



# **POSITIVE AND PREGNANT: HOW DARE YOU**

**A study on access to  
reproductive and maternal health  
care for women living with HIV in  
Asia**

Findings from six countries:  
Bangladesh, Cambodia, India, Indonesia, Nepal, Viet Nam



**Women of the Asia Pacific Network of People Living with HIV**

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**Gina Davis**

**Women of APN+**

## List of Abbreviations

3TC	Lamivudine
ANC	Antenatal Care
APN+	Asia Pacific Network of People Living with HIV
ARV	Antiretroviral medicine
AZT	Zidovudine
d4T	Stavudine
EFV	Efavirenz
FGD	Focus group discussion
HIV	Human immunodeficiency virus
JOTHI	<i>Jaringan Orang Terinfeksi HIV Indonesia</i> (Indonesian Network of PLHIV)
NVP	Nevirapine
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission
SRHR	Sexual and reproductive health and rights
STI	Sexually-transmitted infection
TDF	Tenofovir
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session
UNICEF	United Nations Children's Fund
WAPN+	Women's Program of the Asia Pacific Network of People Living with HIV
WHO	World Health Organization

### Executive Summary

#### Background and method

Globally, an estimated 17 million women and girls are living with HIV, and more than two million pregnancies occur amongst HIV-positive women each year. In 2009, an estimated 370,000 children acquired HIV. While the total number of children being born with HIV has decreased due to the increased access to services that support women living with HIV to have HIV-free babies (usually referred to as prevention of mother-to-child transmission or PMTCT), the majority of remaining cases occur in resource-poor nations. Key challenges in the provision of effective services include: i) low levels of HIV testing; ii) low coverage of services; iii) low knowledge about the need for PMTCT, and the components for effective PMTCT; iv) poorly resourced health care systems; v) loss to follow-up; and vi) poor drug adherence. Pregnant HIV-positive women face stigma, discrimination, and sometimes violence, compromising their health and endangering the lives of themselves and their children. Discrimination may lead to poor quality care or refusal of antenatal care and delivery services, and increased coercion to be sterilised.

It is in this context that the Women's Program of the Asia Pacific Network of People Living with HIV (WAPN+), together with the Regional Treatment Working Group, conducted a study on positive women's access to reproductive and maternal health care and services in six Asian countries: Bangladesh, Cambodia, India, Indonesia, Nepal, and Viet Nam. The objective of the study was to assess the experience of accessing reproductive and maternal health services as reported by HIV-positive women over 16 years of age and pregnant in the past 18 months. The study used quantitative and qualitative methods: a survey among 757 women, 17 interviews and 10 focus group discussions.

#### Key findings

Mean age of respondents was just under 30 years old, they had on average at least one existing child, and most had either primary or secondary school level education (71%). About half (53%) were dependent on their families for income; 57% lived in urban settings, and 77% were married or living with a partner. The majority of the women (56%) were diagnosed prior to their most recent pregnancy, 27% during, and 10% after their most recent pregnancy. In India, a majority was diagnosed during pregnancy.

#### Counselling

Most women (73%) received pre-test counselling, but in India, only 50% of women tested during pregnancy received pre-test counselling. The vast majority of women (90%) received post-test counselling although only 9% of women who said the test was *not* voluntary received post-test counselling. Quality of counselling ranged from barely adequate, to comprehensive. The importance of timely, accurate, and appropriate counselling provided by HIV-positive women themselves, covering a range of issues, and available consistently and on a long-term basis, was a recurring theme.

#### Disclosure

Over 90% of women surveyed reported having told their husband or partner about their HIV status, and between 40-60% had disclosed to female family members. Many women faced discrimination as a result of disclosure, usually from mothers-in-law or health care workers. Some women did not reveal their HIV status to their gynaecologist for fear of discrimination.

### Antiretrovirals

The majority of women (64%) were currently taking ARVs, with 50% initiating ARVs before their current pregnancy and the remainder initiating ARVs during pregnancy or at the point of delivery; 29% of respondents were on a regimen that included d4T. Several women who initiated ARVs had discontinued them but were still pregnant at the time of the survey. Reasons for stopping treatment or not seeking treatment include: cost (of transportation, doctor's fees, laboratory tests, procedures); adverse side effects; and stock-out of drugs.

### Contraception

Only 64% of respondents sought advice or counselling regarding their sexual and reproductive health prior to their most recent pregnancy. Condoms were the most preferred contraceptive method (64%). Condoms are not used consistently because partners object to condoms and find them inconvenient, or they cannot afford them. Condoms are usually the only contraception promoted among HIV-positive women, whereas they need family planning methods that they can control – IUDs, pills, or injectables.

### Pregnancy

Among women pregnant in the last 18 months but not currently pregnant, 72% had live births, and 28% had an abortion, miscarried or had a still birth; 27% of pregnancies were unplanned, and 37% were reported as unwanted. Planned pregnancies tended to be first pregnancies, or first pregnancies with a new husband or partner. Less than half of respondents reported that decisions regarding their pregnancy were made together with their husband or partner.

### Abortion

Among the 573 respondents no longer pregnant at the time of the survey, 125 (22%) reported that they had an abortion, and most occurred specifically because of their HIV status; 29% of women who had an abortion said the pregnancy had been wanted. Many women coerced into an abortion faced considerable discrimination when they went for the procedure.

### Delivery

Overall, 63% of the 426 deliveries were vaginal, and 37% caesarean. Many women were not given a choice to have a vaginal delivery. Women often faced terrible neglect, abuse and discrimination from maternal health care workers at the time of delivery.

### Sterilisation

Overall, 30% of women surveyed were encouraged to consider sterilisation. The majority of recommendations (61%) came from gynaecologists and HIV clinicians and were made on the basis of the woman's HIV-positive status. There was a positive correlation between women who had caesareans and women who were recommended to be sterilised.

### Maternal health services

Of women surveyed, 81% reported receiving some pregnancy-related health care, including 58% of women seeking services within two months of the pregnancy. Most women only seek obstetric care around times of pregnancy or active gynaecological problems. Cost is the most important factor for most women in deciding whether to utilise services. There was a strong correlation between receiving care and having a live birth.

The quality of care varied depending on affordability, convenience and availability. Satisfaction with services ranged from India 78%, Cambodia 68%, Nepal 68%, Bangladesh 67%, Indonesia 60%, to Viet Nam 34%.

Overall 42% of women had difficulty finding a gynaecologist to care for them during their pregnancy due to their HIV-positive status, and 18% were not satisfied with the confidentiality afforded to them. Most respondents believed that confidentiality could be better maintained in an integrated health care setting and said they would utilise health care services more regularly if they were integrated within the same facility.

### Infant health care

Formula feeding was most commonly practiced (except in Nepal). Of the 89 infants who were breastfed, only 35% were on ARV prophylaxis. Among women who had live births at last pregnancy, 57% reported that their child had been tested for HIV.

## Key recommendations

### Invest in positive women's organisations

- Increase capacity of HIV-positive women's organisations to respond to their needs
- Train positive women and their partners at national, provincial and local level about their sexual and reproductive health and rights and increase positive women's capacity in decision making
- Facilitate positive women's capacity to advocate for their rights to sexual, reproductive and maternal health care services

### Expand counselling

- Train and employ HIV-positive women as counsellors at all government testing centres
- Expand HIV counselling beyond post-test to include psycho-social/emotional support, ARV treatment, SRHR advice and support; consider couple and family counselling when women do not have decision-making authority; strengthen referral systems to health care services

### Uphold positive women's rights

- Ensure governments fulfil their obligations to protect HIV-positive women's rights according to international treaties
- Ensure no woman is coerced into testing, abortion, sterilisation, caesarean
- Ensure HIV-positive women have access to a range of contraceptive options that they can control, to avoid unwanted pregnancies
- Ensure WHO Guidelines on ARVs are adopted
- Ensure no positive woman experiences discrimination within the health sector
- Train obstetric and gynaecological service providers to be sensitive to the needs and rights of HIV-positive pregnant women; include training on quality of care and positive women's sexual and reproductive health and rights in clinical management and curriculum training of health care workers
- Integrate services to improve access, utilisation and follow-up, and reduce discrimination



### Expand social security

- Review national guidelines for social services requirements and expand social welfare and nutritional support for positive women and children
- Provide transport subsidy for mothers on low income to attend ARV centres
- Improve HIV-positive women's income generation capacity

## 1. Background and methodology

The Women's Program of the Asia Pacific Network of People Living with HIV (Women of APN+, or WAPN+) was established in 2006. WAPN+'s vision is the empowerment of women living with HIV in the region to provide a united voice, improve the quality of our lives, and ensure our rights are protected.<sup>1</sup> WAPN+'s key objectives are to advocate for HIV-positive women's needs and rights, improve our capacity to take on leadership roles, and increase our full participation in decision- and policy-making, including on key issues related to our sexual and reproductive health.

This study on positive women's access to reproductive and maternal health care and services was conducted in six South and South-East Asian countries: Bangladesh, Cambodia, India, Indonesia, Nepal and Viet Nam. Countries were selected to include a mix of low and concentrated epidemics and coverage of services that support women to have HIV-free babies (usually referred to as prevention of mother-to-child transmission or PMTCT). The objective of the study is to examine the experience of access to reproductive and maternal health care and services by HIV-positive women who have been pregnant in the past 18 months.

The mixed-methodology study was conducted in three phases: a quantitative questionnaire in the six selected countries, in-depth interviews with women in Cambodia, India and Indonesia, and focus group discussions with women in Bangladesh, Cambodia, Nepal and Viet Nam.

The findings from this study provide a perspective into the social realities experienced by positive women and girls living with HIV when trying to utilise reproductive and maternal health care services. The recommendations provide guidance on action to be taken in collaboration with governments, the health care sector, civil society and other partners, towards ensuring national HIV policies and programs respond and protect the specific needs and rights of all positive women.

### Relevance

Globally, an estimated 17 million women and girls were living with HIV in 2009 (nearly 52% of the estimated 33.3 million adults living with HIV), and more than two million pregnancies occur each year among HIV-positive women.<sup>2,3</sup> HIV prevalence rate among women has increased since the early 1990s, partly due to increased HIV testing during pregnancy. In 2009, an estimated 370,000 children acquired HIV worldwide, a 24% drop compared to 2004 due to the increased access to services that support women to have HIV-free babies.<sup>4</sup>

HIV testing among pregnant women is estimated to be at 42% coverage worldwide,<sup>5</sup> however some studies indicate that only 9% of pregnant women in Nepal were tested for HIV in 2009, and in Indonesia, less than 1%.<sup>6,7</sup> According to the World Health Organization (WHO), the main barriers to the expansion of HIV testing and counselling among pregnant women is the lack of access to

<sup>1</sup> Asia Pacific Network of People Living with HIV (APN+), 2010. "Women of Asia Pacific Network of People Living with HIV". Available at [http://www.apnplus.org/main/Index.php?module=project&project\\_id=3](http://www.apnplus.org/main/Index.php?module=project&project_id=3)

<sup>2</sup> UNAIDS, 2010. Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010. Joint United Nations Programme on HIV/AIDS (UNAIDS)

<sup>3</sup> McIntyre, James, 2005. Maternal Health and HIV. *Reproductive Health Matters* 2005;13(25):129–135. Available at <http://www.rhm-elsevier.com/article/S0968-8080%2805%2925184-4/abstract>

<sup>4</sup> *ibid*

<sup>5</sup> WHO, 2010 Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector (Annex 5).

<sup>6</sup> Government of Nepal, Ministry of Health and Population, UNGASS Country Progress Report Nepal 2010.

<sup>7</sup> National AIDS Commission Indonesia, *Republic of Indonesia - Country Report on the Follow up to the Declaration of Commitment On HIV/AIDS (UNGASS): Reporting Period 2008 - 2009*. 2009, National AIDS Commission Republic of Indonesia.

antenatal care (ANC) services.<sup>8</sup> Factors influencing access include: i) knowledge and awareness; ii) distance to the health facility; iii) availability and cost (of transportation, services, laboratory tests, procedures, doctor fees, and medications); and iv) confidentiality and attitudes of healthcare providers.

Table 1: Estimates of the HIV epidemic in selected Asian countries, 2009<sup>9</sup>

Country	Estimated adult (15-49 yrs) HIV prevalence (%)	Estimated people living with HIV (adults + children)	Estimated women living with HIV (15+ yrs)
Bangladesh	<0.1	6,300	1,900
Cambodia	0.5	63,000	35,000
India	0.3	2.4 mil	880,000
Indonesia	0.2	310,000	88,000
Nepal	0.4	64,000	20,000
Viet Nam	0.4	280,000	81,000

The WHO estimated that in 2009, 45% of women and 37% of men in need of antiretrovirals (ARVs) received them.<sup>10</sup> A 2007 study from South-East Asia showed that more women than men received ARVs despite the fact that more men are living with HIV.<sup>11</sup> This is explained partly by earlier access by women to HIV testing during pregnancy, and prioritisation of mothers for treatment following the death of a husband or child. WHO reported an estimated 53% of pregnant women living with HIV received ARVs to reduce the risk of transmitting HIV to their infants in 2009, up from 15% in 2005.<sup>12</sup> In Asia, only 23,800 (32%) of the estimated 73,800 women in need of services to support them to have HIV-free babies received such care.

Key challenges in the provision of effective services, particularly in resource-limited settings, include: i) many pregnant women are unaware of being HIV-positive and there are low levels of HIV testing; ii) low coverage of PMTCT services; iii) low knowledge about the need for PMTCT, and the components for effective PMTCT; iv) poorly resourced health care systems; v) loss to follow-up (due to various economic and socio-cultural factors); and vi) poor drug adherence.

<sup>8</sup> WHO Regional Office for South-East Asia, 2010. HIV/AIDS in the South-East Asia Region: Progress report 2010. World Health Organization.

<sup>9</sup> UNAIDS, 2010. Global Report: UNAIDS Report on the Global AIDS Epidemic, 2010. Joint United Nations Programme on HIV/AIDS (UNAIDS).

<sup>10</sup> WHO (2009). Women and Health: Today's Evidence, Tomorrow's Agenda. World Health Organisation.

<sup>11</sup> Le Cœur, Collins, Pannetier *et al.*, 2009. Gender and access to HIV testing and antiretroviral treatments in Thailand: Why do women have more and earlier access? *Social Science & Medicine* 69: p. 846-853.

<sup>12</sup> WHO, 2010. Scaling up HIV services for women and children. Chapter in *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector. 2010 Progress Report*.

Table 2: Global and regional estimates of HIV services for women and children<sup>13</sup>

HIV service parameters	2009	2005
Pregnant women who received an HIV test (in low- and middle-income countries)	26%	7%
Pregnant women who received HIV testing and counselling (in East, South and South-East Asia)	17%	2%
Pregnant women living with HIV receiving ARVs in low- and middle-income countries	53% [40-79%]	15% [12-18%]
Pregnant women living with HIV receiving ARVs in East, South and South-East Asia	32% [22-52]	9%
Infants receiving ARV prophylaxis in low- and middle-income countries	35% [26-53%]	12% [26-40%]
Infants receiving ARV prophylaxis in East, South and South-East Asia	32%	7%

Pregnant HIV-positive women face stigma, discrimination, and sometimes violence, compromising their health and endangering their lives and the lives of their children. Discrimination may lead to poor quality antenatal care or refusal of ANC, labour and delivery services for pregnant positive women, and increased coercion to abort or be sterilised.<sup>14</sup>

In 2010, the WHO released updated guidelines on ARVs for pregnant women. These guidelines recommend that pregnant women living with HIV, and their exposed infants, receive more efficacious regimens as opposed to single-dose Nevirapine, and that all women needing ARVs for their own health receive it.<sup>15,16</sup> Overall recommendations include:

- Earlier start and longer duration of ARVs in women and children
- Need for strategies and increased capacity to assess eligibility for ARVs
- Long-term monitoring, including of adherence to ARVs
- Scaling up interventions to reach more women and children
- Where appropriate, integrating HIV interventions within routine maternal, child and other health services
- Provisions of ARVs to the mother or child to reduce the risk of HIV transmission during the breastfeeding period.

WHO now recommends breastfeeding as a good option for every baby, including those born to mothers living with HIV.<sup>17</sup> Updated guidelines on infant feeding recommend that national health authorities decide whether to counsel and support mothers known to be HIV-positive to either: i) breastfeed and receive ARVs; or ii) avoid all breastfeeding, with the choice governed by which is most likely to result in HIV-free survival of HIV-exposed infants.

Positive mothers should only give formula milk as a replacement to breastfeeding if:

- safe water and sanitation are assured at the household level and in the community; *and*

<sup>13</sup> WHO, 2010. Scaling up HIV services for women and children. Chapter in *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector. 2010 Progress Report*.

<sup>14</sup> *ibid*

<sup>15</sup> WHO, 2010. Antiretroviral drugs for treating pregnant women and preventing HIV infection in infants.

<sup>16</sup> WHO, 2010. *Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector*.

<sup>17</sup> WHO. 2010. Guidelines on HIV and infant feeding 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence.

[http://www.who.int/child\\_adolescent\\_health/documents/9789241599535/en/](http://www.who.int/child_adolescent_health/documents/9789241599535/en/)

- the mother or caregiver can reliably provide sufficient formula milk to support normal growth and development of the infant; *and*
- the mother or caregiver can prepare it cleanly and frequently enough so that it is safe and carries a low risk of diarrhoea and malnutrition; *and*
- the mother or caregiver can, in the first six months, exclusively give formula milk; and
- the family is supportive of this practice; *and*
- the mother/caregiver can access health care that offers comprehensive child health services.

In the six countries covered in this study, there is limited overall progress in providing access to services to support women to have HIV-free babies. In 2009, approximately 30% of positive pregnant women in Cambodia and Viet Nam received ARVs to reduce the risk of HIV transmission to their child, whereas India reportedly achieved lower than 20%, and Indonesia and Nepal less than 4% (no data available for Bangladesh).

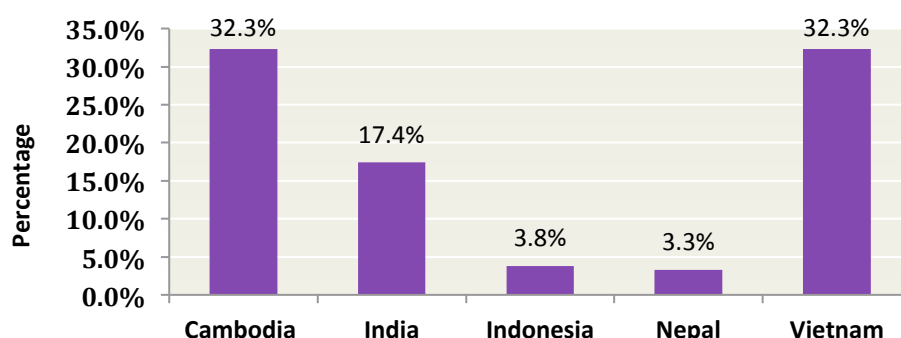


Figure 1: Percentage of HIV-positive pregnant women who receive ARVs, 2009<sup>18,19,20,21,22,23</sup>

## Methods

The study included a quantitative survey (n=757) in the six selected countries, 17 in-depth interviews in Cambodia, India and Indonesia, and ten focus group discussions with 95 positive women in Bangladesh, Cambodia, Nepal and Viet Nam. Discussions were also conducted with the positive people's organisations in each country. The selection of study countries included a range of low and concentrated epidemics and coverage of services in South and South-East Asia. The existence and capacity of national networks of women living with HIV to participate in this survey, as well as follow-up on previous studies such as WAPN+'s 2009 research into women's access to HIV services in Asia,<sup>24</sup> were also taken into consideration in the selection of countries.

<sup>18</sup> Data not available for Bangladesh.

<sup>19</sup> National AIDS Authority, *Cambodia Country Progress Report: Monitoring the Progress towards the Implementation of the Declaration of Commitment on HIV and AIDS - Reporting period January 2008 - December 2009*. 2010.

<sup>20</sup> National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India, *Country Progress Report: Reporting Period - January 2008 to December 2009*, India.

<sup>21</sup> National AIDS Commission Indonesia, *Republic of Indonesia - Country Report on the Follow up to the Declaration of Commitment On HIV/AIDS (UNGASS): Reporting Period 2008 - 2009*. 2009, National AIDS Commission Republic of Indonesia.

<sup>22</sup> Government of Nepal, Ministry of Health and Population, *UNGASS Country Progress Report Nepal 2010*.

<sup>23</sup> The Socialist Republic of Viet Nam, *UNGASS Country Progress Report: Reporting period January 2008 - December 2009*. 2010: Hanoi.

<sup>24</sup> Women's working group of APN+ (WAPN+), 2009. *A Long Walk: Challenges to women's access to HIV services in Asia*. Bangkok. [www.apnplus.org/publications](http://www.apnplus.org/publications)

### Quantitative survey

Convenience sampling was carried out utilising known networks of women living with HIV. The eligibility criteria was women above the age of 16 with a confirmed HIV-positive test, and a confirmed pregnancy within the past 18 months.

The 757 women who completed the survey included: Bangladesh 33, Cambodia 200, India 172, Indonesia 109, Nepal 40, and Viet Nam 203.

Selected members from each participating national network of people living with HIV (PLHIV) administered the survey. Prior to the survey, a three-day training workshop was conducted in Bangkok to review and discuss ethical issues, rationale for the study, research methods and the application of the questionnaire. The questionnaire was translated into local languages. Data collection was conducted between February and March 2011. Because many respondents were semi-literate, surveys were administered orally. The questionnaire included sections on:

- i. Social demographics
- ii. HIV treatment
- iii. Pregnancy
- iv. Sexual and maternal health
- v. Infant health care
- vi. Health care facilities

Completed surveys were sent to the WAPN+ office in Bangkok for compilation and data entry into SPSS Statistical Package. Simple descriptive statistical analyses were carried out.

### Qualitative assessment

Discussions were held with leaders of the participating PLHIV networks to identify critical issues concerning positive women specific to their countries. Participating networks included the Ashar Alo Society, Bangladesh, Cambodian Community of Women living with HIV, Indonesian Network of PLHIV (JOTHI), Gujarat State Network of People living with HIV, Nepal Network of PLHIV, and the Viet Nam Network of PLHIV.

Seventeen interviews were conducted in three sites: Phnom Penh, Cambodia (6), Ahmadabad, India (6) and Jakarta, Indonesia (5), in June 2011. Ten focus group discussion (FGDs) were conducted in five sites: Dhaka, Bangladesh (2), Phnom Penh, Cambodia (2), Kathmandu, Nepal (2), Ha Noi, Viet Nam (2) and Ho Chi Minh City, Viet Nam (2) in October/November 2011. FGDS included 6-12 participants (total 95).

With the help of local translators all interviews were conducted by one researcher and all FGDs by another researcher. Interviews and FGDs ranged from two to three hours. Pseudonyms were identified by all interview respondents and most FGD participants, but in Cambodia, Nepal and Viet Nam several FGD respondents insisted their real names be used if quoted. Respondents were not paid for their participation but their transportation and accommodation expenses were reimbursed.

### Limitations

There were several limitations to the study.

#### Sampling

Convenience sampling may have led to a geographical bias, though effort was made to find participants from both rural and urban centres, on and off roads. Half of the women had a connection to an existing PLHIV network, and therefore may have more exposure to information on reproductive and maternal health than other positive women have.

### Survey instrument

The wide range of issues included in the survey resulted in a long questionnaire (over 100 items) and prevented detailed probing. While this was to a certain extent mitigated by the FGDs and interviews, it became clear after data collection that specific key questions were missed in the survey. For example, although women were asked whether they had been encouraged to be sterilised, women were not asked whether they had been or intend to be sterilised. Back translation was not employed and some questions were translated differently in different countries. Consequently some data was not collected (e.g. in Viet Nam and Cambodia, women were not specifically asked whether their pregnancy resulted in a miscarriage). The study would have benefited greatly from pilot testing.

### Sample size

Distance and time limited the number of respondents that could be reached within the data collection period. Although many findings are expressed as percentages, particular care should be taken when interpreting results for Bangladesh and Nepal because of the small sample sizes ( $\leq 40$ ).

### Data quality

There were some contradictions in respondent answers to similar questions in different sections of the questionnaire, and different understanding of some questions within and between countries. Given the length of the questionnaire, the format, and the amount of time it took to administer (ranging from one to three hours), there was little opportunity to clarify questions and answers.

For these and other reasons, caution should be used when extrapolating the findings to other countries in Asia.

## 2. Respondent -demographic characteristics

A total of 757 women were surveyed (Bangladesh 33, Cambodia 200, India 172, Indonesia 109, Nepal 40, Viet Nam 203). On average, the respondents were 29.3 years old (range: 17-47 years; standard deviation 5.4 years) and had one existing child (range: 0-8). The majority of respondents (77.2%) were currently married or living with a partner, 2.0% had never married or lived with a partner, and the remainder were widows or women no longer living with a partner. Overall 57.2% of respondents lived in urban settings and 42.8% lived in rural areas.

Table 3: Socio-demographic characteristics of survey respondents, by country

Socio-demography characteristics	TOTAL	Bangladesh	Cambodia	India	Indonesia	Nepal	Viet Nam
<b>Total respondents</b>	<b>757</b>	33	200	172	109	40	203
<b>Age (years)</b>							
Mean	<b>29.3</b>	25.3	33.0	25.5	27.9	30.5	30.1
Range	<b>17 – 47</b>	17 - 38	18 - 47	18 - 39	18 - 36	20 - 40	19 - 45
<b>Residence</b>							
Urban	<b>433</b>	10	61	127	89	20	126
(%)	<b>(57.2%)</b>	30.3%	30.5%	73.8%	81.7%	50.0%	62.1%
Rural	<b>320</b>	23	135	45	20	20	77
(%)	<b>(42.8%)</b>	69.7%	67.5%	26.2%	18.3%	50.0%	37.9%
<b>Marital status</b>							
Currently married/with partner	<b>581</b>	30	116	162	91	16	166
(%)	<b>(77.2%)</b>	90.0%	58.0%	94.7%	83.5%	40.0%	83.0%
Ever married/with partner	<b>157</b>	3	79	9	9	24	33
(%)	<b>(20.8%)</b>	9.1%	39.5%	5.3%	8.3%	60.0%	16.5%
Never married/with partner	<b>15</b>	0	5	0	9	0	1
(%)	<b>(2.0%)</b>	0%	2.5%	0%	8.3%	0%	0.5%
<b>Number of children</b>							
Mean	<b>1.7</b>	1.5	2.4	1.7	1.3	1.7	1.2
Range	<b>0 - 8</b>	0 - 5	0 - 8	0 - 7	0 - 4	0 - 6	0 - 4

Half of all respondents (52.8%) depended on their family or members of their household for their main source of income, 37.3% had some form of independent income and 7.9% had no source of income. In Viet Nam substantially more respondents (46.5%) were self-employed than in other countries. Whilst the majority of women (70.9%) had either primary or secondary level education, 15.7% had never been to school. Respondents from Indonesia and Viet Nam spent the longest time in school (average 11.9 and 9.4 years), whereas the women from Nepal and Cambodia spent least time in school (average 3.3 and 3.4 years).



**Table 4: Main sources of income and education level, by country**

<b>Socio-demography characteristics</b>	<b>TOTAL</b>	<b>Bangladesh</b>	<b>Cambodia</b>	<b>India</b>	<b>Indonesia</b>	<b>Nepal</b>	<b>Viet Nam</b>
<b>Total respondents</b>	<b>757</b>	33	200	172	109	40	203
<b>Main source of income (%)</b>							
None	<b>60</b>	9	17	10	17	2	5
(%)	<b>(7.9%)</b>	27.3%	8.5%	5.9%	15.6%	5.1%	2.5%
Household/family	<b>400</b>	21	133	130	53	17	46
(%)	<b>(52.8%)</b>	63.6%	66.5%	75.6%	48.6%	43.6%	22.8%
Self-employed	<b>144</b>	1	33	2	8	6	94
(%)	<b>(19.0%)</b>	3.0%	16.5%	1.2%	7.3%	15.4%	46.5%
Salary (regular employment)	<b>84</b>	1	9	1	23	7	43
(%)	<b>(11.1%)</b>	3.0%	4.5%	0.6%	21.1%	17.9%	21.3%
Daily wage	<b>53</b>	1	6	26	4	6	10
(%)	<b>(7.0%)</b>	3.0%	3.0%	15.1%	3.7%	15.4%	5.0%
Other	<b>11</b>	0	2	0	4	1	4
(%)	<b>(1.5%)</b>	0%	1.0%	0%	3.7%	2.5%	2.0%
<b>Education level (%)</b>							
Never been to school	<b>131</b>	2	52	56	1	13	7
(%)	<b>(17.3%)</b>	6.1%	26.0%	32.6%	0.9%	32.5%	3.4%
Primary/elementary	<b>266</b>	11	121	47	9	12	66
(%)	<b>(35.1%)</b>	33.3%	60.5%	27.3%	8.3%	30.0%	32.5%
Secondary	<b>271</b>	15	23	36	74	8	114
(%)	<b>(35.8%)</b>	45.5%	11.5%	20.9%	67.9%	20.0%	56.4%
Higher secondary/intermediate	<b>73</b>	2	2	32	23	5	9
(%)	<b>(9.6%)</b>	6.1%	1.0%	18.6%	21.1%	12.5%	4.4%
University	<b>4</b>	1	1	0	1	0	1
(%)	<b>(0.5%)</b>	3.0%	0.5%	0.0%	0.9%	0.0%	0.5%
<b>Years in school (years)</b>							
Mean	<b>7.0</b>	7.2	3.4	4.6	11.9	3.3	9.4
Range	<b>1 - 19</b>	3 - 12	1 - 16	2 - 16	5 - 19	1 - 6	2 - 16

Most respondents were members of a PLHIV network (Bangladesh 97.0%, Cambodia 40.0%, India 43.0%, Indonesia 34.9%, Nepal 100%, Viet Nam 60.1%). More than half of the respondents (59.9%) joined before their most recent pregnancy, 22.2% during their pregnancy and 17.9% after their most recent pregnancy.

### 3. Living with HIV

#### HIV diagnosis

On average, respondents had been diagnosed with HIV for a mean of 3.6 years (range: 0-18 years). The majority (56.3%) were diagnosed prior to their most recent pregnancy, 27.4% were diagnosed during pregnancy, and 9.9% after their most recent pregnancy. There were large variations between countries in terms of timing of HIV diagnosis. Cambodia recorded the highest percentage of women who knew their HIV status prior to their most recent pregnancy (82.5%) and India recorded the lowest (22.2%), with the majority of Indian women in the study (73.7%) learning of their HIV status during their most recent pregnancy.

Table 5: Timing of HIV diagnosis, in relation to most recent pregnancy, by country

Country	Timing of HIV diagnosis in relation to most recent pregnancy			No answer (%)	Total (n)
	Before	During	After		
Bangladesh	19 (57.6%)	0 (0.0%)	14 (42.4%)	0.0%	33
Cambodia	165 (82.5%)	30 (15.0%)	4 (2.0%)	0.5%	200
India	38 (22.2%)	126 (73.7%)	5 (2.9%)	1.7%	172
Indonesia	65 (59.6%)	26 (23.9%)	14 (12.8%)	3.7%	109
Nepal	14 (35.0%)	3 (7.5%)	14 (35.0%)	22.5%	40
Viet Nam	125 (61.6%)	22 (10.8%)	24 (11.8%)	15.8%	203
<b>TOTAL</b>	<b>426 (56.3%)</b>	<b>207 (27.3%)</b>	<b>75 (9.9%)</b>	<b>49 (6.5%)</b>	<b>757</b>

Women who tested positive at government facilities are usually referred to the nearest hospital that prescribes ARVs, and linked to outreach workers for follow-up, but women who test at private facilities rarely received counselling or referral.

#### Counselling

Overall, 85.5% of women surveyed said they had taken the HIV test voluntarily and most women received pre-test (72.9%) and post-test counselling (89.8%). In India, only 50% of women tested during pregnancy received pre-test counselling. Post-test counselling rates were lowest in Viet Nam, where one in four women reported *not* receiving post-test counselling.

Whether women received counselling was significantly related to whether or not the test was voluntary, with 90.6 % of women who said the test was voluntary receiving post-test counselling, compared to only 9.1% of women who said the test was not voluntary. One Vietnamese woman in an FGD said that after testing her blood, a health care worker told her she had a problem, took more blood and asked for more money, and then just gave her the result without any counselling or information.

Table 6: Pre-test and post-test counselling received, by country

Country	Pre-test counselling received	Post-test counselling received
<b>Bangladesh</b>	25 (75.8%)	31 (93.9%)
<b>Cambodia</b>	185 (92.5%)	194 (97.0%)
<b>India</b>	86 (50.0%)	167 (97.1%)
<b>Indonesia</b>	94 (86.2%)	100 (91.7%)
<b>Nepal</b>	29 (72.5%)	33 (82.5%)
<b>Viet Nam</b>	133 (65.5%)	155 (76.4%)
<b>TOTAL</b>	<b>552</b> <b>(72.9%)</b>	<b>680</b> <b>(89.8%)</b>

Although policies in all countries state that testing should be voluntary and include counselling, several women in the qualitative arm of the study indicated that they were unaware of being tested for HIV when the test was done, and results were often given to family members (and in one case, a neighbour).

According to survey respondents, the quality of counselling women received ranged from barely adequate to comprehensive, depending on the testing facility, the doctor and the counsellor. Some women in FGDs said they were given no hope on diagnosis. One doctor gave a woman her test result with the words, "Get ready because you are going to be dead soon". Another woman was told, "There is no need to save money because you will not have a long life". Many women in different countries were given misinformation by doctors and other health care workers at the time of their diagnosis. One woman was told that the risk of her baby getting HIV was 60%; another was told that if she and her partner did not have safe sex there is a risk of transmission of HIV to the baby; another woman was warned of the virus "switching" between her and her husband. One woman was told to take paracetamol daily for a year.

*"The provincial hospital has a policy to test all pregnant women. I didn't know I had been tested. They put me in a separate room and isolated me and I was given no information. Shortly after the birth the hospital informed my mother and my husband of my status. I was told by my husband one month after the birth so it wouldn't shock me too much. I was not given any information except they said I could not breastfeed my baby because I had a difficult delivery and I had lots of medication. I only found out information about ARVs later by a relative who works at the district health station."*  
(Ha, Viet Nam)

*"At the time of the first HIV test, I was not counselled, only informed that the routine tests would include HIV. I picked up the blood report from the laboratory myself, and opened it on the way to the doctor's office. I had heard of HIV when I was in school, but did not understand what it was, and was not sure what the test result meant... I decided to take my mother-in-law to my next appointment, and the gynaecologist told her I had HIV, but she misinformed her by telling her that if anybody shared food with me or touched me they would also get HIV. After that, it became very difficult for me. My mother-in-law treated me very badly and it was very hard to convince her and other family members that the information was wrong, especially when I do not understand HIV much either."*

(Muskan, India)

In India, where a high percentage of respondents were tested during pregnancy, women reported that pre-test counselling was more persuasion to be tested than counselling. According to members of the Gujarat State Network of People Living with HIV, "Women are pre-counselled to say 'yes' and agree to the HIV

test." Where pre-test counselling did exist, most women reported it was more to solicit acknowledgement that they understood they were being tested for something requiring a blood sample. Several women admitted that, even when pre-test counselled, they did not understand what the blood test was for or what HIV was at the time of their diagnosis.

The importance of timely, accurate, and appropriate counselling was a recurring theme in all interviews. In particular, women commented on: i) the need for counselling to be available long-term, not only pre- or post-test, when many women are unable to absorb the information; ii)

*"Before my diagnosis, I had only ever heard the word HIV from a TV advertisement. I was in the fifth month of pregnancy, and I went to the hospital for an initial check-up and was ordered to undergo a number of blood tests, including one for HIV. I remember receiving some pre-test counselling about HIV transmission and prevention, but I didn't understand properly and didn't take much interest in what the counsellor said. I actually didn't collect the lab report when it was ready because I was ill, and sent my husband. When he took the report to the doctor, he told him that I had HIV... I have some reports from the hospital but I don't know what they are. I was told I can prevent HIV to my child, but I don't know how. Probably with medicine. The doctor did tell me that I should not go for a third pregnancy and suggested that two children were enough for me. On the doctor's suggestion I agreed that I should be sterilised... I do not understand how I could have gotten this disease. What kind of disease has no cure after treatment? I do not understand what it is. It was very surprising to me how I got this infection."*

(Sita, India)

the need to incorporate emotional support with basic HIV information and treatment literacy, as well as sexual, reproductive, maternal and child health information; and iii) the need to include advice on navigating the health care system as a positive woman. Most Indian women interviewed felt that counselling should involve extended family members, in order to dispel myths and inaccurate information about HIV transmission, and emphasised the need for regular and consistent follow-up care.

*"When I received the news I was despairing but then I was referred to Ashar Alo Society [peer support organisation] and I received peer counselling and I saw other positive women who gave birth to a negative child and then I became hopeful."*

(Nasrin, Bangladesh)

In interviews and FGDs, women in all countries highlighted the importance of having trained HIV-positive female counsellors, who are peers and

therefore more able to help female clients open up and ask questions because they understand their issues.

### Disclosure of HIV status

Of women surveyed, 90.2% reported having told their (current or previous) partner or husband of their HIV

status. Between 40 -60% of women also disclosed to female family members, namely their mothers (61.4%), mothers-in-law (41.5%), and other female relatives (47.6%). In Cambodia 15.0% of respondents said they had disclosed to neighbours; no respondents in other countries had done so.

*"The counsellors and other support team should be HIV-positive and that would help women to learn from others' experiences. This is why people are free to talk openly with me, because my HIV status is known by everyone."*  
(Phala, Cambodia)

Table 7: Disclosure of HIV status, by country

Country	Who knows your status?					
	Husband/ partner	Mother	Mother-in- law	Other female relative	Child(ren)	Support group members
Bangladesh	31 (93.9%)	18 (54.5%)	18 (54.5%)	19 (57.6%)	3 (9.1%)	15 (45.5%)
Cambodia	191 (95.5%)	151 (75.5%)	79 (39.5%)	161 (80.5%)	49 (24.5%)	148 (74.0%)
India	165 (95.9%)	82 (47.7%)	55 (32.0%)	33 (19.2%)	0 (0%)	13 (7.6%)
Indonesia	79 (72.5%)	51 (46.8%)	25 (22.9%)	49 (45.0%)	1 (0.9%)	22 (20.2%)
Nepal	39 (97.5%)	19 (47.5%)	21 (52.5%)	19 (47.5%)	15 (37.5%)	26 (65.0%)
Viet Nam	178 (87.7%)	144 (70.9%)	116 (57.1%)	79 (38.9%)	19 (9.4%)	60 (29.6%)
<b>TOTAL</b>	<b>683 (90.2%)</b>	<b>465 (61.4%)</b>	<b>314 (41.5%)</b>	<b>360 (47.6%)</b>	<b>87 (11.5%)</b>	<b>284 (37.5%)</b>

Reasons for non-disclosure were largely due to fear of stigma and discrimination, and in some cases a desire to protect family and loved ones from information that might cause them pain and anxiety. In India, disclosure to family was often made by health personnel without the consent of the female client.

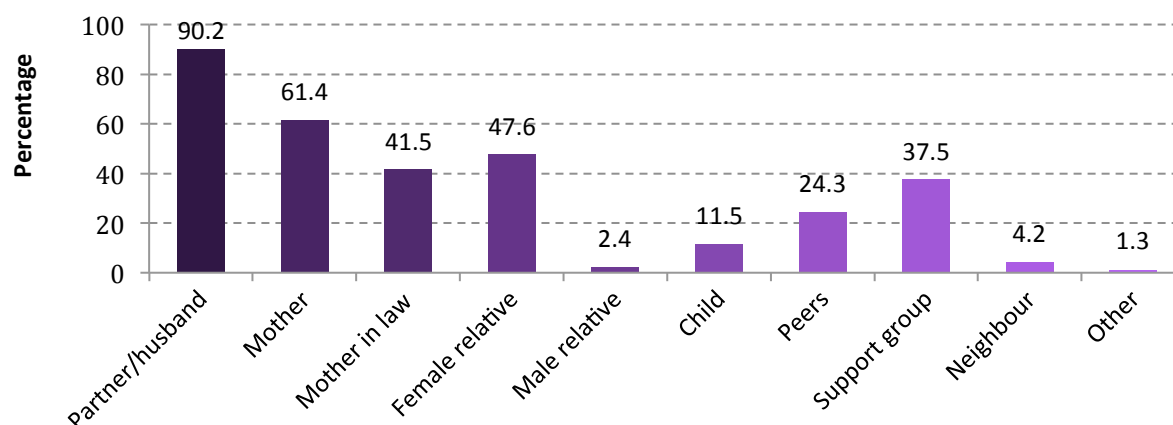


Figure 2: People to whom HIV-positive pregnant women disclosed their HIV

Many women in the FGDs described discrimination they faced after disclosure to family members. The mother of one respondent took her children away from her, believing they would get HIV if they continued to live with her. More commonly discrimination came from the mothers-in-law, who often blame the woman for bringing HIV into the family, particularly after the death of the husband. Many family members do not believe it is possible for an HIV-positive couple to have an HIV-negative child; some in-laws will not touch the HIV-positive women's child, change nappies, etc, even if the child has received a confirmed HIV-negative result.

*"I immediately told my in-laws, but instead of comforting me, they kicked me out of the family and would not even allow me to touch my husband's coffin. Then, when I told my own mother, she beat me and told me to get off the property. The next few years were very difficult for me."*  
(Phala, Cambodia)

One woman in Viet Nam said her in-laws, who are afraid that they will catch HIV, wanted to throw her out after her husband died but they could not because she had a son and they would lose face and harm their reputation if they did so. In Bangladesh, of the women who had disclosed their status to their in-laws, only one said hers were supportive. One woman faced particularly atrocious treatment.

*"[My in-laws] beat me and treated me very badly and used loose words on my character throughout the neighbourhood. They told everybody I had HIV. Then they tried to force my husband to abandon me saying that I would not give a son to the family and was therefore a useless woman. But my husband... said he would continue the marriage."*  
(Rashma, India)

In several countries, when women go for medical check-ups they are put in separate rooms specifically designated for infectious diseases patients. Several women admitted not having disclosed their HIV status to their gynaecologists when they went to seek care for their pregnancy because of fear of discrimination, fear of refusal of services, or fear of being referred for a caesarean.

Several incentives are offered to encourage Cambodian positive women to disclose their HIV status in order to get them to deliver in hospitals and thus receive appropriate treatment for their infants.

*"My husband worked abroad for fifteen years and sent all his money home but when he was diagnosed with HIV the discrimination started. My in-laws separated everything - plates and cups. I planned to have my baby in the hospital by caesarean. My mother came to stay with me and was prepared to help me if necessary. She even had some gloves. My mother-in-law told her there was no need to stay so she went back home. The next day my labour pains began. The delivery happened early. The baby was coming quickly and I was crying but my mother-in-law stopped everybody from coming into the room. I was alone crying, crying. Some of the neighbours were willing to help me but my mother-in-law stopped them and said that as I'm positive and I'm infectious, nobody needs to go there. From the outside the neighbours told me to try to lie on the floor and when I tried to move from the bed to the floor, the baby was born, but it died. They didn't want the baby to survive because it was an issue of property inheritance."*  
(Jasmine, Bangladesh)

In some districts, if a woman discloses, doctor's visits are free and/or delivery costs (normally around USD10) are waived. Despite offers of free services, many women still choose not to disclose and opt to pay the extra cost because they are afraid of discrimination.

### Antiretrovirals

Among the women surveyed, 485 (64.1%) were currently taking ARVs. The majority of women in all countries were on ARVs except in India where only 26.7% of respondents were. The average time since initiating ARVs was 27 months (Bangladesh 43 months, Cambodia 19, India 5, Indonesia 30, Nepal 30, Viet Nam 34). The longest time any respondent had been on ARVs was 141 months (almost 12 years).

Of the 354 women who provided details of their ARV the regimen, the majority of (51.4%) were on Lamivudine (3TC) + Zidovudine (AZT) + Nevirapine (NVP), with an additional 14.7% on 3TC + AZT + Efavirenz (EFV); 29.3% of respondents were on a regimen that included Stavudine (d4T); and only 4.5% of women were on a regimen that included Tenofovir (TDF), even though it is now available in most countries.

Stavudine is still commonly used in Cambodia (by 30.5% of respondents) and Viet Nam (31.5%), as well as India (18.7%) and Indonesia (14.7%), despite WHO guidelines which now advise against its use. Some women are afraid of the negative side effects of d4T they have seen among their peers, losing weight on the face and limbs and gaining swollen bellies (lipodystrophy), but say that they cannot ask their doctor to change their regimen. Some doctors in Viet Nam insist on continuing on

d4T for at least one year. Some members of national networks suggested that the reason for continued use may be because the government has purchased the drug and there is still a great deal of stock in reserve in the country.

Among 338 respondents who gave details of when they initiated ARVs in relation to their pregnancies, a minority (41.2%) reported initiating ARVs before their current pregnancy, 50.9% during their pregnancy and 7.9% at the point of delivery.

Table 6: ARV combination among respondents

Antiretroviral combinations*	n	%
3TC + AZT + NVP	182	51.4
3TC + AZT + EFV	52	14.7
3TC + d4T + NVP	89	25.1
3TC + d4T + EFV	15	4.2
3TC + TDF + NVP	7	2.0
3TC + TDF + EFV	4	1.1
3TC + AZT + TDF	5	1.4
	<b>354</b>	<b>100%</b>

Table 9: ARV uptake and time of ARV initiation in relation to pregnancy, by country

Country	N	Currently on ARV	Initiation of ARV		
			Before pregnancy	During pregnancy	At delivery
Bangladesh	33	21 (63.6%)	42.9%	52.3%	4.8%
Cambodia	200	170 (85.0%)	56.4%	43.6%	0%
India	172	46 (26.7%)	11.1%	59.7%	29.2%
Indonesia	109	77 (70.6%)	37.7%	59.0%	3.3%
Nepal	40	26 (65.0%)	66.7%	33.3%	0%
Viet Nam	203	145 (71.4%)	44.7%	51.1%	4.3%
<b>Total</b>	<b>757</b>	<b>485 (64.1%)</b>	<b>41.2%</b>	<b>50.9%</b>	<b>7.9%</b>



## Key issues

Reasons for starting ARV medication included: low CD4 cell count (55.6% of respondents); doctor recommended (44.1%); opportunistic infections (34.4%); pregnancy (23.9%). Most women not on ARVs said this was because their CD4 cell count was still high, yet only 7.5% of women initiated ARVs at CD4 counts greater than 350 cells/ $\mu$ l and 40.1% of respondents did not start ARVs until their CD4 count was below 200.

*"I was diagnosed during my pregnancy and referred to Kathmandu. My husband didn't want me to come because he thought that if I start taking medicine the baby will die. I started on ARVs and after one month I returned to my village and then I miscarried one month later. My husband blames me for killing the baby with the medicine. I also believe that it is because of the medicine. Before I started the medicine the baby was fine."*  
(Laxmi, Nepal)

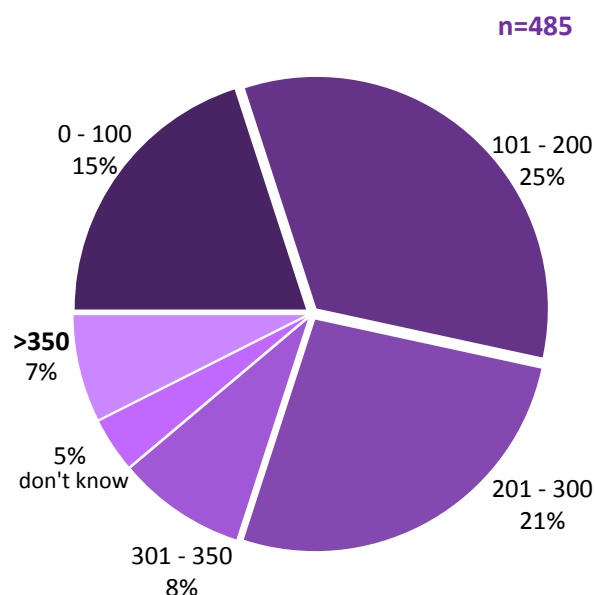


Figure 3: CD4 cell count (/ $\mu$ l) at time of ARV initiation

Of the 338 women who received ARVs during pregnancy, 113 women (33.0%) admitted having difficulties staying on the ARV regimen. The main reasons women faced difficulties were side effects (85.7%), fear for baby (68.1%), illness (68.1%) and inability to access the clinic (53.8%). Some women in FGDs said they receive very little information and many are afraid ARVs might harm their infant. One woman who was put on ARVs during her pregnancy blames the medication for the death of her child.

In Cambodia women are now starting ARVs once their CD4 count drops below 350. In Viet Nam practice is slowly changing; in provinces with low HIV prevalence, people are being put onto ARVs earlier but in provinces where there are many positive people it is still difficult to get on ARVs early.

*"I don't know what CD4 is only that the doctor told me to take five big pills and ten small pills. But when I got pregnant the last time, the baby did not allow me to take the pills. Every time I took a pill, I vomited, and I always felt hot. So I quit taking them."*  
(Soriya, Cambodia)

*"Because I looked healthy, when I was first tested, the doctor said I didn't need any more tests or treatment, but then other women I met through [the PLHIV network] said that was wrong and that I needed to have a CD4 test. I went back to the doctor after a month and demanded the test. My CD4 was 310. He told me that my CD4 was still high and I was healthy and not eligible to start ARV. But my friends insisted that, according to some new guidelines, if my CD4 was below 350 I should be taking ARVs, so I went back again because I saw how sick my husband was, and I was pregnant, and I said I wanted to be on ARVs. Finally the doctor agreed."*  
(Yeni, Indonesia)



Some women who have shown adverse side effects to one ARV are put on dual ARV therapy only.

*"I am afraid to be taking these medications [AZT + 3TC]. I am afraid of the side effects. I still have a skin rash, and the doctor says my haemoglobin is low. What is this doing to the baby?.. I wish I had more information on ARVs, but there is only one HIV doctor in my province, and I have to rely on what he tells me."*  
(Dewi, Indonesia)

Of the women not currently on ARVs, 61 women reported having initiated ARVs previously either during the pregnancy (43 women) or at the point of delivery (18 women) for the purpose of preventing HIV transmission to their unborn infant. Of those not on ARVs and who delivered, all were given a single dose of NVP when labour began. Following delivery, these women were taken off ARVs by their doctor or they stopped due to transportation and other costs. One woman in Indonesia said she was ineligible for free ARVs because she was not legally married, and as she could not afford to buy ARVs, she did not take any during her most recent pregnancy.

In interviews, several reasons were cited for discontinuing treatment, not adhering to regimens, or not seeking ARVs, including: i) cost (of transportation, administration and doctor's fees, laboratory tests, procedures); ii) adverse side effects; and iii) stock-out or expired drugs. One interviewee said that some women feel better after taking their medicine, and think they are cured, so they stop taking it.

Some women have never had a CD4 count to monitor their HIV progression and have never discussed ARVs with their doctor. Although ARVs are free in Cambodia, women have to visit the clinic several times before they are put on treatment in order to demonstrate they are capable of adherence and somebody is committed to helping them. One woman who has had no medical check-up since her diagnosis three years earlier and does not know her CD4 count said it is too expensive to pay for the transport as well as the doctor's visit (USD2).

Many women said that the biggest challenges to staying on treatment is finding the money to cover transportation expenses. Every month most women must travel to their ARV centre to get their ARVs but often they do not have enough money for transport. One Indonesian woman said it costs her one eighth of her monthly income to travel to the government hospital. Many women have to borrow money to make the trip.

## 4. Reproductive health

### Contraception

Condoms were the most known (88.1%), available (83.4%), used (79.3%) and preferred (63.9%) method of contraception, followed by oral pills. Preference for condoms ranged from 48.6% in Indonesia to 80.0% in Nepal. Bangladesh showed the highest preference for pills (36.4%), compared to just 2.5% in Nepal. The use of injectables was not a preferred option for any respondents in India, yet in Indonesia 22.9% indicated preference for this method. Awareness of intrauterine device (IUD) was 38.2%, but their availability, usage and preference were substantially lower: IUD was not a preferred option (0%) in Bangladesh, Cambodia or Nepal, but was preferred by 8.3% Indonesia and 8.7% of women in India. Four respondents could not name any method to prevent pregnancy.

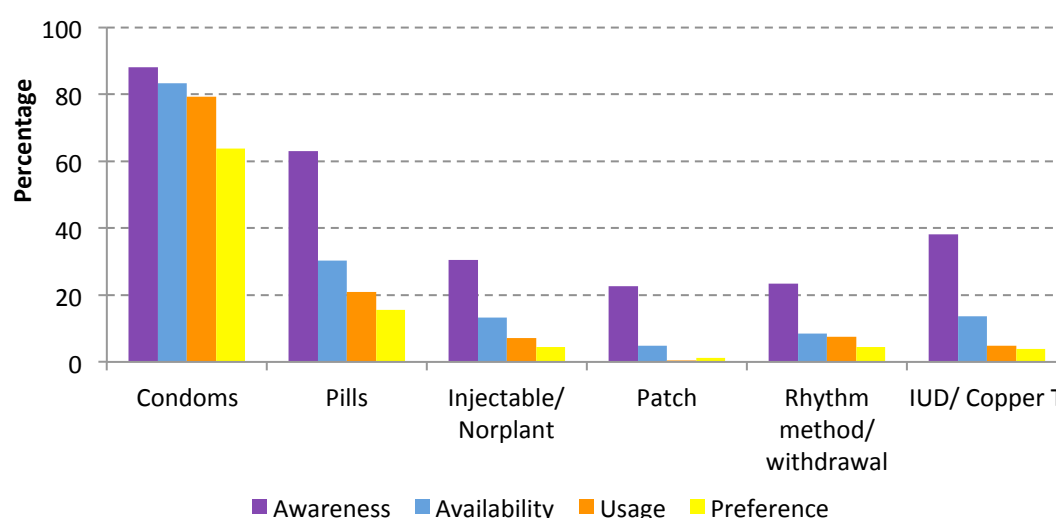


Figure 4: Awareness, availability, usage and preference of contraceptive methods

Despite the stated preference for condoms in the survey, they are not used consistently. The major reason given was because the woman's partner makes decisions on condom use (Bangladesh 36.4%, Cambodia 63.0%, India 39.5%, Indonesia 23.9%, Nepal 7.0%, Viet Nam 19.2%). Women in interviews and FGDs said consistent condom use was very difficult because i) their partners object to condoms and complain that they do not enjoy sex with them, ii) they find them inconvenient or iii) they cannot afford them. One woman, whose HIV-negative husband insists on not using condoms, suggested that he needs more counselling. The need to counsel couples together about consistent condom use was raised by several women in different countries.

While most women said they preferred condoms for prevention of STIs, to prevent pregnancies, they want family planning methods that they can control - IUDs, birth control pills or injectables. Women were not asked in the survey whether they used microbicides, female condoms or sterilisation as a form of contraception however some women in the qualitative part of the study indicated that they opted for tubal ligation to avoid pregnancy. Women who were sterilised said they now found it more difficult to convince their husbands or partners to use condoms.

*"When the doctor provides counselling on pregnancy prevention they should also provide counselling to men because it's men who want to have the babies. Most women who have a pregnancy don't want it. It's the men."*  
(Semlay, Cambodia)

Many women said that 100% condom use is the only contraceptive option promoted amongst positive women, including with sero-concordant couples, because health care workers do not want them to spread the virus. Women are advised to use condoms exclusively to avoid cross infection of a different strain of HIV. Women in FGDs in Viet Nam said they would like better access to female condoms which are not readily available and suggested promoting female condoms.

The persons who respondents were most likely to approach for advice on reproductive and maternal health options were medical practitioners, with half of the respondents seeking support from them. Although less women (23.0%) sought help from support groups, they were viewed as most supportive.

Only 64.2% of respondents sought advice or counselling (usually from a facility-based medical practitioner) regarding reproductive health options prior to their most recent pregnancy (Bangladesh 57.6%, Cambodia 78.0%, India 76.2%, Indonesia 67.9%, Nepal 35.0%, Viet Nam 44.8%). In Cambodia, 46.0% of respondents also sought advice from their peer support group. For most poor women, interactions with the health system were limited to their HIV care and treatment, and during pregnancy. Opportunities for counselling on family planning were few. Women interviewed did not have much information on pregnancy prevention or birth spacing, and family planning is a topic few women are comfortable to raise with their (mostly male) HIV doctors. Amongst those who did raise issues about their sexual and reproductive health, responses from their doctors varied, but often they discouraged further discussion. Several women chose to seek sexual and reproductive health care services at private or NGO-sponsored clinics, sometimes without disclosing their HIV status for fear of discrimination.

### Pregnancy outcomes

Of the 757 survey respondents, 186 women (24.6%) were still pregnant at the time of the survey. Among the remainder who were pregnant in the past 18 months but were not currently pregnant, 72.0% had live births and 28.0% had either an abortion, miscarried or had a still birth.

Table 10: Outcome of most recent pregnancy among women who delivered in past 18 months

Country	Outcome of birth		Total
	Live birth	Abortion/ miscarriage/still birth	
<b>Bangladesh</b>	24 (96.0%)	1 (4.0%)	25
<b>Cambodia</b>	98 (76.6%)	30 (23.4%)	128
<b>India</b>	116 (95.1%)	6 (4.9%)	122
<b>Indonesia</b>	74 (87.0%)	11 (13.0%)	85
<b>Nepal</b>	14 (42.4%)	19 (57.6%)	33
<b>Viet Nam</b>	85 (47.7%)	93 (52.3%)	178
<b>Total</b>	<b>411 (72.0%)</b>	<b>160 (28.0%)</b>	<b>571</b>

It was rare for women in most countries to find supportive health care workers during their pregnancy. In Cambodia and Viet Nam, some women who were determined to have a child educated themselves about current HIV science, and discovered supportive doctors within the public health system.

*"We both understand about positive prevention and were consistently using condoms, so when we decided to have a baby we went to discuss it with our HIV doctor. At first, he was surprised we wanted to have a baby, but later he explained about the best time of the month to try for a baby, and also about PMTCT. We only had sex three times without a condom and I got pregnant."*  
(Kagna, Cambodia)

*"Six years ago my first baby died because of the stigma and neglect. With this second pregnancy I saw a private gynaecologist who was also an HIV specialist. I went on ARVs and I was well prepared. I arranged for a C-section ten days before the due date and I bought the formula feed. My baby was delivered in the public hospital by the gynaecologist and I faced no discrimination. My baby has been tested and is negative."*  
(Nhan, Viet Nam)

However, most women in FGDs and interviews said they were discouraged by health care workers from becoming pregnant. Doctors were often unsupportive and proffered a range of reasons for discontinuing a pregnancy, including:

- the baby may be positive
- the baby may be orphaned
- pregnancy may weaken the woman's health
- the woman has a poor economic situation
- older women shouldn't have a baby
- the woman already has children.

One doctor said, "Even though the risk is very low, what if you are the one percent?". In many cases women who were discouraged from becoming pregnant chose to ignore the advice.

*"When I went to the obstetrics department the staff were afraid of me and said, 'How dare you have a baby. Aren't you afraid to die?' The doctor said, 'You are already positive so your health is not good so you should have an abortion'. He gave me many reasons why I should not continue with the pregnancy. I said to the doctor that I have a right to have a baby under the law."*  
(Kieu, Viet Nam)

*"[The gynaecologist] told me it was my choice to continue the pregnancy or abort, and that I should consider my HIV status. Then she paused a long time. She was not helpful and didn't give us much time or attention when we told her we would continue the pregnancy."*  
(Mena, India)

*"The doctor asked me why I wanted to have another baby when I was so weak and tired all the time. He tried to talk me out of it but I was determined to have a baby so I left without his advice and when I came back the next time I was pregnant, and he couldn't say anything then."*  
(Dalin, Cambodia)

Of women surveyed, 26.6% said their pregnancy was unplanned. Planned pregnancies were usually first pregnancies, or first pregnancies with a new husband or partner. Overall, 37.1% of women reported their most recent pregnancy as unwanted (Bangladesh 33.3%, Cambodia 43.5%, India 10.3%, Indonesia 33.0%, Nepal 47.5%, Viet Nam 53.2%). There was no significant relationship

between knowing HIV status before pregnancy and wanting the pregnancy, but whether or not the woman was currently living with a partner was significantly related to whether the pregnancy was wanted. Several Cambodian women said that it was their husbands, not them, who wanted the pregnancy.

Less than half (44.8%) of respondents reported that decisions regarding their pregnancy were made together with their husband or partner; in 21.0% of cases, the male alone made the decisions; and in 10.6% of cases, the woman alone made the decision. Indonesia, Nepal and Viet Nam had substantially more women as sole decision-makers (range: 12.8% to 19.2%) compared to Bangladesh, Cambodia and India (range 3.0% to 6.4%).

Overall 70 women (9.2%; range: Nepal 2.5% to India 16.9%) said their mother or mother-in-law was also involved in decisions around pregnancy. In-laws often pressurise a woman to have a child, especially if she has no son. This can be very difficult if the woman has not disclosed her HIV status or if she has been sterilised. In Nepal, some women consequently screen their pregnancies and if it is a girl, have an abortion.

*"My mother-in-law said she needs at least one grandson. I didn't want to get pregnant once I knew my status, but she didn't know my status and she pressurised me to have a child. She told my husband to find another woman to marry if I didn't get pregnant. My husband also wanted to have a son and he said if I gave birth to a girl he will kill the baby and dig a grave and put the baby in the grave. When I was six months pregnant I had an ultrasound to determine the sex of the baby and when we knew it was a boy I went ahead and gave birth."*  
(Sunita, Nepal)

Table 11: Pregnancy decision-maker among couples, by country

Country	n	Pregnancy decision maker		
		Couple together	Partner only	Woman only
Bangladesh	33	54.5%	12.1%	3.0%
Cambodia	200	50.0%	21.5%	4.5%
India	172	51.7%	37.8%	6.4%
Indonesia	109	37.6%	20.2%	12.8%
Nepal	40	37.5%	27.5%	15.0%
Viet Nam	203	37.4%	6.9%	19.2%
<b>Total</b>	<b>757</b>	<b>44.8%</b>	<b>21.0%</b>	<b>10.6%</b>

In total, nine women (1.2% of all respondents) had still births. In Nepal, the number of miscarriages was considerable with eight of the eighteen pregnancies resulting in miscarriage, the highest number in one of the smallest samples. Women in the Nepal FGDs did not consider that this rate of spontaneous miscarriage was particularly high compared with the general population.

### Abortion

Among the 573 respondents who had been pregnant in the previous 18 months and were no longer pregnant, 125 (21.8%) reported that they had an abortion. There is wide variation in the proportion of pregnancies that resulted in abortion, from Bangladesh and India 0-1%, Indonesia 8.3%, Cambodia 11.5%, Nepal 25.0%, to Viet Nam 43.9%.

Whether a woman's pregnancy was aborted directly correlated with whether the pregnancy was wanted. Nevertheless, among the women who had abortions, 29.4% said the pregnancy had been wanted.

## Key issues

Reasons for having an abortion included poor economic situation, fear of infecting the baby, and the pregnancy being unplanned; 60.0% of women reported that the abortion occurred specifically because of their HIV status. Many Vietnamese women in FGDs said they had an abortion because they assumed or were told that the baby would be HIV-positive or their health status was too weak. Some said doctors often say the pregnancy is not normal after the ultrasound. One woman was advised to have an abortion just before the delivery.

Many women were asked to consider abortion either by health personnel and/or by their family members. In the majority of cases women said that the decision to have an abortion was made by themselves, although sometimes it was made by their husbands.

*"When I found out my husband was HIV-negative I was so happy and thanked God because I felt that now, if the child was also healthy, there would be at least one parent to care for him. But the first thing my husband said was that he did not want me to continue the pregnancy. He mentally tortured me to have an abortion, even after the doctor told him it was too late in the pregnancy. I was confident that I could deliver the child free of HIV by having a caesarean, not breastfeeding, and other things, as I was counselled... But my husband and my mother-in-law continued to insist that the baby would be born positive, and pressured me to have an abortion. My husband threatened that if I didn't abort the pregnancy he would divorce me."*  
(Ritika, India)

*"One doctor asked me why I wanted to have the baby when I'm HIV-positive. He said the baby will also be infected and advised that I should not have the baby. Then he discussed it with my husband and asked him if he wanted the baby, and he decided against it."*  
(Mina, Nepal)

Many women who were urged to have an abortion faced discrimination when they had the procedure. Some women had to pay higher fees than HIV-negative women paid. Other women were made to wait until the end of the day when all procedures among HIV-negative women were completed. Some women who had a medical rather than a surgical abortion suffered severe pain and blood loss as a result.

*"When I went for the abortion I had to wait for all the negative women to go first. They used three pairs of gloves and covered all their body with plastic, like a raincoat, and they wore glasses because they were afraid."*  
(Hong, Viet Nam)

*"I found out my status when I had a medical check-up during my pregnancy and I decided to have an abortion because I was afraid my baby would be positive. When they found out my status they did not want to give me an abortion and referred me to a specialist hospital saying that they did not have the right equipment. I had to bribe them to get an abortion."*  
(My, Viet Nam)

Because many doctors in government hospitals refuse to perform an abortion if the woman has HIV, many women avoid disclosure by going to a private clinic. One woman went to a private clinic and said she had hepatitis; she was charged more than other women for "preventive materials and expensive chemicals to sterilise the instruments", but she did not face discrimination, whereas if she had told them she had HIV, they would not have allowed her have the procedure at that clinic.

One woman tried to use traditional medicine to induce an abortion because she was afraid of the stigma she might face if she went to the hospital. She began to haemorrhage and was forced to go to the hospital where she faced lots of discrimination from the doctor.

### Delivery

Of 420 women who had delivered by the time of the study, 63.1% had vaginal deliveries and 36.8% were by caesarean section. The proportion of caesarean sections varied considerably between countries: Cambodia 7.1%, Nepal 33.3%, India 35.8%, Viet Nam 41.4%, Bangladesh 56.5% and Indonesia 67.1%. There was no relationship between length of time women had been on ARVs and type of delivery.

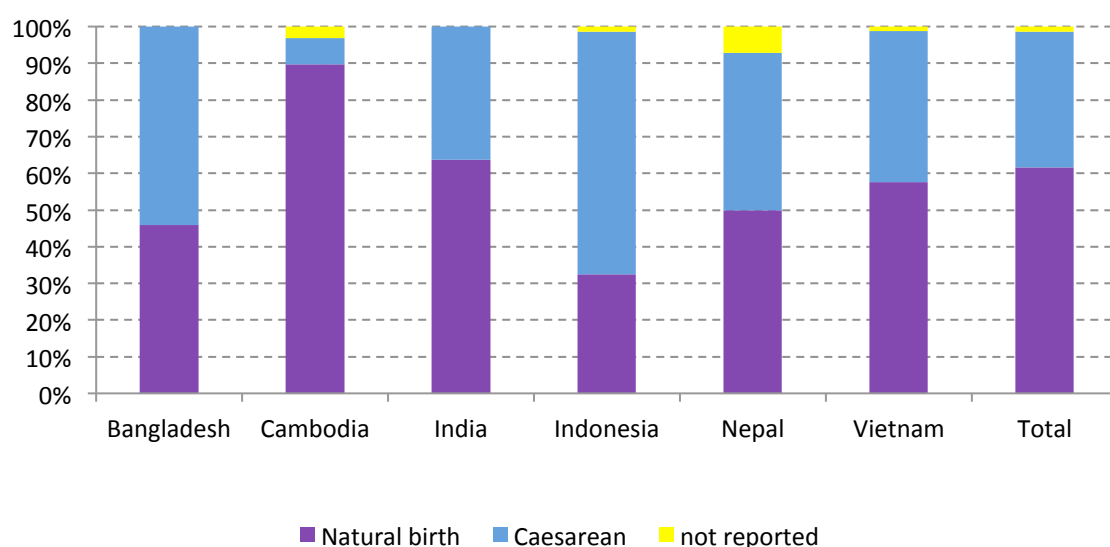


Figure 5: Proportion of live births conducted through natural deliveries or caesarean sections

Proportionately more women who knew their HIV status delivered at government healthcare facilities (84.7% versus 71.1%), except in Bangladesh where all women surveyed delivered at an NGO clinic. Among women who did not know their HIV status, there were three times as many home deliveries (29 in total). Women in rural areas who knew their status usually travelled to an urban area for the delivery.

*"I went into labour prematurely and went to the hospital. It was a different hospital and I did not know any of the staff, but it was the closest to my house. The first thing they asked me was why I was having a baby when I knew I was HIV-positive. One person asked me why I had not had an abortion. Then I was told to lay down with my feet up [in stirrups]. I was left alone for hours in labour like that, and nobody came to check on me. The first baby came out and fell directly into the rubbish bin under my feet. I could not do anything because the second baby was coming out so quickly. When someone finally came to check on me, the first baby was all black and blue, and dead, and the second one was halfway out. They did not want to touch the baby because they did not want to touch my blood. I heard the second baby cry. He was a real person. But they took him away before I could properly see him and put him on oxygen for five hours, and then told me that he died. I never saw him except for five seconds. I was so sad because I think my babies would have lived if they had gotten proper treatment. But I didn't say anything because I didn't want to hear more harsh words directed at me."*  
(Navi, Cambodia)



In the FGDs and interviews extreme instances of discrimination at the time of the delivery were cited by women in all countries except Bangladesh. Many women recounted their experiences of being

*"During the delivery of my baby the doctor wanted to put on two sets of gloves. He had put up on one set of gloves but the baby was already coming out and the doctor tried to push it back in so he could put on another set of gloves."*  
(Saru, Nepal)

completely neglected by staff before, during and after their delivery,

*"I felt very sad. The nursing staff wrapped my baby in plastic because they did not want the blood to get anywhere. I never thought that this kind of situation would happen to my baby and me. The doctor was very good, but not the support staff."*  
(Lina, Indonesia)

or of staff abusing the woman for getting pregnant when she was in the throes of labour pains. Women were left alone in labour, and often staff refused to touch them or bathe their newborn infant. Women recounted stories of them or their mother or husband having to bathe the newborn infant, and one incident where the woman's mother was made to wash the blood off the floor after the delivery. Most women in Viet Nam

are put in separate rooms and isolated during delivery, and must pay the cost of the private room.

*"When I was delivering the doctor left me alone and the baby came and just fell down."*  
(Xuan, Viet Nam)

*"When I was in labour I went to the hospital and they tested my blood without telling me. Then they just left me alone. Other women who came after me were attended to and transferred to a ward but from 8am in the morning until 5am the next morning I was left alone in the waiting area. After the delivery I was moved to the corridor and again left alone until the next morning. All the women who gave birth were taken to a ward and I was left there. Later I asked the doctor why they had treated me like that. He said that there was no room. I said, 'This is not a good enough explanation. If you don't have the space why did you accept me at this hospital?'"*  
(Suong, Viet Nam)

## Caesarean

Many women in all countries except Cambodia said they were rarely given the option to have a vaginal delivery if their HIV status was known. Many women believe it is necessary to have a caesarean. In Viet Nam women said it is

*"The doctor yelled at me for not having said [I am HIV-positive] and scolded that if I had said something earlier, they could have handled the delivery in a more 'appropriate' way... That was why I had not told them I was HIV-positive, because I could not afford the caesarean. Lucky for me I was already dilated eight centimetres and it was too late to do anything."*  
(Riri, Indonesia)

government policy for HIV-positive women to have a caesarean delivery, but often it is difficult to find doctors willing to perform the operation because they are afraid of HIV.



*"The doctor told me to have a caesarean because my baby was already well-developed. I went to the operating room and when the doctor looked at the paper and saw that this was not a normal case, that it was a PMTCT case, the doctor said, 'This is not my case and another doctor look after you'. I waited three hours and nobody came. Then I heard a big discussion between the doctors so I said, 'Okay, I don't need to have the baby today.' So I went downstairs and I had to wait another one week to have the baby."*

(Sharmila, Nepal)

Some women did not reveal their HIV status to their gynaecologist in order to avoid what they perceived to be a mandatory referral for a caesarean delivery. In Indonesia, the cost of a caesarean section is prohibitively expensive for many women (over USD 800 without insurance).

A woman in Viet Nam said that usually after a caesarean HIV-negative women recover in the hospital for seven or so days but if the woman is HIV-positive, after one or two days staff start asking her if she wants to go home and she is usually pushed out whether she wants to go or not.

*"Everything for the caesarean had to be paid for even though it was a government hospital. Before my caesarean my doctor was asking other nurses to assist but they all had excuses like, 'I have a cut finger'. Eventually the doctor got staff to help. When I had the caesarean the bed was covered with hard disposable plastic. Afterwards I was very cold due to the air-conditioning and I asked for a cover but nobody would give me a blanket. My status was disclosed. My bed was marked as HIV-positive and the clinical staff started to ask questions like, 'How did you get infected?' I was not given any bed sheets and the day after the delivery I had to leave the hospital."*

(Sharmin, Bangladesh)

## Sterilisation

Of the women surveyed, 228 (30.1%) said they were asked or encouraged to consider sterilisation. Of these, 140 (61.4%) felt they were given the freedom to decline and 86 women (37.7%) said they did not have the option to decline. Women in Cambodia, India, and Indonesia recorded the highest rate of being asked to undergo sterilisation (over 35%). Indonesian women recorded the highest proportion who were given the option to decline the procedure (39 of 44 women) whereas Cambodian women recorded the least choice to decline sterilisation (34 of 70 women).

Women who were urged to undergo sterilisation tended to have more children (average two) than other women, however, 4.6% of those encouraged to undergo sterilisation did not have any children. Where women resided, their education level, or their age had no significant relationship to recommendations for sterilisation. There was, however, a significant relationship between whether a woman had a caesarean section and whether she was encouraged to be sterilised; 43.5% of women who gave birth by caesarean section were encouraged to be sterilised compared to 29.9% of women who had vaginal deliveries.

Table 12: Recommendations for sterilisation, by country

Country	n	Asked to undergo sterilisation	Had the option to decline
Bangladesh	33	5 15.2%	2 40.0%
Cambodia	200	70 35.0%	34 48.6%
India	172	67 39.0%	39 58.2%
Indonesia	109	44 40.4%	39 88.6%
Nepal	40	6 15.0%	1 16.7%
Viet Nam	203	36 17.7%	25 69.4%
<b>TOTAL</b>	<b>757</b>	<b>228</b> <b>30.1%</b>	<b>140</b> <b>61.4%</b>

"I wanted a C-section, but the doctor said, 'Just let it go. Wait for a natural delivery'. After two days of pain in the end they had to give me a C-section because my baby was two weeks overdue. But I had to sign a paper agreeing to a tubal ligation as well. I wanted to have another child but I had no choice. It is not reversible for women." (Mai, Viet Nam)

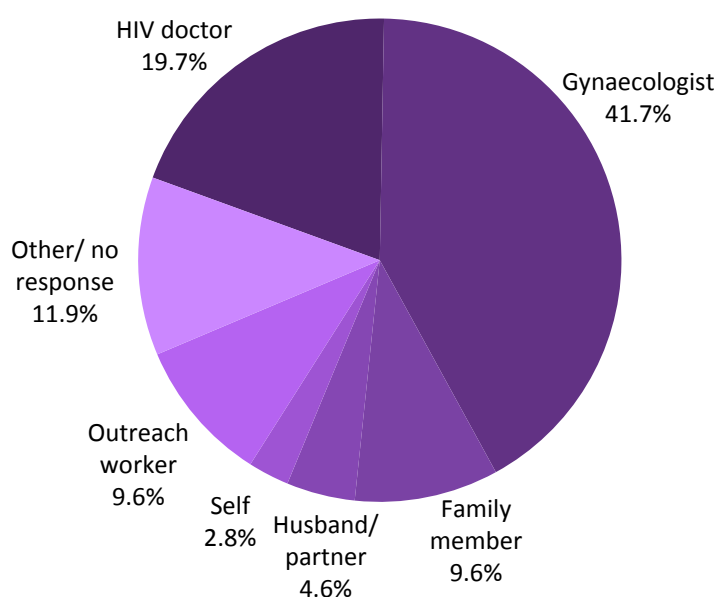


Figure 6: Persons who made recommendation to undergo sterilisation

The majority of recommendations for sterilisation (61.4%) came from gynaecologists and HIV clinicians and most respondents (82.6%) believe that the recommendation was made on the basis of their HIV-positive status. Doctors offer a range of reasons for sterilisation, despite the fact that the risk of infants becoming HIV-infected is very low if women are on ARVs. In 9.6% of cases outreach workers, and in another 9.6% of cases family members made the recommendation for sterilisation, in 4.6% of cases the husband or partner recommended it, and in only 2.8% of cases was it the woman's own suggestion. One woman who was coerced into being sterilised at the time of delivery said her child died one month after birth.

In some cases, women do not know whether they were sterilised during their caesarean. At least one woman had been sterilised without her consent.

In India, some women said that often women and their families did not understand what sterilisation was, and thought it meant a more 'sterile' delivery, to which families eagerly agreed. Additionally, where the choice to be sterilised was available, several women indicated they did not have the power themselves to refuse or to accept, either because their health decisions were made by their husbands, partners, or family members, or (in the case that they wanted to be sterilised) the hospital required spousal consent. In some places, while the choice was left to the woman, incentives were offered such as free formula, which many poor women could not pass up. In Indonesia, sterilisation is actively encouraged as a family planning method, not just for positive women, and is offered free at the time of both natural and caesarean delivery; only occasionally do

doctors discourage positive women from getting sterilised either because they are too young or because it may negatively affect the woman's health.

In the FGDs only one woman said her partner had been encouraged to have a vasectomy.

*"At the hospital, staff told my husband that if he had a vasectomy they would give him 2000 taka [USD25] and new clothes but he refused."*

(Kabita, Bangladesh)

*"Men should have a vasectomy because it is more of a burden on women, but none of them do."*

(Sreymom, Cambodia)

*"The counsellor talked to me about sterilisation, and I agreed to have it done at the time of delivery, but because my [estranged] husband was not there to sign the documents, only my mother, the hospital refused."*

(Ritika, India)

## 5 Maternal health care

Most women (80.9%) received some form of maternal health services during pregnancy, although 12.4% did not receive any services despite seeking them, and 5.5% did not seek maternal health services. The majority of respondents (89.6%) knew that HIV could be transmitted from mother to child (except in Nepal where only 17 of the 40 women surveyed said they were aware that HIV could be transmitted to their child).

Most respondents (57.9%) sought maternal health services by the second month of their pregnancy in all countries except Bangladesh, where only 32.3% sought maternal care that early in their pregnancy; a small proportion of respondents (2.1%) did not seek services until their eighth or ninth month of pregnancy.

Of the women who did seek services, 62.7% had more than three antenatal check-ups. The number of check-ups had no significant relation to education level, age or whether women lived in urban or rural areas. Women who were dependent on their husbands and family members for their income were more likely to receive at least three ANC checks (73.1%) compared to women who were self-employed or earned their own income (50.5%).

There was a strong correlation between receiving care and having a live birth; 47.3% of pregnancies to women who sought pregnancy-related health care but did not receive it resulted in miscarriage or abortion.

For most respondents (69.3%) the health care facility where they obtain their HIV care and treatment is the closest to their home, with an average travel time of 40 minutes (range: five minutes to one day). In all countries except Bangladesh, a majority of women reported obtaining maternal health care services from government centres in urban areas (69.2% overall). Most respondents from Bangladesh obtained services from a non-government health care centre and eight women delivered at home.

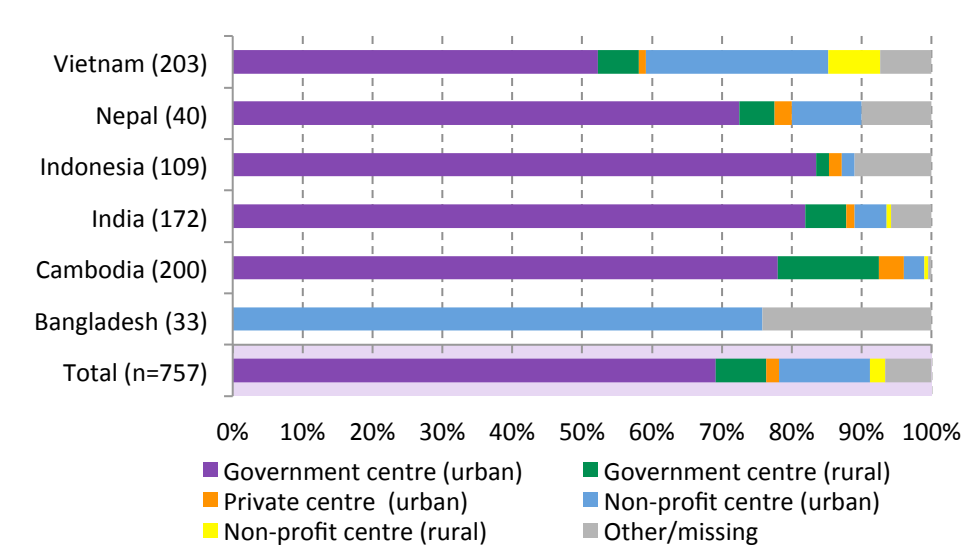


Figure 7: Where women seek HIV treatment services

Services women received include: ultrasound (68.5%); gynaecological counselling and testing (60.9%); vitamins (56.3%); blood tests (53.7%); obstetric care and delivery (51.7%); feeding and nutrition counselling (47.3%); immunisation (37.7%); STI counselling and testing (32.7%); internal

examinations (21.7%). A majority of women in all countries except India and Nepal had an ultrasound. In Viet Nam, only 7.9% of women received an internal examination.

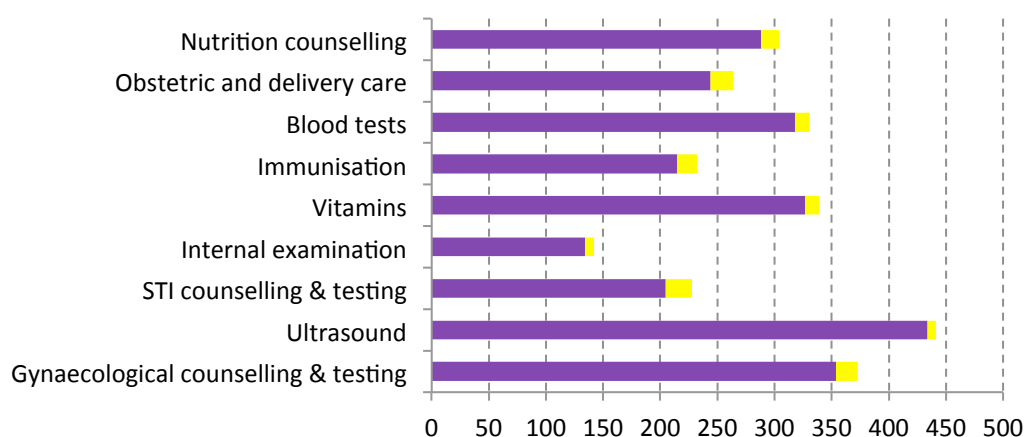


Figure 8: ANC services reported to be available and the number of women who received services

Only about one in four women have ever had a pap smear (28.9%). Most women had no idea why it is important for HIV-positive women to have regular pap smears, and many only realised they have had one once the procedure was explained, while other women said they would have one if it was recommended by their doctor.

### Satisfaction with services

Overall 37.8% of women who received maternal health care said they were dissatisfied with the treatment they received and 18.0% stated they were dissatisfied with the confidentiality afforded to them. Levels of satisfaction (most or all of the time) with services offered ranged from: India 77.7% (highest level of satisfaction), Cambodia 67.8%, Nepal 67.5%, Bangladesh 66.7%, Indonesia 59.7%, to Viet Nam 34.4% (lowest satisfaction with services). The quality of maternal health care often depended on whether services were available at a single facility.

*"I am very happy with the HIV clinic at the government hospital. Compared to the private doctor, this doctor did everything. He provided me with basic information on HIV and ordered many laboratory tests... I don't remember what they told me about PMTCT except that I will have to deliver by caesarean. I just hope the drugs will help the baby. I'll find out my CD4 count at my next appointment, then they will tell me whether I can breastfeed... My husband and my mother-in-law make all the decisions. I'm usually not consulted. I have many concerns and questions in my heart, but I have never discussed them with anyone, not even my husband or the counsellor."*  
(Pragya, India)

*"We are offered the same services as negative women but we are treated differently. The healthcare worker won't sit on the same chair that I have sat on or use the same pen. When they look into my mouth to examine my throat they stand far away and won't touch me. The doctor also has a security guard with her because she's afraid that positive people might harm her though she has never been attacked. We want to be treated the same as everybody else."*  
(Chau, Viet Nam)

In Nepal, although most respondents said they were satisfied with the care they received, one member of the positive network said that in fact most women do not know what a high standard of care is. In Viet Nam, one FGD participant said that as soon as health care workers find out that you are positive, even if your health problem has nothing to do with HIV, they refer you to infectious diseases, and even within the infectious diseases section, there is a special place for people with HIV.

*"Most nurses at the government hospitals behave badly towards HIV-positive women. They ignore us, and make us wait a long time to see the doctor. The HIV doctors are much better."*

(Lani, Indonesia)

Several women spoke of discrimination from health care workers if they disclose their status, particularly from nursing staff and obstetricians and gynaecologists. In several countries, women complained of health care workers breaching confidentiality with negative consequences. Some healthcare workers ask questions such as, "How did you get HIV?" and "Why did you get pregnant?" in front of other patients in the ward. One woman had to move house because an outreach worker

who came to visit her told the head of the local authority that she had HIV and he told all her neighbours.

Women in Cambodia, Indonesia, Nepal and Viet Nam said they are often made to wait until last to see a doctor for any procedure, even an ultrasound, regardless of how early they arrive at the centre. Women in Nepal said that when doctors do treat them, they put on three or four pairs of gloves.

One woman in Nepal, who had had a caesarean, was left to do everything by herself and in the process tore her stitches and was then chastised by the doctor for being careless and had to wait two days to get new stitches.

Cambodian women said that if a woman is under a government program and she wants to switch her HIV doctor, she cannot do so. Women repeatedly said that they just want to be treated like normal people.

*"When I first visited the antenatal clinic I didn't disclose my status. They welcomed me and were very friendly and told me I had to have a vaccination. But on the second visit, when they saw I'm HIV-positive they treated me differently, didn't want to give me any information and told me I didn't need a vaccination, that I am okay."*

(Thida, Cambodia)

## Integration

Referral services are rarely available at the same facility as the HIV clinic, and whether services are free or subsidised varies by institution and province, and sometimes depend on a woman's ability to negotiate, or whether she reveals her HIV status (in which case, some services are free of charge).

*"I was admitted to a private hospital for complications and I needed surgery. When the doctors realised I had HIV they started asking me questions like, 'How did you get infected?' I waited seven days but I was not operated on. Then I was transferred to a government hospital where I waited another nine days. There also the doctors treated me differently. The bed was separate from other patients and the behaviour of the doctors was different. On their rounds they didn't want to touch me."*

(Mina, Nepal)

Overall, 61.0% of survey respondents reported that they could access HIV, reproductive, maternal, and childcare services at the same government facility. This excluded Bangladesh, which did not report access to a government hospital. India had the highest percentage of women reporting integrated health care services from government hospitals (82.6%), followed by Indonesia (79.8%). Indian women were also most satisfied with the level of confidentiality afforded them (87.2%) and

with the overall maternal health care provided to them. In the survey, 57.7% of women said confidentiality could be better maintained in an integrated health care setting.

In Cambodian FGDs, several women complained that, for a single ANC visit, they were required to travel to different locations with referral slips for ultrasound and laboratory testing, often consuming an entire day for each visit, and discouraging them from seeking continued care. In Nepal women said they are shunted from one hospital that provides ARVs to another that provides maternal health care, and are constantly referred around in circles because nobody wants to deal with a positive woman who has a pregnancy. Ultimately this results in some women not disclosing their status in maternal health care settings. Consequently, the sexual and reproductive health of HIV-positive women is often neglected in this loop. Many women said they would utilise health care services more regularly if they were integrated within the same government health care facility.

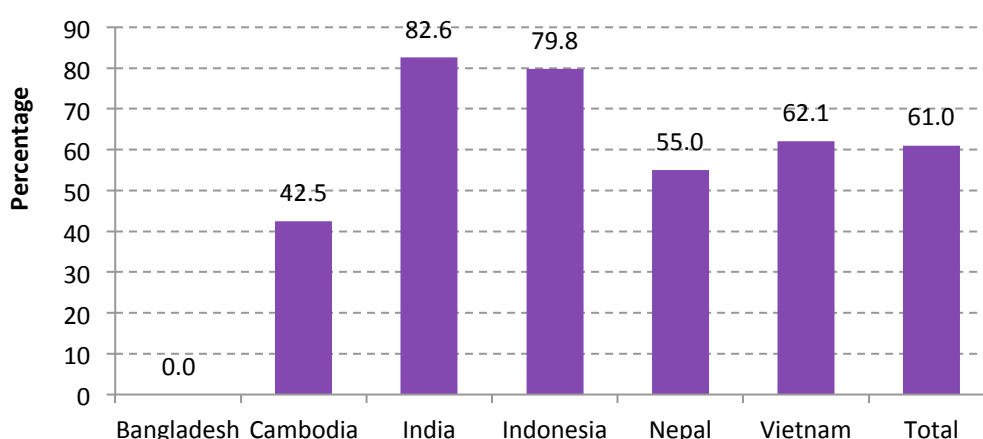


Figure 9: Access to integrated health care services at government hospitals, by country

In the survey, 291 respondents (41.6%) reported having difficulties finding a gynaecologist to care for them during their pregnancy due to their HIV-positive status. In Cambodia, 69.0% of women said there was communication between their HIV doctor and their gynaecologist about their delivery but in Viet Nam only 7.9% of women said this was the case. Many women interviewed said they want advice about how to get pregnant safely and how to deliver a healthy baby but they do not know where to seek advice because so many HIV doctors are unsupportive of positive women's desire to have children. Without access to information through the health care system, many women rely on friends for advice on decision-making about their health.

*"The doctors don't answer our questions. If I want answers, I have to go and find them myself. I trust my friends more than the doctors because they speak from their life experiences. My hope is that all women living with HIV can fully access information on HIV treatment for themselves and their children. That is my hope."*  
(Lina, Indonesia)

*"If you don't know what information is available, how can you know what you don't have access to?"*  
(Navi, Cambodia)



### Cost

Cost is a major factor for many women in deciding to utilise health care during pregnancy. Most women enrolled in maternal health programs must pay for ultrasounds, laboratory tests and delivery charges, especially if conducted at different facilities. Because many services are not available at the same location, there are also additional transportation charges, making them too expensive for many poor women. In Indonesia, the government national health insurance subsidises HIV services for pregnant women, however subsidised services are restricted to the province of insurance scheme registration and unmarried women are ineligible to register. In Viet Nam, women on health insurance receive free treatment, but many women cannot afford the USD25 per year for insurance, and those on insurance schemes say that the way they are treated is not as good as treatment given to women who pay outright. Even if subsidised, women often have to pay around 50% or more of doctors, administration, and laboratory fees.

Ability to afford cost of transport significantly influences health-seeking practice. In Cambodia women in FGDs said it costs them between USD2-10 to get to the clinic, and as one woman said, "With this money I could buy food for my family". Many women in the Kathmandu Valley in Nepal come to the capital for maternal health services because they are the best available or because they can be guaranteed confidentiality, but the transport costs are very high. Some rural women travel all day to get to an urban clinic and often must make excuses to their in-laws as to why they are continually travelling to the city.

Many women exhaust all local traditional health options before seeking conventional medical care at a health facility. One woman said she will go to a traditional healer first, then to a pharmacy, and if that does not work, to the hospital, trying to find the cheapest treatment possible. Some Cambodian women said that HIV reduces the quality of life for the family because of the increased cost of health care.

*"There are many free services out there but most poor and uneducated women do not know how to access them. Most women are shy to reveal their HIV status so they either do not go to seek services, or end up paying for services that should be free. Transportation costs are also very high and many women are discouraged from seeking even free services because they cannot afford to get to them."*  
(Kagna, Cambodia)



## 6 Infant health care

Of the women who reported live births, 37 (9.0%) said their babies had subsequently died; 14 of these women found out their HIV status during pregnancy and eight women were diagnosed after the birth.

### Infant feeding

Formula feeding was most commonly practiced in all countries except Nepal. Overall 78.7% of women formula fed their infants, but in Nepal more than half the women breastfed. This is consistent with findings of the Nepal Demographic and Health Survey, which indicated that breastfeeding is almost universal in Nepal, and Nepal's National Guidelines, which recommend exclusive breastfeeding.<sup>25</sup> In Cambodia, new Ministry of Health guidelines recommend exclusive breastfeeding, in line with revised WHO Guidelines in 2010, which recommend breastfeeding as a good option for all babies, including those born to HIV-positive mothers.<sup>26</sup> But, many women are afraid to breastfeed, even if they are on ARVs. In the FGDs, women's understanding of the benefits and challenges of breastfeeding versus formula feeding was low and women receive little or no guidance on what feeding option to choose.

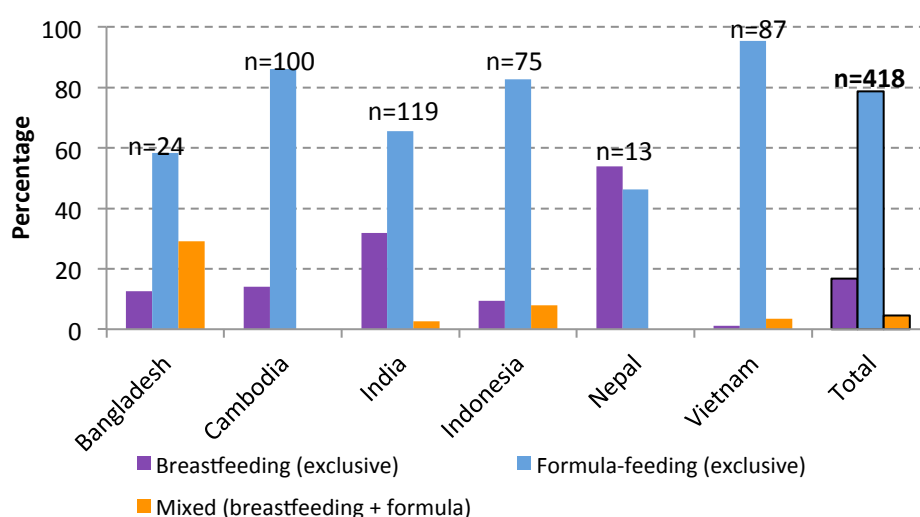


Figure 10: Infant feeding practices, by country

*"[When my son was born] they took him away from me and I didn't see him for two days until I was discharged from the hospital. By then he had already been given formula, so there was no choice to breastfeed."*

(Lani, Indonesia)

Free formula milk is available for between 6-12 months if enrolled in government programs in India and Viet Nam, and in the government health insurance scheme in Indonesia; in some provinces of Cambodia formula milk is subsidised by NGOs for up to eight months.

<sup>25</sup> Nepal Ministry of Health and Population, 2007. Nepal Demographic and Health Survey 2006.

<sup>26</sup> WHO. 2010. Guidelines on HIV and infant feeding 2010. Principles and recommendations for infant feeding in the context of HIV and a summary of evidence.

[http://www.who.int/child\\_adolescent\\_health/documents/9789241599535/en/](http://www.who.int/child_adolescent_health/documents/9789241599535/en/)

*"I did not have any formula and my baby was crying all night from an empty stomach so the next day my husband sold my mobile for formula. I felt guilty that I had brought the child into the world and I cannot feed her."*  
(Nasima, Bangladesh)

Of major concern where formula milk powder is not provided, for example in Bangladesh and parts of Cambodia, is cost. This can be USD40-100 per month (equivalent to a government officer's salary in some countries) depending on the baby's age. Some women go without food in order to buy formula for their baby, and believe this is why their CD4 has decreased. Sometimes women have no money for formula so they give their baby sugar water. Some women breastfeed only because they cannot afford formula milk. Many women said financial support is needed for formula feeding.

Cost is not the only challenge with formula feeding. Women who do not breastfeed are often criticised, with friends accusing them of trying to be "too modern". Women have to make excuses why they bottle feed, such as they do not have enough milk or they are taking antibiotics that might harm the baby.

Of the 89 women who breastfed their infants, only 21.3% were on ARVs and only 34.8% of their infants were on ARVs. Most of these were from Cambodia and India, where ARV drops are readily available.

Table 13: ARV uptake among mothers and infants who breastfeed, by country

Country	N	Mother on ARV	Newborn on ARV
Bangladesh	10	0	0
Cambodia	14	10	12
India	41	0	18
Indonesia	13	1	1
Nepal	7	7	0
Viet Nam	4	1	0
<b>Total</b>	<b>89</b>	<b>19</b>	<b>31</b>

### Infant ARV prophylaxis

More than half of the respondents (54.8%) reported that PMTCT services were available if they wanted them and 52.3% reported receiving the services. Women in Cambodia reported the highest level of PMTCT availability (72.5%), followed by Indonesia (62.4%), India (47.7%), Viet Nam (44.3%), Nepal (40.0%) and Bangladesh (36.4%).

*"Unfortunately, we faced a lot of problems getting the Nevirapine syrup. Most medical stores do not carry it. The hospital prescribed the medicine and gave us the names of four medical stores, but they were all out of stock. The government hospital medical store had stock, but they give first priority to babies born at their hospital, and refused to sell to us because we delivered at a different hospital. We finally found the syrup at a private medical store far from our home. Because it was private we had to pay for it, but we were happy just to have found it."*  
(Mena, India)

Government policies on ARV prophylaxis and insufficient education for women influence whether infants receive ARV prophylaxis. One woman was unable to get ARV drops because available stock had expired; two weeks later when she asked again, the doctor told her it was too late to start. Other women are forced to "shop around" for ARV prophylaxis for their infants.

*"They gave my son AZT while he was in the hospital, and then I continued to give it to him every six hours until he was six weeks old. Then I had no more medicine and it was too expensive to buy. I have not taken him back to see a paediatrician. I am afraid he is also HIV-positive and that it is too late to know his HIV status. Many of my friends' babies have died because they didn't know their HIV status until too late. Also, I cannot afford the HIV test for him."*

(Riri, Indonesia)

Many women in the qualitative arm of the study expressed frustration with the quality of paediatric care available, including the inconsistent information they receive about ARV prophylaxis among infants. Many women are given misinformation by health care professionals about the future outcome of their infant: one woman was told that because she was taking ARVs, her baby would be underweight and might have mental issues compared to other children; another woman's son was given ARVs to take twice a day, but when he was a month old he got the flu, so her doctor stopped the ARVs and no further medication was proposed.

Infants are often prescribed co-trimoxazole after birth to prevent opportunistic infections but mothers do not receive adequate information about why this is

important for an infant exposed to HIV and many women worry that the medicine will harm their infant's health. The length of time women were told to continue their child on co-trimoxazole varied from six to eighteen months. It is difficult for women to explain to family members who do not know their HIV status why their child is taking medicine.

*"We had to break up the pills to give him, because drops are not available here. Then, at six weeks, the paediatrician told me my son looked healthy and I did not need to bring him back until he was 18 months old and they could test him again for HIV. He gave me co-trimoxazole and told me to give it to him every day until then. But I do not know why he has to take this medicine (crying). My son is 15 months old now and has been taking this medicine every day. His weight is very low. What developmental barriers is this drug causing?"*

(Lina, Indonesia)

In Viet Nam, some babies of women who have been on ARVs for at least six months prior to their pregnancy and who exclusively formula feed, are still prescribed co-trimoxazole for up to eighteen months, even though their infant has no exposure to HIV.

Other health care services available to newborn infants include immunisation, feeding and nutrition, and growth monitoring. In Bangladesh, India and Indonesia, a majority of respondents said their children had been immunised compared with 48.0% in Cambodia, 36.5% in Viet Nam, and 15.0% in Nepal. The practice of growth monitoring varies widely between countries: Bangladesh 12.1%, Cambodia 45.0%, India 78.3%, Indonesia 35.8%, Nepal 2.4%, Viet Nam 29.6%. According to members of JOTHI, "PMTCT services and paediatric HIV care are still not available in many rural Indonesian locations. For poor women, the problem of accessing these services is accentuated."

*"When my baby was 12 months old the test was negative. The doctor said that even though my baby was negative I still had to wait until 18 months for the confirmation. The doctor recommends using co-trimoxazole until he is three years old. My friend told me to stop giving the co-trimoxazole to my baby. I still get it from the doctor but I never give it to my baby. If I told the doctor I didn't want it he would get very angry."*

(Trang, Viet Nam)

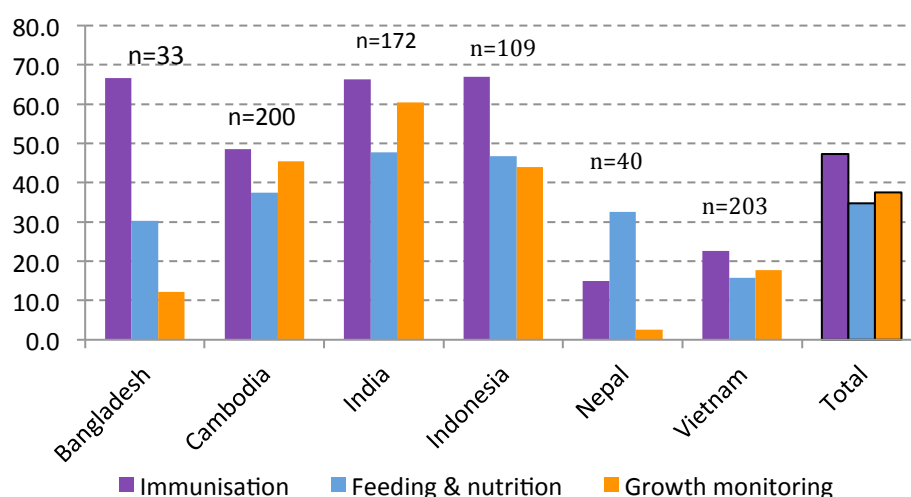


Figure 11: Available newborn and child health services, by country

### Infant HIV testing

Many women are unsure when testing of their infants can be carried out: 13.6% believed it should be done immediately after birth, 19.5% at six months, and 14.6% after 18 months. In Bangladesh, all women must wait until their child is 18 months old to have their HIV test. The most important priority for women when considering having their child tested is the guarantee of confidentiality.

Among women reporting live births, 56.7% said their infant had tested for HIV, ranging from 12.5% in Bangladesh to 82.7% in Cambodia. The survey did not ask the result of the baby's HIV test. In FGDs only two women, one of whom had a home birth, said that their child was HIV-positive.

One woman said she has a daughter who is over two years old and has not been tested because her husband is afraid and makes excuses like, "If we take her for a test she has to have a needle and it will hurt her." Some women think that the man's HIV status influences the status of the baby.

One Indonesian woman heard from other HIV-positive mothers that her son could have an HIV test sooner than 18 months, but when she asked her doctor, he scolded her for questioning his decisions. A woman in Viet Nam said her child had two HIV-negative results but she does not know if she needs to test him again.

## 7. Current challenges

### Government obligations

As governments move to achieve the Millenium Development Goals, including the reduction of HIV infections among newborn infants, care must be taken to uphold the rights of HIV-positive women. Furthermore, whilst many countries have developed successful policies and programs to prevent HIV transmission from HIV-positive pregnant women to their infants, strategies to prevent unintended pregnancies among women living with HIV have largely been forgotten and family planning needs among HIV-positive women remain high.

All countries involved in this study have signed and ratified a number of important United Nations Treaties. These include the International Covenant on Economic, Social and Cultural Rights, which obliges governments to ensure that all citizens have the right to social security (Article 9), the right to the highest attainable standard of health (Article 12) and the right to enjoy the benefits of scientific progress (Article 15). The International Covenant on Civil and Political Rights states that nobody shall be subject to degrading treatment (Article 7). The Convention on the Elimination of Discrimination Against Women (CEDAW) affirms women's rights on an equal basis with men, including the right to decide freely and responsibly on the number and spacing of their children (Article 16). The Convention on the Rights of the Child affirms young people's right to health care (including appropriate pre- and post-natal care for mothers), nutrition, social security, education and information; under Article 24 of CRC, states are committed to take appropriate measures to develop family planning education for parents.

As well as these international treaties, all ASEAN countries involved in this study have signed a regional Declaration of Commitment in response to HIV<sup>27</sup> and SAARC countries have a Regional Strategy on HIV<sup>28</sup>, both of which articulate provision of appropriate standards health care and promote the dignity and human rights of people living with HIV and the elimination of HIV-related discrimination. Furthermore, Cambodia and Vietnam have specific legislation to protect people living with HIV from HIV-related discrimination.

Despite these internationally recognised declarations to protect citizens' rights, findings from this study indicate that many HIV-positive women in Asia experience extreme levels of discrimination and violations of their rights in relation to their reproductive and maternal health, including coercion into abortion and/or sterilisation. Many governments do not provide women living with HIV with the standard of health care equal to that provided to HIV-negative or untested women, and a significant proportion of women receive inadequate counselling, inappropriate ARVs and little or no information or services related to their sexual, reproductive and maternal health care. Furthermore, many HIV-positive women face degrading treatment within maternal health services.

<sup>27</sup> ASEAN, 2011. ASEAN Declaration of Commitment: Getting to zero new HIV infections, zero discrimination, zero AIDS-related deaths.

[http://www.aseansec.org/documents/19th%20summit/ASEAN\\_Declaration\\_of\\_Commitment.pdf](http://www.aseansec.org/documents/19th%20summit/ASEAN_Declaration_of_Commitment.pdf)

<sup>28</sup> SAARC, 2006. SAARC Regional Strategy on HIV/AIDS. [http://www.saarc-sec.org/uploads/document/SAARC%20Regional%20Ttrategy%20on%20HIVAIDS\\_20100419123220.pdf](http://www.saarc-sec.org/uploads/document/SAARC%20Regional%20Ttrategy%20on%20HIVAIDS_20100419123220.pdf)

### Testing and counselling

Policies exist in each of the study countries stating that HIV testing should be voluntary and confidential, and that women have the right to information about their test, but the practice is often very different. It is shocking that half of the women in India diagnosed during pregnancy did not receive counselling and many did not realise they were being tested at the time the test was done. These women are not only deprived of psycho-social support at an extremely vulnerable time in their lives, they receive no information about HIV and its impact on themselves and their unborn infant. This is unacceptable.

Women clearly stated that having HIV-positive peers as counsellors and outreach workers is an extremely effective approach, putting positive women at ease and increasing their perception that their concerns are heard and understood and that advice is from experience and grounded in reality. Mentoring programs can be established in clinics, so that mothers learn from peers who have "walked in their shoes".

### Discrimination

This study highlights endemic discrimination within government maternal health systems in many parts of Asia. Some women in every country experienced HIV-related discrimination during their pregnancy, however the levels of discrimination vary enormously. In Bangladesh, only one woman who delivered after the survey at a government hospital, faced discrimination whilst all other women who delivered at the Marie Stopes clinic were treated with respect. At the other end of the spectrum very many women in both Nepal and Viet Nam experienced levels of discrimination by healthcare workers which at times bordered on paranoia. The fear of getting infected by touching an HIV-positive woman or her newborn infant was oftentimes extreme. Despite advances in ARV access, and results of many studies that indicate PLHIV who are successfully on ARVs can live long, normal, healthy lives with minimal risk of ever infecting others, many health care workers still disapprove of positive women becoming pregnant and try to encourage them to have an abortion. Constant messages of "Don't get pregnant" mean some women avoid health care during pregnancy because of the fear of discrimination, and subsequently miss out on appropriate antenatal care and ARV prophylaxis.

Where there is specific HIV legislation, women cannot sue because there are often no witnesses to their treatment, they do not have the means to pursue a case of discrimination or they are afraid to do so.

All women have the right to decide freely on whether or not she has children. No one must be sterilised without her voluntary and fully informed consent and no woman must be coerced into an abortion.

### Contraception

There is an unacceptably high number of unwanted pregnancies (one in four) and abortions (one in five). Only condoms are promoted among HIV-positive women, and health care providers do not consider other options. Counselling is targeted towards women, not their partners. Positive women have as little control as negative women over condom use, so unwanted pregnancies are common. Their partners do not want to use condoms, either because they enjoy sex better without them, they cannot afford them or they want to have a child, and women have relatively little control over their use.

Women are discouraged from pregnancy but given no realistic means to avoid unwanted pregnancies. It is unfair not to give women alternatives to condoms to reduce unwanted pregnancies.

### Lack of information

Lack of access to information, in combination with patriarchal family structures and arranged marriages (in South Asia), means that women often have little control over health-seeking decision-making regarding their sexual and reproductive health needs.

Many women do not know where to go for information about HIV and pregnancy and many HIV doctors do not have the information women need to advise them accurately and appropriately about specific female health concerns. According to members of the Cambodian Community of Women living with HIV, "In the clinics, HIV doctors are mostly male and it is difficult for women to openly share their concerns or ask questions. Additionally, counsellors are trained to provide information on treatment and care of HIV, not sexual and reproductive health, so there is a gap in the information being provided."

*"My first baby was positive and when I was pregnant again the doctor at the national hospital said HIV-positive women should not have children but I knew there was a lot of progress in terms of treatment and advances in technology and that it is possible for an HIV-positive mother to have a healthy baby."*  
(Mai, Viet Nam)

Pregnant women who disclose their HIV status to their doctor need to be provided with information and support to establish a family, without judgment. If women's rights are not respected and HIV-positive pregnant women are not treated with dignity and respect, many women will continue to hide their status and thus place the health of their newborn infant at considerably greater risk.

Some women fear staying on ARVs because of harm they might do to their infant; they need better treatment literacy training. Women need information about the risks and benefits of ARV prophylaxis during pregnancy, formula feeding versus breastfeeding, and caesarean sections. If women have adequate information and support, they can have successful pregnancies.

In order to eliminate discrimination against HIV-positive pregnant women, knowledge about HIV and pregnancy has to increase among reproductive health and HIV specialists. HIV care and treatment providers need to be sensitised to the reproductive and maternal health needs of their female clients and obstetric and gynaecological service providers need to be taught to treat positive women with respect. HIV positive women can be engaged in this work. Peer support services play a pivotal role in raising awareness about women's sexual and reproductive health and rights (SRHR), however very few positive women's networks at local, national or regional level are funded to provide peer support, education or counselling.

### Inconsistent policies and lack of service integration

Not all countries have adopted current WHO Guidelines for HIV-positive pregnant women, and outdated policies and practices are widely implemented in Asia. Wide variations exist in the implementation of guidelines on voluntary counselling and testing, ARV initiation, delivery methods, and infant feeding, between and within the study countries. The continuing widespread use of d4T in Cambodia, India, Indonesia and Viet Nam, the high rates of delivery by caesarean section in all countries except Cambodia, and the significant correlation between sterilisations and caesareans cause are all cause for alarm. Mechanisms are needed whereby up-to-date information on changing guidelines is frequently disseminated to health care workers so they can adopt more dynamic policies and procedures.

Where services are not integrated, women are shunted between infectious diseases and reproductive health services. If all procedures, laboratory tests and medications can be obtained at one location and in one visit, less time is required to administer and receive care and treatment, and maternal and infant care follow-up is better maintained, leading to improved health outcomes. Integration ensures that all care providers are aware of a patient's HIV status. Given that many positive women's rights are violated, integrated services could build linkages with legal referrals and



services. Integration of services should also consider linkages with PLHIV-networks and involvement of HIV-positive women in service delivery.

### Infant care

Some women choose formula feeding because of fear of infecting their infant, yet many of these women cannot afford to buy formula milk consistently, so the health of the infant is threatened when infant formula is replaced with inadequate substitutes. In Bangladesh, India, Indonesia and Viet Nam a high proportion of women who were breastfeeding were not on ARVs. Women need to know that the risk of HIV infection and infant mortality are reduced considerably when women are successfully on ARVs.

It is worrying that so many women in Nepal had miscarriages; women in Nepal also had lowest knowledge levels about HIV and poorest ANC attendance.

Waiting for infant test results for 18 months is stressful for mothers. It is a long and difficult time to wait, and procedures need to be in place to ensure women can get early, reliable HIV tests for their infants.

### Social security

Cost was mentioned repeatedly as a barrier to accessing services. This is consistent with findings from the APN+ 2009 study on women's access to HIV services in Asia, "A long walk", which found that 78.7% of the 1306 female respondents from six countries said they did not have adequate financial resources to access services, including transport. Transport subsidy is needed for many women during the first couple of years on ARVs, until their health improves, their babies are old enough to eat solid food, and the woman develops a possibility to generate her own income.

HIV-positive women need sustainable livelihoods but have limited opportunities to pursue them. Economic support is missing from most HIV interventions worldwide and, where present, sometimes encourages further isolation and discrimination by community members. Many positive women are in an economic crisis. Often all financial resources have been spent on the health care of the woman's husband and many women have been subsequently widowed. Poverty, lack of income, illiteracy and socio-cultural norms all affect a woman's decision-making ability. This is particularly true when it comes to a woman seeking health care for herself, particularly preventive healthcare. Most women only seek gynaecological services when they are pregnant or have a specific health problem. Other women commented that even when they did utilise services, they were often unable to process or retain information provided because of the more pressing concerns of feeding their families. Governments need to consider incorporating livelihood opportunities into comprehensive care and support packages, including access to low or no-interest loans for HIV-positive women

*"I wish I could access support for a micro credit loan or that some NGO organization would teach me some skills for better income generation. I want to make sure my children have enough food and can go to school. I also wish I had more information on treatment and how I can survive longer. I try not to feel hopeless."*  
(Chantha, Cambodia)



## 8. Key recommendations

Findings from this study highlight issues for future reproductive and maternal health programming for women living with HIV in Asia. The recommendations are broad and capture the themes that emerged from the study, for governments, donors, and PLHIV networks to consider, independently and jointly. Several of the recommendations below have been made by APN+ on many occasions over the past decade, including, in particular, upholding women's right and engaging HIV-positive women in the response in a meaningful and effective way, including as peer counsellors. With more HIV-positive women choosing to become pregnant and increasing numbers of women being diagnosed during pregnancy, the need to act on these recommendations is now urgent.

### Invest in positive women's organisations

Appropriate and ongoing training of positive women as counsellors and as HIV educators is critical to increase knowledge and understanding of HIV- positive women's sexual and reproductive health and rights, including HIV treatment guidelines.

Financial support is needed for positive women's organisations at national and regional level to enable positive women to advocate for their rights including rights to sexual, reproductive and maternal health care among their peers, their families, health care providers and policy makers. Peer-based support services need to be viewed as an integral part of the overall spectrum of women's care and be scaled up with a long-term investment perspective.

- Increase capacity of HIV-positive women's organisations to respond to their needs
- Train positive women and their partners at national, provincial and local level about their sexual and reproductive health and rights and increase positive women's capacity in decision making
- Facilitate positive women's capacity to advocate for their rights to sexual, reproductive and maternal health care

### Expand counselling

Counselling and provision of information needs to go beyond pre- and post-HIV test counselling to be consistently available to women at many care points. Counselling needs to be comprehensive and appropriately tailored to the socio-cultural context.

Counselling has to be delivered by HIV-positive women and needs to incorporate emotional support with HIV information, sexual, reproductive and maternal health and rights awareness, child health information, and treatment literacy. It also should include advice to positive women on navigating the health care system of their country. In addition, it should consider when and where it is appropriate to provide counselling to couples and families.

- Train and employ HIV-positive women as counsellors at all government testing centres
- Expand HIV counselling beyond post-test to include psycho-social/emotional support, ARV treatment, SRHR advice and support; consider couple and family counselling when women do not have healthcare decision-making authority; strengthen referral systems to health care services

### Uphold positive women's rights

Governments have an obligation to provide HIV-positive women with the same standard of health care as that available to HIV-negative women. Women must be given the right to freely decide on the number and spacing of their children and be supported in their decision to do so, according to the Convention for the Elimination of Discrimination Against Women, which all countries in the study have signed and ratified. Relevant human rights bodies must respond to HIV-positive women's needs

- Ensure governments fulfil their obligations to protect HIV-positive women's rights according to international and regional treaties and declarations
- Ensure no woman is coerced into testing, abortion, sterilisation, and/or caesarean
- Ensure HIV-positive women have access to a range of contraceptive options that they can control, to avoid unwanted pregnancies
- Ensure WHO Guidelines on ARVs are adopted
- Ensure no positive woman experiences discrimination within the maternal health sector
- Train obstetric and gynaecological service providers to be sensitive to the needs and rights of HIV-positive pregnant women; include training on quality of care models as promoted by WHO, and training on positive women's sexual and reproductive health and rights in clinical management and in curriculum training of health care workers
- Integrate services to improve access, utilisation and follow-up, and reduce discrimination

### Expand social security

Where services are subsidised or free, some women are unable to get access to them because they cannot afford the cost of transport. Comprehensive care and support packages with innovative and sustainable livelihood components linked to market-based opportunities are urgently needed. Transport subsidies are needed for many women to be able to access appropriate HIV services.

- Review national guidelines for social services requirements and expand social welfare and nutritional support for positive women and children
- Provide transport subsidy for mothers on low income to attend ARV centres
- Improve HIV-positive women's income generation capacity