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HIV, pregnancy and parenthood: a qualitative study of the prevention and treatment of hIV in pregnant women, parents and their infants in papua new guinea

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HIV, pregnancy and parenthood

A qualitative study of the prevention and treatment of HIV in pregnant women, parents and their infants in Papua New Guinea



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Papua New Guinea Institute of Medical Research
The University of New South Wales
2013



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A note on terminology

In Papua New Guinea both the phrases *prevention of parent-to-child transmission* (PPTCT) and the *prevention of mother-to-child transmission* (PMTCT) are used, sometimes interchangeably, although greater emphasis is given to the former. In order that our report reflects the dominant way of discussing HIV prevention and treatment in this area we will use PPTCT unless PMTCT is specified.

Acronyms

ANC	Antenatal care
ART	Antiretroviral therapy
MCH	Maternal and child health
PICT	Provider initiated counselling and testing
PLHIV	People 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
VCT	Voluntary counselling and testing

Thank you to the families who consented for the images in this report to be used. Their inclusion does not denote that these people are living with or affected by HIV. The photographers include Tammy Gibbs, Angela Kelly, Jacinta Welch and Lisa Vallely. Please do not reproduce any images in this report without first consulting the lead author of the report.

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EXECUTIVE SUMMARY



This research was carried out between January and December 2011. It sought to understand the gendered socio-cultural factors influencing the uptake and outcomes of prevention of parent-to-child transmission (PPTCT) programs from the perspective of antenatal women, their partners and health care workers.

This was a qualitative study that employed in-depth interviews with women and men engaged in PPTCT programs, and health care workers involved in the delivery of PPTCT programs in Papua New Guinea's Western Highlands Province and the National Capital District.

In total, 113 women, men and key informants participated in the study. Of the 67 women, 53 were HIV-positive, with similar numbers recruited across the two sites. Eighteen (18) husbands were involved in the study, of whom 14 were HIV-positive. Ten men and 30 women were followed longitudinally. There were 28 key informants including nurses and midwives, medical officers, people living with HIV (PLHIV) advocates and patient experts, social workers and maternal and child health (MCH) or HIV specialist staff.

Most women reported that they consented to be tested for HIV. A few women, however, indicated that the opt-out option of 'Provider Initiated Counselling and Testing' (PICT) is sometimes not clearly stated, and that they had been told that they were going to be tested. A very small number of women reported that they had never consented to be tested. Around half of the HIV-positive women in the study had already tested positive prior to the current/most recent pregnancy. In PNG reproduction is viewed as a risky experience – for both the mother and the unborn infant. The virus played an important further complicating role in the reproductive decision-making of couples affected by HIV.

Reactions to a positive diagnosis were varied. In most cases the women were alarmed and did not know what to do. Group counselling did not appear to assist women in being prepared for an HIV-positive result. Several women (and men) reported wanting to commit suicide but later found hope by focusing on their child, often the result of support from health care workers.

HIV-negative women were told about the importance of not contracting HIV from their husbands during their pregnancy and advised to use condoms during sex while pregnant and to be faithful to their husband. Particulars about preventing mother-to-child transmission of HIV were given only to HIV-positive women, who were informed about antiretroviral therapies (ART), giving birth in hospital and, for the first six months of the baby's life, exclusive breastfeeding.

Although it is standard treatment of infants exposed to HIV to receive ART within hours of delivery, no women in the study reported on this. Health care workers stressed the importance of adherence to ART, including how and when to take the treatments. Almost all of the participants mentioned side effects of ART. However, almost half spoke of the positive impacts of treatments on their lives. Most HIV-positive people in the study were on ART; however, a number of men were not. Reasons included personal choice, recent diagnosis, CD4 cell count being too high. Others were afraid of treatment side effects and unwanted disclosure.

Almost all the women mentioned that they were advised to live a positive life: to disclose their status to their immediate families and husband so that the families and husband might support them. Some were encouraged to attend church regularly and to seek the Lord's support through prayer when taking medicine.

Health education messages as part of antenatal care (ANC) services were diverse and included the pros and cons of sex during pregnancy, delivery, personal hygiene, HIV testing, nutrition and family planning. A number of HIV-positive women were instructed not to have more children because of their HIV status. Tubal ligation was the most commonly discussed and emphasised method of preventing further pregnancies. Excluding the need to have a supervised delivery, no additional support was offered to women about delivery.

Most of the participants said that sex is culturally restricted during pregnancy and breastfeeding, and would result in the foetus being affected ('spoiled'). They felt that there would also be delays and protraction in delivery. Some health care workers advised some women that abstaining from sex would lead a husband to seek extra-marital relationships, while others encouraged women to abstain from having sex both during and after pregnancy out of fear of risk to the baby and the added risk of super-infection. Women were told that if they could not abstain from sex they should use condoms. Most women reported having sex up to the beginning of the third trimester.

There did not appear to be any formal written consent process for infant testing, and women did not report verbal consent being given. The consent process for HIV testing of infants appears to be solely that of women bringing their newborn to the PMTCT clinic at the times indicated by their health care team. Testing appeared routine for infants at six weeks, but women and their husbands faced delays in receiving the results of their child's HIV test. Several babies were required to repeat the test due to misplaced results, poor handling of blood samples, and indeterminate results. Others gave up on accessing their child's result due to costly ongoing delays.

Women's infant-feeding practices were strongly influenced by their health care worker. The majority of women received advice to exclusively breastfeed, and to abruptly wean their baby at six months. Only a few women had been advised to gradually introduce food and other liquids with the continuation of breastfeeding after six months. Few women followed the recent infant-feeding guideline (2009), which recommends exclusive breastfeeding for six months followed by the gradual introduction of solids and other liquids with

the continuation of breastfeeding. Several men highlighted clashes between health care workers' feeding instructions and community practices, resulting in tensions within the couple and with the community. Interestingly, many men played an active role in facilitating prolonged breastfeeding and protecting their wives from community pressure in relation to mixed feeding.

The key informants reflected the policy approach of the National Department of Health regarding women's choice around infant-feeding, but also reflected an avoidance of blame or retribution in cases where an HIV-exposed infant may seroconvert. While the majority of informants were familiar with the national policy of exclusive breastfeeding, this was less so in relation to the recent change in the national policy, which recommends continuation of breastfeeding after the first six months.

While involvement of men in antenatal care is seen as important, few attended ANC with their wives. Most notable was the perception that pregnancy in general, and ANC services in particular, were highly gender-segregated domains, restricted to women. This led to poor access to knowledge related to PPTCT and rare direct clinical and counselling encounters. Perceived risk of stigma with regard to coming to women's places was common, as men reported frequently feeling that they had limited control over the experience of pregnancy and childbirth. Men tended to provide indirect support (emotional, financial and material) to their wife and newborn.

INTRODUCTION/BACKGROUND



In 2011 UNAIDS launched a Global Plan to eliminate new HIV infections among children and to keep their mothers alive (UNAIDS 2011). This plan focuses on reaching pregnant women living with HIV and their children—from the time of pregnancy until the mother stops breastfeeding.

When we began to plan this research in 2008 HIV prevalence was estimated at 2% amongst adults aged between 15 and 49 in Papua New Guinea (PNG). At the end of 2007, PPTCT services existed in health care facilities in only seven of the existing 20 provinces, with coverage of only 2.32%, and only 84 HIV-positive women had accessed those services that year (Papua New Guinea National AIDS Council and Partners 2008).

A review of PPTCT was conducted in March 2009 by an Inter Agency Task Team (see Papua New Guinea National AIDS Council and Partners 2010, p.25). It found that integration of PPTCT services with maternal and child health services had been challenging. This was compounded by poor quality of services and human resource constraints, including: lack of formal PMTCT training; lack of capacity to manage the program; and a limited clinical and scientific understanding of PMTCT. At that time, while the Health Sector HIV and STI strategy had clear PPTCT objectives, these objectives had not been operationalised. There were also no systems for linking services and assuring quality implementation. Women and men's narratives of their experiences in PPTCT were a notable absence from that important review, an absence this study sought to correct.

Things have changed dramatically in PNG since then. The HIV prevalence among adults aged between 15 and 49 has been revised downwards two years in a row to less than 1% (National Department of Health and the National AIDS Council Secretariat 2011). By 2010, 203 sites in every province were offering PPTCT services. HIV prevalence among pregnant women attending ANC clinics was estimated at 0.6% in 2011 (Government of Papua New Guinea, 2012). However, the PNG UNGASS Country Progress Report 2008–2009 (2010) indicates that only 11.1% of HIV-positive pregnant women received ART to reduce the risk of mother-to-child transmission. This figure only rose to 12.3% in 2011 (Papua New Guinea National AIDS Council and Partners, 2012), so although there has been substantial increase in coverage since 2007, this has slowed in recent years (Papua New Guinea National AIDS Council and Partners, 2012). On the other hand, it must be stated that this percentage is likely to be an underestimation, as women already on ART who fall pregnant are not recorded in these figures. In 2009, 399 infants, just over a fifth (22.06%) of those born to HIV-positive women, received a virological test for HIV within two months of birth (Papua New Guinea National AIDS Council and Partners, 2012).

Not all pregnant women in PNG access ANC services. Many of the pregnant women without access to ANC and PPTCT services live in the most remote and less accessible locations in PNG where there is generally a lower prevalence of HIV infection. In 2011 an estimated 60% of all pregnant women had attended an antenatal clinic at least once (Papua New Guinea National AIDS Council and Partners, 2012), and HIV testing had been offered to

only 49,280 (23%) of these women. The PNG UN Global AIDS Report (Papua New Guinea National AIDS Council and Partners, 2012) estimated that in 2011, 640 cases of mother-to-child transmission of HIV among children 0 – 14 years old, from an estimated total of 1809 HIV-positive pregnant women occurred. This is a transmission rate of 35.4%. Of these, only 479 (26.5%) were new infections amongst infants. According to the report, the difference (161) between these estimations is mainly due to breastfeeding practices.

These data concur with the National HIV and AIDS Strategy 2011–2015, which acknowledges that while there has been an increasing effort to provide PPTCT interventions, the coverage rate for the full package of PPTCT interventions has remained at a low level. The weakness of MCH and the public health system have been major constraints to scale-up. The lack of a strategy for overall strengthening of the health system has not assisted, and an absence of systems for coordinating the different service components of testing (including the availability of testing materials), and treatment and care, have resulted in loss to follow-up of pregnant HIV-positive women.

In 2010, PNG was advised by the Global Fund that their Round 10 grant application, which partially focused on PPTCT, was successful. In 2011, PNG adopted WHO guidelines for PPTCT that will provide ART to all HIV-positive mothers until at least the end of breastfeeding (Papua New Guinea National AIDS Council and Partners, 2012). One of the top 10 interventions by the National HIV and AIDS Strategy 2011–2015 is to ensure that all pregnant women and their partners have access to the full range of prevention of parent to child transmission interventions through strengthened maternal and child health service delivery.

This research report details work carried out between January and December 2011. The research sought to understand the gendered socio-cultural factors influencing the uptake and outcomes of PMTCT programs from the perspective of antenatal women, their partners and health care workers. We expect these findings to assist in the policy and programmatic response to HIV and MCH in PNG. And in this way contribute to PNG's commitment to the Millennium Development Goals 4–6.

Research Objectives

This study had the following research objectives:

1. Examine knowledge, attitudes and decision-making processes regarding PMTCT
2. Test enablers of return for safe delivery and postnatal care
3. Examine experiences of consent, counselling and confidentiality
4. Determine gender-specific barriers and facilitators to accessing PMTCT programs
5. Develop recommendations for improved PMTCT programs

Methods

This was a qualitative study which employed in-depth interviews with women and men engaged in PPTCT programs and health care workers involved in the delivery of PPTCT programs in PNG. The study was undertaken in two provinces in PNG, each with high burdens of HIV: Western Highlands Province and the National Capital District. These sites were identified in a stakeholder meeting held in Port Moresby at the beginning of the study. Data was collected between January and December 2011.

Recruitment and ethics

Using a convenience sampling methodology and in order to reduce the risk of researcher-induced coercion, women and men engaged in PPTCT programs were informed about the study by health care workers in the services that they access to ANC, PPTCT and ART services. Once a potential participant was interested to participate, they themselves provided approval to be approached by a member of the research team.

All women and men were informed of their right to decline involvement and of their right to withdraw from the study at any stage without penalty, and importantly, without any repercussions to their access to or quality of health care. Although we enrolled more women who were HIV-positive, women who tested HIV-negative during antenatal testing (the first stage of PPTCT) were also included. The researchers directly approached key informants. All participants were provided with information and consent forms and provided written informed consent.

Ethical approval in Papua New Guinea was granted from the PNG Institute of Medical Research Internal Review Board, the Medical Research Advisory Committee and the PNG National AIDS Council Secretariat Research Advisory Committee. In Australia, ethical approval was granted from the University of New South Wales. An Australian Development Research Award Scheme Grant funded this study.

Description of Sample

Description of women and men

In total, 113 women, men and key informants participated in the study. The breakdown of the sample was as follows:

- 67 women (pregnant or recently given birth)
- 18 husbands
- 28 key informants

Of the women, 53 were HIV-positive, with similar numbers recruited across the two sites. A breakdown of the HIV status of the female and male study participants is available in **Table 1**. When we designed the study it was expected that the vast majority of women would have recently been diagnosed as HIV-positive during their current or most recent pregnancy. This was not the case. Although a convenience sample, a substantial number of the women with HIV in this study (41%; N=21/53) already knew that they were HIV-positive prior to the most recent or current pregnancy. Of these 21 women, 6 had tested HIV-positive during a previous pregnancy, 2 had tested HIV-positive following the birth of a previous baby, and 13 tested HIV-positive at a voluntary counselling and testing (VCT) centre prior to their current/most recent pregnancy. For a breakdown of where women tested HIV-positive see **Table 2**.

Of the 18 husbands involved in the study, 14 were HIV-positive. Sixteen of the 18 husbands had wives with HIV. Of the 14 couples enrolled in the study (7 at each site), four husbands had wives who were not enrolled in the study. These men were invited by the health care workers who knew that their wives were enrolled in the PPTCT program. Of these couples, 10 were seroconcordant. For a breakdown of the HIV status of couples in this study see **Table 3**.

Table 1: Participants by HIV status and gender

	HIV-positive	HIV-negative	HIV status unknown
Women	53	13	01
Husbands	14	03	01
TOTAL	67	16	02

Table 2: Place of HIV testing for HIV-positive women in relation to current/most recent pregnancy

ANC	Prior to current pregnancy	Labour ward	Postpartum at VCT
25	21	5	2

Table 3: HIV status of couples in the study

	HIV-positive husband	HIV-negative husband	HIV status of husband unknown
HIV-positive woman	10	2	1
HIV-negative woman		1	

Cross-sectional and longitudinal interviews

This study was both cross-sectional and longitudinal. Only women with HIV and husbands of HIV-positive women were eligible to be followed longitudinally. Key informants were interviewed once.

Of the 53 HIV-positive women eligible to be followed longitudinally, 30 agreed to a follow-up interview, with 16 women interviewed twice, and 14 interviewed three times over the course of the year of fieldwork. Of the husbands of HIV-positive women, 10 were followed longitudinally, with nine participating in two interviews, and one participating in three over the course of the year of fieldwork (see Table 4).

Table 4: Numbers of interviews given by HIV-positive women and their husbands

	One interview	Two interviews	Three interviews
HIV-positive Woman	23	16	14
Husband of HIV-positive Woman	3	9	1

From the 113 participants, 168 interviews were yielded and subjected to analysis. Of those who were followed longitudinally, approximately equal numbers were from the two field sites (22 from Western Highlands Province and

18 from the National Capital District). Women who were interviewed prior to delivery were followed up as soon as possible after delivery. Another important milestone where follow-up interviews were scheduled included early infant testing.

Participants in the longitudinal component of the study were followed up using a number of different techniques with differing success. The most successful technique was trying to pre-schedule follow-up interviews at ART/medical review dates. Mobile phones were a poor method for continuing contact and making follow-up appointments.

Description of key informants

Of the 28 key informants, 22 were in current clinical practice. The majority of these were nurses or midwives, of whom four were PPTCT program managers or coordinators, and four were sisters in charge of their respective clinical areas (well-baby clinic, labour ward, and antenatal clinic). The remaining informants included senior medical officers, VCT and HIV testing counsellor, a nurse working in a well-baby clinic and a midwife from an antenatal clinic. The majority of the informants (n=24) were women.

Data analysis

All interviews were digitally recorded with the consent of the participants. Interviews were transcribed verbatim and when necessary translated from Tok Pisin into English. All interviews were thematically analysed using NVIVO 9, a computer software package for the analysis and management of qualitative data. A codebook for interviews was designed by the research team using an inductive, grounded theory approach. As emerging themes were identified, a new code was added to the codebook. Two coding workshops were held with the local researchers in order to cross-check coding and to fine-tune the coding framework.

Quotes

In order to illuminate the key findings we have included numerous quotes. In order to easily differentiate quotes from women, men and key informants we have coloured the quotes accordingly. For women look for **Orange**; for men look for **Green**; and for key informants look for **Blue**.

KEY FINDINGS



HIV testing and care during pregnancy

HIV testing and counselling at the antenatal clinic and labour ward

Most of the women in the study had their HIV test at the ANC. While most women stated that they agreed to be tested, many women stated that the health care workers 'told' them that they were going to be tested for HIV as opposed to being advised to test. These women appeared not to understand that they could decline the offer to be tested for HIV. During group counselling the health care workers emphasised to the women the importance of testing for HIV while pregnant. They stressed that testing was important and necessary to save the baby. It appeared that a few women did not consent to be tested. A number of women who tested HIV-positive at the ANC and labour ward said that they had agreed to the test, but thought they would test HIV-negative and had not considered themselves at risk of HIV.

I went because they told us to. They said that we cannot miss that. It was my first ANC clinic, they said, so we must get tested, so we just went and got tested.

Rita, 25-year-old woman, diagnosed HIV-positive during second pregnancy, 1st pregnancy, 7 months gestation, Port Moresby

They asked me, they said, 'We always check people if they have the virus or not to help the children'. They said 'This is where babies are born [in the labour ward where she was] and that will help the baby so we will check you whether you have it or not. If you agree, then we will check it but if not, it all depends on you'. They asked me that. I said that it was OK. 'It's your work to check if I have it or not'. I thought that I would not have it so I told them to check me. They checked me [while I was in labour] and they said that I had the virus. Then I was confused. I thought that I wouldn't have it so they could check me. I knew that I was healthy and I thought that I wouldn't have it so I said, 'Just check me'.

Demam, 23-year-old woman, diagnosed HIV-positive at labour ward during 1st pregnancy, 27-month-old baby, Mt Hagen

Men, on the other hand, most frequently considered HIV testing only after their wife (or their child) was tested and returned a positive result. The main motivators to engage in HIV testing were the fear and guilt related to their spouse testing positive, the awareness of the risk of HIV transmission to the baby and following the recommendation to test from the health care workers. Most men described as barriers to testing: a fear of HIV, including the stigma associated with it; and discomfort in entering ANC settings.

I never even knew myself that I had this disease or I never thought, but later I knew when my wife died. I thought that if the child dies the mother will also die, and they did and then I realised that I had the disease. So my hair became loose and later I realised I had the disease and came to Rebiatul Hospital in here. Only this hospital helps us, they said, and when I came here it was actually true. I came for the blood testing and they said that I had the disease

Aba, 24-year-old man, HIV-positive, currently with his second wife who is HIV-negative; first wife died of an AIDS-related condition, 7-month-old baby, Mt Hagen

Overall, the key informants spoke positively about how group counselling, with an opt-out HIV test, was established and working in their workplaces. That said, there was confusion at times about what type of HIV counselling and testing they were providing – PICT or VCT.

I think what the girls do is that for every new mother they offer a group counselling first, and in that group counselling the Health talk is given to them. They do condom demonstrations – female and male condoms, give them information about all the risk factors, how to look after the baby, how to look after themselves and all that, and then they go in for individual counselling. VCT is offered to them so they have the right to opt out if they don't want to sit, stay in for the VCT test.

Dr Saipa, Medical Officer in Charge

There was one health care worker who would prefer women to have the explicit option of opting in rather than the more difficult option of opting out.

Basically, I really want the mothers to know about the importance of this program and they must really opt into us taking the test.

Bolu, HIV Counsellor

A number of the health care workers reported that there were numerous women who came to the ANC and were tested for HIV but who already knew that they were HIV-positive. Rather than informing a midwife that they are HIV-positive, such women deny having ever been tested for HIV. Some women, due to a fear of disclosing their HIV status, even go to the extreme of coming into the labour ward claiming that they are unbooked or had "lost" their health record.

Although great care is taken to keep confidential the names of women who test positive, the fact that these women are offered individual counselling when receiving their result, compared to women who test negative and have group counselling, makes disclosure an issue within the ANC.

The negative result is very easy to give; but the difficult one is the positive result. So as we, you know, as usual we ask them to come in. For a negative result sometimes we put them in groups to give the negative result, but for positive it's always individual, so when they come in, we always, confidentiality and privacy of this is always maintained at the first place, so as soon as they come in, we don't waste time we just tell the. It depends on how you give the pre-counselling that you have to prepare them to accept the result when they come in. So as soon as they come in, we just tell them straight their result, or the last time I collected your blood and I told you that, about all this and that, now you are here so the result is saying that you are confirmed positive.

Sr Jocky, Antenatal clinic

HIV testing was more complicated in the labour ward and it is here that issues to do with consent and counselling were most apparent. It was reported that in one of the sites HIV testing was conducted on unbooked (and therefore assumed untested) mothers without their consent because of human resource constraints.

That we don't ask them for their consent, we just do it. Sometimes we are busy so we have no time to do this, so it takes time. So when we are busy, we don't actually ask them for their consent.

Sr Karim, Labour ward

The thing is that when they come in, we make sure that we have all the mothers who come to the labour ward get tested. They get the HIV rapid test done in the clinics [labour ward] Our practice is that we don't tell them that we are do it. We just do that as a routine thing for every mother. And then if they are reactive then we spend time to counsel them, which makes it easier for them to come for the counsel on all the mothers who come in. It's like a routine test were we are doing.

Dr Nais, Obstetrician

I think it's not an easy thing to do testing in labour ward when generally we know that the staffing level is very minimal. I mean we don't have enough staff in most labour wards in the country so if you don't have that kind of time, you know the time that would be spent to let's say have a talk with the mother in whatever condition she is. For all you know, she's just not in the condition to listen to anything except trying to have the baby and then the time that the midwife or the nursing staff have is just, I find that that's actually a very, it's not an easy situation really to be doing HIV testing. But, on the other hand, if HIV test is not done then we miss that opportunity to try and protect, you know to make a baby become negative .

Dr Kondu, Program coordinator

It was reported that in Port Moresby General Hospital more women test HIV-positive on the labour ward than they do in the ANC. The reason for this was not clear to the health care workers, although one senior clinician did have his informed opinion of why it was so.

When you see some of the data, for example the Port Moresby General Hospital, where comparatively the women in the labour ward when they are tested the higher number tend to be generally comparatively a higher proportional number seem to be positive, compared to antenatal. I don't know what to make of that you know.

Dr Kondu, Program coordinator

But I know that it's a higher rate than those who get tested in Antenatal clinics. So the overall positive rate for last year was about 2%, and the positive rate for those who get the test in the labour ward is about double that. The fact that you are usually lower socio-economic status, that you have a less stable marital and family life relationships and all that sort of stuff, just means that you have been more at risk of contracting this infection.

Dr Opi, Obstetrician

Diagnosis with HIV

The reactions to being diagnosed with HIV were varied. In most cases the women, irrespective of whether they were tested at the ANC, or an STI or VCT clinic prior to pregnancy, said they were alarmed and did not know what to do. They had no physical signs of the virus that they could identify and thus had agreed to be tested but they thought they would test negative. Group counselling

did not appear to assist women in being prepared for an HIV-positive result by helping them to think through a self-assessment of risk for HIV. In several extreme cases women reported wanting to commit suicide, although they later found hope by focusing on their child, as a result of support from health care workers. Post-test counselling was routinely provided to all women who tested HIV-positive. Counselling focused on encouraging the women not to worry and to take ART. Several were told to attend church and lead a positive Christian life.

I went and got my result. The male nurse who got my blood test told me and said, 'It's like this and that', and I heard it but I didn't say anything. My facial expressions changed, my eyes were filled with tears and my heart was beating faster. Like I didn't expect that, so I felt that I was going get a high blood pressure or shock and fall down there. So the nurses there comforted me and talked nicely to me and such, but my eyes went red and were filled with tears and I just stared so they took me to a small room and sent me here the same morning. I started coming back and forth here, they gave me HIV treatment and I get it here and now they look after me here, so I'm here.

Velma, 21-year-old woman, diagnosed HIV-positive at ANC during current 1st pregnancy, 8 months gestation, Port Moresby

When they told me that I had the virus, I was so worried. I was having a lot of thoughts in my mind that I wanted to kill myself or wanted to run into a moving vehicle...

Tati, 19-year-old woman, diagnosed HIV-positive prior to current pregnancy, 2nd pregnancy, 6 months gestation, Mt Hagen

Most of the men in this study became aware of their HIV-status only as a result of their wives undergoing HIV testing at the ANC. Men had similar psychological reactions and levels of stress to testing HIV-positive. Moreover, a sense of direct responsibility and guilt towards their infected spouse or child added to their distress. Several talked about contemplating suicide. Testing appeared to be a major life event for men. They frequently discussed refocusing on the family and changing previous 'wayward' behaviours. In only one instance did the husband report getting angry with his wife and blame her for infecting him.

I really did not think about myself and what will happen to me later. I was very sorry about my wife only... We are just following the advice that was given; we are not worried about the sickness. Our concern is to bring up the child. That's all.

Igiri, 31-year-old man. Both he and his wife are HIV-positive. He tested positive prior to marriage; she tested positive at ANC, Mt Hagen

I gave it [HIV] to her; she shouldn't have it. I feel sorry for her and the baby as well.

Akowe, age unknown. Both he and his wife are HIV-positive; his wife tested positive prior to current pregnancy, Mt Hagen

When I knew that I had the virus, I knew that I wasn't going to die. I was still standing with my two feet; life still goes on so which way it takes me then it takes me. [...] Ok, so we told ourselves to live a positive life, live life as it is and be strong with our medication. My thoughts do not go well. I always wish that I as the father should be like that [negative] then that will be fine but I am like this and the child is like that. He is also my greatest concern; I must keep an eye on him because he will be the one who will carry on my name.

Pipi, 29-year-old man. Both he and his wife are HIV-positive; both tested positive after their first baby was diagnosed with HIV; three children, Port Moresby

I changed some of my behaviour, which I used to do in the past, since the child was here [was born] and the child might be sick or die if I carry on doing what I used to do. I usually think that I must stay with my wife and my child.

Pana, 28-year-old man. Both he and his wife are HIV-positive; his wife tested positive at ANC, Mt Hagen

The key informants similarly commented on how women (and their husbands) reacted to an HIV-positive diagnosis; most of them cried.. When a woman did not cry, several health care workers reported that they suspected she had already tested HIV-positive earlier but still be in the phase of 'denial'.

Most of the ladies, they fight their tears. They sit there and fight their tears. Sometime we allow them to, I mean they are allowed to cry, so some they cry, but most of the women they'll sit and wipe away their tears and then hold back their tears and things like that. Most of them they have nothing to say, they really do know what to say they won't even ask whether the baby is okay or what, because it's their first time to hear the result so. We have to really emphasise that this is just a rapid test. Real result will come after two weeks.

Bolu, HIV Counsellor

HIV disclosure

A number of the key informants spoke of the difficulties faced by women in disclosing their status, especially to their husbands. A couple of informants explained how they would try and support women to have their husbands tested by encouraging them to return with their husbands. If they did so, they were offered couple counselling, with the woman treated as a new enrollee, and the couple were tested together. This was seen as a way to try to prevent blame between the couple as well as a way to have the husband tested.

Some women they do disclose their status but their husbands don't want to come for testing... So they bring them [as new clients], so we can do couple counselling... she [the nurse] will do the couple counselling and the test, upon their agreement. But when the husband said 'No I want to do my own.' Well, we can't force them to do the test together so... but most of the women they don't bring their husbands; they are scared... Maybe some of them [the men] they know their status, but they don't want to disclose it to their wives... these are some of the things that we find hard, getting them come.

Sr Alare, ART prescriber

I ask them if their partners are aware [of the wife's HIV-positive result] and if they say no, I ask them if they would want their partner to be tested and some of them they are scared, scared to inform their husbands because some they kind of get angry with their husband, thinking that, you know, the husband must have went around and contracted the virus or something like that. Yeah, some usually inform the husband but some they don't because they get scared that they might belt them up or something.

Sr Akito, Program coordinator

Maybe some of them [the men] they know their status, but they don't want to disclose it to their wives so those are some of the things that we are really, you know, finding it hard to you know get them to come. But there are a few that come. The girls are really doing a good counselling to make them understand the fact that they are, you know, HIV-positive and their status and all that.

Sr Alare, ART prescriber

Prevention of parent-to-child transmission

Prior to being tested for HIV, all expectant mothers were advised about the importance of not contracting HIV from their husbands during their pregnancy. While pregnant, they were advised to use condoms during sex and to be faithful to their husband. These particulars about preventing mother-to-child transmission of HIV appeared to be given only to women who had returned a positive result, who were given information about the ways an infant can become infected during pregnancy, childbirth or through breastfeeding. Women were told that the risks were greater if a mother was not on ART during pregnancy, was not adherent to her treatment, did not attend the hospital to give birth and mixed-fed her infant (ie gave fluids and food in addition to breastfeeding in the first six months of life). There was no mention of ART treatment for the newborn baby at birth. One of the health care workers reported that she believed that the reason why many children were being diagnosed with HIV at the age of three and four was because their mothers had acquired HIV during breastfeeding and that not enough attention was given to this risk period for HIV seroconversion.

They told me to drink the medicine, this drug of ours, to drink it every day and I will take care of myself well so that the virus would not be passed onto the baby. It will protect her.

Dorin, 35-year-old woman, diagnosed HIV-positive prior to current pregnancy, 1st pregnancy, 5-month-old baby, Port Moresby

And also for the baby they said, "You must go deliver at the hospital and if you deliver at home, it will contract the virus and if in the womb, will contract if the womb breaks. They usually say that and give this sort of advice.

Geto, 22-year-old woman, diagnosed HIV-positive prior to current pregnancy, 1st pregnancy, 3-month-old baby, Mt Hagen

Overall, men showed limited knowledge about specific measures to prevent the transmission of HIV to infants. However, they displayed high levels of confidence in safe delivery taking place in hospitals and in the need for a mother's strict adherence to ART. Moreover, they saw feeding as a major source of protection, both quantitatively by ensuring a steady supply to the mother and the child, and qualitatively by managing the potential conflicting recommendations from the health care workers and the community. It was in the domain of infant feeding where men's engagement was most prominent.

[the health care worker said] 'She [the baby] was born all right so now what the both of you will do is that your wife must not work. The breast milk must be fresh; if she works then she will give off sweat and will produce a lot of dirt. And if the breast has small sores or scratches or stuff like that transmission will occur, the baby must not contract it [HIV]. That's one of the things that they told us about, like the mother must always be faithful in taking her drugs, which they gave her to take and to take it on time.

Tau, 34-year-old man. Both he and his wife are HIV-positive, both tested positive to current pregnancy, Mt Hagen

Antiretroviral therapy (ART)

According to the majority of the HIV-positive women and men, the health care workers stressed the importance of adherence to antiretroviral therapies. Participants in fact cited that they were adherent to their medication because they were following the advice of their health care workers. Many reported other reasons, including: that ART would enable them to live longer; that being adherent meant reducing viral load ('decrease the amount of virus in the body so good blood will circulate'); and finally in order to protect their baby and ensure that she/he was HIV-negative. Numerous participants spoke of ART as a normal part of their daily lives and as such that they no

longer forgot to take it. Women with HIV were also advised that once they delivered their infant they would undergo a change in their treatment regimen.

I am following the instruction from the nurse who gave me (ART). If you miss a day, you are opening the way and giving space for the virus to work.

Kekeni, 26-year-old woman, diagnosed HIV-positive prior to this pregnancy, 1st pregnancy, 13-month-old baby, Mt Hagen

I usually think, it's because of the virus and I don't miss the date given. I usually think of the baby and I don't miss a day so I used to come every time to get the medicine. If I was not on medication, then the baby won't be fine or I won't be fine also or we will fall sick. One of the things is that I used to be happy just to be with the little girl and me being on medication is an important thing.

Ambai, 18-year-old woman, diagnosed HIV-positive at ANC, 2nd pregnancy, 1-week-old baby, Mt Hagen

From my point of view, this is a lifetime medication so I must take my medicine faithfully because if I don't, I might get sick and it might go worse or I might die.

Nongo, 34-year-old woman, diagnosed HIV-positive tested prior to this pregnancy, 3rd pregnancy, 7 months gestation, Mt Hagen

Most participants said that they had been advised about how and when to take the treatments. For example, they were advised to take the treatment with food. Only a few said that they were advised about possible side effects such as headaches, feeling dizzy or nausea. Almost all of the participants mentioned side effects of ART including feeling itchy, fatigue, aching body, nausea, feeling dizzy, weakness in the body, boils and small sores. Others reported well-known side effects such as numbness to hands and legs (peripheral neuropathy). Only a few participants did not report any side effects from their treatment. One participant mentioned that she was becoming fatigued by taking her ART every day and was considering abandoning it.

Most of the women and all of the men in the study talked about the positive impacts of treatments on their lives, including regaining weight, being happy, being physically strong and active once more, being able to do normal things like HIV-negative people do and, most importantly, to have an HIV-negative baby. Almost all understood that ART was a medication for life. Combined with God's support, ART was viewed as giving a second chance at life. ART was also a means by which men could provide support to their family by taking an active role in ensuring that their wife and child were adherent and by providing resources and support to ensure strict continuity in treatment.

When I was pregnant I was faithful in taking my medication, and I ask God to help me so I could have a healthy child. The results showed that she is negative and I was very happy because I am on drug so my daughter is healthy. Later when I think of having another child, I will follow this way of delivering another child.

Kopuna, 24-year-old woman, diagnosed HIV-positive, tested prior to this pregnancy, 2nd pregnancy, 6-month-old baby, Port Moresby

They said they would give a medication for the virus, so when I heard that it is a medication for the virus, I was kind of happy. I was happy to take the medication. I was so happy because it's my life and I will live on this medication and so I drink it every day. Just imagine it, I put it under my pillow and I go to sleep. I think only of this medication and that alone.

Tati, 19-year-old woman, diagnosed HIV-positive, tested prior to current pregnancy, 2nd pregnancy, 3-month-old baby, Mt Hagen

My body, fingernails and my face all went very dark when I was not on medication and I felt ashamed of going around. They said that this woman got HIV, otherwise she wouldn't do such. I was ashamed and I really lost weight and this blouse, which I am wearing, was really loose and I wore a jumper on top and I came for clinic at Tininga clinic. The sister there said that I lost weight and advised me, so I am now on medication and I saw that I am changing after drinking the medicine and I am here.

Hamo, Age unknown, diagnosed HIV-positive prior to current pregnancy, 5th pregnancy, 2-month-old baby, Mt Hagen

Treatment means life for me. Treatment means life, nothing else.

Soko, 54-year-old man. Both he and his wife are HIV-positive; his wife tested positive at ANC, Mt Hagen

Both of us see that the medicine is our lifeline. If both of us play up with that medicine then we will give chance to this virus so both of us used to be very faithful to our medicine. And what little money we have we only look for food because everytime we take our medicine we need food first to strengthen us to take that medicine.

Pipi, 29-year-old man,. Both he and his wife are HIV-positive, both tested positive after their first baby was diagnosed with HIV; three children, Port Moresby

OK, my wife went to the antenatal clinic and they advised her that she must always adhere to her treatment which is the medicine so that she can try and protect that baby inside her and she can deliver. They gave her that information and advice so I am always up-to-date with my wife and she doesn't miss her ART until she delivered the baby. So currently that is all I advise her to do and she has been faithful to her medicine and it is true that we saw the result, our baby is negative.

Erick, 28-year-old man. Both he and his wife are HIV-positive, both tested positive prior to current pregnancy, Port Moresby

Most HIV-positive people in the study were on ART, with only eight HIV-positive women saying that their husbands, although HIV-positive, were not. Some of the reasons for not being on treatment included personal choice, recent diagnosis, ineligible because their CD4 cell count was too high, while others were afraid of treatment side effects and unwanted disclosure. One of the husbands reported that, although he and his wife (who was pregnant) were on ART, he had another wife, also HIV-positive, who was not on ART.

ART also meant frequent and costly journeys to the health care facility that affected the family economy and organisation. Several men adopted strategies to reduce the costs associated with accessing ART by either extending the interval between visits or sending a single family member to collect the family treatments.

Other care during pregnancy

Positive living

Almost all the women mentioned that they were advised to live with a positive outlook. However, whether to live positively or not depended wholly on each individual. These women were encouraged to advise their immediate families and husband of their HIV status so that these people know and may support them in times of need. The majority of the women mentioned that they were advised to live positively by not worrying, because worry affects the mind and this may result in premature death. Positive living also meant adhering to advice given by the health care workers, which for some meant being encouraged to attend church regularly and to seek support from God through prayer when taking medicine.

This is what they said. The female nurse said, 'You have this problem (HIV)'; and I told her, 'I will remove [abort] this baby because I fear it might die like the previous baby'. She said, 'No it will be alright'. She said, 'You go live like this, live a good life. Keep an eye on your husband. You must go to church and live a good life.'

Mulas, 35-year-old woman, diagnosed HIV-positive prior to current pregnancy, 4th pregnancy, 8 months gestation, Mt Hagen

For men, positive living was similar to that mentioned by women, but they also emphasised the importance of appropriate infant feeding, as well as good food for himself and his wife. Of interest, many mentioned that the experience with HIV in the family had a positive impact on couple communication and mutual support.

I treat my wife, because both of us are HIV-positive, so when she says something I just follow what she says and she listens to what I say; so we just live happily. We know that we are a sick couple so we must always listen to one and other, so we do that.

Timon, 26-year-old man. Both he and his wife are HIV-positive; his wife tested positive at ANC, Port Moresby

Health education messages during pregnancy

Health education messages were a routine part of the delivery in?? ANC. Messages provided to the pregnant women were diverse, including: the pros and cons of sex during pregnancy; delivery; personal hygiene; HIV testing; nutrition and family planning. For those women who tested HIV-positive, additional health education was provided in relation to adherence to treatment, positive living, HIV prevention and infant feeding. It was emphasised that women must adhere to the health information provided. The majority of women appeared to appreciate these messages as it provided them with 'strength' to live well. Many reported that they wanted more health education.

My feelings towards it, I wonder whether it be good or bad, but I must accept it. I am telling you how I feel. Whether I have it or not, or whether good or bad, I must accept it. They sit with me and explain to me some things that I don't understand. I take advice from them so whether it be good or bad, I must still accept it. I didn't go to school regarding this, you are the one that went to that school, so whatever you say will be accepted by me. They are not speaking for themselves but speaking for the good of our children and us. So we must listen to what they say and follow.

Retame, age unknown, diagnosed HIV-positive at ANC, 1st pregnancy, 8 months gestation, Port Moresby

With the exception of few fathers who attended health information sessions at the ANC clinic or had knowledge from previous experiences with ANC, most men only accessed information indirectly through their wife.

Family planning

All pregnant mothers were educated on the importance of family planning and the different types of family-planning methods available. These included: Depo-Provera, condoms, pills and tubal ligation. Women were advised to plan before having children and to attend clinic for family planning six weeks after giving birth or to use condoms during sexual intercourse. The importance of family planning was emphasised and the cost of goods and services was given as a key reason to plan the size of a family.

Delivery

All of the women reported that they were provided with detailed information on what they were required to bring to the hospital for delivery: baby blankets, nappies, baby's health record book, umbilical cord clamp, toiletries, sanitary pads and the hospital fee. For those HIV-positive women emphasis was placed on the necessity for them to return to the hospital to give birth.

Personal hygiene

All expectant mothers were instructed to have daily baths, to have regular sleeps, keep their house clean, and after the birth to always wash their hands before feeding the baby. The cleanliness of the newborn was also stressed. Women were also advised to refrain from smoking, chewing *buai* [betel-nut] and drinking alcohol.

Nutrition

Eating balanced and nutritional meals is important during pregnancy and so this was emphasised to all mothers in the health information sessions. They were advised to eat more food grown in their garden, in particular, different fruit and green leafy vegetables every day.

Sex and pregnancy

Cultural beliefs, health messages and sex during pregnancy

Most of the participants, including men, stated that sex is culturally restricted during pregnancy and breastfeeding. Overall, they believed that sex during this time would result in the foetus being affected ('spoiled'), resulting in sickness and malnutrition in the child. Some expressed the view that it is the responsibility of parents to protect an unborn child from polluting acts (sex) and substances (semen).

The most common reason for abstaining from sex during pregnancy was a belief that sexual intercourse would result in delays in delivery dates as well as a prolonged labour. Other cultural reasons provided for abstinence at this time included: preventing miscarriages; birth defects; stillbirth; and difficulty in delivery, resulting in the death of either or both the infant and the mother. Another less common reason included respect for the foetus, which is viewed as already being human.

According to the village custom, according to their beliefs, when a man sleeps [has sex] with a woman who is six, seven, eight or nine months pregnant then that woman will not give birth quickly. So if you sleep with a man then you won't give birth quickly, that's what the people in the village believe.

Rita, 25-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 7 months gestation, Port Moresby

Concerning those of us from the highlands, that's like when a woman is pregnant a man must not sleep [have sex] with her... But we women have the power, like we are educated so we have the power to look after ourselves when we are pregnant... Like according to our custom you must leave the baby and stay on your own because the baby might go through a hard time or will get affected. They always say that when a man's sperm flows into you then you will find it difficult to give birth or that will affect the baby. That's according to the custom of the people here.

Wena, 35-year-old woman, undecided to test for HIV, 1st pregnancy, 8 months gestation, Mt Hagen

There was inconsistency between and within sites regarding messages that were delivered about whether or not to abstain from sex during pregnancy. A number of the women said that the health care workers advised them that they should have sex during this time, because abstaining from sex might lead a husband to seek extramarital relationships. If he and his wife were HIV-negative this extramarital relationship might result in the husband becoming infected with HIV and transmitting the virus to his pregnant wife. During one of the ANC visits, a health care worker was observed instructing a woman on how to position herself during sex so that she was comfortable and the weight of the man was not pressing on the baby. A similar number of women reported that they had the opposite health education at the ANC, that they were encouraged to abstain from having sex both during and after pregnancy. Abstinence was encouraged out of fear of the risk to the baby, and for women with HIV there was the added risk, according to the health care workers, of super-infection. Women were told that if they could not abstain from sex they should use condoms.

Yeah, they said that, 'Don't have sex with your husband, and if you do that, the baby will also get sick and you'll be affected too.' They said, 'You must attend church and by taking your medicines, you will be strong and fit.'

Hol, 17-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 21-month-old baby, Mt Hagen

That's what I heard and what the nurses said is, 'While you're pregnant and the man wants to sleep with you, let him do and don't say no.' If you say no and when men want to release their seminal fluid, they will try to sleep with you and if you don't, they will look for another woman and bring back the disease. Therefore they said, 'If he wants to sleep with you and you reject him, he will go out with prostitutes and transmit the virus to you.' That's what the nurses told us.

Bane, 24-year-old woman, diagnosed HIV-positive at ANC, 2nd pregnancy, 8 months gestation, Mt Hagen

That, they usually tell us, 'When you are pregnant, you must like, after delivery you must not have sex with your husband because the man's virus is different from yours so you must not have sex and if so, you must use condom.' They used to say that. And also for the baby, they said, 'You must go deliver at the hospital and if you deliver at home, it will contract the virus and if in the womb, will contract if the womb breaks.' They usually say that and give this sort of advice.

Geto, 22-year-old woman, diagnosed HIV-positive prior to 1st pregnancy, 3-month-old baby, Mt Hagen

They asked if our husbands were faithful to us and some of us said, 'Our husbands are faithful but we don't know about their side movements.' They said, 'Concerning that, you must always insist that they use safety. Use condom when they go out and also when they come back to you. You must also use condoms when they want to come on to you.'

Eva, 31-year-old woman, diagnosed HIV-positive at ANC, 2nd pregnancy, 8 months gestation, Port Moresby

Sex during pregnancy was discussed rarely by the key informants; mostly they mentioned the need to use condoms. However, at least one health care worker stated that women are unaware of their ability to have sex while pregnant, and thus there was a need to educate women on different sexual practices, as well as the importance of a woman having sex with her husband to ensure he does not have extramarital relationships.

This mother comes and she's pregnant and she doesn't know that she can have sex till late. So there are other forms of doing sex, other ways that we can show them how to do sex they are not shown. So the poor woman is left to just, there is nothing you know that sort happening so the husband is waiting around and eventually goes off to somewhere.

Dr Min, Paediatrician

Sexual practices during pregnancy

Despite strong cultural beliefs governing sexual practices during pregnancy, participants in this study discussed at length having sex during these times. Although some participants reported having sex throughout their pregnancy, most continued to be sexually active only until the beginning of the third trimester. The most common reason reported by women for having sex during pregnancy (and breastfeeding) was to prevent their husbands having sex outside of the marriage. For those who were HIV-negative, it meant preventing their husbands from becoming infected with HIV and bringing the virus back into the family.

They sleep elsewhere and have sex. HIV is currently here so we must always be on family planning and have sex with our husbands. Otherwise we would send the men away.

Aki, 31-year-old woman, diagnosed HIV-positive at ANC, 2nd pregnancy, 11-month-old baby, Mt Hagen

I will honestly share my fears that when I don't satisfy my husband with what he wants, especially about having sex, he might leave me and go. I mean there is 70–80% chance of him doing such because I try my best to stop and he sees that I leave the house frequently to avoid him from having sex.

Magdelene, 25-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 8 months gestation, Port Moresby

A few women continued to have sex during their pregnancy because they feared retribution from their husbands in the form of physical violence. A few seroconcordant couples reported abstaining from sex during pregnancy or using a condom during sex because of a fear of super-infection which health care workers had discussed with women.

Treatment of HIV-positive parents by health care workers

Most of the HIV-positive parents in the study reported that they were happy with their relationship with the health care workers. Particular qualities identified included the way they were spoken to, the useful and constructive advice provided relating to positive living, being seen in a timely manner, and support with food, milk, costs of bus fares and medication if sick.

Yes, I like them. Because they like myself, I feel it, or I see when they like me. I'm now is positive, so I see those doctors and nurses. They came and talk with us nicely, proper that's why I said I like it.

Saina, 20-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 2-month-old baby, Port Moresby

Like, it's good they help us. We, these kind of pregnant mothers, go up there and stay with them and they used to be happy with us and they talk to us nicely and they give us these little things like bus fare and protein just to cook and eat at home, at least we have tinned fish. Like, they provide good services so I'm happy and I like it. They give milk for the baby as well, so it's good.

Nondo, 26-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 18-month-old baby, Port Moresby

Far fewer reported any bad experiences in their relationship with the PPTCT program. Of those who did report ill-treatment, this included being told not to have more children because they were HIV-positive, being spoken to in an improper manner and a lack of empathy as to why people may miss an appointment.

Yeah, the other doctor told me that I have the HIV virus and I must stop having children. He strongly said it and I was not happy when he said it.

Abade, 29-year-old woman, diagnosed HIV-positive prior to this pregnancy, 3rd pregnancy, 7 months gestation, Mt Hagen

Yes, sometimes some of the sisters don't talk politely. They talk harshly. Sometimes it rains heavily on that day and when we go on another day they used to talk to us harshly. 'We gave you the date, you must come on the exact date. You sit on the side and when we are finished with this people then you will be last,' they used to say that, so 'Shh it's your problem we won't be coming back again.' We used to say that and lose interest and just leave and stay until we feel that the child is going to be sick or is a little bit sick and then we go to the hospital. When [the] child is healed we take them back for review again.

Julie, 22-year-old woman, diagnosed HIV-positive prior to current pregnancy, 2nd pregnancy, 7-month-old baby, Port Moresby

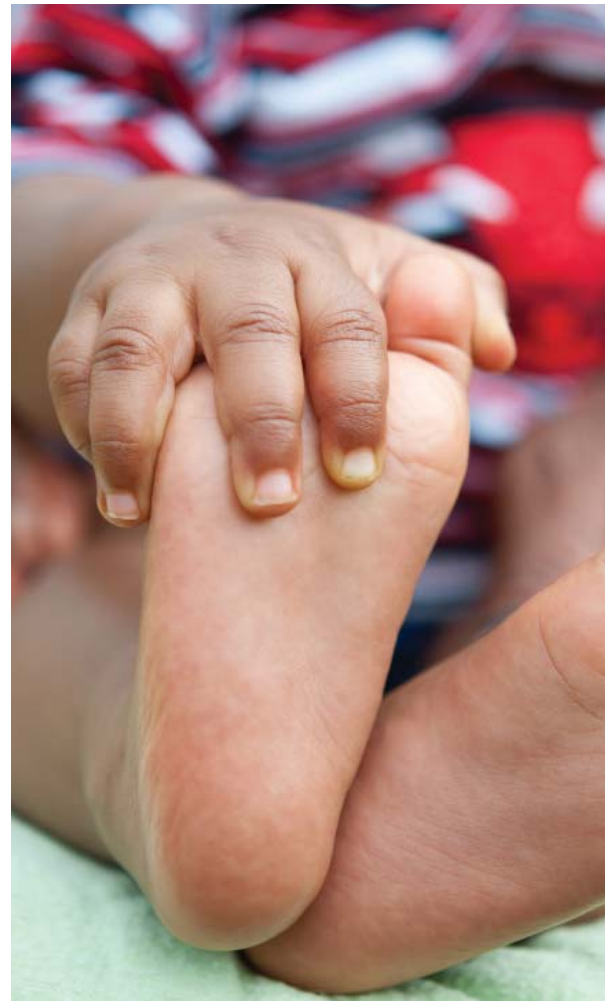
Postnatal and follow-up care

Early infant diagnosis

There did not appear to be any formal consent process for early infant diagnosis. Testing appeared routine for infants at six weeks. While early infant diagnosis is an important aspect to the PPTCT program in PNG, the women and their husbands in this study discussed at length the issues they face with delays in receiving the results of their child's HIV test. Several babies were required to repeat the test due to misplaced results, poor handling of blood and indeterminate results. Women discussed the anguish they experienced while waiting for their child's HIV test results, with many turning to God for support. For some, the ongoing delay in receiving results was costly as they kept returning to the hospital for the results only to be told that they were still not available; some women reported giving up trying to get their child's results.

I went three times but did not get the results, so I gave up.

Saina, 20-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, - month-old baby, Port Moresby



HIV, family planning and reproductive decision-making

All women attending ANC are provided with information and advice on family planning. For women with HIV, particular aspects of this were unique. A number of HIV-positive women were instructed not to have more than two or three children. Reasons given by health care workers for limiting the number of children included because they were sick and because of related concerns about who would take care of the children if the mother died from HIV-related conditions or from the loss of blood during birth.

Although all family-planning methods were discussed, tubal ligation was the most commonly discussed and emphasised method of preventing further pregnancies for women with HIV. Several women in the study described how doctors had instructed them to have a tubal ligation because they were positive women, had already given birth to a child and needed to focus on their own care and life.

Yeah, they gave me health talks about how I can stay. They came several times and told me, 'You are a positive mother and now you also have twins, so stop having children and go for tubal ligation and stop it.' They said that and I said, 'I will ask my husband first'. I came and asked him and he said, 'No'. With what he saw with many mothers who were affected when they do tubal ligation. My husband said, 'Condom is available. I can use condom to be with my wife. Just let her be that way'. He said that, so I didn't do tubal ligation and just stay. That is what they said to me.

Morin, 31-year-old woman, diagnosed HIV-positive prior to current pregnancy, 4th pregnancy, 17-month-old baby, Port Moresby

The virus played an important, complicating role in the reproductive decision-making of couples affected by HIV. Women and men living with HIV who were diagnosed prior to the current pregnancy primarily viewed and narrated reproduction as a risky experience. Risk was associated with both the mother's health and for the unborn infant. Perceived risks to the mother included physical and immunological weakening, which could result in death. Risks for the unborn infant included becoming infected with HIV and the death of the mother. These risks were emphasised by health care workers who advised against having children after being diagnosed with HIV. A minority of couples affected by HIV had the view that, like all other couples, they had the right to reproduce and create a family.

When we went to get our medication, the nurses used to tell us that if we want to have some more kids, we must go and see them in order to get another baby. I heard from them and I planned to have another baby when [the baby] is big and she can walk.

Geto, 22-year-old woman, diagnosed HIV-positive prior to current pregnancy, 1st pregnancy, 3-month-old baby, Mt Hagen

It's not a problem when HIV negatives make decisions for us, the HIV positives, for a woman to be pregnant.

Erick, 28-year-old man. Both he and his wife are HIV-positive, both tested positive prior to current pregnancy, Port Moresby

On the other hand, to have a child is a burden and later we saw that people who have this disease are just normal, it's life so we take it that way. Because those people that have the virus can live like normal people. Many women who have the virus are having children, and children have rights to be on this earth also.

Timon, 26-year-old man. Both he and his wife are HIV-positive; his wife tested positive at ANC, Port Moresby

Many of the key informants spoke of the importance of family planning for women with HIV as a means of planning timing and spacing of children. Family planning is viewed as an important, albeit vexed aspect to the prevention of parent-to-child transmission of HIV.



With regards to family planning and that's another issue of course because if you got HIV, you got life-long disease requiring drugs. It's not a good scenario to be planning lots of extra pregnancies in the near future and the counselling about family planning is really quite difficult because often these are very young women, often they are teenagers... We had a 21-year-old from [name of place] here last week. She had a baby last year and she was found to be HIV-positive last year in the first pregnancy and here she was in the labour ward just 13, 14 months later with another, having another delivery. And it's not that she wanted to have another baby 12 months later. It's just that we didn't ever really get through to her. She never got treated, you know, and she didn't get treatment in the second pregnancy either so she just wasn't with it. We've never got through to her. So having another baby shortly after or within a reasonable space of time after being diagnosed as having HIV in a previous pregnancy just indicates mostly that we haven't got through to the person. With regards what it means, what their status is then with regards to the treatment the fact that it is life long. It is a life-threatening disease and it's also dangerous for a baby, you know having another kid.

Dr Opi, Obstetrician

Unlike the feeding guidelines, which emphasise choice, the narratives of key informants reflected strong opinions on reproduction for positive parents; many stated that they tell women what to do.

We can't tell you not to have a child, but if somebody's got like 4 children or 5 children already, family planning is big on my list. It's just from family-planning issues that I tell, 'No, that's enough; you just can't have any more.' But not if somebody has no child and want to have a child, that's a different story, but if someone's got 3 children or 4 children and they want to have a child, it's like: you have enough already.

Dr Min, Paediatrician

Reflective of the advice reported by HIV-positive women and their husbands about the need to prevent drug-resistant HIV from developing in a seroconcordant couple, at least one health care worker said that such couples must always use condoms unless they are trying to have a baby.

Several of the health care workers recommended the simultaneous use of two forms of family planning for HIV-positive couples such as Depo-Provera and condoms, or the pill and condoms.

But I am trying to get everybody to have at least a form of family planning or dual form of family planning so, you know, you re-think the whole issue about your own health and about the risk of transmission before you decide to have another child.

Dr Leota, Paediatrician

One informant spoke of the change in some health care workers' attitudes towards HIV-positive couples having children. Previously it was discouraged, but now, with the ability to offer biomedical intervention, health care workers are more supportive of couples reproductive decision-making and therefore more accepting.

Some years back, what I've realised, was that the staff attitude (and specially the doctors) towards people living with HIV was to totally discourage them from getting pregnant because of the risk of transmission from the mother to child. Because if they are pregnant. And if they die there is a chance of their kids being orphaned. Then there was no proper intervention and the child or the baby got infected. So like not having any more children was thoroughly advocated - it was family planning.

But some people living with HIV - they decided to get married and then they want to have a child. So I think we gave to have some kind of rethink. Now it is being accepted you know and what we are all doing now is promotion of intervention at the antenatal, intervention at the labour ward and also postnatal intervention. But there are still some difficulties to accept that some people living with HIV will want to have children.

Dr Nais, Obstetrician

HIV and infant feeding

Advice

The majority of the women with HIV reported that they received advice about exclusive breastfeeding, with most saying they were advised to abruptly wean their baby at six months. Only a few women mentioned that they had been advised to gradually introduce food and other liquids with the continuation of breastfeeding after six months.

They said that I must feed the child with food and stop him from breastfeeding when he is six months old. They told me to buy lactogen myself if I have money and feed him and my husband is working ... so he said to buy it himself and feed him. She told me things like: wash hands before feeding the baby, look after myself and feed the baby, do not smash the food with my mouth.

Geto, 22-year-old woman, diagnosed HIV-positive prior to current pregnancy, 1st pregnancy, 3-month-old baby, Mt Hagen

The nurse put some drop of medicine, sugar water to the baby and told us to give S26 milk [formula]. They told us to feed her with S26 and not to breastfeed her and the hospital will provide the formula.

Koko, age unknown. Both he and his wife are HIV-positive; his wife tested positive at ANC, Mt Hagen

Practices

Women expressed concern about infecting their baby through breastfeeding; the majority had or were still currently exclusively breastfeeding. Those women who had ceased breastfeeding their child had been recommended exclusive breastfeeding for six months, followed by the gradual introduction of solids and other liquids. A small number of women had mixed breast and formula feed with other food and fluids for infants less than six months. Formula feeding appeared acceptable for the few women in formal employment. For women with twins, infant-feeding practices were not necessarily the same for both of the infants

Women's infant-feeding practices appeared to be strongly influenced by the advice given by their health care worker. Although most women appeared strong in resisting village and extended family pressures to feed differently, they nonetheless discussed the tensions that their feeding practices brought about. Others were not able to negotiate these pressures as they would have



liked and thus succumbed to community pressure. Men played an active buffering role between their spouse and the sometimes conflicting information emanating from diverse sources. They either took the lead in making the decision or engaged with family to explain the feeding choices.

They [the health care worker] said six months but the people in the village don't know that we have HIV and they got cross to me so I gave him solids. We said this but they said feed him, feed him and kept on getting cross so we fed him [food].

Wandari, 22-year-old woman, diagnosed HIV-positive at ANC during current pregnancy, 1st pregnancy, 6-month-old baby, Mt Hagen

They used to say 'When a child is three weeks we feed solids, so why aren't you giving food to your child?' I used to say, 'No, I am following the doctor's instructions'. He is my first born and because I know [I have HIV] and I don't want to disclose and it's shameful...

Kekeni, 26-year-old woman, diagnosed HIV-positive mother prior to current pregnancy, 1st pregnancy, 13-month-old baby, Port Moresby



Sex and breastfeeding

Cultural beliefs around sex during breastfeeding

Women had similar beliefs about abstinence during breastfeeding as they had about abstinence while pregnant, with almost all participants reflecting on such beliefs. The most common reason given was to ensure the well-being of the child. Sexual abstinence during breastfeeding would prevent childhood illnesses such as diarrhoea and malnutrition. For others, it offered a method of family planning where a woman would not conceive before her youngest child was more independent. Sex immediately following childbirth is particularly restricted because of the postpartum bleeding. Menstrual blood and other vaginal secretions are, in cultural terms, highly contagious body fluids and must be avoided. There were several participants who reported not being aware of any cultural sanctions about sex during these important times. However, what they did report were their own opinions, which reflected the same cultural values and taboos.

So they don't sleep together [have sex]. I used to hear that when the baby is still breastfeeding and when the man and woman sleep together, they will give bad milk to the baby and the baby will go no good. The stomach will swell up, small legs and hands and such, that's what they said. So don't go and sleep together until the baby grows big, walks around by itself and starts to walk, and then they can sleep together because baby is fit to eat and such.

Opena, 21-year-old woman, diagnosed HIV-positive at ANC, 1st pregnancy, 8 months gestation, Mt Hagen

Yeah, in the village, according to our custom, our belief is that the man will not come and have sex with the woman when she had just delivered and the blood is still flowing. When he comes and sleeps (have sex) with her, the baby will cry constantly and it will give you hard time... According to our custom, they say that when the lady had delivered and when she is still bleeding, men must not have sex with the woman, in case the man might see the cervix [through having sex] so the baby will cry a lot.

Jema, 26-year-old woman, diagnosed HIV-positive prior to current pregnancy, 5th pregnancy, 19-month-old baby, Port Moresby

Sexual practices during breastfeeding

The majority of the participants reported engaging in sex again between three and six months after giving birth. In rare cases, a few women reported abstaining up to two years after giving birth in previous pregnancies. Those who reported having sex while breastfeeding or during pregnancy used condoms as a means to protect the baby from polluting sex and HIV.

Sex and breastfeeding is life. It's life so how will I stop it because he does not have another wife and he isn't a promiscuous man and how could I reject him? Family means staying together, right? Because we are married, marriage means share yours, as you are one... So when you argue, fight and over-protect yourself, you are protecting yourself so the man will go and look for another woman and you are opening the door for sicknesses to come inside.

Ito, 25-year-old woman, diagnosed HIV-negative at ANC, 4th pregnancy, 8 months gestation, Mt Hagen

That, they usually tell us, 'When you are pregnant, you must like, after delivery you must not have sex with your husband because the man's virus is different from yours so you must not have sex and if so, you must use condom.' They used to say that.

Geto, 22-year-old woman, diagnosed HIV-positive prior to current pregnancy, 1st pregnancy, 3-month-old baby, Mt Hagen

Both of us know that we are HIV-positive so I used to be a little scared to have sex with my wife when she was breastfeeding but when I do have sex with her, I always use condoms.

Erick, 28-year-old man. Both he and his wife are HIV-positive, both tested positive prior to current pregnancy, Port Moresby

Men's Involvement

Antenatal care/clinics and at childbirth

The involvement of men in antenatal care is hailed as important to improving the health outcomes of women and infants. However, few men attended ANC with their wives. From men's point of view they avoided attending ANC for fear of gossip and other negative attention from family and friends because they were of the view that men's attendance at the ANC was culturally inappropriate. Because the ANC is a gendered place for women, men reported that they would accompany their wives to the hospital but wait for her outside, thus avoiding the gossip and stigma attached to accompanying women into ANC. For a few men who were involved in extramarital relationships, there was a fear that he and his wife would be seen by another girlfriend and that this could lead to disclosure and conflict.

From the women's perspective, it did not seem practical to have men attend the ANC with them, especially when the husbands were in paid employment and would be required to wait for long periods for appointments.



The act of giving birth was interpreted as a woman's responsibility. While no men in the study were with their wife when she gave birth (it is not a practice in public delivery wards in PNG), none of them voiced a desire to have attended the birth. This reinforces the cultural perception that men's attendance is not appropriate. While the absence of men from antenatal clinics and the birth of their children is clear, this has not excluded men from finding other ways of providing support to their wives and newborn children. Men spoke of supporting their wife with money, food and the purchasing of nappies, escorting her to the hospital, supporting her in adhering to her treatment. In one case, a man whose wife was ill with HIV-related conditions bathed her and took care of her daily needs. Men's involvement in the formal medical care of their infants was unclear; no one dominant them emerged.

In our custom we don't follow the woman when she is pregnant.

Pana, 28-year-old man. Both he and his wife are HIV-positive; his wife tested positive at ANC, Mt Hagen

I usually think that it's the woman's place to deliver and men are not allowed to go in, so I don't think of following her.

Pipi, 29-year-old man. Both he and his wife are HIV-positive, both tested positive after their first baby was diagnosed with HIV, three children, Port Moresby

I came with her many times and used to wait outside and she goes in and weighs herself and comes and both of us go home.

Mike, 47-year-old man. He is HIV-negative and his wife is HIV-positive, tested positive prior to current pregnancy, Port Moresby

Male-friendly services

Key informants spoke of the importance of making services 'men friendly' to try and encourage men to come to ANC. However, space was recognised as a problem in trying to cater for this potential increase in numbers attending the clinics. One suggestion by a number of informants was a 'men's clinic', similar to the well women's clinic.

We recognised that men's clinics are, I think it gives an answer to many of our struggles. Mingende men's clinic wonderful very good reports that man come for the checkup and they bring their wives for treatment for STIs In Enga we have sixty-one young men coming for the men's clinic; forty-one brought their wives back for treatment. So it tells me something the same I have in Milne Bay it's came up spontaneously because I am kind of advertising this like of man's clinic they should start everywhere. And we have the same thing at couples coming there, so it tells me that we have neglected something in all our years of service. They have most probably neglected to most important part.

Sr Kuku, Program Coordinator

And then you know when the mother or a woman is positive then there is this, you know, time when sometimes they are a bit reluctant to expose themselves to the husbands. They feel that they'll be chucked out of the family, all these kind of things. And it's a bit challenging for us. We actually get the partner, a lot of them like one partner like with one to one. When the wife and the husband there is no other wives beside them, that's when we see the man coming in, but when the husband had other wives it's just not possible to bring in along with other wives. So getting full participation of the husbands it's a big challenge for us. We are just thinking, no, no how best can we come up with very innovative way to really get this? Can we have another like men's clinic or, you know, some kind of way that we can actively involve the husband and that will be very good because when we are looking at the antenatal population it represents the general population. So when we want to get the true, you know, know the true prevalence to know the picture of true HIV in the community these are the true representation so we really like to get the husband involved and that's being a challenge for us.

Dr Marie, Program coordinator

So if we are going to encourage fathers to come, we will need that space to be built. We can't ask them to come and sit under a tree; they got to have space in the clinic too. Wards and our services providers are not friendly to them. You come to the gate, there the husband comes bringing a nappy to bring it to the ward and they'll say, 'What are you doing here? It's not visiting hours!' 'I brought nappy for my child. 'Get out, wait for 12.'

Dr Min, Paediatrician

What my suggestion would be like to create a well men's clinic apart from well women's clinic, to like a well men's clinic to offer like circumcision, like penis circumcision, and encouragement to come in, and then it's going to be part of the gynaecological clinic like we put these things in the same area. So you the things that we provide from the well men's clinic, things like circumcision and sperm counts from men who are infertile, I mean not infertile but don't have any children, and they want their sperm count. You know what services free of charge so this kind of this clinic can be run alongside the well women's clinic.

Dr Nais, Obstetrician

PPTCT Programming and policy

Changes to infant-feeding policy

Since the introduction of the PPTCT program in PNG in 2003, health care workers have been exposed to changing advice relating to infant feeding. Specifically, the shift in thinking from abrupt cessation of breastfeeding HIV-exposed infants at four to six months, as advised in 2006, to the continuation of breastfeeding after the introduction of food and other fluids at six months, as advised in 2009 and in line with recommendations from the World Health Organization (WHO). Current infant-feeding options (see box) recommend exclusive breastfeeding of all infants for the first six months of life (NDoH 2009c), with other feeding options proposed in situations where exclusive breastfeeding is not an option. Breastfeeding, even in the context of HIV, was viewed as the most beneficial and locally appropriate feeding practice for women in PNG.

The notion of choice permeated how the key informants discussed infant-feeding options for women living with HIV. This appeared to reflect the policy approach of the National Department of Health regarding women's choice but appeared to also reflect a way to avoid risk of blame or retribution in cases where an HIV-exposed infant may seroconvert.

We don't choose for them [the mothers], we just tell them the advantages and the disadvantages of it [the option they have chosen]. So they choose for themselves... then we ask them [if they choose formula feeding], whether the parents are working: Are you able to buy milk for one year? And then sometimes we tell them go and sit down with your husband and talk it over again and see which option is best for you.

Sr. Naomi, Well-baby clinic

We give them option. We just don't want to tell them to continue on breastfeeding and all that, and then later they find that they have problem with the baby. We don't want them to blame us, so we give them option. We just say choose. What do you want to choose to feed them?...

Sr Kaira, Antenatal clinic.

The findings from this study highlight that while the majority of informants were familiar with the national policy of exclusive breastfeeding, this was less so in relation to the continuation of breastfeeding after the first six months; by far the most important change to PNG's updated HIV and infant-feeding guidelines. Despite the recommendation from the National Department of Health (2009a) for dissemination of the revised 2009 infant-feeding guidelines, responses from our informants indicate that, more than two years after the revised policy was released, the updated information was not fully disseminated. Another important issue raised by key informants who had worked with women who had previously lost an infant to HIV-related conditions was that these women appeared to require extra and indeed highly skilled support and counselling to understand the benefits of exclusive breastfeeding as recommended by the National Department of Health.

... we have some who have lost their first or second child and this is like their third child and they are not willing to even risk that little per cent that will come through the breast milk. So they opt to just bottle-feed straight away... They think any kind of breastfeeding will bring the virus over. Even if it's exclusive breastfeeding they don't have enough knowledge to say that [make that choice]... But now, if the counselling has been given very well, I have spoken to a few mothers... who have been counselled through Susu Mama and counselled through the other clinic and they've been told that you have to exclusively breastfeed for 6 months and they have.

Dr Min, Paediatrician

Challenges to delivering PPTCT services

Not surprisingly, the majority of the key informants discussed in some detail the constraints they face in delivering PPTCT services in PNG. These constraints included inadequate staffing levels, particularly in the rural sites, limited financial resources to roll the program out into the provinces and districts and ensuring that the most up-to-date guidelines were followed, and a shortage of medical supplies, including ART and rapid HIV test kits. The 'loss' of women to follow-up was also identified as a major obstacle to the prevention of mother-to-child transmission in PNG and thus a weakness of the PPTCT program.

Where you have a lot of capacity in terms of everything from manpower, skills, knowledge and also other I suppose resources then you're more likely to get a program going. So, generally in hospitals where lots of doctors and other staff, you know, are there, where these programs run is more likely to happen there than in the rural settings where resources are limited – not only the knowledge but the skill base and resources. Maternal Child Health resources, they're probably not likely to happen as readily as behind the major hospitals.

Dr Kondu, Program coordinator

I think staffing is probably one, ah manpower. Like in the clinic it's okay, we have three midwives there, three nursing officers and a CHW [community health worker] so in terms of doing the clinic it's okay. But once they come to labour ward and up in the wards we are really short-staffed. We can't really concentrate on one patient, and there is twenty other mums to look after so, but we try our best. I think that's one staffing issue. And then the other one is supplies of drugs; once in a while we run short of drugs, and the third one is strips for testing. In the clinic we have a sort of constant supply but in the wards, you know, we like, if we run out of strips then that's several days no strips and no testing done. And then when once the mums go to Ward 11 they are basically lost; we can't really follow them up. So I think it's manpower and resources mainly.

Dr Akuda, Obstetrician

Because like the things we do not want to miss any mother who come in. The problem we are having here is that we normally run out of supply [rapid tests] so often, but otherwise we do test on all the mothers who come.

Dr Nais, Obstetrician



Box 1: Infant-feeding options in PNG (Source: NDoH 2009a)

Option 1: Exclusive and continued breastfeeding

Exclusive breastfeeding – nothing other than breast milk is given to the baby for the first six months. Continued Breastfeeding means the continuation of breastfeeding after the introduction of other fluids and food at six months. In addition to the promotion of breastfeeding, the importance of proper breast attachment to reduce the risk of subsequent breast problems (e.g. mastitis, breast abscess, and engorgement) is emphasized. Maternal combined ARV therapy should continue to help reduce the risk of transmission of HIV through the breast milk.

Option 2: Express and heat-treat breast milk

While heat-treating breast milk offers an ideal nutrition for the baby and has some protection against infections and a low risk of HIV transmission, in nearly all circumstances in PNG this option will be impractical.

Option 3: Breastfeeding by another woman

Also referred to as 'Wet Nursing', the woman chosen to breastfeed the infant should be counselled, tested and shown to be HIV-negative. A wet nurse should have access to breastfeeding support and assistance to establish effective breastfeeding.

Option 4: Artificial or replacement feeding from birth

Except in rare situations, artificial and replacement feeding is not an option in the PNG context due to the risks involved with replacement feeding in resource-limited settings resulting in significantly higher infant mortality.

CONCLUSION

UNAIDS has called for all pregnant women to have access to quality life-saving HIV prevention and treatment services—for themselves and their children. This is to ensure that HIV, maternal health, newborn and child health, and family-planning programmes work together, deliver quality results and lead to improved health outcomes. PNG aims to provide a comprehensive range of services that will facilitate reducing primary HIV infection in women in the reproductive age group

(15 to 49 years), preventing unintended pregnancies in women with HIV, preventing transmission during pregnancy, childbirth and breastfeeding and providing care and support for HIV-infected women, children and families (Papua New Guinea National AIDS Council 2010). The target for PPTCT in the National HIV Strategy 2011–15 (Papua New Guinea National AIDS Council 2010) is that 80% of pregnant women are tested for HIV and received their results – during pregnancy, during labour and delivery, and during the post-partum period (<72 hours), including those with previously known HIV status.

Our research has shown that HIV-positive pregnant women and their husbands are key agents in determining the future of MCH and PMTCT services. They report mainly good experiences in these services, although a minority gave examples of some bad experiences. For most women, group pre-test counselling and the 'opt out' method of gaining consent to be tested for HIV did not create any issues. For most, however, it still did not adequately prepare them for receiving an HIV-positive result. There was a lack of information about mother-to-child transmission for HIV-negative women. Information on sex during pregnancy varied from clinic to clinic, although most women did have sex up to the third trimester. Husbands and wives seemed to be happy with men being a support in PMTCT and birth. One area of weakness was up-to-date information about breastfeeding; most clinic staff were giving out-dated advice. HIV testing of infants seems to be a hit-and-miss affair, with sporadic delays and loss of records.



KEY RECOMMENDATIONS



Following the completion of the draft report, key findings were presented at two stakeholder meetings at the respective study sites. The following recommendations were designed in partnership between the research team and the community, including women living with HIV:

- Increase human resources to support the implementation of PPTCT in PNG.
- Increase the involvement of people living with HIV in all aspects of PPTCT, including testing and counselling.
- Consider how to improve HIV counselling for antenatal women, while being conscious of structural and human resource limitations.
- Ensure that all women consent to HIV testing prior to testing, particularly in the labour ward.
- Improve the delivery of Early Infant Diagnosis.
- Ensure timely and effective dissemination of up to date Infant Feeding Guidelines to all health care workers, particularly those in the provinces and districts and who provide infant feeding advice.
- Increase community understandings of the importance of exclusive breast-feeding for the first six months, irrespective of the mother's HIV status.
- Ensure that health care workers have accurate information of HIV risk in couples where both people are HIV-positive, particularly the issue of super-infection.
- Encourage and support men's involvement in all aspects of maternal and child health, particularly outside of the clinic setting. Where required, improve the structure of care and service delivery including the option of providing men's health clinics.
- Improve health care workers understandings of the safety of sex during pregnancy and breastfeeding.
- Ensure that health care workers provide medically accurate and non-judgemental family planning advice.

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