



## Systems, Stigma and Satisfaction: Quality of Maternal Care for Women Living with HIV in Uttar Pradesh, India

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Prepared for the International Community of Women Living with HIV Asia  
Pacific and the Centre for Health and Social Justice

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## **Abstract**

This study provides a qualitative assessment of the quality of maternal care, including the prevention of parent-to-child transmission (PPTCT), in public facilities for women living with HIV in Uttar Pradesh, India to determine areas for advocacy and further research. It was conducted in one district having high HIV prevalence and one with low HIV prevalence in eastern Uttar Pradesh, India. The purposive sample included nine women living with HIV, two of their husbands, four community health workers, one Ministry of Health official for that division, one multilateral organization employee, one member of a district-level network of people living with HIV, two PPTCT counselors, two doctors, one ART center manager and one sister-in-charge (a nurse manager), totaling twenty-four participants. Qualitative data were generated using semi-structured interviews.

Standards for perinatal care in the form of institutional delivery were met, but services did not consistently meet national standards for antenatal, postnatal and PPTCT care. Despite efforts to provide a range of services at the local level, most maternal care and PPTCT services are provided at tertiary facilities. Health system users report being stigmatized and discriminated against by healthcare providers, while those in the health system report fear of being infected with HIV due to inadequate supplies. Despite poor indicators of quality, users report moderate satisfaction with facilities. We conclude that advocates must focus on increasing visibility of people living with HIV and reducing stigma; ensuring that underutilized standards for quality PPTCT care are implemented; and finding meaningful ways for women living with HIV to participate in holding the government accountable for its own quality standards in facilities.

## Introduction

Currently, an estimated 34 million people are living with HIV/AIDS worldwide.<sup>1</sup> Perceptions of the impact of the disease have changed substantially in the thirty years since its identification. Once regarded as a death sentence, the scaling up of anti-retroviral therapy (ART) has changed this disease into a chronic condition. Even more promising, many global leaders now see ending the AIDS epidemic as a feasible goal.<sup>1</sup>

To that end, UN member countries pledged to take specific steps laid out in the 2011 United Nations Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS to produce significant gains by 2015. One of the key steps in this declaration is to “eliminate new infections among children and substantially reduce the number of mothers dying from AIDS-related causes (p. 6).”<sup>1</sup> This represents a challenge, as HIV/AIDS-related deaths have surpassed direct obstetric causes as the main reason for maternal deaths in some areas with high HIV prevalence.<sup>2</sup> Globally, there were an estimated 287,000 maternal deaths in 2010, putting the Maternal Mortality Rate at 210 per 100,000 live births.<sup>3</sup> HIV is regarded as a major factor that has kept the rate from falling further. In 2010, 19,000 maternal deaths, or about 7% of the total, were attributed to HIV-related causes.<sup>3</sup>

In addition, in the absence of any intervention about 20-45% of infants of HIV-infected mothers will become infected themselves.<sup>4</sup> This resulted in an estimated 400,000 children worldwide who were infected with HIV from their mothers in 2010.<sup>5</sup> Well-established methods of prophylaxis, including maternal and infant ART, Caesarean delivery where conditions are safe, and appropriate infant feeding, however, can reduce transmission to less than 5%.<sup>2</sup> With these interventions in mind, the global community has made new commitments to eliminating vertical transmission, which was articulated in the *Global Plan Towards the Elimination of New HIV Infections Among Children by 2015 and Keeping Their Mothers Alive*.<sup>5</sup> Several of the Millennium Development Goals, including Goal 5, which aims to reduce by three quarters the maternal mortality ratio, and Goal 6, which calls for the reversal of the spread of HIV, give additional urgency to improving these outcomes. Quality maternal care for women living with HIV (WLH) is essential for reducing these preventable maternal deaths, as well as for curbing the transmission of HIV to children.

Few existing studies examine quality of maternal care, including prevention of parent-to-child transmission of HIV services (PPTCT\*) for women living with HIV in India, where public sector facilities are rapidly scaling up and converging HIV/AIDS services with primary care. Assessing care in these settings is important, as they often serve the poorest and most vulnerable women seeking maternal health care. It also can help ensure that facilities are meeting government standards, promoting accountability for users.

The specific aim of this project is to provide a qualitative assessment of the quality of maternal care, including the prevention of parent-to-child transmission (PPTCT), for women living with HIV in Uttar Pradesh, India to determine areas for advocacy and further research.

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\* In many settings throughout the world, these services are referred to as prevention of mother-to-child transmission of HIV (PMTCT). In India, however, the more gender neutral PPTCT is the preferred term.

The objectives of this project are:

- To assess quality of maternal care, including PPTCT, for women living with HIV as perceived by health systems users, service providers, accredited social health activists (ASHAs) and others within the public health care system in two districts in Uttar Pradesh, India.
- To compare qualitative data relating to quality to standards established by the Government of India.
- To assess how HIV-related stigma and discrimination affect quality of care in public facilities.
- To identify recommended focus areas for health advocacy for pregnant women living with HIV.

This project will provide information that the participating groups supporting women living with HIV can use to further advocate for improved care and government accountability for the quality of health services provided. A number of other NGOs, including the Uttar Pradesh statewide network of people living with HIV, can use this information as a basis for local activism. Women living with HIV and their children can benefit by having systematic information to judge the quality of their health services. If they are empowered and activated, this could ultimately lead to improved services for others living with HIV in their communities. Finally, this project could be useful to other researchers in the field of quality maternal care for women living with HIV, as there is limited literature on this topic.

## **Literature Review**

The following section describes the burden of disease in India related to maternal health and HIV, as well as the ongoing government efforts to improve health outcomes for those affected. The Indian government directives for quality are described, along with the literature on quality maternal care generally and for women living with HIV in particular. Finally, the literature on the effects of stigma and discrimination on appropriate care are described.

Despite its significant economic gains in recent years, India still bears a significant burden of maternal deaths from preventable causes and HIV transmission to children. Indeed, 19% of maternal deaths worldwide happen in that country.<sup>3</sup> While HIV prevalence is relatively low at 0.32%, India has the third highest number of people living with HIV globally with about 3 million infected.<sup>6</sup> Women comprise about 39% of those infected.<sup>7</sup> Parent-to-child transmission was the route of transmission for 5.4% of new cases in 2009-2010; this resulted in more than 16,000 infections in children in that period.<sup>8</sup> In that same time, only 28% of mothers living with HIV received appropriate ART prophylaxis.<sup>9</sup>

The Government of India (GOI) has adopted innovative practices in recent years to improve health outcomes, particularly for rural poor women and children, through the National Rural Health Mission (NRHM), which was initiated in 2005.<sup>10</sup> This program, which aimed to increase public sector funding on health from 0.9% at baseline to 2-3%

by 2012, includes several schemes to specifically address maternal and child health outcomes. One key strategy is to improve the public health delivery system by revitalizing existing facilities and building new ones with a focus on decentralization and community-level services.<sup>11</sup> The generic framework for local services is shown in Appendix A. This framework relies on basic services provided by community health workers at the village level and by paramedical staff at the Sub-Health or Community Centre level, which is also called the First Referral Unit. This is followed by increasingly skilled and comprehensive care being provided at Primary Health Centres and Block Level Hospitals. Finally, tertiary care is provided at District Hospitals or Regional Academic Centers.

Other key practices for improving maternal health outcomes as part of NRHM include creation of a corps of incentive-rewarded community health workers called Accredited Social Health Activists (ASHAs), and provision of conditional cash-transfers for women who deliver institutionally. Under the NRHM, services for people living with HIV, including prevention of parent-to-child transmission, are meant to be converged with standard primary care in local health centers.<sup>12</sup> This is a marked difference from previous HIV/AIDS strategies, which focused solely on vertical programs and interventions.<sup>13</sup>

Standards of quality for NRHM services come in several forms, depending on the level of assessment. Service Guarantees and Indian Public Health Standards address the infrastructure and types of services that should be available at different centers within the health system.<sup>14</sup> Standard Treatment Guidelines provide uniformity in care for particular conditions or populations to ensure standardization across the health system. Finally, Charters of Citizens' Health Rights are to be publically displayed in all health centers and inform users of services available, the quality of services to which they are entitled and the means through which complaints will be addressed.<sup>14</sup>

To improve overall health outcomes, quality of care must be integrated along with rapid scale-up of facilities on a system-wide basis. According to the WHO<sup>15</sup>, health care must seek quality in the following dimensions:

1. Effectiveness
2. Efficiency
3. Accessibility
4. Acceptability and patient-centeredness
5. Equity
6. Safety

Others have proposed specific frameworks for understanding quality in the context of maternal care. Pittroff and colleagues<sup>16</sup> propose the following definition:

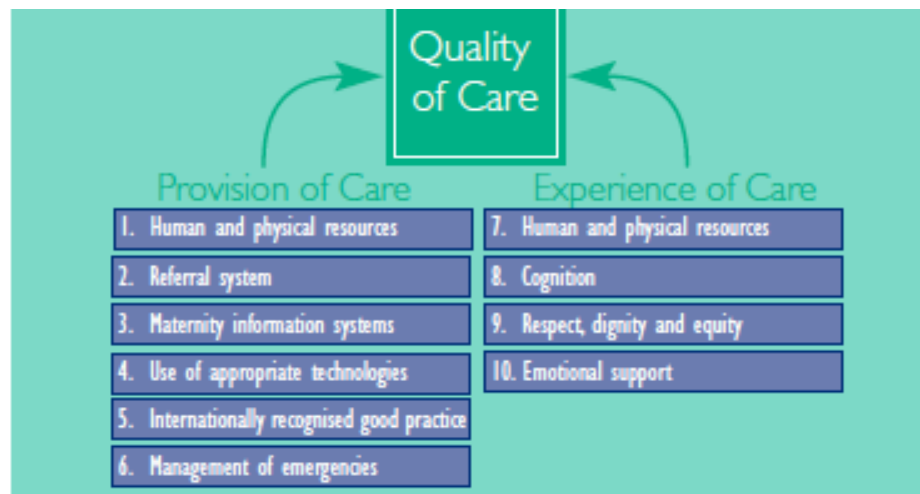
High quality of care maternity services involves providing a minimum level of care to all pregnant women and their newborn babies and a higher level of care to those who need it. This should be done while obtaining the best possible medical outcome, and while providing care that satisfies women and their families and their care providers. Such care should maintain sound managerial and financial performance and develop existing services in order to raise the standards of care provided to all

women (p. 278).

Women living with HIV are among those groups needing a higher level of care.

Finally, Hulton et al. identified ten elements of quality care, which fall under the dimensions of provision of care and experience of care (see Figure 1).<sup>17</sup> This framework is useful in that it recognizes elements contributing to quality of care from both the health system and user perspectives. The authors applied this framework to an assessment of maternal care in an urban Indian slum, finding that quality in both private and public facilities was severely lacking.<sup>18</sup>

**Figure 1: Framework of Quality of Care in Maternal Services.** Source: Hulton et al, 2000.



elimination of parent-to-child transmission in India. Their investigations found that follow-up after initial antenatal HIV tests was insufficient, ART prophylaxis standards do not match current WHO guidelines, prophylaxis is infrequently administered and mothers are given unclear infant feeding advice.<sup>9</sup> A 2009 qualitative study in Hanoi, Vietnam authored by Nguyen and colleagues assessed barriers to quality PPTCT services by health care workers. The workers identified their high workload, lack of knowledge of PPTCT regimens, lack of supplies, lack of national standards and fear of infection as barriers to providing quality care.<sup>19</sup> A 2005 study at three sites throughout in South Africa by Chopra et al. found that quality of counseling for mothers living with HIV was quite low, particularly in regards to infant feeding.<sup>20</sup>

Other studies examine the effect interventions have on quality of maternal care or PPTCT. For instance, a 2009 study by international NGO PATH in Ukraine demonstrated that specific training on voluntary HIV counseling and testing for medical providers significantly improved quality of initial PPTCT services and reduced stigma towards WLH.<sup>21</sup> Similarly, in a 2011 randomized control field trial of thirty-six facilities in two districts in Zambia, providers using counseling cards to discuss infant feeding methods used better educational techniques, were able to have more full discussion on the advantages and disadvantages of different methods, and were more likely to involve male partners in decision making. Clients appreciated this approach, as they were

The literature on quality of maternal care for women living with HIV and/or PPTCT services is limited. The International Community of Women Living with HIV Asia-Pacific (ICW-AP) recently authored a study of community barriers to the

more likely than those in the control group to describe their provider as caring and understanding.<sup>22</sup> Finally, recent studies in Swaziland and Cote D'Ivoire demonstrated that improvements in either maternal care or PPTCT services were found to support increased quality in the other.<sup>23,24</sup> Few studies examine the full continuum of maternal care and PPTCT services, despite their inherent linkages.

There is a wealth of literature, however, on the role stigma and discrimination play in maternal care and PPTCT for WLH. Two studies in India elucidate how stigma and discrimination, including lack of confidentiality, health providers not providing appropriate treatment and increased costs for procedures, are common in both private and public settings. WLH report hesitancy to seek further care for fear of how they will be treated in facilities.<sup>9,25</sup> It is well documented that actual or fear of stigma affects use of maternal care and PPTCT services for both seropositive and seronegative women in settings throughout the developing world.<sup>26–32</sup> Thorsen and colleagues argue that several aspects of PPTCT are catalyst to stigmatization in and of themselves, and that specific strategies should be applied to alleviate this process.<sup>33</sup> In an important comparison, however, Kinuthia et al found that health system factors were more influential than stigma in uptake of PPTCT services,<sup>34</sup> suggesting that gaps in quality may be an important underlying factor for use and effectiveness of these services.

**Figure 2: Map of Uttar Pradesh, India. Source: Wikipedia.**



### **Local Background**

Uttar Pradesh (UP) is located in the north-central part of India, bordering Nepal (Figure 2). It is the most populated state in India, with more than 199 million people.<sup>35</sup> UP is one of several high-focus states in the NRHM, as the maternal mortality rate is higher than the national average at 440 per 100,000 (vs. 254 for India); the infant mortality ratio is also high at 69 per 1,000 live births (vs. 55 for India).<sup>36</sup> The total fertility rate is 3.9 per woman and 21.2% of women have an unmet need for family planning. Only 43.6% of married women of reproductive age report using a method of family planning, with only 29.3% using a modern method.<sup>37</sup> Maternal care use is low, with just over a quarter of women having at

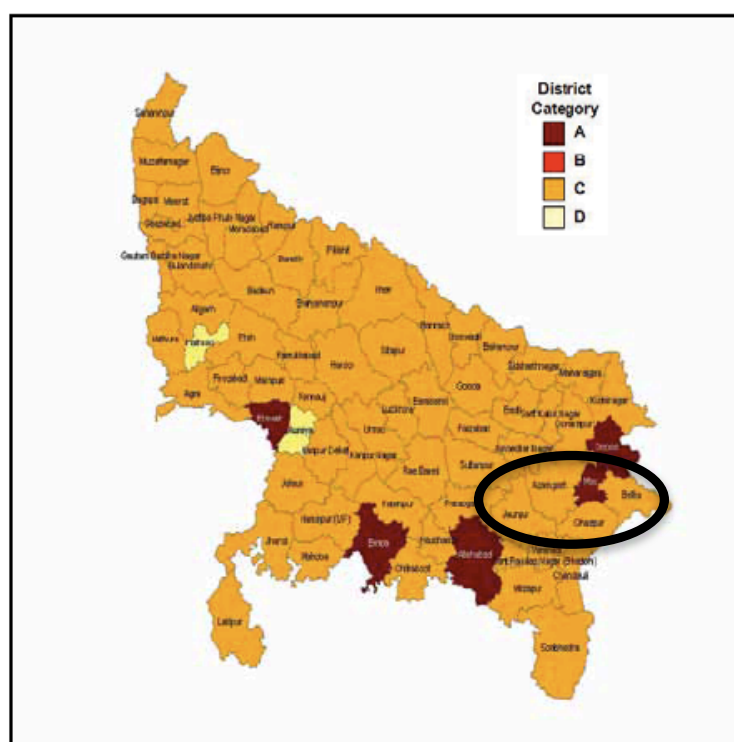
least three antenatal visits for their last birth, only 22% delivering institutionally, 29.2% delivering with a skilled birth attendant and 14.3% receiving skilled postnatal care within two days of their delivery.<sup>37</sup>

While its HIV prevalence rate is only 0.09%, Uttar Pradesh is considered one of seven high burden states, accounting for 4% of people living with HIV/AIDS in the



country overall.<sup>7</sup> Knowledge of HIV/AIDS is relatively low, with only 40% of ever-married women and 74.3% of ever-married men age 15-49 reporting that they have heard of HIV. Additionally, only 27.2% of women and 66.3% of men know that consistent use of condoms can reduce the risk of contracting HIV.<sup>37</sup> With approximately 6 million annual births in UP in 2011-2012, only 424,086 pregnant women received an HIV test in that period. Of those, 501 were identified as living with HIV, but only 325 mother-baby pairs received Nevirapine prophylaxis.<sup>38</sup> These harrowing statistics indicate that maternal care and PPTCT services are indeed lacking on a statewide basis.

**Figure 3: District categorization of HIV/AIDS prevalence in Uttar Pradesh, with assessment districts indicated. Source: NACO, 2012.**



This assessment was conducted in Azamgarh and Mau districts in the eastern part of the state (see Figure 3). Mau is a district of focus because it is categorized as an “A” district by the National AIDS Control Organization (NACO), meaning it has high HIV prevalence. Azamgarh is adjacent to Mau, but is only categorized as a “C” district. Utilizing data from both areas provides insight into the government response to the HIV epidemic in both high- and low-priority districts in a state that is recognized as having low prevalence overall.

Two organizational partners brought distinct yet complementary experiences to this project. The International Community of Women Living

with HIV – Asia Pacific (ICW-AP) has conducted research and led advocacy efforts throughout India and the Asia Pacific region on issues pertinent to women living with HIV. Reproductive and maternal health have been a particular focus in recent years, although they have not investigated these services solely from the perspective of public sector facilities. Although based in Delhi, the Centre for Health and Social Justice (CHSJ) has conducted its own studies and has trained partner organizations to assess quality of many aspects of the NRHM and maternal care throughout UP and India. They are recognized as leading advocates for government accountability of services and have been selected by the Government of India to accelerate communitization of the NRHM. They have investigated aspects of HIV care previously, but not the intersection of HIV and maternal care.

ICWAP provided the main logistical support for this study by providing a “home

base” for study conduct, facilitating connections with local networks of people living with HIV, communicating participant recruitment needs to local partners, finding a local interpreter, assisting with travel and lodging for data collection and advising on salient issues for women living with HIV in India. CHSJ conducted local ethical review of the study, advised on study design and methods, and connected the investigator with local activists and NGOs who assisted with participant recruitment.

## Methods

This study used qualitative methods, since previous research has shown that surveys on quality of care often show high levels of population satisfaction, while qualitative investigations in the same areas will provide evidence of dissatisfaction.<sup>17</sup>

Staff for district-level networks of people living with HIV and local NGOs that provide PPTCT services recruited study participants living with HIV who were users of the health system. Recruiters used a purposive sampling methodology to protect the confidentiality of people living with HIV. Women and their partners who were currently pregnant or had given birth within the last year, were at least 18 years of age and had a diagnosis of HIV were eligible to participate. Purposive sampling through district-level networks was also used to recruit one ASHA and one member of a district-level network of people living with HIV. Since PPTCT services are provided mainly at the tertiary level, we purposively recruited service providers and the remaining ASHAs at either district-level general or women’s hospitals. This yielded a sample of nine WLH, two of their husbands, four ASHAs, one Ministry of Health official for that division, one multilateral organization employee, one member of a district-level network of people living with HIV, two PPTCT counselors, two doctors, one ART center manager and one sister-in-charge (a nurse manager), totaling twenty-four participants.

The University of Washington Human Subjects Division and the Centre for Health and Social Justice Ethics Review Committee provided institutional ethical approval. Oral consent was obtained for all interviews to protect the identities of those living with HIV, and to allow for participation of those with low literacy skills. No identifying information was collected for any participants living with HIV. Users of the health system living with HIV were provided with financial compensation for participating. The remaining participants were not compensated.

We collected qualitative data using face-to-face semi-structured interviews in July 2012 (see Appendix B for interview guides). Interviews utilized an interpreter from Hindi to English when necessary, and were tape-recorded in English. A sample of the transcripts of the English portions of the discussions was reviewed for accuracy. Codes were developed based on predominant themes and findings, and were also informed by the Indian Public Health Service’s Standard Treatment Guidelines for Pregnancy Care<sup>39</sup> and HIV – Antiretroviral Therapy and Post-Exposure Prophylaxis<sup>40</sup>, as well as facility guidelines for primary health centers<sup>41</sup> and district hospitals<sup>42</sup>. Other documents provided information on the NRHM’s infrastructure, including the Ministry of Health and Family Welfare’s National Rural Health Mission Framework for Implementation 2005-2012<sup>11</sup> and CHSJ’s publication summarizing community entitlements<sup>14</sup>. Finally,

government PPTCT standards were not available publicly while this study was being conducted, so information on current standards was gleaned from several internal and external publications<sup>4,43–45</sup>. Transcripts were entered, coded and analyzed using DeDoose Version 4.5.94. Two users who utilized private facilities for their delivery were excluded for analyses relating explicitly to quality of delivery care. For areas relating to health-seeking behavior, such as number of antenatal visits or institutional delivery, however, they were retained.

### Limitations

While this study provides important insights into quality of care for women living with HIV, it has several limitations. The first is the small sample size, which was a result of the difficulty of finding participants who met the inclusion criteria. Additionally, since only qualitative methods were used for data collection, there was no verification of findings via other methods such as observation or review of facility records. Additionally, qualitative methods introduce the possibility of several types of bias, including recall bias and response bias. The latter is especially salient due to the interviewer being a foreigner. Finally, a male interpreter was used for the majority of interviews with women living with HIV. This may have kept participants from sharing details about pregnancy and delivery due to discomfort in discussing these details with a male.

## **Results**

### Demographics for Women Living with HIV (n=9)

Demographic information for the users of the health system who are living with HIV is shown in Table 1. Most live in village or rural areas and have a minimum of 6 years of schooling. The majority are members of disadvantaged castes and two-thirds have had an HIV diagnosis for at least one year. The average age of participants was 29, with a range from 22 to 40. The number of pregnancies, including a current pregnancy for one participant, ranged from two to six, while the number of living children was between one and four. Apart from a currently pregnant participant, the most recent delivery for women took place between two and eleven months prior. In addition to the information presented in the tables, it is worth noting that all of these participants were of the Hindu religion, except for one Muslim, and all participants stated their occupation as being a housewife, except for one woman who assisted her husband as a porter.

**Table 1: Demographic information for sample of women living with HIV (n=9)**

<b>Characteristic</b>	<b>Number</b>
District of Residence	
Azamgarh	4
Mau	5
Area of Residence	
Urban	1
Village/Rural	8
Years of Formal Education	
None	2
6-8	3
9-12	4
Caste Membership	
Scheduled Caste	1
Scheduled Tribe	1
Other “Backward” Caste	6
General	1
Relationship Status	
Currently Married	7
Widowed	2
Time Since HIV Diagnosis	
< 2 months	1
2-6 months	2
1-2 years	3
> 2 years	3
Currently on ART	
Yes	4
No	5
Partner’s HIV Status	
Living with HIV	6
Unknown	2

Existing standards for public facilities and treatment were used to guide theme creation for domains of maternal care and the associated benchmarks that should be met. These themes were related to antenatal care, perinatal care, postnatal care, and PPTCT care. Additional themes emerged from content analysis about barriers to quality care and participants’ satisfaction with facilities.

Excerpts relating to each theme were examined for indicators of quality and compared to Government of India standards. Standards were categorized as being adopted when there was general agreement between users and others that the particular indicator was met. Standards were categorized as being inconsistently adopted when there was disagreement between multiple participants, and they were

categorized as not being met when multiple participants indicated that they indicator was not functional.

### Antenatal Care

Analysis of antenatal care (ANC) shows that several standards of care have been inconsistently adopted in this area; there are a few, however, that have been consistently adopted (see Table 2).

Table 2: Standards of Antenatal Care and Their Adoption in Eastern Uttar Pradesh, India.

Standards of Care Inconsistently Adopted	Standards of Care Consistently Adopted
<ul style="list-style-type: none"><li>• Registration</li><li>• Minimum of Four Visits</li><li>• Laboratory tests and investigations</li><li>• Counseling on Danger Signs</li></ul>	<ul style="list-style-type: none"><li>• Counseling on Diet and Nutrition</li><li>• Responsive to Specific Complaints</li></ul>

Several standards were, according to study participants, not consistently part of ANC care in these facilities. The first standard is that a woman should be registered for ANC as soon as her pregnancy is suspected, preferably in their first trimester. Registration was discussed by service providers as a foundation for further maternal and PPTCT care. No users, however, discussed registration or the card they are supposed to receive once they are registered.

Pregnant women are supposed to receive a minimum of four antenatal checkups. This standard, however, does not seem to be used in this area, as division-level staffers discussed having a goal of three ANC visits and service providers said that they tell their patients to come for monthly check-ups. Despite, or perhaps because of, these disparate messages, there is wide variation in the amount of antenatal care users received. Some women reported receiving no antenatal care, while others reported going several times per month. Only two reported attending at least four ANC visits. No participants reported that their providers counseled them to come for regular check-ups.

Similarly, there is variation in participants reporting that they received any laboratory tests or investigations during their pregnancy. Those who did receive tests stated that they were investigated for hemoglobin levels and blood sugar via a blood test (results for antenatal HIV tests will be discussed in the PPTCT section). Two, however, reported that they did not have any investigations.

Counseling on danger signs is an important standard for reducing the high burden of maternal and infant mortality in this region. Users of the health systems said that they were not counseled on any danger signs. Those within the health care system, including providers, ASHAs and paramedical staff, however, report that patients are frequently counseled on warning signs:

*Service Provider: We say if you have got swelling of feet...swelling of face...they are feeling any pain or anything, they should come.*

Two standards were frequently cited as being part of ANC and appear to be consistently adopted. The first is counseling on diet and rest. Almost half of the health system users mentioned that they had been counseled to eat nutritious food, to rest and not to do heavy work during pregnancy:

*Partner of woman living with HIV: Actually, they discussed with us that she should mostly focus on the healthy nutrients so that she may not be infected by some other diseases... and her hemoglobin level should not decrease. So, they basically told her that she may eat leafy vegetables and some leaves like Tulsi. She needs to eat healthy foods and have regular treatment and medicines. She should totally avoid the things from outside, she shouldn't eat the outside things.*

Additionally, two ASHAs also discussed how they counsel women in this area. This appears to be the most universally adopted standard in this area.

While not specifically part of the standard of care, a functional health system should be able to respond to specific complaints or problems brought by patients. Indeed, according to participants, this may be the most prevalent form of ANC, as more users described going to health centers for acute concerns rather than regular check-ups. The related narratives mostly revolve around a user having a specific complaint, usually physical, presenting at a health facility, and receiving a medicine without any further discussion:

*Woman living with HIV: I got pain in my stomach...They simply told me to go for this medicine only, they never discussed anything else.*

Even though these visits present a great opportunity to provide routine care and further interventions for quality maternal care, it appears that providers are not taking advantage of this opportunity.

## **Delivery Care**

Users of the health care system did not discuss many specific details about their labor and delivery, perhaps due to a lack of comfort. Thus, the only important theme to emerge from this discussion was regarding institutional delivery. This standard is being adopted in this area, as all of the women except one were either planning to or had delivered institutionally. Most sought care at the district or regional level facility, with those having elective Caesarean deliveries going to the latter. On participant's story also indicates that the referral system from secondary to tertiary centers for emergency obstetric care appears to be in effect:

*Woman living with HIV: Actually, when I visited the block level government hospital, doctors told me I have to go to, they refer me to the district hospital because I got some serious problem, that's why the delivery took place in the district hospital.*

Only one participant indicated that she had given birth at home, due to her not being able to go to the hospital at night when her labor began.

## Postpartum Care

Analysis for items related to postpartum care showed that none of the related standards have been consistently adopted in this area (see Table 3).

Table 3: Standards of Postpartum Care and Their Adoption in Eastern Uttar Pradesh.

Standards of Care Not Adopted	Standards of Care Inconsistently Adopted
<ul style="list-style-type: none"> <li>• Postpartum visits for mother and child in first month after delivery.</li> <li>• Counseling on postpartum visits</li> <li>• Counseling on danger signs</li> </ul>	<ul style="list-style-type: none"> <li>• Counseling on family planning</li> <li>• Newborn care</li> </ul>

Standards of treatment state that new mothers should have a postpartum visit 7-10 days after delivering, and newborns should be seen at 3 and 7 days. Those who are low birthweight should be seen at least 3 more times over the first month of life. Again, this standard may not be in place in this area, as the division-level health official stated that they aim for women to have three postnatal visits. This may refer to visits for both the mother and child.

Despite the standards, women generally do not seek care after they are released from the hospital after their deliveries:

*Division-Level Multilateral Employee: So, this will be the case...you will get some type of care-seeking behavior for during pregnancy and before pregnancy, but the postpartum care is highly ignored. So, it's not the priority for the family also once they get the child, everything is OK. So... no focus on mother and she also thinks that the job is over. So, the postpartum care is highly ignored, highly ignored.*

Users of the health system may not seek treatment because it seems unimportant in light of their day-to-day issues:

*Woman living with HIV: Actually, after the birth took place, we never visited any hospital... We are working hard for our livelihood and the facilities we provided to our children ... like food and all those things, so we're focusing on that, we never visited again.*

As with antenatal care, there does not appear to be a community expectation for check-ups and there were no mentions that providers are counseling women in this area, potentially contributing to low compliance with this standard.

Another critical recommendation for reducing morbidity and mortality is counseling on postpartum and newborn danger signs. As with antenatal care, participants denied receiving any counseling in this area when questioned about it.

Other standards are only being offered under certain conditions to families, or may not be offered by every provider. The first is counseling on family planning, which standards indicate should be discussed with families at least twice in the postnatal period. Preventing unintended pregnancies is an important step to reducing vertical transmission of HIV. Counseling in this area was not consistently provided to all women. When it was provided, it never seemed to be discussed in terms of birth spacing. Indeed, providers only counseled women on family planning when they perceived that the family had a sufficient number of children and there was no discussion of the women's preference for the size of their family:

*ASHA: I talk with women who have more than two children about family planning. I won't raise the talk with a person with one child because there is the tendency for people in this area to have two or three children, so after three, I just tell them to go for some family planning.*

Sometimes, the advice provided to women was far from practical:

*Man living with HIV: Actually, the doctor said we shouldn't have physical contact and, if physical contact is happening, it should be properly with safe, safe...practices.*

Newborn care is an area worthy of investigation in and of itself, but was mentioned by participants in the context of postnatal care. PPTCT regimens, which include testing an infant for HIV and provision of certain medications, give families a reason to seek care for their infants. As with the acute concerns in ANC, however, these visits are mostly used for strictly PPTCT services and do not seem to include routine care for infants. Indeed, users of the health system indicated that providers did not counsel them on bringing their children for check-ups nor give much direction as to how to care for themselves or their children.

## **PPTCT Quality**

Analysis of areas related to PPTCT quality shows mostly inconsistent adoption of standards, and inconsistent messages even when they are used (see Table 4). Even though on-the-ground operations are not fully aligned with standards, however, providers do seem to achieve results in preventing vertical transmission to newborns.



**Table 4: Standards of PPTCT Care and Their Adoption in Eastern Uttar Pradesh.**

Standards of Care Inconsistently Adopted	Standards of Care Consistently Adopted
<ul style="list-style-type: none"> <li>• Testing of all pregnant women for HIV</li> <li>• Counseling on risk of transmission</li> <li>• Counseling on delivery method</li> <li>• Availability of Caesarean delivery</li> <li>• Counseling on breastfeeding</li> <li>• ARV prophylaxis for mother-baby pair</li> <li>• Follow-up with child for 18 months</li> </ul>	<ul style="list-style-type: none"> <li>• Counseling on institutional delivery</li> <li>• Early infant diagnosis of HIV</li> </ul>

Several key areas in PPTCT care have been fairly widely adopted in this region. The first is counseling on institutional delivery for women living with HIV. Whether women had a pre-existing HIV diagnosis or were newly diagnosed in pregnancy, they were counseled to either go to the district hospital or the regional academic medical center for their deliveries:

*Woman living with HIV: Doctors told me that, for the delivery, I should come to the district hospital so that if delivery takes place there, we take care that the child should not get infected by HIV. We have some medicines for that and we should provide it for the delivery, you should come to the district hospital.*

Standards also indicate that an HIV-exposed newborn should be tested at several stages in infancy, usually at 6 weeks, 6-9 months and 18 months. In this region, providers follow a modified timetable, aiming to provide an additional test to children at birth. It is noteworthy that not only are children being tested, but they are given an extra test above recommendations. This may be for the benefit of parents, who wanted to know their child's HIV status, and who indicated that receiving test results takes time. Nonetheless, this variation still ensures that the standard of early identification is being met.

While the previous standards were uniformly available in this region, many others are available in a limited fashion, in inconsistent ways within the same health centers or utilized outdated standards of care. One that is essential to the cascade of PPTCT services is antenatal HIV testing for all pregnant women. Three of the users indicated that they received their HIV diagnosis during their pregnancy, including one who specifically sought it out. The standards, however, do not encompass testing for those who only present at delivery. One participant had an institutional delivery but did not receive an HIV test at that time. She received her diagnosis several months later and was concerned she had transmitted the infection to her child. Another determining factor is the facility where participants sought care, as testing is available at district

hospitals and some secondary health centers in Mau, but not in community or primary health centers:

*ASHA: Actually, only those pregnant women who come to the [district] hospital, every woman who came to the hospital for a delivery [sic] has the test for HIV. The women who are not willing to come to the hospital, are willing to be inside their house, they don't have [the test]... Every block [in Mau] has HIV testing and if people belonging from this district, they go to the block level and all the rest go on to the district hospital...*

In Azamgarh and other areas lacking these facilities, individuals are required to go to separate integrated counseling and testing centers.

Service providers report that they provide extensive counseling when women realize they are pregnant or receive their HIV diagnosis, letting them know the risks of transmission to the child and the ways that transmission can be prevented. This counseling influences women decisions to carry their pregnancies or have an abortion. Indeed, both districts employ a specific PPTCT counselor at the district women's hospital. Participants, however, did not widely report that they received this counseling.

Women are also receiving inconsistent counseling on delivery method, even though standards indicate they should be counseled to receive an elective Caesarean section. A few users were counseled in this way, but were also told that the district hospitals are not able to offer this service. They were told to go to the regional academic center.

Counseling on breastfeeding is similarly inconsistent. Standards indicate that providers should counsel the woman to breastfeed exclusively for 6 months, followed by a complete weaning. Only one user, however, indicated that she followed this guidance. The more prevalent message is to entirely discourage women from breastfeeding entirely, which several users indicated they had done:

*ART Center Manager: When the women are enrolled there, having HIV and are pregnant and enroll in ART center, they counsel them in such a way that they totally forget about breastfeeding. After the child is born, they send a man to the woman's house to see if breastfeeding is happening... The women having children have milk, the doctor tells them how to get rid of it – by using their hands to disperse it... If women aren't breastfeeding, people who are living in the home may know that they are positive. They didn't let others know that breastfeeding isn't happening.*

Some service providers indicate that they are still following the previous set of guidelines, which advised providers to counsel patients on an appropriate method based on their personal circumstances:

*Service Provider: Afterwards, we counsel the patient on breastfeeding. The ladies who are below poverty line should not be able to provide all of the facilities to their child from outside – they don't have the resources to only provide other feeding... So they counsel the patient in such a way that only one should be opted: to go for breastfeeding or to go*

*for the outside feeding. It's better for them to go for the breastfeeding for first 6 months and after that, they stop the breastfeeding and provide the sources from outside. I only guide the patient and give both the options.*

While the personal consideration in this approach is certainly appealing, it does not follow the current standards, and may put the infant's health at risk.

Another critical standard for preventing parent-to-child transmission is ensuring appropriate medication is provided to mother-baby pairs to reduce the chances of transmission. In India, standards were revised in 2010 to require combination ART for the mother for most of the pregnancy along with prophylactic medication for the infant if the mother is not already on ART already (i.e. has a CD4 count  $\leq 350$ ). Service providers, however, indicate that they are only providing an outdated and less efficacious regimen, single dose Nevirapine. Users of the health system confirmed that they are receiving this regimen:

*Woman living with HIV: When the child was born, then Nevirapine, some medicine – ...they gave it to the child. The patients who have HIV and having regular treatment, regular medicines, they don't give the medicines to the mother. They simply give the medicines to the children, Nevirapine.... they don't give anything specially [to the mother] at the time of delivery.*

While this is not the most current standard for treatment, reports from users and those in the health system indicate that this regimen is provided consistently, often with success.

Finally, it is unclear if HIV-exposed children are having suggested follow-up for 18 months to confirm their HIV status. While users did discuss having HIV tests for their children within the first year of life, there was no discussion of plans for future testing.

Despite these inconsistent standards, PPTCT care for the women interviewed was successful, with the majority of women reporting that their child's status is negative. The exceptions were those who came to the health center only for delivery and did not receive an antenatal HIV test, and one woman who was not able to be transported to the health center when her labor started at night.

## **Barriers to Quality Care**

While some participants indicated that they found the facilities and care to be sufficient, others described a multiplicity of factors that they perceived as barriers to the provision of quality maternal care for women living with HIV. These can be categorized as system-level, facility-level and community-level barriers to quality of care (see Table 5).

**Table 5: Barriers to Provision of Quality Maternal Care for Women Living with HIV, Uttar Pradesh, India.**

System-level Barriers to Quality Care	Facility-level Barriers to Quality Care	Community-level Barriers to Quality Care
<ul style="list-style-type: none"> <li>• Lack of availability of maternal care services at local facilities</li> <li>• Lack of services for people living with HIV at local facilities</li> <li>• Insufficient staffing</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of medicines and other supplies</li> <li>• Lack of supplies for universal precautions</li> <li>• Lack of specific training for HIV/AIDS</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of public knowledge of health systems</li> <li>• Lack of knowledge of HIV</li> <li>• ASHAs not identifying all pregnant women or providing all services</li> </ul>

Many of the barriers that participants identified related to the overall health system, and many of the components that should be in place as part of the NRHM. The first barrier identified in this area is lack of maternal care services at local facilities. According to Indian Public Health Standards, basic ANC and normal delivery services should be available at Primary Care Centers while emergency obstetric care should be available at block-level facilities. Centers in this area, however, are not equipped for these services, and women are required to travel to secondary or tertiary facilities farther from their homes. This is problematic, as users often cited going to a facility because it was close to their home, and may mean others may not be accessing services because of their distance. One doctor at the district hospital discussed how she is mainly supposed to attend to high risk pregnancies, but ends up seeing a wide variety of clients due to patients seeking ANC at the hospital. This may cause women who need additional care to go without due to high volume of patients.

Similarly, services for people living with HIV, including PPTCT services, are supposed to be converged with primary care at local facilities. In reality, these services are even more centralized, with provision of ART and CD4 testing only available at a specialized ART center (of which there is one in Mau), district hospitals or the regional academic center. Several users reported travelling several hours to the large city in the region for their regular care and deliveries. This can undermine affordability of services for users:

*Woman living with HIV, currently pregnant: Actually, [Benares Hindu University, the regional academic medical center] is far away from here. So if we have to go for the operation only, then the cost at BHU is about the same as if we go here at a private clinic, so we are consenting to go to a private clinic for tomorrow's delivery only.*

HIV testing is more widespread in Mau than in Azamgarh, but is still not available as part of routine ANC through most of the area. These restrictions on care can prevent

women from receiving the full cascade of PPTCT services, increasing the risk of their pregnancy.

An additional barrier that was cited, and one that may influence the former two, was insufficient staffing for all facilities:

*Government Official: Because of the scarcity of allopathic doctors, especially lady doctors, we don't have sufficient number. If we required about twenty or twenty-five, than we have one or two. This is scarcity. So, just a mentality that we have our boundaries, restrictions. Within these restrictions, whatever we can do, we try to do it. I'm not saying we do it, but we try to do it...In every CHC, there is a post of gynecologist. But we don't have gynecologist at every CHC. We have a post-op [inaudible] physician, radiologist, pathologist, surgeon, sometimes surgeon, sometimes orthopedic surgeon, but we don't have a sufficient number. These are our boundaries and restrictions.*

These barriers not only affect quality of care, but call into question the full implementation of the NRHM in this area.

Participants also discussed several facility-level barriers to care. The one that most determined dissatisfaction for users was a lack of availability of medicines and other supplies for appropriate maternal and PPTCT care. Many participants described having to get medicines from “outside,” usually private pharmacies, which creates an additional cost for them. Dissatisfaction with having to get medications this way was a determining factor for one user to use a private hospital rather than public facilities:

*Woman living with HIV: In my block, there are not such facilities, but much better facilities at the block-level hospital. So, I would rather [not go] there, because I have to take medicine from outside anyway. If I went there, then also I need to bring the medicines. So, I simply prefer to go to the private clinic.*

Providers also describe how they are not equipped with appropriate supplies for universal protection from infectious diseases:

*Service Provider: Suppose there are fifty cases of deliveries, each person at least have six pair of gloves that should be provided. But here, six people are provided one pair of gloves. That's the reason there has paramedical staffs are hating the disease.... Suppose this person is HIV positive, next time, with same gloves, without any sterilization, only washing with water and soap, they apply to the other person. They are spreading diseases... They supply 400 gloves, but we are getting only 50 gloves.*

This inability to take appropriate precautions may drive some of the fear service providers have of working with patients living with HIV, which is described more fully in the following section.

While the division-level official described training in facilities on HIV, service providers described a need for additional training, particularly for paramedical staff.

This could help to familiarize staff with the state of the epidemic in their area, help to align care with standards, and reduce stigma.

Finally, participants identified several community-level barriers to quality care. One is that users of the health system have low health literacy generally, and little awareness of the entitlements available to them through the health system:

*Multilateral Organization Employee: No, I think women, first of all, their knowledge on the health is not very that much optimal of what facility exactly they want... What the doctors, they have fully faith in the doctors. Most of the people, if you can say, it's faith or it's lack of knowledge or it's lack of education, they don't have any medical literacy. So, whatever the doctor will suggest, they will go with that in most of the cases. So, their own choice is very late.*

Additionally, one participant stated that she did not feel like she got the information she needed to have a healthy pregnancy and delivery, but did not know how or from whom she could get that information. This lack of information can influence health-seeking and the facility a user consults to receive information.

More specifically, the lack of community understanding of HIV was also identified as a barrier to care. Indeed, lack of knowledge was identified as a factor preventing patients from being able to properly receive any care:

*Service Provider: We have encountered many problems to handle patient because basically, these patients are illiterate. Counseling illiterate patients is very much difficult. For example, a patient is illiterate. Due to that, she never accepts that she is suffering from the disease HIV or AIDS. She has many misconceptions in her mind and she never accepts our advice. In that process, she lost her husband and then also, she said no, this is not HIV, this is something else. The particular community of people who are belonging from rural or remote areas, they believe some misconceptions are there like a ghostly appearance [they think someone may have cursed them]. They counsel again and again, and she still denies. She thinks she does not have HIV, she has something else.*

Even with functional facilities, this lack of knowledge could still contribute to the spread of HIV:

*Government Official: Yes, facilities is also needed. They are our primary needs. But who will go to take the facilities if we don't have the knowledge? Until, unless I or my brothers or my sisters did not have the knowledge, what is HIV, why should they go to the facilities? They will not go to...and they will spread and spread and spread HIV in the society. And one day, they will be excluded like animal and everything will be destroyed. So, to control that, it is very important, in my view, it is very important that we spread the knowledge as soon, as wide as possible.*

An important contributor to improvement of health outcomes at the community level is the ASHA, who is supposed to provide basic maternal care services to women and bring them for institutional deliveries. Many participants, however, stated that they had never had an interaction with an ASHA. The ASHAs themselves report that they are counseling women on many health topics, but users stated that the ASHAs only brought them for their deliveries or discussed incentives available to them through NRHM. Not having this important community health worker available as a local link to the health system could be a salient barrier to quality care.

### **Stigma and Discrimination**

One significant barrier to provision of quality care that people living with HIV discussed is that a real or perceived threat of stigma or discrimination informs many of their interactions with service providers. Several participants described being “ignored” or “separated” at health facilities because of their HIV status:

*Woman living with HIV: Doctors don't treat us properly. They try to ignore us and first, when we visited firstly, somehow they check me but now ... somehow they're ignoring [me].*

*Woman living with HIV:... The doctors, first they denied me and they used to check me last...the very last. Firstly, they used to check up the normal patients, afterwards when they completed them, then only I used to be checked.*

Service providers described their fear of working with patients living with HIV, which is driven by their lack of supplies for universal precautions:

*Service Provider: In the beginning the staff nurses have some fear among themselves regarding HIV but after facing some of the delivery of HIV patients they became normal and understand it that by this process they are not going to infected by the HIV.*

*Service Provider: ...So, not only public, our [inaudible] staff are also afraid of this disease. They are very much aware and not sit with them, so they avoid their care... They always try to avoid them. They always try that HIV patients deliver in next treatment room, not their treatment room...this is the problem here.*

*ASHA: I don't get any type of patient who is HIV positive and I don't want any type of patient. I don't want that any HIV positive should be in my area...I don't want that anyone go from this state, HIV positive, because it's very bad...very bad. HIV positive is not good.*

*Service provider: Generally they come, unknown patients, HIV positive patients came to us bleeding profusely with no investigation, no records and we have to evacuate them in*

*emergency. We have to touch them, we have to give them IV fluids and medicines. We are always in danger.*

Because of this perceived or actual threat of stigma or discrimination, many patients living with HIV do not reveal their status to their health care providers or to ASHAs. In fact, all of the ASHAs interviewed said that they never encountered a patient living with HIV, despite living in a high prevalence area. Several users reported not telling their doctors of their HIV status when they presented for delivery, which was confirmed by health staff:

*Government Official: In the same way, for HIV and AIDS cases, today we have the hidden patients that we should not disclose these and people should not know me as I am HIV case. So, they conceal themselves. Or, even our law had that identity should not be disclosed because previously we had the cases where one, if, family or villagers or the society came to know that he's an HIV patient, they isolated him. Even we have heard of or read cases where they committed suicide, so many cases. Just for social stigma. All these things need spread of knowledge, training, training and training.*

Clearly, this threat severely impacts the quality of care people living with HIV are receiving, and may be an underlying driver of continued HIV infection. Despite its prevalence, elimination of stigma is not overtly discussed in care standards.

## **Satisfaction**

Despite the evidence that care quality is not matching established standards, users reported an overall moderate level of satisfaction with the facilities provided. Additionally, several service providers report high satisfaction with the facilities and believe the quality to be good. Despite their level of satisfaction, however, people living with HIV are constrained in facilities they can attend to receive care for their condition:

*Man living with HIV: For HIV, we totally depend on the district hospital and we don't consult for any private doctor for HIV. And the facilities which are provided here, we are not satisfied fully. Somehow, we visit [Benares Hindu University in Varanasi, the local regional academic medical center]. There, the facilities are good but a little crowded there, and at a distance, so we face difficulties being far away from there. So we visit here only to the district hospital, and somehow we are satisfied with these facilities. We're totally dependent on them.*

Having a captive population of patients gives those providing services for people living with HIV few incentives for improvement.

## **Discussion**

According to perspectives from this sample of participants, several important standards are being met and some aspects of of maternal care and PPTCT for women



living with HIV in eastern Uttar Pradesh are high quality. Indeed, women are receiving important counseling to prevent anemia, which can profoundly affect their risks in the maternal period as well as the long-term success of their children. They are being counseled to have institutional births, and are following that advice. This is an especially significant finding in an area where almost 80% of women still deliver at home. Their children are being tested for HIV at an early age so that they can receive the appropriate cascade of services during infancy to provide them with a long and healthy life. Among those in this sample, PPTCT interventions were mostly successful in preventing HIV transmission to infants.

Despite these highlights, this study also paints a disturbing picture of maternal care for this vulnerable population. Whether women know of their HIV status or receive their diagnosis in pregnancy, they often only seek care when they are in pain or have a similar acute concern. When they do visit the doctor, they are not provided with adequate information on their pregnancy, how to recognize if their health is in danger, or how they can prevent HIV transmission to their child. They may seek care for their delivery, but are stigmatized and discriminated against when they do, and fear their status may be revealed to others in the facility. They are provided with outdated treatments and counseling for preventing their children from acquiring HIV. They are not given information on how to care for their child and are not told to return for care to keep themselves and their offspring healthy. When they do return, it is often just to know the HIV status of the child. This narrative of care falls far short of the vision of quality care for rural poor women and children on which the NRHM was founded.

The health system appears ill-equipped to handle the demand it has generated for services, particularly for women requiring a complex cascade of services and interventions, such as those living with HIV. This quality gap could have serious consequences for health outcomes in India and for the goals of NRHM as a whole. Indeed, in an assessment Ng and colleagues conducted on the effect of conditional cash-transfer on maternal mortality in neighboring Madhya Pradesh, they found that the percentage of institutional deliveries did increase, but there was no effect on maternal mortality<sup>46</sup>. They posited that the low quality of care – perhaps with similar problems that were found in the current assessment -- may be the reason for the lack of improvement.

This study also points to serious gaps in care for PPTCT services. Service providers are still relying on standards from 2006, and seem unaware of updates that were made in 2010. The UP State AIDS Control Society urgently needs to implement the newer standards to ensure the most up-to-date evidence-based services are provided to women living with HIV. Decision-makers should also consider implementing new rapid testing technologies to ensure that all eligible women are enrolled into appropriate PPTCT services. Pai et al implemented a round-the-clock rapid testing program for women in delivery in rural India with success<sup>47</sup>, indicating that this is likely a feasible intervention for this setting. The burden of stigma and discrimination in this area is significant and impacts the quality of care provided to people living with HIV, but is not addressed in any government standards. All of these issues need to be considered in the National AIDS Control Plan IV, which is being rolled out across the country in the coming year.

Finally, this study indicates a paradox where users of the health system and service providers are moderately satisfied with care and facilities despite the poor indicators. This is similar to a finding amongst recent mothers in Malawi; the author posits that satisfaction was high because users had low expectations of what to expect.<sup>48</sup> Pittroff et al. describe how users, “may feel satisfied with the care they receive despite poor biomedical outcomes, if they feel everything possible was done. Alternatively, the value given to good biomedical outcomes, such as having a healthy baby, may override other aspects of care deemed to be poor (p. 280),”.<sup>16</sup> Whatever the reason, there is a continued need to educate health system users on their entitlements and to continue to generate evidence and advocate on behalf of better services. Meaningful means of inclusion for women living with HIV in these education and advocacy efforts is a necessity. This, however, presents a significant challenge since those living with HIV in this area are hesitant to self-identify and also live with gender norms that keep women close to home. This kind of inclusion, however, is essential to creating any community demand for improved services, and ultimately improving the quality of care for this hidden and often neglected population.

## **Recommendations**

Staff from the International Community of Women Asia Pacific and the Centre for Health and Social Justice should consider:

1. Discussing the results of this study with representatives from the state and district-level networks of people living with HIV to ensure results have community validity, and to generate discussions on the issues raised herein.
2. Advocating at the national level for inclusion of standards relating to prevention of stigma and discrimination for those living with HIV in government care guidelines.
3. Working with local health centers to include items relating to stigma and discrimination in Citizens Charters in community and primary health centers.
4. Collaborating with national partners to bring visibility to those living with HIV to reduce stigma.
5. Partnering with organizations working on safe motherhood and reproductive choice to ensure the perspectives of those living with HIV are considered in policy and program considerations.
6. Lobbying the National AIDS Control Organization (NACO) and UP State AIDS Control Society to immediately implement the most up-to-date standards in HIV care, including stopping the use of single-dose Nevirapine as ART prophylaxis.
7. Developing innovative community involvement strategies to engage women living with HIV with their healthcare.
8. Campaigning to ensure the goals for local, community-based care through NRHM are met for populations at large, as well as for people living with HIV.
9. Ensuring people living with HIV are included in communitization and evaluation efforts investigating NRHM services.
10. Conducting a more rigorous study on the maternal care system for women living with HIV to validate findings and determine strengths and areas for process

improvements.

11. Supporting efforts to improve the livelihoods of those living with HIV, particularly widows and orphans.

### **Capstone Project Reflection**

The ultimate impact of this work on the community remains to be seen, as the results have not yet been disseminated. I hope, however, that the conduct of the study exemplified the Uncertainty Principle in that it changed the very people and concept I was studying just by investigating this. I hope that the act of listening to the stories of women living with HIV gave them some sense that they and their experiences are important. I also hope that the local networks of people living with HIV considered examining these issues as part of their advocacy work. When I was in the communities in Mau and Azamgarh, I also received some media attention just for the work I was undertaking. I hope that this attention made some local community members who may be fearful about HIV reconsider their views and the importance of caring for people living with the virus.

The fact that I was able to conduct this work at all feels like a major success. Ultimately, being able to accomplish anything was a result of partnering with two well-established and respected organizations that had many connections with other local partner organizations. I learned quickly that work in India all happens because of connections, and untested outsiders will have their efforts shunned. Working with local organizations in this way not only connected me to advocates working very hard to improve conditions in their local communities, but provided me with essential inroads to conducting interviews with both users of the health system as well as high-level government officials. Having two organizations with two complementary sets of expertise and connections also contributed to the success of the work, as well as providing two useful lenses with which to examine my work.

One goal that I hoped to attain in study was to base my work on principles of community-based participatory research and include stakeholders at multiple stages throughout my project. As many researchers have probably found in their work, however, finding appropriate stakeholders and logistically arranging for them to be involved at all stages has proven to be difficult and time-consuming. This was not aided by the significant language gap between my participants and myself, as well as my admitted weakness in not maintaining connections with people I met very well. This certainly provides a lesson in the additional time and resources that need to be devoted to true CBPR. Shifting the focus of the study a bit when I was on the ground and adding an additional population of HIV negative women without appropriate discussion of how their data would be used led me to feel that the project was not as focused as I would have liked, and greatly increased the time it took me to complete it over the last nine months.

In my first few weeks of arriving in Delhi, I told my friends and family that my experience was the exactly what I wanted and I was the person I needed to be to have it. Some of this initial enthusiasm dimmed as I faced some struggles with dealing with

culture shock while spending significant amounts of time on my own, but overall, I think of this fondly both as a tremendously fruitful personal experience as well as a great application of my knowledge of public health research and Indian culture. As I mentioned, I would have liked both my work and my life in the community to have been more grounded, but it can be difficult to adjust to a place and its cultural norms in such a short amount of time. I also hoped to complete the project in a more timely matter, and am continually aware of and working on my issues that prevented that from happening.

In the course of my literature review, I was quite pleased to find that I am indeed adding to the evidence on this topic, and that other investigators have not looked at the full cascade of maternal and PPTCT services even though they are inherently linked. While my study may not be wholly comprehensive, it does provide a precedent for looking at these issues broadly and continuing to advocate for fully converged services. The qualitative approach allows me to comment not only on the actual quality of the work, but the barriers in place. In terms of weaknesses, this work attempts to address issues that would better be suited to quantitative or mixed methods research with a qualitative approach and the small sample size that inherently involves. The study also turned out to be quite broad because it took a long time to pin down the exact focus of it. Having a better sense of the aim and focus would have made the whole study process much easier at every step.

Knowing what I know now, I would have tried to find a way to take a qualitative methods class, perhaps by auditing, so that I would have had a firmer grasp of my research question and aims. I also would have attempted to communicate more clearly with my partner organizations on the scope of my study, and their expectations for what I would produce. I also would have communicated more clearly on the information dissemination plan, as that is still uncertain at this point.

As mentioned above, the scope of my study is much broader than others. While this has been challenging logistically, it supports the need for fully converged services, and I believe is important in that regard. My sample size is fairly typical for smaller qualitative studies, but seems to have drawn out less rich material from some of the participants. This may be due to several factors, namely that I am a foreigner, that my interpreter was male, that I was not sure how much probing was comfortable for participants and that it was sometimes difficult to conduct interviews with complete privacy.

The implications of this project are quite large, as they point to the Government of India providing services that do not live up to their own standards. This points to significant body of work, particularly organizing and advocacy, that must be done by the partner agencies. Additionally, the implication of stigma as a major barrier points to some major cultural shifts that must be made, and need to be addressed on local and national levels. It also points to significant work to be considered by local organizations working on these issues, which means they need to decide if these are local priorities or not and, if so, how to take action on these findings.

This project also strengthens the evidence the public health practitioners, particularly funders, need to break down their silos and look at health issues in a broad and comprehensive way. It also points to the need for reproductive and maternal health

programs to include perspectives of those living with HIV and vice versa. For next steps, once my advisors approve my report, I hope to create a 1 page sheet of findings to share with local partner organizations. If appropriate, I would like to rework the report into a manuscript for publication.

## **Acknowledgments**

There are so many people and resources without whom this project literally would not have been possible, and I owe them lasting and eternal gratitude. First, I would like to thank the University of Washington Thomas Francis, Jr. Fellowship for support of this study and my trip to India. Dr. Sanjay and Rajdev Chaturvedi provided essential support at a critical juncture in the project, and ensured I was connected to key stakeholders. Gaurav Singh and Sumiksha were wonderful interpreters and traveling companions. Renu Singh, Brijbhaan Yadav and other members of district networks of people living with HIV welcomed me and extended their connections to community members to me, as well as providing critical perspectives on the local health care system. Thank you to service providers and staff members who agreed to be interviewed, as well as providing important information on the situation on the ground. This study would not have happened without Sumeet Singh and Saroj Laniya, but more importantly, their care and friendship buoyed me when I was so far from home. I owe significant gratitude to my on-site advisors Anandi Yuvaraj and Abhijit Das, who took a chance by allowing me to take on this work, but ultimately provided with a rich and formative global health experience. I thank them for their patience, flexibility, mentorship and encouragement. Thank you to my faculty advisor Mary Anne Mercer, who has provided a steady, guiding hand, support and grace through many ups and downs over the past year. Finally, and most of all, I would like to thank the people living with HIV, who took great courage and overcame many fears and barriers to speak with me. I hope that I am doing right by you by sharing your stories.

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VH & SC=Village Health and Sanitation Committee



## Appendix B: Semi-Structured Interview Guides

### Interview Guide for Woman Living with HIV

Date of Interview

District:

Specific Area:

ID number

#### 1) Introductions

- a) My name is Jenna Udren and I am working with two voluntary organizations, the International Community of Women Living with HIV and the Centre for Health and Social Justice. They are organizations that work on health issues throughout the country. This is [translator name], who is working as my translator. We are looking to find out about public health care facilities in this area. We would like your opinion on these issues because we feel that you have much that you can teach us with your experiences. *[If have not gotten consent yet: First, I'm going to provide you with information to decide if you would like to participate in the study. Read consent script.]*

Please answer as well as you can and know that there is no right or wrong answer. If you agree, I would like to record this conversation *[show how recorder works]*. If you do not want, however, we do not need to use the recorder. All of your responses will be confidential. We think that this conversation will take about an hour.

Do you have any questions?

#### 2) First, I will ask you some basic questions about yourself.

- a) What is your age?
- b) What is the highest level of education you've reached, even if you didn't finish? No formal education, primary, secondary, college, university, higher than university.
- c) Do you belong to a scheduled caste, scheduled tribe, OBC, General, don't know?
- d) What is your religion? Hindu, Muslim, Christian, Sikh, Buddhist/neo-Buddhist, Jain, Jewish, Parsi, no religion, other.
- e) What is your relationship status? Currently married, living with a partner, in more than 1 relationship, divorced, separated, widowed, deserted, never married.
- f) What is your present occupation?
- i) Homemaker/housewife/does not work
  - ii) Housewife but does routine household work e.g. cooking, cleaning.
  - iii) Domestic worker (housemaid)
  - iv) Manual skilled (tailoring garment factory worker)
  - v) Manual unskilled (shop/sales/printing press/house-based work such as agrbatti, beedi rolling)

- vi) Services (vending e.g flowers, produce, kerosenes)
  - vii) Services (office work)
  - viii) Other
- 3) Do you own your home?
  - 4) Does your home have a toilet?
  - 5) How many children do you have that are living?
  - 6) How many pregnancies have you had?
  - 7) When was your most recent delivery?
  - 8) For how long have you known that you have HIV?
  - 9) [if has a partner] Does your partner have HIV?
  - 10) Are you currently on medication for HIV?
    - a) If yes, for how long?
- 
- 1) Tell me how long you've lived in this area.
  - 2) What do you usually do when you or a family member needs medical care that you cannot provide at home?
  - 3) One of the options for health care in the area are government facilities. Locally, these facilities are [give names or locations sub-centres, CHC, PHC]. What has been your experience using these facilities?
    - a) Probe if haven't used facilities: what do you know about these facilities?
  - 4) For what reason did you to use this or other facilities?
  - 5) How did you find out information about the government facilities?
  - 6) Have you used facilities that focus on care for people living with HIV?
  - 7) I am interested to know about health services you have received around your most recent pregnancy and birth. Can you tell me generally about services you used during that time?
  - 8) I'm now going to ask specifically about your care at different times. First, what kind of care did you seek while you were pregnant?
    - a) Probes: in which facilities were they sought/received? How many times did you visit the provider? What influenced your decisions?
  - 9) What topics did the provider discuss with you while you were pregnant?
    - a) Probes: nutrition, medications, danger signs
  - 10) What did the provider discuss with you about preventing your child from contracting HIV?
    - a) Probes: Drug regimen – which one? CD4 tests? Cesarean section for delivery? Breast feeding?
  - 11) What tests did the provider give you while you were pregnant?
  - 12) Were you able to follow the advice or treatments given during these visits?
  - 13) What was your experience in labor and delivery?
    - a) Probes: who was with you? What influenced decisions about where to give birth? Were there complications?

- 14) What actions were taken during your labor and delivery to prevent your baby from contracting HIV?
- 15) What is your level of satisfaction with your labor and delivery experience?
- 16) What was the outcome of the delivery for the baby?
- 17) What kind of care have you sought after your pregnancy, either for yourself or for your child?
- 18) What topics did the provider discuss with you after you gave birth?
  - a) Probes: bleeding, infections, family planning, infant feeding, infant care, immunizations.
- 19) What did your provider discuss with you about breastfeeding?
- 20) Has your baby received tests for HIV? If so, at what ages? What were the results?
- 21) Describe your experiences seeking or receiving these services at government facilities.
  - a) Probes: What was the facility like? Did they seem to have the supplies they needed? How did the providers treat you?
- 22) During this time, did you interact with the local ASHA? If so, what topics did she discuss with you?
- 23) What was your level of satisfaction with the ASHA?
  - a) Was she knowledgeable? Helpful?
- 24) If you needed health care for yourself or your family in the future, would you use the local government facilities? For what services? Why or why not?
  - a) Which are the most important to you?
- 25) How did you feel about your experiences seeking this care as a person living with HIV?
  - a) Probes: how did you disclose your status? How were you treated by providers?
- 26) One important part of government health care services is that they are supposed to be monitored by the local community. In what ways would you be interested in providing feedback and monitoring of your local facility?
  - a) Which are the most convenient for you?
- 27) If you could talk to the government planners in charge of this facility, what would you say?
- 28) Is there anything else important that you would like to share?

Thank you for your time answering these sensitive questions. Your opinions will be very helpful in providing suggestions for how health care in this area can be improved. If you have any additional thoughts, comments or questions, feel free to contact me. [Provide reimbursement].

## Interview Guide for ASHAs

Date of Interview

District:

Specific Area:

ID number

### 1) Introductions

- a) My name is Jenna Udren and I am working with two voluntary organizations, the International Community of Women Living with HIV and the Centre for Health and Social Justice. They are organizations that are based in Delhi but work on health issues throughout the country. This is [translator name], who is working as my translator. We are looking to assess health care facilities in this area. We would like your opinion on these issues because we feel that you have much that you can teach us with your experiences. *[If have not gotten consent yet: First, I'm going to provide you with information to decide if you would like to participate in the study. Read consent script.]*

Please answer as well as you can and know that there is no right or wrong answer. If you agree, I would like to record this conversation. If you do not want, however, we do not need to use the recorder. All of your responses will be confidential. We think that this conversation will take about an hour.

Do you have any questions?

### 2) First, I will ask you some questions about yourself.

- a) What is your age?
- b) What is the highest level of education you've reached, even if you didn't finish? No formal education, primary, secondary, college, university, higher than university.
- c) Are you able to read and write?
- d) How long have you worked as an ASHA?
- e) What training did you receive to be an ASHA?
- 1) Tell me how long you've lived in this area.
- 2) Describe your main duties as an ASHA.
- 3) Generally, what do you think is necessary to be able to carry out your duties as an ASHA well and provide high quality care?
- 4) Are those elements in place here as you carry out your duties?
- 5) What are the challenges you face in carrying out your duties well?
- a) Which are the most important?
- 6) I am interested in your role in maternal health locally. Can you describe the services and counseling you provide to women who are pregnant, those in labor and in the postpartum period?
- a) Probes: nutritional counseling; iron supplementation; care-seeking in local facilities; counseling on warning signs; importance of institutional delivery; referral for complications; infant feeding; family planning.

- 7) Based on what you described earlier about quality care, what parts of your maternal health services are high quality?
  - a) Probes: local person? A known/trusted person? Have supplies on hand? Free/low-cost?
- 8) What challenges do you have in providing quality maternal care?
  - a) Of these, which are the most important?
- 9) What are the challenges women have in accessing services and acting on the advice and treatment given?
- 10) This district is categorized as having a high level of HIV prevalence/vulnerable to spread of HIV. How do you care for women who are pregnant and disclose that they are living with HIV, or discover they have HIV during their pregnancy?
  - a) Probes: counseling, testing during pregnancy, CD4 tests, warning signs, PPTCT, medications for mother and child, referrals, delivery method, counseling on infant feeding, counseling/actions against parenthood e.g. abortion, sterilization, family planning.
- 11) Based on the elements of high quality care we discussed previously, what services that you provide for maternal health care for women living with HIV are high quality?
- 12) How do you feel working with patients living with HIV?
- 13) What are the challenges HIV positive women face in accessing your services and acting on advice and treatment given?
- 14) What additional resources do you need to address the needs of HIV positive women?
  - a) Probes: supplies, training, facility changes, organizational policies.
- 15) The government has plans to increasingly provide maternal health services for women living with HIV at local level facilities. What counseling or training have you received on these plans?
- 16) If you could speak to the government planners about maternal health care for women living with HIV, what would you say?
- 17) What are ways women living with HIV could be involved in community monitoring of this facility?
  - a) Which are the most important?
- 18) Is there anything else important that you would like to mention?

Thank you for your time answering these sensitive questions. Your opinions will be very helpful in providing suggestions for how health care in this area can be improved. If you have any additional thoughts, comments or questions, feel free to contact me.

## Interview Guide for Providers

Date of Interview

District:

Specific Area:

ID number

### 11) Introductions

- a) My name is Jenna Udren and I am working with two voluntary organizations, the International Community of Women Living with HIV and the Centre for Health and Social Justice. They are organizations that are based in Delhi but work on health issues throughout the country. This is [translator name], who is working as my translator. We are looking to assess health care facilities in this area. We would like your opinion on these issues because we feel that you have much that you can teach us with your experiences. *[If have not gotten consent yet: First, I'm going to provide you with information to decide if you would like to participate in the study. Read consent script.]*

Please answer as well as you can and know that there is no right or wrong answer. If you agree, I would like to record this conversation. If you do not want, however, we do not need to use the recorder. All of your responses will be confidential. We think that this conversation will take about an hour.

Do you have any questions?

### 12) First, I will ask you some questions about yourself.

- f) What is your age?
  - g) What is your sex?
  - h) What is the highest level of education you've reached?
  - i) What is your title at this facility?
  - j) How long have you worked at this facility?
- 1) Tell me how long you've lived in this area.
  - 2) Generally, what do you think is necessary to be able to provide high quality care to patients?
  - 3) From what you described, can you say elements of quality care are present at this facility?
  - 4) What are the challenges you or your colleagues face in providing a high quality of care at these facilities?
    - a) Which are the most important?
  - 5) I am interested in the maternal health services provided at this facility. Can you describe the services available, starting with antenatal care, going through labor and delivery and continuing with postpartum care?
    - a) Probes: nutritional counseling; iron supplementation; tests for hemoglobin, HIV, diabetes, blood pressure; tetanus prevention; counseling on warning signs; importance of institutional delivery; delivery care and staffing; referral for



complications; care against hemorrhaging and infections; infant feeding; family planning.

- 6) Who is eligible to receive these services?
- 7) Based on what you described earlier about quality care, what parts of your maternal health services are high quality?
  - a) Probes: choice of services? Well-trained staff? Good interactions with patients?
- 8) What challenges do you or your colleagues have in providing quality maternal care?
  - a) Of these, which are the most important?
- 9) What are the challenges women have in accessing services and acting on the advice and treatment given?
- 10) This district is categorized as having a high level of HIV prevalence/vulnerable to spread of HIV. How do you care for women who are pregnant and disclose that they are living with HIV, or discover they have HIV during their pregnancy?
  - a) Probes: counseling, testing during pregnancy, CD4 tests, warning signs, PPTCT, medications for mother and child, referrals, delivery method, counseling on infant feeding, counseling/actions against parenthood e.g. abortion, sterilization, family planning.
- 11) Based on the elements of high quality care we discussed previously, what parts of the maternal health care for women living with HIV are high quality at this facility?
- 12) How do you feel working with patients living with HIV?
- 13) What are the challenges HIV positive women face in accessing your services and acting on advice and treatment given?
- 14) What additional resources do you need to address the needs of HIV positive women?
  - a) Probes: supplies, training, facility changes, organizational policies.
- 15) NRHM and NACO documents indicate that PPTCT and maternal health services for women living with HIV will increasingly be provided at local level facilities. What are plans at the facility to improve services for women living with HIV?
- 16) If you could speak to the NRHM planners about maternal health care for women living with HIV, what would you say?
- 17) What are ways women living with HIV could be involved in community monitoring of this facility?
  - a) Which are the most important?
- 18) Is there anything else important that you would like to mention?

Thank you for your time answering these sensitive questions. Your opinions will be very helpful in providing suggestions for how health care in this area can be improved. If you have any additional thoughts, comments or questions, feel free to contact me.