Appendix B(3): E-survey

E-Survey on PMTCT Components One and Two:

Primary Prevention of HIV and Prevention of Unintended Pregnancies

Global Network of People Living with HIV

&

International Community of Women Living with HIV

11 January – 28 January 2011

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List of Acronyms

AIDS	Acquired immunodeficiency syndrome
ANC	Antenatal care
ARVs	Antiretrovirals
ART	Antiretroviral therapy
AZT	Zidovudine
CBOs	Community based organizations
FGDs	Focus Group Discussions
GIPA	Greater Involvement of People Living with HIV
GMT	Greenwich Median Time
GNP+	Global Network of People Living with HIV
IATT	The Interagency Task Team
ICW	International Community of Women Living with HIV
MDGs	Millennium Development Goals
MTCT	Mother-to-child transmission (of HIV)
NAM	National AIDS Manual
NGO	Non-governmental organizations
PCR	Polymerase chain reaction
PIT	Provider Initiated Testing
OIs	Opportunistic infections
PITC	Provider initiated testing and counselling
PMTCT	Prevention of mother-to-child transmission (of HIV)
SRH	Sexual and reproductive health
SRHR	Sexual and reproductive health and rights
STI	Sexually transmitted infection
WLWHIV	Women Living with HIV
WHO	World Health Organization

Introduction

The IATT for Prevention of HIV Infection in Pregnant Women, Mothers, and their Children in collaboration with GNP+ and ICW (a member of the IATT) developed a strategic framework to scale-up comprehensive PMTCT, which is comprised of four components[1]:

1. Primary prevention of HIV among women of childbearing age
2. Preventing unintended pregnancies among women living with HIV
3. Preventing HIV transmission from a woman living with HIV to her infant
4. Providing appropriate treatment, care and support to women living with HIV and their children and families

Implementation of the four components has been skewed with components three and four receiving greater emphasis and demonstrating significant progress while components one and two have not benefited from appropriate recognition, commitment, or programming support.

The Draft Strategic Framework (2010-2015) on the first two components of PMTCT aims to scale-up these components by strengthening policy and programming. In addition, the Framework highlights strategies and packages of essential services that are offered through community based integrated sexual and reproductive health and HIV programs.

The Global Network of People Living with HIV and the International Community of Women Living with HIV Global conducted an e-survey on the first two components of the Draft Strategic Framework on PMTCT among people living with and affected by HIV (such as family members, partners, and friends). The purpose was to incorporate their personal experiences into the final Strategic Framework. Contribution from the community of people living with and affected by HIV is key to informing the Framework development process to ensure their lived experiences are clearly articulated and integrated.

Methodology

GNP+ and ICW Global developed a survey with forty questions in ten areas based on key issues in the Draft Strategic Framework on the first two components of PMTCT. Both closed questions (respondents had to tick predefined answering options) and open-ended questions (respondents could provide their personal answer in a text box) were given. The majority of questions were framed as closed questions.

The survey was available online on the NAM website and a number of avenues were used to ensure the survey reached a broad array of respondents. The link to the survey sent to networks of people living with HIV and key populations, pertinent listservs, forwarded to friends and colleagues and posted on the GNP+ website. The e-survey took place over a three-week period,

[1] Various documents use the terms 'prongs', 'elements', and 'pillars' instead of 'components' when referring to comprehensive PMTCT.

from 11 January to 28 January 2011. During the survey period, emails were sent at the beginning of each week to potential respondents, encouraging them to complete the questionnaire.

The e-survey was translated into French, Spanish, Portuguese, and Russian to ensure greater reach and participation from non-English speaking communities. In addition, careful consideration was taken in timing the launch of the PMTCT e-survey to assure maximum participation. Respondents' answers were anonymous. Quantitative results were analyzed descriptively, for instance through the use of frequencies. Qualitative results (provided to open-ended questions) were analyzed manually to illustrate the quantitative results. Where appropriate such quotes are given as examples throughout the report to highlight the qualitative findings.

All data from structured and un-structured questions were entered onto excel spread sheets to allow for validation and analysis. Structured data was then graphically analyzed to generate quantitative values. Thematic analysis was carried out with all qualitative data where data was identified, coded and arranged according to emerging patterns and themes. Data was triangulated to support emerging findings and quotes from un-structured responses used to support conclusions.

Survey results

This report presents key findings of the e-survey. Quantitative data are presented as well as critical themes identified from the responses.

1) Overview of survey respondents

Five hundred and ninety one (591) individuals responded to the e-survey on PMTCT from 58 countries in 6 continents. The largest region represented was Africa, with thirty-two percent (32%) of participants from 21 African countries. Fifty five percent (55%) of the respondents were male and forty-five percent (45%) female with a median age of 30-39 years.

Table 1: Number of respondents by continent.

Continent	**No. of countries responded**	**No of respondents**	**%**
Africa	21	110	32
Asia	14	52	15
Europe	13	61	18
North America	6	85	25
South America	2	8	2
Oceania	2	6	2
Missing		19	6
Total	**58**	**591**	**100**

In relation to respondents' countries of residence, it should be mentioned that seventy-four percent (74%) of them were residing in countries where mother-to-child transmission of HIV was not a criminal offence while eight percent (8%) were from countries where it was a criminal offence. Seventeen percent (17%) did not know whether it was an offence in their country.

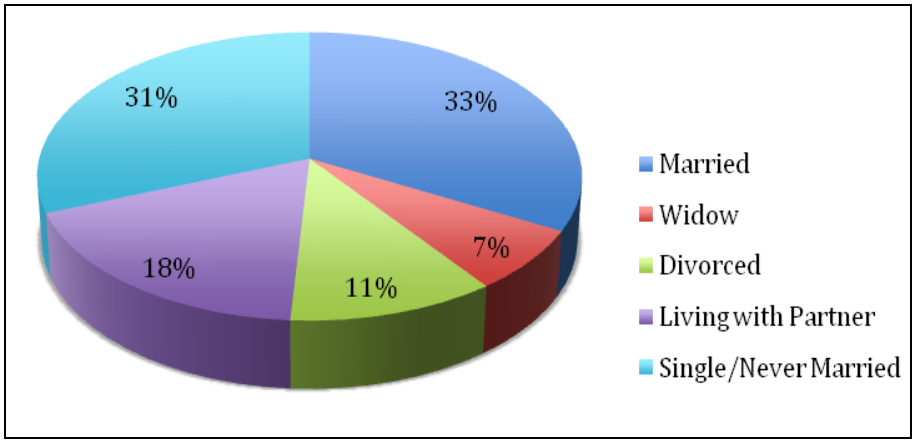
HIV status

Eighty three percent (83%) of the participants were living with HIV, while nine percent (9%) were not living with HIV. Six percent stated that they were affected by HIV (e.g. having a family member, friend, or partner who was living with HIV) and 2% did not know their status at the time of the e-survey.

Marital status

The majority, thirty-three percent (33%) stated that they were married while thirty-one percent (31%) were single/never been married. The rest were either living with a partner, divorced, or separated.

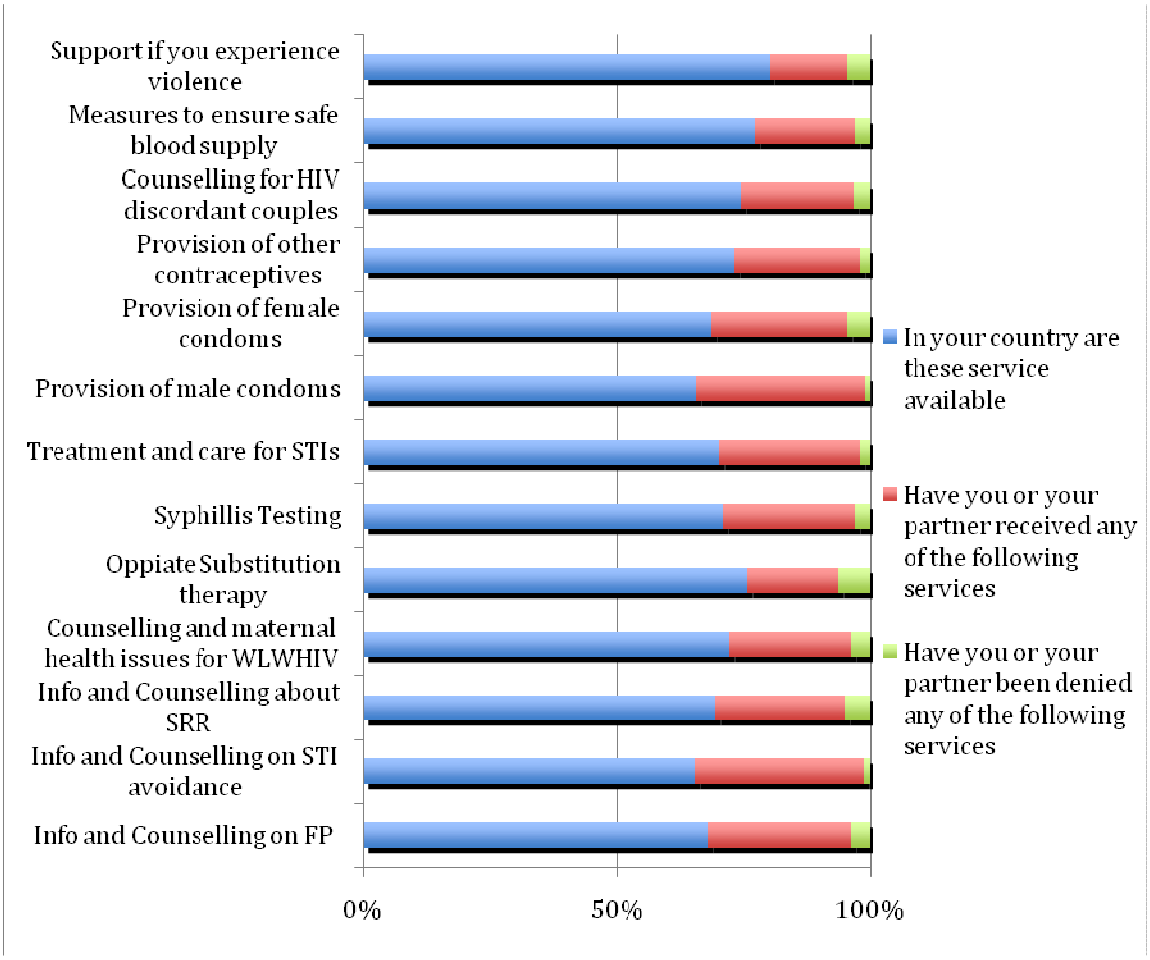
Figure 1: Participants' marital status.



2) Accessibility to key PMTCT services

Participants were given a list of key PMTCT services (as stipulated by the Draft framework) and asked whether these services were available in their countries. Of the services provided, participants most often have had access to information and counseling on how they can reduce the risk of acquiring HIV, followed by voluntary HIV testing and counseling and provision of male condoms. The services that participants stated were least available included male circumcision services, provision of female condoms and counseling for discordant couples. Figure 2 below shows the accessibility to PMTCT services.

Figure 2: Accessibility to PMTCT services.



The main factors contributing to accessibility to the listed services were awareness and availability of information services. Sources of information were mainly from support groups, web sites, doctors office, media, and community level campaigns. Respondents stated that confidential and free services encouraged their utilization.

Facilitators of accessibility:

"Being able to find information about the services, knowing that they were confidential and free of charge".

For participants who mentioned that services were denied to them, reasons included denial of testing to individuals who did not fit within the 'high risk category', sexual and reproductive health services denied due to a health worker's judgmental attitude, individual's fear of disclose to family, the distance to services, and the cost of services.

Barriers to accessibility:

> *"Although some HIV clinics offer FP services, many are still staffed by providers who are very uncomfortable with addressing reproductive health and see their role as providing focused HIV specific care. Also, there are still pervasive views that women living with HIV should not have children and should focus on staying healthy and not transmitting the virus or putting their partners at "undue risk" as it may be the case should they desire to conceive. Although pre-conception care and services to prevent HIV transmission between partners who have pregnancy intention is an emerging area in the US, much work is still required around messaging, sensitization and education".*

Places where HIV prevention services were accessed

The majority of participants stated that they had accessed HIV prevention services at HIV treatment centres, followed by family planning clinics and community based outreach services respectively. The least frequent place HIV prevention services were accessed was in the workplace.

The majority of participants stated that they had received pregnancy prevention services at family planning clinics, followed by antenatal clinics. This can be seen as an indicator of some degree of integration between SRH and HIV services. Again, workplaces ranked last on the list of places where pregnancy prevention services could be accessed.

Table 2: Where women access prevention and pregnancy prevention services.
Respondents were asked: In your country, where can women access (1) HIV prevention services and (2) services to prevent unintended pregnancy. Respondents pick all that applied. 202 respondents answered the question.

Service delivery site	Accessing HIV prevention services	Services to prevent getting pregnant if they did not want to
	n (%)	N (%)
HIV treatment centre	185 (91%)	84 (41%)
Family planning clinic	150 (74%)	130 (64%)
Community-based outreach services	143 (70%)	72 (35%)
Antenatal clinic	142 (70%)	87 (43%)
Youth centre	114 (56%)	68 (34%)
Workplace	76 (37%)	29 (14%)

When asked where participants would prefer to receive services for HIV and family planning if such services were integrated, the largest percentage of respondents (36%) indicated HIV clinics, closely followed by community based facilities (32% of respondents). The least popular places to receive these services were antenatal clinics, with only 5% of respondents preferring this option. The second least popular option was family planning organizations, which only 15% of participants preferred. Unfortunately, these least popular options are the ones where these

services are provided most often, as shown in reporting table 1 above. This issue should be addressed with urgency.

Factors affecting accessibility to services

The majority of participants (70%) stated that health workers' attitude was one of the factors affecting accessibility of services. This was followed closely by financial problems (65%), transportation problems (58%), and long waiting hours (55%).

Table 3: Problems in accessing prevention and pregnancy prevention services.

Question: "Can you give an example of a problem, you, your partner, or someone you know, has had in accessing any of the above services?"

Answer Options	N	%
Attitude of the healthcare workers	214	70
Financial problems	199	65
Transport problems	177	58
Long waiting hours	169	55
Long waiting list	142	46
Services in different locations	138	45
Shortage of ARVs	124	40
Shortage of condoms	83	27
Other (please specify)	50	16
Total	307	

(Multiple answers possible)

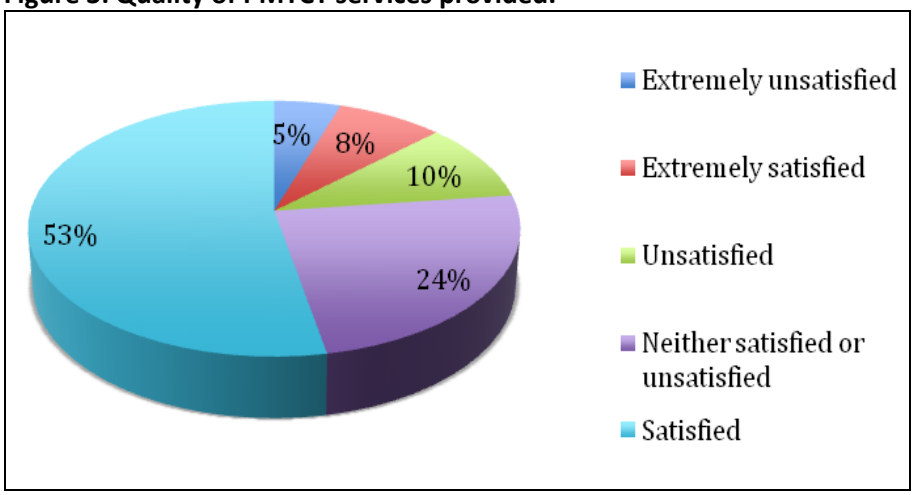
When asked whether the problem had been resolved, the majority of respondents (43%) said that it had it not been resolved or that they did not know (24%). Only 23% of the respondents stated that the problem had been addressed to their satisfaction.

When asked how problems could be resolved the majority of responses were related to health system strengthening such as better integration of services, case management, strengthened referrals, decentralization of services and enhanced community involvement in the management of health centres.

3) Quality of PMTCT services provided

Participants were asked to rate the overall degree of their satisfaction with PMTCT services. The majority of participants (53%) stated that they were satisfied with the PMTCT services they had received, but only eight percent reported having been extremely satisfied. Ten percent were unsatisfied with the services provided (see figure 3 below).

Figure 3: Quality of PMTCT services provided.

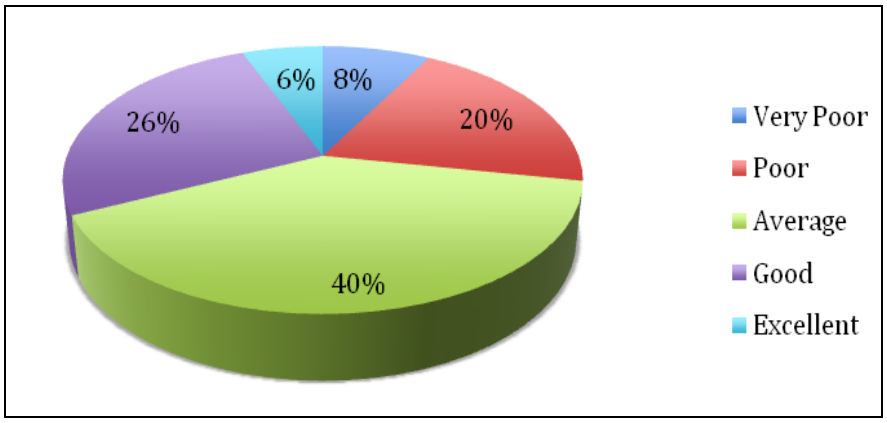


4) Quality of counseling received when offered an HIV test as part of family planning, STI, or antenatal services

"Firstly, the ideal is to know your status BEFORE pregnancy...it is twice as traumatic to get the results when you are in the process of creating a life. However if that is the time you find out then your circumstances should be used to inform the counseling needs. Is there a partner that needs to know? What is the level of spousal/ family support? Is there risk of violence in disclosing? What social services will best help her/family?"

Participants were asked to rate the quality of counseling when offered an HIV test as part of family planning STI, or antenatal services. The majority of respondents rated the quality of counseling as average to very poor, whereas only 26% rated it as good and 6% excellent.

Figure 4: Quality of counseling when offering an HIV test as part of family planning, STI, or antenatal services.



When asked what quality counseling should look like for a pregnant woman living with HIV, responses to the open-ended question fell within the following seven thematic areas:

- **Positive attitude from the service provider**: Respondents felt that the attitude of the counselor should be non-judgmental and supportive
- **Competent service providers**: Respondents felt that service providers need to have adequate knowledge of HIV and pregnancy
- **Peer support:** Respondents felt that the peer support, i.e. provided by other women who have been through the service, would be beneficial
- **Support from partners and family:** Respondents felt that involvement of partners who also may be in need of counseling and testing services was crucial
- **Ongoing psychological support**: Respondents felt that ongoing psychological support through further counseling and support in the community should be provided
- **Referrals and linkages**: Respondents felt that referrals to other services should be strengthened
- **One stop services**: Respondents felt that access to integrated services should be promoted.

"PMTCT is one of the great success stories in HIV treatment. It is so important for woman to receive accurate information so that they can make an informed decision. Relationship building between the clinic and the family is the key to successful outcomes."

Many respondents referenced experiences with providers who emphasised the importance of disclosure of one's status, without provision of adequate counseling and information. Counseling sessions were sometimes rushed and generic without providing adequate time for women to process the information and make decisions based on their individual circumstances.

Participants also provided information on the required elements for counseling for women who test negative. For them, the counseling should focus on:

- Information on how to remain negative throughout the pregnancy and to re-test later in the pregnancy
- Information on increased risk for the child if a woman gets HIV when pregnant
- Counseling and testing for partners should be emphasized
- Risk assessment of personal environment to find out whether there are experiences (or risk) of violence in the relationship

However, respondents also emphasized that counseling given to HIV positive and negative women in principle should be similar, with no major differences. Competent counselors who are non-judgmental and can empathize with pregnant clients should provide the counseling.

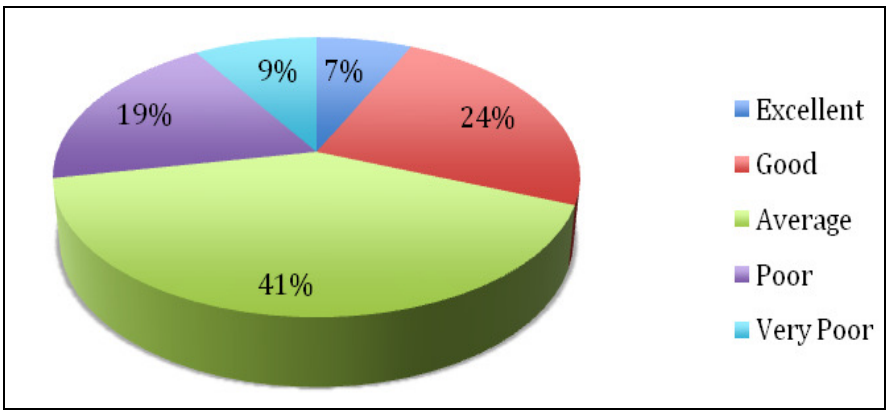
"Accurate prevention information should be provided. The counselor should try to learn what specific risks she may be facing and work with her to determine strategies for risk reduction. If

she feels vulnerable to infection herself, or the counselor determines that she may be at risk, then she should be encouraged to re-test during the pregnancy (as obviously some women become positive after becoming pregnant). It would be very important to determine her risk of domestic violence (as this increases during pregnancy) and refer to appropriate services for help. Condoms or other STI prevention tools should be made easily available and she should know the phone numbers of nurses or counselors who she can reach confidentially should she have any questions".

Quality of counseling provided to HIV positive women who want to prevent pregnancy

Less than half of respondents (41%) rated the overall quality of counseling that women living with HIV receive when they do not want to get pregnant as average. A significant number (19%) rated the quality of counseling as poor and nine percent as very poor.

Figure 5: Quality of counseling provided to HIV positive women who do not want to get pregnant.



When asked how quality counseling should look like for HIV positive women who wanted to prevent pregnancy, respondents emphasized the need for a rights based approach that focuses on the women's individual SRH needs, as opposed to focusing on avoiding pregnancy for the greater public good (for instance, to prevent transmission to a sexual partner or to a child). Service providers should be competent and have adequate information on available options for preventing pregnancy and interactions with ARVs. The counseling should be nonjudgmental and emphasize that should the woman desire to become pregnant in future, it is possible to give birth to an HIV-negative child.

Respondents also mentioned the need to explore potential reasons why a woman would not want to have children to ensure it is an informed choice that is being made without coercion and with full information on the ability of HIV positive women to give birth to an HIV negative child.

"Focus on her SRHR needs and rights and not the greater public good. [Counseling should always include the following:] Education on STIs- Education on the limitations of diaphragms, pills, and other contraception that do not protect from STIs and HIV- Education on options around pregnancy for women living with HIV. Some women are not interested in having children. Other

women fear having children due to false messaging, lack of information on options and poor self-concept related to being HIV positive."

In the case of couples counseling, the information provided to the couple should be similar to that provided to individual women. However, it would be important to establish the couples HIV status to determine the unique counseling needs and ensure that each partner's right to confidentiality and autonomy is respected.

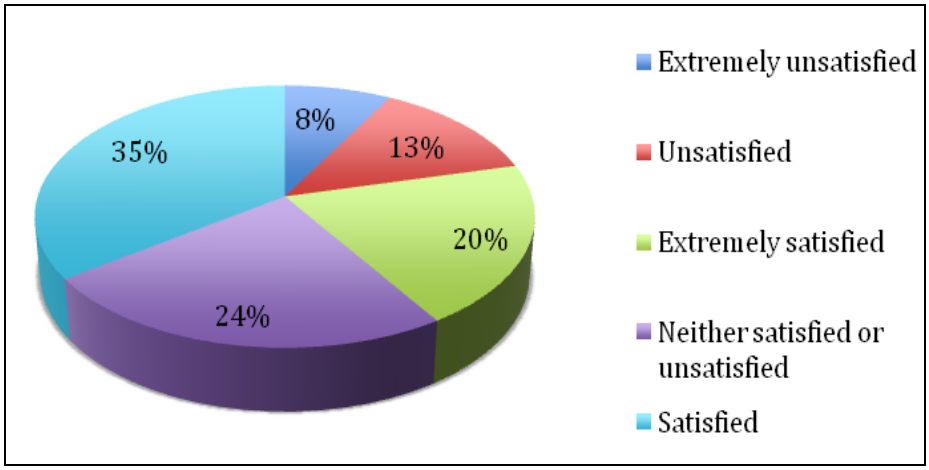
5) Support provided to HIV positive women for conception

> *"The sector is heavily influenced by biomedical views whose approach is to advise [couples] no, [and] tell discordant couples to have little or no sex at all let alone conception."*

Overall, respondents felt that HIV positive women did not receive adequate support for safe conception. Fifty eight percent (58%) of the respondents stated that they felt that HIV positive women and couples living with HIV do not have enough support to conceive safely. Twenty five percent (25%) felt that there was enough support and seventeen percent (17%) did not have an opinion on this issue.

Twenty nine percent (29%) of respondents stated that their partners had received support to conceive safely. When asked whether they were satisfied with the support that their partners received to conceive safely, forty-three (43%) rated the services positively (either very satisfied or satisfied).

Figure 6: Satisfaction with quality of services to conceive safely.



Factors affecting the perceived quality of support provided to women for safe conception included negative health worker attitude, lack of information by women living with HIV and their partners, long distances to health centres and the added financial burden of travel, lack of male partner involvement, prejudice, stigmatisation, and discrimination. The single greatest barrier, identified by the majority of respondents, to safe conception by women living with HIV was health workers' attitude.

6) Male participation in family planning, HIV testing and PMTCT

Fifty one percent (51%) of the respondents felt that men are not encouraged to go for family planning services, yet fifty-three percent (53%) could name places where such services are provided to men. This implies that although there are many places that could offer these services to men, programmes that create demand among men are still lacking. Respondents thought that this is because family planning is still regarded as a "woman's domain" and most men do not present with their partners for these services.

Figure 7: Male involvement in SRH services (measured by the question: "In your country, do you know of any programmes or services that encourage the involvement of men in sexual and reproductive health, including family planning and PMTCT")?

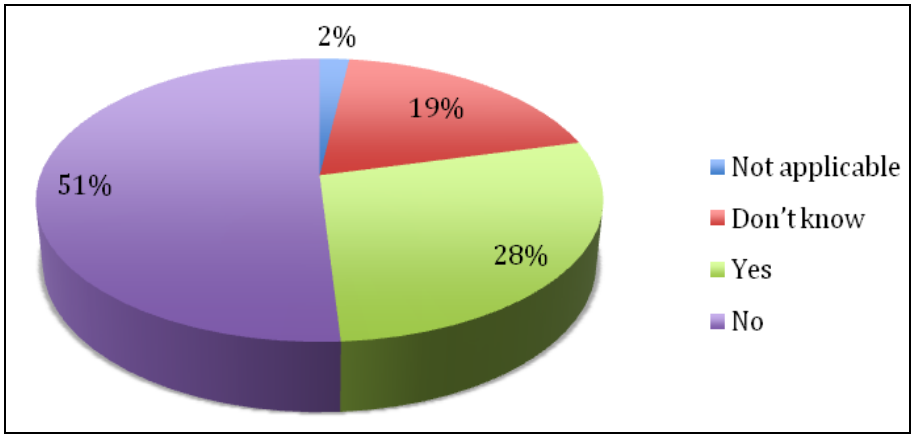


Table 4: Barriers to male involvement in SRH services.

In your country, what are the main barriers to men getting involved?

Answer Options	**%**	**N**
Men's attitude about it being a women's issue	77%	140
Women's attitude about it being women's issues	34%	62
Societal/community perception that the services are for women	74%	135
Lack of programmes for HIV discordant couples	63%	115
Stigma and discrimination	83.5%	152
Traditional/Cultural norms	72%	131
Not knowing what their role is in preventing HIV and unintended pregnancies	49%	89
Low perception of risk to contracting HIV	46%	84
Limited or no programs that focus on empowering men on these issues	66%	120
Other (please specify)		13
Total respondents who answered the question:		**182**

7) Sexual and reproductive health rights

The majority of respondents (59%) felt that women generally are not aware of their reproductive and sexual rights while thirty-two percent (32%) felt that women are aware. The SRH rights respondents most commonly identified as those known by women were those rights related to access to information in respect to PMTCT, sexuality and reproductive health. The rights least known were related to the exercise of personal freedom against discrimination and gender based violence.

Table 5: Women's sexual and reproductive health and rights.

Here are a few examples of sexual and reproductive health rights (SRHR). Overall, which rights do you think women have in your country?		
Answer Options	N	%
To decide freely on sexual relationships	194	71
To decide freely on sexual activity (which types of sex to have) including safer sex	170	63
To enjoy sexuality	180	66
To access information and support on sexuality, for example through sex information, information on SRHR, etc	190	70
To decide freely if and when to have children	186	68
To access information and support on reproductive health issues family planning, contraceptives, antenatal care, delivery, abortion	207	76
To access information on PMTCT and safer conception	193	71
To be free from discrimination in their sexual lives	132	49
To be free from sexual pressure or violence	137	50
Total Respondents	272	100

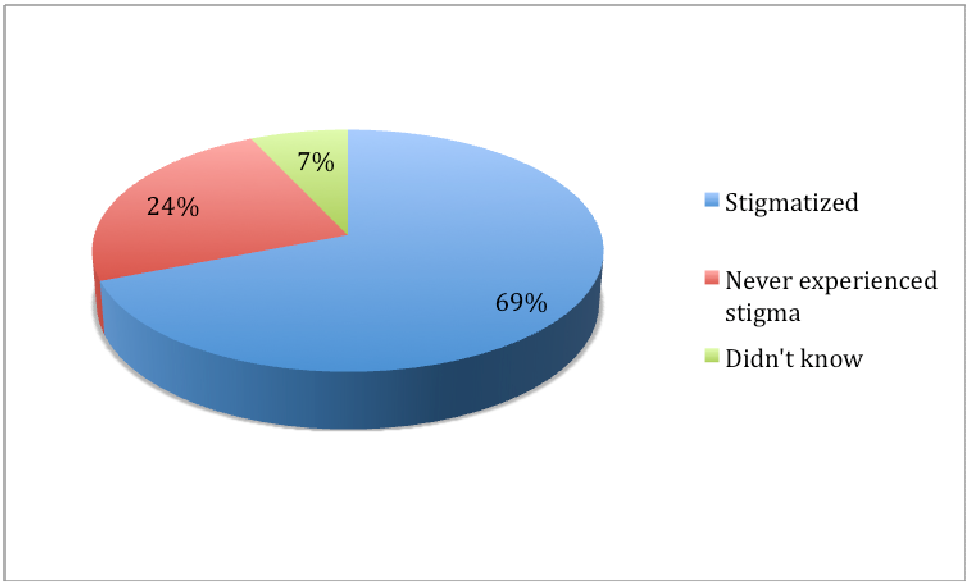
About two thirds (69%) of the respondents stated that they had never been pressurized by a healthcare worker to make a decision about their sexual or reproductive health. Nineteen percent (19%) had been pressurized at least once and twelve percent (12%) several times. Among those who had been pressurized by health workers, it was related to the following:

- Abstain from sex and/or other judgmental attitude – 11 respondents
- Hysterectomy and/or tubal ligation – 8 respondents
- Abortion – 5 respondents
- Condom provided without other choice – 2 respondents
- Refusal to assist with delivery – 1 respondent

Just over half of all respondents (53%) stated that their right to confidentiality about their HIV status had been violated.

The number of respondents reporting that they had been stigmatized in health care settings was very high, with sixty-nine percent (69%) reporting at least one experience of stigma directed at either themselves or their partners. Only twenty-four percent (24%) stated that they had never experienced stigma in health care setting and seven percent (7%) did not know. Most of those who had experienced stigma in health care settings stated that it was related to HIV care facilities (54%) followed by primary health care facilities (53%) and dental care facilities (37%).

Figure 8: Exposure to HIV-related stigma in health care settings.



Limitations

Respondents were self-selected and therefore may represent those who either may have a greater interest in the issues at stake or those who may have had specific experiences in relation to PMTCT, which they are willing to share.

The study reached only those who have online access and are able to read and fill in an online survey.

Conclusions and Recommendations

In spite of the above mentioned limitations, which are common to most cross-sectional studies using surveys of this type, we may draw some relevant conclusions and policy recommendations.

1. Linkages between HIV care and typical SRH services (such as family planning and antenatal services) must be strengthened. Efforts to popularize and increase uptake of integrated HIV services and family planning at the antenatal clinic and family planning organizations are urgently needed.

2. Both health system strengthening and enhanced community involvement in the management of health centers was cited as key in addressing challenges currently experienced in accessing HIV prevention services.

3. The survey revealed important criteria for quality counseling for the prevention of unwanted pregnancies. Quality counseling should be nonjudgmental and free of coercion. It should provide information on contraceptive choices and also potential interaction with HIV treatment. It must emphasize women's right to make informed choices, without coercion and with full information on the ability of HIV positive women to give birth to an HIV negative child.

4. Greater efforts are needed to ensure HIV positive women and couples receive tailored support to conceive safely as the majority of the respondents felt that the currently available support was inadequate, in particular because of health care workers' negative attitudes.

5. Changing perceptions among both women and men that family planning is purely a woman's domain and increasing demand for innovative services that will specifically target and involve men will be critical in increasing uptake to HIV prevention services.

6. Intensified efforts to sensitize women, especially women living with HIV, on their sexual and reproductive health rights. There is particular need to educate women about their right to be free from discrimination and gender based violence, as these were the least known rights among participants and identified as the least well-known in participants' countries.

Next steps

The findings of the PMTCT e-survey will be merged with the results of the e-consultation, the focus groups discussions, and the expert teleconference call. The merging with data from different sources will help to improve the validity of the findings.

The recommendations emerging from the e-survey will be shared with the IATT on Prevention of HIV Infection in Pregnant women, Mothers and their Children to ensure the perspectives and personal experiences of people living with HIV are accurately reflected and integrated in the final Strategic Framework on the first two components of PMTCT *(i) Primary Prevention of HIV and (ii) Prevention of Unintended Pregnancies in Women Living with HIV in the Context of PMTCT: Strategic Framework 2010-201*5. In addition, the consultation reports will be made available on GNP+ and ICW Global websites to inform broader advocacy efforts on PMTCT.