



EARLY INFANT DIAGNOSIS

Understanding the
perceptions, values
and preferences of
women living with
HIV in Kenya, Namibia
and Nigeria

ICW



INTERNATIONAL COMMUNITY OF
WOMEN LIVING WITH HIV



GLOBAL NETWORK OF
PEOPLE LIVING WITH HIV

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ACRONYMS

AIDS	Acquired immunodeficiency syndrome	ICWEA	International Community of Women Living with HIV Eastern Africa
ANC	Antenatal clinic/care	ICWWA	International Community of Women Living with HIV West Africa
ART	Antiretroviral therapy	ICWSA	International Community of Women Living with HIV Southern Africa
ARV	Antiretrovirals	PCR	Polymerase Chain Reaction
ASWHAN	Association of Women living with HIV and AIDS in Nigeria	PVT	Prevention of vertical transmission
CDC	Centers for Disease Control	PMTCT	Prevention of mother-to-child transmission
DNA PCR	Deoxyribonucleic acid polymerase chain reaction	SRH	Sexual and reproductive health
FGD	Focus group discussion	SRHR	Sexual and reproductive health and rights
GNP+	Global Network of People Living with HIV	TBAs	Traditional birth attendants
HIV	Human immunodeficiency virus	WHO	World Health Organization
ICW	International Community of Women Living with HIV		



Executive Summary



Women living with HIV are central to the success of efforts to prevent vertical transmission of HIV, yet their perspectives and experiences have not always been fully considered in the design, monitoring and implementation of programmes to prevent mother-to-child transmission (PMTCT). The result has been lower than ideal uptake of services, loss to follow-up and poor adherence to treatment. Efforts to scale up early infant diagnosis (EID) have similarly been constrained by the lack of consultation and engagement of women living with HIV.

This qualitative study seeks to respond to this deficit. The research explores the perceptions, values and preferences of women living with HIV and mothers of infants exposed to HIV regarding early infant diagnosis in anticipation of upcoming revisions to the World Health Organization (WHO) guidelines. This report presents key experiences and concerns about early infant diagnosis from mothers living with HIV in three countries – Namibia, Kenya and Nigeria.

Our research confirmed that women living with HIV continue to face persistent barriers to care such as stigma, discrimination and abuse when seeking maternal healthcare services including those to prevent vertical transmission. Current programmes to prevent vertical transmission (known commonly as PMTCT) in all three countries do not provide sufficient information or support and are failing many women with regard to quality and acceptability.

Women living with HIV feel strongly that increased uptake of infant testing is dependent upon the quality and availability of education, peer counselling, decentralisation of services and home or community-based testing. The current policy of testing infants within 4-6 weeks of birth was seen as advantageous by many mothers for the sake of their child's health. Given the long delays and high levels of anxiety mothers experience in receiving infant test results, women viewed rapid turnaround testing for infants at point of care as a positive and welcome development.

However, women living with HIV have mixed feelings about the prospect of testing at birth. Women expressed significant concerns about issues of disclosure and recovery from the experience of birth and will require information about the nature of the tests and the need to return for a confirmatory diagnosis. Mothers living with HIV see both benefits and challenges in the possibility that their children would be able to access treatment immediately.

The findings of this study highlight critical areas that must be addressed to improve uptake of services and reduce loss to follow-up in early infant diagnosis efforts.

1

Introduction



In response to evidence supporting increased survival benefits for diagnosing infants with HIV and initiating antiretroviral therapy (ART) as early as possible, WHO issued revised guidelines on the diagnosis of HIV infection in infants and children in 2010.¹ They recommended, in part, that all infants who have known exposure to HIV or whose exposure status is uncertain should undergo virological testing at 4–6 weeks of age. Further, the guidelines recommended that if an infant received an initial positive virological test, they should initiate ART as soon as possible to ensure survival. Since the implementation of these guidelines, the rate of testing of HIV-exposed infants in the first two months of life has increased from 15% to 34%.²

Although this increase is a step in the right direction, the current rate of testing remains low and research is needed to understand why so few infants who are exposed to HIV gain access to early testing and diagnosis, which is a necessary prerequisite for timely initiation of ART and child survival. There is an urgent need to obtain the perspectives of mothers living with HIV to understand what accounts for the ‘loss to follow-up’ in terms of early diagnosis and treatment of infants.

This qualitative research was undertaken to identify barriers to early infant testing and follow-up treatment from the perspective of women living with HIV and to inform upcoming revisions to WHO’s guidelines on early Infant diagnosis (EID), due to be published in December 2015.

This research aimed to:

- capture the perspectives of women and mothers who are living with HIV and who have infants who have been exposed to HIV regarding early infant diagnosis and early ART treatment;
- gain a better understanding of the concerns of and barriers for mothers living with HIV and caregivers of infants exposed to HIV in accessing early diagnosis and starting and maintaining their children in ART; and,
- identify key facilitators for testing, follow-up, and introduction and maintenance of ART infants and children living with HIV.

1 WHO recommendations on the diagnosis of HIV infection in infants and children. Available at http://whqlibdoc.who.int/publications/2010/9789241599085_eng.pdf

2 WHO New Strategies for Infant Diagnosis: WHO Offices, Geneva September 18th – 19th, 2013 attended by Teresia Njoki Otieno.

Focus Countries Background

The countries were selected to represent low (e.g. Nigeria), middle (e.g. Kenya) and high performance (e.g. Namibia) countries according to their progress toward Global Plan targets.

Namibia

Namibia is a high-performing country and is well placed to achieving the Global Plan targets for reducing mother-to-child transmission. Namibia first rolled out its PMTCT program in 2002 and has revised its policy guidelines in line with the 2006, 2010, and 2012 changes in WHO guidelines. Aligned to the Global Plan, the Ministry of Health and Social Services has a costed National Strategy and Action Plan for the Elimination of New Paediatric Infections and Keeping their Mothers Alive 2012–2016.³ Namibia has adopted Option B+ of the WHO recommendations and aims to provide antiretroviral drugs for PMTCT to all women living with HIV during pregnancy and the breastfeeding period as well as to all HIV-exposed infants and young children. The plan calls for counselling and support on maternal nutrition and infant and young child feeding, including the use of ARVs while practicing exclusive breastfeeding for the first six months of life, which in continued with complementary feeding until the child is one year of age.⁴

The comprehensive PMTCT plan aims to provide cotrimoxazole prophylaxis to all HIV-exposed infants from six weeks of age and conduct HIV tests on all HIV-exposed infants using the DNA-PCR methodology at about six to eight weeks of age. Under the plan, additional HIV tests would be conducted after all breastfeeding has stopped. Identified HIV-infected infants and young children are to be linked to ART sites for initiation on treatment. Follow-up support and counselling is to be provided under the plan throughout the antenatal, labour and delivery, and breastfeeding period while ensuring that either the mother or baby is taking ARVs.⁵

Namibia has seen the rate of mother-to-child transmission drop from 25 percent in 2006–2007 to 13 percent in 2012–2013.⁶ HIV testing among pregnant women has seen a nearly two-fold increase in HIV testing among pregnant women between 2005 and 2010, from 47 percent to 86 percent.⁷ The percentage

of women living with HIV who received ARVs for PMTCT has increased from 42 percent in 2006–2007 to 85 percent in 2012–2013.⁸ As of 2010, 95 percent of infants born to a mother living with HIV received ARVs for PMTCT⁹ and, as of 2013, 61 percent of infants born to a mother living with HIV receive a virologic test within two months of birth.

Kenya

Kenya is a middle performance country in its progress toward Global Plan targets. Kenya's national PMTCT Programme started in 2002 and since then over 60 percent of facilities provide PMTCT services, only 20 percent of these facilities, however, provide a comprehensive PMTCT package. According to the National Strategic Framework 2012–2015 (NSF), following the release of WHO 2010 guidelines, Kenya adopted Option A with a provision to implement Option B in areas that have capacity for initiation and monitoring systems.¹⁰ The NSF includes a four-pronged approach to eliminating mother-to-child transmission including primary prevention among women of reproductive age, family planning for all HIV+ women who want to delay their next birth, ARV prophylaxis during pregnancy, delivery and breastfeeding, and care and treatment.

The NSF contains several process indicators for its PMTCT program, including the percentage of HIV-exposed infants who received an HIV test within 12 months of birth and the percentage of exposed infants who were initiated on cotrimoxazole (CTX) within two months of birth. Indicators also included the proportion of mother-baby pair on care or treatment by 18 months after delivery. Process indicators directly relating to pregnant women living with HIV include the proportion of HIV-positive women assessed for ART eligibility by either WHO staging or CD4 at first antenatal care visit and the number of HIV-positive pregnant women who received ARVs to reduce the risk of mother-to-child transmission.¹¹

Despite a scale-up in PMTCT efforts, mother-to-child transmission in Kenya has remained relatively stable from 2011 to 2013 at about 14 percent.¹² As of 2013, 92.2 percent of pregnant women had been tested for HIV, up from 68.3 percent in 2009. However, the percentage of mothers living with HIV who are given ARV prophylaxis showed a slight decline in coverage from 73 percent in 2009 to 70.6 percent in 2013, with a peak of 75.5 percent coverage in 2011.¹³ In 2013,

3 See National Strategy and Action Plan for the Elimination of New Paediatric Infections and Keeping their Mothers Alive 2012/13–2015/16 (Namibia National Strategy and Action Plan), available at <http://www.zero-hiv.org/wp-content/uploads/2013/05/Namibia-eMTCT-Plan.pdf>

4 Namibia National Strategy and Action Plan at 27.

5 Namibia National Strategy and Action Plan at 28.

6 Global AIDS Response Progress Reporting 2013: Monitoring the 2011 Political Declaration on HIV/AIDS, Reporting Period: 2012–2013 (Namibia AIDS Response Progress Reporting) at 11, available at http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/NAM_narrative_report_2014.pdf

7 UNICEF, Countdown to Zero (Namibia) available at: http://www.unicef.org/french/aids/files/hiv_pmtctfactsheetNamibia.pdf

8 Namibia AIDS Response Progress Reporting at 11.

9 UNICEF, Countdown to Zero (Namibia).

10 National Strategic Framework 2012–2015 (Kenya NSF) at 10, available at http://emtct-iatt.org/wp-content/uploads/2012/11/Strategic-Framework-for-EMTCT-in-Kenya_2012.pdf

11 Kenya NSF at 24.

12 Kenya AIDS Response Progress Report 2014: Progress towards Zero, March 2014 (Kenya AIDS Response Progress Report) at 13, available at http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/KEN_narrative_report_2014.pdf

13 Kenya AIDS Response Progress Report at 20.

55.7 percent of infants born to HIV-positive women received ARV prophylaxis to the risk of transmission.¹⁴

Early infant diagnosis in Kenya remains low, with 45.18 percent of infants born to HIV-positive women receiving a virological test for HIV within two months of birth, a number up from 38.93 percent in 2011.¹⁵ Additionally, as of 2011, only 35 percent of exposed infants had received a Polymerase Chain Reaction (PCR) HIV test six weeks after birth.¹⁶

Nigeria

Nigeria is a low performance country in its progress toward Global Plan targets. The PMTCT program in Nigeria started in 2002 in six tertiary facilities in six geopolitical zones of the country. Nigeria has developed a national scale-up plan for elimination of mother-to-child transmission (2010–2015) and has adopted a combination of WHO 2010 Guidelines Option A and Option B regimens for prophylaxis.¹⁷ In 2012, Nigeria developed a PMTCT scale-up plan to support the acceleration of PMTCT programming at the state level focusing on the 12+1 priority states with the highest burden of HIV, accounting for about 70 percent of new HIV infections.¹⁸

The national PMTCT scale-up plan contains highly ambitious objectives, including: at least 90 percent of all pregnant women have access to quality HIV counselling and testing by 2015; at least 90 percent of pregnant women requiring ART for their own health receive lifelong ART; at least 90 percent of HIV-positive pregnant women and breastfeeding infant-mother pairs receive ARV prophylaxis by 2015; and at least 90 percent of all HIV-exposed infants have access to early infant diagnosis services by 2015.¹⁹

Despite these ambitious targets, PMTCT program coverage is still very limited in Nigeria. Mother-to-child transmission in Nigeria has remained relatively stable, decreasing to 27.3 percent in 2014 (Spectrum Modelling) from 29.1 percent in 2010 (Spectrum Modelling).²⁰ As of 2013, 30 percent of HIV-positive pregnant women were receiving ARVs to reduce the risk of transmission, a number up from 5.25 percent in 2007.²¹

As of 2013, only 4 percent of HIV-exposed infants received a virological test for HIV within 2 months of birth.²² In 2010, 11 percent of children born to pregnant women living with HIV received ARVs for PMTCT²³ and as of 2009, only 2 percent of HIV-exposed infants were on cotrimoxazole prophylaxis.²⁴

14 Kenya AIDS Response Progress Report at 21.

15 Kenya AIDS Response Progress Report at 22.

16 Kenya NSF at 10.

17 UNICEF, Countdown to Zero (Nigeria), October 2012, available at <http://www.emtct-iatt.org/wp-content/uploads/2012/10/PMTCT-Factsheet-Nigeria.pdf>

18 Federal Republic of Nigeria Global AIDS Response Country Progress Report, 2014 (Nigeria AIDS Response Country Progress Report) at 33, available at http://www.unaids.org/sites/default/files/en/dataanalysis/knowyourresponse/countryprogressreports/2014countries/NGA_narrative_report_2014.pdf

19 National Scale Up Plan Towards the Elimination of Mother to Child Transmission of HIV in Nigeria, 2010–2015 (Nigeria National EMTCT Plan) at 17, available at http://emtct-iatt.org/wp-content/uploads/2012/11/Nigeria_National-EMTCT-Plan_2010.pdf

20 Nigeria AIDS Response Country Progress Report at 15.

21 Nigeria AIDS Response Country Progress Report at 15.

22 Nigeria AIDS Response Country Progress Report at 15.

23 UNICEF Countdown to Zero (Nigeria), available at <http://www.emtct-iatt.org/wp-content/uploads/2012/10/PMTCT-Factsheet-Nigeria.pdf>

24 Nigeria National EMTCT Plan at 14.



2

Research Methodology

Sampling & Selection of Participants

The Project Partners (the International Community of Women Living with HIV (ICW) in partnership with the regional networks of ICW West Africa, ICW Eastern Africa and ICW Southern Africa and the Global Network of People Living with HIV (GNP+) conducted 10 focus group discussions (FGDs) in Kenya, Namibia and Nigeria during June and July of 2014.

A judgment sample of women living with HIV who gave birth in the past three years (n=106), were recruited by national networks of women living with HIV and interviewed using the FGD questionnaire. Participants were mobilised through networks of women living with HIV, support groups, community health workers and local partner organizations and recruited using a snowball (respondent-driven) sampling method where participants with the aforementioned specific characteristics who were willing to participate in the study were selected. Those participants were then asked to identify women like themselves for the study.

Focus group discussions (FGDs) are interviews with small groups of people with relatively similar backgrounds and experiences. FGDs provide a range of material and a solid perspective on group dynamics. Participants are asked to reflect on the questions asked by the facilitators, provide their own comments, listen to what the rest of the group have to say, and react to their observations. The main purpose is to elicit ideas, insights, and experiences in a social context where people stimulate each other and consider their own views along with the views of others. FGDs are an opportunity to clarify shared understanding or perceptions held by the group and weed out false or extreme views, thus providing a quality control mechanism. FGDs can also create ownership and engagement among participants because they are given an opportunity to express their views and be heard by others.

Development of Focus Group Questions

ICW and GNP+ developed a focus group discussion guide in partnership with a research consultant to explore the perceptions, values, and preferences of women and mothers living with HIV regarding early infant diagnosis practices. Representatives of regional and national networks of women living with HIV reviewed the questions and provided suggestions for improvement. The questions were also shared with members of the Community Engagement Working Group of the Interagency Task Team (IATT) on PMTCT including the CDC and WHO. The feedback received helped to shape the final questions and guides.

The Consent Process

A consent form was developed and distributed to each FGD participant. The facilitator read through the consent form with participants, in English or the local language. All participants were told that their participation was voluntary and that they could leave at anytime. They were also told that



they did not have to answer any questions they felt uncomfortable answering. The facilitator explained the objectives of the FGDs, the commitment requested of participants, and how the information would be used. The participants were given the contact information of the local facilitators and information about how to access the final report. They were told that the FGDs would be recorded and transcribed verbatim but that the information would not be attributed to specific participants by name. An opportunity was presented for questions. Each participant was then asked to sign and date the form if they wanted to participate. Copies of the signed consent forms were made available for participants to take home when possible.

Focus Group Information

Kenya: ICW and GNP+ conducted 3 focus group discussions with women living with HIV in partnership with ICW Eastern Africa and ICW networks and support groups in Kenya where a total of 31 participants women in Nairobi (Urban) (n=10), Chuka (Semi-urban) (n=12), Nakuru (Peri-Urban) (n=9). were interviewed for approximately 120 minutes in duration and were facilitated by Teresia Njoki Otieno, ICW East Africa. The discussions were mainly held in Swahili.

Namibia: ICW and GNP+ conducted 3 focus group discussions with women living with HIV in partnership with ICW Southern Africa and the Namibian Women's Health Network (NWHN), an ICW member network. The focus groups had a total of 29 women in Windhoek, Namibia. In Namibia, the FGDs were approximately 120 minutes in duration and were facilitated by Jenifer Gaatsi for the first focus group and by Veronica Kalambi for the second and third focus groups. Participants spoke several indigenous languages and the questionnaire was translated into the primary language spoken by participants, Oshiwambo. Unfortunately, the transcript from the second FDG was lost and therefore this data is not reflected in the report. The report reflects a total of 19 focus group participants in Namibia.

Nigeria: ICW and GNP+ conducted 4 focus groups with 45 women living with HIV in partnership with ICW West Africa and ICW networks in Nigeria. Two focus groups were held in Abuja with 12 and 9 participants respectively and two focus groups were held in Lagos both with 12 participants. In Nigeria the FGDs were approximately 120 minutes in duration, and were facilitated by Patricia Ukoli of ICW West Africa. The discussions were mainly held in Yoruba, Hausa and Igbo.

In all countries, each focus group discussion was audio recorded on digital recorders and transcribed and translated.

Participant Incentive

All participants were provided with a small transportation stipend and refreshments including lunch during the course of the focus groups.

Data Analysis

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

1. Collation of the transcript data under key questions (as per the FGD guides) by country.
2. Unitisation of the data (identifying units of information that form the basis for defining categories).
3. Categorisation of units (sorting of units into groupings to represent key themes).
4. Organisation of categories into main themes.
5. Selection of key quotes to support main themes.

In addition, detailed sub-analysis of the data was conducted to look at individual women's stories within groups, and to focus in on key topics such as testing knowledge, breastfeeding, the role of traditional birth attendants and caesarean section.

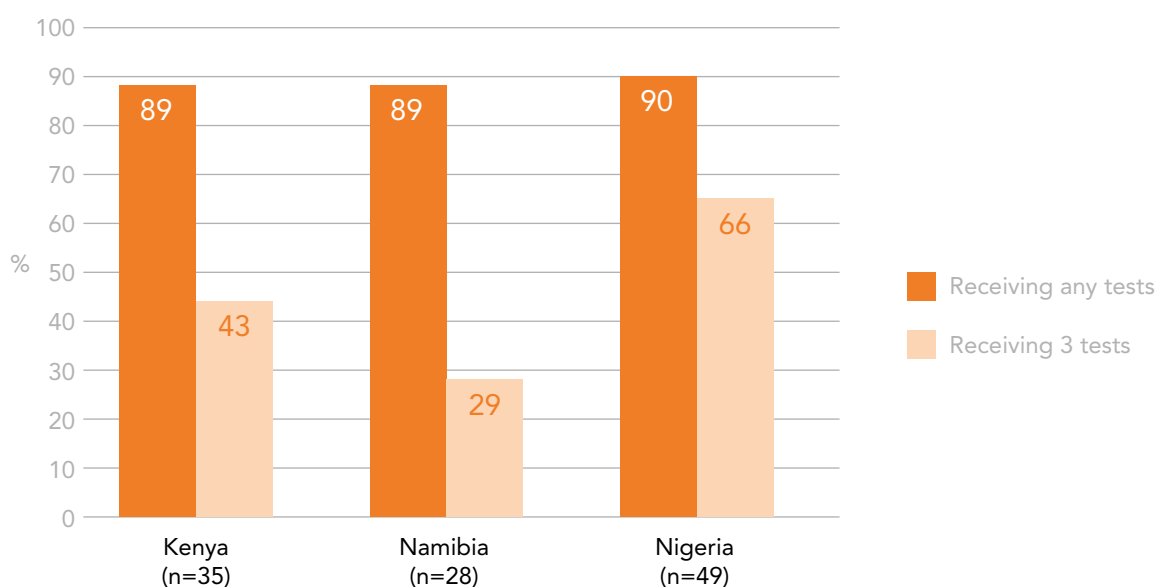
Statement of Limitations

There are some limitations associated with the research methodology used for this study. The selection of FGD participants was not random, which presents some bias. Additionally, given the smaller sample size the FGDs, and surveys are limited in their ability to produce results that are can be generalized to the broader population. Further, although three focus groups were conducted in Namibia, one of the transcripts was lost. Therefore the data from Namibia is based on only two of the original three FGDs.

Demographic Summary

A total of 105 women participated in the focus groups with an average age of 34 years old. Data was recorded for 95 of the women.²⁵ 80 of the women participating had given birth within the last 4 years, representing a total of 105 children. The majority of focus group participants were receiving treatment for their own health. While most of the children of focus group participants had received at least one HIV test, with many receiving between 1–2 tests the majority of children had not received the recommended 3 confirmatory diagnostic tests. It is interesting to note that a higher percentage of the children of Nigerian participants who gave birth in 2010 or later received 3 tests (66%).

Percentage of children of focus group participants receiving any tests and receiving 3 tests.



25 Please see the statement of limitations.

Kenya

- 31 women living with HIV participated in the focus groups in Kenya. 28 of those participants reported that they had given birth at least once since 2010.
- Average age of participant: 33.7 years old
Median Age: 34 years old.
- Mothers accessing ARVs: 97%
- Children accessing some testing: 88.6%
- Average number of tests received by children of FGD participants: 1.7
- Children receiving the full diagnostic process of 3 tests: 42.9%

- Children accessing some testing: 85.7%
- Average number of tests received by children of FGD participants: 1.1
- Children receiving the full diagnostic process of 3 tests: 35.3%

Nigeria

- 45 women living with HIV participated in the focus groups in Nigeria. 35 of those participants reported that they had given birth at least once since 2010.
- Average age of participant: 33.8 years old
Median Age: 34 years old.
- Mothers accessing ARVs: 98%
- Children accessing some testing: 89.8%
- Average number of tests received by children of FGD participants: 1.7
- Children receiving the full diagnostic process of 3 tests: 65.7%

Namibia

- 19 women living with HIV participated in the focus groups in Namibia. 17 of those participants reported that they had given birth at least once since 2010.
- Average age of participant: 35.1 years old
Median Age: 35 years old.
- Mothers accessing ARVs: 84%

3

Findings

Section 1: Lived Experiences of Prevention of Vertical Transmission



"No mother wants to give birth to a positive baby."

– Woman living with HIV, Namibia (WDH2#3)

Successful efforts to prevent vertical transmission should include a full cascade of care for expectant mothers and their infants. This cascade of care includes information provision around family planning and should follow the woman through all aspects of pregnancy, childbirth and infant and child feeding, care and prophylaxis. Ideally, PMTCT programmes to prevent vertical transmission are a key entry point to facilitate uptake of infant testing and treatment.

However, the research revealed that these programmes are failing women living with HIV in two key ways: 1) by failing to provide adequate information about key aspects of preventing vertical transmission including infant testing and treatment and 2) by failing to address stigma, discrimination and abuse in healthcare settings. The focus groups also revealed the important role peer support plays for women seeking accurate and comprehensive information about preventing vertical transmission from conception to birth and beyond.

Confusing and Inadequate Information

The quality of services to prevent vertical transmission was found to be varied across countries and settings, with women in this study reporting very diverse experiences even within the same geographical area. Yet, in all three countries, focus group participants stated that they were not given adequate information about how to prevent HIV transmission to their child or about the availability and importance of PMTCT services. In particular, many mothers are not adequately prepared for infant testing once the baby is born, nor are they asked to give consent before their babies are tested for HIV. Women living with HIV cited lack of information as a key reason why mothers do not return for follow-up testing and care:

"Women are supposed to be given information on testing. No mother wants to give birth to [a] HIV positive baby...the [reason] some of the women don't come for baby tests was because they were not given enough information on the importance of baby testing."

– *Woman living with HIV, Namibia (WDH2#3)*

In Namibia, a country reporting 80% coverage of antiretroviral services for pregnant women living with HIV,²⁶ experiences with antenatal care were mixed. Some women described positive experiences of receiving good counselling during antenatal care. They reported receiving comprehensive information given over time, demonstrations of how to give their infant medication, having their options regarding infant feeding explained, and being asked about their feeding preferences. However, women also reported receiving little to no information prior to birth from healthcare workers about what methods are available to prevent HIV transmission to their baby, including information about infant testing. Women also reported being given confusing or incorrect information about aspects of prevention of vertical transmission. Language remained a significant barrier to obtaining useful information with healthcare staff only providing information in English or Afrikaans.

The focus group discussions revealed that advice and information on options for delivery in Namibia was generally lacking. Women reported that they are often not given a choice about their delivery method and are frequently instructed to or informed that they will deliver via caesarean section (c-section) (see box on c-section). Experiences of family planning advice in particular were mixed, with some women describing they felt they had received good information and others reporting that they received poor information or none at all.

Women also reported that negative and discriminatory attitudes and behaviours of healthcare workers hampered their ability to obtain useful and comprehensive information on preventing vertical transmission and testing infants by deterring them from asking questions. Women reported that the information they received more frequently came from their support groups, rather than public sector health workers.

"The nurses don't give information. The environment in the hospital is not good because some of the nurses the way they talk to us patients is not good. Instead of talking to you in a polite way they are just shouting at you, laughing at you, saying look at yourself you are HIV positive and you are giving birth. It is the attitude of the nurses that contributes to the problem [of women not coming forward for infant testing]."

– *Woman living with HIV, Namibia (WDH3#8)*

"If you go to hospital and don't ask questions you will not be given information and sometimes you ask and the nurse will say you are asking too many questions."

– *Woman living with HIV, Namibia (WDH1#1)*

"Some of the women don't come for baby tests was because they were not given enough information on the importance of baby testing."

– *Woman living with HIV, Namibia (WDH1#3)*

In Nigeria, a country with low PMTCT performance, some women reported receiving no information about how to prevent vertical transmission, whereas others reported that they felt they had received good information during their antenatal care. Most women in Nigeria reported having had some family planning advice after giving birth and several women reported that they felt they had received detailed and comprehensive information on infant feeding and prophylaxis, although there was still significant confusion around breastfeeding and risk of transmission. A significant number of women reported that they were told to have a c-section in the context of conversations with their doctors about their HIV status.

"I was pregnant for my first child [in 2012] when I knew my status, at the ANC they asked me to do the test, and come the next day for my result, when I came for my result the nurse gave my result and said it was positive but that I can come back and repeat the test in 3–6 months, she didn't tell me anything, no advice on how to prevent my baby from getting it. I went home and told my husband [about positive test] who said, it was not possible since am looking healthy, so I just forgot about it...I never knew or heard about PMTCT. I was still going for ANC in the primary health centre nobody said anything to me about my status. Soon after I delivered, my son started falling ill frequently."

– *Woman living with HIV, Nigeria (ABJ1#11)*

"Some doctors will tell you not to breastfeed that it's a 50:50 chance, but the paediatric doctors will tell you breastfeed, that since you have been on the drug for long there is no risk."

– *Woman living with HIV, Nigeria (LA2#1)*

"When I told my husband and we both went back for the test, he was negative and mine was positive again, he (husband) said how can it be that he is negative and me positive, maybe the test was mixed up...Due to the advice my husband [gave] me, that I could not be positive since he is negative, I stopped going to the hospital, and didn't take my child too, I breastfed her for a year and three months, then one day she fell seriously sick, I even thought she was going to die, we took her to the hospital they did an HIV test and said she was positive."

– *Woman living with HIV, Nigeria (ABJ2#9)*

26 AIDS by the numbers UNAIDS 2013 available at: http://www.unaids.org/sites/default/files/media_asset/JC2571_AIDS_by_the_numbers_en_1.pdf

In Kenya, a middle performance country, some women reported receiving good information and advice about prevention of vertical transmission and some reported receiving no advice at all. However, responses were often somewhere in the middle, with confusion and misinformation around key topics, and different facilities giving different advice, particularly around infant feeding and transmission risk. Women felt that information they received on family planning after birth, however, was generally good.

"From other women who were in our support group, another one said they were told to give the baby Septrin till 18 months and when they get the final PCR test then they release the child from Septrin. By then I had released mine from Septrin since I was told to give for 2 months after weaning from breastmilk. Another one said they stopped breastfeeding the child and immediately that day they were told never to give the child any medication. I came to realise the information given from these places is different and I thought at least it should be mended so that information all over Kenya is uniform."

– *Woman living with HIV, Kenya (KEN1#10)*

"There was contradicting information. I heard, especially from support groups some women say they were told that they can also continue with breastfeeding after 6 months and also feed the baby as long as they are on ARVs. There was that contradicting information for a year."

– *Woman living with HIV, Kenya (KEN2#4)*

In addition, Kenyan women frequently mentioned the positive impact of peer supports and information:

"Also have someone who is already in the shoes to advise you to take the test...If someone like me tells another mother that 'I have been there so take your child for testing.' I will relate to her more than someone else."

– *Woman living with HIV, Kenya (KEN1#6)*

"In the clinic and there are peer educators that tell you that this will happen at this point and at this point. Even when you do not bring the baby for PCR you are called."

– *Woman living with HIV, Kenya (KEN1#5)*

What I can say, the information we get from these mentor mothers is better than what we get from the doctors ...You know the doctor cannot have time...I prefer mentor mothers so that you follow up at the support groups."

– *Woman living with HIV, Kenya (KEN1#4)*

"We have seen this with the mother mentor programme it has helped a lot of women who are in that situation. They were encouraged to take their babies for medication."

– *Woman living with HIV, Kenya (KEN2#6)*

Discrimination and Abuse

Women in all three countries reported specific and personal experiences of stigma and discrimination including abuse in antenatal and maternal health settings. In all three countries, women identified stigma and discrimination in healthcare settings as a key driver of why they may drop out of care. The experiences and perspectives of women living with HIV suggest that a focus on improving the quality and acceptability of counselling, including engaging trained peer counsellors, along the cascade of care could reduce discrimination and stigma from healthcare workers and encourage women to remain in care.

Women described an extremely poor quality of care during labour and delivery, especially in Namibia, where women reported that they were abused and discriminated against by healthcare workers due to their HIV status:

"When I gave birth I went to the hospital ... and I was told to go and walk around... later when the pain was too much I just came back and the baby came without any nurse attending to me. When they came they found the baby out and one nurse came in to help me then when she came she said that I must behave myself not to infect her because she has her kids and they still need her because she knows that I am HIV positive."

– *Woman living with HIV, Namibia (WDH1#8)*

"I want to talk about the counselling which is lacking in most of the hospitals I would really like to see that people who are there have the knowledge of HIV and how to work with people living with HIV or maybe people living with HIV themselves to be the counsellors because now it seems that those who are there [have a] 'don't care' attitude because normally if you go to the hospital and are not that strong yourself or vocal enough they will not help you and the way they talk to you is already discriminatory... they don't show you any sympathy and shout at you and say you die."

– *Woman living with HIV, Namibia (WDH1#3)*

"There should be nurses that are specifically trained on HIV. At private hospital you will find those hospitals working in the field. In our public hospitals they are not trained in a specific field. They are not sensitive or they are making fun of the women ... It seems that if you are HIV positive you don't have dignity and everybody is dissing you and laughing at you saying whatever they want to say about you and look down upon you."

– *Woman living with HIV, Namibia (WDH3#15)*

"One of my friends gave birth to three children and two of them died and she left with one. She became pregnant again and was told why did you fall pregnant? That child will die like the others died. When that woman gave birth that child fell sick and a friend told me not to take the baby to the hospital but give traditional herbs. The baby dies because of this, because she was scared to go to the hospital because of fear of the nurses."

– *Woman living with HIV, Namibia (WDH3#19)*

Some women in Namibia also expressed that negative experiences during pregnancy or birth deterred them from returning for follow-up care, in particular to avoid further mistreatment or embarrassment.

"What makes women not to go back for follow up is because sometimes you look at the services you receive when you go to access [the] hospital. The way the nurses talk to you, look at you, shout at you. Now when you are pregnant they will tell you, you are HIV positive and you are pregnant and the child you will give birth to will also be HIV positive. Once you give birth you will be scared to take the baby for testing because you are thinking of all the insults you received when you were pregnant and they told you you were going to give birth to an HIV positive baby so to avoid embarrassment you will keep the baby at home and avoid tests. They will look [at] you and tell you- you are dirty and they look down on you before they help you or give you information."

– Woman living with HIV, Namibia (WDH3#19)

Kenyan women also reported specific experiences of abuse and discrimination from health workers:

"[I found out] I was positive and I was almost 9 months and I remember this health worker telling me... 'Look at you! You are positive and this is the time you are knowing. Your chances of infecting the baby are 100 even 110%.' So, I remember I went outside I cried for a while then I went home. I think I was given Septrin or something...I feel I was not handled well. I think I should have been counselled, told what to do, my options and what to do from there. I had no idea."

– Woman living with HIV, Kenya (KEN1#6)

"I went there and introduced myself but the person I got there asked me; 'you mean you are HIV+ and you have come here to deliver. Who made you pregnant?' Actually I was mad and told her 'you mean that is what you can ask me?' I told her that I am a human rights activist and I can start with you before I deliver. (Laughter) She feared then she told me; 'No, let me just admit you.' Then I asked her; 'you are asking me who made me pregnant do you know it could actually be your husband?' She kept quiet and told me to go to my bed. Very early in the morning at 6 I had not delivered and from there I told her I need a discharge. A very tall doctor who knew me came and asked, 'you know you are going to deliver very early by around 1 pm. Why are you going home?' I told him that I had been abused in that facility and I knew I had my bed, food and so many things in my house and that I needed to go back home."

– Woman living with HIV, Kenya (KEN2#5)

In Nigeria, women reported stigmatizing behaviour and delays in care due to their HIV status, including being publicly asked to provide additional gloves that were not medically necessary. Additionally, women living with HIV reported that nurses refused to attend or touch them.

"If we (people living with HIV) are not there to support each other, I don't think we can survive, imagine a matron, would turn JIK (bleach) into the hand washing soap, just because she is dealing with us and she will wear double elbow covers, just to take blood pressure, once I had to ask her if she was going to move corpse from the mortuary. A new matron that was just post to service there, came to her and ask how do you do it where, she said to her don't allow them to touch you, when she saw a patient was watching her she now took her to the inner room."

– Woman living with HIV, Nigeria (LA1#6)

"Two of the nurses recognized me and said they should attend to me, the baby was still breathing when I got there, but because of the delay, the baby gave up, and they told me sorry the baby is not breathing, but we will see what we can to save your life but you must get all the things we will use in the theatre before we attend to you."

– Woman Living with HIV, Nigeria (LA2#7)

"They say positive women should bring elbow covers and two packs of covers...I felt they should have told us these things individually because announcing it exposes the woman's status. If other women see you bringing two they will know you are positive."

– Woman living with HIV, Nigeria (LA2#8)

"In my centre confidentiality was maintained. The only issue was at labour. Some nurses did not want to come to my bed. I experienced discrimination by health workers in the health facility, my bed was separated."

– Woman living with HIV Nigeria (LA2#4)

Caesarean Section and Informed Consent

Across countries and focus groups, many of the women reported that they did not receive comprehensive information about the risks and benefits of giving birth via elective caesarean section (c-section). Yet, many women in this study reported having or being encouraged to have a c-section. Although it is unclear from the responses why c-section was advised, the number of women reporting having had a c-section was striking. Only a few women reported they had been given additional medical justifications such as high blood pressure. The WHO recommendations state that "although Caesarean section has been shown to protect against HIV transmission, especially in the absence of ARV drugs or in the case of high viral load, WHO does not recommend it in resource-limited settings specifically for HIV infection; rather it is recommended for obstetric and other medical indications."²⁷

The lack of information provided to women about the risks and benefits of c-sections reported in this study suggests a fundamental and pervasive violation of the rights of women living with HIV to informed consent and a need for better dissemination of updated guidance on the risks and benefits of c-sections for expectant mothers living with HIV. Although not explored directly in these focus groups, women living with HIV have reported experiences of forced and coerced sterilization in the context of receiving c-section.²⁸

In the focus groups held in Nigeria, 11 of the 45 participants stated that they were instructed to have a c-section:

"They told me not to have normal delivery; that I should go for CS so as to protect my baby."

– Woman living with HIV, Nigeria (ABJ2#2)

"We all know the safest way to deliver a baby for the baby not to be infected is CS."

– Woman living with HIV, Nigeria (LA2#11)

"I was told to use my drugs on time, and not miss them, the doctor said I should go for CS, that I won't be able to deliver normally, I didn't have money for CS, and was worried but luckily I delivered normally."

– Woman living with HIV, Nigeria (ABJ2#5)

"I was pregnant when I knew my status, they advise me to go for caesarean section, I told them, it's not the caesarean section am worried about, but who will take care of me, if I go through caesarean section."

– Woman living with HIV, Nigeria (LA1#3)

Further, in Kenya women do not appear to have been given clear information about the reality of the risks, such as higher morbidity associated with c-section as opposed to vaginal delivery and it is unclear from this data whether their refusal of c-section was respected. However, it is important to note that some of the medical rationales they report being provided with do meet with WHO guidelines recommending c-section.

"They were really insisting that I should not push because the viral load was high."

– Woman living with HIV, Kenya (KEN1#3)

"I chose for a caesarean delivery because I was scared and I did not want to infect my second born."

– Woman living with HIV, Kenya (KEN2#4)

"When they started taking my blood pressure, they started educating me on the BP aspect that if I push, seizure may occur, that I shouldn't try doing the vaginal delivery, that it's not really about the CD4, but about my BP."

– Woman living with HIV, Nigeria (LA1#8)

Very few women appeared to have a preference for c-section, primarily because of concerns around recovery and needing assistance after the birth. Several women stated that they had insisted on a vaginal delivery, with some success.

"When I went to maternity to deliver that day... actually those people they see money. Personally, I was told; 'Prepare for caesarean.' Then I told them, who told you I cannot push? Who told you I cannot push?"

– Woman living with HIV, Kenya (KEN2#5)

"They told me not to have normal delivery, I try to talk to other doctors, I think it was the last doctor that took his time to explain things to me, he said my pelvic was too small that I can't push it myself, that if I take too long during the labour I might infect the child, I had to go through CS to delivery, though I was stubborn, I still wanted to try and deliver myself."

– Woman living with HIV, Nigeria (LA1#2)

27 Consolidated ARV guidelines, June 2013 Box 7.1: Special considerations for the care and management of pregnant women available at http://www.who.int/hiv/pub/guidelines/arv2013/art/box7_1/en/

28 Robbed of Choice, Forced and Coerced Sterilization of Women Living with HIV in Kenya available at <https://www.uonbi.ac.ke/kihara/files/report-on-robbed-of-choice-forced-and-coerced-sterilization-experiences-of-women-living-with-hiv-in-kenya.pdf>

Infant Prophylaxis and Dosages

In all three countries, women raised concerns about confusing or inadequate information and instructions regarding infant prophylaxis and in particular dosages of nevirapine for their babies. Several women stated that misinformation or poor instructions resulted in overdoses and potential injury to their child.

"The pharmacy wrote 5mls boldly on the pack... My son had been taking 5 ml twice daily for 3 days....I said to the doctor is it true that my baby has been overdosed? She said yes...I went home mad, I was filled with fear, I had giving him his 6 weeks dose in 3 days and for the next 2–3 days completely stop giving him but with pressure from my family I placed him back on the prophylaxis for the 6 weeks period. To me it was a big capacity gap from the facility; I just gave birth, going through trauma and then this. Most time our facility gets it wrong and if you try to question them or such, they just leave you aside."

– Woman living with HIV, Nigeria (LA2#12)

"When I gave birth, that's where the hospital gave me nevirapine and they did not give me the correct dose. They did not tell me what dose I was to give my child and so my son was...it was like I was overdosing him. That nevirapine that I was given I gave him until it got finished. Then I stopped giving him and we stayed like that. At nine months he became sick only for like 3 days and he passed on."

– Woman living with HIV, Kenya (KEN1#4)

Also, in Kenya, several mothers reported being given incorrect or expired dosages of prophylaxis.

"When I was pregnant you can imagine I was given expired nevirapine! [Moderator: For the baby?] Yes. When I went to Kenyatta for delivery the doctor asked if I had been given medicine for the baby. In fact they were very good. After they checked the medication they confirmed the date was not right for the baby."

– Woman living with HIV, Kenya (KEN1#3)

"After delivery [the baby] was put on nevirapine prophylaxis and after 6 weeks I was told to stop the nevirapine and give Septrin. But then later when I went back to the clinic I learnt that I was not supposed to stop the nevirapine since I had started the ARVs late. I was so worried because I had broken the cycle for a whole month then I was told to restart. I am still worried I don't know what happened in between. I still have some worry since waiting up to 9 months is a long time. Hoping God will preserve me. Currently I am in that situation."

– Woman living with HIV, Kenya (KEN2#4)

Confusion Around Breastfeeding

In the past, the World Health Organization (WHO) advised mothers living with HIV to avoid breastfeeding if they were able to afford, prepare and store formula milk safely. But there is now ample evidence to show that a combination of exclusive breastfeeding and the use of antiretroviral treatment can significantly reduce the risk of vertical transmission of HIV to infants through breastfeeding. This means that the child can benefit from breastfeeding (improving infant's chances of survival with low risk of becoming infected with HIV). In 2010, WHO released new recommendations on infant feeding by HIV-positive mothers, based on this new evidence. For the first time, WHO recommended that HIV-positive mothers or their infants take antiretroviral drugs throughout the period of

breastfeeding and until the infant is 12 months old. However, national authorities were given leeway to choose whether to recommend a specific infant feeding practice, for example breastfeeding with an antiretroviral intervention or avoidance of breastfeeding.²⁹

The information mothers are given about infant feeding, in particular breastfeeding, have a critical impact on the infant's risk of HIV acquisition and also the parent's need and motivation to return for infant testing. Focus groups revealed that the different testing protocols for different infant feeding approaches, and a lack of provision of

29 WHO Guidelines on HIV and infant feeding 2010 available at http://www.who.int/maternal_child_adolescent/documents/9789241599535/en/

consistent up-to-date guidance on breastfeeding for women has lead to confusion over infant feeding and therefore confusion about early infant diagnosis practices. This was particularly true in Kenya:

"This other clinic was telling me to stop breastfeeding completely and introduce food at 6 months while this other one was telling me you can breastfeed and still give the baby food. So I don't know if maybe the information is being relayed badly because this one tells you this while the other one tells you something else."

– Woman living with HIV, Kenya (KEN1#6)

"Just this week a lady called me in so much distress. Five weeks to delivery and she was sternly warned not to breastfeed the baby once she gave birth. Despite the fact that she was on medication they insisted she had high chances of transmitting and they did not want to risk."

– Woman living with HIV, Kenya (KEN1#2)

"Actually they (women living with HIV) were saying they were told to breastfeed for a year while others were saying they were told up to 6 months. We did not know which one was correct."

– Woman living with HIV, Kenya (KEN2#4)

Women reported community pressure to breastfeed their child and that they would face difficult questions from family and friends if they were not breastfeeding. Women in the focus groups suggested that if women were advised not to breastfeed but they had not disclosed their HIV status to their partner, they may elect to breastfeed anyway. Giving women accurate information about the risks and benefits of breastfeeding is critical.

"You know when you get a baby, they (friends, relatives and neighbours) come to check whether you are breastfeeding or not. They do not come to check on the baby. If you are not breastfeeding they ask questions of why you are not doing it. Even if you are sitting with them and the baby cries they insist that you breastfeed the baby."

– Woman living with HIV, Kenya (KEN3#7)

"Because you will be scared that if the doctor said I must not breastfeed when I go back home I cannot tell my partner I cannot breastfeed because I cannot disclose my status to him and sometimes there are financial issues. I do not have money for milk so I will just breastfeed and I don't want the doctor to see that my baby is HIV positive and he will tell me not to breastfeed which will be difficult for me to explain to my partner back home."

– Woman living with HIV, Namibia (WDH3#9)

"When I got pregnant, the doctor said madam you have to go on infant formula for your child, that troubled me, as I have to go back to the village where I had told all the women to breastfeed their baby (to avoid diarrhoea), now I will now go back and they will now see me not breastfeeding, they will now see me using bottle to feed my child how will it look like?"

– Woman living with HIV, Nigeria (LA1#9)

Women in Namibia and Nigeria also raised the cost of formula milk as an issue as well as other key barriers to obtaining nutrition supports, such as birth certificate requirements:

"My baby is now negative but I am still breastfeeding this baby. Sometimes I go around looking for help to get (money for) formula milk but the problem is I don't know where the father of my baby is. That makes it difficult to get a birth certificate. And now I am so scared that I might end up because the people who are supposed to provide me with formula need the birth certificate of my baby, infecting my baby by continuing breastfeeding my baby, what should I do?"

– Woman living with HIV, Namibia (WDH3#3)

"When I gave birth, they ask me not to breastfeed, but if I get pregnant again I will breastfeed, because the cost of baby food was like, sometimes we don't eat so the baby can eat. So if am not there who will take care of the baby, next time I will do everything possible to breastfeed."

– Woman living with HIV, Nigeria (LA2#8)



Traditional Birth Attendants (TBAs)

Traditional birth attendants (TBAs) provide an alternative form of pregnancy and delivery care utilized by women in all three countries. Women make use of TBAs for a variety of practical reasons, including cost. The focus group discussions revealed that women might also elect to utilize TBAs because they do not demand HIV testing as a condition of services and women can therefore prevent unnecessary stigma and disclosure of their HIV status. However, women also expressed concerns about the quality of care provided by TBAs and worries that TBAs may divert women from standard antenatal services as well as PMTCT programs. The focus groups suggest that the prevalence of TBA usage reveals both a gap in services and a potential opportunity to get needed information to women at the margins.

In Nigeria, the topic of TBAs was raised in both of the focus groups in Lagos.

"I asked some people why they go to TBAs, they say that they can deliver for N3,000 while [the government hospital] is asking for N40,000 – N50,000. This makes us lose the opportunity of getting positive mothers on PMTCT and testing their babies."

– Woman living with HIV, Nigeria (LA-1#6)

This view was also supported in Nairobi:

"There are some mothers who fear attending clinic since they will be tested and their HIV status will come out. Now that will make them follow up on the clinic visits till they give birth and also their baby will have to go for testing. They prefer going to the traditional birth attendants to be massaged than to attend clinic."

– Woman living with HIV, Kenya (KEN1#1)

However, several women in Lagos expressed concerns about whether TBAs are suitably qualified to support pregnant women living with HIV:

"TBAs cause a lot of harm at times, they are important but they are inexperienced in terms of professional reasoning... We all know they the safest way to deliver a baby for the baby not to be infected is CS, TBAs cannot do CS, also they need to know their limit, last week a woman died in my street from prolonged labour, the TBA should have referred her to general hospital for CS. They play key roles in our communities but they need to be equipped."

– Woman living with HIV, Nigeria (LA2#11)

"For us women living with HIV, there is something special delivering in the hospital, that's one reason why I don't like TBAs. For a positive pregnant woman there is a way they take their delivery is different, even in the hospital, the nurses say, even if you are not going to deliver your baby here, ensure you tell the doctor were you want to deliver that you are positive because there is a special way to take the delivery. The TBAs are just after the baby coming out, they don't even know if the woman is positive or not."

– Woman living with HIV, Nigeria (LA2-#6)

"One thing about TBAs, once they know it's a HIV case, they completely ignore the women, it has happened to one of our members. And they don't test."

– Woman living with HIV, Nigeria (LA2#4)

"At the ANC, they said we should not go to the TBAs that we should go to general hospital."

– Woman living with HIV, Nigeria (LA2#2)

Women in the focus groups also expressed that, with support, TBAs could be an asset to efforts to prevent vertical transmission and help disseminate accurate information for women:

"TBAs are very important in our community, if you go to a typical community, you will notice that weeds have outgrown the health centre there, people patronize the TBAs more, they play a big role, they bridge the gap. My suggestion or advocacy will be that government recognize them, and support them in terms of training them and also helping them to set up HIV counselling and testing services in their facilities, so they can test and refer women living with HIV to government facilities."

– Woman living with HIV, Nigeria (LA2#11)

"The Government should use every opportunity to get women and provide them with serve and information, if they prefer TBAs, then the TBAs should be equipped with the right information and kits."

– Woman living with HIV, Nigeria (LA2#12)

Section 2:

Early Infant Diagnosis



“Positive women need to sensitize fellow positive mothers on the need to test their babies”

– Woman living with HIV, Nigeria (ABJ1#7)

Early infant diagnosis refers to the practice of testing babies within the first 4–6 weeks of life. The focus groups explored women’s views on this currently recommended practice to understand the reasons that some women may not return for follow-up testing and to discover how new guidelines on rapid testing and testing at birth might be received. Although not all women had been adequately informed prior to delivery that their baby would be tested for HIV and how this would work, many women regarded the idea of infant testing as desirable.

In all countries:

- Mothers expressed a desire to know the status of their child and that prevention efforts had worked for them.
- Knowing their child’s status would help mothers know what to do next and what is best for their child regarding feeding (during and after the breastfeeding period).
- Mothers would be happy if the child is negative and healthy.

Understanding and Experiences of Testing at 4–6 Weeks

“They didn’t seek my consent, it was more like force.”

– Woman living with HIV, Nigeria (LA2#12)

The most recent WHO Guidelines issued in 2010 strongly recommend that all HIV-exposed infants have HIV virological testing at 4–6 weeks of age or at the earliest opportunity thereafter (Recommendation 5). It is also strongly recommended that the test results from virological testing in infants be returned to the clinic and child/mother/carer as soon as possible, but at the latest within four weeks of collection. Positive test results should be fast-tracked to the mother-baby pair as soon as possible to enable prompt initiation of ART (Recommendation 7). For well, HIV-exposed infants, it is recommended that they undergo HIV serological testing at around 9 months of age or at the time of the last immunization visit (Recommendation 9).³⁰

In Namibia, the comprehensive PMTCT plan aims to provide cotrimoxazole prophylaxis to all HIV-exposed infants from six weeks of age and conduct HIV tests on all HIV-exposed infants using the DNA-PCR methodology

30 See World Health Organization, WHO Recommendations on the Diagnosis of HIV Infection in Infants and Children (2010) at 4–5, available at http://whqlibdoc.who.int/publications/2010/9789241599085_eng.pdf?ua=1

at about six to eight weeks of age.³¹ In Kenya, the National Strategic Framework contains several process indicators for its PMTCT program, including the percentage of HIV-exposed infants who received an HIV test within 12 months of birth and the percentage of exposed infants who were initiated on cotrimoxazole (CTX) within two months of birth.³² Nigeria's national PMTCT scale-up plan contains several highly ambitious objectives, including an aim for at least 90 percent of all HIV-exposed infants to have access to early infant diagnosis services by 2015.³³ The plan does not define "early infant diagnosis" but in other governmental data sources, data is provided for virological testing for HIV within 2 months of birth.³⁴

Women's knowledge about the current testing requirements ranged from full information to confusion about the number of tests required for confirmation of diagnosis across the groups, revealing that some women have access to better information about the full complement of testing requirements. Women did not have good information about the need for final or confirmatory testing as a part of a series of tests required to reach a final diagnosis. Women also reported delays in testing and long wait times for test results.

In Namibia, there was confusion about when and how often infants are supposed to be tested, with some women saying twice, three times or four. Generally, the women thought that testing at 4-6 weeks was a good idea, so that babies with HIV would be identified "early" and would be able to receive treatment. These statements were made in the context of women witnessing children reach the age of 3 or 4 years old and then suddenly falling ill and passing away.

"It was difficult for me first because my baby was tested at three years and by that time the baby was already tired and I experienced so many difficulties coping with it I was emotionally tired, and it was so difficult for the child to take medication at first because it was very late. My baby developed some skin rashes which was very emotional for me to see my child on that state which could be prevented if my baby was tested at birth and put on treatment as soon as possible."

– Woman living with HIV, Namibia (WDH1#1)

"[My daughter] went through a difficult time when she gave birth to twins and one passed away without knowing what was the case. And one was tested when he was four and now he is seven, because he also becomes sick when the other one who died without saying why and they only find out when I took him to Newstart Center for testing but I have been taking him to the hospital but he did not tell me what was wrong with my baby. Then the result came out HIV positive so it was also difficult for this child to cope with the treatment because he developed some side effects and the mother was going through so many problems, coping with the situation and also thinking of the baby that passed away. And I was hoping that if the test was done earlier, [the] baby could be alive today because the one who is now on treatment is doing well although he was sick at first. I think it could have been prevented"

– Woman living with HIV, Namibia (WDH1#6)

Most Namibian participants appeared to understand that an early negative test does not exclude infection and that the child was still at risk, although they suspected that women who were not in support groups may not be aware of this.

"[An early negative test] might not be good for some women because once they find out their baby is negative they will get excited and not come back for tests. It might be that the virus did not show during the first test but they are really positive and do not get another test. Few women will come back for testing. If my baby is tested at birth and I am told he is negative I will not think about coming back for more tests."

– Woman living with HIV, Namibia (WDH3#11)

"When I gave birth my baby was tested at one month, then the test came out negative and I was told that if I am not going to breastfeeding my baby that means that the results are negative and she, my baby will remain negative. Then they said if I decided to breastfeed I would have to come for further testing because through breastfeeding I may end up infecting my baby. I was told that I can still breastfeed for two years but I had to continue going for tests."

– Woman living with HIV, Namibia (WDH3#18)

Women in Namibia also had a detailed understanding that testing outcomes were not definitive result until breastfeeding has stopped.

"The doctor asked me when I gave birth. He asked [me] to choose whether I will breastfeed or going to give my baby formula. If I am going to breastfeed for a year then my baby will be tested three times. If I breastfeed for three months my baby would be tested first and after I remove my baby from breast milk the baby will take formula milk for a month then I will have to take my baby for a test again."

– Woman living with HIV, Namibia (WDH3#4)

31 See National Strategy and Action Plan for the Elimination of New Paediatric Infections and Keeping their Mothers Alive 2012/13–2015/16 at 28, available at <http://www.zero-hiv.org/wp-content/uploads/2013/05/Namibia-eMTCT-Plan.pdf>

32 See National Strategic Framework 2012–2015 at 24, available at http://emtct-iatt.org/wp-content/uploads/2012/11/Strategic-Framework-for-EMTCT-in-Kenya_2012.pdf

33 See National Scale Up Plan Towards the Elimination of Mother to Child Transmission of HIV in Nigeria, 2010–2015 at 17, available at http://emtct-iatt.org/wp-content/uploads/2012/11/Nigeria_National-EMTCT-Plan_2010.pdf

34 See Federal Republic of Nigeria Global AIDS Response Country Progress Report, 2014 at 15, available at http://www.unaids.org/sites/default/files/en/dataanalysis/knownyourresponse/countryprogressreports/2014countries/NGA_narrative_report_2014.pdf

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– Woman living with HIV, Namibia (WDH3#18)

In Kenya, women were generally aware that infants should be tested more than once, with the initial test at six weeks. Although some women reported that they felt they were well informed, women in the FGDs from Nairobi and Nakuru generally reported that there was little, if any, information provided nor was their consent for infant testing sought.

"Even when you return to the clinic after 6 weeks you are not informed that the baby will be tested for PCR. You normally go for the 1st immunization. After you are done is when they tell you to enter a certain room and then the doctor will tell you; 'we want to do the 1st testing... 1st PCR. Remove the socks.'"

– Woman living with HIV, Kenya (KEN1#9)

"I was told to come back after 6 weeks for the 1st PCR. When I went I was told to first go into a room for the child to be extracted blood. Just that, there was no counselling since they just say its compulsory and because you are HIV positive the baby must be tested."

– Woman living with HIV, Kenya (KEN1#2)

"Personally when I tested my baby they did not give any counselling, they just tested and told me to go home. I did not even know when I would get the results. I went and asked my sister since she is also positive. She is the one who told me that I will get them on my next visit to the clinic. They did not give me any information."

– Woman living with HIV, Kenya (KEN1#7)

Testing at 4–6 weeks was thought to be a good idea across the focus group discussions in Kenya, as the women expressed a wish to know the HIV status of their infants.

"It is good you are happy when your child is negative. Like me now when I had the pregnancy people used to ask; 'now why is this one giving birth? This one is just stressing her body for nothing.' Now if they see my baby, even me I am very happy, you see... What delights me now is even when am down I know I have someone that I can send for water. It is good you know your child's status earlier so that you follow up."

– Woman living with HIV, Kenya (KEN1#1)

"[If] you find they are positive they will start treatment earlier so that they do not get illness that will put them down."

– Woman living with HIV, Kenya (KEN2#4)

"That was also my joy, to know my baby's status. Like now I have a mother who refused to give their baby prevention medicine. I taught her and told her what I did and that I also have children and they are healthy. Most mothers come visiting in my house and they open up and ask questions. They later feel it's better to protect their children."

– Woman living with HIV, Kenya (KEN3#2)

In Nigeria, there was some confusion, but generally the women had a good grasp of current recommended testing practice for infants. Focus group participants reported having good awareness of infant testing, but also concerns that there was little attempt by health workers to seek their consent to perform tests:

"They didn't seek my consent, it was more like force."

– Woman living with HIV, Nigeria (LA2#12)

"They don't ask the question, like 'we are going to run the HIV test for your baby do you agree or not', they just take samples and run."

– Woman living with HIV, Nigeria (LA1#10)

Women in Lagos, Nigeria expressed a belief that getting the test results does not actually take that long, but that healthcare providers may delay giving the results to mothers for various reasons, such as not wanting mothers to be stressed by having to make an extra trip solely for the test results rather than being given the results at the next routine appointment; or facilities wanting to give multiple infant test results on a specific day – and sometimes a delay in performing tests.

"The result does not take more than 3 days to be out, but just because of the stress, they wouldn't want to stress the mother coming back to the facility just because of the results, they tell her in your next appointment you will get the result, and when she comes for the next appointment, she will surely get the result. They do the test and ask you to come back to be sure, they ask to come back not only because they want to give the test result but to check the baby and take other blood samples, assuming that take sample for 6 week, they still have to take the 6 months, and one year, I don't think it's the issues of logistics, they are specific days for mothers who had gone through PMTCT to get the result of the child, they put such specific days, because they don't want to get the result messed up."

– Woman living with HIV, (Nigeria LA1#2)

"Especially when it's a positive result, they don't disclose immediately, they have to repeat the test but, am very sure of NIMR they run the test every day, but it's because of the stress."

– Woman living with HIV, Nigeria (LA1#1)

Nigerian participants in the groups in Lagos and Abuja felt that mothers would be more likely to come back to the clinic if their child tests positive for HIV at 4–6 weeks, compared to receiving a negative HIV test. This is because they felt that mothers would want their child to receive medical care.

As in Namibia and Kenya, there was also support from some Nigerian women for testing at 4–6 weeks because mothers want to know the status of their child as soon as possible:

“Me, what will make me take the baby for test, it’s because I want to know if the PMTCT, the caesarean and all I did worked.”

– Woman living with HIV, Nigeria (ABJ1#5)

“The woman will be so anxious [to know the child’s status] that even the 41 days tradition of keeping the baby at home will not matter; she will break the rule and take her baby for the test.”

– Woman living with HIV, Nigeria (LA1#8)

Reasons for Loss to Care

In all three focus group countries, women reported significant barriers that prevent women from getting their babies tested at 4–6 weeks and returning for test results. The barriers they reported can be grouped into two major categories focused on 1) fears and stigma and 2) gaps in health system infrastructure.

Fear and Stigma

Stigma, discrimination and the threats of violence resulted in significant fear from women living with HIV in all three countries. Women reported that fear constituted a persistent barrier to infant testing and follow-up. Fears reported by women included:

- Fear of the consequences of disclosure of own status or child’s status to partner, family, and community (e.g. stigma and discrimination, threat of violence).
- Fear of what it means to have a child living with HIV, ability to cope, not ready to deal with the pain of a positive result, especially after prevention efforts.
- Fear that they would be instructed to stop breastfeeding by a medical professional regardless of the HIV test result, which has both financial and social implications (e.g. stigma).

In Kenya and Namibia, it was notable that women reported staying away from hospitals and clinics in order to avoid being treated badly by healthcare workers.

“What makes women not to go back for follow up is because sometimes you look at the services you receive when you go to access hospital. The way the nurses talk to you, look at you, shout at you. Now when you are pregnant they will tell you, you are HIV positive and you are pregnant and the child you will give birth to will also be HIV positive. Once you give birth you will be scared to take the baby for testing because you are thinking of all the insults you received when you were pregnant... so to avoid embarrassment you will keep the baby at home and avoid tests. Also the quality of services at the hospital is not that good because health workers

are not willing to speak in the language that the people understand.”

– Woman living with HIV, Namibia (WDH3#19)

The barriers to testing raised by Nigerian women were primarily related to fears including facing the possibility that their child might have HIV as well as denial of one’s own HIV status. As in Namibia and Kenya, women from Nigeria expressed fear of stigma and blame upon disclosure as key deterrents from early testing.

Mothers raised concerns that that they would face difficult questions from partners, family and friends if the baby was taken out of the home before socially accepted number of days for the baby to be kept inside. Some women also believed that an HIV test would be irrelevant as prevention of vertical transmission would have been successful if they had followed the PMTCT instructions and process carefully.

“The woman is not ready to know, because she is afraid of a positive result, even in concordant couple, nobody wants their child to be positive, if the child is positive they will push the blame to the woman like if you have done the right thing, it’s possible this child may not have been positive.”

– Woman living with HIV, Nigeria (LA1#1)

“I was afraid and never took my baby for test...it was my husband that took her when she was 2 years, I was filled with fear she might be positive, if it was left to me alone, I don’t think I will ever do it, till she is ready for marriage and does it herself. If it left to me I won’t test her, I will just be watching to see if she present any symptoms, then I will know.”

– Woman living with HIV, Nigeria (LA2#8)

“If the child comes out positive, people may start stigmatizing her and stigmatizing the child, so fear of stigma is one of the reasons.”

– Woman living with HIV, Nigeria (LA1#9)

“Somehow in our community we still have women who are not following [PMTCT]. You will find a woman has delivered in the house and yet she knew of her status. Probably this is a woman who wants to evade the story of her being positive. Mostly she is a first timer who was tested and later decided to hide and deliver from home... By the time she goes back to the hospital nobody will note that she was HIV+ and the child may not be tested at 6 weeks. There needs to be a lot of sensitization for these mothers to stop delivering in the home.”

– Woman living with HIV, Kenya (KEN2#3)

Gaps in Health System Infrastructure

Other significant barriers highlighted by women in all three countries barriers were focused on gaps in services and health system infrastructure, including:

- Lack of understanding about the need for testing, in particular whether mothers needed to bring a child back for additional follow-up testing if the first test was negative.
- Long waiting times for infant test results—women may have to wait months to get the test result.
- Long distances to HIV clinics, delays and long waiting times at clinics, and cost of transportation, particularly if they must travel from outside of the capital city.
- Having to make repeat visits to the clinic for tests when results are lost.

In Nigeria, specific health system barriers cited included shortages of testing kits and the cost of accessing care, particularly for delivery. For obstetric and delivery services high user fees and long waiting times induce many women to turn to traditional birth attendants (TBAs) instead (see box on TBAs).

"Apart from the kits not being available, sometimes the hospital staff tells you that they have close for that day, after waiting for hours and that 2 weeks old baby will go home without testing for that day and they will now expect the mother to come the following day, most women will not come till another 6 weeks or 3 months, some time they don't even come back, that why some times they don't even see the blood to take in the next few months."

– Woman living with HIV, Nigeria (LA1#1)

"The stress is much for the baby and the mother, when staying too long in the hospital, it's a big issue, I would rather go to private hospital where they don't know my status and I will get quick service, this delay is actually chasing many women from the hospital."

– Woman living with HIV, Nigeria (LA1#1)

Kenyan women experienced high levels of anxiety waiting for test results, which they reported were sometimes lost by the clinics/hospitals. If test results are lost, women are compelled to re-take tests. The majority of women reported that it takes at least one month to get the infant test results, with some women reporting wait times of up to two months because of doctors being on strike.

Most women in Kenya reported waiting 1–2 months for the test results, although some reported that results are now available straight away.

"Nowadays you get the results immediately. You get tested and then you are told to come back the next day to pick your results."

– Woman living with HIV, Kenya (KEN3#12)

For some, waiting times varied significantly, with some women stating that they had not received any results to date, while other participants reported that the results are now available in 1–3 days. Delays in test results were reportedly due to technical challenges, including problems with the machine used for testing or spoilage of the blood sample for testing:

"There is a time that we did a PCR test and when we went for the results in the next appointment a month later, the results were not ready because something was wrong with the machine somewhere thus there was a delay with the results."

– Woman living with HIV, Kenya (KEN1#3)

In Namibia, there was also a variance in waiting times, ranging from on the same day to a month. Some women, however, experienced lost or delayed test results, and felt that nurses were being untruthful about the availability of the results in some cases.

"Sometimes you go there and the results aren't ready and they will tell you to come back. And when you come back they will say the results are still not available and say they need to retest the baby."

– Woman living with HIV, Namibia (WDH1#3)

"The nurses do not want to go through the files and get the results so they just say they are too busy or they can't find it."

– Woman living with HIV, Namibia (WDH3#4)

Nigerian women had experienced the severest delays in receiving test results, with the shortest turn around being three weeks and the longest six months. In one group, the women thought that test results were available to the clinic staff much sooner, within a few days, but that the results weren't communicated to the mothers until their next scheduled appointment. There was a suspicion expressed by the focus group participants that that nurses are reluctant to give a negative test result as a strategy to get women to return for confirmatory testing.

"Finally when they collected the sample, it was over 2 months before they did the test, and the result was out 6 months after."

– Woman living with HIV, Nigeria (ABJ2#4)

As a result of long waiting times, anxiety and delays in receiving results, women in all three countries welcomed the WHO proposal for rapid turnaround testing, whereby infants receive an HIV test at the clinic and results are returned within the same day or up to one week of blood being taken. Women in all three countries expressed that knowing the result quickly would allow mothers to plan ahead and take critical steps for prevention as well as reduce anxiety.

"It will encourage mothers to really bring their children for testing, if 'come today, come tomorrow' will be taken off, it will give the mother at rest of mind."

– Woman living with HIV, Nigeria (LA1#9)

"If it's possible to have test for babies that will give the result within ten minutes like the adult test, it's very okay, not that the women will run the test for the baby and her mind won't be at rest, she will be worried about what the outcome of the result will be, and if it stays for so long, her mind won't be at rest for the period on waiting. It's not only about testing; the result should also be made available."

– Woman living with HIV, Nigeria (LA2#3)

"It will be better, then you will know what it is and what to do"

– Woman living with HIV, Nigeria (ABJ1#1)

"Waiting for those 2 months (for the test result) is the longest wait you can have in your life!"

– Woman living with HIV, Kenya (KEN1#6)

"It is good since you will go home knowing the status of your child and you will not be worried...you can really get thin during that month asking yourself if they have or not. When done there and results given then it reduces anxiety."

– Woman living with HIV, Kenya (KEN-02#9)

"I am happy if the test will be done and results will be given within a short period...it also makes it easier for a woman, not to (have to) go back home and come back to hospital... sometimes that woman does not have money to come back to hospital and she will just wait at home and not bring the baby for testing."

– Woman living with HIV, Nigeria (WDH3#17)

Views on Testing at Birth

WHO is considering recommending that infants born to women living with HIV receive a virological test at birth and then the infant will be tested again at 4–6 weeks of age. Women in all three countries expressed concerns and mixed feelings about this policy.

The majority of women had not heard about the possibility of testing at birth and in all countries the main perceived benefit of testing at birth was that mothers would know how to feed their child and take care of the child from the beginning. Kenyan women suggested that the advantages of knowing their child's results early included the option of getting babies on treatment earlier, reduced anxiety, and the possibility that more babies would receive testing. There was also a consensus among the Namibian participants that rapid testing at birth would be the best scenario.

"[Testing at Birth] will kill the anxiety since to be tested and then you are told to go home and wait for 1 month to be told whether your child is positive or negative, you turn into a form of depression. You start even dreaming. It's better to be told immediately so that you know what to do next."

– Woman living with HIV, Kenya (KEN1#2)

"[It makes it] easier for a woman not to go back home and come back to hospital and sometimes that woman does not have money to come back to hospital and she will just wait at home and not bring the baby for testing. It can be avoided by bringing the baby straight away for testing right after birth."

– Woman living with HIV, Namibia (WDH3#7)

In Namibia, none of the women had heard of the possibility of testing for HIV immediately after birth. Women felt that testing at birth was a good idea because the child may not become ill and can get treatment immediately—but they also cautioned that women should receive adequate counselling in their own language so that they know what to expect. They also felt that testing at birth would reduce the chance of women not returning for follow-ups, and would also reduce the stress and hassle of having to return to the hospital for testing with an infant.

"We feel it is a good idea as long as we receive the necessary information before giving birth and counselling should be provided in a language that the women understand and it will not stop, there should be ongoing counselling... If the baby is tested at birth the mother will make an effort to come back for a follow-up test."

– Woman living with HIV, Namibia (WDH1#1)

"Some of the women when they give birth they are told to come back for a test but they don't come back. If the test result is given back right away it will be good and we will have more babies being tested for HIV and those who qualified for treatment will be put on treatment at the right time."

– Woman living with HIV, Namibia (WDH3#9)

In Nigeria, the majority of women had not heard of testing at birth, although a select few had. In Nigeria, as in Kenya, women mentioned that a key benefit of testing at birth would be the reduction in anxiety from waiting for the test to happen at 4–6 weeks.

In Kenya, most women had not heard of the possibility of having a baby tested at birth. There was a mixed reaction to the idea. Some women said they would rather know the test result as soon as possible, but others thought it was better to rest and recover before dealing with the difficult information about a positive HIV test for their child. The group thought it might have a positive impact for some women but for others it might have a negative impact, by inadvertently revealing her HIV positive status to other people including family present in celebration of the birth in the labour ward, or creating problems with the baby's father. Some women thought the test should be done at birth, but that perhaps the results shouldn't be given straight away: or letting women decide when to receive the results.

"You learn early and protect your child. You will know how to take care of them. Even those coming to check on your baby; you know not all need to be told of the baby's status. You will live with it and not despise yourself."

– Woman living with HIV, Kenya (KEN3)

"You recall during delivery time...all that tiredness and having carried the pregnancy for all the 9 months. After all the many stresses now the baby is out. Wait till they tell you he has the virus yet you have been watchful all along. Isn't it better you be left to rest for some time surely!"

– Woman living with HIV, Kenya (KEN1#2)

Some women thought that efforts to support women to have the father present for the results could help some mothers shoulder the burden of a positive diagnosis, and could help reduce the likelihood of intimate partner violence. However, women did express concerns about the father finding out that the child is positive or being required to disclose their HIV status.

"It could be better if during the testing, the baby's father is also there to be told since sometimes you can go to the house and you decide to keep quiet for fear of disclosing to your husband. The man doesn't know and you feel the pain alone. It will be better if both of you share the pain."

– Woman living with HIV, Kenya (KEN3#4)

"Even the baby's father if he hears that you have delivered and immediately you tell him that your child is positive, even if he had wanted to purchase a baby shawl for the baby, he will stop. I would not want him to know. You might be abandoned in the hospital and not even discharged."

– Woman living with HIV, Kenya (KEN1#4)

However, in all countries women perceived clear disadvantages to testing at birth.

- Women were concerned that new mothers would not be prepared or strong enough for the shock of the result so soon after the physical ordeal of giving birth and adjusting to caring for a new baby, especially if she recently received an HIV diagnosis herself. Participants were particularly concerned that women may become depressed. The need to recover from c-section was given as another reason why not to test at birth, especially in Nigeria where many women had experienced this operation.
- As the mother may not have disclosed her own status to her family, testing at birth could trigger difficult questions, and could increase the risk of rejection by her husband and family who are likely to be present in the hospital at the time the child is tested.
- The WHO recommends follow up testing after 9 months for well, HIV-exposed infants. However, if the first test is negative, participants were concerned that the mother may not return for recommended follow-up testing, as they may believe the first test is definitive.

For Nigerian and Namibian women, although some women expressed a desire to know right away after the child is born, others were concerned about the possible negative psychological impact on a woman who has just given birth. This potential impact was seen as a downside to testing at birth.

"For me it's not okay... am still in bed (recovering), thinking about how to get well and you now tell me my child is negative or positive, the worse aspect is when the child is positive, do you want to kill me?"

– Woman living with HIV, Nigeria (LA1#2)

"It's a good idea, but for a woman who did CS, it's not okay, I would [wait] at least 3 months after birth, let her overcome the trauma first stabilize before we can start talking about testing the baby."

– Woman living with HIV, Nigeria (LA2#4)

"A woman that just put to birth and has lost a lot of things from her body, and you now tell her that her child is positive, it may kill her."

– Woman living with HIV, Nigeria (ABJ1#4)

"It might be difficult for me, I will just give birth, I know I am HIV positive, then come the baby's results which might also be positive. This makes me sad, and uncomfortable. I wouldn't want to add stress to the stress of my own status in that stage."

– Woman living with HIV, Namibia (WDH3#8)

"It is well appreciated, for instance am positive, I don't wish for my child to be positive, I will want to know, the status of my child immediately. Whatever the result, I am comfortable knowing it immediately. My family is aware."

– Woman living with HIV, Nigeria (LA2#3)

Namibian women also raised fears of rejection and violence from partners.

"It might be that if my baby tested at hospital soon after birth and the test is positive and they might put the baby on treatment when I come home with medication my partner might reject me together with the baby, start blaming me because most of the time it's women who get tested and sometimes men know where they stand with their HIV status and they do not go for tests and they will not tell you but if you come home and say you are HIV positive or your baby is HIV positive they will blame you for being the reason you are HIV positive."

– Woman living with HIV, Namibia (WDH3#9)

In Kenya and Nigeria, participants raised concerns that, in practice, if the mother is unconscious or if healthcare workers do not strictly adhere to best practices around patient confidentiality, relatives present for the birth may be informed about the mother's HIV status, violating the mother's privacy. Women expressed concerns that testing at birth may contribute to discrimination against the mother and child in the labour and recovery wards.

Trusting the Test

Women had diverse levels of comprehension of the differences between virological and antibody tests for HIV. Many women expressed disbelief that such a test result either at birth or at 4–6 weeks would be accurate. In all three countries the concern was that because mothers would be breastfeeding, there would remain a chance that the child could later acquire HIV.

“There are those who are tested say for the 6 weeks and you get the baby is positive. When tested for the 9 months you find they are negative. Some are negative at 6 weeks and after you start feeding them they turn positive.”

– Woman living with HIV, Kenya (KEN2#8)

In Kenya and Nigeria, women were aware that babies have the mother’s antibodies in the first few weeks of life, highlighting the importance of providing accurate information to women to empower their decision-making and efforts to prevent vertical transmission.

“I would say it’s not okay, because, we believe that at this point [testing at birth], the child still uses the mother’s blood, so it won’t be reliable.”

– Woman living with HIV, Nigeria (LA1#6)

“Because the child is still having the mothers’ blood, it’s not reliable.”

– Woman living with HIV, Nigeria (LA2#5)

“What we were told is that the baby still uses some of the mother’s blood, so the test is not reliable then, but if there is a test that could really pick the baby’s actual status, then it’s a welcome development.”

– Woman living with HIV, Nigeria (LA2#10)

“How do you do the testing? Is it like PCR, is it detailed or is it like RAPID which will show my antibodies in my baby’s blood? The baby will be positive yet his antibodies are negative.”

– Woman living with HIV, Kenya (KEN1#)

“Information has really taken us a step further into zero HIV infections in our infant babies. At least now we are aware we will test them at 6 months to first of all know if our antibodies got into theirs or not and then further testing at 18 months to confirm that the baby is definitely free of HIV.”

– Woman living with HIV, Kenya (KEN1#2)

Perspectives on Integration of Early Infant Diagnosis and Immunization

The WHO is considering recommending integration of infant testing with routine infant follow-up visits such as immunizations as a strategy to improve testing uptake. Women in all three countries reported having routine monthly follow-up visits for their infants. Women expressed a number of barriers to full uptake of these routine follow up visits that would likely remain barriers for follow-up should infant HIV testing be integrated with existing services.

In Namibia, when asked about challenges to attending follow up visits, the mothers described stock-outs of medicines and testing kits, and issues of transport and distance to clinics.

“Sometimes they run out of stock and you have to go somewhere else.”

– Woman living with HIV, Namibia(WDH1#10)

“At her nearest clinic at Hakahana they are out of stock so she is forced to go to other clinics which is distant from her location.”

– Woman living with HIV, Namibia (WDH1#6)

In Kenya, women described negative treatment and a lack of understanding by healthcare workers when they were unable to attend scheduled appointments. When asked about challenges to attending follow-up, the mothers spoke of quality issues with the postnatal clinics, including a lack of information and counselling, stress of disclosing to partners, and long waiting times at the clinic.

"As she is saying, you see I could be ill and that's why I fail to come back. If I come back 2 days later, that now becomes an issue and [healthcare providers] ask why I did not come on the specific day I was supposed to. Could be I was coming from a distant place and didn't even have bus fare but nobody wants to understand that. They say I have a whole month [between appointments] and should have planned around that. There are other emergencies and could be I had one of those but now it's like she said everybody wants to quarrel and ask you why you did not come. They do not even want to understand or let you explain."

– *Woman living with HIV, Kenya (KEN2#3)*

"Whenever we go to the clinic is normally a whole day's event. You find yourself going there, the doctor reaches the clinic at 9–10 am and that is when they start attending to you. The mentor mothers also need to attend to you and other issues that you may have. So you find yourself spending the whole day within the facility. We are not like any other women because, as a HIV positive woman you stay longer in hospital raising suspicion from other women from your neighbourhood who ask you what you normally do at the hospital all that while yet you wake up in the morning even before they do."

– *Woman living with HIV, Kenya (KEN2#7)*

In Nigeria, women described follow-up appointments when their infants were two weeks old to check on infant prophylaxis, and monthly follow-ups, which become less frequent as the child gets older. When asked about challenges to attending follow-up, the mothers described the quality of care they received as good, but felt that mothers should be encouraged to ask more questions. The women felt having to travel to facilities and wait around for results, or being told to come back another day, was a significant frustration as well as a barrier, and that government facilities are over capacity.

"You go to the hospital, even if you get there 6:30am, you will see like a 100 women already, for me it's very stressful, not because of PMTCT, but generally ANC clinics."

– *Woman living with HIV, Nigeria (LA1#10)*

"Time spent in government facility is too long. Test kits and reagents are not always available, you can travel all the distance and get there and they tell you come another day, which is not even sure that they will have it then. Traditional here we don't move babies around that much, so when you start doing that it calls for questioning, is the child sick, etc, especially when other members of the family are not aware of the woman's status, so issues of disclosure."

– *Woman living with HIV, Nigeria (LA2#12)*

Women in Namibia saw integration of testing with other infant follow-up visits such as immunization as a positive move because working mothers would then not have to take time off for several appointments. However, in Kenya and Nigeria, women highlighted some potential problems with care being combined. Specifically, integration may mean that health workers who are unfamiliar with proper protocols around confidentiality and non-stigmatizing treatment would discriminate against women living with HIV and women may risk inadvertent disclosure of their and the child's status because they receive more services for their child. Women also expressed that combined services may reduce their opportunities to get questions answered and may result in less personalized care.

"At times you have so much to do you do not remember to tell the doctor some other issues. Let's say you have gone for family planning alongside many other issues. You have a problem on family planning and when you leave there is when you recall you didn't even say you are bleeding. You have not also said that the baby was in pain or what. This is because all the visits have been squeezed together."

– *Woman living with HIV, Kenya (KEN1#10)*

"Let's say, if you know they were supposed to get a certain injection (immunization) you can opt not to take [the baby] as you will fear them [also] getting tested [for HIV]. It's better for someone to go differently."

– *Woman living with HIV, Kenya (KEN3#2)*

"Too many people will have information on my status, my ART centre and now the PHCs, I don't think that's good, I will rather I do HIV issues in the ART centre and immunisation at PHC. Also because it's close to my house, you never know, the health worker there knows me and may tell other people in the community."

– *Woman living with HIV, Nigeria (LA2#8)*

Any planned integration of early infant diagnosis and immunization programs will need to keep in mind the basic challenges women living with HIV face, must be handled carefully, and should involve women from the community in the design and implementation.

How Can Testing Uptake be Improved?

Mothers expressed strongly that increased uptake of infant testing is dependent upon the quality and availability of information, education, peer counselling, decentralisation of services, and home- or community-based testing.

Women in all countries said:

- Infant testing should be made available in all health facilities and decentralisation of services, mobile clinics, and home visits would increase testing uptake and follow-up;
- All pregnant women need to receive accurate information about infant testing for HIV through a range of communication channels;
- Community health workers, traditional birth attendants, mentor mothers, peer counsellors, and health workers in general have a critical role to play in improving support to pregnant women living with HIV throughout pregnancy and post-partum, including in educating mothers about the reasons for infant testing; and,
- Stigma and discrimination within the health sector needs to be urgently addressed at all levels.

Women also wanted to see the introduction of the option of testing at birth and government guarantees on universal treatment access.

Women in Nigeria suggested that the removal of user fees for ANC and hospital delivery, the provision of free infant formula and improved health facilities and services would increase uptake of infant testing.

"If there is no money for treatment, they must make sure that there is a budget for treatment of babies who will be in need of treatment."

– Woman living with HIV, Namibia (WDH2#3)

Peer Support

Kenyan women suggested making testing more accessible by using peer counselling and communicating the information to mothers in a respectful way.

"When we are here talking it looks like it's very easy because we share something in common. It looks very normal but when you sit out there with HIV free people and then you hear what they have to say about HIV+ people then you will think otherwise about even knowing your HIV status in the first place... I think what we fear most is the stigma; how people would view you as HIV is perceived to be for prostitute or people of loose morals. We forget that there are so many ways of contracting it."

– Woman living with HIV, Kenya (KEN1#6)

In Nigeria, women highlighted the importance of information and peer support to improve testing uptake. Women in Nigeria additionally suggested that in addition the removal of user fees for ANC and hospital delivery, the provision of free infant formula and improved health facilities and services would increase uptake of infant testing.

"When I was pregnant and got to know of my status, all I was thinking was 'so this is how am going to die', so the psychological issue is there, to fight it, so we need a lot of health workers, a lot of counselling, a lot of follow up with the mothers, support to the mother."

– Woman living with HIV, Nigeria (LA1#9)

"Accurate information, we need to identify community gate-keepers, talk to them, and create more awareness. Also other positive women need to sensitize fellow positive mothers on the need to test their babies."

– Woman living with HIV, Nigeria (ABJ1#7)

In discussing ways of increasing uptake of infant testing and follow-up, much of the discussion in Namibia was around peer support and community education activities such as radio shows, and sharing experience, as well as providing information in more simple language and in the language the woman is most comfortable in.

"Community and support group leaders have the quality of care. They should be given a chance to talk to these women in a polite way to encourage women to come back for follow ups."

– Woman living with HIV, Namibia (WDH3#19)

Section 3: Pediatric Treatment



"It is beneficial to start early since their health is fragile."

– Woman living with HIV, Kenya (KEN2#4)

Mothers of children living with HIV in all focus groups were asked about their experiences of their own children starting treatment. Kenyan women talked about positive outcomes of talking with their children, and techniques they use to help adherence. They shared challenges with disclosure and emotional stress on the mother, including fear of the medication not working for the child. Several women mentioned the importance of support from both family and peer groups.

In Nigeria, women spoke about being motivated to manage their child's adherence to the medication so they would survive. They also described problems children have with taking treatment, and difficulties talking to their children about HIV. Namibian women also spoke about the difficulty of coping emotionally when their child started treatment. They also described problems with side effects, problems with adherence, lack of family support, and lack of food.

"I was told about the drugs, but what was important to me at that time was for my baby to live, I said anyhow I will give my baby the drug, and I will not lose that baby. I didn't find it difficult because I give him and I take same time, now he is use to it."

– Woman living with HIV, Nigeria (ABJ1#11)

"My child is 9 years now, I started giving him [ARVs] when he was a baby sometimes he tells me, mummy why are you not giving others the drug, you are given only me... There are many challenges in giving children these drugs. Though we take it together, but he asks so many questions."

– Woman living with HIV, Nigeria (ABJ1#8)

"When she comes from school she is always complaining that she is tired and she does not want to take the medication. She is saying the medication is making her tired and she wants to sleep and she cannot concentrate on her school work...it is very hard for me to convince this child to take HIV medication."

– Woman living with HIV, Namibia (WDH3#9)

Mothers in Kenya and Namibia also spoke of the challenges that their children had in taking medication, including lack of food and difficulties swallowing pills.

"Sometimes also difficult when the children are taking medication and they don't have food to give to them. So sometimes you are forcing the child to take the medication but child will tell you I am hungry but the child is saying I won't take the medication because I am hungry so you as a mother feel bad as much as you want your child to take medication it is true that the child doesn't want to take medication with empty stomach so it is hard for both mother and child."

– Woman living with HIV, Namibia (WDH1#1)

"When they take medicine they get hungry within every 30 minutes and need food. It's like those in school; if they took medication in the morning and say they only took tea. While in class they become withdrawn and sleep a lot due to hunger. The teachers get worried of what is happening since the parents do not disclose anything to them."

– Woman living with HIV, Kenya (KEN3#4)

"The major difficulty that was there in the beginning (he started at 10 years) was the size of the pills. It was so big, he used to choke and puke everything out. He gradually got used to it. At the beginning he used to take so many pills at the same time. Abacabude were 3, Lamivudine were 3 also, Nevirapine 1 in the morning half at the evening. That one I could not do anything. But then now at his status it came to 1 big Aabacabine, 1 medium Lamivudine and another medium Nevirapine. I thank God since now he even puts all three of them and comfortably swallows."

– Woman living with HIV, Kenya (KEN1#2)

Qualified Support for Children Starting Treatment Immediately

Across all focus groups, mothers could see both benefits and challenges with all children under the age of five being able to access treatment immediately. In all countries, the expressed benefits of this policy were that the child is more likely to be healthy and survive, and that mother and child can take treatment together. Some Kenyan women, particularly those in urban settings, saw clear benefits for the child's health, and also in practical terms of getting the child used to taking medication. Nigerian women, particularly those based in urban Abuja, could see the benefit for children's health with immediately starting treatment, and were generally in favour.

Namibian women were in favour of early initiation of treatment for the most part, provided there would be suitable information and support available. In both Kenya and Namibia, women felt that immediate treatment would improve adherence and make disclosure to their child about the child's status easier, and ultimately result in a better quality of life for the child.

"Personally I see it is better because the child's immunity is very weak. It should be immediately so that the body gets used to the medicine."

– Woman living with HIV, Kenya (KEN1#10)

"I think the importance of a child being put on medication is mainly because we have lost many children who have been put on drugs at the wrong time. The children do not have strength like that one of a grown up. When the child starts ailing, it is difficult to reverse the condition."

– Woman living with HIV, Kenya (KEN3#13)

However, in all three countries, strong concerns were raised by individuals about starting babies on treatment immediately. The issue of early initiation of treatment sparked long discussions in one of the focus groups in Namibia and the rural one in Kenya. Women were concerned about treatment resistance and running out of treatment options, as well as about treatment side effects and ARVs being too strong or toxic for babies. Some women expressed that children do not need treatment if they are healthy and were worried about putting a young child on treatment for life. Women also raised concerns about daily treatment causing inadvertent disclosure of HIV status and protecting the child from stigma, as well as the difficulties of giving a child daily medication.

"I feel they still do not have the strength to cope with the medication. They may take the medication and their health will not improve since they are not breastfeeding."

– Woman living with HIV, Kenya (KEN3#8)

"Now, why should the one who is not sick take the medication?"

– Woman living with HIV, Kenya (KEN3#1)

"If the child is not sick, adherence will be very poor because the mother will not see the need of placing the child on treatment, starting on the drug, I think they should really look in to it, because if you start the drugs and at some point there is resistance...they will run out of options by the time the child get to adulthood."

– Woman living with HIV, Nigeria (LA1#9)

"What about the side effect of the drugs, how will the children cope, how do we manage it?"

– Woman living with HIV, Nigeria (LA2#10)

"What makes me happy is that my first-born is a son and he is very responsible in taking his ARVs. I was so worried that if he came to know why he was taking his medicine he might refuse but he is very responsible... Currently he is in school and very healthy, you cannot tell whether he is on any drugs or anything. He is just normal like any other child."

– Woman living with HIV, Kenya (KEN2#4)

"My husband said no, when he heard the drug is a life time treatment he refused, he said the doctor should tell him what else can be done...we visited the hospital more than four times before he agreed, I had to threaten leave the marriage."

– Woman living with HIV, Nigeria (LA2#6)

"I think if the child is healthy, they should delay, because children don't like drugs, by the time they get 1–3 years, you start facing difficulty of them not taking the drugs and it's something they will have to take for life."

– Woman living with HIV, Nigeria (ABJ2#4)

Messages from Mothers Living with HIV

In Namibia, women identified the need to address the stigmatizing attitudes of healthcare staff, as well as a need for more counselling for women as key issues. They suggested more education about HIV for healthcare staff, better information for pregnant women, and more awareness of HIV outside of clinical settings, including in schools. The women also called for funding for early infant testing and treatment to be made widely available, with more community health workers and mobile clinics to improve access.

"I want to talk about the counselling which is lacking in most of the hospitals... Normally if you go to the hospital and are not that strong yourself or vocal enough they will not help you and the way they talk to you is already discriminatory...they don't show you any sympathy and shout at you and say you die. I think women need to receive information on baby feeding, baby testing before they give birth."

– Woman living with HIV, Namibia (WDH1#3)

"I will tell them to make sure there is a budget for infant diagnostic and testing and treatment so that all the babies will be put on treatment at the right time to avoid death. If there is no money for that baby they should look for funds, the way they look for treatment for adult people."

– Woman living with HIV, Namibia (WDH3#4)

"I [would] tell all the leaders to make sure mobile clinics are available at all constituencies because currently it is only some constituencies where the councillors are vocal and advocate for these mobile clinics. But some of them are not vocal enough and their communities are still suffering from the distance of the clinics and health centres."

– Woman living with HIV, Namibia (WDH1#1)

Kenyan women spoke about the need for more welcoming, integrated services for mothers, children, and young people and having testing services closer to home. They also emphasised the importance of good staff training, so healthcare staff are encouraging, and confidentiality is respected. The women talked about ways to ensure mothers and children are diagnosed as early as possible and suggested that reducing the time between testing and results would reduce anxiety. They emphasised the importance of counselling and support for mothers, and the need for better HIV education outside of clinical settings.

"First of all I would really encourage that paediatric facilities be child friendly...I wish babies and especially women, HIV positive women, would have their place whereby from the beginning they have a friendly environment so that even if the results come out positive, they will already be warmed up to the environment."

– Woman living with HIV, Kenya (KEN1#2)

"Some of our clinics do not have quality services—where I go to there is no confidentiality. They should not disclose someone's status. You find once you have started taking your medication from there, even the watchman at the gate knows what you are going to do there... You find that even the cat that passes there knows your status. It is very bad."

– Woman living with HIV, Kenya (KEN1#3)

"I can tell them to motivate and encourage those who are going for the testing since some can go while under stress. You know taking the medication is not easy. If they teach you well and talk to you well you will be motivated and you will give the child's medication well."

– Woman living with HIV, Kenya (KEN1#7)

In Nigeria, women highlighted free infant formula, early diagnosis and treatment, avoiding stock-outs, and better educated health workers as urgent issues that need to be addressed by the government. They also spoke of cost as a barrier to access and suggested working with traditional birth attendants as long as they are well equipped.

"I want the Nigerian government to take full ownership (of EID), sometimes you go [and there are] no materials, even the ARVs, for some of us that don't have the funds to buy, it will be difficult."

– Woman living with HIV, Nigeria (ABJ2#4)

"I would appeal that [the government] make treatment free and accessible for both adults and children."

– Woman living with HIV, Nigeria (LA2#4)

4

Key Findings and Recommendations



Provide Infant Testing Options

Women living with HIV have expressed mixed feelings about testing at birth and require more accurate information about their options to identify the testing approach that will work best for themselves and their children.

- A one-size-fits-all testing method for babies and infants is not ideal. WHO should recommend a complement of testing options for babies and infants and ensure that implementation complies with basic human rights principles including informed consent.
- Given the concerns about potential increased stigma around testing at birth, women living with HIV should be provided with information about testing options and properly counselled and supported at an early stage (not just prior to or directly after delivery), to give mothers time to make an informed choice on the timing of HIV testing for infants.
- Governments and donors should invest in community initiatives, particularly those led by women living with HIV to address barriers and motivate increased testing of infants through peer counselling, psycho-social support and community education so that women living with HIV can:
 - better understand the need for multiple tests for infants and trust the results of the tests;
 - have support for disclosure planning for themselves and their infants;
 - have support for receiving a positive HIV diagnosis for themselves and/or their children; and,
 - have support and resources for infant feeding including breastfeeding support.
- Countries should speedily implement WHO's proposed new recommendation around "point of diagnosis with rapid turnaround testing" as it would address concerns and anxiety caused by waiting, delay and loss of test results for infants, which has a negative impact on the health and well-being of some mothers.
- Governments should consider providing free antenatal care (remove user fees) to encourage more women to go to health facilities for care.

Better Quality Information and Counselling

Women and mothers living with HIV must be provided with accurate and comprehensive information on all aspects of preventing vertical transmission of HIV. In order to address confusing messages and misinformation that continue to be given to women living with HIV, accurate information is particularly needed on:

- current recommendations on breastfeeding and other infant feeding options, in particular, individualized counselling on breastfeeding options is recommended;
- C-section risks and benefits, and the requirements of informed consent;
- current guidance on early initiation of ARV treatment and lifelong treatment for pregnant women; and,
- recommended ARV prophylaxis and accurate dosing for infants.

Ensure Human Rights

Stigma, discrimination and rights violations have been identified by women living with HIV as key drivers of loss to follow-up. Women have the right to access reproductive and maternal health services free of stigma, discrimination and coercion, and healthcare workers play a key role in ensuring that these rights are respected.

- Stronger protocols and training for healthcare workers at all levels is needed to ensure protection of the rights of women living with HIV, such as the right to informed consent for all services, including for HIV testing of women and their infants, and birthing options.
- Ensure ongoing sensitization and training (including in-service training) for health workers to help them provide more accurate information and reduce stigma and discrimination in order to create more welcoming mother- and child-friendly services.

Prioritize Peer Support

Women living with HIV often do not receive sufficient or accurate information from healthcare workers. Countries should prioritize capacity building and funding for networks and groups of women living with HIV to enable them to continue to provide essential peer support within their communities.

- Invest in community initiatives, particularly those led by women living with HIV to address barriers and motivate increased testing of infants through peer counselling, psycho-social support and community education so that women living with HIV can better understand the need for multiple tests for infants and trust the results of the tests.
- Accurate information around current recommendations, options and protocols on HIV testing for infants must be provided to women living with HIV, through a variety of avenues including healthcare workers, women's support groups, traditional birth attendants and networks of women living with HIV, as well as wider community education campaigns.

Integrate with Care

Any planned integration of early infant diagnosis and immunization programs must take into account the persistent barriers women living with HIV face in accessing services.

- Women living with HIV must be involved in the conceptualization, design and implementation of any integration efforts.
- Service providers must receive adequate training and sensitization to ensure women living with HIV can access integrated services free of stigma and discrimination.

Address Infant Treatment Concerns

Women living with HIV have expressed serious concerns about adherence, toxicity of long-term medications, the potential for drug resistance and increased stigma.

- Women living with HIV must be engaged and involved as countries introduce and implement new treatment guidelines.





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