



Transcript provided by the Kaiser Family Foundation<sup>1</sup>  
[Tip: Click on the binocular icon to search this document]

---

**Hormonal Contraception: The Role of Fertility Choice in HIV  
Prevention  
Kaiser Family Foundation  
July 26, 2012**

---

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

[START RECORDING]

**HELEN REESE:** If we could all take our seats. So we are going to have to contend with a little bit of background noise I'm afraid. But I'll make sure the speakers all speak loudly so that you can all hear. And we have four speakers but we also have time for discussion because I think this issue of fertility choice and HIV prevention is one where we by no means have cracked what we should be doing.

I think it's a field where a lot of us are saying there are a lot of questions both scientifically and programmatically. So it really lends itself to hearing a richness of debate after we've had the inputs. We've got four excellent speakers. My third speaker is here but she forgot to load her slide so we sent her scurrying off to the slide room. So she will join us just now and if there is any delay than I'll switch order and we'll change the order.

So the first topic is one where some of you might have heard quite a lot of debate already and it's a hot topic and it's a complex topic. The issue of contraception and HIV acquisition. It's also a topic that had a lot of international discussion with WHO taking the lead in that dialogue. Because it's complex it requires a real clarity of mind to sort of set out what the issues are and challenge us. He's laughing. I know this man well, you can tell this from my build up.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

But Ward Cates is somebody who I think gives the best exposition that I've heard on taking us through how we got to where we're going and what the questions are that should challenge us. Ward.

**WARD CATES:** Thank you Helen but I should say I learned from the master. Helen gives the clearest clock and she was moderator so she needed someone else lets go with this. Well today throughout the conference we've had a variety of talks on this topic beginning with Helen and extending all the way through yesterday's session which was absolutely superb. And what I'm going to do in the next 15 minutes is just try and synthesize exactly where we are on this and then present to you what are some of the implications.

Now molecular level scientists always end with their acknowledgements and have casts of thousands of individuals. Epidemiologists that are population level acknowledge groups. And many of you in this audience are part of this, including my FHI colleagues in the audience, my co-moderators at the session and everybody else associated with these particular organizations. This is truly a global village that we use in order to get this information.

And it all starts, I can't emphasize this enough, this entire field starts with ensuring that we ask a woman, each women what are her fertility intentions. Do you currently

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

intend to get pregnant? And if yes as we heard from Kenya yesterday we set up a preconception counseling program that assures the best available outcome for that pregnancy.

But if no, she doesn't currently intend to get pregnant, then contraceptive choices are hopefully available and the choice here that we'll be looking at is hormonal or other methods and their affects on HIV acquisition. So in today's talk I have to start with a history of a hypothesis, it's nostalgic. A brief review of the current evidence referring to what's already been discussed this week, how we got to the WHO recommendations and beyond. And then so what, what does it mean for women and what does it mean for policies.

Well when we start the research timeline, literally it began 25 years ago in this town in the Hilton Hotel, up the street on Connecticut Avenue with a presentation from Nairobi about increased risks in Kenyan sex workers. From that time on, synthesized yesterday we have had multiple up to 20 what we call secondary analysis and a few primary studies addressing this question. In 1996 we had a major NIH consultation after some data from monkeys came out and then in 2008 we had the first WHO hormonal contraception HIV consultation and report there from.

But it really hit a crescendo in Rome last year initially when Renee Hefron, who we heard yesterday do an

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

update analysis from the database presented the data from the partner study. That got over shadowed a bit by the hoopla accompanying HPTN052. So only those of us in the reproductive health field were sort of massaging the data at that point. But then when it was published, the global viral media took over. And it took over in Kenya and with each iteration of spread the information got a bit more blurred and a bit more dramatic and a bit more inaccurate. And this is what we face in trying to come up with accurate information about this highly complex topic.

Well what are we talking about? This with a study discordant couples for acquisition purposes looking at HIV negative women using hormonal contraception and at the very top line you see less than a quarter of women were using these methods. And what they found which we heard several times at yesterday's session was an increased risk for both combined oral contraceptives, COCs and for injectable DMPA. Both around twofold increased risk in this population.

And then as Chelsea showed us yesterday when you meta-analyzed these results according to the others that have been done, it forms an array of findings. She focused on the top 8 that we looked at WHO and then Renee yesterday did sensitivity analysis trying to ferret out what was just the DMPA and her result here would go from about two up to about four.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

But in these observational studies, they are replete with all types of limitations in terms of making causal inferences. Whether there is what we in epijargon call selection bias that women who chose different methods are just inherently different and do safer things. All the way up to the comparison group in these studies frequently contain more condom users than the hormonal groups.

Therefore perhaps driving the incidence of HIV and that group down with increased condom use making it artifactually elevated increase in the hormonal groups. We wrestle with these, we wrestle with these. For those of us who make a living epidemiologically we love wrestling with these but it doesn't provide conclusive answers.

Now what about other contraceptive options? What about what – how are those actually available. We talked a lot about injectables and DMPA. Well the most effective methods and this is a WHO slide are those that are sort of forgettable and that's these top lines implants, IUDs and sterilizations. But what is available in most settings including many public settings in the United States, are these methods, the pills, injectables, breast feeding, lactation amenorrhea and male condoms. So those methods are really what are available, not those in the top line that are the most effective.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

We need greater method choice, I'm going to emphasize this again and again. But wait a minute. What about pregnancy the alternative to less effective or no contraceptive use? The same database analyzed by the now absent Nellie but she'll be back, showed that in fact that same database if an uninfected woman became pregnant she had a – between a 1.5 after adjustment or a 2 full increase risk of becoming pregnant. But again, observational studies, but the same database are you – so really what is an uninfected woman to do on the basis of these data? Well she uses injectables, she'll have less risk of pregnancy but possibly inconclusive evidence more risk of HIV acquisition.

But if she becomes pregnant, she has more risk of HIV possibly acquisition and those two in fact cancel themselves out and more risk of pregnancy complications. So there are tradeoffs involved to that and unfortunately she's damned if she does or damned if she doesn't. So here that's the setting for this gathering and Shelly Geneva about now six months ago.

WHO uses a system mentioned very quickly yesterday the grade ratings that looks at all of these data and starts with randomized controls being the highest quality, observational being low quality and they look as Chelsea guided us through the eight key studies and gave it an overall rating of low quality evidence over all.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

And that then forced this gathering to sort of focus on how do these low quality evidence affect the eligibility criteria for DMPA for this category of women in high risk of HIV. And so for some of the group, if we left it a category one and didn't change the existing recommendation which was a category one no restrictions on depo for women at high risk of HIV that would let depo get away with a clean bill of health.

But if we moved it to category 2 that change implied that that evidence was strong enough in order to taint that low quality evidence would taint depo and might imperil it's availability as one of the few effective contraceptives available in these public settings and low resource settings.

And there was a total bell shaped curve of opinion, just like – well it's like life. And you had the strong category ones and the strong categories two and most of us in the middle. So the statement in record time Dr. Abizo [misspelled?] for WHO came out in two weeks approximately after the meeting. Congratulations.

And what it recommended was because of the inconclusive evidence no restrictions on depo for women at risk because the evidence was inconclusive but with an asterisk clarification urging women who chose this method to strongly use condoms. And probably – in fact definitely more important to me than

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



even that particular rating were the programmatic and research recommendations that followed all of these deliberations.

That based on this rating clearly would draw all of injectable contraception from programs was not warranted. That the method mix, remember the limitations we have the method mix needed to be expanded and needed to be quickly expanded for women at risk of HIV emphasizing condoms and then the integration of programs to make these choices more convenient to clients who are accessing HIV resources as well.

For research we can't grovel in low quality evidence for ever. We need some attempt to get higher quality randomized trials. Also a drive for developing multipurpose technologies - dual purpose technologies that can prevent both pregnancy and HIV in one method. And finally, further investigations of what are the underlying interactions at the molecular level that might lead to any possible increased risk if shown to be true.

Well the messaging around this was really difficult. We realized that actually as we were going home from that meeting. So the WHO convened a follow up meeting that was with community advocates, leaders, and national organizations. And they were really wonderfully candid discussions of the evidence in plain terms, interpretations and attempt at messaging.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

And this report has just been published. If you click on WHO micromeeting or something it will come up. It was published at the end of last week and contains some basic recommendations that I'll mention.

So where are we? What does this mean for women right now? Well as I showed at the outset, the basic issue is do you currently intend to become pregnant yes no. Her fertility intentions drive the algorithm of the services we provide. Having contraceptive options available to act on if she chooses not to deliver is crucial. Without options there really are very little choice.

Accurate information – full accurate information about each method to each woman to allow her then to make her choice is fundamental to the informed choice part of informed consent. And I loved the way Sharon reframed the question to the audience yesterday about after having been informed fully what would choose for – what would you hope your teenage daughter would choose. Because your teenage daughter would probably not be choosing for your teenage daughter. Why? Because women's rights are fundamental so all of this it is her choice and her context about this.

But what does this now mean for policies going forward. Again, only at the top its rights and justice as Geeta Gupta

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

told us about yesterday. Rights and justice are what an AIDS free generation is all about.

This now is an opportunity even more to make our case to all the countries and all the policy makers for increasing the method mix for getting the regulators to approve more methods and getting them into our country system. Having those methods available in country also means we have to make them accessible to where women have an unmet need for family planning. To have research on this multipurpose technology on these dual approaches is accelerating. We heard about some of the sessions in this meeting.

And finally the integration of our services, again, as we've had whole separate session on is a goal to make all of these choices convenient for clients.

So here we are in conclusion the recent findings are definitely concerning. Let's not have no doubt about that. But the evidence is not conclusive and we remain in a sort of vacuum of ideological uncertainty. WHO is continuing and will continue to evaluate these findings as they come in, however, reproductive health tradeoffs are an inherent part of contraceptive choice and even pregnancy itself carries its own risks. And now is the time to get on the band wagon for method mix increase. Thanks so much.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**HELEN REESE:** Thanks very much, so what we're going to do I think we'll see how each speaker – but if they take up their time then we'll save questions on that's speakers talk to the end. I do apologize for the noise I hope it's not too distracting, but I think all the speakers will really project their voices. The next speaker, and that leads very nicely from Ward's talk is Dr. Viviane Black, my own institute the Reproductive Health and HIV Institute in Johannesburg. And she's going to talk about fertility and HIV.

**VIVIANE BLACK:** Thanks Helen. It's a great honor to be here to talk to you about fertility and HIV. And certainly the thing that is coming through this conference is that the times have changed. If I think back previously if we had spoke about HIV infected couples having children, it was completely tabooed and frowned upon. But the time have changed I would go so far as to say that it's medically negligent for healthcare workers not to engage with HIV infected couples who are talking about fertility or family rights.

This failure to do is a failure – human rights issue, it will continue to pertain to prevent the – continue to transmit HIV horizontally and it will hamper our efforts to achieve elimination of the PMTC by 2015. We know and Ward a lot of what I'm going so I think ties in very well with what you've said as well. HIV infected couples or people have some

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

[inaudible] to the general population. We know that fertility desires change with life events and life experiences. And this is certainly true when antiretroviral therapies initiated fertility desires seem to go up.

But also with life changing events such as changing a partner, fertility desires also increase. And one thing I have noted is that healthcare workers and researchers seem to focus on women, but men also have the fertility desires. And they may influence a family hugely and fertility desire is couple decision very often over and above an individual's decision.

I'm going to share some research from our unit. I'm sharing a Ph.D. doctoral thesis conducted in our unit of 858 HIV affected women who are on antiretroviral therapy at the time of enrollment and they were followed for a year. The first thing that we learned from these women is that their contraceptive use was probably not ideal. Only 32 of them were on hormonal contraception. Among 742 who said they were not actively trying to conceive 54 percent were using consistent condoms and 15 percent said they were using a dual method. But certainly there was an unmet need about 30 percent.

This is not unique to Sub-Saharan Africa and when I looked at a study from Atlanta, infectious disease clinic, which surveyed 127 HIV positive women, I was quite surprised to see very high rates of sterilization. Among those who were

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

sterilized, 18 percent of these women said that they would like to have children and over half said that they were sterilized because they were HIV infected. And again in this cohort there were very, very low rates of hormonal contraception uptake.

And this I think is a key message that comes from this is that patient provider communication is critical. And if we look at both those studies, the Atlanta study only half of women had spoken to their healthcare workers about contraception in the previous year and a third had admitted to either never speaking to them or only speaking to them once in the previous five years about contraception. Another thing is that half of the women believe that the use of intrauterine contraception or hormonal contraception was unsafe if you were HIV infected.

In the South African cohort 93 percent said that their healthcare workers had spoken to them about condoms so that message is getting through, but less than half said that a healthcare worker had spoken to them about nonbarrier methods of preventing children. It is encouraging to note, although overall the numbers are still very low, where the HIV caregiver had spoken to the patient about hormonal contraceptive use or nonbarrier use, the use was statistically higher.

The consequences of poor communication, if we looked at this observational cohort from Johannesburg that of the 850

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

women there was 170 pregnancies in 161 women. 62 of these pregnancies were unplanned. 53 conceptions were on [inaudible] and of these 36 women elected for a terminational pregnancy. I think this is an absolutely tragedy if you consider that these women are in [inaudible] they are coming to a healthcare facility at least four times a year and yet they're ending up requiring a termination of pregnancy. I think we are really failing the women in this program.

There are special groups that need to be considered as well, and the first of these is perinatally infected youth or women and this study of 252 women from UK and Ireland showed that among these 252 women there were 42 pregnancies among 50 women. The median age of these young women was 18 with the youngest being 14.

81 percent of the pregnancies were unintended and over half of their sexual partners are unaware of their HIV status. 36 percent elected a terminational pregnancy, 33 percent had detectable viral loads during pregnancy. And of those that delivered one child was HIV infected. And this shows the outcomes if healthcare workers do not engage with the issues with their patients.

The other groups that need special consideration are those with subfertility as certainly there is some evidence to suggest patients may engage in riskier sexual behavior

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

including relationships outside the immediate relationship and same sex relationships. I'm not engaged with these other than to say that options are available to them and the options available to them are largely the same as the non HIV infected cohorts with the same principles that I'm going to allude to overland.

This data that I have spoken about really, really speaks about the need for healthcare workers to truly engage with the patients and not just once but repeatedly so that the people know what their choices are. And integration of family planning services into HIV is key. What we do to the couple or the individual that comes to us and says that they would like to have a child, well certainly there are a number of variables that would determine how you would deal with this. And that would depend on the resources available, also whether you're dealing with an HIV infected man, woman or couple.

All patients would need preconception counseling and in this counseling one could explore the reasons behind why they are choosing to have a family. I would certainly encourage disclosure of the status and support couples to do this, informed decisions are important.

Understanding the choices available to the risks of the various choices and the costs of the various choices. They should consider the consequences or failure to prevent

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



horizontal transmission and what that would mean. And this was also an ideal opportunity to optimize the health of both the HIV infected partner but also the women who is potentially planning a pregnancy bearing in mind that substance abuse is harmful to pregnancies and optimizing nutrition.

I've highlighted here the minimum preconception medical management, thus as our cities a minimum [inaudible] and depending on the available resources you may build on this to provide a different level of care. But certainly I would want to include any sexually transmitted infection within the couple. This can be done on clinical examination and through syphilis urology testing as a minimum. I would want to exclude AIDS, I would do this by a CD4 cell count testing but also a thorough clinical examination.

Those who are on antiretroviral therapy should ideally have an undetectable viral load and one can screen for infertility through history. And the usual pregnancy tests can be done. Based on your findings when we're optimize the health of both the HIV affected partner and the couple any medical illness should be treated optimized and one can use various strategies to determine the ovulation cycle. Again one can purchase kits, some couples opt to do that or can use timed ovulation. I think those are the two most common used methods in our environments at any rate.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

If you have an HIV infected male with an HIV uninfected female partner, for me ideally your infected partner should always be on antiretroviral therapy with a suppressed viral load. And if you have available resources, one can use assisted techniques such as sperm washing, which probably costs between 150 and 200 dollars per – and it's quite a simple technique to do. One thing that people sometimes over look though is one attempt doesn't always mean success and you may need repeated attempts which will certainly add to the complexity and the cost.

In resource poor environments couples may attempt natural conception, which they will use condoms for the duration of sexual activity except during the fertile period, in which time they will practice unsafe sex. [Inaudible] published criteria in 2007 around natural conception. Now I just want to highlight two issues, the first is that the responsibility of adherence rests with the HIV affected partner but the decision to consent to having unprotected sex should really lie with the HIV unaffected partner.

If you're dealing with an HIV positive woman with an uninfected male partner, again, antiretroviral therapy should be used and suppressional viral load would be ideal. But there is in essence no need to expose the male partner to HIV. As one could use conception using intravagial or intrauterine

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

insemination. This obviously would be a couple choice and based on the 052 information they still opt to have natural conception. And this again would be an individual couple's choice. It's quite easy to manage your HIV co-infected couple. Ideally you should optimize patient health, optimize HIV health avoid any [inaudible] drugs and the couple can continue with natural conception.

If one is unsuccessful after six months, certainly the previous [inaudible] would advise it would be unhealthful to continue trying to conceive without some sort of intervention because you may not be successful but you will potentially could be continuing to exposing your partner to HIV infection. And investigations at this stage may be warranted with appropriate counseling.

Remember during interventions with, which always repeat test to HIV unexposed partner. When [inaudible] successful, again, repeated testing of the uninfected partner is important, particularly, the woman because if she happens to seroconvert during pregnancy, she needs to have interventions to reduce the risk of mother-to-child transmission.

As Ward has alluded to and we will subsequently hear, pregnancy itself may increase the risk of horizontal transmission of HIV so condomization once conception has been successful is important for the couple to consider.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Remember and I'm not going to talk about PMTCT interventions, but one wants to reduce the risk of mother-to-child transmission to the maximum. I would advocate using antiretroviral therapy, but I will largely go with the original guidelines.

I would like to thank some of my colleagues that I work with who always inspire and support me in the work that I do, not least of which is Helen sitting to next to me. Also, I put on the slides some further readings for the guidelines. Those of you in the field who would like additional information can look at it. Thank you. [Applause]

**HELEN REES:** Thank you. Again, if you can hold questions, we will move on to the—it's a flow as you can see of thinking here. Both Ward and Viv have referred to the issue of pregnancy and HIV acquisition, and very appropriately, we've got Nelly Mugo who is going to provide us with that data. She's published, as many of you know, on this topic from her own cohorts. Nelly. [Applause]

**NELLY MUGO:** Good morning. Thank you, Helen. Helen was part of that work on the risk of HIV acquisition. [Pause] Very briefly, I'll talk to you about pregnancy and HIV acquisition. A lot of it is all data and I'll present some of our own data that Helen has referenced to. I'll talk about fertility rates,

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

the association, the plausibility, and the evidence of increased HIV incidence in pregnancy and breastfeeding.

I think through this season, we've talked a lot about the fact that women are very vulnerable to HIV. They represent more than 50-percent of those people who are infected and 42-percent of the new infections and this is within the reproductive years of women. This really makes this issue important if the majority of infections are occurring amongst young women.

I just thought as we're talking about this is to remember it's really part of MDG-4 and 5 issues around maternal health and neonatal health when we talk about risk of HIV acquisition for women and children. These are old slides. I think they come from South Africa and we see the peak HIV prevalence again occurs around ages 24 and 34. We know that the majority of women, these are the years that they're having the babies. There're high fertility rates in sub-Saharan Africa. This graph really shows a drop, but still 5.3 is high, which means that women spend many years pregnant within their life.

Does pregnancy increase HIV risk? There're physiological reasons why we believe this could be true. High progesterone levels can induce systemic and immunologic changes and unprotected sex that takes place when people are desiring pregnancy increases that risk. We know from our own cohorts of

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

serodiscordant couples that they have told us again and again that they would rather risk getting HIV than stay without a baby.

They say that when they found they had HIV infection, they still have to negotiate family issues, pressure from family members to have children. For many women, you cannot stay married if you don't have a child in the marriage. The issue of HIV risk is the issue of female vulnerability for acquisition and the risk of transmission to their male partner when the woman who is HIV infected is pregnant.

I looked at data on incidence. It started very early. Mbidzo from Zimbabwe started reporting very high incidence as far back as 2001 and we have had continuous evidence that there is high HIV incidence through pregnancy and breastfeeding. Male-to-female HIV transmission, we've had observational studies showing about a twofold increased risk during pregnancy.

There is only one trial, the contraceptive study that didn't show a difference in incidence between non-pregnancy state and pregnancy state. For female-to-male transmission, there isn't much data outside of our own reports about increased risk to the male partner from the HIV-infected pregnant woman.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

There was an early study done in the 1990s that showed that there was increased HIV shedding during pregnancy. As has been mentioned already, acute HIV infection in pregnancy is a key concern and it confers about 26-percent and in some data sets 29-percent risk for the newborn baby.

In majority of our setups, we only test women once in pregnancy to make the decision whether or not we should have PMTCT algorithms for her. We do not do repeat testing. Even when we see women postpartum, we rarely ever test them again. When we have such high incidence of HIV and a transmission risk of 29-percent, I think this is a great cause of concern and will be a big lost opportunity as we move towards eradication of neonatal HIV infections in our setup.

I'll give you a summary. I presented this data before about pregnancy incidence in a herpes trial. This study was across 14 sites in both East and Southern African regions. One of them was Helen's site. We had 3,321 eligible couples and we looked at the seroconversions between male-to-female transmissions and female-to-male transmissions. We had the opportunity to look at the linked infections when we're sure that the transmission was within the partnership and look at the difference in incidence during pregnancy and outside pregnancy.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

From this slide, you can see that there is twofold increased risk for male-to-female transmission and this held true—this risk wasn't observed after adjustment. The statistical significance went down, but for the female-to-male transmission even after adjusting for confounders, the significance was retained at a twofold increased risk.

As I've said before the data showed a twofold increased risk for HIV risk during pregnancy for both the uninfected pregnant woman and the risk of a pregnant HIV-infected woman to transmit HIV to their partner. I think of key importance is that even if we say that the significance went down after adjusting for confounders, the key issue is that that infection does take place, that the risk exists to the woman, that she has an increased risk of acquiring HIV.

If we're thinking about how to manage this, we cannot say that it's simply behavioral. We can adjust the behavior issues around it, but we cannot ignore it. I think I've already talked about the issue of socio-cultural pressures and desire for pregnancy. For serodiscordant couples, that outweighs the risk and fear of HIV infection.

Interestingly enough, this is true for both the male and the female partner. Very often, we think it's the woman who has to conceive otherwise she loses the marriage, but when we've talked to the couples in qualitative research, the same

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



pertains to the man, the HIV-negative man. They are willing to take the risk of acquiring HIV so long as they can attain fertility within their partnership.

I've often felt after spending this amount of time with serodiscordant couples that HIV is a virus. If you're in a relationship, your partner doesn't change because they have a virus. Whether it's a man or a woman, you don't simply change partnerships and these risk profiles exists and we have to take care of that for both men and women.

In conclusion, I've said that women in sub-Saharan Africa, especially, spend a substantial number of years pregnant and it exposes very high risk of HIV to both mother and baby, and husband. Male partners are often not factored into perinatal HIV strategies. I now we talk a lot about couples counseling, but I'm not sure how many of our antenatal services actually cater to men. They look lonely in our clinics when I see them.

Sometimes, when the woman comes in with the man, I ask her, "Where's your husband?" She's says, "He's sitting outside, looking very shy." It's the one environment men lose their voices. We need to have them have their voice and when they turn up to know that they are welcome to the clinics.

I think there's also a need for advocacy in community level to encourage men in those regions in the world where

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

they're not involved in issues of pregnancy to know that they are welcome to take partnership with their partners in going through pregnancy and safe delivery for both themselves and their babies. Thank you very much, FHF, for inviting me to do this, the conference organizers, and all of you, and my fellow investigators in the partner studies. Thank you. [Applause]

**HELEN REES:** Thank you very much, Nelly. Nelly is always a pleasure to hear because she mixes science with anecdotes from the field seamlessly, and it makes it very real. Thank you very much, indeed. We'll come back as I say to the discussion. Our final speaker on this panel is Angelina Namiba who's from the i-Base Training Program based in the UK, but is from Kenya. She's going to talk about sexual and reproductive health rights for HIV-positive women. Angelina. [Applause]

**ANGELINA NAMIBA:** Thank you very much, Helen. I wear many hats, but in my everyday life I am, first and foremost, a mother living with HIV having been diagnosed some—I think it's about 18 or 19 years. I forget as the years go by.

In my other life, I am a training advocate, but also previously before that, I worked as a project manager for Positively UK which is an organization that provides support for families living with HIV. During that time, I led on the development of projects titled From Pregnancy to Baby and Beyond which was aimed at providing targeted support and

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

ascertainable model of education, information, emotional and practical support for women living with HIV either diagnosed HIV positive antenatally or those who are planning to start families after an HIV diagnosis.

What was unique about this project was the fact that it was led by an advisory group of healthcare clinicians and women living with HIV where mentor mothers were trained to provide support to the women living with HIV in order to complement the clinical care that they're already receiving.

What I wanted to say, I just want to start off by thanking the organizers for inviting me to come and speak about an issue that is really, really close to my heart and one that I'm particularly passionate about. What I'm going to do is I'm just going to take us back just remind us a little bit about what SRHR are.

I'm going to use SRHR at the risk of tripping over my tongue if I keep saying the full term. I'll remind you a little bit about what they are, what they mean for people living with HIV, give us a few examples of how these rights—how they're protected, where they're sometimes violated, how we can continue to protect them, make a few recommendations, and then I'll finish.

We all know very well that these rights are the rights of people to make informed choices with regard to their own

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

sexuality, reproductive health and well-being, but of course, this on condition that these rights do not infringe of the rights of other people. They also include the rights to access information and education, and other services in healthcare.

When I was growing up, like many other young women I dreamed of having a decent lifestyle, a stable relationship, and four children. When I was subsequently diagnosed HIV-positive in my early 20s, I kind of thought that that this dream would never materialize. However, years later and being lucky enough to be living in the UK where I accessed integrated services to prevent vertical transmission, I'm proud to say that I'm obviously a very proud mother of a 13-year-old who was born after my diagnosis. I haven't met my dream man yet, but I do have a job; so, I guess two out of three isn't doing too badly.

On a serious note though, I really am acutely aware of how extremely crucial these rights are for women living with HIV. What are these rights? People living with HIV have always wanted and deserve to have the right to have healthy, satisfying sexual productive relationships, to bear and raise children if that's what they choose to, to protect themselves and their partners for both unplanned pregnancies and STIs, and also to have safe legal abortions if that's what they choose or

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

if circumstances within their lives dictate that that is the right option to go for.

I'm not going to go through too much about this, but these key rights are clearly articulated in the ICW which is the International Community of Women living with HIV and GNP Plus which is the Global Network of People Living with HIV. They have a guidance package on advancing the sexual and reproductive health and human rights of people living with HIV and they clearly articulate all these rights.

We also know that these rights are currently protected in the Millennium Development Goals and in several instruments that enshrine SRHR and why the rights to equality including—I'm just going to mention a couple of this—the 1994 International Conference on Population and Development Program of Action which is also known as the Cairo Conference. This was the first and most comprehensive international document to embody the concept of reproductive health rights and sexual health.

We also know that they are protected in the CEDAW which is the 1979 Convention of the Elimination of All Forms of Discrimination Against Women. This was a binding treaty, so that any country that signed to it is committed to ensure and respect for women's rights and women invoked rights in fundamental freedoms. We know these rights are protected, but unfortunately, and despite all these protection and some 30

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

years into the epidemic, sadly these rights are still being violated.

I'm just going to give you a couple of examples and these are reports that have been written which document some of these rights. The first report I'd like to mention is one that's titled, *Robbed of My Motherhood* and this gives concrete examples of coerced sterilization in Namibia.

As a followup, the Open Society Foundation or OSF and I'm sure most of you know what that stands for have also done a followup DVD which charts stories of torture in the health services and those who do have—one of the women who actually underwent coerced sterilization who was featured in the DVD. There's also another report which gives examples of these violations from Asia and it's called, *Positive and pregnant: How dare you?*

The third report I'd like to mention—and I'm sure Nelly probably will know all of it—is one that's titled, *Realizing Sexual and Reproductive Health Rights in Kenya: A myth or reality?* It was a report of the Public Inquiry into the Violations of SRHR in Kenya which was done by the Kenya National Commission on Human Rights.

We also know women's rights are violated in terms of the real risk of being prosecuted and especially for these

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

examples from Sierra Leone where women run the risk of being prosecuted simply because of being HIV positive and pregnant.

Now, I chose to have a baby after my diagnosis and it was for very personal reasons. One of them was the fact that as I earlier already mentioned. I did want to exercise my right to have a baby and also the fact that before I was HIV positive, I also had, always had maternal instincts. I wanted lots of children.

I wanted to exercise that right, but even more importantly, I wanted to have a child because I didn't know what my prognosis was like. I did not want to die and leave nothing of myself behind. Now, for me to choose to have a baby after my diagnosis, does that make me a criminal? I'll leave it to my law for that one.

We do know that these rights can be protected. I'm sure most of you know about these and we know that there're already programs which exist which actually assure that these rights are protected. However, I just want to mention a few of these just to remind us in case we want to take away one or two messages.

We know it's extremely important that we train and sensitize healthcare workers to respect the rights and support all people living with HIV including their colleagues, volunteers, and clients. It is also really, really important to

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

screen for gender-based violence which is often heightened in pregnancy anyway, even without an HIV diagnosis. It's also very important to provide necessary information and services for women living with HIV.

We're talking about the integrated services that were already mentioned before which provide family planning, protection from STIs, psychosocial support, financial support, housing, holistic integrated services. There're lots of models of good practice that exist and I just like to mention three. I already mentioned the project that I worked on in the UK, but we also have lots of positive developments such as the Mama's Club in Uganda, and of course, mothers2mothers who have very good programs in seven of the global planned countries.

It goes without saying that we also need to have better laws, policies, and guidelines which protect confidentiality and provide information and support for women living with HIV.

There're a couple of programs like the SHE program which stand for Strong, HIV-positive, and Empowered. They provide funds and support for groups of women living with HIV to continue the wider advocacy in community and with policymakers and people like police and social services.

Of course, one resource that I really feel is important is called Stepping Stones Plus and this gets all community onboard with understanding what their rights are and how they

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



can continue to support people living with HIV within their communities.

What works? We've already had that integrated services work and a new study published in the *Journal of International AIDS Society* highlighted lots of successful intervention that's already in place which worked to meet the SRH needs and desires of women living with HIV.

We are talking about those that provide contraceptives, family planning, cervical screening, etcetera. Those are to ensure early postpartum visits and provide family planning, and other information and services. Of course, very, very important those that provide youth-friendly services because we know there are not that many services that are adolescent-focused and centered. It is important to provide those.

Those ones are the ones that actually work. Services that provide the support and information, skills building, and also supporting voluntary disclosure, those are really, really key; and of course, services that promote male and female condom use for dual protection against birth pregnancy and HIV; and also very important, of course, services that provide ARVs when needed which if well-supported can increase protective behaviors including condom use.

However, provision of ARVs should not be dependent on women also accessing other services. Of course, as mentioned

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

earlier, we need to have services that provide meaningful engagement of men and boys in gender transformative ways.

Just coming to the end now, and again as we're talking about the sexual and reproductive rights of women living with HIV for me, I feel that it's extremely important that we always support and enable women living with HIV to be involved in making decisions, in forming services, etcetera.

Again, I'm going to mention the ICW and GNP Plus Package of Advancing Sexual and Reproductive Rights of Women Living with HIV and People living with HIV because it clearly articulates how you can actually do that, how you can involve both women and men living with HIV in being involved and in forming services. We also need to continue supporting women living with HIV to monitor experiences of programs and policies in order to shape and continuously improve them.

Now, as a woman living with HIV, we are a key resource in integrating services. We have the skills, the abilities, the expertise, and the invaluable experiences to actually make services work. It's also very important to ensure that we, as women living with HIV, are part of decision-making bodies such as technical working groups and national AIDS councils; bodies that make decisions about policies, programs, and where and how resources are spent.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

To reiterate, it is not just enough to consult us when you're planning services. We need to be meaningfully involved in the planning, the development, the delivery, and the monitoring of services.

I'd like to end with a quote from Stephen O'Brien who is the Parliamentary Undersecretary of State for the Department for International Development in the UK. This is a quote which he said just before the recent UK Family Planning Summit. For me, it kind of summarizes a lot of what I'm trying to say this morning and I let you read it for yourselves.

Okay. Then very, very finally before I leave, I'd like to share with you an image which I saw when I was putting this presentation together. This is an image which really made me smile, but one which captures in its own very unique way just how extremely crucial these rights are for women living with HIV. Thank you.

**HELEN REES:** Thank you. I think those are four absolutely excellent speakers, and what I thought was very nice was how each one led into the other. Angelina, your comment about I wanted to leave something behind of myself, I think that's just absolutely right. I think all women have that feeling—not all women, but many women have that feeling. It doesn't matter what your HIV status is.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Again, on the background of those four excellent talks, I invite people to come to the microphone. You can ask questions of the speakers and/or make comments about this field which fertility choice quite frankly and the way we respond to it has not been well-responded to. I think that we can see this from the presentations we've had. All comments are welcome.  
Mike.

**MICHAEL MBIZVO:** Thanks very much, Helen. I would like to send my thanks to the panel, very rich and informative. My name is Mike Mbizvo from Zimbabwe currently with WHO Department of Reproductive Health and Research. Certainly, what is emerging I've seen three things here: contraceptive coverage, widening choice, and universal access to family planning, and [inaudible] family planning framework.

But I think a major issue that also often confronts us within WHO and from the data is that of barriers and bottlenecks to uptake of methods of family planning issues or of methods like implants, IUDs, and some other work going on in the vaginal ring—the potential for the vagina ring. I really would like advice from the panel in terms of one, what are the key barriers to some of the methods outside the mainstream and bottlenecks? Two, what suggestions in terms of way forward for widening contraceptive choice coverage and access? Thank you.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**HELEN REES:** Excellent question. Who would like to tackle that? Ward, do you want to start? I think it's on you don't have to touch the mike.

**WARD CATES:** Okay, great. Thanks, Mike. As has been part of a rich discussion during many of the different sessions even at this conference, it's regularity barriers that we need to overcome to get methods approved in country, and therefore, available. It's provider barriers and myths that the medical eligibility criteria are intended to overcome.

It's client barriers in terms of myths and inaccuracies in terms of information that has been fed to them through a variety of circles, anyway. There is sort of availability of new methods that are easier to use and available through their routine facilities, but all of us on the panel have more experience with actually confronting barriers in the real world than I do.

**HELEN REES:** Nelly, do you want to add something from a real world?

**NELLY MUGO:** I think Ward has said most of it and just even access to that method mix. I think if you go to the peripheral clinics what you will find most commonly is injectables because they're easy. The provider barrier that's been mentioned—the time taken to insert a IUCD, cleaning of speculums. I think a lot of work and commitment and funding

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

needs to be put in, but every day you try to push the IUD  
sometime back. I think you made efforts in that direction and  
that fear of infertility and anesthesia is—I think their  
teaching even in medical schools has not changed. Maybe that's  
where we—we need to start doing the undoing.

**HELEN REES:** Thank you. Yes, please.

**LYNN MATTHEWS:** Hi, Lynn Matthews from Massachusetts  
General Hospital in Boston. I just wanted to I guess make two  
comments to touch on things that multiple people talked about  
and Dr. Cates' presentation sort of the first step in all of  
this is really a patient-provider interaction around what are  
your fertility intentions. I think the way that question gets  
asked is sometimes not amenable to getting an accurate  
response. Sort of are you planning to have a pregnancy?

It's a pretty specific question and I think it needs to  
be more of a conversation that includes the partners, ideas  
about pregnancy, the woman's ideas about pregnancy, maybe other  
pressures they are feeling. It's not—I think planning sounds  
pretty specific. We work with a lot of people who say, oh, I'm  
not planning to have a pregnancy, but I'm having sex and I'm  
not using contraception.

I'll be happy if I get pregnant. I think it's just one  
of those patient-provider interactions. Many patient-provider  
interactions will need some work. I think the other piece of

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

that patient-provider interaction, I think that doctors are coming around and are feeling like yes, people with HIV can have kids and that's fine; but the people we're talking to don't necessarily know that.

So, when we ask that question they may not answer honestly because they're afraid someone's going to shout at them and say no, you shouldn't have children. You have HIV. I think it's an area pretty ripe for work on trying to improve patient-provider interactions around this topic.

Then just one other thing I wanted to say quickly which came up in Nelly's fabulous plenary two days ago, but didn't come out today yet, is that this may be people in serodiscordant relationships who want to have children may be key people for PrEP around the time of conception, particularly if the infected partner doesn't want to take treatment or isn't likely to adhere to treatment or doesn't meet local criteria for treatment. Thanks.

**HELEN REES:** Viv, do you want to just comment on the latter part about the—well, either part of the comments made?

**VIVIAN BLACK:** I agree with those comments and those observations are spot on. I've been thinking a lot about the PrEP use. Certainly, I think if you've got a known discordant couple, the optimal intervention would be to find antiretroviral therapy and to suppress the viral load of the

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

affected partner, but failing that I think PrEP would be an alternative. But that would be the second choice, not the first choice.

**HELEN REES:** What further research would need to be done for that to be regarded as safe in the field?

**VIVIAN BLACK:** There've been pretty little studies around PrEP, and well, certainly conception. It's also in the combination. If you have somebody who's on antiretroviral therapy, does the use of either PrEP or post exposure prophylaxis add any transmission reduction benefit? I think that's an unknown. Obviously, the adherence issue—the long-term issue is an ongoing question.

**HELEN REES:** Please.

**SEEMA YASMIN:** Seema Yasmin with the CDC's Epidemic Intelligence Service. This is a question primarily for Dr. Cates. [Inaudible] referred to the WHO statement as being less than definitive and perhaps not so useful for certain countries. Given that many resource-limited countries rely heavily on WHO guidance to then form their national policies, what do you think is the impact of this particular statement on resource-limited countries and are there any other plans to review and revise the advice?

**WARD CATES:** Fascinating, CDC adapted the exact same statement, I guess; but for a resource-rich country it might

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



have different implications where contraceptive options might be more widely available.

In terms of what implications that guidance document has on resource-poor nations, I think the main implication is that it continues to allow injectable contraception to stay in programs, and at the same time, we hope puts pressure on national policies to increase method mix so that we could, in the long run, scale down perhaps that if the data—if the evidence continues to show concern. That to me is the main implication.

The first questioner sitting in the audience is the person who actually oversees WHO on that, but once again, the other issue that really we've been struggling with and don't have a perfect answer for is how do you message in term of giving full and accurate information? How do you message the ideologic uncertainty? As you and the EIS learn all about the principles of ideologic reason during your training, if you could help us in terms of explaining this highly complex situation that would be great.

**HELEN REES:** Thank you. Please.

**JONATHAN FUCHS:** Hi. Jonathan Fuchs from the San Francisco Department of Public Health thanking all the panelists for superb talks. A question for Ward about counseling and the provision of reproductive technologies in

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

the context for a large-scale efficacy trials testing by medical prevention strategies—what are your recommendations for current research in terms of ongoing studies and for planned studies in how we counsel through the informed consent process in providing these technologies as we move forward?

**WARD CATES:** Dr. Rees, number one is running the preeminent trial that involves exactly the question you ask, Jonathan, which is how do you counsel women about methods of preventing pregnancy in a situation where limited options are available? What you do, as with any situation hopefully, is give very accurate information about the available methods so that they can choose among what they have in front of them.

At the same time as she is doing, start pushing for approval of additional methods that then can be inserted into that choice for which accurate information is provided. There is nothing more important than the way Sharon rephrased the question yesterday afternoon for anyone who was there. Namely, our goal is to have as many options available as possible to provide the information about the pros and cons of those options.

Then the woman makes the choice of which method is best for her particular setting. It's also fitting and I don't know if Gerard wants to talk or others about even just designing right now for the trials going forward. What are the messages

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

given the inconclusive evidence that we will be giving to women?

In fact, anyone planning a prevention trial, what we really ought to start doing is sharing this information as to how we're messaging in our informed consent, as well as in our informed choice—two being very different issues. How we're actually explaining that, so that we can always learn from each other in term of what works in the clinic. You guys are the ones who are on the frontlines of implementing this. How are you doing it?

**NELLY MUGO:** That's a very, very challenging question. I don't think we've gotten to really doing that. Unpacking the WHO conclusion is a challenge and I'm not sure I have an answer to that question right now. I think I just wanted to go back what Matthew stated that—I didn't mention that to think about what the tools we have now that we can give women in pregnancy to protect them from transmitting and acquiring HIV. I think the other thing we had during the WHO meeting is that all contraceptives are safe in HIV-infected women. For that arena, we don't have any controversy.

**HELEN REES:** Angelina, from the rights perspective, I mean, this issue how do you tell women? From what sort of women's rights perspective would you want us to do with the ambiguity of the information that Ward presented?

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**ANGELINA NAMIBA:** I think for me what is key, is ensuring the women have all the information. Again, as already mentioned this is what is available. This is what we know about it. This is what we don't know, because women really—when given the information, we are able to make the right choices. I'd rather have the information and the choices to actually be able to make a decision than not. I think just being given the right information very honestly, this is what it's supposed—this is what isn't. We decide.

**HELEN REES:** Thank you. Please.

**HEIDI:** This was a really excellent panel. It was really good to see the discussions of fertility for HIV-positive women, a lot of really, really good stuff. I want to discuss the—to follow on the discussion of Depo and the studies. Yesterday when we had a panel, one of the questions was there was biological evidence presented about the difference in those women that were using Depo and the women that were not.

I wonder if that evidence you could explain whether that would worry us. Does that evidence, that biological evidence in any way go towards an understanding of the risk? That's my number one question. The second question is I am an advocate of choice. I think I've worked on this issue for a long time.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

That's the thing I believe in for women. Now, we are autonomous, and essentially in a sense, we make our decisions with information, but there is a way in which you have to evaluate medically and take responsibility. We also need to understand the science and the risk involved and at what point you do not want to go on providing things and that's the question here for me. Then the question is, if we look at the studies of Depo, have we looked at young women? Because when you look at the Heffron study, those are partners.

Now, I don't think that most women under 18, and I may be wrong, but many, many woman under 18 would not necessarily come in with partners. I wonder if the Heffron study just in that way may be kind of biased or selective to slightly older groups. I think that when we look, and this is something that Seema [misspelled?] brought up yesterday, you look at some of the other studies that were in that evaluation of risks that they're with older groups.

The question then is, if you look at the data that you have today and you look at the particularly young women who are biological greater risk then can you still go forward? I'm not saying that pregnancy isn't a risk for AIDS. I'm not saying that maternal mortality might not be a risk, but if we just take DMPA [Depo-Provera] can we reexamine the way that risk is evaluated? That's my question to Ward or to-

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**WARD CATES:** Sure. Thanks, Heidi. Two questions, as I sort of discerned them—number one, the biologic data and then number two, a focus on youth. There are a whole host of biologic findings over the years whether they be immunologic as we heard yesterday, whether they be anatomic such as cervical ectopy, whether they be microbiologic such as other STIs, whether they be virologic in terms of types of effects on the virus itself or steroids. Those are all put forward as part of the ideologic reasoning process as either supportive or not supportive of a study outcome.

Actually, a lot of those studies are not as conclusive as we'd like in one direction or the other. For example, even with those immune markers we saw yesterday, there are lots of studies of immune markers with lots of different immune markers either implicated or not implicated in sort of the susceptibility realm.

With regard to youth, the question is this is prime population to examine. I think one of my colleagues, Charlie Morrison, will be having more data to look at youth through a meta-analysis that he's doing. We need those larger databasing in which to come up with any type of reasonable recommendations.

In terms of pulling a method, I guess the third one's, when do we have enough evidence to pull a method? When do we

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

have enough evidence of harm? Actually, there really is, in all countries, a regulatory body that's responsible for doing that when the data are presented to them. There is a process globally that allows that.

**JILL GAY:** Jill Gay, [whatworksforwomen.org](http://whatworksforwomen.org) and my question is to all the panelists. In resource-limited settings, how can we restructure health services to create a safe space for preconception counseling? It's not going to happen in the ANC. Where can we—how do we do this restructuring?

**HELEN REES:** Viv?

**VIVIAN BLACK:** That is a good question, yes. We have to shift our services to non-primary healthcare providers. I think conversations need to be had with your doctors and your nurses, but I think we need to start bringing in the HIV-infected couples themselves, particularly those with experience and maybe create these forums and share information as much as possible.

We have a lot of challenges around this. If I think about experiences in South Africa where we have potentially 300,000 HIV-infected women coming through our antenatal clinics a year, it is a huge task and we currently use our lay counselors, but their level of education and the complexity and the time that they have—I don't think that that's going to be the solution. I think we have to look at other strategies. My

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

immediate thought would be, we need to use the patients themselves.

**HELEN REES:** Nelly, do you want to comment?

**NELLY MUGO:** My opinion on this is that a lot of these things need to go to pre-service training, that if you sensitize your nurses and your doctors and your providers very early, young women or people who are going to seek out these issues and wherever they are, wherever they meet them, they need to think about this and address them. You probably have a larger audience for them.

As you were talking, I was thinking about the family planning clinic, but a lot of women will get pregnant, they are 28 weeks and then they turn up to the clinic. That would only be effective for the second pregnancy. The other issue, I think, when the question was asked about the things that we can do to implement the WHO guidelines, as I was thinking about it, is that we need to integrate our HIV services in our family planning clinics because if you walk around, there is not much HIV testing going on where contraceptive is given.

The providers in family planning clinics—everybody has their tunnel vision. They are not the HIV people. They don't do testing. They don't do counseling and if we're really saying—if we are actually going to actualize the recommendation by WHO, the provider for family planning needs to have some form of

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



criteria to say you're at risk because we're saying for those at risk. Not every woman is at risk.

Many women can simply use Depo, but does the provider know how to pick out who is likely in any manner that they need this message in a strong way because if you give it as a general message, it doesn't really hit home. I don't have a perfect answer for that question, but my general thinking now has gone to that. We must do more pre-service training and sensitization for prevention. I think that doesn't happen.

**HELEN REES:** I think just to add that in South Africa, we're developing a contraceptive policy, but it's now the contraceptive and fertility policy. We, ideally, want to have fertility counseling as a step and to achieve that we're looking at, as we've said, using lay health workers bringing them much more into the system because, certainly, the current nursing staff would not cope with this load. Yes, please.

**STEPHANIE MARHEFKA:** Hi. I'm Stephanie Marhefka University of South Florida. Nelly was just talking about pre-service counseling and training and I think that's clearly a very important issue. I'm wondering what models are there already in place and is there anything evidence-based that will help to guide those kinds of services so that providers are better able to support women in these choices?

**HELEN REES:** Nelly, who wants to take that? Angelina?

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**NELLY MUGO:** The only thing that I know is currently going on at my university is that they've taken HIV training to pre-service in a very directed manner, but I don't know how much prevention is in their package. That's the other problem. How do we distill to make sure that when these things are happening, the prevention messages are in there because as providers we're very keen to treat disease? We're very interested, in fact, in very complicated disease, but prevention is not given the space that it needs.

**STEPHANIE MARHEFKA:** And stigma reduction.

**NELLY MUGO:** Yes.

**HELEN REES:** Angelina, do you want to comment on that?

**ANGELINA NAMIBA:** What I wanted to say was some of the models of good practice that I mentioned before would very much utilize community-based treatment literacy, as well as for the program that I was working on. What we did was we trained up the peer mentors who are then able to provide preconception advice, issues around pregnancy.

A lot of taking on, what was said, the burden from the healthcare providers because I know—we know that even with the best will in the world, no one healthcare provider can provide women with all the psychosocial support, the clinical support and we know that women will present a lot of issues upon diagnosis or if they're diagnosed antenatally.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

I think the community is such a valuable resource and there are so many positive people out there who have the skills and the resources and it works. I mean, you can look at the example of mothers2mothers. You can look at the Mama's Club. They're there and we do have an evaluation report of the program that I did. I'm sure there's lots more information around, but I think don't underestimate the value of community peer support.

**STEPHANIE MARHEFKA:** Thank you.

**HELEN REES:** Thank you. I'd like to get through the last four questions. Very briefly, please.

**GABRIELA PAZ-BAILEY:** Gabriella Paz-Bailey from the CDC. I have a question for Nelly about the increased HIV transmission from uninfected pregnant woman to her partner. You mentioned that this was still important after adjusting for behavioral factors, and I suppose, that includes reduced condom use during pregnancy. What is known about the biological mechanisms that would explain the increased risk of transmission?

**NELLY MUGO:** There's one study that was done in the early 90s that showed that those increased shedding—HIV shedding during pregnancy. I think that's is one that points us to that direction and the whole cervical area changes around

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

pregnancy. That would help, but not a whole lot more data unless somebody else has some further information.

**HELEN REES:** Anyone else?

**GABRIELA PAZ-BAILEY:** It sounds like it could do with a bit more work to understand that.

**NELLY MUGO:** Yes, absolutely.

**JANET FLEISCHMAN:** Hi, thank you very much. My name is Janet Fleischman from CSIS Global Health Policy Center. Thank you for your presentations and for shedding light on all these important issues. I wanted to bring it for a second to the policy level.

Obviously, there's important work that's being done on the national level and Helen has referred to some of the new policies that are being developed in South Africa, but could you speak to other national level policies and/or donor level policies that are facilitating some of this integrated work or that are blocking that work and that you're seeing as barriers to being able to pursue this?

If I could throw in one last thing, I 'm just wondering on the question of hormonal contraception. What you're seeing on the ground are women, HI-positive women coming to you and saying no, I don't want Depo anymore. Is this getting out and are you seeing that on the ground level?

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

**HELEN REES:** Who'd like to talk to the policy question and donors, does anyone want to talk to that?

**WARD CATES:** As Janet knows, there have been several donors including [inaudible] and the Tides Foundation and others that have specifically sponsored, and of course, the big three donors: USAID, NIH, and The Gates Foundation that have actually funded studies looking at the most efficient way of integrating family planning and HIV services as we move forward and attempt at health system strengthening and horizontalizing the care, so to speak.

Then through PEPFAR, we've had a variety of programs at this conference including one last night that the moderator will sum up for us in terms of what have been approaches and successes and barriers to further integration. I don't know if you've had a chance to go to those, Janet; but there are many attempts out there. We're gaining experience. It's not a slam dunk in every country, in every context. I shouldn't go on when Helen summarized it last night.

**HELEN REES:** The one thing I would add to that is that discussions like this—we've had different forums in this conference to have different types of discussions around this broad issue. This starts to drive processes. Last night, we had somebody from [inaudible], someone from RHA, people from USAID. This starts to—this is a process. It's a continuum of thinking.

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

Certainly, if you look at the Netherlands, they have an ambassador who used to be an ambassador for HIV. She is now the Ambassador for SRHR and HIV. We have the opportunity with the London Declaration on Family Planning and I'm quite certain that people that are not going to say we're going to ring the fence here, just as PEPFAR is no longer saying, we're ring fencing that way. I think that this is a continuum and the more dialogue we have like this, the more people are going to actually say we need to be supporting these initiatives. Thanks. Please.

**CHRIS O'CONNOR:** Chris O'Connor from BASELINE Magazine in London, England. A question for Vivian about the 44-percent sterilization rates in the Atlanta Clinic. Did you discover—I mean, that seems incredibly high—if there was anything behind that? Another point is looking at the three studies in the UK, South Africa and in the U.S., it seems that the problem is not confined to the developing world, but especially to—and the UK rate of unwanted pregnancies and terminations were the highest.

Also one final point, while I've been standing here and looking at that sign, Sexual and Reproductive Health Rights of Women Living with HIV, and also men live with HIV, and couples live with HIV, and I think that aspect has been missing in action in 2012 especially after last year's HPTN 052 trial. That image that Nelly gave of the man sitting outside on a

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

chair while his partner's in with you—that man's got to be in that room, I think that at the base if those issues especially when it goes through assisted conception seems to be missing a little bit.

**HELEN REES:** Viv?

**VIVIAN BLACK:** Thanks for the question. I chose those cases really just to illustrate different points. Certainly, I don't believe that the right to sterilization we'll be finding across states, but it might also reflect the age of that cohort. You might find that when HIV first came out, you might find that they might have been rigorous encouragement around sterilization.

Certainly, times have changed and I don't think you would see that possible now and I think that's a historic thing. I hope, at any rate. Also, one thing I have really learned from this conference is a lot of the problems we experience in sub-Saharan Africa are not sub-Saharan Africa problems, but they're world problems.

When I spoke about the different approaches to managing discordant couples, I was even thinking here in Washington a lot of strategies for the poorest of the poor would be relevant, and you would use the minimum standard of care because that is what resources are available to those people in

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

these communities. I think we're becoming smaller and smaller in terms of common problems.

**HELEN REES:** Thank you and the point about men, is very well taken. Thank you. Last comment, please.

**NYANDA LABOR:** I'm Nyanda Labor with Planned Parenthood Federation of America's Africa Regional Office. I'll just like to add on to Nelly's comment that she made about family planning practitioners being able to talk to women with HIV. In Kenya, we know that there are so many VCT Counseling Centers. I would like us to also think about those VCT Counseling Centers where many positive women show up for the first time. The practitioners there are also able to talk to women about their fertility intentions and provide family planning counseling right there on the spot.

**HELEN REES:** Thank you. I think we've had an excellent discussion. I'm just going to pick up a few things as we close that I think have come out. This session was about the role of fertility choice in HIV prevention and it's absolutely clear to me that the rights issue is once again coming out very loudly as underpinning this.

I mean I'm struck not only by the extremes, for example the examples of forced sterilization in Namibia and some of the experiences that Angelina shared with us, but I think that the DMPA single method choice and availability is also a rights

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.



issue because where has our voice gone to say that that isn't acceptable. We also have to say, where are the methods and the available methods most limited? It's throughout the world, whichever community's poor women—poor women who are not actually accessing a range of methods. There are many rights issue that are actually underpinning this.

The second thing that struck me is there is a real positive data on the issue of fertility and choices, just as there is a paucity of programs. We haven't thought about this, but in the hyperendemic countries, we have literally millions of women every year choosing to get pregnant in the absence of any programmatic intervention that is going to be aimed at them and their partners. I think that this is going to be a new challenge and in the next five years, I think that we will see this thing increasingly addressed. As Viv said that treatment on the one side and this where the male partner becomes very important, but also PrEP.

The third thing I think that's come out very loudly again is the community as a resource because if we are going to start getting women to either demand their rights to be more aware that they can actually get contraception and/or that they need to think about fertility intentions.

We can't do it in the constraints of our resource settings with the staff that we currently got, and actually

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.

engage in communities with the examples that we heard, and actually pulling in lay people to actually talk about experiences and to be trained to actually share information has to be a first step.

I think with that it's been an excellent session. The four speakers were superb and all built on each other. Thank you very much for your excellent questions.

[END RECORDING]

<sup>1</sup> The Kaiser Family Foundation makes every effort to ensure the accuracy of written transcripts, but due to the nature of transcribing recorded material and the deadlines involved, they may contain errors or incomplete content. We apologize for any inaccuracies.