

**icaso**

until **we** end aids

# STORIES OF STIGMA, STORIES OF HOPE:

EXPERIENCES OF PREGNANT WOMEN  
AND MOTHERS LIVING WITH HIV



**In memory of Robert Carr, an unfailing and passionate advocate for those marginalized and excluded by society.**

## ACKNOWLEDGEMENTS

Our most heartfelt thanks go to the women in Cameroon, Ivory Coast, Ethiopia, India and Indonesia who agreed to openly share their stories about the stigma and discrimination they have faced as pregnant women and mothers living with HIV.

### Partners

ICASO would like to thank the partners in five countries who advocate on these issues and enthusiastically agreed to undertake this research.



#### Cameroon

##### ITPC Central Africa/CATAG

James Kayo, [jamesckayo@yahoo.fr](mailto:jamesckayo@yahoo.fr)

##### Communauté Camerounaise des Femmes Positives (CCaF+)

Calorine Kenkem, [ckenkem174@gmail.com](mailto:ckenkem174@gmail.com)



#### Ivory Coast

##### ITPC West Africa/WATAG

Sylvère B. Bukiki, [biziyaremyes@yahoo.fr](mailto:biziyaremyes@yahoo.fr)

##### Coalition des organisations de Femmes vivant avec le VIH (COF-CI)

Rose Dossou, [rosdossou@yahoo.fr](mailto:rosdossou@yahoo.fr)

Christine Houssou, [damhouss@yahoo.fr](mailto:damhouss@yahoo.fr)



#### Ethiopia

##### National Network Of Positive Women Ethiopians (NNPWE)

Eyelachew Etsub, [eyelachew@yahoo.com](mailto:eyelachew@yahoo.com)

Tinos Kebede, [tinoskebede02@gmail.com](mailto:tinoskebede02@gmail.com)

Senait Zenebe, [senzenebe@gmail.com](mailto:senzenebe@gmail.com)



#### India

##### Gujarat State Network of People living with HIV (G SNP+)

Dinesh Prajapati, [info.gsnppplus@gmail.com](mailto:info.gsnppplus@gmail.com)

Daxa Patel, [daxa1999@yahoo.co.in](mailto:daxa1999@yahoo.co.in)

##### Maharashtra Network of People living with HIV (NMP+)

Manoj Pardesi, [manojpardesi@gmail.com](mailto:manojpardesi@gmail.com)



#### Indonesia

##### Indonesia Positive Women Network (IPPI)

Oldri Mukuan, [oldri.sherli@gmail.com](mailto:oldri.sherli@gmail.com)

Baby Rivonia, [babyrivona@gmail.com](mailto:babyrivona@gmail.com)

We also thank our global partners: the Global Network of People living with HIV (GNP+), the International Community of Women Living with HIV and AIDS (ICW), and International Treatment Preparedness Coalition (ITPC) for their advice and support for this project.



Strengthening Community Responses to HIV Treatment & Prevention

Our gratitude is owed to the Canadian Government through the Canadian International Development Agency (CIDA) who provided generous support to this project.

The project was coordinated and the report written for ICASO by Aditi Sharma, [aditi.campaigns@gmail.com](mailto:aditi.campaigns@gmail.com), with support from Kataisee Richardson, Program Manager, [kataiseer@icaso.org](mailto:kataiseer@icaso.org) and Daniel Townsend, Program Officer, [danielt@icaso.org](mailto:danielt@icaso.org). Vicci Tallis, Rodney Kort and Callie Long provided technical and editorial advice.

Art and design by Harold Sikkema:  [harold@nsitu.ca](mailto:harold@nsitu.ca)

### About ICASO

Our mission is to mobilize and support diverse communities for an effective response to end the AIDS pandemic. ICASO facilitates the inclusion and leadership of communities in the effort to bring about an end to the pandemic, recognizing the importance of promoting health and human rights as part of this undertaking.



65 Wellesley St. E., Suite 403  
Toronto, ON Canada M4Y 1G7

TEL +1.416.921.0018

FAX +1.416.921.9979

[www.icaso.org](http://www.icaso.org)

[icaso@icaso.org](mailto:icaso@icaso.org)

# TABLE OF CONTENTS

Executive Summary .....	6
1. Global context: Women .....	9
2. Towards ending vertical transmission of HIV .....	13
3. Women's voices – Documenting the experiences of pregnant women living with HIV, in their homes, communities and health care settings.....	23
A. Methodology .....	23
B. Stories of Stigma.....	26
C. Stories of Hope .....	46
4. Conclusion and Recommendations.....	51

## EXECUTIVE SUMMARY

Across the world, governments are scaling up national programs to prevent vertical transmission.<sup>1</sup> The aim of the scale up is to meet the the Global Plan<sup>2</sup> targets to *eliminate new infections in children by 2015 and keep their mothers alive*. However, systemic barriers that prevent women living with HIV from accessing reproductive and maternal health services or adhering to drug and feeding regimens still pose the biggest threat to efforts to end vertical transmission, and may lead them to drop out of prevention of vertical transmission programs in spite of the science and tools to bring about success. Along with gender inequality and violence, HIV related stigma and discrimination remain the most important reasons why women may not use or adhere to services or guidance. Previous studies have shown that the impact of stigma and discrimination remains one of the biggest stumbling blocks when it comes to women’s willingness to seek health care. For example, in Vietnam, 60 percent of pregnant women who refused HIV testing cited fear of stigma and discrimination as the dominant reasons.<sup>3</sup> In Kenya, pregnant women identified fear of discrimination by health providers as a reason to avoid delivering their babies at a health facility, or deliberately destroying their antenatal cards (which included their HIV status).<sup>4</sup>

At every stage of the cascade of services available to prevent vertical transmission, stigma can deter women living with HIV from accessing these critical services. Pregnant women may refuse an HIV test due to the fear

of discrimination by healthcare workers, and the fear of rejection, blame or abandonment by their partner or families following a positive result. Mothers may not be able to adhere to infant feeding guidance due to a fear of involuntary disclosure of their HIV status and pressure from their family and the community to breastfeed. Similarly, a fear of being seen at an “HIV clinic” or lacking private places to store drugs may compromise women’s adherence to antiretroviral treatment for their own health. And critically, stigma or the fear of stigma affects the ability of women living with HIV to make their own reproductive decisions in the first place.

Bearing these considerations in mind, the goal of this research was to improve understanding of the facets of stigma and discrimination faced by pregnant women living with HIV when accessing antenatal care and reproductive health services. While the experiences of the women interviewed in this study are consistent with findings from other qualitative research studies (including peer-reviewed research), they are not necessarily representative of the experiences of all pregnant women living with HIV.

Between November 2012 and March 2013, ICASO supported networks of women living with HIV and other advocates in five countries - Cameroon, Ivory Coast, Ethiopia, India and Indonesia - to hear and document the stories of pregnant women or mothers living with HIV, who had experienced stigma or discrimination in the course of making reproductive choices or accessing services to prevent vertical transmission of HIV. This report highlights some of the common themes that emerged across the diverse settings and countries in Africa and Asia.

Testimonies from forty mothers living with HIV, between the ages of 19 and 40, were gathered for this study. Many more spoke up and shared their experiences of the stigma they faced during their pregnancy and delivery during focus group discussions and meetings. The stories represent women from urban centers and capital cities, smaller towns and rural districts.

Some of the women interviewed had been told they should not have children; others had been turned away from hospitals as they prepared to go into labor. Mothers living with HIV had been disinherited by their families or abandoned by their husbands. The stories confirmed the complex and multiple layers of discrimination women living with HIV encounter on a daily basis. But the stories also demonstrate their courage and hope, even while experiencing the most inhumane treatment in clinics or cruelest rejection at home. There is optimism and self-assurance even as the women speak of their own fears and feelings of shame.

- 
- 1 The terms commonly used to describe HIV transmission from parents to their children include mother-to-child transmission, parent-to-child transmission, perinatal transmission, and vertical transmission. In this document, prevention of vertical transmission is used interchangeably with prevention of mother-to-child transmission. However, many advocates recommend abandoning the term “mother-to-child” transmission because this term implicitly blames women for infecting their unborn children (GENDER-AIDS eForum, 2003).
  - 2 Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive. UNAIDS 2011.
  - 3 Nguyen, T. A., Oosterhoff, P. &Ngoc, Y.P. (2008) Barriers to access prevention of mother-to-child transmission for HIV positive women in a well-resourced setting in Vietnam. AIDS Research and Therapy.
  - 4 Turan JM, S Miller, EA Bukusi (2008) HIV/AIDS and maternity care in Kenya: How fears of stigma and discrimination affect uptake and provision of labor and delivery services. AIDS Care.

With the support of local networks and associations of women living with HIV, many of the women interviewed have gained critical knowledge and confidence to be able to know and assert, “*I have not done anything (wrong), just ‘I live’ and then I had this disease.*” Many women now stand up to family members and doctors, demanding their right to make their own reproductive choices. And many had clear advocacy messages for their governments.

The research findings show without a doubt that it is simply not enough to scale up services without paying careful attention to the quality of the services. Three decades into the AIDS epidemic, and many health care workers continue to demonstrate lack of knowledge about modes of transmission, an extreme lack of empathy, and unacceptable levels of stigma, discrimination and cruelty. As the AIDS response is currently facing funding cuts,<sup>5</sup> it is vital for advocates to ensure that local organizations, networks and support services have sufficient funding to continue empowering women to assert their rights. If we are to make real progress in ending AIDS, eliminating vertical transmission and improving maternal health, there needs to be a partnership between donors, governments and local organizations to ensure that services are appropriate, accessible and affirming. Furthermore, the women’s experiences clearly highlighted that the experience of accessing antenatal and post-natal health care is not a positive one. Overwhelmingly, the women reported a lack of confidentiality, coercion, denial of treatment and inhumane behavior.

To promote and protect the human rights of all women living with HIV to full autonomy, non-discrimination, health and effective ante and post-natal services for all women, and to meet the targets set in the Global Plan, it is vital for advocacy to demand the funding and scale-up of rights-based PMTCT programs, interventions and related services for women living with HIV: adequate funding for PMTCT programs and stigma and discrimination initiatives, the enactment of national laws, policies and programs that prohibit discrimination, protect human rights with a woman-centered approach, health care settings that are stigma-free, supportive and uphold women’s sexual and reproductive health and rights, community settings that are mobilized and well-resourced and normative agency guidance that incorporates the promotion and protection of human rights and the ethical delivery of PMTCT all have critical roles to play in ensuring that meeting the targets in the Global

---

5 For example, funding for PEPFAR has fallen 12 percent since 2010 in the State Department HIV bilateral budget line. | IRIN News Services, June 6, 2013 <http://www.irinnews.org/report/98168/pepfar-budget-cuts-cause-anxiety> (accessed June 20, 2013).

Plan and other global and national commitments do not compromise ethical and human rights imperatives.

## 1. GLOBAL CONTEXT: WOMEN

In many instances women are still only viewed in their role as mother, mostly to the detriment of their own realities, needs, and rights, which can include HIV-related treatment and prevention. It has long been acknowledged by UN agencies, governments and NGOs that gender inequality is one of the key driving factors in the AIDS epidemic, especially in developing country contexts, where women continue to fight for, and in some cases lose, their reproductive and sexual rights. Increasingly, women living with HIV face violations of their reproductive rights, including forced abortions and sterilization. The sexual and reproductive rights of women living with HIV are seldom taken into consideration, and specific services that would benefit them are not offered, or simply do not exist.<sup>6</sup>

The prevention of transmission of HIV during pregnancy, delivery and/or breastfeeding (vertical transmission) has been a critical issue in the AIDS pandemic globally. The prevention of mother to child transmission (PMTCT), as it is also known, has become a cornerstone of HIV-prevention programming across the world. National AIDS programs have seen PMTCT as an important element of strengthening primary health care services as it relates to antenatal care, seeing the offering of voluntary counseling and testing of women at antenatal clinics as central to their AIDS responses. In June 2011, the United Nations General Assembly adopted the ‘Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS’ with the aim to eliminate new HIV infections among children by 2015, and to substantially reduce AIDS-related maternal deaths.

---

6 Mantell, Smit and Stein in Tallis, V. (2012). *Feminisms, HIV and AIDS. Subverting power, reducing vulnerability.* Basingstoke. Palgrave Mac Millian

## Political Declaration 6

Commit to working towards the elimination of mother-to-child transmission of HIV and substantially reducing AIDS-related maternal deaths by 2015.

### BOX ONE

While PMTCT programs have proven highly effective, they have not been sufficiently scaled up to eradicate vertical transmission. Research shows that there are many barriers to prevention of vertical transmission.<sup>7</sup> These include:

- Stigma from the community.
- Lack of male partners' support for women accessing the services.
- Fear of gender-based violence resulting from disclosure.
- Negative attitudes of health workers.
- Lack of availability of antiretroviral drugs and infant formula.
- Inadequacy of physical infrastructure and staff shortages to deliver services.
- Challenges in the procurement and supply chain management, all of which contribute to stock-outs
- Unmet training needs of the health staff and capacity of healthcare workers to deliver PMTCT, among others.

Any discussion on PMTCT must pay attention to all four prongs of PMTCT (SEE BOX TWO). Elements of Prong 1 and 2 address women's rights and health beyond what is often a disproportionate emphasis on Prong 3. As some of the stories in this report indicate, women have had problematic experiences within PMTCT programs in exercising their reproductive health rights. Further, while it is critical that all pregnant women are offered HIV testing and counseling, concerns have been raised that, in practice, approaches such as Provider-Initiated Testing and Counseling (PITC) often leave women feeling coerced into being tested during pregnancy, undermining both the quality and propriety of the counseling (in terms of consistency with normative guidance) and informed consent (two of the three C's of counseling, confidentiality and consent).<sup>8</sup>

7 Anderson, G et al (2012). Community voices: barriers and opportunities for programmes to successfully prevent vertical transmission of HIV identified through consultations among people living with HIV

8 Kehler J, Cornelius AH, Blossie S, Mthembu, P. Scale-up of provider-initiated HIV testing and counselling of pregnant women: The South African experience. AIDS Legal Network, Cape Town, 2010.

## The UN Framework to prevent vertical transmission of HIV<sup>9</sup> (Four Prongs)<sup>10</sup>



### PRONG ONE My Health

Prevention of HIV among women of reproductive age within services related to reproductive health such as antenatal care, postpartum and postnatal care and other health and HIV service delivery points, including working with community structures.



### PRONG TWO My Choice

Providing appropriate counseling and support, and contraceptives, to women living with HIV to meet their unmet needs for family planning and spacing of births, and to optimize health outcomes for these women and their children.



### PRONG THREE My Child

For pregnant women living with HIV, ensure HIV testing and counseling and access to the antiretroviral drugs needed to prevent HIV infection from being passed on to their babies during pregnancy, delivery and breastfeeding.



### PRONG FOUR My Life

HIV care, treatment and support for women, children living with HIV and their families.

9 Preventing HIV and unintended pregnancies: Strategic framework 2011–2015. UNFPA. Retrieved from [http://www.unfpa.org/webdav/site/global/shared/documents/publications/2012/PreventingHIV\\_UnintendedPregnancies\\_SF2011\\_2015.pdf](http://www.unfpa.org/webdav/site/global/shared/documents/publications/2012/PreventingHIV_UnintendedPregnancies_SF2011_2015.pdf)

10 Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive. UNAIDS 2011.

### BOX TWO

Without  
intervention,

**25-40%** of  
infants born to women  
living with HIV will  
become infected with  
HIV during pregnancy,  
labor and delivery, or  
postpartum through  
breastfeeding.  
However, effective  
interventions  
can reduce  
transmission  
of HIV from mother to  
child to

**1%-2%**<sup>11</sup>

---

11 Nandi Siegfried N, van der Merwe L, Brocklehurst P, Sint T. Antiretrovirals for reducing the risk of mother-to-child transmission of HIV infection. Cochrane HIV/AIDS Group, 2011.

Notably, discussions in the literature on stigma and discrimination focus on stigma in communities, as well as general stigma towards people living with HIV in healthcare settings, but rarely focus on the stigma experienced by women living with HIV who are pregnant. The International Community of Women Living with HIV (ICW) has been breaking the silence on this issue, calling policy makers' attention to barriers to accessing prevention of vertical transmission programs for women living with HIV in antenatal settings around the world.

## 2. TOWARDS ENDING VERTICAL TRANSMISSION OF HIV

The first national programs to prevent vertical transmission of HIV (commonly known as preventing mother to child transmission or PMTCT) were rolled out in 1997. Such programs initially had at their core a focus on the child and not the mother. Only through intense advocacy by women living with HIV and their allies did the focus begin to change and shift. While vertical transmission of HIV has been virtually eliminated in developed countries, many pregnant women in the developing world do not receive the vital services needed to safeguard their own health, and prevent infection in their unborn-infants.

At the historic United Nations General Assembly's Special Session on HIV/AIDS in 2001, world leaders made a commitment to halve the proportion of infants infected with HIV by 2010. This would be achieved by:

- ensuring that 80 per cent of pregnant women accessing antenatal care have information, counseling and other HIV prevention services available to them;
- increasing the availability of and by providing access for HIV-infected women and babies to effective treatment to reduce mother-to-child transmission of HIV;
- through effective interventions for HIV-infected women, including voluntary and confidential counseling and testing, access to treatment, especially anti-retroviral therapy;
- and, where appropriate, by providing breast milk substitutes and the provision of a continuum of care.<sup>12</sup>

---

12 Declaration of Commitment on HIV/AIDS 2001.

Despite being one of the most achievable targets and one of the most cost-effective interventions to prevent HIV, progress has been slow. From 2003-2009, new HIV infections in children only dropped by 23%<sup>13</sup> and only a third of the women in need received antiretroviral prophylaxis to prevent HIV transmission during pregnancy or delivery. This shameful record spurred world leaders to accelerate progress and in the 21 African priority countries of the Global Plan, vertical transmission rates decreased from 26% in 2009 to 17% in 2012. 65% of pregnant women living with HIV received ARV medicines for PMTCT in 2012, compared with 49% in 2009.<sup>14</sup>

With renewed global attention on the lack of progress on improving maternal health in the context of HIV as well as more broadly, the *Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*, launched in 2011 committed the world to two new global targets: 1) Reduce the number of new HIV infections among children by 90% and 2) reduce the number of AIDS-related maternal deaths by 50%.<sup>15</sup> This was a turning point. The new targets were bold and ambitious. More importantly, the world was starting to acknowledge that previous efforts to prevent vertical transmission had failed in part due to the narrow focus on preventing HIV in infants, rather than on providing comprehensive care for women and their families based on the four pillar approach recommended by the UN. (SEE BOX TWO)

The Global Plan sets two targets for the global community to achieve by 2015:

**2015 TARGET 1:**  
reduce by **90%** the number of new HIV infections among children

**2015 TARGET 2:**  
reduce by **50%** the number of AIDS-related maternal deaths

<sup>13</sup> UNAIDS World AIDS Report 2012

<sup>14</sup> Global Update on HIV Treatment 2013: Results, Impact and Opportunities. WHO, 2013.

<sup>15</sup> Global Plan, 2011. Retrieved from <http://www.zero-hiv.org/wp-content/uploads/2011/12/GlobalPlan.pdf>

## What is the Global Plan?

The *Global Plan towards the Elimination of New HIV Infections among Children by 2015 and Keeping their Mothers Alive* (Global Plan) was launched in July 2011 at the United Nations General Assembly Special Session (UNGASS) High Level Meeting by a Global Task Team, led by UNAIDS and PEPFAR. This plan covers all low and middle-income countries, but focuses on the 22 countries<sup>16</sup> with the highest estimates of pregnant women living with HIV. The Global Plan sets out how by 2015 countries can work to ensure that mothers are supported to stay healthy and that children are born without HIV.

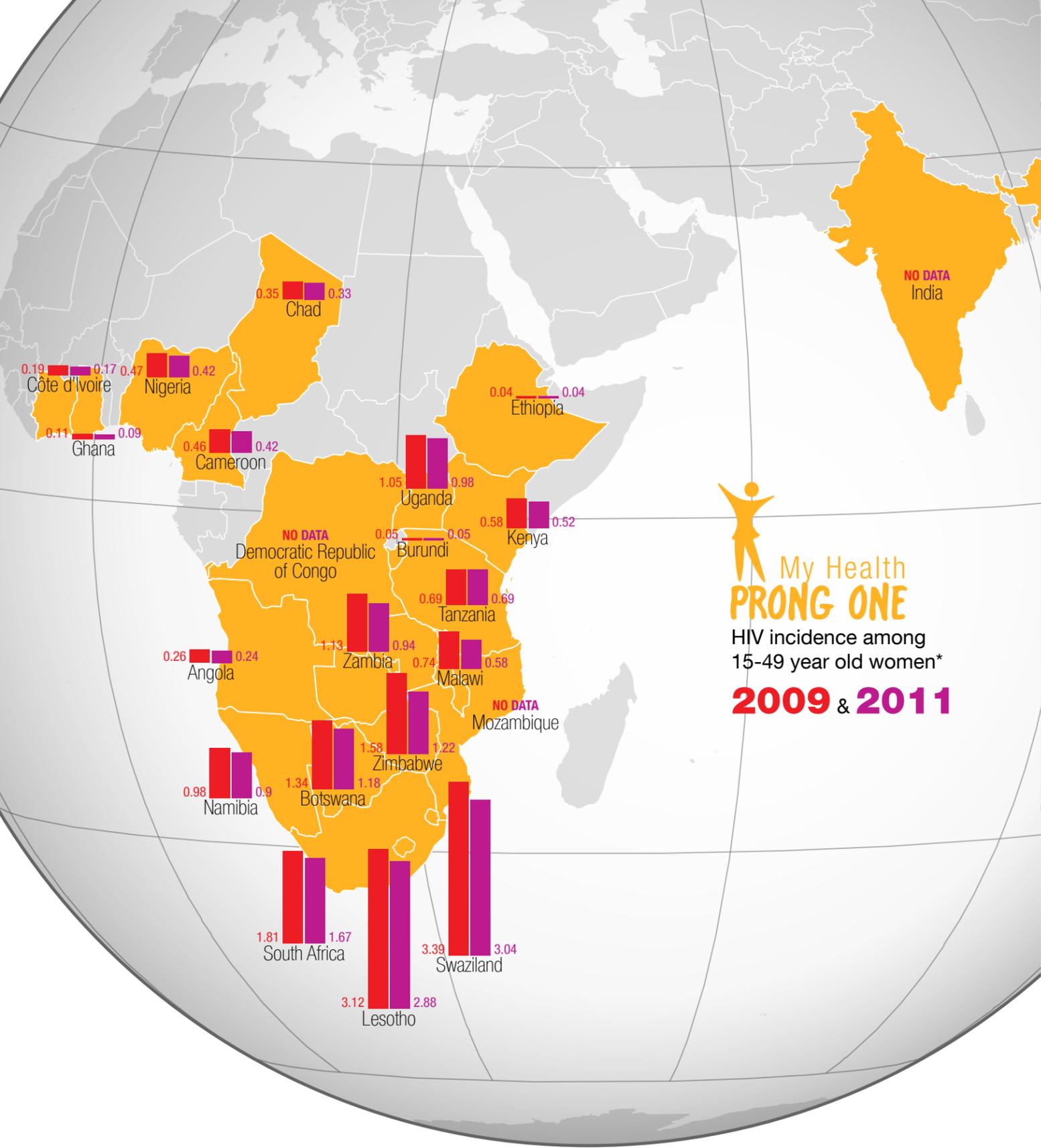
## BOX THREE

### Mapping Progress on the Global Plan

The Global Plan also provides a critical advocacy opportunity to ensure a more comprehensive approach to preventing vertical transmission of HIV, which consists of giving young women the tools and knowledge to prevent HIV, and ensuring that women living with HIV can make their own reproductive choices, prevent HIV transmission to their infants, and access treatment for their own health.

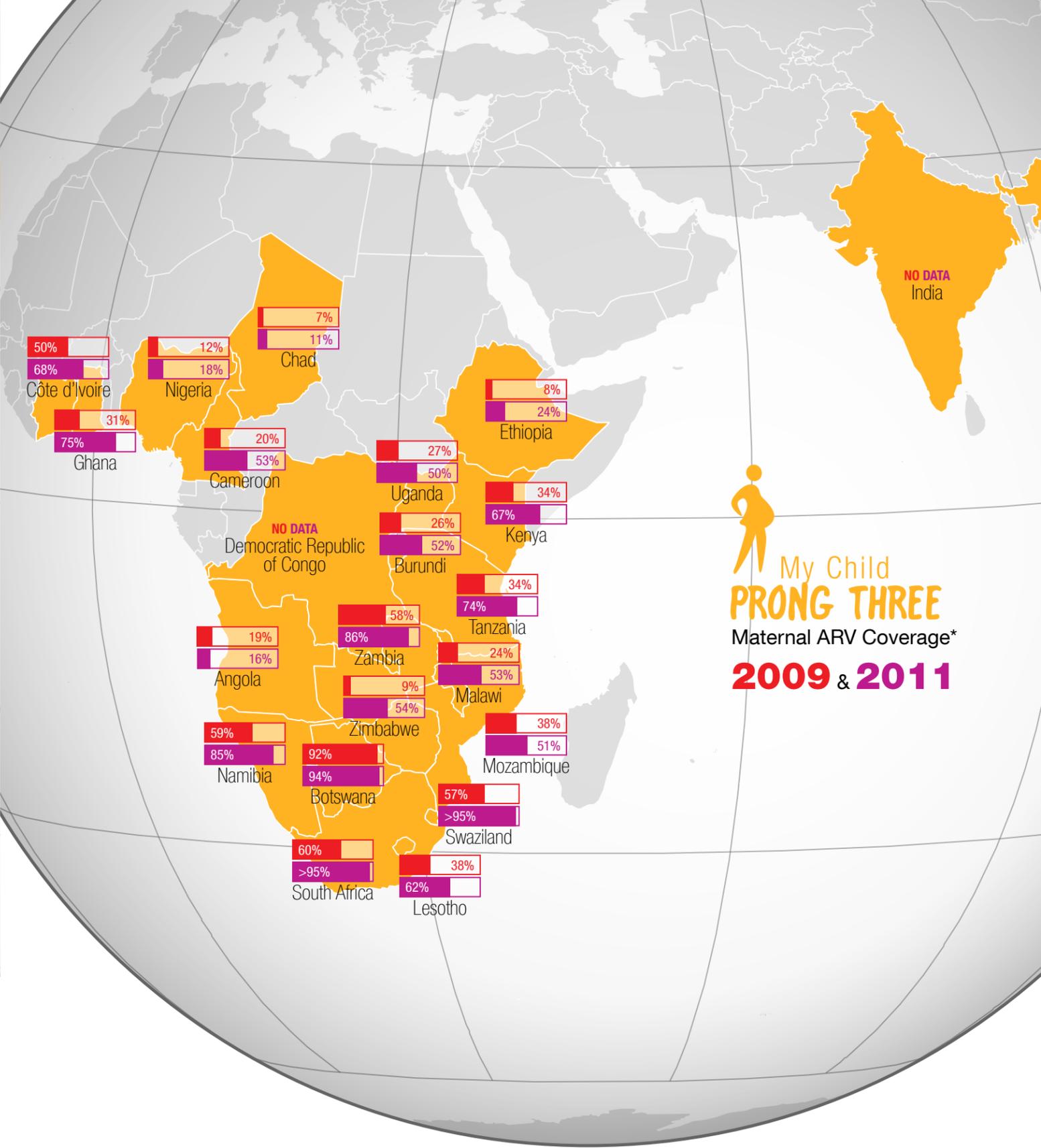
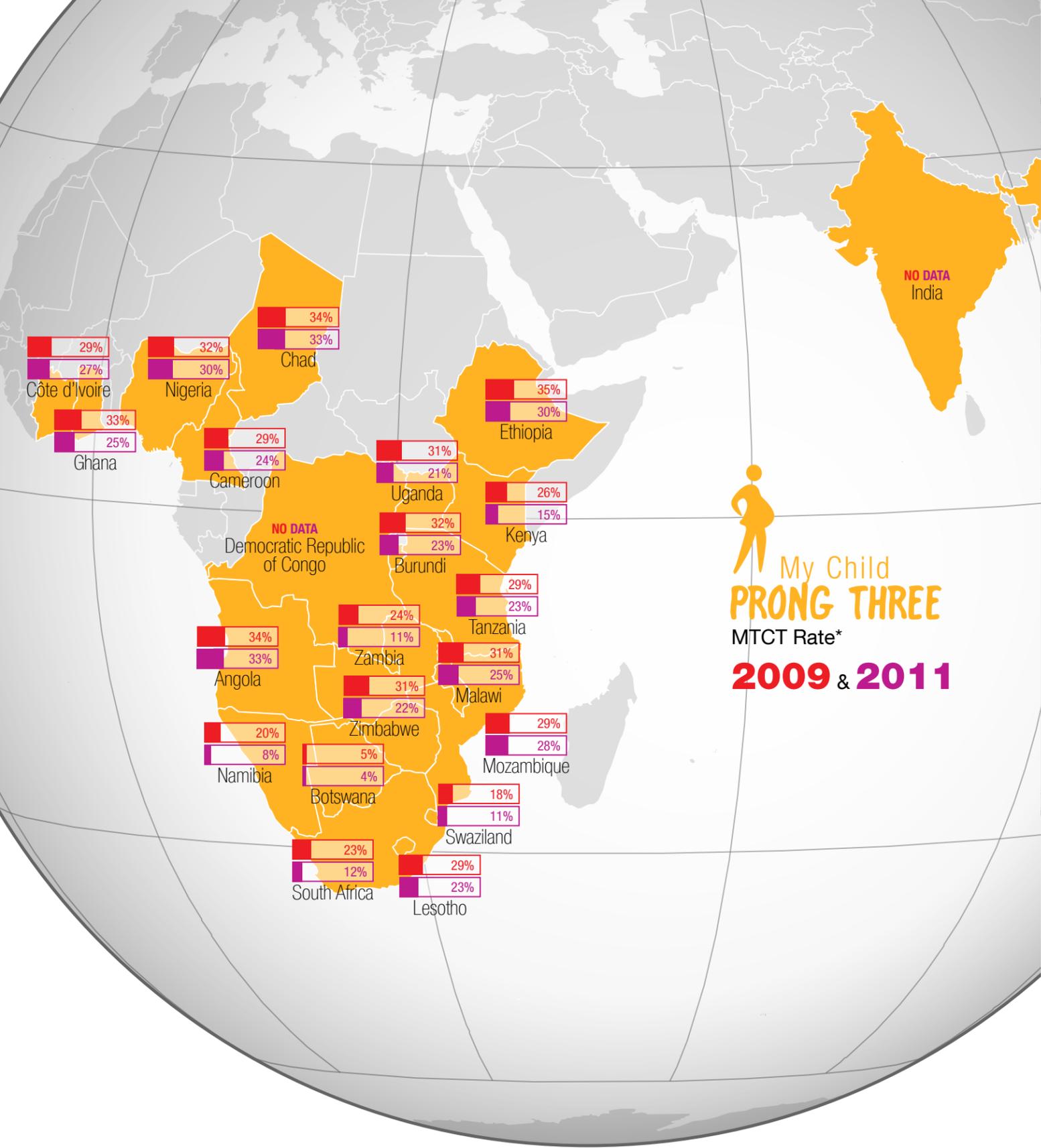
One of the key principles of the Global Plan is that “women living with HIV must be at the center” of developing programs for prevention of vertical transmission and maternal health. It is only by involving women and mothers living with HIV and ensuring that their rights are respected and their needs are met that we will see effective progress on efforts to prevent vertical transmission of HIV.

<sup>16</sup> Angola, Botswana, Burundi, Cameroon, Chad, Ivory Coast, Democratic Republic of the Congo, Ethiopia, Ghana, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Nigeria, South Africa, Uganda, United Republic of Tanzania, Swaziland, Zambia and Zimbabwe



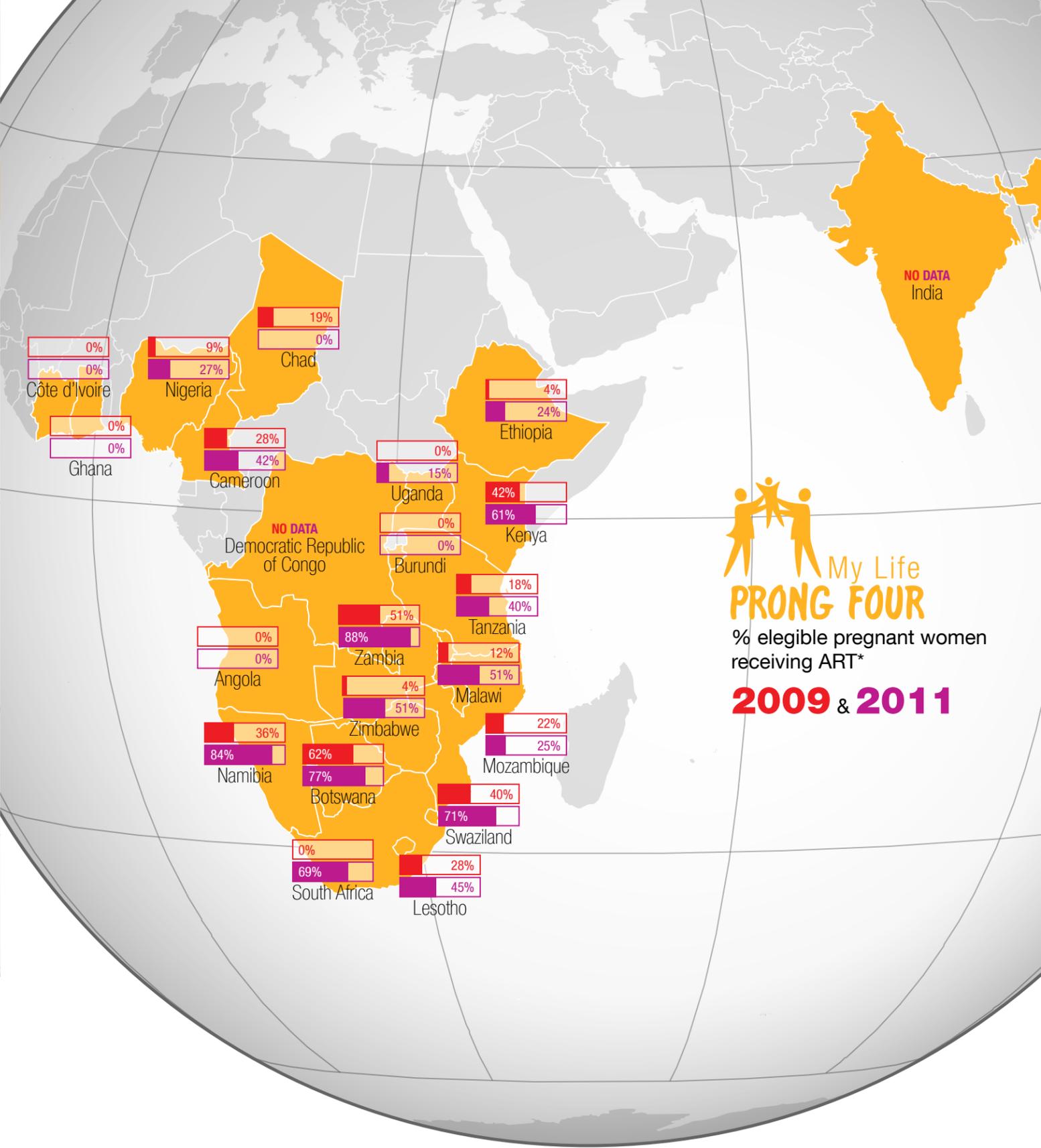
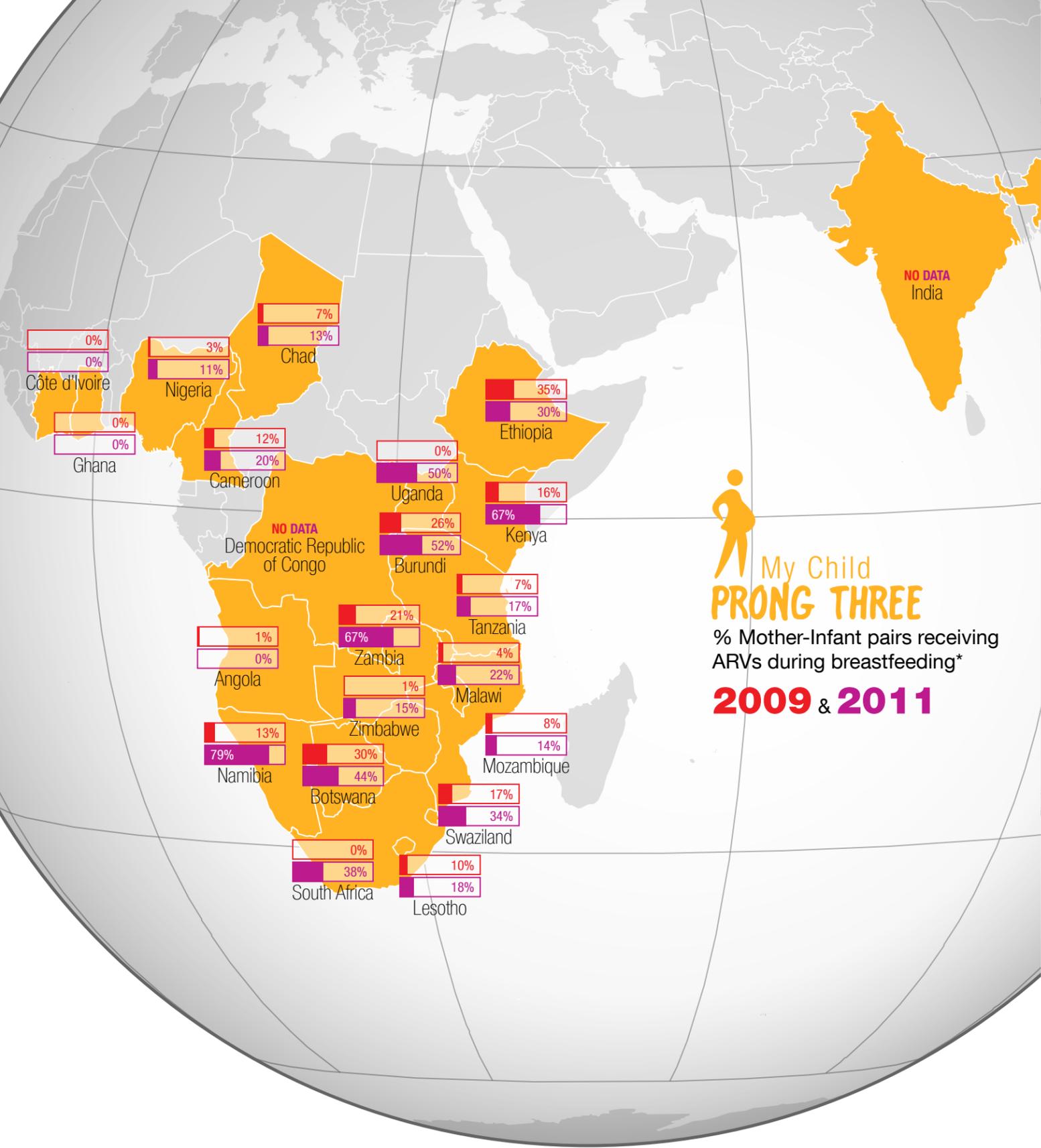
\* UNAIDS, Report on the Global AIDS Epidemic, 2012, unpublished estimates  
Note: For DRC and India, country Spectrum files have not been approved by Ministry of Health  
Source: <http://www.emtct-iatt.org/>

\* UNAIDS, Report on the Global AIDS Epidemic, 2012, unpublished estimates  
Source: <http://www.emtct-iatt.org/>



\* UNAIDS, Report on the Global AIDS Epidemic, 2012, unpublished estimates  
Note: For DRC and India, country Spectrum files have not been approved by Ministry of Health  
Source: <http://www.emtct-iatt.org/>

\* UNAIDS, Report on the Global AIDS Epidemic, 2012, unpublished estimates  
Note: For DRC and India, country Spectrum files have not been approved by Ministry of Health  
Source: <http://www.emtct-iatt.org/>



\* UNAIDS, Report on the Global AIDS Epidemic, 2012, unpublished estimates  
Note: For DRC and India, country Spectrum files have not been approved by Ministry of Health  
Source: <http://www.emtct-iatt.org/>

\*UNAIDS, Together We Will End SIDS, 2012, published estimates  
Note: For DRC and India, country Spectrum files have not been approved by Ministry of Health  
Source: <http://www.emtct-iatt.org/>

WHO has recently launched the “Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection”. In the Consolidated guidelines, WHO moves away from the previous terms “Options A, B and B+” for the use of ART for prevention vertical transmission. Instead, these guidelines recommend two options: Option B and Option B+ (SEE BOX FOUR). While the recommendation to use Option B or Option B+ is conditional, based on the epidemic setting and country program, it should take into consideration issues about toxicity, health outcomes for the mother and the child and adherence. Additionally, the experiences of stigma documented in this report need to be addressed in order to implement any of these two options.

*PMTCT in the new consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection*<sup>17</sup>



OPTION B

**ARV drugs for women living with HIV during pregnancy and breastfeeding** refers to a triple-drug ARV drug regimen provided to mothers living with HIV primarily as prophylaxis during pregnancy and throughout breastfeeding (when there is breastfeeding) to prevent mother-to-child transmission of HIV. In this option, the mother’s regimen is continued lifelong after delivery or after the breastfeeding ends, only if she meets the ART eligibility criteria for her own health based on CD4 count or clinical stage. Previous WHO guidance referred to this as **option B**.

OPTION B+

**Lifelong ART for all pregnant and breastfeeding women living with HIV** refers to the approach in which all pregnant women living with HIV receive a triple-drug ART regimen regardless of CD4 count or clinical stage, both for their own health and to prevent vertical HIV transmission and for additional HIV prevention benefits. Previous WHO guidance referred to this as **option B+**.

BOX FOUR

<sup>17</sup> Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. WHO, 2013

### 3. WOMEN’S VOICES: DOCUMENTING THE EXPERIENCES OF PREGNANT WOMEN LIVING WITH HIV, IN THEIR HOMES, COMMUNITIES AND HEALTH CARE SETTINGS

Policymaking and programming at national level are often done without understanding the realities of people’s lives, resulting in faulty planning that does not meet the requirements of those most in need of services. Data and analysis are vital in enabling us to better understand the nature of the epidemic and design evidence-informed responses. However, whether through lack of political will or technical capacity, there is a dearth of high quality, reliable data in too many contexts. The study, *Stories of Stigma, Stories of Hope*, was designed to put women’s voices and experiences in the spotlight, to better understand the realities of women living with HIV in making reproductive choices and accessing antenatal, maternity and post natal services.

#### A. METHODOLOGY

The goal of this research project was to improve the understanding of the layers of stigma and discrimination pregnant women living with HIV face when accessing antenatal care and reproductive health services. While the experiences of the women interviewed in this study are consistent with findings from other qualitative research studies (including peer-reviewed research), they are not necessarily representative of the experiences of all pregnant women living with HIV. ICASO partnered with networks of women living with HIV and civil society organizations in five countries to document the testimonies of the experiences of stigma and discrimination of women living with HIV during their pregnancies.



Five countries were selected – Cameroon, Ivory Coast, Ethiopia, India and Indonesia – based on the following criteria:

- High HIV prevalence amongst pregnant women, ensuring that comprehensive prevention of vertical transmission services are important.
- Geographic diversity (Africa and Asia)
- Active engagement of a national partner (network of women living with HIV or an organization working with them) who had some previous experience of community-led research or advocacy on issues of prevention of vertical transmission or sexual and reproductive rights of women living with HIV.

Four of the countries (apart from Indonesia) are among the 22 priority countries identified by the Global Plan, with Ethiopia reported to be making rapid progress, Cameroon and Ivory Coast making moderate progress, and India making slow progress in meeting the global targets.



## *Research guidance and process*

ICASO provided the in-country research teams with a standard questionnaire as a framework for interviews, which was adapted by the teams to suit to their national contexts. The research was carried out during December 2012 and January 2013, and country reports were drafted and finalized by March 2013. The research process was community-led. In most cases the interviewers were women or men living with HIV or from networks of people living with HIV. In some cases, partners sought limited assistance from local consultants either to conduct interviews or help draft the report.

The research methodology used was mainly one-to-one interviews with selected interviewees. However, some countries started the process with focus group discussions to help prioritize issues and select the final list of interviewees. In each country, up to nine women were interviewed, and at least six testimonies were published in the final country report.

The criteria used to select women to be interviewed included:

- Women who were open about their HIV status.
- Women who had been or wanted to be pregnant.
- Women who had intense experiences of stigma and/or discrimination.
- Women who were willing to share their stories publicly, including for publication.

Country partners were provided mentorship and support throughout the process. They were also provided guidance and tips on writing the reports and extensive feedback and editorial help on their draft country reports.

The voices in this report represent only some of the stories of women living with HIV who were interviewed across the five countries in Africa and Asia. While each story is unique, common themes emerged that demonstrate the level of stigma and discrimination that many women living with HIV face in their homes, communities and specifically in health care settings. To read each individual story and learn more about the country context, please contact the country teams listed in the acknowledgements section.

The names of the women interviewed have been changed to protect their identity. Quotes have been edited for clarity and brevity.

## B. STORIES OF STIGMA

Stigma is commonly understood as a process of devaluation. It can have many outcomes (such as discrimination, which is also known as enacted stigma) and in the context of HIV can adversely affect how and when someone accesses services (including testing, support and treatment), how people interact with each other (including friendships, intimate partnerships and professional relationships), and how someone perceives themselves and their self-esteem.<sup>18</sup>

HIV and AIDS related stigma is highly complex, dynamic, and deeply ingrained in society as demonstrated by the stories and voices that follow. Rooted in broader, existing inequalities evident in society, and in societies' often negative view of expressions of sexuality and gender, stigma is linked to power, and is used to perpetuate and entrench social exclusion and inequalities.<sup>19</sup> Layers of stigma may be experienced differently; for example, on the basis of race, age, sexual orientation, class, gender. Stigma undermines prevention, care and treatment efforts, which increases the impact of the epidemic on women.

---

18 Give Stigma the Index Finger <http://www.nat.org.uk/media/Files/Publications/Nov-2009-Give-Stigma-the-Index-Finger.pdf>

19 Tallis, V. (2012). *Feminisms, HIV and AIDS. Subverting power, reducing vulnerability.* Palgrave MacMillan. Basingstoke.

Robert Carr,<sup>20</sup> a longtime HIV advocate who dedicated his life to bringing attention to issues of stigma and discrimination against people living with or affected by HIV said:

“Whether as wives or mothers, as women who use drugs or as women who sell sex [...] women and girls, because of gender inequality and stereotypes, experience profound stigma. For example, women experience greater stigma than heterosexual men for selling sex – as it goes against ideas of women upholding societal virtues and needing to belong to one man. As a result, female sex workers are more likely to experience housing discrimination, violence, discrimination against their children and other forms of stigma. Across the board, we see stigma made worse by gender prejudices and the idea that a woman’s biology sets her destiny. We will never make progress in the response to HIV – prevention, treatment, care or support – unless we deal with the gender dimensions of HIV-related fear and ill-treatment.”<sup>21</sup>

---

20 Dr. Robert Carr was the Director of Policy and Advocacy at ICASO at the time of his untimely passing in 2011 – this project was the born out of his vision, passion and leadership.

21 Piecing it Together for Women and Girls: The gender dimensions of HIV-related stigma. March 2011. IPPF

Although the terms stigma and discrimination are often used interchangeably, it is important to distinguish between them. HIV related stigma refers to negative beliefs and statements about HIV and especially people living with HIV. Discrimination refers more to actions and behaviors, for example, excluding people living with HIV or treating people in a way that disadvantages them. Stigma and discrimination can undermine efforts to implement effective HIV responses, and in addition, often lead to violations of human rights of people living with HIV.

The stories and experiences of the women interviewed for this project highlight the insidious nature of the stigma and discrimination they faced, and demonstrate that for some women, there is simply no “safe zone”. Stigma occurs in many places and spaces – in intimate relationships, families and the home, communities, and paradoxically in health “care” settings. The lived realities of the women also show that women experience many negative feelings as a result of stigma. Greater visibility of women in public discourse, policy and practice has not fundamentally changed how women living with HIV are viewed: women are still blamed for bringing HIV into the relationship and the home. This spills over into the community and society, and impacts on how women living with HIV are treated in many different settings, often with stigma and discrimination against women living with HIV a commonplace occurrence. Stigma and discrimination is experienced by PLHIV at many levels across the prevention-treatment-care continuum and can result in reduced access to appropriate interventions. Women’s own fears of stigma and discrimination also impact their health seeking behaviors.



**The People Living with HIV Stigma Index** is a community research and advocacy initiative that has been developed by and for people living with HIV. Led by the Global Network of People Living with HIV (GNP+), it documents both how people have experienced, and been able to challenge and overcome, stigma and discrimination relating to HIV. The core principle that underpins The People Living with HIV Stigma Index is that of championing a community research model, a research and advocacy initiative by and for people living with HIV, in which the process is just as important as the product. A peer-interviewing approach puts people living with HIV at the center of the process. The interviews aspire to be empowering not only for the participants, but also for the interviewers. The data from the Index can be used as: 1) a monitoring tool to analyze and compare changes in stigma over time; and 2) to better understand the experiences of stigma for different groups of people according to location, time since HIV diagnosis, group identity, gender and/or age.<sup>22</sup>

BOX  
FIVE

**STIGMA** /'stigmə/  
**DISCRIMINATION** /diˌskrɪmə'neɪʃən/



THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX

22 <http://www.stigmaindex.org>

Stigma invokes powerful psychological feelings in women living with HIV. These can include fear, depression, sadness, or a lack of confidence. These emotions and feelings in turn impact how women view themselves – it is not uncommon for women to take on and absorb the negative treatment and messages from the broader society – leading to internalized stigma. While a majority of the women interviewed belonged to support groups and were aware of their rights as well as modes of HIV transmission, many still reported feeling shame or even guilt – contributing to self-stigma. This is likely to be an even greater issue among women who do not have the same level of awareness or who do not benefit from peer support.



When people identify me or called me as 'HIV positive', I feel shame. I am positive but need a healthy and HIV free child. I fear society's response if they know I have HIV and I need support of my community, other women, organizations and hospital staff, which I am not getting presently.

**Asha, 22 years, Banaskantha district, Gujarat, India**

Women living with HIV have many fears for their future and the future of their children (born and unborn).

I am not comfortable with procreation knowing my HIV status because I am afraid of giving birth to an infected child and even infect my partner; so I have decided to have safe sex. I would overcome this fear only when a cure against HIV will be found.

**Joane Mariama, 38 years, Douala, Cameroon**

What scares me is when I look at my son; I wonder how long I will live to take care of him.

**Marina, 18 years, Koumassi Hospital, Ivory Coast**



Women also live with the fear of being stigmatized by the family, community or in health care settings and these results in women being unable to look after their sexual and reproductive health, for example, not going to health service providers or not taking medication. *Traore* (below) fears the pressure to conform to “normal” cultural practices, namely breastfeeding, but the consequences of not doing so could lead to disclosure of her HIV status.<sup>23</sup>

As a person living with HIV, I fear (what will happen) if I have another pregnancy and I do not want to breastfeed. I do not know what explanation I will give to parents and others (for not wanting to breastfeed).

**Traore Aissata, 34 years, Grand Bassam Hospital, Ivory Coast**



<sup>23</sup> Traore's experience regarding the pressure to conform to 'normal' cultural practices by breastfeeding her infant is puzzling because WHO guidance on HIV and Infant Feeding has not changed since 2010; it recommends that pregnant women living with HIV who are either on ART or have been provided with effective ARV prophylaxis to prevent vertical transmission should breastfeed their children as this results in the best health outcomes for HIV-exposed infants. It is unclear from the quote whether Traore has access to these interventions, in which case the counseling on breastfeeding which should have been provided as a standard part of antenatal care has resulted in a lack of knowledge regarding the immunological benefits of breastfeeding. In settings where maternal ART or ARV prophylaxis is unavailable, then other options aimed at ensuring the HIV-free infant survival should have been discussed, depending on national policy guidance. See Guidelines on HIV and Infant Feeding 2010: Principles and recommendations for infant feeding in the context of HIV and a summary of evidence. WHO, 2010.

Women living with HIV have experienced stigma first hand in many different settings. Women across all the countries most commonly reported facing verbal insults and disapproval – from health care workers, family members and others in their community. Stigma occurred as a result of unfounded fears of becoming infected by HIV through casual contact or associating HIV with “immoral” or “promiscuous” behavior.

### *Intimate Relationships*

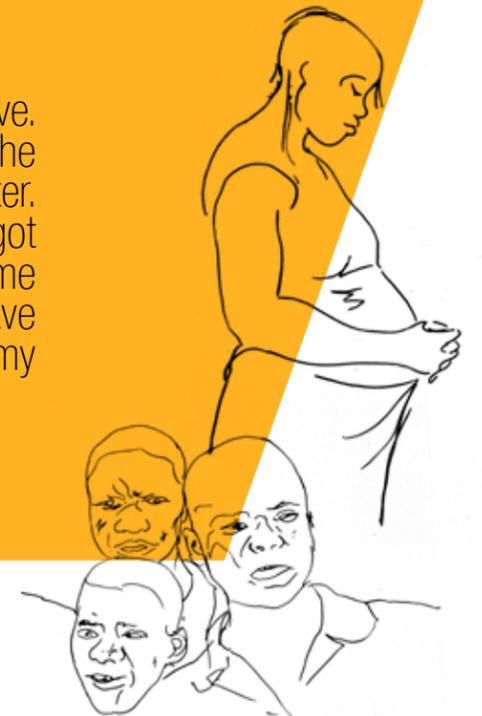
Intimate relationships are for many the most significant relationships of all. Most women interviewed discussed their intimate relationships and described their experiences with their husbands or partners either as positive (where women felt supported and loved) or negative. Although some women were in supportive relationships, many women experienced rejection, abandonment and betrayal from their husbands or partners.

I got HIV from my boyfriend who injected drugs. He never revealed his HIV status to me since when we were dating until I got pregnant and got married. I was never informed about HIV or PMTCT from anyone.

**Juriah, 20 years, Bekasi, Indonesia**

After my positive result, my husband was tested negative. Since that day he does not eat with me, nor does he sleep with me. He even disclosed my status to his sister. The latter spends all her time trying to mistreat me. I got calls from people I don't know. These people insult me and laugh at me. Because all know that I got sick. I have decided to forget all that and lead my life because my children are still small.

**Moaé, 33 years, Koumassi Hospital, Ivory Coast**



Sexual rejection was also a common feature in the interviews.

What I feared the most is the fact that my husband has not yet accepted the situation. My husband left and came back when my baby was 9 months old. There is no more sex between us, when we are in the bed, he sticks to the side, and he does not even want his body to touch me. Even if my husband has come back home, he has not accepted my status.

**Enni, 30 years, Koumassi Hospital, Ivory Coast**

Women reported that their partners do not always accept their own HIV status and keep it hidden from them – adding to their feelings of betrayal.



The good life I started with my husband started falling apart when he got sick. The cause of his illness was never discussed and I was in fear and doubt. I decided to go to a health facility to get tested for HIV. My worst fears came true - I tested positive. After taking some time to take the news in and breathe, I wanted to tell my husband what I knew but I was too afraid to tell my bedridden husband this shocking news. I never told him my status and he did not stay alive that long to ask me. He knew all along that he was living with HIV. I found his test results in his pockets when he died.

**Beletech, 30 years, Addis Ababa, Ethiopia**

A few intimate partners even publicized the woman's HIV status within the family or community without her consent.

I have not yet had the courage to tell someone about my status. But my husband who knows my status went to publicize it to the other pastors, women in the church and everyone.

**Enni, 30 years, Koumassi Hospital, Ivory Coast**



## Home and family

As discussed earlier, HIV-related stigma further contributes to the discrimination faced by women due to their unequal status in society. Characteristically, the home is the place in which most women experience oppression and inequality. The women we interviewed reported being blamed for “bringing the virus home” either because they were the first to test for HIV or because they had a lower CD4 count. At best, they received little or no support when needed. *Zinash’s* story clearly illustrates her isolation, when her sister rejected her due to fear of casual contact, leaving her without any close family support. For *Jyoti*, it meant being evicted from her home.

It was obvious that she is not going to be with me during labor and after. Even as single aunt for my baby I know she didn’t dare to hold him as any normal baby. That hurts.

**Zinash, 30 years, Addis Ababa, Ethiopia**

I was thrown out of the house because my CD4 was very low and my husband’s CD4 was higher, he is blaming me for his infection.

**Jyoti, 29 years, Pune, India**



Blame was a common theme as experienced by the women we interviewed.

My husband did not know that he was living with HIV, we found out when his physical condition dropped at the hospital. At the time when my husband found out his HIV status, my second child was two months old. My husband asked me to cover up his HIV status to his family and mine. My first son is HIV negative. My second child died when she was nine months. She had a severe fever and diarrhea for around two months. I did not check her HIV status. After my husband died I was widely blamed for my husband’s HIV status, and told I was unable to maintain and protect a husband.

**Sri Rahayu, 27 years, Bekasi, Indonesia**

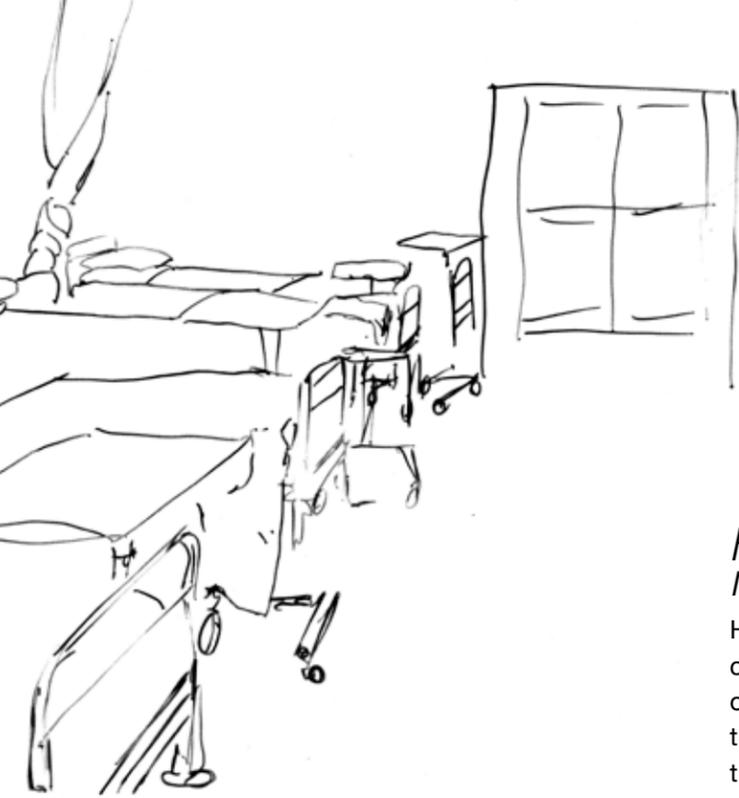
The lack of inheritance rights of women in general, and women living with HIV particularly makes them extremely vulnerable. This came up time and again during the interviews.

My parents even started selling my property and inheritance to raise my children, considering me dead. My neighbors were waiting for when I will be pronounced dead. Whenever I tried to talk to my brothers on the hospital bed, they would tell me that I would not make it and it is all my fault for not starting the treatment earlier.

**Aynaddis, 40 years, Dukem, Ethiopia**

I also saw myself disinherited when my mother knew about my HIV status. According to our traditions, the last-born are successor of their mother. But, I saw my mother starting to make provisions so that another sister plays this role. I did not complain because I was satisfied with my situation.

**Mamie Fameh, 39 years, Yaoundé, Cameroon**



### *Health care settings as negative spaces*

Health care settings can be anything but places of care. The women reported many and varied incidents of verbal abuse and discrimination which, apart from the trauma and emotional impact, also impacted on their health seeking behavior later. Incidents ranged from breaches of confidentiality, disclosure of status, to denial of treatment based on their HIV status.

The women reported feeling stigmatized by the identifying signs on their medical records, which labeled them as “HIV positive”. Furthermore, they found health education materials, depicting people living with HIV as very ill, distressing and insensitive. This added to their negative experiences associated with accessing services at health care facilities.

My medical booklet had a special sign on it that permitted every medical personnel to quickly identify me as an ‘HIV positive patient’. There were posters of people living with HIV in a very deplorable health state; this frustrated me because I imagined I would one day look like that.

**Joane Mariama, 38 years, Douala, Cameroon**

Some women experienced health care workers as rude and patronizing.

When I was eight months pregnant, during a consultation, a nurse at the hospital told me, “You little girl do not behave yourself and then you catch weird diseases.” I was eight months pregnant and her words made me feel guilty. On August 11, 2012, the day I gave birth to my baby, I was the victim of discrimination by a midwife who did not want to look after me because of my status. When I came to give birth, she looked in my booklet and isolated me in a bed at the end of the room. I was suffering and she did not care about me. I felt the baby coming, I called her but she did not come. She rather looked after another woman who came after me. It was another midwife who entered the room, saw me and helped me deliver my baby.

**Marina, 18 years, Koumassi Hospital, Ivory Coast**

The educated nurses use piles of gloves (more than they do for other patients) when they give us injections and examinations. They know the routes of transmission and yet they show such stigmatizing behavior.

**Beletech, 30 years, Addis Ababa, Ethiopia**

Because of my HIV status, when I go to antenatal care, my health card is put to the bottom of the pile and I am the last person to be called for my appointment. This is not good and I want everyone to be treated in the same way. I have not received family planning advice.”

**Moaé, 33 years, Koumassi Hospital, Ivory Coast**



### *Confronting coercion and pressure from healthcare workers*

Coercion from health care workers has been widely reported in many studies – the most blatant being the forced sterilization of women living with HIV.<sup>24</sup> In this study women too reported feeling coerced by healthcare workers or doctors to follow their recommendation on a range of issues – on the method of contraception or delivery, on the best infant feeding option, and most importantly on the decision to have a child. While many may have given in to the pressure, some women who were interviewed stood by their choices even against the advice of medical professionals (see next section). This is worth further exploration – informed women who know their rights and are able to stand up for themselves is an important feature of ensuring that health services meet women’s needs.

I had the desire to have children but the medical staff discouraged me by insisting that due to my situation I can only give birth through caesarean and that I would not be allowed to breastfeed the child. I was asked not to be pregnant again. But, my support group and a friend encouraged me to have children. Later, I agreed with my husband to become pregnant. The medical staff blamed me for falling pregnant again. I was frustrated because I was told I was unable to breastfeed my child. When I saw posters where women breastfeed baby and when midwives said that the mother’s milk is the best, I was uncomfortable.

**Angeline Samaa, 40 years, Bamenda, Cameroon**

<sup>24</sup> See for example, Wilton K, Double Stigma: Forced Sterilization of Women Living with HIV in Kenya and Namibia, Population and Development Program, US, 2013. <http://popdev.hampshire.edu/projects/dt/80>

Often women blindly follow the doctor or nurses instruction – “doctor knows best” is firmly entrenched in women’s minds.

After the delivery process, I saw the doctor in Hermina Hospital for a family planning consultation. He suggested me that I use spiral contraception without explaining what it entailed and did not mention other contraception options. I just followed his advice because I believed him as a professional medical officer.

**Rani, 31 years, Bekasi, Indonesia**

Even when women know their rights and assert them, the authority of the medical profession may cause distress.

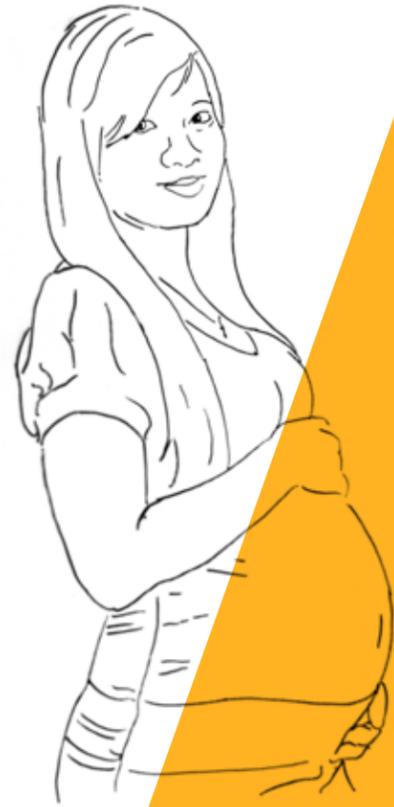
I was shocked with how she (doctor) treated me. The doctor told me that I couldn’t have a baby if I had HIV. She proposed abortion, which I refused. I knew what the doctor said was not true and I can have a baby. I decided to have it. But her words made me restless. I began thinking, what if she is right and my baby would indeed be born with HIV?

**Rahel, 37 years, Addis Ababa, Ethiopia**



## Denial of treatment

Many of the women reported being stigmatized and receiving differential treatment from healthcare workers, for example, nurses wearing extra pairs of gloves or being made to wait the longest. Some were denied treatment or forced to go to other hospitals.



I have been [a] victim of stigmatization from health staff (nurse). It was at the beginning of my pregnancy. She refused to take care of me. She said that there are too many of such conditions here in the hospital and 'every time what we bring is AIDS problem'. I told her that I did not buy it (the disease) at the market and it just happened. I told her: if you do not want to take care of me, you must leave. She said that it is not because she does not want to take care of me, but when people give us advice we do not put them into practice and we go out a lot. I got angry and refused that she consults me. I switched to an older midwife who took care of me.

**Jocelyne Seka, 25 years, Ivory Coast**

RSUD Bekasi, one of the hospitals that provide PMTCT services, refused to handle me. I knew it as I accidentally overheard the conversation between the nurses and doctors. The nurse said, "Doctor, there is a flamboyant B20 (HIV) patient who wants to undergo Caesarian, and the doctor replied, "Oh no, just say I am not around, just find somewhere else."

**Rani, 31 years, Bekasi, Indonesia**

When my child needed treatment, the health-care workers let him wait in the emergency room without any further treatment, and they said that the ward was full. In fact when I checked availability, there was still an empty room. And medical officers continued to refer us to another hospital. After returning home, my in-laws discriminated against me as I could see my soap and cutlery had been separated. My in-laws did not want to treat my child because they felt that sooner or later my child would die because of HIV."

**Adikti Purwati, 27 years, Bekasi, Indonesia**

One woman resorted to giving bribes in order to get treated.

I would have to always motivate medical staff by giving them some money before they take the risk of coming near me and taking care of me.

**Joane Mariama, 38 years, Douala, Cameroon**



## *Inhumane treatment and torture in health care settings*

Stigma and discrimination cannot be quantified and no matter how insignificant an incident may seem to others, for the person on the receiving end it is often devastating and cruel. The following experiences voiced by women we interviewed demonstrate the extremes that stigma and discrimination can lead to, including the most inhumane treatment that meets the United Nations definition of torture as *any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as (...) punishing him for an act he or a third person has committed or is suspected of having committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.*<sup>25</sup>

The stories of these women clearly illustrate the most savage of actions designed with only one thing in mind – to inflict as much pain as possible as punishment for their HIV status.

After a marathon struggle of ten hours with no one taking care of me, I delivered a stillborn male child. When my mother approached the medical officer he responded by saying, “the more you respond to a PLHIV, the more demanding they become”. He refused to treat me. When my mother asked the duty nurse she replied “How many times should we check HIV woman with our hand?”

**Rashmika, 22 years, Banaskantha district, India**

<sup>25</sup> 1984 UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. Article 1. <http://www.un.org/documents/ga/res/39/a39r046.htm>

At the time of birth when the midwife saw the Nevirapine tablet stuck in my book, she told me I had to wait that she first serves other women because of my health status. When it was my turn, she asked me to manage to push. This makes me to have severe lacerations when the child came out. After that, the midwife sutured me with a napkin in my vagina. I discovered this several days later when it started to rot.

**Noella Ambe, 36 years, Yaoundé, Cameroon**

As it was my first time to give birth, I did not know how and when I should start pushing and no one was next to me to tell me how and when I should push. The midwife was looking at me from quite a distance and told her assistant: “Hey, go and see how dilated she is because she wants to push”. It was very, very painful, the assistant gave me a shot, they said it was to make a quick delivery, after that the midwife went to sit in a car outside and was talking with others. I could feel and I touched my baby’s head and I shouted, “auntie, come” nobody came; the baby went back in my belly and at this moment, the midwife wrote on a paper and called my husband to tell him to take me to another hospital. My husband replied that they should save me even if my child should die. Then four women came and sat on my stomach, they have torn me and removed the baby. Five minutes later, the baby died. My baby weighed 4 kilos.

**Asha, 27 years, Koumassi Hospital, Ivory Coast**



## C. STORIES OF HOPE

Although all of the women told stories of stigma and discrimination and how it had affected them or some aspects of their lives, their stories also demonstrated resilience, strength and hope. Many of the women highlighted how important the support of their partner or a family member was, especially in helping them deal with their own fears and negative thoughts.

My husband eats with me, does everything with me, he is very supportive, and there is no problem. I received family planning counseling. I've chosen the condom with my husband. At first I was angry when I knew my status because I have not done anything just "I live" and then I had this disease. I'm afraid of infecting my kids inadvertently with sharp objects hanging around in the house. But my husband is very supportive. I avoid being stressed out now.

**Kouassi Florence, 29 years, Grand Bassam Hospital, Ivory Coast**



At first, when my mom learnt about my status, she became distant; I was given a plate, a spoon that I was supposed to use for myself only. But at the PMTCT appointment, she was explained everything and her behavior changed. Now, we eat together and she washes my baby.

**Marina, 18 years, Koumassi Hospital, Ivory Coast**

My husband was not shocked to learn about my HIV status although he tested negative. He comforted me with words of encouragement. "If the baby can be born negative, the rest is history. There is the antiretroviral treatment for you. I'll be by your side" said her husband.

**Zinash, 30 years, Addis Ababa, Ethiopia**

### *Backed by women's support groups*

Women interviewed often mentioned practical help, such as financial or nutritional assistance, and the emotional support and backing provided by peers and support groups. This helped them stand up to medical staff and make their own reproductive choices.

It was during pregnancy that I knew I had HIV. So I had both the pre and the posttest counseling. This gave me a lot of moral support. I had also received moral and financial help from my husband. Moreover, the association of which I am a member provided me various support such as milk at the birth of my daughter, nutritional and medical support (free appointment for myself and my children).

**Maureen Chanteu, 36 years, Yaoundé, Cameroon**





I get support first of all from God almighty then my family who has spared no effort in supporting me financially, morally and spiritually. I equally get continuous support from AFASO, an association of women living with HIV. AFASO gives me financial, medical, nutritional support and also help in paying part of my son's fees. My special thanks also goes to CCaF+ a newly created female network of positive women that helps me contribute in the fight against HIV and AIDS.

**Dodo Ngotam, 37 years, Yaoundé, Cameroon**

### *Speaking up for their rights*

Some of the women who were interviewed demonstrated an awareness and ability to assert their rights as evidenced in the advocacy messages below. Many also showed an understanding of their responsibilities in living healthy lives and helping to prevent HIV transmission.

I'm not ashamed and do not feel guilty of anything and do not care about what the community says. I have decided to constantly take my ARV treatment and I live positively. For me, it is a duty to protect myself and protect others.

**Balkissou Adjidja, 38 years, Maroua, Cameroon**

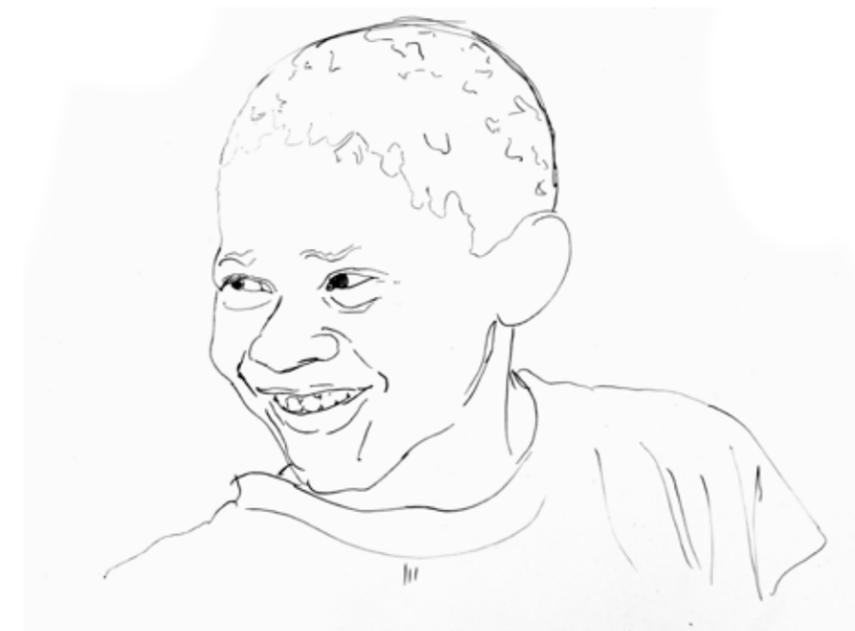
### *Advocacy messages to the community*

I believe people living with HIV enjoy equal rights like everyone else thus should behave normally and have safe sex. My rights were trampled upon when I discovered my HIV status and that I could not freely have sex and the fact that I was in constant fear of being operated upon at childbirth. However, I am neither ashamed nor guilty. I have decided to live my life normally by taking my ARV treatment and making more children if God gives me the chance. I eat and sleep well; I also pray and avoid thinking about it.

**Angeline Samaa, 40 years, Bamenda, Cameroon**

I am happy overall about the hope brought to women living with HIV especially those having babies. I take antiretroviral treatment and despite disapproval from my family, I live with my HIV negative husband raising our son happily. I don't know what the future holds. But I am now happy and hopeful.

**Beletech, 30 years, Addis Ababa, Ethiopia**



### *Advocacy messages to health care workers*

I would like people living with HIV be treated like any other person without difference.

**Marina, 18 years, Koumassi Hospital, Ivory Coast**

Health workers in Indonesia should open arms towards people living with HIV in providing good quality service.

**Rani, 31 years, Bekasi, Indonesia**

Midwives need to be aware so that they do their job well, with no differences between women.

**Traore Aissata, 34 years, Grand Bassam Hospital, Ivory Coast**

### *Advocacy message to government*

I want the government to inform the public about AIDS, so people will not reject us, we too will no longer hide, if people are well informed and accept in their mind that it is a disease like any other, there will be no more stigma.

**Enni, 30 years, Koumassi Hospital, Ivory Coast**

People living with HIV have all the rights. For sex, it must be with your partner who knows the situation and accepts it. Government must pass on informational messages so that people who have HIV are not despised.

**Asha, 27 years, Koumassi Hospital, Ivory Coast**

## 4. CONCLUSION & RECOMMENDATIONS

Policies and programs exist to eradicate vertical transmission and to ensure that women living with HIV are at the center of planning and implementation. WHO guidelines also identify principles and recommendations on how PMTCT programs should be implemented, including the principle of promoting human rights, equity and ethical standards in counseling, informed consent, privacy and confidentiality. However, despite overwhelming scientific evidence, effective interventions, clinical and programmatic guidance and an increased and sustained commitment from donors and governments to address vertical transmission head-on, much remains to be done, including ensuring that the services are delivered ethically and that the human rights of pregnant and breastfeeding women are respected.

The stories recounted by the women in this study offer a compelling case to address stigma and discrimination in communities, health centers and families, as part of a comprehensive approach to prevent the vertical transmission of HIV, while ensuring the health and well-being of mothers and pregnant women. While this study is not the first to highlight the drivers of stigma and discrimination as significant barriers, it does aim to give a voice to the women at the center of the epidemic, humanize the statistics, and provide some insights into how these barriers can be overcome. Furthermore, the study clearly illustrates just how regularly lack of confidentiality, coercion, denial of treatment and inhumane behavior still occur in ante and post-natal health settings.

The current consolidated WHO guidelines now recommend either Option B (maternal ART for all pregnant and breastfeeding women and cessation of ART after the risk of vertical transmission has ceased for women with CD4 counts >500 mm<sup>3</sup>) or Option B+ (lifelong ART for all pregnant or breastfeeding women, irrespective of CD4 count). The decision regarding whether to offer Option B or Option B+ (or both) rests with national PMTCT programs. Option B+ introduces a potentially revolutionary approach that is simpler to implement because it does not require clinicians to rely on laboratory testing to determine post-breastfeeding eligibility, it harmonizes maternal ART with those of adult regimens and offers important maternal health benefits. Option B+ has the potential to help realize the Global Plan targets. However, whether Option B or Option B+ is implemented, it is critical to ensure that human rights abuses and violations are not scaled up in tandem and that women's agency is fully supported. The focus on integration and decentralization of

PMTCT and related maternal and child health services to make them more comprehensive and accessible to women are not, in themselves, sufficient to overcome the pernicious social barriers that keep women, their partners, and their children from fully accessing health services.

In the rush to scale-up PMTCT services to meet Global Plan targets, it is essential that greater attention be paid to how these services are implemented, and that national policy guidance follow WHO recommendations in providing clear guidance in a number of areas and address not only quantitative increases in the number of pregnant women enrolled and retained in PMTCT programs, but also on the quality of the services provided and on how these programs are being administered at the community level.

To promote and protect the human rights of all women living with HIV to full autonomy, non-discrimination and effective ante and post-natal services and to meet the targets set in the Global Plan, it is vital for advocacy to demand the funding and scale-up of rights-based PMTCT programs, interventions and related services for women living with HIV: adequate funding, national laws, policies and programs, health care settings, community settings and normative agency guidance all have critical roles to play in ensuring that meeting the targets in the Global Plan and other global and national commitments do not compromise ethical and human rights imperatives.

### *Funding*

- Increase investment in PMTCT programs from international donors and national governments to fund, implement and evaluate the activities, programs and interventions outlined in the recommendations below.
- Prioritize funding for effective stigma-reduction initiatives in donor-funded programs, national AIDS plans and the national AIDS budget.

### *National Laws, Policies And Programs*

- Ensure the meaningful involvement of women and mothers living with HIV in developing, implementing and evaluating all four prongs of PMTCT policies, plans and programs.
- Ensure that national policies and programmatic guidance are reviewed/ revised as necessary to address the experiences of stigma and discrimination reported by women living with HIV.

- Enact laws and policies prohibiting discrimination on the basis of HIV status and establish mechanisms for reporting and remedying HIV-related discrimination which protect individuals from potential retaliation. Ensure that adequate and relevant technical assistance is available to support the scale up of rights-based PMTCT programs and related health services.
- Ensure national PMTCT policies, plans and programs are consistent with the human rights principles and ethical requirements outlined in WHO Provider-Initiated Testing and Counselling Guidelines, HIV and Infant Feeding Guidelines, and Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, including ensuring a supportive social, policy and legal framework for pregnant and breastfeeding women.

### *Health Care Settings*

- Ensure that health care settings are free of stigma and discrimination by incorporating human rights promotion and the ethical delivery of PMTCT services in health care worker training, including coercion-free HIV testing and counseling, informed consent, confidentiality and privacy
- Regularly train health care workers on HIV and Infant Feeding Guidelines, with a focus on clear, current and accurate communications to pregnant and breastfeeding mothers living with HIV.
- Ensure sexual and reproductive health services and related maternal and child health services are integrated in PMTCT programs to provide comprehensive care for women living with HIV.
- Develop and implement strategies to engage male partners in PMTCT programs in order to reduce stigma in the family.
- Review national plans and budgets for preventing vertical transmission and ensure stronger focus on sexual and reproductive rights of women living with HIV.

### *Community and family settings*

- Support community mobilization and collective advocacy to ensure that initiatives to reduce stigma, discrimination and violence against women living with HIV are central to the ambition and plans to meet the 2015 targets.
- Develop and evaluate community-based interventions and programs aimed at reducing stigma and discrimination faced by women living with HIV in the community and family settings
- Ensure women living with HIV that are pregnant and breastfeeding have access to community-based organizations and other community resources and tools.

### *Rights-based normative guidance*

- Ensure that WHO, UNICEF and UNAIDS incorporate the promotion and protection of human rights and the ethical delivery of PMTCT and related maternal, newborn and child health services as integral elements of all future clinical, programmatic and operational guidance on the public health approach.



STORIES OF STIGMA,  
STORIES OF HOPE

Experiences of pregnant women and mothers living with HIV