

UNDERSTANDING THE PERSPECTIVES AND/OR EXPERIENCES OF WOMEN LIVING WITH HIV REGARDING OPTION B+ IN UGANDA & MALAWI

IN SUPPORT OF THE FORTHCOMING WHO CONSOLIDATED ARV GUIDELINES



7 February 2013

ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ANC	Antenatal Clinic
ART	Antiretroviral Therapy
ARV	Antiretrovirals
COWLHA	Coalition of Women Living with HIV/AIDS (in Malawi)
FGD	Focus Group Discussion
GCWA	Global Coalition on Women and AIDS (in Uganda)
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
ICW	International Community of Women Living with HIV/AIDS
ICWEA	International Community of Women Living with HIV/AIDS East Africa
MANET+	Malawi Network of People Living with HIV/AIDS
MASYAP	Mai Aisha Sisters and Youth AIDS Programme (in Malawi)
NAFOPHANU	National Forum of People Living with HIV/AIDS Network in Uganda
NAPHAM	National Association of People Living with HIV and AIDS in Malawi
PLHIV	People living with HIV
PVT	Prevention of Vertical Transmission
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health & Rights
UYP	Uganda Young Positives
WHO	World Health Organization

ACKNOWLEDGMENTS & DEDICATION

This report was produced by Rebekah Webb Consulting in partnership with ICW and GNP+. The consultants were Rebekah Webb and Marta Monteso Cullel.

This report was coordinated by Amy Hsieh, with support from Adam Garner, Georgina Caswell and Sonia Haerizadeh.

We would like to thank those who participated in the focus group discussions for their contribution to this study. Our sincere gratitude humbly goes out to ICWEA in Uganda and COWLHA in Malawi and for their partnership and role in recruiting participants for the focus groups.

We would also like to express our sincere appreciation to Sonia Haerizadeh and Moono Nyambe for facilitating the focus group discussions and their contribution to the editing of this report.

All Project Partners are immensely grateful to the World Health Organization, which made this study possible.

Some participants in this study reported having lost children due to HIV infection acquired vertically. This report is dedicated to the memory of those children and many others for whom advancements in preventing vertical transmission came too late.

Contents

ACRONYMS	2
ACKNOWLEDGMENTS & DEDICATION	3
EXECUTIVE SUMMARY	4
BACKGROUND & INTRODUCTION	7
FOCUS GROUP METHODOLOGY	9
Sampling and Selection of Participants.....	9
Development of Focus Group Questions.....	10
Venue	10
Participant Incentive/Reimbursement.....	10
The Consenting Process	10
DATA COLLECTION AND ANALYSIS.....	10
Languages Used for Data Collection	10
Audio Recording and Transcribing.....	11
Facilitation & Duration	11
Data Analysis	11
RESULTS	12
Uganda: Perceptions and Experiences of PLHIV regarding Forthcoming Option B+ Implementation	12

Malawi: Perceptions and Experiences of PLHIV regarding Option B+ Implementation.....	19
DISCUSSION AND CONCLUSION.....	25
Community Perspectives and Experiences In Favour of Option B+.....	25
Community Perspectives and Experiences against Option B+	26
Areas of Ambiguity.....	27
Areas Warranting Further Research	28
Contextual Constraints on the implementation of Option B+.....	28
RECOMMENDATIONS	30
ANNEX A – PARTICIPANT DEMOGRAPHICS.....	32
ANNEX B – FGD GUIDES	36
ANNEX C – OPTION B+ PRESENTATION	43
ANNEX D – FOCUS GROUP DISCUSSION CONSENT FORM.....	44
ANNEX E - DEMOGRAPHICS QUESTIONNAIRE	47
ANNEX F - CHART ATTACHED TO ACCESS ALL DATA.....	Error! Bookmark not defined.

EXECUTIVE SUMMARY

To inform the development of the forthcoming World Health Organization (WHO) Consolidated ARV Guidelines, focus group discussions (FGDs) were held during November 2012 in Uganda and Malawi with women and their partners who are living with or affected by HIV in relation to Option B+ (lifelong ART to all pregnant women living with HIV), an emerging programme option to prevent vertical transmission (PVT), which is under consideration for recommendation in the 2013 WHO ART Consolidated Guidelines. The discussions were part of a consultative process between WHO and communities of people living with HIV (PLHIV) to understand the experiences and needs of PLHIV with regard to their treatment programmes, including PVT programmes, with specific focus on the perceptions and acceptability of B+ in two countries – Malawi (Option B+ proposed and implemented) and Uganda (Option B+ recently endorsed by national programme). This report presents the key experiences and concerns, as well as recommendations that emerged.

In Uganda, the objective of the FGDs was to understand the perspectives of individuals living with or affected by HIV regarding Option B+ as the country prepares to move towards this programming approach. FGDs were held with: (1) young women living with HIV, (2) women living with HIV from rural communities, (3) women living with HIV in leadership roles, and (4) men living with HIV.

Generally, women living with HIV in Uganda had a varied understanding of what Option B+ entailed. However, most understood that the regimen offers treatment to pregnant women living with HIV regardless of their CD4 count. Option B+ is being presented to women and their partners who are living with HIV as a programme primarily to protect the baby, with secondary benefits for the mother living with HIV, which caused concern among some participants. Ugandan participants perceived the following key benefits in relation to Option B+: (a) the possibility to breastfeed for longer periods and the associated improved health of the child, (b) feeling healthier because they are on treatment, and (c) the reduction of stigma towards mother and child. However, Ugandan

participants perceived the following key concerns: (a) ARV stock outs and health system readiness, (b) long term effects of being put on lifelong treatment regardless of CD4 count, and (c) potential conflicts with partners and resultant domestic violence, especially related to treatment access inequity.

In Malawi, the study sought to explore the perspectives and experiences of PLHIV regarding the implementation of Option B+. FGDs were held with: (1) Muslim women living with HIV from Blantyre, Malawi, (2) women living with HIV from rural communities in Machinga, Malawi, (3) women living with HIV from the capital city of Lilongwe, and (4) women living with HIV from Dowa and professionals from Lilongwe.

Although there was general awareness of a new PVT regimen in Malawi, again, there were varied levels of understanding across the different FGDs about what it entailed and the reason for its use over other PVT options. Only professional women knew this was called Option B+. Similar to Uganda, Malawian women in FGDs stated that Option B+ is being presented as primarily for the child's health, with concurrent benefits for mothers living with HIV. Despite being called an "option," Option B+ is being offered as the only available method in Malawi to prevent vertical transmission. Pregnant women were generally expected to start treatment as soon as they tested HIV positive, either the same day or within a week, but often did not receive enough information to understand the choice involved. Women reported little or no support to make decisions about their treatment.

The majority of women in Malawi spoke positively about Option B+, though some urban women expressed more concerns. Malawi participants perceived the following key benefits in relation to Option B+: (a) being able to breastfeed for longer periods and associated improved health of the child, (b) improved health of the mother, and (c) the reduction of stigma towards mother and child. However, Malawi participants perceived the following key concerns: (a) conflict with partners, sometimes related to treatment access inequity, (b) risk of future ARV stock outs if donors pull out, and (c) side effects associated with ARVs. Community members perceived the ability to access a particular type of treatment with fewer side effects through Option B+ (i.e. 5A - tenofovir / lamivudine / efavirenz) as a potential incentive for pregnancy.

For the most part, participants from both countries were pleased that Option B+ protects babies born to mothers living with HIV from vertical transmission and that it provides women with lifelong treatment. However, there was a notable lack of consensus regarding the extent to which Option B+ will have a positive or negative impact on the closely interwoven dynamics of disclosure, testing, stigma/discrimination, conflict, and violence. Additionally, participants in both countries noted that stigma from health care providers continues to prevent some women, notably younger women and Muslim women from accessing Option B+ (and antenatal care in general), even if they wanted it. Finally, confusion and misinformation about breastfeeding for women living with HIV, including whether to breastfeed at all, whether to breastfeed exclusively, and how long to breastfeed, continue to undermine PVT efforts.

Despite the different stages of Option B+ implementation in Uganda (being planned) and Malawi (more than 1 year of full implementation), all FGD participants reported that they were not meaningfully involved in their country's decision-making process to adopt Option B+. Consequently, women living with HIV and their communities have had very limited involvement in Option B+ implementation. Participants were supportive of advocacy led by women living with HIV to ensure that under Option B+, governments and funders understand and provide for the needs of pregnant women living with HIV, in addition to ARVs, while also ensuring their right to informed consent prior to beginning treatment.

Participants offered recommendations to improve Option B+ implementation. Chief among these is the need for clear information about what Option B+ entails, including counselling around treatment initiation, the risks/benefits of beginning treatment for life, and guidance around the best breastfeeding options for each individual situation. Women who commence lifelong treatment through Option B+ should have access to follow up support and thorough medical checkups from health centres or community health workers, as well as ongoing lab and toxicity monitoring. Finally, male involvement and sensitisation should be encouraged at all stages, including through couples testing and counselling programs, but should never be made a requirement for women to access care.

To increase women's ability to make informed and empowered decisions about their own health, including whether or not to commence lifelong treatment, the following areas stemming from the FGDs warrant further research: (1) Health risks/benefits for women resulting from starting lifelong treatment with high CD4 counts, especially for younger women; (2) Health implications for women stopping and starting treatment with each pregnancy as per Option A and B (on high CD4 counts), especially for younger women; and (3) Implications for child nutrition and mortality of allowing women to breastfeed for longer than six months.

Ultimately, the forthcoming WHO ARV Guidelines should be based on the best, current scientific knowledge. Information from this study supported the view that regardless of treatment eligibility criteria, the ARV Guidelines should recommend that treatment is initiated when individuals are ready and choose to start. Additionally, women living with HIV should be always given accurate information about treatment options, side effects, drug resistance and co-infections. Finally, all PLHIV, especially women who start lifelong treatment during pregnancy, should have access to regular CD4 counts and periodic viral load tests. The role for resistance testing needs to be further consideration and discussion.

OVERVIEW OF BENEFITS/CONCERNS

Individual	
<p>Benefits:</p> <ul style="list-style-type: none"> • Easier access to ART because it would be irrespective of CD4 count • Option to breastfeed longer (reduction in infant mortality, lower household expenditure) • Improved health and wellbeing of mother • Reduction in stigma towards mother and child (breastfeeding, healthier appearance, child is negative) • Possibility to have more children • Decreased fear of resistance from stopping and starting each time) • Encourages disclosure, behaviour change, testing and ARV uptake • Enables natural childbirth 	<p>Concerns:</p> <ul style="list-style-type: none"> • Initiation of treatment with high CD4 counts (related side effects and adherence problems) especially when young • Option B+ is mandatory to ensure child is HIV negative (risk of coercion) • May discourage disclosure by pregnant women • Lack of information, support and counselling • Women may seek pregnancy as a means to access ARVs • Adherence concerns related to side effects or the fact that ARVs are not for personal health • Resistance concerns due to a potential need for 2nd or 3rd line sooner

Child	
<p>Benefits:</p> <ul style="list-style-type: none"> • Babies are born HIV negative • Reduction in stigma towards mother and child (breastfeeding, healthier appearance, child is negative) 	<p>Concerns:</p>

Partner	
<p>Benefits:</p> <ul style="list-style-type: none"> • Partners are protected (TasP) 	<p>Concerns:</p> <ul style="list-style-type: none"> • Conflict with male partners (disclosure, equity), male involvement as a requirement possibility of increased domestic violence • May discourage condom use by male partners • Lack of access to treatment by men may disincentivize their involvement

Programmatic/Health System

Benefits:

Concerns:

- ARV stock outs & weak health systems (particularly in Uganda)
- WLHIV and communities are not being consulted
- Potential inequity if pregnant women are accessing ARVs before other eligible PLHIV

BACKGROUND & INTRODUCTION

As part of the forthcoming 2013 WHO Consolidated ARV Guidelines, WHO will be developing recommendations regarding treatment options for pregnant women living with HIV, including Option B+, lifelong ART to all pregnant women living with HIV, which was first proposed and is now being implemented in Malawi. Given the relative novelty of Option B+ as a treatment as prevention program, it is important to widely explore the risks and benefits of the intervention, as well as feasibility and costs, particularly for women living with HIV who are the end users of the program. This includes the perspectives and experiences of women and their partners who are living with or affected by HIV in places where the intervention will be or has been implemented (i.e. Uganda and Malawi, respectively).

Through focus group discussions (FGDs), the Project Partners, led by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), aimed to assess how Option B+ is understood and accepted by the population that will receive the program, and to ensure that their perceptions, values, and preferences are considered during the guidelines development process.

In Uganda, the Project Partners' objectives were to:

- Identify and understand the perspectives of women living with HIV regarding the Option B+ treatment regimen
- Understand the perceptions of women living with HIV and their communities regarding the forthcoming implementation of Option B+
- Explore issues around starting lifelong treatment during pregnancy for women living with HIV in Uganda, including acceptability, and suggestions on strengthening/improving the programme from a civil society perspective

In Malawi, the Project Partners' objectives were to:

- Understand the perspectives and experiences of women living with HIV regarding the Option B+ treatment regimen
- Understand the possible concerns of women living with HIV and their communities regarding the current implementation of Option B+
- Explore benefits and concerns around starting lifelong treatment during pregnancy for women living with HIV in Malawi, including acceptability, and suggestions on strengthening/improving the programme from a civil society perspective

FOCUS GROUP METHODOLOGY

The Project Partners chose to collect information through the use of focus group discussions (FGDs), which offer a range of material and a perspective on group dynamics that cannot be captured in a survey. FGDs are an opportunity to clarify shared understanding or perceptions held by the group. FGDs can also create ownership and engagement among participants because they are given an opportunity to express their views and be heard by others. However, because of the smaller sample size, the FGDs are limited in their ability to produce results that can be generalised to the larger population.

Sampling and Selection of Participants

In planning the focus group discussions, the Project Partners employed a *Judgment Sampling* method, where the sample was chosen with the purpose of representing specific inclusion criteria:

- Young women living with HIV (aged 18-30)
- Women living with HIV from rural communities
- Women living with HIV in leadership roles

The Project Partners identified local networks of people living with HIV (PLHIV) in Uganda and Malawi to assist with participant recruitment. It was originally expected that the groups would consist of 15-20 individuals. However, after further discussion with external consultants, the Project Partners decided to decrease the size of the focus groups to 10-15 individuals.

In Uganda, ICW East Africa (ICWEA) identified five local networks and support groups to participate. ICWEA, the National Forum of People Living with HIV and AIDS Network in Uganda (NAFOPHANU), the Global Coalition on Women and AIDS (GCWA), Uganda Young Positives (UYP) and Mama's Club each recruited 2-3 representatives for each of the focus groups based on the inclusion criteria outlined above. These networks and support groups also proposed to conduct a focus group of men living with HIV in Uganda. This resulted in four FGDs of the following groups:

- Young women living with HIV (aged 18-30)
- Women living with HIV from rural communities
- Women living with HIV in leadership roles
- Men living with HIV

In Malawi, the Coalition of Women Living with HIV/AIDS (COWLHA) and ICW Malawi identified three additional local networks and support groups to help identify participants. COWLHA, ICW Malawi, the National Association for People Living with HIV and AIDS in Malawi (NAPHAM), the Malawi Network of People Living with HIV/AIDS (MANET+), and the Mai Aisha Sisters and Youth AIDS Programme (MASYAP) recruited participants in their respective districts according to the inclusion criteria. This resulted in four FGDs of the following groups:

- Women living with HIV of Muslim faith
- Women living with HIV from rural communities
- Women and men living with HIV from urban communities
- Mixed group of people living with HIV, including women from rural communities and professionals from urban communities

A total of 45 people from Uganda and 43 people from Malawi participated in the eight focus groups (See Annex A).

Development of Focus Group Questions

The Project Partners collaborated to develop three sets of questions to explore the perspectives and experiences of women and their partners living with or affected by HIV regarding Option B+: (1) WLHIV in Uganda, (2) male partners of WLHIV in Uganda, and (3) WLHIV in Malawi. All three data collection tools were developed in English. A short presentation explaining the difference between Options A, B, and B+ was also developed to use during the FGDs.

ICWEA, COWLHA, and ICW Malawi provided useful suggestions for improving both the presentation and the focus group questions. The questions were also shared with representatives from WHO and UNAIDS for review. Their comments helped to shape the final set of questions and the presentation (Annex B and C).

Venue

In Uganda, ICWEA organized the FGDs at Eureka Place hotel in Kampala. In Malawi, COWLHA and ICW Malawi organized the discussions to be held at Budget Lodge in Lilongwe.

Participant Incentive/Reimbursement

Transportation reimbursement was provided to all participants and light refreshments were served during each FGD. In Malawi, women from rural communities were provided with accommodation for the night, as some had to travel from over five hours away.

The Consenting Process

A consent form was developed by the Project Partners and was distributed to each participant in the eight FGDs (See Annex D). The facilitator read through the consent form with participants in English in Uganda and in Chichewa in Malawi. All participants were told that their participation was voluntary and that they could leave at anytime. The facilitator explained the objectives of the FGDs, the commitment requested of participants, and how the information would be used. The participants were given the contact information of the local facilitators and information about how to access the final report. They were told that the FGDs would be recorded and transcribed verbatim but that the information would remain anonymous (i.e. not be attributed to a specific participant by name). An opportunity was presented for questions. Each participant was then asked to sign and date the form if they wanted to participate. Copies of the signed consent forms were made available for participants to take home when possible.

DATA COLLECTION AND ANALYSIS

Demographic information for all participants was collected using an anonymous demographics form (Annex E).

Languages Used for Data Collection

The participants' preferred languages were used in the FGDs.

In Uganda, the focus groups took place largely in English, as every participant felt comfortable speaking English. Occasionally, participants felt more comfortable expressing themselves in Luganda, and in these rare cases, representatives from ICWEA immediately translated the comment word for word to be transcribed.

In Malawi, the FGDs were conducted in Chichewa with simultaneous English translation by representatives from COWLHA and ICW Malawi.

Audio Recording and Transcribing

All the FGDs were recorded on digital recorders. The FGDs conducted in English were subsequently transcribed verbatim. For the Malawi FGDs, the responses offered in Chichewa were immediately translated into English by COWLHA and ICW Malawi staff and were immediately transcribed verbatim.

Facilitation & Duration

The eight FGDs, four in each country, were scheduled for 3-hour periods over four business days (8-13 November 2012). Each group was facilitated by a representative from GNP+, ICW and a project partner (ICW EA, COWLHA, and ICW Malawi) at the country level.

A representative from GNP+ (a woman openly living with HIV with extensive experience of conducting FGDs) led the FGDs in English and Chichewa. A representative from ICW took notes and transcribed the participants' responses. Representatives from ICW EA, COWLHA, and ICW Malawi introduced the Project Partners, and provided logistical support, clarity, and information where needed.

Data Analysis

Standard qualitative thematic analysis was applied to the FGD transcripts. The data analysis methodology consisted of the following steps:

1. Identification of the big ideas (later developed into themes);
2. Unitization of the data (identifying those units of information -including quotes- that later become the basis for defining categories);
3. Categorization of units (units have been sorted into relevant piles to represent categories or themes)
4. Organisation of categories into main themes.

The units emerging from each of the eight FGD transcripts were classified into over fifty categories. The categories have been organized into nine themes that have been presented in the format of questions. (See Annex F - Chart attached to access all data).

Each FGD analysis includes a section of main findings, linked to each theme, which synthesizes the information related to those categories that have more units, or contain information that shows consensus amongst the group interviewees or statements where interviewees have put particular emphasis.

All data (units and quotes, categories, main findings and themes) were synthesized first for each focus group separately and then collated by country as main findings.

RESULTS

Uganda: Perceptions and Experiences of PLHIV regarding Forthcoming Option B+ Implementation

As a country that has committed to move towards Option B+, consultations in Uganda focused on the key perceptions or concerns that women living with HIV and their communities have regarding impending implementation.

In Uganda, the four FGs consisted of participants who were grouped by the following criteria:

1. Young women living with HIV (ages 17-28) (n=11)
2. Women living with HIV from rural communities (n=12)
 - a. Includes representatives from Wakiso, Mukono, Mpigi, and Kampala districts
3. Women leaders living with HIV (n=12)
 - a. Includes network leaders, health care workers, civil society representatives, government employees, and university professors
4. Men living with HIV (most were partners of women living with HIV) (n=10)

What have women living with HIV and their communities heard or been told about Option B+?

The level of understanding about Option B+ varied across FGDs but was generally limited. Only a few women and some men who attended the Option B+ launch knew it was called 'Option B+'. Women from urban areas in Uganda had different interpretations of what it consisted of. Some professional women confused Option B+ with treatment as prevention more broadly. Women living in rural areas and young women showed some level of understanding of Option B+ but still lacked clear information and often confused it with other PVT methods.

FG3#1: I am just getting more and more confused. My first question is, what does the B stand for?

FG4#5: And another thing is that Option B+ could be good but we still lack information not only among rural women but also in the urban city. Very few people can explain what Option B+ is.

Amongst those that had heard something about Option B+, the main elements they identified about the program are: a) pregnant women who test positive for HIV are put on treatment for life at their first antenatal clinic (ANC) visit b) women can breastfeed longer; c) women are put on treatment even if their CD4 counts are high. One woman understood she was already on B+.

FG1#4: So putting you on ARVs regardless of your CD4 count, to me that is what I understand to be Option B+.

Other women reported that Option B+ is not yet implemented in Uganda and that health workers at community level are not aware of it. Professional women were aware that it will be phased in gradually.

FG3#10: So far from Uganda and from the community where I serve, this option B+ has not yet started and what I know from it is that some health service providers are not aware of option B+. They have no information.

How is Option B+ being presented?

From the groups' experiences, it seems that the emphasis in the messaging of Option B+ is on the health of the child and secondarily on the health of the mother. Participants also reported being told that it will also help reduce transmission to sero-discordant male partners. It appears that, in the majority of cases, Option B+ is presented as if it will be the only option available for pregnant women living with HIV in the future in order to prevent vertical transmission. There was a general

feeling amongst participants in Uganda that B+ was better at preventing the actual transmission of HIV (than the other options).

FG2#8: They are aiming at the new born baby, but with the chance that it comes in that it can protect older women. But the main issue to protect the newborn.

FG2#7: B+ promotes zero infections [as compared to other methods].

FG1#2: Actually, people were happy about that Option B+. Mostly women...because they knew it would save their babies from acquiring the virus. Even men who were around were also happy.

Young women expressed some discomfort with the idea that their health was given less priority. They reported that doctors are already expressly 'leaving them out' and targeting only the child.

FG1#4: Emphasis was put on the baby. Because when I started the ARVs I wasn't weaning they told me that it's good for your baby. For me, I was left out.

FG1#3: Option B+ I started a long time ago because the doctors say "Listen we are not giving you these ARVs to save you, we are saving the baby, we don't mind about your CD4 count."

What kind of support do women living with HIV have to make decisions about treatment?

The support being received varied between the groups. Rural women living with HIV seem to be receiving poor and confusing counselling; many have experienced situations where the doctors encourage them to deliver by C-section and not to breastfeed. Women expressed that they have been told for a long time not to breastfeed and to deliver by C-section, and now they are told the opposite. Breastfeeding guidance (exclusive or not, for how long, etc.) seems to be the key issue.

FG2#9: And this Option B – me I welcome,...because, at first they were not breast feeding at all – when they told them to breast feed for the first 6 months – at least it saved some women, because at first, people were misinterpreting the information.

Women in leadership roles confirmed that there is inadequate counselling or proper information being given to women at the moment (FG3#7). Young women also requested better counselling and psychological support (FG1#11).

FG1#6: It's a good thing - like all of us fear having positive babies, but they never told us that if you get pregnant they put you on the drugs immediately. We thought there were other options like they tell you what to do to your baby when you're giving birth.

FG3#7: There is no counselling and discussion about B+

The main recommendations given by all the different groups regarding this were the need for good information, at an earlier stage, and more counselling, especially for those that start on ARVs for the first time.

FG3#8: Before I start on B+, I should be informed of all options and all of the advantages of all of the options so that I make informed decisions based on the benefits that are there.

Are women living with HIV part of the decision-making process to switch to Option B+ or helping to plan the implementation?

All focus groups in Uganda reported a lack of participation of women living with HIV and grassroots communities in the decision-making around the country's adoption of Option B+ and a consequent lack of involvement in the implementation. Only one woman (a professional) reported being aware of a stakeholder meeting convened by the government in the lead up to the decision to adopt Option B+.

FG3-7: No women living with HIV of childbearing age were consult[ed]. They sit at the top and they think [they] speak for us and we just sit and they tell you something you have never heard of this. Beneficiaries, we are not aware of what is taking place. ...It was launched by people who are not even going to [re]produce. For us who are here, we were left out. I'm 18 years, you are telling me drugs for life?

Participants claimed that information sharing and trainings on Option B+ are happening only at higher levels (at offices, expensive workshops) and are not reaching health workers, community

services or women at the grassroots. There is a shared request to involve young women living with HIV and train them.

FG1#5: Involve young WLHIV because we can make forums or workshops. Train women who have not yet given birth on how this can work for them because a lot of them don't know that this is true, that they can get children who are not positive. If we involve them in such trainings, forums, workshops, especially in their clinics or train their counsellors so that by the time they get pregnant they know what to expect.

FG4#9 (Man living with HIV, partner of WLHIV): People think it's just the women's thing, it's the women who are coming up, who are coming up to advocate for it. So, for me, I think we need to involve the grassroots level like the local councils, faith based leaders, the village health team because they are the ones that visit these pregnant women. We need to involve the community arm to see that at least they are the ones that follow up and make sure they are getting the services that they need.

What are the perceived benefits of Option B+?

The top three benefits identified by all women in relation to Option B+ were: a) the possibility to breastfeed for longer and associated improved health of the child; b) feeling healthier because they are on treatment; c) reduction of stigma towards the mother and child. All of these were interlinked.

a) Being able to breastfeed longer and associated improved health of the child

Women in all groups expressed that an important benefit will be fewer babies dying of malnutrition as a result of the possibility to breastfeed the child safely and for a longer period of time.

FG2#10: B+ is good – because most of babies have been dying of malnutrition, but if HIV positive mothers are encouraged to breastfeeding, I think it will minimize the dying of babies because of malnutrition. Because mothers have [not been] breastfeeding their babies - hoping that they will be able to buy milk for their babies, but they end up not feeding them well – giving them diluted milk. But if they are allowed to breast feed, I think it will save our babies.

FG3#2: For me, as an educated and well-informed woman, at that level, it [formula] was very expensive for me. And I feel there is that level where we have changed with Option B+. For me, when I say that probably it is a better move, I am saying it through experience. Painfully, I could not give my baby the breast. Painfully, I paid through the nose to feed by baby. And painfully, I was in and out of the clinics and I thought that was really expensive for my baby. And even now, I think that her immunity is low because definitely she never breastfed. I wish my baby had breastfed. So I think Option B+ will be really good.

a) Improved health of the women

Women expressed that they will be healthier, stronger and more productive because of lifelong treatment.

FG3#3: The mothers will not be sickly any more. They will be productive throughout their lives.

FG1#7: In addition to protecting the baby you are also getting some treatment because you never know you CD4s can go down during the pregnancy when you had 1000 and you don't take the drugs so I think B+ is better.

b) Reduction of stigma towards the mother

Many women also expressed that by looking healthier, being put on treatment would reduce stigma and discrimination against them. Further, the mother will also not be stigmatized by others because she does not breastfeed or stops breastfeeding too soon.

FG1#3: If you start treatment you look well and nobody will recognize that you have the disease so you look well and it will prevent you being stigmatized.

FG4#6 (Man living with HIV, partner of WLHIV): This one is for lifetime, which means for the mother, I know that I will have good health and my CD4 will be high. And for the father, I know I'll have a newborn baby that is HIV negative. This reduces the stigma for both parents.

The groups also shared other important perceived benefits of Option B+.

a) Ability to have more children

Young women identified the fact that Option B+ will give them the opportunity and hope to have children in the future as an important benefit.

FG2#9: And what I see here, we have been having problems with adolescents – after testing, results are given, the first question is: ‘Counsellor, won’t I have a baby, won’t I marry?’ This time, the answer will be Yes, because you know, with this one, there will be no questions, from antenatal up to delivery – you deliver like any other person – and you go home like any other person, you breast feed your baby openly without stigma and discrimination – those will be reduced with this option.

FG1#3: The baby will be protected, so that fear of producing a baby that is sick is going to go away.

b) *Reduction in household expenditure/associated domestic violence*

Rural women living with HIV in particular felt that the extended breastfeeding component of Option B+ would reduce costs at a household level because men would not have to buy milk. Women and men stated that this would reduce rates of domestic violence.

FG2#9: Domestic violence will be reduced, because there will be no issues of requesting for - today we want money for milk; there and then ... there will be no domestic violence because what disturbs men is – ‘we don’t have this one’ now, there is that issue of the positive child – he [the man/partner] does not have money but the baby wants milk.

FG4#12: What I’ve seen here is that when my wife’s life is improved that gives me happiness and less expense because instead of spending, spending, spending my wife will be healthy, will be maybe working, which means improving lives.

c) *Reduction of transmission among sero-discordant partners*

Young women, citing treatment for prevention, felt that Option B+ could reduce infections of sero-discordant partners.

Other benefits that were mentioned include: helps women adhere/continue treatment; improves HIV positive women’s lifestyle and wellbeing; promotes testing; allows for different childbirth methods; gives hope to women; promotes disclosure and testing (although there was no consensus on this); and will be cost-effective.

What concerns do women and men raise about Option B+?

Numerous concerns were raised about the introduction of Option B+. The top concerns raised vary slightly across the groups. Nevertheless, there were three main concerns raised by all the groups:

a) *ARV stock outs & health system readiness in Uganda*

The fear of ARV stock outs was consistent amongst all participants, who questioned how Uganda will be able to implement and sustain this programme in the future if the government is already struggling to secure the ARV supply. Some participants were particularly concerned about media reports suggesting donor agencies could stop treatment support funding in Uganda because of corruption. Participants also agreed that the current health care system is not ready to implement this new programme; they believe health workers still need a lot of training for it to be implemented, especially at grassroots level.

FG2#8: Will Uganda as a country afford this? Because there are even some health centres in Uganda today whereby for one person to go on treatment, it needs another person on treatment to die.

FG3#7: I’m telling people it is forever and ever, and tomorrow they go there and there is no drugs. What will happen?

b) *Being put on treatment regardless of CD4 count*

The reasons for this concern varied per group. For rural women living with HIV, the concern is that mothers are being put into treatment without proper screening and routine tests (liver functioning etc) before putting somebody on ARVs.

FG2#10: [I am concerned] whether mothers introduced to treatment, whether they check their liver functioning. Like for us when we are starting on ARVs, they used to check for their liver function and

other tests. I don't know if they just put them on drugs because you're pregnant or whether they do the tests.

Amongst young women there was considerable resistance to accepting being put on ARVs for life when CD4 counts are still high. The concern appeared to be mainly that they feel well, so why should they receive treatment, and that starting something for life when you are so young is very stressful:

FG1#3: Actually I felt so uncomfortable that I could not take that pressure of taking everyday drugs.

FG1#7: It can cause some emotional feeling when you are just starting drugs, you are pregnant, the drugs are for life, not only for 9 months. It can be making you very emotional, very stressed.

For male partners, the concerns about starting on high CD4 counts were around toxicity:

FG4#8: For B+, for someone whose CD4 counts are higher, my worry is that this person's toxicity, would it be too high? Because with Option A, after giving birth and weaning the baby, the mother would stop the ART regimen but here in B+ you always continue, no matter your CD4 count.

For women in leadership, there were still doubts about the convenience of this approach and they foresee it might not be well received, given that once a pregnant woman starts on ARVs, she will have to take them for life:

FG3#3: I am in support of this program, however, I'm wondering, if I knew anyone with a CD4 of 800, I think I would tell her "please wait until maybe almost 1 month to delivery and then you can start." Because I know that 6 months is nothing compared to a lifetime.

c) Conflict with partners/perceived inequity

Men and women alike shared a number of concerns around equity and potential conflict with Option B+.

FG1#3: Actually, the first time I was told about Option B+, the first question I remember I asked was "what about the men?". Why did I ask this? Because I really saw that there were going to be issues of conflict of interest because men are going to now say "Why women? Aren't we also human beings?" FG1#3: Men are going to start public dialogues where they are going to be coming up and saying no this is not right, this is not working. They are going to say "why are you on the side of women more?" Because we are seeing option B+ they are giving the medicine to only a woman who is pregnant. Men will say "it's me who made that woman pregnant. Why am I not started on treatment too?"

Men and women also shared concerns about conflict arising from the perception that whoever learns of their positive status first is the one who acquired the virus first.

FG4#12 (man living with HIV): There is that belief still in our people that whoever knows their status first means you are the one who brought in the virus.

Young women perceived Option B+ as a risk to continuity of drug supply (given the country's constraints in providing ARVs to all), which may turn into an equity issue.

FG1#9: In Uganda today, we know that half of the people who need drugs do not have it. Out of the total number of people who are in need of drugs, half of them cannot access their drugs. Now I imagine that if a woman whose CD4 count is high is set on drugs, I'm sure there will come a time when health workers will say "no, there is so many people in need of drugs. This man here his CD4 count is 200 why don't we put off this woman whose CD4 counts are high?" So issues of continuity might not work out and we will end up losing so many people.

For these women, disclosure was also a concern.

FG3#2: I feel like it is difficult because you are told you are HIV positive and you are going home with packets of medicines immediately.

FG1#2: If you disclose it will cause violence. You will be kicked or cut. You have many women being hurt because of disclosing they are positive.

d) Adherence & nutrition

Women raised a number of fears about whether women would be able to adhere to treatment for life. Some young women felt that they would stop as soon as they had given birth.

FG1#9: After giving birth, I'll stop that drug because you know I was started on the drugs with pressure just to protect my child.

FG1#11: Me personally, after giving birth if my CD4 was high, I would stop those drugs.

Another concern relevant to most of the groups was that many women lacked sustained access to food and nutrition, which they need in order to take ARVs and to breastfeed.

FG3#1: I appreciate the services, it's good, but it also comes with guidelines that this person has to follow. When I look at this yes it is more at the hospital setting, but what happens at the community level? Because it comes maybe with like good feeding, certain conditions which these which these women will not be able to afford...Because a young mother will tell you, I cannot afford breast milk because I can't get food but at the same time I cannot afford a cup of milk every day. Which other services are they bringing alongside this for it to be effective?

FG2#5: My concern is [for women who do not have milk] how are they going to be helped, because I can see that if the milk doesn't come the baby will suck the blood from their breast. How are we going to help to bring out that concern – nutrition?

e) *Women will get pregnant to secure access to treatment*

The women in leadership positions raised a concern that some women will be likely to seek pregnancy in order to access ARVs. Access to life treatment is seen as an incentive for women who are not accessing ARVs and for women with high CD4 count but with skin problems associated with HIV.

FG3#1: Some people are desperate, especially those with bad skin or maybe they have some complications. It's not always about being pregnant it's about looking good and looking healthy. So I think this would motivate girls to do what it takes to get a better service.

FG3#13: If I was still in that category where I could give birth and I wasn't on treatment and I heard about this option about being started on treatment for life, believe me I would make sure that I get pregnant immediately. And I'm sure there are so many women there who are just saying I am going to pregnant so that I am able to get started on treatment.

f) *Male involvement as a requirement of receiving treatment*

Women leaders raised the issue that the current requirement in Uganda that pregnant women bring their partners to ANC has led to some unintended consequences. Although they acknowledged that the policy has been successful in encouraging men to get tested, they also highlighted that single women are being denied ANC services and therefore have to 'hire' men to attend ANC with them in order to access PVT services. Whilst most groups did not mind the preferential treatment shown to women who attend clinic with their partners (for example, being attended to first), a key recommendation was that male participation should not be a condition for women receiving care.

FG3#12: Because when you go for antenatal you are asked to come with your partner, women have chose to hire boda boda (motorcycle taxi drivers) to go with them to access the services.

Other concerns that were raised in connection with PVT were as follows:

- Side effects
- Stigma when taking treatment
- Reluctance by male partners to use condoms or get tested
- Leadership behaviour (of politicians, officials)
- Doctors and health workers' behaviour
- Lack of uniform information/implementation
- Follow up support by health centre/distance from community to health centres/no outreach
- Fear of infecting the child through breastfeeding
- Women living with HIV not disclosing their status anymore (risk of infecting others)

What services do people living with HIV want to see offered to the community for the implementation of Option B+?

Women and men expressed the need for a variety of support services to complement Option B+. These included: a) clear information, training and educational guidelines for beneficiaries, health workers and communities; b) counsellors; c) food; e) drug availability and better clinical checks; f) income generation support; g) integrated services; and f) male sensitisation and involvement.

All groups identified the need to deliver clear information and training that will reach all women and their communities at the grassroots level. In particular, they highlighted the need for development and dissemination of clear educational guidelines applicable at all levels (doctors, officials, community group, health workers, women, etc.). People also identified the need for the government to educate and train health workers and community groups as a priority. They requested information to be harmonized and uniform so that everybody has access to coherent messages around the implementation.

FG2#9: With Uganda, the program is very good. But the people who give the service are not in place. Who will give the information to the people who need it. They have to train those people first at the centres. All those who give out services should get it. It's a new program. It might have some changes from PMTCT to B+. The same communities must give the right information.

Another request shared by all groups is to raise public awareness on Option B+ via the media:

FG3#?: Even prior to the person knowing she is pregnant, it should be the government's role to send these messages out like on the media and newspapers, just educating the people on the services. Because I know young girls who would love to go for it, but the challenge now is I have tested positive, does that mean I can never have a child? But now we are guiding them that you can have a child if you do A and B and C. So this shouldn't be our role, the government needs to have it and clearly set out the information to inform the public about it.

Other important services called for included the following.

a) Counselling

All participants agreed that they need more counselling and follow up support. Some identified the need for counsellors and community groups to be supported to raise awareness in the villages.

Young women asked for youth counsellors.

FG2#5: There are some people where you take long to impart knowledge for them to understand. And it takes a long time. Adherence is really poor in the local areas – in the villages.

b) Income generation support

Women identified the need for support to start businesses through loans, income generation activities and business management training in order to ensure they can have good nutrition and pay for related treatment (such as malaria treatment).

c) Integrated services

In Uganda, women stated that ART can be accessed from ANC facilities but highlighted concerns that woman are appropriately referred from ARV clinics if they are pregnant and that clinics are not accessible to rural women (FG3#7). They called for even greater integration of family planning and HIV services. Groups also suggested that screening for other diseases and family planning services should be integrated into ANC and ART clinics, and referrals to local centres encouraged.

FG5#1: It's preferable that everything is in one center but my center is small. I get my meds from a community center so they only provide ARVs (they are not a health center).

FG3#7: We need community distribution points. If I am coming from some place and you are referring me 40 kms, you find that the mother does not have that transport and this will hurt adherence. So we need community distribution points.

d) *Support for male sensitisation and involvement*

Groups also discussed the importance of male involvement. Men expressed that they wanted to have a more active role than just attending clinic appointments, such as being enrolled in their own support groups and savings programs.

FG1#4: Male involvement. If we want option B+ to be a success and we leave out men we are doing a mistake. So I'm looking at involving men at all stages. If we are to train health workers and expert clients, let's also train men in option B+ so that they are informed and have information that is updated. If these men are having the information, they are willing to support their wives at home because a woman needs the man from the work to go home. So men really need to be involved at all stages.

Malawi: Perceptions and Experiences of PLHIV regarding Option B+ Implementation

As one of the few countries where Option B+ has been implemented (adopted in 2010 and implemented beginning in 2011), FGDs in Malawi focused on the perceptions and experiences of women living with HIV regarding its implementation.

In Malawi, the four focus groups consisted of participants who were grouped by the following criteria:

1. Women living with HIV of Muslim faith from the Blantyre District (n=9)
2. Women living with HIV from rural communities of Machinga District (n=10)
 - a. Includes one woman who started ARVs under Option B+
3. Women living with HIV from urban communities in Lilongwe District (n=11)
4. Mixed group of people living with HIV, including women from rural communities of Dowa and professionals from Lilongwe District (n=13)
 - a. Includes 10 women who started ARVs under Option B+

The majority of women spoke positively about Option B+, although urban women expressed more doubts and concerns.

What do people know about Option B+?

Overall there was quite a lot of knowledge about Option B+ across all focus groups. However, the level of understanding varied. Urban women and professional women seemed most familiar with the new regimen, even though only the professional women knew it was called 'Option B+'. Among Muslim and rural women, there was some understanding of the concept but this was clouded by incomplete or inaccurate information. One young Muslim woman reported being put on treatment without being informed about the details of the regimen.

FG5#7: The baby is 1 month old and she and I are still on medication. I'm supposed to go for a 6-week check up and they are going to check the baby. I don't know how long I am taking the medication but two women in the room said they understand it is for their whole life.

The perceived main elements of the new regimen identified by focus group participants were: a) a pregnant woman living with HIV is put on treatment for life at her first ANC visit if she is tested HIV positive without additional CD4 tests; b) the woman is put on treatment even if her CD4 count is high; c) the child is put on Bactrin; d) the woman is told she can breastfeed for 2 years; e) the woman and her partner need to use condoms during the pregnancy; f) the woman needs to be adherent and follow counselling.

FG8#4 (Woman on Option B+): Before, we used to breastfeed for 6 months and then they told us to stop. Now they are telling us that we have to take ARVs even if our CD4 is high. And then when we give birth the child should breastfeed for 2 years.

Participants in focus groups expressed a variety of opinions on why the new regime was being introduced:

- a) with previous methods, child mortality was high due to shorter breastfeeding and malnutrition (often due to lack of resources to buy food);
FG5#5: Malawi is a poor country so they thought that to let us breastfeed children longer than 6 months is better for starving children.
FG7#4: Most of the babies die if you stop breastfeeding at 6 months because of malnutrition. This [breastfeeding for 2 years] has helped to bring down the infant mortality rate.
- b) with previous methods, lack of money to buy infant formula would push women to breastfeed more than six months;
- c) with previous methods, many pregnant women died due to low CD4 counts, which can be avoided if they are put on medication.

However, other women, particularly those from urban areas, noted that other regimens were also effective in preventing vertical transmission.

FG7#7: In 2000, I was diagnosed at the ANC and the child was born in 2001. I started Nevirapine in the 8th month and I was told when I was discharged to breastfeed to 6 months and then switch the baby to solids. My second child was born in 2003 and I was given the same advice. Both of my children are HIV negative.

How is Option B+ being presented?

From the groups' testimonies, it appears that women in Malawi are being told that the treatment is for their children's health primarily, and at the same time it will also benefit their own health. It is not being presented as a benefit for prevention for partners and in the community.

FG6#5: They (doctors) say that even though your immunity is high you are put on ARVs to protect the baby.

FG7#10: Because the woman needs treatment - it is affecting her pregnancy and her immunity. The pregnancy reduces the immunity and the mom has to protect the child.

In Malawi, Option B+ is not being presented as an "option" or choice for the individual, but as the only method available to protect the child and the mother's health. There was consensus across all groups that Option B+ is being presented as strongly recommended, potentially to the point of coercion.

FG3#8: I understand the health workers are being trained on Option B+ which means that women may not be given an alternative to choose if they want Option A or Option B or Option B+.

FG5#8: From my experience, the women they are not given a choice. If you like it or not you have to take treatment because it is for your health and the health of your child.

However, women in Malawi were happy to initiate lifelong treatment because it would save their babies' lives and help them feel better. They did not seem to be upset about not having a choice between not taking ARVs or which regimen because they want their child to be healthy and trusted the doctors.

FG7#3: This is what the doctor recommends to us and because they are educat[ed] we do as they tell us.

Some women said they were expected to start on treatment immediately, while others were given the chance to think about it for the night. Rural woman said that they were expected to return the following week on the day that the ARV clinic operates:

FG6#5: You are given the option of starting immediately or you can come back next week.

FG8#3 (Woman on Option B+): The same day that you are brought to the antenatal you must start [treatment].

What kind of support do women living with HIV have to make decisions about their treatment?

Women reported little to no support to make decisions about whether and/or when to start treatment. Even though they were happy to start for the sake of the baby, they expressed a need for counselling (including group counselling) and support at the ANC at the onset of the PVT program.

It seems that women were mainly finding support in other women living with HIV and female relatives:

FG8#2: When they told me [I] should start taking ARVs, I was afraid and I was so depressed, but my sister encouraged me by saying you are not going to die today. When you start taking these ARVs you are going to look beautiful, you are going to look smart. So I just made the decision that ok, this is how I am and I just have to deal with it and move on with my life.

Muslim women reported that they all received some counselling when they initiated treatment. However, most Muslim women also reported being stigmatized by doctors and other health care workers in public clinics, being discriminated against or verbally abused, and being denied services on the basis of their religion:

FG5#7: When I tested positive I was referred to an ART clinic but when I went I was sent home because they said "As a Muslim woman why are coming here? The way that you dress how could you get infected?" I was stigmatized based on my religion. I was still sick. It was a public hospital so my husband took me to a private hospital, Christian Health Association... there it was mentioned that I should have been started on medication a long time ago.

Rural women also reported stigma by health care workers when they became pregnant:

FG6#8: When I went to the health centre I was asked, "Why are you pregnant when [as a woman living with HIV] you are told not be pregnant?"

What are the perceived benefits of Option B+?

The top three benefits identified by all women in relation to Option B+ were: a) the possibility to breastfeed for longer and associated improved health of the child; b) feeling healthier because they are on treatment; c) reduction of stigma towards mother and child. All of these were interlinked.

a) Being able to breastfeed longer and associated improved health of the child

The health of the child was reported as being better in two main respects. First, the child remained HIV negative due to the treatment, and was healthier due to the longer breastfeeding without risk, and therefore more likely to survive. Second, the child did not look sick and was therefore not identifiable as being HIV positive and their children could look forward to having negative children of their own. The longer breastfeeding duration also made male partners happy about not having to buy milk.

FG7#4: Most of the babies die if you stop breastfeeding at 6 month because of malnutrition. This (breastfeeding for 2 years) has helped to bring down the infant mortality rate.

b) Improved health of the women

All the women confirmed that they feel healthier and stronger on treatment. Rural women said that before starting on treatment they were sick and could not grow their own food. It was noted that fewer women were dying in pregnancy.

FG7#8: Previously when the woman was HIV positive, many would die. But when she is put on medication the CD4 remains high and this results in less risk of dying due to pregnancy.

FG5#5: We were ill with diseases but now that we are taking the medication we have good health and we expect to have this for life.

FG8#3 (Woman on Option B+): The women can work hard. They have the health to be productive. No one would think that any of us are HIV positive.

In addition, women noted improvements in their mental health because treatment gives them hope for a healthier life and for the future.

FG8#9: I was happy because I started taking treatment. Because I was diagnosed I was HIV positive and I was upset so when I was told I could start taking treatment I was happy.

FG8#2: We look good. We are happy. We are free. We are not burdened and we can go to the hospital to get health.

c) Reduction of stigma towards mother and child

Equally important as the actual health of the mother and child, was the fact that mother and child looked well. Women unanimously agreed that owing to treatment effects and longer breastfeeding, people could not tell that they were living with HIV and they could hide their status. Additionally, since lack of breastfeeding or breastfeeding for limited periods was associated with being HIV positive, women were happy to breastfeed for longer period and avoid involuntary disclosure and subsequent stigmatisation.

FG8#2: The children don't look sick. They look very healthy and before they looked malnourished and anybody could say that this child will die and that he/she is positive.

FG5#3: Another benefit is when you stop breastfeeding at 6 months people talked about you and think "she's got AIDS" but now people can hide their status because they are like everybody else and that will resort to a reduction in stigma and discrimination.

Other important benefits of Option B+ raised in the groups were as follows:

a) Promotion of testing

The certainty that treatment is available is encouraging Muslim women to go to the ANC and health centres when they feel ill. Urban women concurred that being put on treatment improves health, which might encourage others to test, get treatment and get better.

FG7#2: When you have good health it is an encouragement to other people to test because they see "Oh she was diagnosed in 1999 and she is still taking treatment and she looks good so I will test."

b) Unexpected pregnancies

Muslim women noted that women could become pregnant unexpectedly and still be 'covered':

FG5#6: I think it is beneficial because sometimes you fall pregnant unexpectedly and this is an advantage because then you will already be covered (by the health benefits of treatment).

c) Encouragement of male involvement

Most of the participants in all FGDs associated a push for male involvement with Option B+. Urban women reported that priority is given to women that attend with their partner. Although it is not clear whether this is a requirement within Option B+ in Malawi, urban and professional women agreed across the board that it is good for people to be counselled as a couple. Muslim women also reported that Option B+ was helpful in terms of involving men throughout the process. This was thought to help in the reduction of domestic violence.

FG7#10: This requirement for couples to come in together is very good because with this issue it is two people so they should have the same information and it helps them not to infect others.

FG5#1: In the beginning, all the counselling that I received, I received on my own, but since Option B+ I go with my husband and he accepts because of the counselling that he has gotten.

What concerns do women and men raise about Option B+?

Numerous concerns were raised in the focus group discussions. The top concerns raised varied and no single concern was shared by all groups. Nevertheless, there were four concerns raised in general.

a) Conflict with partners & perceived inequity

Rural women and urban women both reported the risk of increased domestic violence in association with disclosure and starting treatment if one partner starts before the other. If women are tested first, they are accused of bringing the virus into the home.

FG7#3: The alternative is if you test HIV positive before they give you the medication they ask for your spouse to come and be counselled as a couple because often the husbands point fingers at the woman.

FG8#7 (Woman on Option B+): It's not good ... that one person is started on treatment and another is not. This will bring difficulty especially when they say use condoms, a man can refuse. It is unfair because both are positive but one is taking the drugs. There is a risk of re-infection.

Malawi is in the process of transitioning to the 5A regimen for all new patients starting ART. Participants described this as “good treatment” because it has fewer physical side effects. T30 is known in Malawi to cause disfigurement and dystrophy. There was a perception that pregnant women are being offered 5A, while other PLHIV are offered T30. This was perceived as somewhat inequitable, although some said that it was fair for pregnant women to have priority over other populations.

FG8#12: When a woman gets pregnant her CD4 count goes lower and lower. When you are going to deliver the CD4 count is going lower and lower. It is good that the pregnant women immediately start ARVs.

b) Future ARV stock outs

Participants stated that ARV stock outs are not a current concern in Malawi. However, they reported frequent stock outs of Bactrin and other drugs for opportunistic infections. Additionally, urban and professional women expressed some concern that ARV stock outs could happen in future:

FG7#4: There has never been a complete stock out but the stocks are getting low. Instead of giving a 3 month supply they try as much as possible to give you 1 month or if your clinic doesn't have, they send you to another clinic but ARVs never run out.

FG8#7 (Woman on Option B+): My husband goes to a clinic before his treatment runs out so that he has stockpile just in case.

c) Side effects

Several women mentioned dizziness with taking ARVs (5A). The side effects mentioned for T30 included disfigurement, which resulted in being identified as HIV positive:

FG7#3: For people going to school this dizziness can affect their concentration while they are in class. The side effects also make us look different it is something that really troubles us. We don't look the way we used to look.

d) Impact on disclosure

Rural women all agreed that they disclosed because it helps other people. However, urban women mentioned that disclosure also has its risks. In particular, having to disclose the same day to partners was highlighted as a concern. Muslim women reported that some women are being told not to disclose under the B+ regime, which they perceived as a disadvantage of Option B+.

FG5#4: It helps because women are not identified as being HIV-positive. But there is conflicting information about breastfeeding and B+ encourages people not to disclose and this is not good.

FG7#4: It has been that they test and treat immediately... Women have challenges because if they go out of the hospital and with medication they can't think of ways of how to inform their husbands so they take them behind their husband's back and some of them don't take their medication.

Additional concerns that were raised by individuals but which were not widely shared included continued fear of breastfeeding even with the new regimen, especially among those who had lost children (FG5#1), and anecdotal evidence of women being put on treatment while their CD4 counts are high and experiencing adverse side effects:

FG5#1: I am thinking of my neighbor who was diagnosed when pregnant and then started on treatment and before all of this she was fine but now that she has started treatment she has started

having troubles and is unwell. The person looks very troubled. I feel that her health is deteriorating because of the treatment and the woman hasn't adhered.
FG6#10: There is someone from my community that started drugs when her CD4 was too high so she had adverse effects and when she stopped taking the ARVs she is fine. This was because she was taking them before she needed to be.

A number of concerns were also raised that were not directly related to Option B+, but which are part of the context in which Option B+ is being implemented:

- Stock outs of drugs for opportunistic infections (Bactrin)
- Behaviour of doctors and other health workers and the accountability of government officials
- Not having enough food (to take with treatment and produce milk)
- Reluctance by male partners to use condoms or get tested, lack of uniform information/implementation
- Lack of follow up support by health centre/distance from community to health centres/no outreach

Are women able to adhere to treatment?

Adherence was reported to be a concern only for a few women. Although having to take ARVs for life was a concern for most of them initially, most were getting used to the idea and finding ways to integrate it into their lives. There was no suggestion that women wanted to stop treatment after the birth (in contrast to young women in Uganda) or as soon as their child is fully weaned.

FG5#5: Now if I don't take it I feel as if something is missing.

FG5#7: For me, it's not a trouble at all and even my child who is positive I have trained the child and she takes the treatment on time.

FG8#?: Everyone agrees that it's good. Taking treatment means we will have our life. We eat nsima every day so why should we stop taking the drugs we need every day.

For at least one woman however, it is still a burden:

FG5#4: For me, taking treatment is tiresome. Taking it the morning, taking at night, and sometimes I forget. It's a chore. For me, to remember to give the child at the right time and I worry when I go away who will make sure that the child is taking it at the right time.

Were women meaningfully involved in the decision to implement Option B+?

None of the FGD participants had participated in any consultation or decision-making around the design and roll out of Option B+. A professional woman knew of consultations with 'organisations that deal with HIV' but 'not with women from the communities'.

FG#5: We were not consulted but we were told that there is a new thing coming.

Rural and professional women alike expressed their desire to be involved in decision-making about implementation of Option B+ and offered the suggestion that consultation could be done through existing support groups.

FG7#8: When decisions are made in Malawi around HIV or they have big meetings in Malawi usually they ask someone in an office somewhere and that person is there to inform. I would prefer women in the grassroots to go so they can speak about their experiences and inform people.

Are women getting pregnant to secure their access to treatment?

This was not raised as a concern in relation to Option B+ but was discussed in three of the groups, and appeared to be more of an issue in urban settings. It appears that some community members may perceive pregnancy as a means of obtaining lifelong treatment. However, urban women and men unanimously agreed that this was being driven by the specific desire of women to get access to 5A, an ARV regime that does not cause disfigurement:

FG7#8: The issue is the treatment you are given. Ordinarily you are given T30 and it causes disfigurement, where the 5A hasn't been shown to disfigure people so people want to get pregnant to get 5A.

Other women had a less clear cut view - access to lifetime treatment seems to be an incentive to some women, but it is not clear how many of them are actually seeking pregnancy to have access to ARVs. The rationale appears to be more about being able to have healthy pregnancies. Meanwhile rural women reported that some women are still scared to come forward for testing and treatment.

FG8# 12: Nowadays women who were HIV positive before and stopped having babies are now being pregnant again because they have seen that you can be pregnant and still be healthy. Because before they noticed that once they are pregnant they are sick and would die. This is a recent thing since the beginning of Option B+ because of breastfeeding the baby for 2 years.

What services do women/men want to see offered to the community for the implementation of Option B+?

Women and men expressed the need for a variety of support services alongside Option B+. These included: a) guaranteed drug availability (of both ARVs and essential medicines); b) timely and thorough medical checks to prevent other diseases; c) income generation support; d) food; and g) clear information and educational guidelines for everyone, including at the grassroots level. Women also clearly expressed a preference and demand for linkage between ARV and antenatal services. Since the implementation of Option B+ in Malawi, the number of ANCs offering ARVs has increased from c.200 to c.600. The FGs echoed this data, stating that in most cases ANCs are distributing ARVs, with some clinics dedicating certain days for ARV appointments. One woman expressed that having the clinics in one place increased her risk of being identified as HIV positive.

FG7#3: There should be education for everybody that states clearly when people should start treatment so people are prepared and they know "this is the stage that I start." The guidelines should go to the grassroots level so that everybody is clear because right now the people in the village don't know anything. The doctors and those of us in support groups know a little but we need to disseminate the information.

FG5#1: It's preferable that everything is in one center but my center is small. I get my meds from a community center so they only provide ARVs (they are not a health center).

FG6#10: The fact that ARVs are in the same center where everyone is makes people know that you are HIV positive. I wish there was a separate secret place for getting ARVs.

DISCUSSION AND CONCLUSION

Community Perspectives and Experiences In Favour of Option B+

Breast is best

The majority of women in all settings and from all backgrounds were convinced about the benefits of being able to breastfeed their children up to the age of 2 years old. The exceptions to this were 2-3 women whose children had sero-converted during breastfeeding under circumstances of malnutrition, and in two cases had died. With Option A or B, they had to stop breastfeeding at six months and many children died of malnutrition. Not being allowed to breastfeed beyond six months caused a great deal of mental suffering to these women, because they wanted to feed their child well and could not, and their children died from starvation despite having been born HIV negative. Despite the support for breastfeeding, women in both countries were uncertain about the exact parameters that were recommended; there was confusion about the length of time when breast feeding should be exclusive, if at all, and when and how solid foods could be safely introduced.

In addition, mothers and children had experienced stigma and discrimination because they were clearly identified as being HIV positive when they did not breastfeed. Women in both countries reported that their husbands were happy that they could breastfeed for longer because of the

related reduction in household expenditure from not having to buy milk or formula, or treatment for opportunistic infections. Male partners in Uganda confirmed this.

Hope for a HIV free generation

The fact that women could breastfeed again, have negative children and be productive was cited as something that made both women and their male partners very happy. In Uganda, in particular, men were very positive about the idea of having an HIV-free generation.

Access to treatment

Women were in agreement that they felt better on treatment, both physically and mentally. Women in Malawi compared the situation now positively against a time when women did not receive treatment and some women in both countries mentioned that CD4 counts decrease in pregnancy if the woman is not on treatment.

Integration of ART into primary and antenatal care settings

In both Uganda and Malawi, women clearly expressed a preference and demand for linkage between ARV and antenatal services.

Community Perspectives and Experiences against Option B+

Whose option?

The names Option A, Option B, and Option B+ imply that pregnant women who test positive for HIV are being given a range of options to choose from, whereas in reality it is the government that chooses which option to implement as part of the national program. There is no evidence that women are being given a choice of Option A, B or B+ or that there is any discussion with their doctor about this. The name, "Option B+", therefore, is somewhat misleading.

There was ample evidence from focus groups in both countries that Option B+ is being presented as the only available intervention and in some cases perceived as mandatory for pregnant women living with HIV. Some women are being asked to start lifelong treatment on the same day that they test positive for HIV. Other women are permitted to go home and think about starting ARVs, but are expected to return the next day or the same time the following week to begin treatment.

Whose benefit?

Doctors and health workers are telling women in both settings that the baby is the primary intended beneficiary of PVT and that, secondly, the mother will also benefit from good health as a result (even if her CD4 counts are high). While most women are receptive to this approach because they want their child to be born HIV free, some women in both Uganda and Malawi said that they felt pressured and that their own health was not important. For young women in Uganda, this was particularly worrying. Rural women in Uganda expressed anxiety that women might be put on treatment without proper screening for liver and other problems.

Personal readiness and reluctance to start treatment when CD4 > 350

There was not widespread support for women starting on treatment while their CD4 counts were high. Young women, male partners and women professionals in Uganda were particularly vocal against this. Young women spoke of being pressured into starting treatment before they were ready. Women and men in Malawi voiced less concern, although two stories were shared of women that had experienced problems with starting treatment in pregnancy, one 'before she needed to' (FG6#10 and FG5#1). In both countries women felt that starting treatment before they were ready would not be conducive to good health or adherence, and would increase resistance to ARVs.

“Why women... aren’t we also human beings?”

Equity was a concern for women in both countries. In Uganda, women raised fears that if a man’s CD4 count is lower than that of a pregnant woman, they will want to be put on treatment first and that there will not be enough drugs available for men that need them if pregnant women are prioritised.¹

Men also expressed strong concerns that they may re-infect their partner, or may not bother to attend the clinic if they know they will not be getting the same treatment. Because men won’t be able to start at the same time, this will cause conflict in the home, and increase the risk of domestic violence. There is some evidence that these concerns have been alleviated in Malawi by sensitive approaches to disclosure and messaging, couples counselling and support groups.

Fears of forced disclosure and criminalisation

In Uganda, women expressed fears that Option B+ will increase instances of forced disclosures if women are sent home with medication, especially if they do not receive adequate psycho-social support and counselling. This could result in increased domestic violence. There is also a strong belief within communities that the partner who is diagnosed first is the person who brought HIV into the home. Ugandan women were concerned that if pregnant mothers’ know their status first, they may be sued by their partner and/or family under the new criminalisation legislation that is currently being debated in Parliament.

Women in Malawi confirmed that the male involvement component of Option B+ had sometimes caused conflict in the home when men did not want to join their wives at the clinic or when women started treatment (FG7#1). They also talked about men refusing to get tested or wear condoms, particularly when their female partners start taking ARVs (FG8#7, FG7).

Areas of Ambiguity

There was a notable lack of consensus on the extent to which Option B+ will have a positive or negative impact on the closely interwoven dynamics of disclosure, testing, stigma/discrimination, conflict and violence.

In Uganda, focus groups featured strong debates on the theoretical pros and cons of Option B+ in this regard. In Malawi women were equally divided on this topic, suggesting that this is not just a hypothetical discussion.

On the one hand, participants felt that Option B+ decreases stigma and discrimination because women will be able to breastfeed, will look well and therefore be more likely to be comfortable disclosing their status. Partners will be encouraged to test if they know they will benefit from their partners being on treatment. Adolescents will be incentivised to test because they will be able to have negative children.

On the other hand, it was also suggested that by allowing women to hide their status, Option B+ will not promote the uptake of testing by partners. It was felt that it was too optimistic to assume that issues of stigma, disclosure and violence will be solved by Option B+. In particular, concern was

¹ In Uganda, a draft bill currently before Parliament provides that treatment must also be made available to partners of pregnant women who begin treatment to prevent transmission to the child. Section 16(2) of the HIV and AIDS Prevention and Control Bill states "appropriate treatment, care, support or routine medication shall be given to the partner of a pregnant woman." The Bill outlines a potential avenue to address the equity concerns of Option B+ raised by the focus groups. See The HIV and AIDS Prevention and Control Bill §16(2) (2009).

expressed for women who are not ready to disclose to their partner and who are sent home with medication packets and no support. In this way, Option B+ was seen to be forcing women to disclose, thereby possibly exposing them to domestic violence.

Because they are on treatment for life, women also may feel pressured to have more children and have them closer together, because spouses and families know that children can be born without HIV. This may have a negative impact on the health of the mother.

Some women felt that greater disclosure was a good thing for the community as a whole, and feared that if women are on treatment and look well, they won't disclose. However in general, forced disclosure was seen as potentially negative outcome of Option B+.

Areas Warranting Further Research

In order to increase women's autonomy in decision-making around their own health and the whether to commence lifelong treatment, the following areas warrant further investigation in order to be able to answer key questions that are raised:

1. Health benefits for women resulting from starting treatment for life on high CD4 counts, especially for younger women.
2. Health implications for women stopping and starting treatment with each pregnancy as per Option A and B (on high CD4 counts), especially for younger women.
3. Implications for child nutrition and mortality of allowing women to breastfeed for one year instead of six months.

Contextual Constraints on the Implementation of Option B+

ARV stock outs

In relation to starting treatment for life, a major concern was that ARV supplies would run out. This was among the top concerns raised in Uganda, and was less of a concern in Malawi, where treatment is 'always available'. However, a few Malawians expressed fear that in the future, aid may be cut off to the country or newer better regimes may not be universally available as promised. In Uganda, people raised serious concerns that the country was not ready for Option B+ because the government could not sustain a secure supply of ARVs and was dependent on donor funding. Participants felt that the current approach of a phased roll out, whereby some regions would get Option B+ before others, was inequitable.

Weak health systems

In Uganda, the current health system is regarded as being insufficiently prepared for implementation of Option B+. Clinic locations are too few and far between to enable good adherence and referral and follow-up systems are inadequate. Even in Malawi, where efforts have been made to decentralise services, some women reported being 2-3 hours from their health centre and PVT services. CD4 and viral load tests are not always available. Women noted problems in accessing essential medicines, thorough medical checks/screenings and family planning services. There are stock outs of treatments for opportunistic infections in both Malawi and Uganda.

Stigma within the health system

Although women were not explicitly asked about their experiences of the health system, the focus groups revealed a number of insights into the context within which Option B+ is being implemented. Of most concern is the treatment of Muslim women in Malawi by doctors and other healthcare workers, with several cases of negligence and mistreatment being shared. Muslim women were very confused about their treatment and whether or not they could breastfeed. Health workers assume

that because Muslim men are circumcised, they cannot get HIV. Some Muslim and rural women had started treatment without any counselling. Women living with HIV in Malawi have been told not to get pregnant and chastised when they appear in the ANC.

Who gets priority?

In a well meaning effort to reach male partners of women living with HIV and decrease the risk of domestic violence, ANC clinics have started to insist as part of the Option B+ program that women bring their partners with them. In Uganda, this has led to single women being denied treatment or being sent to the back of the line on arrival, which has forced some women to resort to hiring men to act as their partners during appointments so that they can access care. In some rural settings in Malawi, women were fined or had to produce supporting letters from village elders to access services if not accompanied by a male partner.

A balance needs to be struck between sending out a message to men that their partners will get preferential treatment if they accompany them to the clinic, and discriminating against women that are not able to bring a male partner. This is a new area of stigmatisation that needs to be addressed in order not to undermine the goal of Option B+. Women could be asked on arrival whether they have a male partner that could attend with them, and if they don't this should be taken into consideration and handled sensitively. Involving women living with HIV in these protocols is the best way to come up with solutions that will be acceptable and preferred by communities.

Lack of support and information

The way in which Option B+ is presented will help or hinder the effectiveness of the program and the health of women living with HIV.

In Malawi, where Option B+ has already been in place for some time, women from the Muslim community and rural areas still express confusion about the regimen. One woman did not know if she was on treatment for life or not (FG5#7). Others were unsure about the role of Bactrin in Option B+ and how long to breastfeed. Women are also receiving little or no support to make decisions about their treatment. In Malawi, women of Muslim faith report high levels of stigma and discrimination by health workers.

In Uganda, an information campaign has begun over the past six months around Option B+ but women both inside and outside of the health sector report a great deal of confusion over what it is. Information about Option B+ is starting to seep into the health system in an uncoordinated way. In rural settings women are receiving conflicting advice from doctors about C-sections and breastfeeding. They no longer know what is the safest option for their baby and their own health.

Women living with HIV are not being consulted

Women expressed anger and disappointment at not being consulted about the implementation of Option B+ in Uganda, despite existing structures within which this could have been organised. They report that decisions are being made by elites without the involvement of local councils, faith based leaders, community services and women at the grassroots level. In Malawi, women also reported not having been consulted.

Pregnancy as a means to obtain lifelong treatment

Women in both countries felt that it was likely that women would become pregnant to obtain ARVs for life, particularly because the newer and better regimens are not associated with disfigurement. In Malawi, women reported feeling more confident to become pregnant since the introduction of Option B+ because the availability of treatment means that pregnancy is safer for them, their children are unlikely to be born HIV positive, and they can breastfeed for 2 years. In Uganda, it was agreed that women would be incentivised to 'do what it takes' and that they themselves would get

pregnant in order to be able to start on treatment or access better drugs. Services need to be ready to meet this increased demand and this should be strongly considered when deciding whether to push Option B+ in countries which the ARV supply is already inadequate.

Enabling environment

Concerns were raised about a number of contextual issues that will impact the successful introduction of any treatment as prevention program, including Option B+. First among these was nutrition. In Uganda, there were fears about how women would be able to adhere to lifelong treatment and breastfeed their babies in the absence of a healthy diet. Women in both countries highlighted the need for income generating activities so that they can earn money and feed themselves and their families.

RECOMMENDATIONS

1. Option B+ should not be mandatory for all women, but should be based on a balanced assessment of the medical pros and cons for the mother and child by the individual with adequate support/guidance from her healthcare provider/community. If a country chooses to adopt Option B+, women with high CD4 counts should be given a choice to stop taking ARVs after the risk of transmission has passed (i.e. personally choosing Option B), especially if they are under the age of 25. In general, women should be given greater autonomy in decision-making about the commencement and cessation of treatment. If there is no intention to give women a choice of treatment options, refrain from referring to the program as “Option B+” as this is misleading.
2. Governments, in partnership with WHO and other development partners, should ensure the national supply of both ARVs and essential medicines is secured and can be maintained into the future before initiating women (or anyone) on lifelong treatment, especially in countries where ARV supplies have not been stable.
3. PVT programs should refrain from pressuring individuals to start treatment immediately upon testing positive. Women should be allowed sufficient time to process the information, and have support to decide whether or not to start treatment, as well as whether or not to disclose. Adequate support at the initial diagnosis and decision-making stages will ensure better adherence and retention.
4. Countries that are considering implementing Option B+ should meaningfully involve women living with HIV early on in decision-making about implementation, particularly regarding protocols for couples counselling and male involvement, by utilising all available avenues, including existing support groups.
5. Overall there is a clear need for better provision of non-judgmental counselling and support for women living with HIV at all stages of their life cycle.
6. Where implementation is already planned, clear educational guidelines should be drawn up, and a national training program for health workers and the community instituted as a matter of priority.

7. Urgent steps should be taken to address religious prejudice against people of Muslim faith and stigma towards women living with HIV among doctors and health workers in all contexts.
8. Governments, donors, and the WHO should address health system strengthening, including evaluating the need for and the provision of additional health workers and reliable supplies of Bactrin and other treatments for opportunistic infections.
9. Governments who are planning to implement Option B+ should prepare well for increased uptake of antenatal and treatment services in response to larger numbers of women becoming pregnant.
10. PVT programs should ensure that male participation is not a condition for women receiving care. Involving women living with HIV in the development of male involvement protocols is the best way to come up with solutions that will be acceptable and preferred by communities and that will not lead to unintended consequences.
11. PVT programs should ensure clear, accurate and comprehensive information about Option B+, including who is eligible, the potential side effects/health implications and other factors that are relevant to the decision to start treatment, is universally disseminated, including at the grassroots level.
12. Governments and donors should invest in income generating activities (IGAs) to address food security and related long-term rehabilitation and health of women living with HIV.
13. PVT programs should introduce measures that will support women being able to breastfeed for as long as they wish to, including food and nutritional supplements for mother and child.
14. Governments/Donors should invest in support groups, couples counselling, male sensitisation and counselling for women as a way to prevent increased domestic violence when women commence treatment as well as improve support for women in general.

CONCLUSION

It is hoped that the findings in this report will be welcomed by the Ministries of Health in Uganda and Malawi as a basis for further dialogue, better understanding, and programme strengthening with the involvement of women living with HIV and the wider community. Similarly, dissemination within WHO, especially country and regional offices and to IATT partners will be very important.

ANNEX A – PARTICIPANT DEMOGRAPHICS

Uganda

FG	Gender	Age	Living with HIV?	# of children	Last PVT service	Where access PVT services?	How far from PVT services?
1	F	28	Yes	1	0-6 months	Hospital	2 km
1	F	28	Yes	0	N/A	N/A	N/A
1	F	26	Yes	1	Currently	Hospital	10 km
1	F	17	Yes	1	Recently	Hospital	
1	F	23	No	0	N/A	N/A	N/A
1	F	21	Yes	0	N/A	N/A	
1	F	26	Yes	2	0-6 months	Hospital	
1	F		Yes				
1	F	20	No	0			
1	F	26	Yes	1	Recently	Community clinic	150 minutes
1	F	19	Yes	2	0-6 months	Hospital	180 minutes
1	F	28	Yes	1	0-6 months	Hospital	2 km
2	F	28	Yes	4	2-3 years	Hospital	2 km
2	F	39	Yes	3	4+ years	Hospital	120 minutes
2	F	22	Yes	0	N/A		120 minutes
2	F	23	Yes	1	0-6 months	Hospital	120 minutes
2	F	32	Yes	2	0-6 months	Community clinic	60 minutes
2	F	23	No	2	4+ years	Hospital	60 minutes
2	F	32	Yes	1	2-3 years	Hospital	60 minutes
2	F	34	Yes	4	Recently	Hospital	60 minutes
2	F	43	Yes	3	N/A		
2	F	25	No	1	N/A		
2	F	39	Yes	3	7-12 months	Hospital	30 minutes
2	F	40	Yes	3	N/A		
3	F	49	Yes	2	N/A		
3	F	46	Yes	3	N/A	Hospital	
3	F	56	Yes	1	N/A	Community clinic	30 minutes
3	F	46	Yes	3	4+	Hospital	10 km
3	F	26	Yes	1	2-3 years	Hospital	40 minutes
3	F	50	Yes	2	N/A	N/A	
3	F	39	Yes	2		Health center	10 km
3	F	39	Yes	3	N/A		
3	F	30	Yes	2	4+ years	Health center	
3	F	56	No	7	N/A	N/A	10 km
3	F	26		1		Hospital	
3	F	41	Yes	3	2-3 years	Community clinic	8 km
4	M	48	Yes	6	Currently	Hospital	120 minutes
4	M	44	Yes	5	N/A	Community clinic	360 minutes
4	M	40	Yes	5	N/A	Hospital	20 km
4	M	50	Yes	5	Currently and Recently	Community clinic	7 km
4	M	37	Yes	3	4+ years	Hospital	5 km
4	M	18	Yes	0	N/A		
4	M	42	Yes	4	N/A	Hospital	60 minutes
4	M	36	Yes	3	2-3 years	Hospital	1.5 km
4	M	56	Yes	6	7-12 months	Hospital	40 minutes
4	M	21	Yes	0		Hospital	

Total # participants	45
# male participants	10
# female participants	35

Average age	35.95
Average age women	33.7
Average age men	39.2

Living with HIV	89.90%
Women	85.71%
Men	100%

Average # children	2.34
Women	1.94
Men	3.7

Last PVT Service	Number	Percent
Currently	3	6.66%
Recently	3	6.66%
Past 0-6 months	6	13.33%
Past 7-12 months	2	4.44%
Past 2-3 years	5	11.11%
4+ years	5	11.11%
N/A	17	37.38%
No response	4	8.89%
<i>Total</i>	<i>45</i>	<i>100.00%</i>

Where access PVT service	Number	Percent
Hospital	24	53.33%
Community Clinic	5	11.11%
Health Center	2	4.44%
N/A	5	11.11%
No response	9	20%
<i>Total</i>	<i>45</i>	<i>100%</i>

Distance from PVT service		
Average for those who answered in km	7.29 km	
Average for those who answered in minutes	100.63 minutes	

Malawi

FG	Gender	Age	Living with HIV?	# of children	Last PVT service	Where access PVT services?	How far from PVT services?
5	F	30	Yes	5	0-6 months	Hospital	120 minutes
5	F	30	Yes	1	2-3 years	Hospital	60 minutes
5	F	26	Yes	3	4+years	Hospital	180 minutes
5	F	30	Yes	3	0-6 months	Hospital	3 km
5	F	26	Yes	1	4+ years	Hospital	
5	F	26	Yes	2	N/A	Hospital	150 minutes
5	F	27	Yes	3	7-12 months	Hospital	180 minutes
5	F	26	Yes	3	4+ years	Hospital	180 minutes
5	F	28	Yes	4	7-12 months	Hospital	180 minutes
6	F	42	Yes	6	7-12 months	Hospital	
6	F	35	Yes	5	4+ years	Hospital	5 km
6	F	22	Yes	2	Recently	Hospital	22 km
6	F	35	Yes	5	2-3 years	Hospital	3 km
6	F	27	Yes	2	4+ years	Hospital	3 km
6	F	23	Yes	1	Recently	Hospital	3 km
6	F	33	Yes	2	7-12 months	Hospital	3 km
6	F	41	Yes	5	4+ year	Hospital	3 km
6	F	31	Yes	5	4+ years	Hospital	3 km
6	F	43	Yes	5	4+ years	Hospital	12 km
7	F	25	Yes	2	4+ years	Hospital	45 minutes
7	F	29	Yes	1	4+ years	Hospital	55 minutes
7	F	41	Yes	3	2-3 years	Hospital	90 minutes
7	M	44	Yes	3	2-3 years	Hospital	90 minutes
7	F	32	Yes	7	4+ years	Hospital	60 minutes
7	F	32	Yes	3	4+ years	Hospital	120 minutes
7	F	29	Yes	3	2-3 years	Hospital	60 minutes
7	F	42	Yes	3	4+ years	Hospital	90 minutes
7	F	20	Yes	1	2-3 years	Hospital	2.5 km
7	F	40	Yes	3	4+ years	Hospital	60 minutes
8	F	30	Yes	3	4+ years	Community clinic	45 minutes
8	F	28	Yes	3	7-12 months	Hospital	10 min
8	F	24	Yes	3	7-12 months	Hospital	10 min
8	F	21	Yes	2	7-12 months	Hospital	10 min
8	F	37	Yes	1	2-3 years	Hospital	10 min
8	F	34	Yes	5	7-12 months	Hospital	30 min
8	F	31	Yes	3	Currently	Hospital	60 min
8	F	20	Yes	1	7-12 months	Hospital	30 min
8	F	20	Yes	2	7-12 months	Hospital	90 min
8	F	37	Yes	7	7-12 months	Hospital	30 min
8	F	29	Yes	0	4+ years	Hospital	30 min
8	F	30	Yes	3	N/A	Hospital	30 min
8	F	40	Yes	5	2-3 years	Health center	5 km

Total # participants	42
# female participants	41
# male participants	1

Average age	30.86
Average age women	30.54
Average age men	44

Living with HIV	100.00%
------------------------	----------------

Average # children	3.1
Women	3.1
Men	3

Last PVT Service	Number	Percent
Currently	1	2.38%
Recently	2	4.76%
Past 0-6 months	2	4.76%
Past 7-12 months	11	26.19%
Past 2-3 years	8	19.05%
4+ years	16	38.10%
N/A	2	4.76%
No response	0	0.00%
<i>Total</i>	<i>42</i>	<i>100.00%</i>

Where access PVT services	Number	Percent
Hospital	40	95.24%
Community Clinic	1	2.38%
Health Center	1	2.38%
<i>Total</i>	<i>42</i>	<i>100.00%</i>

Distance from PVT service		
Average for those who answered in km	5.62 km	
Average for those who answered in minutes	77.67 minutes	

ANNEX B – FGD GUIDES

Focus Group Discussion Questions on Option B+ (Uganda)

PREAMBLE: Welcome, introductions, opening remarks, review consent forms

SECTION I: Assessment

1. What information have you received about preventing transmission to the unborn baby?
 - a. *What does it mean to you?*
 - b. *How does it make you feel?*

2. What do you know about Option B+?
 - a. *What messages have women living with HIV received about Option B+?*
 - b. *From who/where?*
 - c. *What does it mean to you?*
 - d. *How does it make you feel?*

3. How have your communities perceived Option B+?

4. What stories or media reports have you heard about Option B+?
 - a. *How does it make you feel? What could be the implications for you?*
 - b. *Is civil society engaged in Option B+ programs in Uganda?*
 - c. *If yes, how?*
 - d. *Has civil society in Uganda raised any questions or concerns about Option B+?*

SECTION II: Brief informational presentation on Options A, B, & B+

SECTION III: Opinions & Potential Consequences

1. Have you heard that Uganda was moving towards Option B+?
 - a. *What does it mean to you? How does it make you feel?*
 - b. *How did you react?*

2. What do you understand are the benefits?
 - a. *What are the potential positive consequences?*
 - b. *Does Option B+ provide any benefit to communities or partners of pregnant women?*
 - i. Areas to explore: opportunity for husbands to test by proxy, couples counseling

3. What are your concerns?
 - a. *What potential challenges do you envision women living with HIV will face?*
 - i. Areas to explore: loss to follow up, sustainability, adherence, drug resistance, drug stock outs, ect.

- b. *If Option B+ is offered to the special population of pregnant women living with HIV but not all people living with HIV, how should this be presented? What challenges might this cause?*

- 4. What are pregnant women told at the health clinic about prevention of transmission to the unborn child?
 - a. *How do you feel about it? Do you see any implications for you, your family, or community?*
 - b. *Are they told that treatment is for their health, the health of their child, or both?*
 - c. *What are they told about prevention of vertical transmission?*
 - d. *What are they told about treatment for themselves?*

- 5. What should women living with HIV be told about Option B+?
 - a. *What information do they need to make a decision about whether to begin treatment?*
 - b. *In what ways should women be given this information?*

- 6. What services should women be offered when they begin treatment (*counseling, mentorship, food programs ect*)?

- 7. What are the potential effects of Option B+ on stigma and discrimination? Disclosure?

- 8. How will Option B+ affect your general lifestyle?

SECTION IV: Community Involvement

- 1. Are women living with HIV part of the decision-making process to move towards Option B+?
 - a. *How are you asked to contribute?*
 - b. *How should women living with HIV be involved?*

- 2. How should partners, husbands, and fathers be involved in the roll out of Option B+?
 - a. *How do you feel about it? What are your concerns?*
 - b. *What are the advantages or opportunities that you see in involving them?*

Male Focus Group Discussion Questions on Option B+ (Uganda)

PREAMBLE: Welcome, introductions, opening remarks, review consent forms

SECTION I: Assessment

1. What information have you received about preventing transmission to the unborn baby?
 - a. *How do you feel about it?*
 - b. *What does this mean to you?*
2. What do you know about Option B+?
 - a. *What messages have you received about Option B+?*
 - b. *From who/where?*
 - c. *How does it make you feel? What does it mean to you?*
3. How have your communities perceived Option B+?
4. What stories or media reports have you heard about Option B+?
 - a. *Is civil society engaged in Option B+ programs in Uganda?*
 - b. *If yes, how?*
 - c. *What does that mean to you? How does that make you feel?*
 - d. *Has civil society in Uganda raised any questions or concerns about Option B+?*

SECTION II: Brief informational presentation on Options A, B, & B+

SECTION III: Opinions & Potential Consequences

5. Have you heard that Uganda was moving towards Option B+?
 - a. *How did you react?*
6. What do you understand are the benefits?
 - a. *What are the potential positive consequences?*
 - b. *Does Option B+ provide any benefit to communities or partners of pregnant women?*
 - i. Areas to explore: opportunity for husbands to test by proxy, couples counseling
7. What are your concerns?
 - a. *What potential challenges do you think Option B+ may pose?*
 - i. Areas to explore: loss to follow up, sustainability, adherence, drug resistance, drug stock outs, ect.
 - b. *How would you feel if Option B+ is offered to the special population of pregnant women living with HIV but not all people living with HIV?*
 - i. *How should this be presented?*
 - ii. *What challenges might this cause?*
8. What should partners and husbands of women living with HIV be told about Option B+?
 - a. *In what ways should men be given this information?*

9. What services should women and men be offered when they begin treatment (*counseling, mentorship, food programs ect*)?
10. What are the potential effects of Option B+ on stigma and discrimination?
11. How should partners, husbands, and fathers be in the roll out of Option B+?
 - a. *What does that mean to you? How does that make you feel?*

Focus Group Discussion on Option B+ (Malawi)

Preamble: Welcome, introductions, opening remarks, & review of consent forms

SECTION I: Assessment

1. What information have you received about preventing transmission to the unborn baby?
 - b. *What does it mean to you?*
 - c. *How does it make you feel?*
2. What do you know about Option B+?
 - a. *What messages have women living with HIV received about Option B+?*
 - b. *From who/where?*
3. How have your communities perceived Option B+?

SECTION II: Brief informational presentation on Options A, B, & B+

SECTION III: Opinions & Potential Consequences

4. Have you heard that Malawi has decided to implement Option B+?
 - a. *What does it mean to you? How do you feel about it? Do you see any implications for you, your family or community?*
 - b. *How did you react?*
5. What do you understand are the benefits?
 - a. *What are the positive consequences?*
 - b. *Does Option B+ provide any benefit to communities or partners of pregnant women?*
 - i. Areas to explore: opportunity for husbands to test by proxy, couples counseling
6. What are your concerns?
 - a. *What potential challenges do you envision women living with HIV will face?*
 - i. Areas to explore: loss to follow up, sustainability, adherence, drug resistance, drug stock outs, ect.
 - b. *If Option B+ is offered to the special population of pregnant women living with HIV but not all people living with HIV, how should this be presented? What challenges might this cause?*
7. What are pregnant women told at the health clinic about prevention of transmission to the unborn child?
 - a. *How do you feel about it? Do you see any implications for you, your family, or community?*
 - b. *What are women told about Option B+?*
 - c. *Are they told that treatment is for their health, the health of their child, or both?*
 - d. *What are they told about prevention of vertical transmission?*
 - e. *What are they told about treatment for themselves?*
8. Is the decision to begin treatment presented as a choice?

- a. *How do you feel about it? Does it have any implications for you, your family, or your community?*
 - b. *What kind of support are women given to make decisions about treatment?*
 - c. *Have any women refused to begin treatment? What is the response if a woman says she does not want to begin treatment?*
 - d. *Should the option be presented differently? How? (as opt in/opt out?)*
 - e. *When were you asked/expected to start treatment? Is it same day as they find out their status?*
9. What services are women offered when they begin treatment (*counseling, mentorship, food programs ect*)?
- a. *What does it mean to you? How does it make you feel? What are the implications for you, your family, your community, other women you know?*
 - b. *What services should women be offered?*
10. Are women offered support services if they decline to initiate treatment?
- a. *What does it mean to you? How does it make you feel?*
 - b. *What are the implications for you, your family, your community, other women you know?*
11. What happens after a woman and her child have finished visiting the maternal and child health center?
- a. *What does it mean to you? How does it make you feel?*
 - b. *What are the implications for you, your family, your community, other women you know?*
 - c. *Are they referred to an ART clinic? Are there any concerns about this referral or transfer of care?*
12. What are the effects of Option B+ on stigma and discrimination? Disclosure?
- a. *Do women feel any differently about disclosing their status to their partners/families because of Option B+?*
13. How does Option B+ affect women's general lifestyle?
14. As a result of the policy change to Option B+, do women view pregnancy as a way to obtain treatment for HIV/AIDS?

SECTION IV: Community Involvement

- 1. How have women living with HIV been involved in the roll out of Option B+?
 - a. *What are the implications for you?*
 - b. *What does involvement mean to you?*
 - c. *Should women be more involved? How?*
- 2. How have partners, husbands and fathers been involved in the roll out of Option B+?
 - a. *How do you feel about it? What are your concerns?*
 - b. *What are the advantages or opportunities that you see in involving them?*
 - c. *What should their role be?*
- 2. How has the treatment regimen being accepted by partners, families and communities?

- a. *How does it make you feel? What does it mean to you? What are the implications for you or other women you know?*

3. Optional: What stories or media reports have you heard about Option B+?
 - a. *How does it make you feel? What could be the implications for you?*
 - b. *Is civil society engaged in Option B+ programs in Malawi?*
 - c. *If yes, how?*

4. Optional: Has civil society in Malawi raised any questions or concerns about Option B+?

ANNEX C – OPTION B+ PRESENTATION for the FGDs

Slide 1

**ARV Programme Options
to Prevent Vertical Transmission**

Brief Explanation about
Options A, B, and B+

Slide 2

**Treatment (ART) for Pregnant Women
whose CD4 count < 350 cells/mm³**

	Treatment
Option A	Triple ARVs starting as soon as diagnosed,
Option B	continued for life
Option B+	

Slide 3

**Prophylaxis for Pregnant Women whose
CD4 count > 350 cells/mm³**

	Antepartum	Intrapartum	Postpartum
Option A	AZT starting as early as 14 weeks gestation	At onset of labour, single-dose NVP and first dose of AZT/3TC	Daily AZT/3TC through 7 days postpartum
Option B	Triple ARVs starting at 14 weeks gestation (same as treatment)		If breastfeeding, continue Triple ARVs until 1 week after cessation If not breastfeeding, continue Triple ARVs until childbirth
Option B+	Triple ARVs starting as soon as diagnosed, continued for life (same as treatment)		

Slide 4

Infant Prophylaxis

	Breastfeeding	Not Breastfeeding or Mother on Treatment
Option A	Daily NVP from birth until 1 week after cessation of all breastfeeding	Daily NVP through age 4–6 weeks
Option B	Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method	
Option B+		

Slide 5

3 Options for Prevention of Vertical Transmission

	Treatment (ART) (for CD4 count < 350 cells/mm ³)	Prophylaxis (for CD4 count > 350 cells/mm ³)	Infant receives
Option A	Triple ARVs starting as soon as diagnosed, continued for life	Antepartum: AZT starting as early as 14 weeks gestation Intrapartum: at onset of labour, single-dose NVP and first dose of AZT/3TC Postpartum: daily AZT/3TC through 7 days postpartum	If breastfeeding: Daily NVP from birth until 1 week after cessation of all breastfeeding If not breastfeeding or if mother is on treatment: Daily NVP through age 4–6 weeks
Option B	Triple ARVs starting as soon as diagnosed, continued for life	Triple ARVs starting as early as 14 weeks gestation and continued intrapartum and through childbirth if not breastfeeding or until 1 week after cessation of all breastfeeding	Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method
Option B+	Triple ARVs starting as soon as diagnosed, continued for life	Triple ARVs starting as soon as diagnosed, continued for life	Daily NVP or AZT from birth through age 4–6 weeks regardless of infant feeding method

ANNEX D – FOCUS GROUP DISCUSSION CONSENT FORM

Focus Group Discussion Consent Form

Focus group number	
Location	
Date	

Title of Research Project

UNDERSTANDING THE PERSPECTIVES AND/OR EXPERIENCES OF WOMEN LIVING WITH HIV REGARDING OPTION B+ IN MALAWI & UGANDA IN SUPPORT OF THE FORTHCOMING WHO CONSOLIDATED ARV GUIDELINES

Background & Purpose of Research

The World Health Organization will be developing new Consolidated ARV Guidelines, which will include recommendations regarding treatment options for pregnant women living with HIV, including Option B+. Given the relative novelty of Option B+, it is important to explore the risks and benefits of the intervention, as well as feasibility and costs. The Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV were asked to explore the perspectives and experiences of key affected populations, namely women living with HIV in places where the intervention has been or will be implemented (i.e. Malawi and Uganda, respectively).

Objectives

Through focus group discussions, our goals are to identify and understand the perspectives of women living with HIV regarding the Option B+ treatment regimen in Uganda and Malawi. We also hope to understand the perceptions of women living with HIV and their communities regarding the forthcoming (Uganda) or current (Malawi) implementation of Option B+. Finally, we seek to explore issues around starting lifelong treatment during pregnancy for women living with HIV in Uganda and Malawi, and brainstorm suggestions for strengthening or improving the programme from the civil society perspective.

1. To identify and understand the perspectives of women living with HIV regarding the Option B+ treatment regimen in
2. To understand the perceptions of women living with HIV and their communities regarding the forthcoming implementation of Option B+
3. To explore issues around starting lifelong treatment during pregnancy for women living with HIV in Uganda, including acceptability, and suggestions on strengthening/improving the programme from the civil society perspective

Following the focus group discussions, ICW and GNP+ will draft a summary report to feed into the ARV guideline development meeting in December. The report will be shared with all participants. Based on the feedback from these meetings, ICW and GNP+ may also collaborate on more widespread advocacy work that participants will have the opportunity to be involved in.

Researchers

This project is being coordinated by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), with support from the World Health Organization (WHO).

In Uganda, ICW East Africa is leading the organization of the focus groups, with help from Mama's Club, the National Forum of People Living with HIV/AIDS Network in Uganda, the National Community of Women Living with HIV, the Global Coalition of Women Living with HIV, and Uganda Young Positives.

In Malawi, the Coalition of Women Living with HIV/AIDS (COWALHA) and ICW Southern Africa are organizing the focus groups.

I understand that if I have any questions about the research procedures, I can contact either of the Project Coordinators:

Amy Hsieh, JD, MPA
Health & Human Rights Consultant
GNP+
E: ahsieh@gnpplus.net
S: amyhsiehesq

Sonia Haerizadeh, JD
Human Rights Attorney
ICW Global
E: soniaicwglobal@gmail.com
S: soniaicwglobal

Invitation to Participate

I understand that I am being asked to participate in a focus group to increase understanding of the perspectives and experiences of Option B+ on key affected populations, namely women living with HIV.

Procedures

I understand that my participation in the study will involve taking part in one focus group discussion lasting approximately 2 hours. I will be asked approximately 15 questions relating to the Option B+ programme. The focus group will involve a discussion about personal experiences and perspectives regarding Option B+, as well as prevention of vertical transmission services generally. I understand that the focus group discussions will be audio recorded and transcribed and that all information I share will be coded in such a manner that I cannot be identified. The data will be used only for research purposes and the development of a report on the perspectives of women living with HIV and their communities on Option B+ in Uganda and Malawi.

Voluntary Participation

I understand that my participation in this focus group is purely voluntary and that I am free to withdraw from the discussion at any time. I can choose not to participate in any part of the discussion or to answer any questions that I do not want to.

Risks & Benefits

I understand that as a participant, I might recall emotionally upsetting experiences during the interview. However, I have the right not to participate in any discussions or answer any questions which make me feel uncomfortable.

I understand that although I may not benefit from involvement in this study, the information gathered will be contributing to advocacy for more meaningful involvement of people living with HIV in the response to HIV.

I have also been advised that my participation will in no way impact my agency's or organisation's relationship with or funding from WHO, GNP+ or ICW.

Privacy & Confidentiality

I understand that I will be asked to use only my first name or a nickname (pseudonym) during the focus group discussion and that inadvertent mention of last names will be deleted from the transcript. All first names (or nicknames) will be changed to only initials in the transcript. I understand that only the research team will have access to the research data. All recordings and data will be destroyed at the conclusion of the study.

Publication of Research Findings

I understand that aggregate results of the research may be published in a final report and in professional journals. Quotations from the focus group discussions may be included in the results in an aggregate form without reference to participants' names or identifying information.

Reimbursement

I understand that I will be reimbursed expenses incurred for my participation in this study.

Dissemination of Findings

I understand that as a research participant, I may request a copy of the final report by contacting Amy Hsieh or Sonia Haerizadeh (see contact information above)

Copy of Informed Consent for Participant

I am being given a copy of this informed consent to keep for my own records.

.....
Participant Signature

.....
Date

.....
Research Coordinator Signature

.....
Date

.....
Interviewer Name (Please Print)

ANNEX E - DEMOGRAPHICS QUESTIONNAIRE

Understanding the Perspectives and/or Experiences of Women Living With HIV Regarding Option B+
In Malawi & Uganda
In Support of the Forthcoming WHO Consolidated ARV Guidelines

PURPOSE OF THE QUESTIONNAIRE:

The purpose of this short questionnaire is to get *anonymous*, personal details and confidential input from the people attending the focus group discussion. The questionnaire will be completed prior to the discussion. All of the information that you provide will be kept *completely confidential*—you do not have to add your name to the document.

Your answers, along with the other participants', will be compiled and evaluated to understanding the perspectives and/or experiences of women living with HIV regarding Option B+ in Malawi & Uganda. This information will help to guide the World Health Organization (WHO) as they develop new ARV guidelines and help to support advocates' input into this process.

If you have questions or concerns, after we are finished, contact details of the local support group will be shared after the group discussion.

1. **Gender** (Please choose the option that best represents you):

Female Male Transgender Female Transgender Male

2. **Age** (Please specify your age at your last birthday): _____ years

3. **Your HIV Status** (Please choose the option that best represents you):

Living with HIV (HIV+) Not Living with HIV (HIV-)
 Unaware of HIV status

4. **How many children do you have?** _____

5. **Experience with Prevention of Vertical Transmission (or PMTCT) Services**

Please choose the option that best represents you (or your partner/s):

Currently pregnant and receiving prevention of vertical transmission services
 Recently pregnant and receiving prevention of vertical transmission services
 Received prevention of vertical transmission services in the past 0-6 months
 Received prevention of vertical transmission services in the past 7-12 months
 Received prevention of vertical transmission services in the past 2-3 years
 Received prevention of vertical transmission services in the past 4+ years
 Not applicable

6. **Where do you (or your partner/s) access prevention of vertical transmission services?**

Hospital Community-Based Clinic Other (specify) _____

7. **How close is the place where you (or your partner/s) access prevention of vertical transmission services?** (Please specify in number of hours walk or kilometers)