understanding for how some of the issues raised in the draft Strategic Framework affect the realities of people living with HIV, and how these realities and perceptions are shaped by cultural and socio-economic factors.

1. Timing: The e-consultation was delayed awaiting necessary partner approval to share the draft Strategic Framework with participants to inform/guide their contribution. Due to the initial delay, the consultation took place during World AIDS (WAD) day week running into the start of the holiday season when many advocates are heavily involved in planning and executing WAD activities and were winding down for the holiday

season. Due to this delay the number of participants may have been lower than what could have been achieved at other moments.

2. Technical issues with regards to registration were identified and quickly resolved. Access to internet may have hindered some participants from developing countries to contribute to the discussion.

3. The nature of PMTCT area of discussion may have been regarded as a topic of discussion for women and this perception may have limited men's participation resulting in the skewed variation by gender participation.

Notwithstanding these limitations, we may draw some important conclusions from the e-consultations' results.

Discussion and conclusion

People living with HIV highlighted important issues some of which corroborated with those articulated in the draft Framework.

Issues mentioned by the participants included: non-prioritization of women (including women in sex work and those using drugs) as a marginalized group in many countries; weak implementation of GIPA and efforts to make SRH accessible to people living with HIV and especially women; inequitable distribution of services with fewer service centers in the rural areas when compared to urban; linkage between HIV and SRH weak; proposed integrated package of services available individually and not as a package and major gender base violence epidemic yet few mitigation programs are in place in majority of countries represented in the e-consultation.

The following is a summary of recommendations arising from the e-consultation and how these integrate with those articulated in the draft Framework.

PMTCT Component One (*Primary Prevention of HIV)*

Perspective and experiences from people living with HIV were for the most part supportive of recommendations in the draft Framework regarding the proposed package of essential services, barriers to accessing these, perception of quality counseling and the various settings women can access HIV testing. However, a few emerging recommendations were highlighted that should additionally be reflected in the final version of the Framework. These were:

- Increase awareness of sexual and reproductive rights including pre-conception care among women (especially young women) and their partners, service providers, policy makers and community emphasizing that benefits of family planning are key to a rights based approach to primary prevention (as part of PMTCT).

- In expanding testing settings for women, appropriate timing, testing venues and supportive counseling must be assured especially among pregnant women. For example, testing a pregnant woman and disclosing an HIV positive diagnosis may have traumatic consequences both for the woman and her child. Efforts must be made to

ensure that no further harm is caused to both the mother and child.

- Appropriate training (including in cultural competency) and supportive environment with adequate resources are essential components of quality counseling. People living with HIV should be provided with appropriate training and resources to deliver quality peer-to-peer counseling. Additionally, health care providers should be culturally competent, and have the capacity to address stigma and discrimination.

- Inclusion of the above people living with HIV perspectives and experiences will contribute significantly to the uptake of PMTCT component one package of essential services among women of childbearing age and their partners.

PMTCT Component Two *(Prevention of unintended pregnancy among women living with HIV)*

Many of the recommendations highlighted under component were similar to those already captured under PMTCT component one and in the draft Framework. Some key recommendations from this discussion included: integrated package of services available to women should be modified/localized to fit cultural context; initiate sexual and reproductive at an early age; develop programs that promote Positive Health, Dignity and Prevention; ensure PMTCT balances the rights of both mother and child and identify appropriate terminology which does not place the blame of HIV transmission on the mother.

Specific recommendations emerging from the discussions that were not included in the Draft Frame work are:

- Efforts to change the perception of PMTCT programs, as interventions that balance the rights of the mother and the child are urgently needed. In keeping with the call for sexual and reproductive and human rights of all people including women living with HIV, developing messages that equally articulate benefits to the mother are urgently needed.

- Revisit the choice of words in '*Prevention of Mother-to-Child Transmission* and agree on a term (s) that accurately describe (s) HIV transmission to the child without placing blame on the mother. Recognizing that HIV prevention is a shared responsibility of everyone irrespective of HIV status should be reflected in the terminology used for averting vertical transmission among children.

- Revisit and carefully consider choice of terminology in PMTCT programming to ensure definitions are clear, not normative, clouded in ambiguity or value loaded. Use of 'elimination' in mother-to-child transmission should be revisited to clarify its meaning among people living with HIV to avoid a situation where there is a perception that the aim is to eliminate positive women in order to eliminate mother-to-child transmission.

- The draft Framework also recommends Provider Initiated Testing as a key although from participants' comments it is not provided in many countries represented in the e-consultation. Testing among women mainly occurs at the ANC, when they present with opportunistic infections or a sick child or partner at the hospital.

Overall Recommendations

PMTCT Component one *(Primary prevention)*

1. Increase awareness of sexual and reproductive rights including pre-conception care among women (especially young women) and their partners, service providers, policy makers and community emphasizing that benefits of family planning are key to a rights based approach to primary prevention (as part of PMTCT).

2. Greater efforts are needed to develop, implement and link gender-based violence prevention and mitigation impact programs to HIV prevention interventions. Gender base violence against women has been shown to contribute to HIV transmission and can compromise a woman's access to health, social, and legal services.

3. Design programs that address barriers related to the socio-cultural context and reduce/remove related vulnerabilities. Vulnerability caused by socio-cultural, economic, and education factors have a profound influence in women's access to HIV and SRH services.

4. Establish a protective legal framework and policy environment for people living with HIV, sex workers, and women who use drugs. Polices should implemented and/or reviewed to ensure they uphold the principle of GIPA and respect the rights of most at risk populations (especially women in sex work and those using drugs) through monitoring and eliminating stigma and discrimination at all levels.

5. Women should be offered an HIV test and should be allowed to determine whether they want to take the test, and when to take it. Programs should create awareness on human rights issues, particularly those pertaining to sexual and reproductive rights, gender base violence, the right to informed consent, confidentiality, disclosure, and freedom from coercion (e.g. HIV testing, fertility decisions etc).

6. In expanding testing settings for women, appropriate timing, testing venues and supportive counseling must be assured especially among pregnant women. For example, testing a pregnant woman and disclosing a positive diagnosis may have traumatic consequences both to the woman and the child. Efforts must be made to ensure that no further harm is caused to both the mother and child.

7. Counseling support for women and their partners must provide accurate, non-judgmental information in accessible format and should be complemented with peer one-on-one support and group support. People living with HIV are a valuable resource in services provision, for example providing peer-to-peer support as demonstrated by experiences from many countries at the service delivery level.

8. Appropriate training (including training in cultural competency) and supportive environment with adequate resources are essential components of quality counseling. People living with HIV should be provided with appropriate training and resources to deliver quality peer-to-peer counseling. Additionally, health care providers should be culturally competent, and have the capacity to address stigma and discrimination.

9. Develop strategies to promote male participation in couple counseling especially in the context of PMTCT. Advocates' experience suggests couple counseling at the level of ANC may help in disclosure of their HIV status. Men tested in the context of PMTCT are more knowledgeable and have greater investment in averting transmission to their child and vested interest in the welfare of his child may provide motivation to disclose.

PMTCT component two *(Prevention of Unintended Pregnancies)*

1. Provide a *comprehensive* package of services modified/localized to fit different cultural contexts linked to other prevention efforts at the community level including; broader sexual and reproductive health education, social services, programs gender violence prevention and mitigation, stigma and discrimination, and economic empowerment as the needs for women living with HIV cannot be addressed in isolation.

2. Sexual and reproductive health education should start at a young age and should for example be included in every school curriculum. The curriculum should have defined criteria that have been demonstrated to have impact on behavior, skills, and knowledge.

3. Strengthen SRH and clinical management of HIV among women and their partners. Research shows optimizing maternal HIV health status can lead to improved maternal and child health outcomes.

4. Access to preconception care including contraceptive, contraceptive counselling, and safe abortion should be among the key services provided to HIV positive women and their partners echoing one of the key message in the draft Framework; " *women's (including women living with HIV) reproductive choices should be safeguarded*".

5. Develop and implement a national strategy linking HIV and SRH that articulates actions at the policy, systems, and service delivery levels to improve coordination of PMTCT at all decentralized levels.

6. Develop programs promoting prevention in the context of Positive Health, Dignity and Prevention within communities. The Positive Health, Dignity, and Prevention framework places HIV-positive people at the center of the responses that impact their lives. Meaningful involvement of people living with HIV demands consistent investment in the development of their organizations and groups.

7. Efforts to change the perception of PMTCT programs, as interventions that balance the rights of the mother and the child are urgently needed. In keeping with the call for sexual and reproductive and human rights of all people including women living with HIV, developing messages that equally articulate benefits to the mother are urgently needed.

8. Revisit the choice of words in '*Prevention of Mother-to-Child Transmission* and agree on a term (s) that accurately describe (s) HIV transmission to the child without placing blame on the mother. Recognizing that HIV prevention is a shared responsibility of everyone irrespective of HIV status should be reflected in the terminology used for averting vertical transmission among children.

9. Revisit and carefully consider choice of terminology in PMTCT programming to ensure definitions are clear, not normative, clouded in ambiguity or value loaded. Use of 'elimination' in mother-to-child transmission should be revisited to clarify its meaning among people living with HIV to avoid a situation where there is a perception that the aim is to eliminate positive women in order to eliminate mother-to-child transmission.

10. The draft Framework also recommends Provider Initiated Testing as a key action although from participants' comments it is not provided in many countries represented in the e-consultation. Testing among women mainly occurs at the ANC, when they present with opportunistic infections or a sick child or partner at the hospital.

Next Steps

The findings of the e-consultation will be merged with the results of the e-survey, the focus groups discussions, and the expert teleconference call, reflecting a mixed method approach to consulting a variety of stakeholders.

The recommendations emerging from the consultation processes will be shared with IATT on Prevention of HIV Infection in Pregnant women, Mothers and their Children to ensure the perspectives and personal experiences of people living with HIV are accurately reflected in the final Strategic Framework on the first two components of PMTCT *(i) Primary Prevention of HIV and (ii) Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT: Strategic Framework 2010-201*5. In addition, the consultation reports will be made available on GNP+ and ICW Global websites to inform broader advocacy efforts on PMTCT.