Quality of family planning services and integration in the prevention of vertical transmission context

Perspectives and experiences of women living with HIV and service providers in Cameroon, Nigeria, and Zambia
This report was authored by Sonia Haerizadeh, Amy Hsieh, and Rebekah Webb.

We humbly thank the participants of the key informant interviews and focus group discussions for their contribution to this study. We would also like to thank AFSU, ASWHAN, CCaF+, CEAM, CISHAN, ICW West and Central Africa, ITPC Central Africa, NEPWHAN, and NZP+ for their partnership and role in recruiting participants.

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ACKNOWLEDGMENTS AND DEDICATION

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ACRONYMS AND ABBREVIATIONS

AFSU  Associacion des frères et soeurs unis (in Cameroon)
AIDS  acquired immunodeficiency syndrome
ANC  antenatal clinic
ART  antiretroviral therapy
ARVs  antiretrovirals
ASWHAN  Association of Women living with HIV and AIDS in Nigeria
CCaF+  Communauté Camerounaise Des Femmes Positives (in Cameroon)
CEAM  Cercle d’entraide et de solidarité des meres (in Cameroon)
CISHAN  Civil Society for HIV and AIDS in Nigeria
FGD  focus group discussion
GNP+  Global Network of People Living with HIV
HIV  human immunodeficiency virus
ICW Global  International Community of Women Living with HIV/AIDS
ICW West and Central Africa  International Community of Women Living with HIV/AIDS West and Central Africa Regional Office
ITPC Central Africa  International Treatment Preparedness Coalition Central Africa
NEPWHAN  Network of People Living with HIV and AIDS in Nigeria
NZP+  Network of Zambian People Living with HIV/AIDS
Project Partners  GNP+, ICW, ICWEA, COWLHA
PVT  prevention of vertical transmission
SRH  sexual and reproductive health
SRHR  sexual and reproductive health and rights
STI  sexually transmitted infection
UNAIDS  Joint United Nations Programme on HIV/AIDS
UNFPA  United Nations Population Fund
WHO  World Health Organization
The Global Plan Towards the Elimination of New Infections Among Children by 2015 and Keeping Their Mothers Alive (Global Plan) has brought unprecedented scale-up of comprehensive prevention of vertical transmission (PVT)1 programs to pregnant women living with HIV in the 22 priority countries.

The implementation framework of the Global Plan includes a broad four-pronged strategy.2 Prong 2 focuses on providing appropriate counseling and support to women living with HIV to enable them to make an informed decision about their future reproductive lives, with special attention to preventing unintended pregnancies. This includes providing contraceptives to women living with HIV to meet their unmet needs for family planning and spacing of birth, and to optimize health outcomes for women and their children. The Global Plan target for Prong 2 is to reduce unmet family planning need to zero, which is one of the targets of the Millennium Development Goals (MDG5B). Although Prong 2 is recognized as necessary to achieve the Global Plan targets, little research has been conducted to understand the quality of family planning services that women living with HIV are receiving in the context of PVT programs.

To inform policy and practice around Prong 2 of the Global Plan, this report presents the findings of a study conducted by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), with the support of many local networks of women and people living with HIV (the Project Partners). The aims of this study were to understand: (1) the family planning experiences of women living with HIV in the context of PVT programs; (2) the preferences of women living with HIV in relation to family planning, especially young women; and (3) how care providers perceive and engage with women living with HIV, especially young women, in relation to family planning.

During August–September 2013, the Project Partners collected information using: (1) key informant interviews, (2) focus group discussions, and (3) a survey on family planning services. All three methods were used with women living with HIV and service providers from Cameroon, Nigeria, and Zambia.

The findings of this study highlight critical areas that must be addressed in any and all efforts to improve health outcomes as they relate to Prong 2 of the Global Plan, as well as demonstrate the potential pitfalls of failing to provide appropriate and adequate care. Additionally, this study points to the need for further research to compare these countries in terms of success rates and positive outcomes, or to adjudicate the quality of services in any particular setting, which were beyond the scope of this study.

1. The term ‘comprehensive prevention of vertical transmission’ (PVT) is being used in this report in line with developing usage among the community of people living with HIV. This term is preferred over ‘prevention of mother-to-child transmission’ (PMTCT).
2. Prong 1: 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 2: 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 3: 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 4: HIV care, treatment and support for women, children living with HIV and their families.
RECOMMENDATIONS

The experiences and perspectives of women living with HIV and service providers shared during a series of interviews and focus group discussions held in Cameroon, Nigeria, and Zambia underline the importance of the following recommendations:

FOR MINISTRIES OF HEALTH

- Develop strategies at the national level to ensure access to and increase the quality of counseling regarding family planning services and rights.
- Prioritize reforms to prevent stock-outs of family planning commodities and antiretrovirals (ARVs).
- Increase the range of family planning methods available to all women and ensure that service providers are well-versed in the impact of each option on women living with HIV.
- Review and update policies, guidelines and practices of service providers to end unnecessary and stigmatizing practices based on outdated information about HIV transmission (e.g. use of doubled gloves and additional cleaning processes during labor and delivery).
- Increase sustainable funding to develop, strengthen and maintain support groups and networks of women living with HIV.

FOR SRH/HIV PROGRAMME MANAGERS AND SERVICE PROVIDERS

- Improve the quality of counseling regarding family planning services, including promoting the rights of women living with HIV.
- Provide youth-friendly family planning services.
- Educate service providers that family planning is a service that must be available to all women and particularly young women, regardless of their current marital or parental status.
- Provide community information, education, and communication (IEC) initiatives targeting young women and support groups that address:
  a. The right of women to have accurate and full information about their reproductive rights and options (including the right of women living with HIV to bear children)
  b. Facts about family planning methods and their side effects
  c. HIV risk and hormonal contraception
  d. ARV literacy (especially in the context of family planning)
e. How to reduce vertical transmission risk
f. The benefits of consulting with service providers when planning to have children
g. Stigma

- Require stronger patient confidentiality procedures that include consequences for violations of confidentiality for clinical service providers.

- Develop and put into practice grievance/accountability procedures for women living with HIV who encounter discriminatory practices in healthcare settings.

- Provide voluntary counseling and testing, as well as psychosocial support upon diagnosis.

- Foster measures to support mothers living with HIV to care for their children.

- Implement HIV prevention approaches that help women to more accurately identify their level of risk (e.g. outside of monogamous partnerships, within marriage, etc.).

- Create programs that will reduce stigma and promote acceptance of women living with HIV.

**FOR RESEARCHERS**

- Further research the causes and impact of discrimination against women living with HIV by service providers and develop specific recommendations for ending discriminatory practices.

- Explore the reasons why Zambian women experience less stigma and discrimination compared to other settings.

**FOR NETWORKS OF WOMEN AND PEOPLE LIVING WITH HIV**

- Train and support women living with HIV to articulate their rights in the context of sexual and reproductive health (SRH) and HIV services.
BACKGROUND AND INTRODUCTION

*The Global Plan Towards the Elimination of New Infections Among Children by 2015 and Keeping Their Mothers Alive* (Global Plan) has brought unprecedented scale-up of comprehensive PVT programs to pregnant women living with HIV in the 22 priority countries.¹

The implementation framework of the Global Plan includes a broad four-pronged strategy. Prong 2 focuses on providing appropriate counseling and support to women living with HIV to enable them to make an informed decision about their future reproductive lives, with special attention to preventing unintended pregnancies. This includes providing contraceptives to women living with HIV to meet their unmet needs for family planning and spacing of birth, and to optimize health outcomes for women and their children. The Global Plan target for Prong 2 is to reduce unmet family planning need to zero, which is one of the targets of the Millennium Development Goals (MDG5B).

Although Prong 2 is recognized as necessary to achieve the Global Plan targets⁵, little research has been conducted to understand the quality of family planning services that women living with HIV are receiving in the context of PVT programs.

Information on the quality of family planning services actually experienced by women living with HIV (e.g. access, confidentiality, freedom from stigma, discrimination, and coercion, privacy, informed choice, range of contraceptive choices, safe conception, and retention in care, etc.) is insufficient in the Global Plan discourse and is necessary to enhance further scale-up of rights-based programs. Additionally, integration of sexual and reproductive health and rights (SRHR) and HIV services is seen as essential to increasing access to SRH and PVT services and to achieving Global Plan and related targets.

Therefore, it is also important to understand what impact, if any, this approach has on the quality of services that women are receiving.

Concurrently, there is a global effort to decentralize and integrate HIV and SRHR in general, and specifically under the Treatment 2.0 Agenda. According to WHO and UNAIDS, "Decentralizing and integrating treatment with other areas of health care, such as ... maternal and child health ... services will help leverage scarce resources for maximum effect."³ With decentralized and integrated care becoming the norm, it is important to understand how the changing service delivery models affect the experiences of women living with HIV.

To inform policy and practice around Prong 2 of the Global Plan, this report presents the findings of a study conducted by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), with the support of many local networks of women and people living with HIV (the Project Partners). The aims of this study were to understand:

1. The family planning experiences of women living with HIV in the context of PVT programs (including contraception and safe conception)
2. The preferences of women living with HIV in relation to family planning, especially young women
3. How care providers perceive and engage with women living with HIV, especially young women, in relation to family planning.
During August–September 2013, the Project Partners collected information using rapid appraisal methods, specifically: (1) key informant interviews (KIIs), (2) focus group discussions (FGDs), and (3) a survey on family planning services. All three methods were conducted with women living with HIV and service providers.

**Key informant interviews** are qualitative in-depth interviews with people who know what is happening in the community. A key informant is an individual, who as a result of her/his knowledge, previous experience, or social status in a community has access to information, such as insights about the functioning of society, its problems and needs. Key informants can also provide information to understand the context of a program, or clarify particular issues or problems.

**Focus group discussions** are interviews with small groups of people with relatively similar backgrounds and experiences. FGDs offer a range of material and a perspective on group dynamics that cannot be captured in KIIs or a survey. Participants are asked to reflect on the questions asked by the interviewers, 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.

**Surveys** provide information regarding the key questions of interest. The survey questions focused on the draft indicators currently being piloted by the Interagency Work Group on SRH and HIV. All participants of KIIs and FGDs completed the surveys.

These three methods captured different dimensions of women’s and service providers’ experiences and were triangulated to assure the validity of the data.

**Development of Key Informant Interview and Focus Group Questions**

Two sets of KII questions were developed to explore the perspectives of: (1) women living with HIV, and (2) service providers (see Annex A: KII Guides). Those questions were modified into two sets of FGD guides, with modifications based on information gleaned from the KIIs (see Annex B: FGD Guide). All KII and FGD participants completed a survey (see Annex C: Surveys).

Local networks provided suggestions for improving the KII and FGD questions. The questions were also shared with other colleagues for review. Their comments shaped the final questions and guides.

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3. The Interagency Working Group on SRH and HIV Linkages has been developing new indicators to measure integrated delivery of SRH and HIV services. Two indicators (a ‘marker’ indicator and ‘basket’ indicator) have been drafted and are being piloted. A list of SRH and HIV services, which could be used in the measurement of the indicators was developed as a step towards defining these indicators. These definitions were also used in the study survey. See SRH and HIV Linkages Indicators Specialist Symposium: Summary and Outcomes, 21–22 March 2013, London, UK.
**SAMPLING AND SELECTION OF PARTICIPANTS**

GNP+ and ICW partnered with local networks of women and people living with HIV in Cameroon, Nigeria, and Zambia to recruit participants for KIIs and FGDs. In Cameroon, CCaF+, CEAM, CISAN, and ITPC Central Africa assisted with recruitment; in Nigeria, ASWHAN, ICW West and Central Africa, NEPWHAN; and in Zambia, NZP+.

All participants were recruited using a snowball (respondent driven) sampling method, where participants with specific characteristics who were willing to participate in the study were selected. Those participants were then asked to identify people like themselves for the study.

For the KII, interviewees were selected using the following criteria:

- Women living with HIV who are of reproductive age, especially those using at least one family planning method
- Service providers who care for women living with HIV in hospitals or health centers that provide antiretroviral therapy (ART) and/or antenatal care (ANC)/PVT services

For the FGDs, participants were selected using the following criteria:

- Young women living with HIV (aged 18–25 years old)\(^4\)
- Women living with HIV from rural communities

One additional FGD was held with service providers in Zambia. Table 1 shows the characteristics of the KII and FGD participants.

**THE CONSENT PROCESS**

A consent form was developed and distributed to each KII and FGD participant (see Annex D). The facilitator read through the consent form with participants, in English or French as applicable. All participants were told that their participation was voluntary and that they could leave at anytime. The facilitator explained the objectives of the KII and 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 KII and FGDs would be recorded (where applicable) and transcribed verbatim but that the information would not be attributed to a specific participant by name. An opportunity was presented for questions. Each participant was then asked to sign and date the form if they wanted to participate. Copies of the signed consent forms were made available for participants to take home when possible.

**COUNTRY SELECTION CRITERIA**

Cameroon, Nigeria, and Zambia were selected for this study because they are among the 22 Global Plan priority countries. Additionally, during the development of this qualitative study, UNFPA was initially planning workshops in each of these countries that focused on Prong 2, which would provide an opportunity for the study findings to be shared with policymakers.\(^5\)

In Cameroon, the KIIIs were held at CCAF+ headquarters in Yaoundé. The FGDs were held at the meeting places of local networks: AFSU headquarters in Yaoundé, CEAM offices in Yaoundé, and CEAM office in Zoetélé (quarter of Sangmelima).

In Nigeria, six KIIIs were held at the treatment centers were the women accessed services. Four KIIIs were held at an agreed meeting venue with the interviewee (e.g. home and other gathering). The KII with service providers were held at the treatment centers were they worked. Two FGDs were held at Nyanya in Abuja. Two FGDs were held at Ojuelegbe in Lagos.

In Zambia, the KIIIs were held at Nanga Rural health centre in Mazabuka, Nangongwe Clinic in Kafue, Chilanga clinic in Lusaka, and Treatment Advocacy and Literacy Campaign offices in Lusaka. One FGD with women living with HIV was held at Nangongwe clinic in Kafue. One FGD with women living with HIV was held at Nanga Rural Health Centre in Mazabuka. One FGD with service providers was held at Nangongwe Clinic in Kafue.

**PARTICIPANT INCENTIVE/ REIMBURSEMENT**

Transportation reimbursement was provided to all participants and light refreshments were served during each FGD.

**LIMITATIONS**

There are some limitations associated with the research methodology used for this study.

The selection of KII and FGD participants was not random, which presents some bias. For example, the service providers who agreed to participate in this study were aware that it was being conducted by networks of people living with HIV, which may explain why they were less likely to express answers that were discriminatory against women living with HIV. Those who do discriminate against women living with HIV may have declined the interview.

Additionally, given the smaller sample size, the KII, FGDs, and surveys are limited in their ability to produce results that are can be generalized to the broader population.

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\(^4\) Fewer young women (18–25 years old) were recruited for this study. In Cameroon, this was because few young women are involved in networks of women living with HIV, which tend to involve slightly older women. In Zambia, the interviewer posited that it is due to the stigma associated with accessing family planning for young people and therefore they were unwilling to participate in the study.

\(^5\) These findings were presented at a regional workshop convened in Tanzania focused on Integrated Models of Service Delivery, which was held in place of the three country workshops.
**TABLE 1. KEY INFORMANT INTERVIEWS AND FOCUS GROUP DISCUSSION PARTICIPANT DEMOGRAPHICS**

<table>
<thead>
<tr>
<th>Key informant interviews</th>
<th>Focus group discussions</th>
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<tr>
<td><strong>Women living with HIV</strong></td>
<td><strong>Service providers</strong></td>
</tr>
<tr>
<td><strong>N=8</strong> Urban: Yaoundé</td>
<td><strong>N=5</strong> Urban: Yaoundé</td>
</tr>
<tr>
<td>21–36 years old</td>
<td>5 female</td>
</tr>
<tr>
<td>Diagnosed between 1990–2013</td>
<td>40–56 years old</td>
</tr>
<tr>
<td>0–5 children</td>
<td>1 self-identified as living with HIV</td>
</tr>
<tr>
<td>Last pregnancy: 2006–currently pregnant</td>
<td>Profession: 2 midwives; 2 nurses; 1 community health worker</td>
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<td></td>
<td>Workplace setting: 3 hospital; 1 community-based clinic</td>
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**FGD#1, N=10**
- Rural/Urban: Douala (urban), Buea (urban), Sangmélima (rural), Tibati (rural), Yaoundé (urban)
- Older (37–49 years old)
- Diagnosed between 1999–2009
- 1–5 children

**FGD#2, N=10**
- Urban: Bamenda, Douala, and Yaoundé
- Young (27–38 years old)
- Diagnosed between 2001–2011
- Number of children: 1–4

**FGD#3, N=10**
- Urban: Douala and Yaoundé
- Older (28–42 years old)
- Diagnosed between 2003–2011
- Number of children: 1–4

**FGD#4, N=10**
- Rural: Zoetele (Quarter in Sangmelima)
- Young (18–30 years old; 50 years old)
- Unmarried
- Diagnosed between 2008–2012
- Number of children: 1–5
- Last pregnancy: 2011–2013

CAMEROON
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<tr>
<th>Key informant interviews</th>
<th>Focus group discussions</th>
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<tr>
<td><strong>Women living with HIV</strong></td>
<td><strong>Women living with HIV</strong></td>
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<tr>
<td><strong>N=10</strong></td>
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<tr>
<td>From Lagos, Abuja, and Kaduna</td>
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<tr>
<td>22–39 years old</td>
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<tr>
<td>Diagnosed between 1999–2010</td>
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<tr>
<td>Number of children: 0–4</td>
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<tr>
<td>Last pregnancy: 1997–2012</td>
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<tr>
<td><strong>N=6</strong></td>
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<tr>
<td>6 female</td>
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<tr>
<td>32–54 years old</td>
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<tr>
<td>None self-identified as living with HIV</td>
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<tr>
<td>Profession: 5 nurses; 1 midwife</td>
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<td>Workplace setting: 4 hospital; 1 community-based clinic; 1 ARV clinic</td>
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<tr>
<td><strong>FGD#1, N=9</strong></td>
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<tr>
<td>Urban: Abuja</td>
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<tr>
<td>29–41 years old</td>
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<tr>
<td>Diagnosed between 2002–2010</td>
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<tr>
<td>Number of children: 2–4</td>
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<tr>
<td>Last pregnancy: 2006–currently pregnant</td>
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<td><strong>FGD#2, N=10</strong></td>
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<tr>
<td>Urban: Abuja</td>
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<tr>
<td>24–34 years old</td>
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<tr>
<td>Diagnosed between 1992–2011</td>
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<tr>
<td>Number of children: 0–6</td>
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<tr>
<td>Last pregnancy: 2008–2013</td>
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<td><strong>FGD#3, N=10</strong></td>
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<tr>
<td>Urban: Lagos</td>
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<tr>
<td>27–46 years old</td>
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<tr>
<td>Diagnosed between 2004–2013</td>
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<tr>
<td>Number of children: 1–4</td>
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<tr>
<td>Last pregnancy: 1990–2013</td>
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<tr>
<td><strong>FGD#4, N=9</strong></td>
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<tr>
<td>Urban: Lagos</td>
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<tr>
<td>20–42 years old</td>
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<tr>
<td>Diagnosed between 2001–2012</td>
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<tr>
<td>Number of children: 1–5</td>
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<tr>
<td>Last pregnancy: 2005–2012</td>
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<tr>
<td>Key informant interviews</td>
<td>Service providers</td>
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<tr>
<td><strong>Women living with HIV</strong></td>
<td><strong>N=5</strong></td>
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<tr>
<td></td>
<td>Urban: Kafue, Lusaka</td>
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<td></td>
<td>19–41 years old</td>
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<td></td>
<td>Diagnosed between 1994–2010</td>
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<td></td>
<td>Number of children: 1–5</td>
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<td></td>
<td>Last pregnancy: 1997–2011</td>
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<tr>
<td><strong>Service providers</strong></td>
<td><strong>N=4</strong></td>
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<tr>
<td></td>
<td>Rural/Urban: Mazabuka (rural), Chilanga (urban)</td>
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<tr>
<td></td>
<td>4 Female</td>
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<td></td>
<td>25–57 years old</td>
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<tr>
<td></td>
<td>0 Living with HIV</td>
</tr>
<tr>
<td></td>
<td>Profession: nurse, midwife, clinical officer</td>
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<td></td>
<td>4 community-based clinic</td>
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<th>Focus group discussions</th>
<th>Women living with HIV</th>
<th>Service providers</th>
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<td><strong>FGD#1 (N=5)</strong></td>
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<td></td>
<td>21–46 years old</td>
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<td></td>
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<td></td>
<td>Number of children: 1–4</td>
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<tr>
<td></td>
<td>Last pregnancy: 1986–2010</td>
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<td><strong>FGD#2, N=5</strong></td>
<td>Rural: Mazabuka</td>
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<td>23–57 years old</td>
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<td></td>
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<td></td>
<td>Number of children: 1–9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Last pregnancy: 1993–2011</td>
<td></td>
</tr>
<tr>
<td><strong>FGD#1 (N=7)</strong></td>
<td>Urban: Kafue</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 Female; 1 n/a</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age range 29–46 years old</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0 Self-identified as living with HIV</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Profession: nurse, midwife</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Workplace setting: 6 community-based clinic; 1 n/a</td>
<td></td>
</tr>
</tbody>
</table>
Demographic information for all participants was collected as part of the Survey (see Annex C).

**LANGUAGES USED FOR DATA COLLECTION**

All data collection tools were developed in English and then translated into French. The participants’ preferred languages were used in the KIIIs and FGDs.

In Cameroon, the KIIIs and FGDs took place largely in French, as every participant felt comfortable speaking French.

In Nigeria, the KIIIs and FGDs took place largely in English, as every participant felt comfortable speaking English. Occasionally, participants felt more comfortable expressing themselves in local English language (Pidgin English) and Yoruba language.

In Zambia, the KIIIs and FGDs took place largely in English, as every participant felt comfortable speaking English. Women living with HIV in Mazabuka and some in Kafue felt more comfortable expressing themselves in Tonga and Nyanja, and the interviewer translated the survey questions in these languages as appropriate.

**AUDIO RECORDING AND TRANSCRIBING**

All the FGDs in Cameroon and Nigeria were recorded on digital recorders or mobile phone recording devices. The KIIIs and FGDs conducted in English were subsequently transcribed. The KII and FGD transcripts from Cameroon were transcribed in French and then translated into English.

In Zambia, a rapporteur took notes during the interviews and FGDs. After the interviews and FGDs were conducted, the interviewer/facilitator added details to the interview notes taken by the rapporteur.

**FACILITATION AND DURATION**

In Cameroon, the interviews were conducted by Calorine Kenkem for approximately 45 minutes, recorded and transcribed. The FGDs were approximately 80 minutes in duration, and were facilitated by Calorine Kenkem and a representative from ITPC Central Africa.

In Nigeria, the interviews were conducted by Patricia Ukoli for approximately 30 minutes, recorded and transcribed. The FGDs were approximately 90 minutes in duration, and were facilitated by Patricia Ukoli and Assumpta Reginald from ICW Nigeria.

In Zambia, the interviews were conducted by Eunice Sinyemu for 45–90 minutes, depending on whether there were interruptions, and were recorded, and transcribed. All FGDs were facilitated by Eunice Sinyemu. The FGDs with service providers lasted approximately 90 minutes long. The FGDs with women living with HIV ranged from 2–3 hours long. Some of the conversations with women living with HIV were longer because this was the first time anyone had asked the participants how they felt about HIV and their services and increase facilitation was needed to focus the conversation.
DATA ANALYSIS

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

1. Collation of the transcript data under key questions (as per the interview/FGD guides)
2. Unitization of the data (identifying those units of information – including quotes – that later become the basis for defining categories)
3. Categorization of units (units have been sorted into relevant groupings to represent categories or themes)
4. Organization of categories into main themes.

The units emerging from the transcripts were classified into over eighty categories. The categories have been organized into 20 themes that have been presented in the format of questions.

Each KII and FGD analysis includes a section of the main findings, linked to each theme, which synthesizes the information related to those categories that have more units, or contain information that shows consensus amongst the group interviewees or statements where interviewees have put particular emphasis. All data (units and quotes, categories, main findings and themes) were synthesized first for each country separately and then collated as main findings.

The results reported in the following section with illustrative quotes from the KII and FGDs to summarize the findings. Quantitative data from the surveys are also presented where relevant.
RESULTS

SECTION I: HIV AND PREGNANCY

1. FEELINGS ABOUT HIV DIAGNOSIS

Women living with HIV said that their HIV diagnosis was a very shocking and sad experience. Many women expressed that they felt ‘like dying’ or felt scared, especially if they were pregnant or in a sero-discordant relationship. Women who are first diagnosed during pregnancy face increased stress because of the pressure to make decisions about the health of her unborn infant and her own health (e.g. whether to start lifelong treatment, worries about the baby being HIV positive), worry about stigma they may experience as a pregnant woman living with HIV, concerns about her ability to care for and raise the child, and concerns about their safety when disclosing this new information to their partners.

Other women were in denial about their diagnosis, particularly those who were married, faithful to their partner, or not feeling ill. Some had no idea what HIV was.

"I was diagnosed after my husband died and I wanted to know if he died of AIDS so that I can look after myself. I was not happy because I was keeping myself well and even if my husband died of AIDS, I was sure I was not positive because I never moved about with other men."

WOMAN LIVING WITH HIV FROM ZAMBIA (FG2#5)

2. RIGHTS VIOLATIONS EXPERIENCED AROUND HIV DIAGNOSIS

Women living with HIV in Cameroon and Nigeria cited instances of rights violations, including mandatory testing and lack of confidentiality regarding their test results.

Young women in Nigeria experienced many instances of breached confidentiality, as their HIV test results were disclosed to family members and church leaders without their consent and often even before they were aware of their positive status.

"I felt terrible, as if the world was to collapse on my head. I was asking myself ‘how did I get it?’ because my husband was not promiscuous."

WOMAN LIVING WITH HIV FROM NIGERIA (FG4#9)

6. Throughout the report ‘women living with HIV’ refers to the women living with HIV that were interviewed as key informants or within the context of the focus groups detailed in the methodology.
suicide because in school I was stigmatized, in the community I was stigmatized, and even in church. I ran away from home.

WOMAN LIVING WITH HIV FROM NIGERIA (FG1#7)

There also appears to be a lack of awareness about HIV in Nigeria, as many women said that they did not know what HIV was when they were diagnosed.

3. PERSPECTIVES OF WOMEN LIVING WITH HIV ON PREGNANCY AFTER HIV DIAGNOSIS

In Cameroon, many women living with HIV had become pregnant following their HIV diagnosis, having benefitted from the counseling of service providers at hospitals and network support groups, and having received information about safe conception and pregnancy through the radio, personal research, and information from family members.

In Zambia, particularly participants from Mazabuka Rural Health Centre, the majority of women living with HIV chose not to become pregnant following their diagnosis for the following reasons: (1) they were worried about transmitting HIV to a child, (2) they were concerned about their personal health, or (3) they had lost a partner or child to AIDS. Some women had started family planning and said they felt upset that they ‘could not have as many children as they would have liked’, in case they became ill and were not able to care for them. Women living with HIV who became pregnant after their diagnosis worried about their personal health and their child’s health. Some reported that they faced stigma from family members and the community about their pregnancy.

In Nigeria, many women living with HIV experienced discrimination by service providers and felt scared about becoming pregnant. This fear led many to avoid going to hospitals to access care.

Each day I kept on waiting for death. I kept on thinking I will die before I give birth…or the two of us will in the labor room. I didn’t make any preparations, like buying baby clothing, because I was sure I would die on or before the ninth month. I was thinking ‘how can someone with HIV have a child?’ Because of the fear and high stigma, I didn’t register for antenatal care in any hospital. I went to a traditional birth attendant [and] I also didn’t tell her I was positive because of the stigma and I was afraid she would reject me.

WOMAN LIVING WITH HIV FROM NIGERIA (FG2#2)
However, an equal number of Nigerian women felt positively about becoming pregnant and felt relieved that they could prevent HIV transmission if they followed the instructions of their doctors.

4. PERSPECTIVES OF SERVICE PROVIDERS ON PREGNANCY FOLLOWING HIV DIAGNOSIS

Most service providers who were interviewed, particularly Zambian providers, expressed positive views towards women living with HIV to have children, because they are ‘human beings’. In each of the three countries, a few providers stated explicitly that it was the ‘right’ of a woman living with HIV to have a child.

“These days women living with HIV can have children just like anyone else... It does not affect my feelings in any way. I have a duty to provide the service for those who need help regardless of their HIV status.”

SERVICE PROVIDER FROM ZAMBIA (FG#10)

However, some service providers mentioned that it was important that women living with HIV were healthy, adhering to ARVs, and had a ‘high’ CD4 count before becoming pregnant. Others mentioned that women living with HIV should have children only if they can afford it and are able attend a clinic in order to deliver. One Nigerian provider felt that women living with HIV should only have children if they did not have children prior to their diagnosis.

Most service providers said that their beliefs about whether women living with HIV should have children have changed because of ARV access and knowledge about the preventive benefits. Some providers, however, expressed that their beliefs have not changed, because they have always felt that women living with HIV have the right to have children.

5. PERSPECTIVES OF SERVICE PROVIDERS ON WOMEN LIVING WITH HIV RAISING CHILDREN

Although the majority of service providers in all three countries felt positively toward women living with HIV having children, most providers said that it is more difficult for women living with HIV to care for children, and cited the following reasons: (1) stigma, (2) challenges of taking ARVs, (3) opportunistic infections, (4) challenges of breastfeeding exclusively, (5) having frequent hospital appointments, and (6) the added financial burden.

“Even those who are negative find it difficult because of poverty, but for positive women it is even more difficult because they have to deal with a lot of other

7. It is unclear whether or not this is a prevalent viewpoint. Service providers interviewed for this project were not living with HIV, but were recommended by networks of women living with HIV, which may have resulted in a biased sample.
things [like] stigma, coping with medication, [and] some have other infections like herpes. All these make it difficult for them to take care of children.

SERVICE PROVIDER FROM ZAMBIA (FG#5)

A few service providers in Cameroon said that having HIV does not affect one’s ability to care for a child, especially because of treatment scale-up.

6. PERSPECTIVES OF SERVICE PROVIDERS ON RISK OF VERTICAL TRANSMISSION OF HIV

Service providers in all three countries expressed that it was unlikely for a woman living with HIV to pass HIV to her child during pregnancy, delivery or breastfeeding as long as: (1) she was aware of her status, (2) she was adhering to ARVs, (3) her CD4 count was high and viral load was suppressed, and (4) she delivered at a clinic.

In Zambia, service providers emphasized the importance of breastfeeding in Zambian society, and some stated that breastfeeding increased the risk of HIV transmission. One provider in Nigeria estimated that the risk of transmission was “70%”.

7. CONSULTING SERVICE PROVIDERS BEFORE PREGNANCY

In Zambia and Cameroon, most women living with HIV consulted a service provider prior to pregnancy in order to check their own health and make sure they could deliver a healthy child. Those who did not consult providers, because they feared stigma and discrimination in the clinics, often received information from their networks of people/women living with HIV. In Cameroon, women living with HIV stated that they are more likely to see a service provider before getting pregnant now than they were in the past.

In Nigeria, the majority of women living with HIV did not consult a service provider before getting pregnant. Some became pregnant unintentionally and others said they were already well-informed about the importance of waiting until their viral load was low and CD4 count high, and therefore did not feel the need to consult a provider. Some women consulted a provider because they wanted advice about how to prevent transmission to the unborn child and to their partner.

8. ADVICE FOR OTHER WOMEN LIVING WITH HIV CONSIDERING PREGNANCY

All the women living with HIV that were interviewed advised that it was important to be well-informed about how to prevent transmission of HIV before getting pregnant. They advised other women living with HIV to seek medical advice in order to: (1) check on their own health, and/or (2) seek [Responding to question about likelihood of vertical transmission]: I think it is very likely, especially in our society where we believe in breastfeeding.

SERVICE PROVIDER FROM ZAMBIA (KI#2)

8. Without any intervention, the risk of vertical transmission of HIV is between 15–45% (15–30% during pregnancy and delivery and an additional 10–20% postpartum via breastfeeding). (http://www.who.int/hiv/amds/who_elimination_vertical_transmission_n_shaffer.pdf)
information on how to prevent vertical transmission of HIV. Some women suggested talking to friends, and emphasized that they would encourage other women who were worried about having children. In Cameroon, women emphasized the importance of safe infant feeding, and having the support of a partner and a network.

In Nigeria, study participants discussed the importance of women having children and of breastfeeding in their society. For that reason, they advised other women living with HIV to have personal autonomy over their decisions, fight self-stigma and community stigma, and to be prepared (mentally, financially and otherwise) to have a child.

9. CONCLUSIONS

Women in all three countries expressed some misconceptions about HIV and about who is at risk for HIV when they were first diagnosed. This impacts whether and when they take an HIV test and their reaction and behaviors upon diagnosis. Lack of confidentiality about HIV test results is a significant problem, particularly for young women in Cameroon and Nigeria. In Cameroon, most women living with HIV had reported receiving positive messages about pregnancy following diagnosis, but women living with HIV in Zambia and Nigeria had received mixed messages. Many felt that they should not have children or feared accessing maternity care in hospital settings because of their HIV status. This was especially true in Nigeria, where very few women living with HIV consulted providers before becoming pregnant.

Most service providers interviewed felt positively about women living with HIV having children, especially given scientific progress and the success of PVT programs. Despite their positive views on pregnancy, however, providers in all three countries felt that it was more difficult for women living with HIV to take care of children.

Addressing stigma around HIV and pregnancy is an important first step in fulfilling human rights, and also contributes to creating demand for health services. In all three countries, women living with HIV expressed that networks were a consistent source of reliable and safe information.

The testimony of women living with HIV and service providers in Cameroon, Nigeria and Zambia reinforces the importance of:

- Voluntary counseling and testing, with an emphasis on non-coercion and psychosocial support at the time of diagnosis (reassurance that it HIV diagnosis is not a death sentence)
Require stronger patient confidentiality and privacy procedures that include consequences for violations of confidentiality for clinical service providers.

Community Information, Education, and Communication (IEC) initiatives that address stigma, the role of ARVs, how to reduce vertical transmission, the importance of consulting with a healthcare provider who supports client rights when planning to have children and the right and ability of HIV positive women to bear children

Training for service providers on up to date science related to PVT, and values clarification to support clients’ rights

HIV prevention approaches that help women to more accurately identify their level of risk (e.g. within marriage), and safe conception in sero-discordant couples

Measures to support mothers living with HIV to care for their children

Funding to strengthen and maintain support groups and networks of women living with HIV, including paid peer educators
SECTION II: EXPERIENCES ACCESSING PVT AND FAMILY PLANNING SERVICES

1. PERCEPTIONS OF WOMEN LIVING WITH HIV REGARDING HEALTHCARE PROVIDER ATTITUDES

Women living with HIV in all three countries expressed that they face stigma from service providers in health centers, particularly in the settings surveyed in Cameroon and Nigeria.

The majority of the negative experiences reported occurred while accessing family planning services, especially by younger, unmarried women living with HIV in this context.

Negative care provider attitudes manifest in many forms, including comments, neglect, failure to provide complete and objective information, and other perceived discriminatory practices during service provision.

In Zambia, women living with HIV said that service providers made remarks that indirectly disclosed their HIV status to others. Women living with HIV in Nigeria and Cameroon had been shouted at and felt that service providers talked about them to other providers behind their backs. They said that service providers often prioritized other clients before women living with HIV or neglected caring for them completely.

In Nigeria, women living with HIV felt discriminated against when services were provided to them separately from the general client population. For example, women living with HIV had experienced instances where they were physically segregated, asked to come on specific days, or only allowed to use certain facilities (e.g., toilets).

At the [antenatal clinic], I don’t like the fact that they have a separate day for seeing positive mothers. To me, any pregnant woman should be able to come to the antenatal clinic or consult with the doctors any day and receive all the services she needs. I feel other people knew that all those asked to come on a different day are women living with HIV. I feel this creates stigma.

WOMAN LIVING WITH HIV FROM NIGERIA (KI#9)

At the ward, people living with HIV are kept at the extreme end of the room. They don’t tell [the] other patients why, but we know we are kept there because of our status.

WOMAN LIVING WITH HIV FROM NIGERIA (KI#2)

When I chose the [hormonal contraceptive] injection they said you are trying to run away from using condoms so that you can infect others.

WOMAN LIVING WITH HIV FROM ZAMBIA (KI#12)

During contractions, the staff neglected me to take care of the negative patients first.

WOMAN LIVING WITH HIV FROM CAMEROON (FG2#16)

I received a girl to whom the nurse asked to go and wait for death in the neighborhood, immediately she tried to commit suicide while at the hospital.

WOMAN LIVING WITH HIV FROM CAMEROON (FG4#10)
Women living with HIV in Nigeria and Cameroon also reported that certain practices during their healthcare visits made them feel stigmatized. For example, women felt that they were being discriminated against when service providers used extra gloves or bleach when caring for them.10

They told stories of instances when service providers would not come close to them, would ask them to cover their mouth while talking, and would ask them not to touch things. Service provider actions sometimes led women to feel self-stigma.

They won’t even let you use their pen. I also refuse my children touching or coming close to me at home, I burnt all the things we shared, remove my cup, plate and spoons from where they kept [theirs], burnt my clothes so they won’t have to touch them when I die, and cut my hair. I told my children not to come close to me, because death was near. I did all this because the nurses were not allowing [me to] touch or move close to them, [so I thought I] would infect my children if they touch my things. “

WOMAN LIVING WITH HIV FROM NIGERIA (FG3#3)

In Cameroon and Zambia, women living with HIV mentioned that some service providers had positive attitudes and were friendly and encouraging. They expressed that levels of stigma and the severity of clinic segregation had improved significantly over the years. In Zambia, many women living with HIV felt that service providers treated them more favorably once they disclosed their status.

In Cameroon and Nigeria, women said that they experienced less discrimination in private or faith-based clinics than in public settings, suggesting that where health services are poorly funded, discrimination against women living with HIV is more likely.

Stigma is higher in public clinics than in private or faith-based clinics. HIV-positive women go [to] public hospitals only to get their ARVs now and for their follow-up and other illnesses, they go to private clinics.

Woman living with HIV from Cameroon (FG1#5)

In all three countries, women living with HIV expressed that stigma and discrimination by families, communities11, or other women living with HIV continues to exist and can be more painful to them than experiences in the healthcare settings12.

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10. ‘Universal Precautions’ refers to the practice, in medicine, of avoiding contact with patients’ bodily fluids, by wearing of nonporous articles such as medical gloves, goggles, and face shields. The differential practice of using extra gloves based on HIV status is not a universal precaution, but was cited as common practice in all three countries studied.

The use of gloves and bleach by maternity care providers (MCPs) in labor and delivery is common in high HIV prevalence settings in sub-Saharan Africa. Studies have shown that HIV is inactivated rapidly after being exposed to bleach. According to the Center for Disease Control’s Recommendations for Prevention of HIV Transmission in Health-Care Settings, “gloves should be worn for touching blood and body fluids, mucous membranes, or non-intact skin of all patients, for handling items or surfaces soiled with blood or body fluids, and for performing venipuncture and other vascular access procedures. Gloves should be changed after contact with each patient.” HIV training programs for MCPs focus on universal precautions, which has led to significant improvement in the availability of gloves, bleach, delivery sets, autoclaves, and other infection control supplies and equipment.


11. Women living with HIV who participated in the study often mentioned experiencing stigma by other women living with HIV in healthcare settings. Zambia participants said that other women living with HIV talked about them as if they were not positive, in order to dissociate themselves and make it seem as if they are not HIV positive. Cameroonian participants clarified that it was a combination of self-discrimination and discrimination on account of employment status, which varied among members of networks.

2. RIGHTS VIOLATIONS EXPERIENCED BY WOMEN LIVING WITH HIV IN THE CONTEXT OF FAMILY PLANNING

Women living with HIV in all three countries documented instances when they felt pressured by providers to undergo abortion, sterilization, or deliver via cesarean section.\(^{13}\)

Interestingly, although women told stories of times that they had faced egregious discrimination and violations of their rights (e.g. to informed consent), when asked specifically whether they believed that their rights had been violated in the context of HIV care, not one woman said yes. However, they did instinctively recognize that they had been treated wrongly. It is clear that the “rights” language does not yet resonate strongly with women in these settings. Many women expressed that they did not know what their rights were.

3. SERVICE PROVIDER PERCEPTIONS OF RIGHTS VIOLATIONS OCCURRING IN HEALTHCARE SETTINGS & AVAILABLE ACCOUNTABILITY MECHANISMS

When service providers were asked whether they have heard of rights violations occurring in the context of HIV care, there was a general denial about these types of incidents happening locally. The vast majority said ‘no’ or that they had ‘no idea.’ Providers in Zambia mentioned that they had heard of rights violations, such as HIV testing without informed consent and the refusal to provide services because of HIV status, but that these happened in other clinics. In Cameroon, providers said that rights violations by family and community members were more pervasive.

Some providers reiterated the concerns of women living with HIV that many women living with HIV do not know what their rights are.

Zambian clinics appear to have far greater accountability mechanisms available for clients than in Nigeria and Cameroon. In Zambia, many service providers said that clients could give feedback on their experiences through a variety of mechanisms, including: (1) submitting a comment in the suggestion boxes, (2) talking to the “sister in charge”, (3) following the complaints procedure, or (4) writing to the Medical District Officer.

In Nigeria and Cameroon, there was general denial amongst service providers about why a client would want to complain about services, and the providers’ only suggestion was for women living with HIV to confront staff directly. Many Nigerian and Cameroonian providers felt that accountability mechanisms were unnecessary or said that if a woman living with HIV felt stigmatized, it was due to self-stigma, rather than a problem with service provision.

4. CHALLENGES IDENTIFIED BY WOMEN LIVING WITH HIV AND SERVICE PROVIDERS

Poor relationships between providers and their clients were cited as a challenge by both women living with HIV and service providers. In Zambia, women living with HIV expressed discomfort being candid with nurses because they often were members of their communities who they would see fetching water or at church. Service providers in Nigeria and Cameroon, particularly younger nurses, stated that they felt that women living with HIV often mistrusted their capabilities and therefore hid their status from them.

Condom stock-outs, particularly of female condoms, were cited by both women living with HIV and service providers as a problem in all three countries. Although condoms were not necessarily a preferred method, women said that they often travel very far to access condoms, and are dissuaded from coming back when none are available. Providers echoed that stock-out of supplies, particularly of family planning methods, is a challenge.

I think there is a problem of getting condoms, especially women’s condoms. They are always not available.
WOMAN LIVING WITH HIV FROM ZAMBIA (FG2#1)

You promise women to come and get condoms and then there is nothing. Then you have to give excuses. It is not good.
SERVICE PROVIDER FROM ZAMBIA (KI#3)

5. OTHER CHALLENGES IDENTIFIED BY SERVICE PROVIDERS

Service providers said they found it very challenging when women living with HIV combined traditional family planning methods (e.g. rings, beads, herbs, etc.) with medical methods.

In Nigeria, providers said that women living with HIV often miss appointments and that there is little demand for family planning services, even if women are counseled. These perceptions and the resulting response may be due to service provider stigma towards women living with HIV.

[If] there was a bill that after having a certain number of children, people are placed or should be on family planning, it would have made people embrace it more. Often women come saying they want family planning [and] we give all the counseling and needed information [and] then ask that they go home and think about it. Most times they don’t come back. As a care provider, I know that she really needs it but they don’t come back and follow up.
SERVICE PROVIDER FROM NIGERIA (KI#4)

14. The service providers did not specify if they were similarly concerned when women not living with HIV used both traditional and medical methods of family planning concurrently.
In Cameroon and Zambia, providers mentioned lack of male involvement, particularly in the context of family planning counseling, demand, and adherence, as a major challenge for women seeking care in general.

6. PRACTICES THAT MAKE WOMEN LIVING WITH HIV FEEL MORE COMFORTABLE IN HEALTH CENTERS

In all three countries women living with HIV said they felt most comfortable when service providers were encouraging about their health, emphasized that HIV is not a death sentence, and noted that treatment will prolong a woman’s life. Women felt good when providers encouraged them that if they continue to adhere to ARVs their children will be healthy upon birth:

In Cameroon, women elaborated that they felt comfortable when staff was well-trained about HIV and willing to learn more. They also appreciated when they received support at the clinic (e.g. emotional, financial, nutrition, etc).

In Cameroon and Zambia, providers mentioned lack of male involvement, particularly in the context of family planning counseling, demand, and adherence, as a major challenge for women seeking care in general.

7. RECOMMENDATIONS BY WOMEN LIVING WITH HIV AND SERVICE PROVIDERS REGARDING FAMILY PLANNING SERVICES

Women living with HIV and service providers proposed recommendations focused on operational aspects of service delivery. In Zambia and Cameroon, women living with HIV expressed the need reduce wait times by having more staff and physical space at the health centers. They said that this would help ensure confidentiality as well. Service providers confirmed this recommendation, stating that clinics were too crowded and that this prevented their clients from speaking freely and openly to them.

In Cameroon, women living with HIV felt that ARVs should be made more accessible and available, suggesting they should be placed in pharmacies. They also mentioned that fees were a major barrier to accessing care in Cameroon. Young women wanted to have a specific time for them to attend the clinic so they did not feel judged by older women when accessing family planning.

Additionally, women living with HIV felt that service providers need more training on SRH and HIV, specifically about the family planning methods that are best suited for women living with HIV. Service providers also felt more training was necessary, particularly about how to insert certain family planning methods (i.e. Implants, IUDs), and interactions between hormone-based contraceptives and ARVs.

For me the biggest challenge is lack of training. We are not properly trained to insert loops and also to tell which family planning methods interfere with ARVs.

SERVICE PROVIDER FROM ZAMBIA (KI#6)

I think they should have separate clinic time for young people like me instead of mixing with older people. Some people I meet at the clinic are my aunties and mothers and sometimes they look at me and say ‘What is she doing here, she is very young.’ I feel ashamed.

WOMAN LIVING WITH HIV FROM ZAMBIA (KI#17)

I think as service providers we need a lot of training in family planning. I want to be trained in drug interference between ARVs and family planning drugs. What I have noticed is that positive women still get pregnant even when they are taking

SERVICE PROVIDER FROM ZAMBIA (KI#4)

I think they should have separate clinic time for young people like me instead of mixing with older people. Some people I meet at the clinic are my aunties and mothers and sometimes they look at me and say ‘What is she doing here, she is very young.’ I feel ashamed.

WOMAN LIVING WITH HIV FROM ZAMBIA (KI#17)

They encouraged me that I will have a baby just like anyone else. I should just keep taking my ARVs. When I was having my baby I was told everything will be fine. It means I can trust them. Even when I bring my baby to the clinic, they take special care and always tell me to make sure the baby is ok. I feel very happy and encouraged.

WOMAN LIVING WITH HIV FROM ZAMBIA (FG2#3)

15. For additional information on preventing unintended pregnancies in women living with HIV, refer to Preventing HIV and Unintended Pregnancies: Strategic Framework 2011–2015, Chapter 6. Available at: http://www.unfpa.org/public/home/publications/pid/10575


their family planning religiously. I think ARVs reduce the efficacy of hormonal tablets. That is the information that we need.

SERVICE PROVIDER FROM ZAMBIA (KI#11)

Women living with HIV also felt it was crucially important to involve people living with HIV as much as possible in the provision of care in order to reduce stigma and discrimination. Interestingly, all clinics in Zambia where women living with HIV were interviewed had a mentor mothers program\(^\text{17}\), and this was the country where women reported the fewest instances of stigma and discrimination.

In all three countries, service providers said that networks and support groups help create more demand, because women living with HIV who were connected to networks came to clinics with a great deal of knowledge and information and are prepared to access family planning services.

8. CONCLUSIONS

Women living with HIV in all three countries expressed that they face stigma from service providers in health centers, including comments, neglect, discriminatory acts, and segregation or isolation from the general client population. Women experienced such discrimination most when accessing family planning services as opposed to other services. However, women living with HIV in Cameroon and Zambia felt that the degree of stigma and clinic segregation has improved over the years, potentially due to initiation of interventions to integrate services and address stigma.

Zambian women living with HIV cited the fewest instances of stigma and discrimination, which may be partly attributable to Zambia being the only country where mentor mothers were present in every clinic site studied and where formal accountability mechanisms most commonly existed. More research is needed to clarify whether there is a causal link between the presence of mentor mothers and a reduction in stigma and discrimination. Although many women living with HIV documented experiences which violate their rights to privacy, confidentiality, bodily integrity, and informed consent, many expressed that they did not know what their rights were.

Service providers had heard of rights violations occurring in other countries, but were generally in denial that issues existed within their own clinics.

Poor relationships between women living with HIV and service providers was cited as a major challenge to accessing family planning services, as were long distances to clinics and stock-outs. Service providers, particularly in Nigeria, stated that the use of traditional family planning methods is still prevalent and creates low demand for family planning services in health centers. In

Have mentor mothers, peer mothers because it feels good when you hear it from someone who has been through it.

WOMAN LIVING WITH HIV FROM ZAMBIA (KI#12)

[When asked whether they faced any particular challenges with clients living with HIV]:

People living with HIV are not posing any challenge to us probably because of training they have had in the groups.

SERVICE PROVIDER FROM NIGERIA (KI#5)

8. CONCLUSIONS

Women living with HIV in all three countries expressed that they face stigma from service providers in health centers, including comments, neglect, discriminatory acts, and segregation or isolation from the general client population. Women experienced such discrimination most when accessing family planning services as opposed to other services. However, women living with HIV in Cameroon and Zambia felt that the degree of stigma and clinic segregation has improved over the years, potentially due to initiation of interventions to integrate services and address stigma.

Zambian women living with HIV cited the fewest instances of stigma and discrimination, which may be partly attributable to Zambia being the only country where mentor mothers were present in every clinic site studied and where formal accountability mechanisms most commonly existed. More research is needed to clarify whether there is a causal link between the presence of mentor mothers and a reduction in stigma and discrimination. Although many women living with HIV documented experiences which violate their rights to privacy, confidentiality, bodily integrity, and informed consent, many expressed that they did not know what their rights were.

Service providers had heard of rights violations occurring in other countries, but were generally in denial that issues existed within their own clinics.

Poor relationships between women living with HIV and service providers was cited as a major challenge to accessing family planning services, as were long distances to clinics and stock-outs. Service providers, particularly in Nigeria, stated that the use of traditional family planning methods is still prevalent and creates low demand for family planning services in health centers. In

\(^\text{17}\). Mentor mothers programs employ women living with HIV to counsel other women living with HIV and their partners and to educate and empower women are experiencing pregnancy for the first time. They include a range of support programs for new mothers living with HIV and have been found to decrease stigma within families, communities, and health centers and to support adherence to HIV treatment.
all three countries, service providers mentioned that networks and support groups are critical to increasing demand for family planning.

The testimony from women living with HIV and their service providers suggests that:

- Discrimination against women living with HIV by service providers is pervasive in many settings but is not acknowledged. Grievance procedures and other programs that will promote acceptance and accountability are needed. Additionally, research is needed to understand why women living with HIV experience discrimination against by service providers.

- Research is needed to understand the reasons why women have fewer experiences of stigma and discrimination in Zambia than in other settings.

- Women living with HIV were not aware of their rights, compromising their capacity to reject rights violations. Training is needed for women living with HIV on how to assert their rights, ideally within the context of support groups and networks.

- Training for service providers on how to provide SRH and HIV care, including information regarding drug interactions between ARVs and family planning medications.

- Review the medical necessity of the practice of wearing extra gloves when caring for women living with HIV and update national guidelines accordingly.
SECTION III. UNDERSTANDING OF FAMILY PLANNING AND OPTIONS AVAILABLE TO WOMEN LIVING WITH HIV

1. KNOWLEDGE OF FAMILY PLANNING AMONG WOMEN LIVING WITH HIV

Family planning refers to the use of interventions, such as contraceptives or treatment of infertility, to attain their desired number of children and determine the spacing of pregnancies. There was a wide variance in women’s knowledge about family planning in the three countries studied. Women living with HIV in Zambia seem to have the best understanding of family planning, including the reasons for using family planning and various methods. They felt that family planning gave them the control to have children when they wanted, which was good for their health and finances. Some women expressed that knowledge about family planning and the ability to exercise it gave them the power to control pressure from their husbands to have children when they personally were not ready.

In Nigeria, far fewer women living with HIV had a positive feeling about family planning. Additionally, younger women living with HIV in Nigeria said that they received negative messages about family planning because service providers communicated that it was for married and older women. Fear of judgment has created low demand for services among younger women.

I have not gone for family planning counseling because I am not married. I say this because I feel [that] because I am young, the healthcare provider will be judgmental. They are judgmental on youth seeking family planning, wondering why we can’t wait for the appropriate time when we are married. I have had such experience before… since then I have not had the courage to seek family planning service anywhere else.

WOMAN LIVING WITH HIV FROM NIGERIA (K1#3)

Women living with HIV in Cameroon had the lowest knowledge of family planning amongst the three countries studied. When asked about family planning, the overwhelming majority of women had no knowledge or confused family planning with prevention of vertical transmission, prevention of HIV transmission to partners, and prevention of sexually transmitted infections (STI). A few women understood family planning to mean birth limitation, and their remarks imply that they understood that they should not have as many children because of their HIV status.
When asked what family planning meant: The general idea is to agree with the partner before falling pregnant, have an undetectable viral load, and high CD4 count. It is necessary to consult the gynecologist two months after the absence of menstruation, to carry on with the treatment. At the time of delivery, as soon as the staff reads the HIV-positive code on the health card, they take all the necessary actions for the baby’s safety.

WOMAN LIVING WITH HIV FROM CAMEROON (FG2#9)

Some Cameroonian women expressed misconceptions about how to properly use certain family planning methods or reported instances where their partners interfered with their family planning method.

Many women living with HIV in all three countries talked about having experienced negative side effects of family planning, including weight gain, frequent menstrual bleeding, pain, and acne.

They also expressed misconceptions about the impact of family planning on fertility and cervical cancer.

2. MESSAGES ABOUT FAMILY PLANNING: DISCORDANT PERSPECTIVES

Service providers affirmed that they feel it is important for women living with HIV to access family planning because of their HIV status, but also said that family planning is for all women because it is about having children at the right time and learning not just how to prevent pregnancy but also how to conceive.

Family planning is making your family the way you want it to be, [having] the number of children you want to have and spacing them. [Also] talking to people about how to get pregnant - not just how to space them or the number they want to have - but also on how to get pregnant.

SERVICE PROVIDER FROM NIGERIA (KI#3)

In all three countries, women living with HIV were told that family planning was especially important for women living with HIV because birth spacing allows for a stronger immune system. Some women said this made them “feel bad”, while others “accepted that this is the way things are.”

I did not feel pleased because although these health practitioners were doing their work by informing us, they have no right to decide whether I need to have children or not. I alone have the right to decide the number of children I wish for.

WOMAN LIVING WITH HIV FROM CAMEROON (KI#1)

It’s a way of preventing pregnancy, but not good for some who has never had a child. That is, if a woman starts family planning, it may be difficult for her to get pregnant [in the future].

WOMAN LIVING WITH HIV FROM NIGERIA (KI#9)

In the community, they say family planning brings cervical cancer.

WOMAN LIVING WITH HIV FROM ZAMBIA (KI#11)

I am told that as a positive mother, I am supposed to rest before giving birth to another.

WOMAN LIVING WITH HIV FROM NIGERIA (FG1#5)

I did not feel pleased because although these health practitioners were doing their work by informing us, they have no right to decide whether I need to have children or not. I alone have the right to decide the number of children I wish for.

WOMAN LIVING WITH HIV FROM CAMEROON (KI#1)

Condoms give side effects like pains and pimples.

WOMAN LIVING WITH HIV FROM CAMEROON (FG4#7)
3. SETTING OF FAMILY PLANNING COUNSELING

The majority of women living with HIV in Zambia and Nigeria had received information about family planning at a health center during or following a pregnancy, in the context of antenatal or post-natal care. Others had received information about family planning from other members of their community or on the radio. In Cameroon, the majority of women living with HIV interviewed had received information on family planning from their networks/associations of women living with HIV or from family members.

4. VARIETY OF FAMILY PLANNING OPTIONS OFFERED TO WOMEN LIVING WITH HIV

Women living with HIV in Nigeria who access family planning in healthcare centers appear to be receiving counseling on various family planning methods, which is important in making an informed choice. Although responses varied, many Nigerian women who were interviewed had been offered injectable and pill-based hormonal contraceptives, intra-uterine devices and condoms. Many had also been counseled about rhythm and withdrawal methods. Service providers in Nigeria confirmed that women living with HIV are offered a variety of methods including injectable hormonal contraceptives, oral pill contraceptives, intra-uterine devices and condoms. Some service providers also mentioned implants, traditional methods (bead and circle), and female and male sterilization.

When asked whether every client is offered the same family planning options, most Nigerian service providers said no, stating that their decision about what to offer a client is based on the medical eligibility criteria and availability.

In Zambia, although service providers highlighted a number of options available at clinics, women living with HIV said that the “choice is not much”. Most women living with HIV had only been offered condoms and injectable hormonal contraceptives. Only a few women living with HIV in Zambia had received information about the full range of family planning methods, how to choose a method, and how to use them properly. Service providers in Zambia confirmed these findings, as the majority said that they do not offer women living with HIV all the family planning options. Providers in Zambia prefer injectable contraceptives for women living with HIV.

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In Cameroon, a number of women living with HIV had only heard of condoms as a family planning method. Fear of rejection by partners was cited as the most common reason for not using condoms. Although some service providers in Cameroon said they offered many family planning options to women living with HIV, other providers said that they only recommend condoms.

Generally, it is the condom since we are dealing with women living with HIV. I advocate the condom which is the means for STI prevention and protection.

SERVICE PROVIDER FROM CAMEROON (KI#5)

**Figure 1.** Family planning use among women living with HIV (survey completed by women living with HIV)

![Graph showing family planning methods](image)

**5. FAMILY PLANNING METHOD USE AMONG WOMEN LIVING WITH HIV IN NIGERIA**

Women living with HIV interviewed in Nigeria were using the widest range of family planning methods of the three countries. It appears that more family planning options were available at clinics and were offered by service providers during family planning counseling in Nigeria, as compared to Zambia and Cameroon. Thirty-three percent of women living with HIV interviewed were using condoms alone, 21% were using injectable hormonal contraceptives, and 6% were using pill-based hormonal contraceptives. No women surveyed in Cameroon and only 2% in Nigeria were using multiple method (i.e. injectable and condom), compared to 33% in Zambia. Over one quarter of the women living with HIV surveyed in Nigeria were not currently using a family planning method. This was a far greater number of women not using family planning than in Zambia and Cameroon.  

19. These were women surveyed generally and did not express an unmet family planning need. This statistic indicates contraception prevalence.
Many women stated that they had tried a contraceptive method but had stopped for a number of reasons, including (1) side effects, (2) partner’s opinion, and (3) failure of the method. Young women stated that condoms were the only feasible and reliable method of family planning because they did not have to attend healthcare centers to access them.

The only family planning method I know of is the condom. It’s difficult to access contraceptives and other family planning services for young persons like myself. We don’t have that access to go to the health facility and say ‘I want contraceptives.’ It is best for me to go to the nearest pharmacy to get a condom, [and] even the condom is not that open to a young girl. First, they will look at you and say, ‘What you need a condom for? Are you a man?’

WOMAN LIVING WITH HIV FROM NIGERIA (FG2#7)

Many women living with HIV in Nigeria also cited traditional family planning methods, such as tribal marks, rings, beads, herbs, or egg shells as preferred methods. The majority of women who did not learn about family planning in health centers were using traditional methods.

6. FAMILY PLANNING METHOD USE AMONG WOMEN LIVING WITH HIV IN ZAMBIA

The majority of women living with HIV in Zambia were using an injectable hormonal contraceptive, some with and some without condoms. Many women had been told by service providers that injectables were the best option for women living with HIV, despite the fact that they did not provide dual method protection against unwanted pregnancy and STIs. Service providers in Zambia confirmed this belief, stating that other methods could interact with ARVs unfavorably. Other women living with HIV in Zambia chose injectables because they felt it was the least complicated method, mainly because it did not require them to remember to take a pill daily. Pill burden was cited as another reason to use injectables, as the majority of women living with HIV interviewed were already taking ARVs daily.

Seventeen percent of women living with HIV interviewed in Zambia were using a condom alone, because they could not manage the pill well due to a variety of reasons including pill burden and side effects, feared needles, or wanted to prevent STIs. Very few women living with HIV mentioned prevention of HIV transmission as a reason to use condoms.

7. FAMILY PLANNING METHOD USE AMONG WOMEN LIVING WITH HIV IN CAMEROON

In Cameroon, 85% of women living with HIV interviewed were using condoms to prevent pregnancy. Most women living with HIV used condoms...
because it was the only option available at the clinic. Others felt that condoms were more accessible, less complicated, and had the fewest side effects.

Five percent of women were not using family planning at all and the rest of the study participants reported using pill-based hormonal contraceptives, the rhythm method, or were abstinent.20 Some women had started injectable hormonal contraceptives but had stopped because of the side effects.

8. CONCLUSIONS

Women living with HIV in Zambia felt more positively about family planning than women did in Nigeria and Cameroon. Young women in Nigeria had received messages that family planning was only for married and older women who already had children. In Cameroon, women had the lowest knowledge of family planning and often confused it with prevention of HIV transmission.

Women in all three countries feared the side effects of family planning, and many had misconceptions about the impact of family planning on fertility and cervical cancer. Many women living with HIV said they feared attending clinics to ask for family planning because of their HIV status, and most had only received information at healthcare centers following delivery, from networks and support groups of people living with HIV, or from family members. It is important that family planning information is disseminated more widely to women at all health centers prior to pregnancy, as it is relevant to women of all reproductive age, not just those who are married or who have already had children.

Among the participants who had received family planning counseling, Nigerian women living with HIV had been told about the greatest number of options. Although stock-outs were cited as a problem in all three countries, health care providers in Nigeria also mentioned the importance of medical eligibility criteria in determining what family planning options to recommend to women living with HIV. The data shows that Nigerian women in this study had also chosen the widest range of family planning methods, although not necessarily because the widest range was available. However, Nigeria also had the largest percentage of women who were not using family planning at all (over 30%).21 It is clear that barriers exist to accessing family planning in Nigeria, but that women living with HIV who did access family planning felt that the quality of counseling was high and the availability of many methods allowed them to make informed choices.
Providers in Zambia and Cameroon did not mention the medical eligibility criteria as a factor in determining what family planning method is best for individual clients. Cameroonian providers preferred offering condoms for women living with HIV. Zambian providers said that they prefer injectable hormonal contraceptives, which correlated with the survey data where two-thirds of women in Zambia reported using injectable hormonal contraceptives. Over 85% of women in Nigeria reported using condoms alone for family planning. Although the majority of women in Zambia and Cameroon had received counselling on family planning, and many had decided to utilize it, the quality of information regarding family planning options provided to women living with HIV was poor. Many women living with HIV in Cameroon had only heard of condoms as a method of contraception. Service providers cited stock-outs as the main reason why they could not counsel women about a full range of family planning methods.

The testimony from women living with HIV and their service providers suggests that:

- Youth-friendly family planning services are needed
- Better quality counseling regarding the full range of family planning option should be provided to all women, including women living with HIV
- Service providers need to clarify and understand that family planning is not just for married women and women who had already had a child;
- In some settings, policy changes are needed to allow young women and girls to access family planning services without parental consent
- Community IEC programs specifically targeting young women and support groups are needed to clarify the interaction between ARVs, HIV risk and hormonal contraception and that give the facts about family planning methods and their side effects22
- Stock-outs of family planning supplies and commodities must be prevented to ensure the full range of family methods are available to all women
- A larger method mix of family planning methods are available to all women

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SECTION IV. PERSPECTIVES OF WOMEN LIVING WITH HIV AND SERVICE PROVIDERS ON INTEGRATION OF SRH AND HIV SERVICES

1. AVAILABILITY AND ACCESSIBILITY OF SRH SERVICES AT HIV CARE SITES IN ZAMBIA

Just over half of the Zambian women living with HIV surveyed (55.6%, n=18) in 3 locations (Nanga Rural health centre in Mazabuka, Nangongwe Clinic in Kafue, and Treatment Advocacy and Literacy Campaign offices in Lusaka) reported accessing SRH and HIV services in the same health site, which was the highest of the three countries studied. However, women living with HIV reported being aware of only a few SRH services available at each HIV care site (only about two services per site), including free condoms, other family planning methods, STI screening, pregnancy testing, and cervical cancer screening at select sites.

Meanwhile, service providers reported that over four SRH services were being offered at HIV care sites per visit, including free condoms, other family planning methods, STI screening, pregnancy testing and cervical cancer screening. Of the eleven providers surveyed, 90% were offering pregnancy testing at HIV sites. According to service providers, cervical cancer screening was also available at 73% of sites.

2. AVAILABILITY AND ACCESSIBILITY OF SRH SERVICES AT HIV CARE SITES IN NIGERIA

Just under half of the Nigerian women surveyed (47.9%, n=48) in 12 locations reported receiving family planning and HIV care in the same health site. They reported being offered more SRH services at HIV care sites than in the other three countries. The most common services were free condoms, followed by other family planning methods, cervical cancer screening and STI screening, and pregnancy testing. Given the small sample in this study, however, this finding might not be generalized to the entire country.

Again, women living with HIV and service providers had different understandings about what SRH services are available at HIV clinics. In Nigeria, the eight service providers surveyed said that at least four key SRH services were available at HIV clinics, with free condoms and other...
family planning methods being available at all sites. Pregnancy testing and STI screening were said to be offered at most sites, with cervical cancer screening and post-abortion care being less common.

3. AVAILABILITY AND ACCESSIBILITY OF SEXUAL AND REPRODUCTIVE HEALTH SERVICES AT HIV CARE SITES IN CAMEROON

About a third of the Cameroonian women surveyed (29.2%, n=48) reported receiving family planning and HIV care in the same health site, the lowest of the three countries studied. STI screening was the most common service offered according to women living with HIV (at over a third of sites), followed by pregnancy testing (at about one quarter of sites), condom provision, other family planning methods, and cervical cancer screening. However, according to service providers, an average of four SRH services was available at HIV care sites. Other family planning methods (besides free condoms), pregnancy testing, and STI screening were offered at all of the sites surveyed according to providers, while condoms and cervical cancer screening were often available.

4. PERSPECTIVES ON INTEGRATION

Women living with HIV and service providers expressed mixed views on whether integration was a positive or negative approach.

In Nigeria, women living with HIV reported a high level of integration of services (most SRH services offered at HIV care sites of the three countries studied) and felt mostly positively about it. They stated that integration increases awareness about family planning, reduces stigma, makes services more accessible, particularly in rural areas, and is necessary to reduce rates of HIV transmission to children. Providers also felt positively about integration, mostly because of accessibility of services. Women emphasized, however, that if services are integrated, it is important to ensure that family planning continues to be an optional service for women living with HIV and that HIV testing also remains optional for women who are seeking family planning.

As discussed above, very few women living with HIV in Cameroon reported accessing the few SRH services available at HIV sites. Most study participants felt that integration would be “ideal” because it would save time and reduce stigma. Providers expressed that integration would lead to better follow up with patients who are currently lost between referrals.

[Integration] will go a long way to help women access HIV care or family planning. The woman can access and no one [will] know what she has gone for. It...will go a long way to save mothers who die from unsafe abortion or having many children that they cannot care for.

WOMAN LIVING WITH HIV FROM NIGERIA (KI#3)

I think it will be better if HIV and family planning are integrated. If it’s separated, then it will cause stigma. So it’s better together so as the woman comes for ART, they will also access family planning.

WOMAN LIVING WITH HIV FROM CAMEROON (FG2#2)

[Integration] is a good thing. When you refer them to another service they can disappear, get out of the circuit, and you won’t even know.

SERVICE PROVIDER FROM CAMEROON (KI#4)

SERVICE PROVIDER FROM NIGERIA (KI#2)

It’s a good one because you bring the care, making it accessible to all instead of being in one clinic today and going to another tomorrow.

WOMAN LIVING WITH HIV FROM CAMEROON (KI#4)

It’s good, but they should not use that avenue to make it compulsory for [the] client. It should be optional. The woman coming for family planning [should not] be force[d] to take [an] HIV test. When the woman knows [she will] benefit, she will willingly opt for the service.

WOMAN LIVING WITH HIV FROM NIGERIA (KI#3)
Compared to those interviewed and surveyed in Nigeria and Cameroon and despite accessing many SRH services at HIV sites, the majority of women living with HIV surveyed in Zambia felt that integration actually increased stigma because women living with HIV were mixed with general clients and confidentiality was not always ensured.

Although stigma can also be associated with stand-alone services, a Zambian healthcare provider reported a similar sentiment:

*I think [integration] creates stigma because some of these people know who is positive and who is not and seeing them at the same clinic getting family planning creates a lot of talking from those who are negative.... Those who are negative sometimes say ‘look at that woman, she is getting family planning even when she knows she is positive.’ This then means the positive woman would either stop coming to the clinic or they would go somewhere else. These are the women we lose in the register.*

SERVICE PROVIDER FROM ZAMBIA (KI#5)

Nonetheless, other Zambian women living with HIV felt that integration was a good thing because of the convenience of having all services in one place and consistency of seeing the same providers. Service providers in Zambia echoed these perspectives, saying integration was important for accessibility and for building relationships with their clients. Furthermore, strategies are available for preventing stigma in integrated service settings.25

5. CONCLUSIONS

Of the three countries studied, most Zambian women living with HIV reported accessing SRH services at their HIV care sites. Nigerian women reported being offered the greatest number of SRH services at each HIV site. Women living with HIV in Cameroon reported having the fewest SRH services available to them at HIV sites and were least likely to access those services.

Women living with HIV and service providers in Zambia were critical of integrated services, citing stigma and lack of confidentiality as challenges. Women in Nigeria spoke positively about the benefits of integration (i.e. accessibility and awareness), but emphasized the need for family planning services to remain optional. Most women living with HIV in Cameroon reported accessing SRH and HIV services separately, but expressed the need for integrated services provided in a manner that will reduce stigma.

There are many benefits of integration, including some that were mentioned by clients and providers (e.g. increased awareness of SRH and HIV, reduction in stigma, accessibility). However, as the testimony of women in Zambia suggests, integration also requires specific measures to prevent potential challenges (e.g. breaches of confidentiality).

It is not good because there is no privacy and sometimes you disclose without knowing. Those who are negative and come to family planning talk a lot.

WOMAN LIVING WITH HIV FROM ZAMBIA (FG2#2)

It also creates good relationship because you are seeing the same nurses or doctors all the time.

SERVICE PROVIDER FROM ZAMBIA (KI#4)

Women living with HIV have a basic human right to determine freely and responsibly the number and the spacing of their children. This qualitative study aimed to understand: (1) the family planning experiences of women living with HIV in the context of PVT programs (including contraception and safe conception); (2) the preferences of women living with HIV in relation to family planning, especially young women; and (3) how care providers perceive and engage with women living with HIV, especially young women, in relation to family planning. It revealed nuanced differences between the perceptions and experiences of women living with HIV and service providers in Cameroon, Nigeria, and Zambia.

The family planning experiences of women living with HIV in Cameroon, Nigeria, and Zambia were mixed. Some women living with HIV (from Zambia and Nigeria) were able to conveniently access a variety of family planning services at their HIV care sites, while others (from Cameroon) were not. Women in Nigeria spoke positively about the benefits of integration (i.e. accessibility and awareness of other services), but emphasized the need for family planning services to remain optional. Most women living with HIV in Cameroon reported accessing SRH and HIV services separately, but expressed the need for integrated services provided in a manner that will reduce stigma. Women living with HIV and service providers in Zambia were critical of integrated services, citing stigma and lack of confidentiality as challenges. There are many benefits of integration, including some that were mentioned by clients and providers. However, integration also requires specific measures to prevent potential challenges (e.g. breaches of confidentiality).

Many women felt positively about family planning. However, others feared the side effects of family planning, or had misconceptions about the impact of family planning on fertility and cervical cancer. Additionally, messages suggesting that only married or older women who already had children need family planning have deterred and prevented young women from accessing contraception and conception care. It is important that accurate family planning information is disseminated more widely to women at all health centers and through support networks prior to pregnancy, as it is relevant to women of all reproductive age, not just those who are married or who have already had children.

Although service providers in all three countries said they supported the right of women living with HIV to have children, women living with HIV still reported discriminatory experiences, particularly when seeking family planning services. This may result from certain perceptions about women living with HIV (e.g. ability to support children) that may color the way service providers communicate and provide services to women living with HIV, among other reasons. Addressing stigma and other misconceptions around HIV and pregnancy held by clients and service providers is an important first step towards fulfilling the human rights of women living with HIV. It may also contribute to creating demand for health services. Additionally, since networks of women living with HIV are seen as a consistent source of reliable and safe information, they should be funded to provide such support to women living with HIV as well as service providers.

The findings of this study highlight critical areas that must be addressed in any and all efforts to improve health outcomes as they relate to Prong 2 of the Global Plan, as well as demonstrate the potential pitfalls of failing to provide appropriate and adequate care. Additionally, this study points to the need for further research to compare these countries in terms of success rates and positive outcomes, or to adjudicate the quality of services in any particular setting, which were beyond the scope of this study.
ANNEX A: KEY INFORMANT INTERVIEW QUESTIONS

KEY INFORMANT INTERVIEW GUIDE: WOMEN LIVING WITH HIV

QUALITY OF FAMILY PLANNING SERVICES IN THE CONTEXT OF PREVENTION OF VERTICAL TRANSMISSION

1. When and where were you diagnosed with HIV?
   a. Were you diagnosed when you came for a prenatal/antenatal care visit?
   b. What did this mean to you? How did it make you feel?

2. Have you been pregnant since being diagnosed with HIV?
   a. What did this mean to you? How did this make you feel?

3. Have you received any information about family planning?
   a. Is so, what information did you receive?
   b. Did you receive this information in the context of PVT/eMTCT/PMTCT services?
   c. Did you receive this information in the same place where you access services related to HIV care?
   d. From whom did you receive this information?
   e. What did it mean to you? How did it make you feel?

4. What does family planning mean to you?
   a. What messages have you received about family planning?
   b. How does it make you feel?

5. What family planning options do you know of?
   a. Were you given options when you were counseled about family planning?
   b. Which options did you choose and why?
   c. What does it mean to you? How does it make you feel?

6. Did you consult a healthcare provider when you were deciding whether or not to get pregnant?
   a. Why or why not?
   b. Did a healthcare provider give you advice about getting pregnant as a woman living with HIV?
   c. If yes, what did they recommend?
   d. How did this make you feel?
   e. What did you think of the options provided?

7. How do you perceive the attitude of your care provider towards you at the antenatal/prenatal or postnatal clinic? Have you noticed any differences between care providers who know your HIV status versus those who do not? (Y/N?)
   a. Have provider services changed the way they provide services to you since you revealed or known that you were HIV positive?
   b. What does this mean to you? How does this make you feel?

8. Did anyone in the health clinic or hospital do or say anything that made you feel more comfortable during your pregnancy, childbirth, or after birth?
   a. What did they say?
   b. What does this mean to you?
   c. How did this make you feel?

9. Did anyone in the health clinic or hospital do or say anything that made you feel uncomfortable during your pregnancy, childbirth, or after birth?
   a. What did they say?
   b. What does this mean to you?
   c. How did this make you feel?

10. Do you believe that you are treated differently in healthcare clinics than other women not living with HIV?
    a. If yes, in what ways?
    b. What does this mean to you?
    c. How did/does this make you feel?

11. Do you know any women (including yourself) who changed their minds about having children upon their HIV diagnosis?

12. Have you had your rights violated in the context of family planning and/or PVT/eMTCT/PMTCT?
    a. Did you face stigma and discrimination in the health center?
b. If yes, can you explain more?
c. How did this make you feel?
d. Have you heard about women whose rights were violated in your communities?

13. Based on your experiences, what advice would you give women living with HIV who are considering pregnancy?

14. What measures would you recommend service providers (doctors, nurses, community health workers, midwives, traditional healers) take to make women living with HIV feel more comfortable during their pregnancies?

15. How do you feel about the integration of HIV and family planning services?

16. Are there any other thoughts or experiences that you would like to share?

KEY INFORMANT INTERVIEW GUIDE: SERVICE PROVIDERS

QUALITY OF FAMILY PLANNING SERVICES IN THE CONTEXT OF PREVENTION OF VERTICAL TRANSMISSION

1. What community are most of your clients from?

2. How do your clients identify themselves? How do you identify your clients?

3. Do you think it is more difficult for a woman living with HIV to take care of a child? Why or why not?
   a. Please elaborate on your feelings about this. Please give examples.
   b. Does having HIV affect your feelings about this? If so, how?

4. What does family planning mean to you?
   a. What are the benefits of counseling a client about their family planning options?

5. What type of family planning options do you offer to your clients?
   a. Do you offer the same options to everyone?
   b. Are there certain clients whom you feel need family planning services more than others? If yes, can you elaborate on some of those circumstances?
   c. Do you think any of these services are more important for women living with HIV? Why of why not?

6. When do you counsel clients about family planning?
   a. What do you say?
   b. What are the objectives of counseling your clients about family planning?

7. Do you think it is a good idea for women living with HIV to have children?
   a. Have your beliefs about this changed over the years? Why or why not?

8. How likely do you think it is for a woman living with HIV to pass HIV to her child?

9. What are the challenges of your job?
   a. Are there specific challenges presented by clients who are living with HIV?

10. If a client feels that you provided her with lesser care due to her HIV status, what would be the best way for her to address this issue?

11. Do you know of any cases where a woman’s rights were violated?
   a. For example, do you know of any women who have been coerced into sterilization?
   b. If yes, what is your opinion of this?

12. What is your opinion on integrating HIV and family planning services?

13. Are there any other thoughts or experiences that you would like to share?
KEY INFORMANT INTERVIEW GUIDE: WOMEN LIVING WITH HIV

QUALITY OF FAMILY PLANNING SERVICES IN THE CONTEXT OF PREVENTION OF VERTICAL TRANSMISSION

Introductions (participants sign informed consent forms and fill out surveys)

Beginning of focus group discussion
1. When and where were you diagnosed with HIV?
   a. Were you diagnosed when you came for a prenatal/antenatal care visit?
2. Have you received any information about family planning?
   a. If so, what information did you receive?
   b. Where did you receive this information? in the context of PVT/eMTCT/PMTCT services? in the same place where you access services related to HIV care?
   c. From whom did you receive this information?
   d. What did it mean to you? How did it make you feel?
3. What does family planning mean to you?
   a. What messages have you received about family planning?
   b. How does it make you feel?
4. What family planning options do you know of?
   a. Were you given options when you were counseled about family planning?
   b. Which options did you choose and why?
   c. What does it mean to you? How does it make you feel?
5. Have you been pregnant since being diagnosed with HIV?
   a. What did this mean to you? How did this make you feel?
6. Did you consult a healthcare provider when you were deciding whether or not to get pregnant?
7. Do you know any women (including yourself) who changed their minds about having children upon their HIV diagnosis?

Experiences at the clinic
8. How do you perceive the attitude of your care provider towards you at the antenatal/prenatal or postnatal clinic?
   a. What does this mean to you? How does this make you feel?
9. Do you believe that you are treated differently in healthcare clinics than other women not living with HIV?
   a. If yes, in what ways?
   b. What does this mean to you?
   c. How did/does this make you feel?
10. Have you had your rights violated in the context of family planning and/or PVT/eMTCT/PMTCT?
    a. Did you face stigma and discrimination in the health center?
    b. If yes, can you explain more?
    c. How did this make you feel?
    d. Have you heard about women whose rights were violated in your communities?

Feedback
11. Based on your experiences, what advice would you give women living with HIV who are considering pregnancy?
12. What measures would you recommend service providers (doctors, nurses, community health workers, midwives, traditional healers) take?
13. How do you feel about the integration of HIV and family planning services?
14. Are there any other thoughts or experiences that you would like to share?
ANNEX C: SURVEYS

SURVEY FOR WOMEN LIVING WITH HIV

EXPERIENCES OF WOMEN LIVING WITH HIV: QUALITY OF FAMILY PLANNING SERVICES IN CENTRALIZED AND DECENTRALIZED PREVENTION OF VERTICAL TRANSMISSION CONTEXT

Purpose of the questionnaire:
The purpose of this short survey is to get anonymous, personal details and confidential input from the participants in this study. The questionnaire will be completed prior to the interview/focus group discussion. All of the information that you provide will be kept completely confidential—you do not have to add your name to the document. Your answers, along with the other participants’, will be compiled and evaluated to increase the understanding of the quality of family planning services for women living with HIV in Cameroon, Nigeria and Zambia. If you have questions or concerns, please contact the researchers (contact information is provided on your informed consent form).

1. Gender (please choose the option that best represents you):
   - Female
   - Male
   - Transgender female
   - Transgender male

2. Age (at your last birthday): _______ years

3. Your HIV Status: Please choose the option that best represents you:
   - Living with HIV (HIV+)
   - Not living with HIV (HIV-)
   - Unaware of HIV status

4. When were you diagnosed with HIV? (year or months ago) _______

5. Where were you diagnosed with HIV? (location) _______

6. How many children do you have? _______

7. When was your last pregnancy? (year) _______

8. Family planning use: Please choose the option that best represents you (or your partner/s):
   - Currently using a family planning method
   - Not currently using a family planning method

9. Family planning counseling: When was the last time that you received counseling about your family planning options?
   - Received counseling on family planning in the past 0–6 months
   - Received counseling on family planning in the past 7–12 months
   - Received counseling on family planning in the past 2–3 years
   - Received counseling on family planning 3+ years ago
   - Never received counseling on family planning

10. Where do you receive family planning care?
    - Hospital
    - Community-based clinic
    - Community health worker
    - Other (specify) _______

11. Do you receive family planning services in the same place that you receive care for HIV?
    - Yes
    - No
    - Not applicable

12. What sexual and reproductive health services have you been offered at your HIV care clinic? (check all that apply)
    - Family planning
    - Pregnancy testing
    - Emergency contraception
    - STI screening, diagnosis, and treatment
    - Condom provision
    - Cervical cancer screening
    - Other (please specify)
    - None/not applicable
13. What family planning methods have you been offered/told about by a service provider? (check all that apply)

- [ ] Hormonal contraceptives (injectables)
- [ ] Hormonal contraceptives (pill based, birth control)
- [ ] Emergency contraceptive pills (ECPs)
- [ ] Intrauterine devices (IUDs)
- [ ] Condoms (barrier methods)
- [ ] Withdrawal/pulling out (coitus interruptus)
- [ ] Rhythm/sex during non-fertile periods (fertility awareness methods)
- [ ] Female surgical sterilization
- [ ] Male surgical sterilization
- [ ] Other (please specify)
- [ ] None/Not applicable

14. What family planning methods do you currently use? (check all that apply)

- [ ] Hormonal contraceptives (injectables)
- [ ] Hormonal contraceptives (pill-based, birth control)
- [ ] Emergency contraceptive pills (ECPs)
- [ ] Intrauterine devices (IUDs)
- [ ] Condoms (barrier methods)
- [ ] Withdrawal/pulling out (coitus interruptus)
- [ ] Rhythm/sex during non-fertile periods (fertility awareness methods)
- [ ] Female surgical sterilization
- [ ] Male surgical sterilization
- [ ] Other (please specify)
- [ ] None/Not applicable

SURVEY FOR SERVICE PROVIDERS

EXPERIENCES OF WOMEN LIVING WITH HIV: QUALITY OF FAMILY PLANNING SERVICES IN CENTRALIZED AND DECENTRALIZED PREVENTION OF VERTICAL TRANSMISSION CONTEXT

Purpose of the questionnaire

The purpose of this short survey is to get anonymous, personal details and confidential input from the participants in this study. The questionnaire will be completed prior to the interview/focus group discussion. All of the information that you provide will be kept completely confidential – you do not have to add your name to the document. Your answers, along with the other participants’, will be compiled and evaluated to increase the understanding of the quality of family planning services for women living with HIV in Cameroon, Nigeria, and Zambia. If you have questions or concerns, please contact the researchers of this study (contact information is provided on your informed consent form).

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

- [ ] Female
- [ ] Male
- [ ] Transgender female
- [ ] Transgender male

2. Age (at your last birthday): _____ years

3. Your HIV status: Please choose the option that best represents you:

- [ ] Living with HIV (HIV+)
- [ ] Not living with HIV (HIV-)
- [ ] Unaware of HIV status

18. What is your profession?

- [ ] Doctor
- [ ] Nurse
- [ ] Community health worker
- [ ] Midwife
- [ ] Traditional healer
- [ ] Other (please specify)

19. In what setting do you work?

- [ ] Hospital
- [ ] Community-based clinic
- [ ] Other (specify)

20. What are the core HIV services currently offered at your facility? Select all that apply:

- [ ] HIV testing and counseling
- [ ] Prevention of vertical transmission (PMTCT/eMTCT)
- [ ] TB screening
21. What SRH services do you offer or recommend to the clients at your facility? (check all that apply)

- Family planning
- Pregnancy testing
- Emergency contraception
- STI screening, diagnosis and treatment
- Condom provision
- Cervical cancer screening
- Other (please specify)
- None/not applicable

22. What family planning methods do you offer or recommend to the clients who are living with HIV at your facility? (check all that apply)

- Hormonal contraceptives (injectables)
- Hormonal contraceptives (pill-based, birth control)
- Emergency contraceptive pills (ECPs)
- Intrauterine devices (IUDs)
- Condoms (barrier methods)
- Withdrawal/pulling out (coitus interruptus)
- Rhythm/sex during non-fertile periods (fertility awareness methods)
- Female surgical sterilization
- Male surgical sterilization
- Other (please specify)
- None/Not applicable

23. What family planning methods do you recommend for women living with HIV? (check all that apply)

- Hormonal contraceptives (injectables)
- Hormonal contraceptives (pill-based, birth control)
- Emergency contraceptive pills (ECPs)
- Intrauterine devices (IUDs)
- Condoms (barrier methods)
- Withdrawal/pulling out (coitus interruptus)
- Rhythm/sex during non-fertile periods (fertility awareness methods)
- Female surgical sterilization
- Male surgical sterilization
- Other (please specify)
- None/Not applicable

24. Does your program employ peer counselors or mentor mothers?

- Yes
- No
TITLE OF RESEARCH PROJECT

EXPERIENCES OF WOMEN LIVING WITH HIV: QUALITY OF FAMILY PLANNING SERVICES IN CENTRALIZED AND DECENTRALIZED PREVENTION OF VERTICAL TRANSMISSION CONTEXT

Background and purpose of research
One of the key guiding principles of the Global Plan to Eliminate New HIV Infections in Children by 2015 and Keeping Their Mothers Alive is to place women living with HIV at the center of the response. In the context of family planning, women living with HIV must be given access to tailored and comprehensive information about sexual and reproductive health, including appropriate options and choices, in order to allow for healthy sexual lives and safe pregnancies.

This is especially true in the context of increased emphasis on decentralization and integration of SRH and HIV services. Information on the quality of family planning services for women living with HIV (i.e. access, quality of care, contraceptive choices, retention in care, etc.) is lacking in Global Plan discourse and is necessary before further scale up of programs is accomplished. Additionally, decentralization of health services via task shifting/sharing is seen as essential to increasing access to SRH and PVT services and to achieving Global Plan targets. Therefore, it is also important to understand what impact, if any, this approach has on the quality of services that women are receiving.

Objectives
Through key informant interviews and focus group discussions, the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW) plan to conduct this research in order to:

1. understand and gather qualitative data on the family planning experiences of women living with HIV in the context of PVT programs, including:
   i. access to family planning care
   ii. family planning methods available (e.g. commodities available – oral contraceptives, injectables, etc.)
   iii. family planning care provided (e.g. overall family planning care, counseling)
   iv. relationships of women living with HIV and their care providers (i.e. stigma/discrimination related to pregnancy ideations of women living with HIV)
2. understand the preferences of women living with HIV in relation to family planning especially young women
3. understand how care providers perceive and engage with women living with HIV, especially young women, in relation to family planning
4. explore what impact, if any, decentralization of services has on stigma/discrimination and women’s access, adherence and retention in care.

The project partners aim to share the perspectives and recommendations from the conversations with women living with HIV and care providers at the IATT Integration Workgroup Family Planning Workshops planned in five countries to be held this year and to inform further policy-making related to Prong 2, integration of SRH and HIV care, and providing rights-based care.

Researchers
This project is being coordinated by the Global Network of People Living with HIV (GNP+) and the International Community of Women Living with HIV (ICW), with support from the UNFPA and UNAIDS.

I understand that if I have any questions about the research procedures, I can contact either of the Project Coordinators: Sonia Haerizadeh, JD, Human Rights Attorney, International Community of Women Living with HIV (ICW); and Amy Hsieh, JD, MPA, Health and Human Rights Consultant, Global Network of People Living with HIV (GNP+).
Invitation to participate
I understand that I am being asked to participate in a key informant interview to increase understanding of the quality of family planning services for key affected populations, namely women living with HIV.

Procedures
I understand that my participation in the study will involve taking part in key informant interview lasting approximately 1 hour. I will be asked approximately 15 questions relating to the family planning, HIV and prevention of vertical transmission (PMTCT, eMTCT). I understand that the interview will be audio recorded and transcribed and that all information I share will be coded in such a manner that I cannot be identified. The data will be used only for research purposes and the development of a report on the quality of family planning services for women living with HIV in Cameroon, Nigeria, and Zambia.

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

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

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

I have also been advised that my participation will in no way impact my agency’s or organization’s relationship with or funding from UNAIDS, UNFPA, GNP+, or ICW.

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

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

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

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

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

Participant signature ................................................ Date ....................

Researcher signature ................................................ Date ....................

Interviewer name (please print).................................
## ANNEX E: COMPILED SURVEY DATA

### INTEGRATION DATA

<table>
<thead>
<tr>
<th>Women Living with HIV</th>
<th>CAMEROON</th>
<th>NIGERIA</th>
<th>ZAMBIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=48</td>
<td>n=48</td>
<td>n=18</td>
<td></td>
</tr>
<tr>
<td># women who accessed family planning at HIV site</td>
<td>29.2% (14/48)</td>
<td>47.9% (23/48)</td>
<td>55.6% (10/18)</td>
</tr>
<tr>
<td>Average # of SRH services offered at HIV site</td>
<td>1.2 (56/48)</td>
<td>2.3 (109/48)</td>
<td>1.8 (32/18)</td>
</tr>
<tr>
<td>Median SRH services offered at HIV site</td>
<td>1</td>
<td>2</td>
<td>1.5</td>
</tr>
<tr>
<td>Mode # of SRH services offered at HIV site</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Range # of SRH services offered at HIV site</td>
<td>0-3</td>
<td>0-5</td>
<td>0-4</td>
</tr>
<tr>
<td>Condoms</td>
<td>18.8% (9/48)</td>
<td>79.2% (38/48)</td>
<td>72.2% (13/18)</td>
</tr>
<tr>
<td>Other family planning method</td>
<td>16.7% (8/48)</td>
<td>50.0% (24/48)</td>
<td>44.4% (8/18)</td>
</tr>
<tr>
<td>Pregnancy testing</td>
<td>27.1% (13/48)</td>
<td>25.0% (12/48)</td>
<td>16.7% (3/18)</td>
</tr>
<tr>
<td>STI screening</td>
<td>35.4% (17/48)</td>
<td>35.4% (17/48)</td>
<td>16.7% (3/18)</td>
</tr>
<tr>
<td>Cervical cancer screening</td>
<td>4.2% (2/48)</td>
<td>35.4% (17/48)</td>
<td>11.1% (2/18)</td>
</tr>
</tbody>
</table>

### Service Providers

<table>
<thead>
<tr>
<th>n=5</th>
<th>n=8</th>
<th>n=11</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average # of SRH services offered at HIV site</strong></td>
<td>4.0 (20/5)</td>
<td>4.1 (33/8)</td>
</tr>
<tr>
<td><strong>Median SRH services offered at HIV site</strong></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td><strong>Mode of SRH services offered at HIV site</strong></td>
<td>3,5</td>
<td>4</td>
</tr>
<tr>
<td><strong>Range of SRH services offered at HIV site</strong></td>
<td>3-5</td>
<td>0-5</td>
</tr>
<tr>
<td>Condoms</td>
<td>60.0% (3/5)</td>
<td>100.0% (8/8)</td>
</tr>
<tr>
<td>Other family planning method</td>
<td>100.0% (5/5)</td>
<td>100.0% (8/8)</td>
</tr>
<tr>
<td>Pregnancy testing</td>
<td>100.0% (5/5)</td>
<td>87.5% (7/8)</td>
</tr>
<tr>
<td>STI screening</td>
<td>100.0% (5/5)</td>
<td>75.0% (6/8)</td>
</tr>
<tr>
<td>Cervical cancer screening</td>
<td>40.0% (2/5)</td>
<td>37.5% (3/8)</td>
</tr>
<tr>
<td>Other: Post-abortion care</td>
<td>0.0%</td>
<td>12.5% (1/8)</td>
</tr>
</tbody>
</table>
REFERENCES


vii. Adesina SK. Traditional Medical Care in Nigeria. 1 December 2013. Available at: http://www.onlinenigeria.com/health/?blurb=574


ix. Isonguyo I, Adindu A. Adolescents and Utilization of Family Planning Services in Rural Communities of Nigeria, Research on Humanities and Social Studies 2013; 3:1.
