Appendix B(2): Focus Group Discussions

Focus Group Discussions in Jamaica on PMTCT Components One and Two:

Primary Prevention of HIV and Prevention of Unintended Pregnancies

Global Network of People Living with HIV

&

International Community of Women Living with HIV

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FOCUS GROUPS DISCUSSION
REPORT
ON
Prevention of Mother to Child Transmission of HIV

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
FGD	Focus Group Discussion
HIV	Human Immuno-deficiency Virus
JCW	Jamaican Community Women Living with HIV and AIDS
JN+	Jamaica Network of Seropositives
KAPB	Knowledge, Attitudes and Practices Behaviour Survey
MOH	Ministry of Health
MTCT	Mother to Child Transmission of HIV
NGO	Non Governmental Organisation
NHP	National HIV/STI Programme
PLHIV	Persons Living With HIV
PMTCT	Prevention of Mother to Child Transmission of HIV
PPTCT	Prevention of Parent to Child Transmission of HIV
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

Executive Summary

The idea for the focus group discussions highlighted in this report arose out of discussions among key experts on the PMTCT from various parts of the world and people living with HIV (PLHIV) around a five year strategic framework being proposed by the Interagency Task Team (IATT) for *Prevention of HIV Infection in Pregnant Women, Mothers, and their Children.* The framework is geared to help inform the way PMTCT services should be organised and run.

The policy framework focuses specifically on the first two components of PMTCT:

1. Prevention of HIV among women of childbearing age
2. Prevention of unintended pregnancy among women living with HIV

The main aim of the FGDs was to gain a better understanding of how people living with HIV perceive and experience PMTCT programmes in Jamaica. In this sense, the FGDs facilitate the meaningful involvement of those living with and affected by HIV in the final version of the strategy and to strengthen the document through key insights of those living with HIV. Next to the FGDs, there were also moderated online consultations among individuals living with HIV and an e-survey for those living with and affected by HIV.

Methodology

Participants for the FGDs in Jamaica were recruited using purposive sampling. A key criteria for involvement was that the women would have had experience using the PMTC programme or fall in the age group most likely to use it such as emancipated minors. Women in the age group 15 to 49 years old were recruited.

They were affiliated with three entities – Eve for Life, Jamaica AIDS Support for Life (JASL) and the JCW+. Participants for the discussions came from nine of the 14 parishes in Jamaica - St. Thomas, Clarendon, Kingston, St. Andrew, St. Catherine, St. James, St. Ann, Portland and Westmoreland. The parishes represented a good mix with all four Regional Health Authorities (RHA) being represented. Some 27 persons participated in the discussions including seven males. The male participants were a mixture of HIV positive and negative men whose partners participated in the PMTCT programme.

Structure of the Document

This report contains four chapters and appendices as follows:

Chapter One: Introduction - This section gives an overview of the HIV situation in Jamaica specifically as it relates to the PMTCT programme.

Chapter Two: Methodology - This reports on the methods used to collect data for the report

Chapter Three: Key Findings and Analysis - Presentation of the results and findings from FGDs. The section also provides discussion around the findings.

Chapter Four: Conclusions and Recommendations - This section puts forward recommendations for the effective roll out of the PMTCT programme in Jamaica.

Main Findings

- Gap in knowledge about PMTCT Programmes: Results of the focus group discussions (FGDs) on the Prevention of Mother to Child Transmission of HIV (PMTCT) indicate that there is a gap in participants' knowledge and understanding of PMTCT programmes even though at least 75 per cent of the women had participated in such a programme at some point. As a result,women were unable to demand the services they required or to ensure that the services provided were the best available.
- Inconsistency in use of PMTCT Protocol: results indicate that various clinics and hospitals follow different protocols when implementing a PMTCT programme. These inconsistencies include: when ARVs are administered to women and babies, the level of counselling that takes place, staff's knowledge of the programme, the length of time the women receive milk, and the amount of milk that they receive on a monthly basis.
- Stigma and discrimination amongst health care workers continues to be a problem: This was raised particularly by adolescent and young positive mothers. This could be grounded in Jamaican culture where "children are to be seen and not heard" and where teenage pregnancy is frowned upon. Adolescents who become pregnant face severe discrimination from their peers and society in general. An adolescent who is pregnant and positive faces double stigma.
- The sexual and reproductive health and rights of women living with HIV are not universally recognised in Jamaica: women in general do not receive counselling on sexual and reproductive health issues. Some are given condoms but their own sexuality and contraceptive options are not routinely discussed and so women are rarely able to make informed decisions about their sex lives. Additionally, women are routinely dissuaded from even the consideration of children and some are forced to be sterilised. There are indications that the lack of counselling around SRH has resulted in a high number of unintended pregnancies – women do not have the skills or information to plan pregnancies that would put their partners at least risk of infection and co-infection
- Male involvement in PMTCT is low: generally, men are not allowed to participate in antenatal activities in the public sector so that when men want to participate in their partners' PMTCT programme, they do not have the opportunity to do so. Additionally, a significant number of positive women have not disclosed their status to their partners making it impossible to difficult to involve them.
- Counselling to promote safe pregnancies among PLHIV is limited or non-existent: generally, counselling is not done and indications are that an increasing number of women are having unplanned pregnancies.

Key Recommendations

- **PMTCT Guidelines** need to be made available to all stake holders including NGOs and clients.
- **PMTCT Protocol** needs to be adhered to uniformly and across the board
- **Programmes must include the active participation of male partners:** In Jamaica, men have not been engaged in the PMTCT programme and have rarely been considered part of the solution to improved prevention, treatment, care and support. Interventions and services to promote sexual and reproductive health, including PMTCT programmes, have focused too narrowly on women.
- **SRH rights handouts should be developed and distributed to all clients.** These should be produced by the National HIV/STI Programme to promote accountability in the implementation of the programme.
- **PMTCT programmes must focus on partner disclosure:** This is a major problem in Jamaica and contributes to the continued high level of stigma and discrimination and increased infection rates. Women should be supported and encouraged to disclose to their partners and vice versa.

- **Increased counselling to prevent unwanted/unintended pregnancies:** A number of the women, especially adolescent and young women who became pregnant did not plan their pregnancies. This has serious implications, not only for the mothers themselves, but for the children and their partners.

1. INTRODUCTION

Jamaica has recorded some significant successes in the HIV response in recent years, especially in the area of treatment. Despite this, the HIV prevalence rate has continued to rise - an estimated 32,000 Jamaicans, or 1.7 per cent of the total population, are living with HIV with 50 per cent unaware of their status.[1]

As of December 2009, the National HIV/STI Programme (NHP) recorded 25,706 persons with HIV, advanced HIV and AIDS. Some 1,489 persons were reported with advanced HIV in 2009. Of these 909 were AIDS cases. The number of persons dying as a result of AIDS declined by 43 per cent when compared to the 665 persons who died in 2004 when there was no public access to life saving antiretrovirals (ARVs). There were 378 deaths in 2009.

Data show that males continue to be infected at slightly higher rates than females, with a male to female incidence ratio of 1,2:1. The cumulative AIDS case rate shows males accounting for 642 cases per 100,000 population compared to 461 cases per 100,000 population for women. The most urbanised parishes in Jamaica are most affected by HIV with St. James recording 1,175 cases per 100,000 population and Kingston and St. Andrew, 822 cases per 100,000 population.

Adults aged 20 – 49 years old, who are within the most active reproductive years, account for 74 per cent of all persons reported with HIV, advanced HIV and AIDS in 2009 and 86 per cent of all people diagnosed with HIV are between 20 and 60 years of age.

Additionally, data from the National HIV/STI Programme indicate that whilst, in general, more men are infected than women, the incidence of HIVamong girls in the 10 -19 age group has increased since 1982. A similar picture is evident among women aged 10 -29 years old, where the number of women diagnosed with HIV outnumbers that of the men diagnosed with HIV in the same age group.

HIV is mainly transmitted through sexual intercourse in Jamaica, 90 per cent of which is heterosexual.

PMTCT Programme
The prevention of mother-to-child transmission of HIV (PMTCT) programme is one of Jamaica's most successful initiatives in the response to HIV. In 2009, Ministry of Health data indicated that for every 1000 pregnant women attending public antenatal clinics, at least ten were HIV infected.

The expansion of testing within the public health sector resulted in at least 95 per cent of pregnant women using the public health sector being tested for HIV. Women who test positive are given antiretroviral treatment to prevent transmission of the virus to the baby. This PMTCT programme resulted in a 19 per cent decline in paediatric HIV between 2008 and 2009. A total of 26 babies were born with HIV in 2009 compared with 32 the previous year and 78 in 2004.

Additionally, five paediatric AIDS-related deaths were reported to the Ministry of Health in 2009, compared to nine in 2008 and 13 in 2004. This represents a 31 per cent decline in the number of paediatric AIDS-related deaths and is attributed to increased access to treatment by HIV-infected children.

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[1] All epidemiology data was taken from the National HIV/STI Programme Annual Report 2009 and the National HIV STI Programme Epidemic Update 2009.

Overall, Jamaica has successfully reduced vertical transmission from a high of 25 per cent in 2004 to less than five per cent in 2009.

Despite this success, almost 20 per cent of mothers living with HIV and five per cent of infants who have been exposed to HIV continue to elude the PMTCT programme. According to the NHP, this is due to the late presentation of HIV positive pregnant women to public health facilities. Additionally, some mothers who live with HIV may refuse replacement feeds due to fear this may be seen as an admission to being HIV positive from her family or community while infants who have been exposed to HIV are lost to follow up.

1.1. Background

The idea of FGDs arose out of discussions among key experts on the PMTCT from various parts of the world and people living with HIV (PLHIV) around a five year strategic framework being proposed by the Interagency Task Team (IATT) for *Prevention of HIV Infection in Pregnant Women, Mothers, and their Children.* The framework is geared to help inform the way PMTCT services should be organised and run.

The policy framework focuses specifically on the first two components of PMTCT:

1. Prevention of HIV among women of childbearing age
2. Prevention of unintended pregnancy among women living with HIV

The main aim of the FGDs was to facilitate the meaningful involvement of those living with and affected by HIV in the final version of the strategy and to strengthen the document through key insights of those living with HIV. Next to the FGDs, there were also moderated online consultations among individuals living with HIV and an e-survey for those living with and affected by HIV.

1.2. Purpose of Report

The purposes of this report are to:

- Document the focus group discussions
- Analyse the findings
- Present the recommendations for improvement in the current programmes to prevent the transmission of HIV to infants.

1.3. Objectives of the Study

- Identify gaps in knowledge about the PMTCT programme in Jamaica
- Assess awareness and knowledge of the PMTCT programme in Jamaica
- Identify challenges and barriers to accessing quality PMTCT services
- Determine models for improving the PMTCT programme

Chapter 2: Methodology

2.1. Recruitment of Study Participants

Purposive sampling was employed to recruit study participants for the FGDs. This sampling strategy implies an intentional and systematic selection of informants with similar experience in the context of PMTCT in Jamaica. This method of recruiting implies that data generated from the study can have substantial relevance beyond the study informants.

A key criteria for involvement was that the women would have had experience using the PMTCT programme or fall in the age group most likely to use it, such as emancipated minors. Women in the age group 15 to 49 years old were recruited. A deliberate effort was made to include the views of men on the programme. As a result partners of women who had participated in the PMTCT programme or were HIV positive and wanted children were recruited to take part in the discussions.

Participants in the focus group discussions were affiliated with four entities – Eve for Life, Jamaica AIDS Support for Life, Jamaican Network of Seropositives (JN+) and the Jamaica Community of Positive Women (JCW+).

Three focus group discussions were held. Two were composed of women only and one of men only. One of the all female groups was composed of women aged 16 to 24 years old and the other of women aged 25 years and over. The male group was comprised of males 20 years and over.

2.2. Focus Group Techniques

The focus group discussion was guided by a list of questions that sought to explore the experiences of males and females with the PMTCT programme in Jamaica. Topics covered knowledge of the PMTCT programme, perceptions of the programme, knowledge of sexual and reproductive health (SRH), knowledge of SRH and rights, access to SRH information and tools; and, SRH rights and PMTCT.

A variety of group techniques were utilised in the conduct of the FGDs. These included brainstorming and general group discussion.

The sessions were moderated by women who had extensive knowledge of gender and HIV issues in Jamaica. Their roles were:

- To guide the discussion utilizing the prescribed guideline;
- To provide relevant background information and clarification to related issues or questions
- To provide an open and non- judgemental space for the participant to have free flowing dialogue
- To maintain focus on the activity objectives.

Each session lasted for two hours.

2.3. Data analysis

Data were recorded with the permission of the participants and transcribed verbatim for analysis. Analysis of data was done manually by the rapporteur using the principles of systematic text condensation. This meant repeated review of the transcripts to gain a thorough sense of the overall content in the texts, identifying central meaningful units in the material, condensation of the content through a coding of the text, and finally creating categories that contain the condensed meaning of the main themes in the material.

Chapter 3: Detailed Findings and Analysis

3.1. General Information on the Participants

Participants for the FGDs were recruited from nine of the 14 parishes in Jamaica - St. Thomas, Clarendon, Kingston, St. Andrew, St. Catherine, St. James, St. Ann, Portland and Westmoreland. The parishes represented a good mix with all four Regional Health Authorities (RHA) being represented. This indicates that an attempt was made by the implementing agency to capture the views of a wide cross-section of persons served by health facilities in the four RHAs.

Twenty seven persons participated in the discussion including seven males. The male participants were a mixture of HIV positive and negative men. Ten participants were aged 16 – 24 years old and 17 were aged 25 to 49 years old. The majority of the participants (12) self described as having visiting relationships (partner does not live in the same house); seven were single; five were living with their partners;two were married; and, one was divorced.

All the participants who were involved in visiting relationships were women and three of the five that were living with partners were also women. Four of the seven participants who were single were females and none of the married participants were women.

Twenty six of the participants had children; 12 wanted to have more children and six were not sure. Of the 12 participants who wanted more children, nine were women. Women were also the only ones who indicated they were not sure they wanted to have more children. The latter group may pose some serious issues as they are the ones most likely not to practice safer sex or to experience an unplanned pregnancy. It could also mean the group did not receive adequate counselling around sexual and reproductive health issues in the PMTCT programme to help them to make informed decisions about child bearing.

The male participants had a combined 15 children. Of the six male participants with children, the highest number of children per father was five and the lowest one.

Among the 20 female participants, the combined number of children was 45. The highest number of children per woman was four and the lowest number of children per woman was one. Of the nine women who wanted to have more children, 6 were in the age group 25 – 49 years. One of the women who wanted to have more children already had four children and two of the women interested in having more children had three children already. The three women in the 16 – 24 years age range who indicated they wanted to have more children had two children each. Sadly, one of the three young women who wanted more children had undergone a tubal ligation, without her consent.

3.2. Organisation of PMTCT Services

The research in all the groups started with a discussion on what participants thought the acronym PMTCT meant. Most persons were unable to accurately define the term but understood enough to take part in the discussion. Generally, participants indicated that while they could not say what the acronym meant, they knew it had to do with "*preventing the baby from getting the virus from the mother"; preventing the child from catching HIV"; "... medication so that they can prevent the child from getting HIV"; "getting the treatments to prevent the baby from getting the virus" and "prevention from the mother to the baby and also for prevention from other persons".*

Additionally, participants noted that sometimes they overhear the nurses and doctors using the term, but had no idea what they were talking about. Still other explained they had heard the term at workshops, on television, at clinics and at support group meetings, but could not recall the meaning. One of the two participants who could define the acronym said she learnt the meaning and about the process outside of Jamaica at a workshop in Trinidad.

Less than 90 per cent of the female participants were able to explain the PMTCT process as it is rolled out in Jamaica. There was general confusion about the basic minimum package of care under the programme and so participants' experiences varied. What was clearly established was that all the mothers were tested for HIV, although only limited counselling occurred. After the testing, it became unclear what the process involved.

Some stated that they began medication immediately after receiving the results and others noted they began receiving 'medication' close to when they were due to have the babies.

"When I was pregnant five years ago, I wasn't told what it was for but I got some medication. The medication was taken when I went to the doctor and the doctor took me off that specific medication and he gave me another one. He was telling me that it was suppose to help to prevent the transition of the disease from myself to the baby and what he told me also is that I would not be able to have the baby vaginally" – **female participant**

"They didn't give me any medication till about one week to the birth date and they give me a pill and they said when I start feeling the pain I should take it. I didn't take it at home. When I went to the hospital they said don't take it as yet so I didn't take it. After about an hour they give me another one so I took that one but not the first one" – **female participant**.

Others who received medication, did not take it as prescribed becausethe reason to take it was not fully explained.

"I have a baby at Victoria Jubilee (Kingston) but when they give me the pill I didn't take too much of it. At the hospital, the nurse give me the pill and when I say what is it for, she said preventing mother to child transmission and I only took one bottle" – **female participant.**

A majority claimed their babies received 'medication' after birth and one claimed the baby was given six weeks later. It also appeared that there was some uncertainty as to the length of time the baby would be required to be on the 'medication' to prevent transmission of the virus.

There appeared to be several inconsistencies in the roll out of the programme. These inconsistencies were most evident in the treatment of the clients at the clinic and/or hospital; medication prescribed and milk substitutes given. The first will be dealt with in the next section.

In terms of medication, as shown above, participants were given 'medication', but the requisite information about the medication was not passed on to them resulting in low adherence. Another situation highlighted was that doctors and nurses and, in some instances, adherence counsellors were either not communicating about treatment issues or they had different opinions on how clients were to be served.

"They send me to high risk clinic and when I went to the clinic the doctor prescribed some medication for me – two bottles of medication. Now when I saw the nurse, she called the adherence counsellor and showed her what I got, then the nurse said no, don't take those. So I was like 'if the doctor prescribed them, why shouldn't I take them?' The nurse went ahead and changed the medication. Instead of two bottles of medication, she gave me one bottle of medication. Even today I ask myself how the doctor prescribed the medication and the nurse change it? – **female respondent.**

Some hospital staff seems not to have all the information regarding the prevention of mother to child transmission of HIV programme. Due to this, there are those who insist that the positive mothers should breast feed.

"When I went to look for my baby, there was nurse who told to me that I should feed him. I said 'no, I'm not feeding him' and then another nurse gave me some milk. She then told me that because of my status then I'm giving you some milk until six months" – **female respondent**

Most participants said they received milk substitutes for up to six months. Others received up to a year. It was difficult to determine what quantities they were entitled to get. The number appeared to depend on the clinic attended, the parish they are situated in, and the relationship with the clinic/hospital staff. Additionally, all received instructions on how to breast feed, but only a few were instructed on how to mix the milk substitute or how to feed the infant. Also, only a few were given information about mixed feeding – breast and milk substitute together.

One participant who had her baby in 2007 stated she received 10 tins of milk per month, another who gave birth in 2009 also noted she got 10 tins.

"Actually I knew persons who had a child within the same period of time that I had who got less feeding. So they give you the things in this system based on how well they probably know you or how they feel about you" – **female respondent in 16 to 24 years old group**.

Others who had no particular relationship with clinic staff got milk ranging between three tins and six tins per month. Then there were others who just collected milk from the clinic whenever they wanted, with some receiving up to 12 tins per month. In Clarendon, women who attended the Denbigh clinic received instructions on how to feed the baby, including timing and how to mix the substitutes.

Another poignant issue that came out of the discussion around the PMTC process was that in their attempts to be 'nice' to participants, clinic and hospital staff inadvertently put clients at risk. One participant noted that she requested that her illness is not recorded on her docket that would be sent to the hospital she was scheduled to give birth. The request was granted.

"This nice nurse said when I go in to have the baby I must tell them that there is this medication that the baby is supposed to get as soon as it born. She didn't really explain to me how everything would work. She only said it help prevent the baby from getting HIV" – **pregnant female participant.**

The reality is that the participant may not be in a position to instruct the doctors or nurses about her status and the risk of transmission to the infant.

The discrepancy in the information regarding the PMTCT process indicates that participants in general were not familiar with what was expected in the programme. Further probing revealed that medical staff do not spend time with the users of the service to explain from the beginning what the process entails. Additionally, the results of the discussion indicate that the PMTCT programme is not being implemented consistently across the regions.

"When I was in hospital in Montego Bay they were saying because my CD4 was high that they were not going to start me on any medication. When I came to Kingston, I was three and a half months going to four months and when I went to UWI (University hospital of the West Indies) I was four months exactly and the nurse said that I have to start even though my CD4 is high. So I got the medication and started it," – **female respondent**.

Another noted that CD4 count test was not offered in the parish she lived in and, therefore, she had to travel to Kingston for the test. As a result, she did not start treatment until she was five months pregnant. Still others started even later.

"*When I went to Comprehensive Clinic for my first child, they said they would start giving me at eight months. So when I found out that I was pregnant last year and went back they started at two months,"* – **female respondent**.

"When I started going to the high risk clinic, I was five months, they still continued me on vitamins and iron tablets. I didn't get any ARVs. They told me that the only time I was going to get any medication is when I start feeling pain. So as soon as I started start feeling the labour pain I took one and go to the doctor. So I didn't have any medication before," – **female respondent**.

3.3. Clinic/Hospital Experience

As indicated above, clinic and hospital experiences are not necessarily uniform across all regions. It appears that each experience is dependent on the region, the clinic/hospital, the staff and the relationship between the client and clinic/hospital staff.

For some, the clinic/hospital experience was pleasant and accommodating. This was especially so for participants who utilised the St. Jago Health Centre in Spanish Town, St. Catherine. Participants noted that staff would call them at their homes to enquire about them and the babies' progress. They ensured that the babies had a steady supply of milk and generally, the care and support was perceived as of high quality.

"They always treat us well. If you miss one appointment, they know and they call you by name," – **female respondent**.

The older women also indicated that they did not feel they were singled out for any negative treatment. In some rural health facilities, they noted that the staff worked hard to protect their status even from other medical staff. They however noted that this is harder at clinics where only one woman is utilising the PMTCT programme. In such cases, it becomes noticeable that the same person goes to the same health care provider all the time and which may evoke questions.

Another important issue highlighted by the participants was that unlike in previous years, everybody now has to do tests for HIV and is treated in the same health centre as those who are HIV negative. Nobody is singled out for special treatment.

For others, the experience was highly negative with reports of stigmatisation and discrimination by clinic and hospital staff. Results from the research indicate that adolescent mothers were more likely to report acts of discrimination than women aged 25 and over. The adolescent women report being ridiculed and made to feel less than human.

"They treat you like dirt especially at Jubilee. When I went in the nurse said: 'see one a dem a come'. When I was in labour, I tell her that I feel something coming out and she said 'what coming out?' So I said 'the something coming out.' What happened was that the head water came out in a bag. Suppose you see how the lady behaving – I told her I'm thirsty, feel like I'm going to faint but she told me to stand up and faint if I wanted to," – **adolescent female respondent.**

One participant noted that she recalls asking for condoms at the clinic and was asked why she needed it since she already had HIV. She never asked for anymore. Another pointed out that her requests for food were always turned down.

"When you go to Comprehensive Clinic and ask for food or vitamins they refuse to give it to us. But, when they are expired, they call us," – **adolescent female respondent.**

The policy of integrating HIV positive women with other women such as those with diabetes in high risk clinics was also pointed out as a source of potential discrimination.

"A lot of them think that when they go to high risk clinic people are watching them, especially when they are not of a certain age. They think that people are wondering if they are HIV positive," – **female respondent**

3.4. Responsibility in the Process

Participants indicated that their responsibility in the PMTCT programme is to ensure that they remain healthy throughout the pregnancy and beyond, that they receive medication to prevent their babies from becoming infected and to get as much information as possible on sexual and reproductive health issues.

"Our main responsibility is to ensure that I look after myself spiritually, physically, that sort of thing. Get as much information as I can, about where I am and what I'm doing as it relates to my illness," -**female respondent**.

3.5. Basic Care

Findings from the FGDs show that the participants did not know what the minimum basic care package for PMTCT is. Although the majority of women said their experiences in the clinics/hospitals were good, they were not able to articulate all that ought to be done under the programme. As a result, they explained it was very difficult to challenge decisions made by medical and other staff as they had no guidelines.

Furthermore, it appeared that different sites did different things. Our research shows that women get pregnant, go to the health centre, get tested, and find out that they are positive but are kept in the general clinic where they visit a regular nurse or midwife for their regular monthly check-ups. Some are put on ARVs to help prevent the child from becoming infected; for some this was three months, for others four months – some were put on it a little later.

3.6. Male Involvement

Like their female counterparts, the majority of the male participants did not know what the acronym PMTCT meant. Some were only hearing the term for the first time when they were invited to sit on the focus group panel and one heard the term before at a meeting. One participant offered that the term meant child birth and another that the woman won't pass on the virus to the child.

As a general rule, Jamaican men play limited or no role in their women's antenatal experience, especially at public health facilities. They are not allowed into consultation rooms nor are they allowed into labour rooms.

The majority of men involved in the FGDs indicated that they wanted to play a more active role in the health and well being of their spouses and children. They noted that they would have liked to accompany their partners to antenatal clinics as they would be able to get first hand information about their own status, the health of the unborn child and what is to be expected under the PMTCT programme.

"Men should go with the women. They need to know what is going on and get information firsthand," **– male respondent.**

One participant noted that love and responsibility should make men want to be involved in the process. Still another pointed out that whilst men want to be involved, there were some women who for varying reasons had not disclosed their status, thus excluding the man from participating. He further noted that the PMTCT programme should include assisting women to disclose to their partners so they can play their role in the process.

"Men can't just get up and go want information. The woman has to let him know from the beginning," – **male respondent.**

The findings of the discussion indicate a need for the current PMTCT programme to be revisited and steps taken to make disclosure less painful for women. The literature points out that women who do not disclose to their partners are more likely to default on the treatment regime for PMTCT. Additionally, the findings corroborate studies done in Kenya, Botswana and Zambia that male involvement improves the outcome of PMTCT programmes. In these settings, couples are counselled and tested together, reducing the potential for blame and violence.

But even while the men agreed that they needed to be more integrally involved in the health care of their partners, some were hampered by culture.

"There is this stigma attached to men going to clinic – I have this friend who has a baby and when the baby mother asks him to help her to carry the baby, he tells her no," – **male respondent**.

Additionally, men were also hampered by the long wait at the clinics and hospitals for essential services. A typical visit to the public health facility can last up to half a day with the client being asked to undergo various tasks before actually seeing a doctor.

"As far as I see it, women have more patience than men. Going to clinic is not a big man thing, it is a woman thing. The wait is too long," – **male respondent**.

In contrast to the resounding need for male involvement coming from the men, the women were a bit more cautious although there was some agreement that it is important.

"You have to incorporate the father from inception, from when you find out that you are pregnant and you start going to the clinic you have to have the fathers participate from that time. Their role is very important," – **female respondent**.

A key barrier highlighted by the women was the fear of violence when the men find out the women are HIV positive.

"When the woman gets pregnant and you go and tell the man, some of them get ignorant and you don't see them again. They blame it all on you and you don't know who to turn to," – **female respondent.**

One participant noted that even if the men would attend antenatal clinics, the women would not allow it as the potential for inadvertent disclosure is a real issue. Generally speaking, the lack of disclosure could prevent men from being a part of the PMTCT programme.

"I have a couple right now – the man is negative, the woman is positive, she is going to have baby next month. The man is fully behind her, because it is his first child. His mother is even coming to Jamaica for the birth of this child. The woman is planning to leave Clarendon, go to St. Ann, have the baby then come back to Clarendon because she doesn't want him to know she is HIV positive," **female respondent who leads a support group for persons living with HIV and an adherence counsellor.**

The findings from the FGDs support the need to define the role that men can play in improving the health outcomes in the PMTCT programme. Male involvement is a currently underutilised facility that could significantly have far reaching impact on the HIV response in Jamaica. Evidence points to the fact that males are not encouraged to attend antenatal clinics with their partners, neither is partner testing done. The findings of the discussion support the need to further define specific male partner factors that are associated with improved PMTCT outcomes. However, before the discussion on male involvement takes place, there is a huge need for empowerment for disclosure so that the partners can be more involved.

3.7. Sexual and Reproductive Health and rights and PMTCT

Evidence from the FGDs point to a failure on the part of health sector workers to adequately provide information on sexual and reproductive health issues that would encourage informed decision making around child bearing and sexually transmitted infections. The PMTCT programme in its current form does not effectively integrate family planning services and participants indicate a reluctance to provide options available to them.

One participant noted that she got pregnant when her second child was less than one year old. She requested an abortion as she would have been unable to care for two babies. She was however turned down in the public health facility, and had to get it done privately.

More than 95 per cent of the females indicated that the most common option available to them as positive women was tubal ligation (TL).

"I have sat in clinical settings, you know in the hospitals and so forth and listened to health care providers *pushing* it down positive persons' throats. 'Doctor mek sure wen yuh kyaah him dong a theatre no bada kyaah him bak up yah an no tie him off," (Doctor, make sure when you take her to the theatre [for c-section] don't take her back without doing the tubal ligation)- **female respondent.**

"*When I had my last child, they never really explained about the tie-off and such they just said 'you need to do a tie-off' an mi just jump go do it,"* – **adolescent female respondent**.

Indications are that participants are not counselled on how to have children safely and only limited information about other sexual and reproductive health issues are provided. Generally, participants also felt that their right to information and their right to have children safely were not routinely honoured. Participants indicated that information is deliberately kept from them because health workers do not think they deserve those rights.

"So when you go to them, you start thinking ok I'm positive and I don't want to talk to anymore man and I don't want anymore man, they encourage you. They don't say to you ok, you don't have to go that route, you can function just as a normal woman," – **female respondent**.

"The nurses advise you, once they find out that you are positive, that you should not have any more children. Everybody decides that you are not to have any more children. I remember when I went to the doctor and I said I'm planning to get married and so and I would like to have another child because I have only one. And she was saying to me 'yes it is possible but don't think about it. Don't think about it.' Basically saying it is possible that I could have another child but I mustn't think about it. I felt as if I was no longer a full functioning human and that that part of me should be dormant – it should be dead. I still feel like I would love to have another child,' – **female respondent.**

All participants felt it was the right of positive persons to have sex and to decide whether or not to have children. However, the perception among the participants was that society in general would rather they did neither.

"First and foremost, society on a whole believes that I should stop having sex. My family believes I should stop having sex. My mother told me specifically, don't think about men; don't think about sex. And when I sat down with her and explained to her that I would like to get married and stuff she pretended not to hear," – **female respondent**.

Persons living with HIV themselves self stigmatise and according to participants, many positive persons give up their rights on diagnosis.

"I think for some of us, when we find out that we are positive we kind of give up that right as well. We say we don't want no more man, we won't have sex, we won't have children, but once we start going to workshops and you start getting all the information and you start understanding about your status then you start changing your mind and knowing that yes I have the right to this and I have the right to have sex and the right to have another child and the right to have a child. So I guess sometimes it starts with us as well," – **female respondent**.

The male participants shared similar views regarding the right to information to protect them from becoming reinfected or infected and information on how to have children safely. They agreed that positive persons have the right to have sex as it is “a natural thing.”

“At the end of the day, we are all human beings. Nobody should tell us we can’t. We have a responsibility to protect our partner and ourselves,” – **male respondent**

They however bemoaned the fact that there were not enough men in the system that they could have one on one session with or who could guide them from a male perspective.

“We relate to another man better with certain information. When it comes on to women now they might go, you know, and talk but they are not going to talk everything,” – **male respondent**

3.8. Mother to Child Versus Parent to Child Transmission

All (100 per cent) of participants in the focus group discussions felt that PMTCT should be changed to PPTCT (Prevention of Parent to Child transmission of HIV). The reasons given were that the scope is broader, that is the services will involve both parents rather than just the mother, and because the responsibility of ensuring the child remains uninfected is not solely the mother’s. Emphasis will have to be placed on disclosure as PPTCT is only successful if both parties are aware of their status and this will require a reduction in gender based violence and the threat of violence or rejection upon disclosure.

“Mother to child sounds like you are blaming the mother. You are taking away from that when you say ‘parent.’ It is not focussed so much on the mother,” – **female respondent**

Another participant noted that parent infers long term commitment.

“Mother to child is just like from the child is in the womb until when the child comes out. So when you say ‘parent’ now, you know it’s a long thing for both parents to help to grow that child right through,” – **female respondent**.

A male participant further hinted that parent to child denotes shared responsibilities, not only as it relates to prevention, but also treatment and care.

3.9 Study Limitations

It required an enormous effort to complete the focus group discussion project within the allotted time and the study was limited by those time constraints.

Recruitment of participants was limited to people living with HIV who are members of networks or non-governmental associations of people living with HIV and through peer referral. No effort to recruit women from treatment sites was made due to ethical concerns.

Fortunately, these limitations did not affect the achievement of the overall objective of the focus group discussion.

Chapter 4: Conclusions and General Recommendations

The discussion in general indicated that the PMTCT programme as it is now being implemented in Jamaica needs to be revised. Five main areas of concern were raised:

Clarity and visibility of the PMTCT programme among users:
Participants noted that there was no document readily available that outlines what is involved in the PMTCT service which they are accessing. Such a document or set of guidelines should contain information on how the programme should be implemented and made available for all clients. Additionally, implementation of the programme itself is haphazard with different health facilities or regions implementing various models of differing quality. This creates confusion, especially in situations where clients are already unsure or uninformed about the services to which they are entitled. To resolve this program, a set of handouts on vertical transmission, the protocol, and sexual and reproductive health and rights should be designed and distributed widely across health facilities and communities to enable women and men living with HIV to demand quality care and make informed decisions. In addition, clear PMTCT Guidelines need to be made available to all stakeholders, including NGOs and clients, and steps taken t o ensure that the Jamaican PMTCT Protocol is adhered to uniformly across all providers' settings.

Holistic and family approach with active participation from male partners is lacking:
There was consensus on the need for the greater involvement of men in the programme with a recommendation that the programme should be renamed prevention of parent to child transmission of HIV (PPTCT) to reflect the roles of both partners in the health of their child. Programmes must include the active participation of male partners. In Jamaica, men have not been engaged in the PMTCT programme and have rarely been considered part of the solution to improved prevention, treatment, care and support. Interventions and services to promote sexual and reproductive health, including the PMTCT programme have focused mainly on women. Failure to target men has weakened the impact of reproductive health programmes since men in general significantly influence their partners' reproductive health decision-making. Male involvement in the programme can therefore lead to higher levels of adherence and better health outcomes for women and their families. The involvement of men at the antenatal stage, however, requires a woman's disclosure of her status to her partner. A major issue in Jamaica is the reluctance or inability of males and females to disclose their status to their partners for fear of stigmatisation, rejection, or violence. Therefore, in order to increase male involvement, PMTCT programmes must first focus on safe, voluntary partner disclosure and then seek ways to actively involve women's male partners and address the men's sexual and reproductive health concerns.

Stigma and discrimination is still an issue especially for adolescent and young mothers:
Stigmatisation and discrimination were highlighted as major barriers to services for adolescent and young mothers living with HIV. The same was not evidenced in reports from the older women. It was not clear whether the age of the women was a contributing factor to being stigmatised.

Sexual and reproductive health and rights issues and the PMTCT programme:
The majority of the participants indicated that they were given little or no information on sexual and reproductive health issues. Most information was related to what not to do, such as how to avoid having more children. Therefore, increased counselling must be made available to women and men living with HIV to prevent unintended pregnancies, including the provision of contraceptives, and to empower them to conceive and deliver safely where they desire the pregnancy. PMTCT programmes must include community

level outreach and support and widespread dissemination of both sexual and reproductive health information and rights, including the right to privacy and confidentiality in the health care setting. Programmes must also strengthen accountability mechanisms within the facilities to ensure that abuses are prevented where possible and immediately addressed where they occur.

APPENDICES

Appendix A

Jamaican Community of Positive Women
Prevention of Mother to Child Transmission Framework Review
Focus Group Discussion
January 2011

Participant Profile

<u>DO NOT put your name on this form</u>
<u>Please use a tick, circle or insert information that applies to you,</u>

Affiliation: JCW+, Eve, JN+, JASL, Other____________

1). Gender: (a) Male (b) Female (c) Transgender

2). Age: (a) 16- 24 (b) 25 – 49 (c) 50+

3). Relationship Status: (a) Married (b) Widowed (c) Single Divorced/Separated (d) Living with partner (e) Visiting relationship

4). Living with HIV for ______years

5. A). Do you have children? Yes/No (If yes), How many? ______.
Do you want to have more children? Yes/No/Not sure

B). If No, do you want to have children? Yes/No How many? _________.

Appendix B

Questions for women:

1. Are you familiar with the acronym – PMTCT? Yes / no
    a. When you hear the term Prevention of mother to child transmission, what images come to mind? (Allow participants to create images either through sketches or descriptive words)
    b. Where did you get the information from?
2. Have you ever heard the 'prevention of parent to child transmission'? Yes/no
    a. What images does this create in your mind?
3. Which term do you think is more appropriate?
    a. Why?
4. Have you ever been in a PMTCT programme? Yes/no
5. Are you aware of what is involved in PMTCT?
    a. Outline/describe the PMTCT service offered in your area
    b. If yes, what was the experience like?
6. What are your expectations of the state and services provided?
7. What are your own responsibilities?
8. How would you define sexual reproductive health?
    a. 8a. What does it involve?
9. Where do you get your information about SRH?
    a. Did you get this information when you were in the PMTCT programme?
    b. Where do you think information about SRH should be given?
10. What is your understanding of SRH rights?
    a. Are these rights available in Jamaica?
    b. If yes, did you get information about your SRH rights while part of the PMTCT programme?
11. Share your experience with PMTCT as it concerns SRHR, family planning and HIV health information.
12. What are some situations that denied your rights to SRH?
13. Are men encouraged to participate in family planning, SRH, support decisions of partner?
14. Are you aware of any prevention service/activity that encourages/targets men accessing SRH? Any male centred services?
15. Does stigma and discrimination influence your decision to access the service of PMTCT?
16. What are the barriers that would prevent you from accessing comprehensive SRH service?
17. Do you feel that there is enough support for positive women and couples to have children safely?
18. How do you think the counseling within the PMTCT service supports/facilitates your right to have children?
19. As a woman living with HIV, were you given family planning information at the treatment site/clinic?
20. What information or tools were you given?
21. What are some of the barriers that make it difficult for you to access information and services to prevent unintended pregnancies?
22. If you had the power, what type of programme would you put in place for HIV positive women and their partners to prevent unintended pregnancies?

Appendix C

Questions for men

1. Are you familiar with the acronym – PMTCT? Yes / no
    a. When you hear the term Prevention of mother to child transmission, what images come to mind? (Allow participants to create images either through sketches or descriptive words)
    b. Where did you get the information from?
2. Have you ever heard the ‘prevention of parent to child transmission’? Yes/no
    a. What images does this create in your mind?
3. Which term do you think is more appropriate?
    a. Why?
4. Have you ever been in a PMTCT programme? Yes/no
5. Are you aware of what is involved in PMTCT?
    a. Outline/describe the PMTCT service offered in your area
    b. If yes, what was the experience like?
6. What are your expectations of the state and services provided?
7. What are your own responsibilities?
8. How would you define sexual reproductive health?
    a. What does it involve?
1. Where do you get your information about SRH?
    a. Did you get this information when you were in the PMTCT programme?
    b. Where do you think information about SRH should be given?
2. What is your understanding of SRH rights?
    a. Are these rights available in Jamaica?
    b. If yes, did you get information about your SRH rights while part of the PMTCT programme?
3. Share your experience with PMTCT as it concerns SRHR, family planning and HIV health information.
4. What are some situations that denied your rights to SRH?
5. Are men encouraged to participate in family planning, SRH, support decisions of partner?
6. Are you aware of any prevention service/activity that encourages/targets men accessing SRH? Any male centred services?
7. Does stigma and discrimination influence your decision to access the service of PMTCT?
8. What are the barriers that would prevent you from accessing comprehensive SRH service?
9. Do you feel that there is enough support for positive women and couples to have children safely?
10. How do you think the counseling within the PMTCT service supports/facilitates your right to have children?
11. As a man in a relationship with a woman living with HIV, were you given family planning information at the treatment site/clinic?
12. What information or tools were you given?
13. What are some of the barriers that make it difficult for you to access information and services to prevent unintended pregnancies?
14. If you had the power, what type of programme would you put in place for HIV positive women and their partners to prevent unintended pregnancies?