

ASSESSING COMMUNITY QUESTIONS AND PRIORITIES AROUND HORMONAL CONTRACEPTIVE USE AND HIV RISK:

OUTCOMES OF A VIRTUAL CONSULTATION



“What if progestogen-only injectable hormonal contraceptives was the only feasible birth control method for me, but I cannot safely and routinely access condoms, male or female, before intercourse? What are my options then? How do I protect myself?”

Against the backdrop of political commitments, such as the 2011 Political Declaration on HIV/AIDS, there is a pressing need for more awareness of and engagement around the question of hormonal contraceptive use and HIV risk. Moreover, there is a need for those who are most affected – young women and women living with HIV – to garner more knowledge of what the science is telling us, to have the opportunity to raise questions and concerns, and to deliberate what the implications are for our health, welfare, and choices.

As a global consortium of women’s health organizations, networks of people living with HIV, and sexual and reproductive health and rights advocates, we developed an online virtual consultation through survey monkey with a related guide for community dialogues in order to engage more community partners and key stakeholders in the discussion around the possible HIV risk associated with progestogen-only injectable contraceptive use and the on-going and renewed importance of female and male condom access and use. Our aim was to gather insights on what key community stakeholders want to know in order to inform the May 2011 WHO/UNAIDS/ UNFPA consultation as well as their ongoing work on this vitally important issue for women’s health.

OP 53 Pledge to eliminate gender inequalities, gender-based abuse and violence; increase the capacity of women and adolescent girls to protect themselves from the risk of HIV infection, principally through the provision of health care and services, including, inter alia, sexual and reproductive health, and the provision of full access to comprehensive information and education; ensure that women can exercise their right to have control over, and decide freely and responsibly on, matters related to their sexuality in order to increase their ability to protect themselves from HIV infection, including their sexual and reproductive health, free of coercion, discrimination and violence; and take all necessary measures to create an enabling environment for the empowerment of women and strengthen their economic independence.

2011 Political Declaration on HIV/AIDS

Background on the current science and WHO recommendations

Some recent studies suggest that women using progestogen-only injectable contraception, such as Depo Provera, may be at higher risk of acquiring or transmitting HIV. The science on the issue, however, is not clear as some studies do not show this relationship.

Excerpt from **Hormonal Contraception and HIV: Technical Statement**¹

Following new findings from recently published epidemiological studies, the World Health Organization (WHO) convened a technical consultation regarding hormonal contraception and HIV acquisition, progression and transmission. It was recognized that this issue was likely to be of particular concern in countries where women have a high lifetime risk of acquiring HIV, where hormonal contraceptives (especially progestogen-only injectable methods) constitute a large proportion of all modern methods used and where maternal mortality rates remain high.

Some studies suggest that women using progestogen-only injectable contraception may be at increased risk of HIV acquisition, other studies do not show this association. A WHO expert group reviewed all the available evidence and agreed that the data were not sufficiently conclusive to change current guidance. However, **because of the inconclusive nature of the body of evidence on possible increased risk of HIV acquisition, women using progestogen-only injectable contraception should be strongly advised to also always use condoms, male or female, and other HIV preventive measures.** Expansion of contraceptive method mix and further research on the relationship between hormonal contraception and HIV infection is essential. These recommendations will be continually reviewed in light of new evidence.

The group further wished to draw the attention of policy-makers and programme managers to the potential seriousness of the issue and the complex balance of risks and benefits. The group noted the importance of hormonal contraceptives and of HIV prevention for public health and emphasized the need for individuals living with or at risk of HIV to also always use condoms, male or female, as hormonal contraceptives are not protective against HIV transmission or acquisition.

The current WHO recommendations from these findings are:

Recommendations for women at high risk of HIV infection

- Women at high risk of HIV can continue to use all existing hormonal contraceptive methods without restriction.
- It is critically important that women at risk of HIV infection have access to and use condoms, male or female, and where appropriate, other measures to prevent and reduce their risk of HIV infection and sexually transmitted infections.
- Because of the inconclusive nature of the body of evidence on progestogen-only injectable contraception and risk of HIV acquisition, women using progestogen-only injectable contraception should be strongly advised to also always use condoms, male or female, and other preventive measures. Condoms must be used consistently and correctly to prevent infection.

Recommendations for women living with HIV infection

- Women living with HIV can continue to use all existing hormonal contraceptive methods without restriction.
- Consistent and correct use of condoms, male or female, is critical for prevention of HIV transmission to non-infected sexual partners.
- Voluntary use of contraception by HIV-positive women who wish to prevent pregnancy continues to be an important strategy for the reduction of mother-to-child transmission of HIV.

1. Available at: www.who.int/reproductivehealth/topics/family_planning/hc_hiv/en/index.html

➤ KEY QUESTIONS AND CONCERNS RELATED TO CURRENT SCIENCE AND WHO RECOMMENDATIONS



“Why are these contraceptives labeled as safe for all women when so much uncertainty remains? This seems misleading... Given these findings, why isn't there an all out effort to protect women from HIV globally using all means at our disposal (making safe contraceptive options available, media campaigns, political leadership)?”

Critical barriers to implementing the current recommendations in the February 2012 WHO Hormonal Contraception and HIV: Technical Statement

➤ **Access and structural issues**

“The problem is not the messages, it's the [lack of] access to real choices in public health services (especially condoms, female condoms, and a range of contraceptive methods) to make real the possibility of choosing.”

➤ **Information and communication**

“These recommendations are necessarily broad, but they need to be communicated with the information about the reality for most women. Also, it would be nice to think women could use contraception for more than just PMTCT! What about themselves as people?”

➤ **Gender/stigma and discrimination/socio-cultural barriers**

“For women at risk for HIV infection it may be difficult to negotiate condom use. What about women who do not want to conceive, but are pressured to? Depo was an option to covertly prevent pregnancy.”

What is needed to act on and implement the WHO recommendations

➤ **Full information and utilizing multiple communication channels**

“The education needs to happen in a way that allows people to engage and come away feeling empowered. The way in which information is relayed to people is as important as giving them the information.”

➤ **Access and advancing real choice**

“How can WHO support us to put their recommendations into action if condom access and negotiation skills are so limited?”

➤ **Policy, programming, and strengthening women's agency**

“Give resources to women's groups and women living with HIV networks to talk about these issues with their peers so that great clarity is achieved to facilitate informed decision with regard to their reproductive choices.”



“I would like accurate and actionable message about what I can do with this information. I would like information in plain language.”

➤ WHAT WOMEN WANT: A CIVIL SOCIETY PERSPECTIVE FROM INSIDE DELIBERATIONS AROUND WHAT HAPPENS NEXT

Our intent has been to bring community priorities and perspectives to the formal technical deliberations on where policies and programmes should move, and in doing so, we share a brief snap-shot of what women have been calling for in those processes.²

Critical issues

- **Information and power:** to enable women to make and enact informed decisions.
- **Accountability:** of institutions, policymakers, and health care systems/providers to women.
- **Choice:** a wider method mix.
- **Investment:** to address the realities of women's lives and responsiveness to our real needs for an environment of agency and protection.

What do women need?

Women are calling for an environment in which real decisions can be made and carried out, including expanded investment in integration and linkages. This is defined to include human rights education; investment in women's agency; expanded access to a range of methods, with an emphasis on expanded access to existing methods **now**. This entails full access to information with which to make decisions, and expanded efforts to address men's role in protection.



Bottom line: There is no reason more methods can't be offered, and no reason we shouldn't have universal access to both male and female condoms.

What do women need to know?

Information: Women need full and clear information about the methods that are available to them so they can make fully informed decisions, including how these methods will/can interact with their bodies, even if there is uncertainty. Questions around what the science is telling us can't mean that we don't rock the boat by keeping silent about the existence of these questions.

Dialogue: Providers must also ask – and listen to – women. If not all prevention tools are accessible to women, women should still be informed about what other methods are on the market for purchase and what other methods exist but are not available. Women need to know and have a right to know what is out there so they can advocate on their own behalf and advocate for immediate and expanded access to methods. All women have a right and a duty to hold the health system accountable to expanding reproductive and sexual health and choice.



Bottom line: Let women make their decision. This is especially important in areas of high HIV prevalence.

2. This analysis is drawn from presentations made during the May 2012 WHO/UNAIDS/UNFPA and Stakeholders Consultation on Hormonal Contraception and HIV: Moving from new recommendations. Our thanks to Jodi Jacobson, Susanna Moore, and Sophie Dilmitis, among many others, for developing the PowerPoint presentation from which these points are excerpted.

Recommendations

- Investment in multiple dimensions of communication that engage and inform women, with women's lives, needs, desires and realities at the center.
- Information is not enough without **access**: If options are not available, service providers cannot make other recommendations to women. But to resolve the lack of access, there must be more investment in new options that we already know work for women. The lack of options is due to funder bias and lack of political will (i.e. there is simply no excuse for not having female condoms accessible to women everywhere).

We need concrete timelines, commitments, and a specific plan from donors and policy makers on how they will expand access to available methods (including female and male condoms) within the next year, two years and five years. What specifically are they doing to accelerate testing and marketing of these other options that are not available to women? Moreover, we need a commitment from donors for meaningful civil society input in all agenda-setting meetings.



The essentials

- **Information and power** to make decisions.
- **Accountability**: Concrete and deliverable commitments and timeframes for expanding programmes to meet the needs of women.
 - Commitments to research and evaluation of current methods and programs.
 - Concrete investments in training and quality of care.
- **Choice**: Let women make the choice that is best for them.
 - Increase access to available methods while addressing the environment in which choices are made.
 - Include in the expansion of the method mix, women's access to a wider range of family planning methods (increasing the number of available methods) and also investing in new methods.
- **Investment** to address the realities of women's lives and responsiveness to their real needs for an environment of agency and protection.
 - Invest in research on multipurpose prevention methods (ie vaginal rings) and strong research designs to answer key questions.
 - Invest in women's networks, grassroots initiatives that enable women to share information amongst ourselves.





Civil society partners

The ATHENA Network in collaboration with: AIDS Legal Network, South Africa; Asia Pacific Alliance for Sexual and Reproductive Health and Rights (APA); AVAC; Balance: Promoción para el desarrollo y juventud, Mexico; Choices: Memphis Center for Reproductive Health, United States; GNP+; GNP+ North America; ICW Global; ICW East Africa; ICW Central Africa; ICW West Africa; Jamaican Community of Women Living with HIV; Namibia Women’s Health Network; Sexual Health and Rights Initiative, South Africa; WAPN+; We-CARE+; WISH Associates, South Africa.



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We gratefully acknowledge the support of UNAIDS for the virtual consultation, and especially thank Kate Thomson for her partnership. We thank Mary Lyn Gaffield and Sharon Phillips for their review of the survey tool, and their commitment to bringing community perspectives to the technical consultation.

An earlier version of this issue brief served as a working paper for the May 2012 WHO/UNAIDS/ UNFPA and Stakeholders Consultation on Hormonal Contraception and HIV: Moving from new recommendations to actionable information.