

Working paper for WHO/UNAIDS/UNFPA and Stakeholders Consultation on Hormonal Contraception and HIV: Moving from new recommendations to actionable information

7 May 2012

Assessing Community Questions and Priorities Around Hormonal Contraceptive Use and HIV Risk¹

“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 that:

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;

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.

¹ We gratefully acknowledge the support of UNAIDS for this initiative, 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.

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 specific aim was to gather insights on what key community stakeholders want to know in order to inform the May 2011 WHO/UNAIDS/UNFPA consultation on this vitally important issue for women’s health.

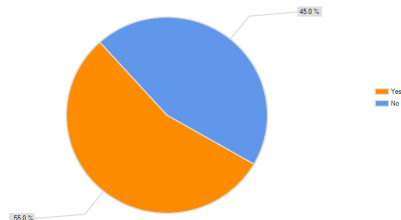
Key questions and concerns related to current science and WHO recommendations

“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)?”

Did respondents know about the scientific findings informing the WHO recommendations before participating in the survey?

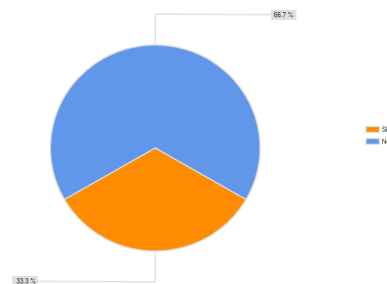
(Key: Orange: yes / Blue: no)

Did you know about the findings described above before you read this survey?

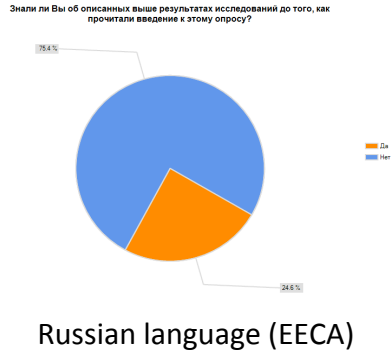


English Language

¿Conocía los hallazgos descritos más arriba antes de leer este cuestionario?

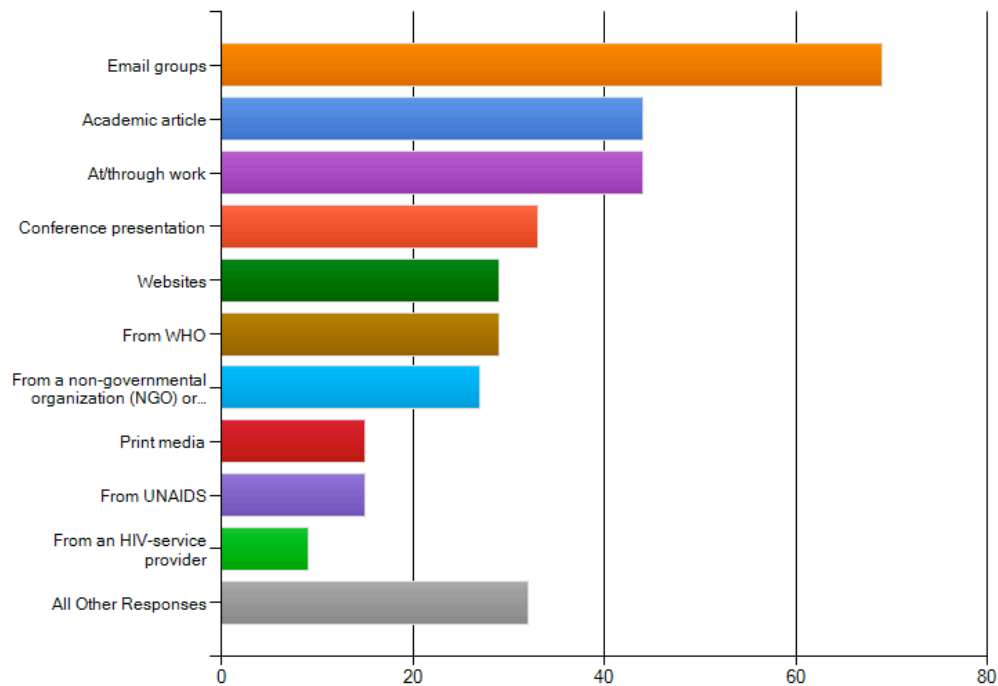


Spanish Language (LAC)



Where did respondents hear about the recent findings on hormonal contraception and HIV risk?

If yes, where did you receive the information about these findings? (check or tick all that apply)



Main sources of information around the findings were email groups, or websites; academic articles and conferences; through work; or directly from WHO and UNAIDS or other NGOs/organisations. Only between 5 - 7% were informed by HIV service providers, and even fewer were informed by a family planning advisor. Where does this leave community women?

How feasible are the current WHO recommendations from these findings to implement?

“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.”

Key issues as identified by respondents:

1. Access and structural issues

- ◆ Consistent use and availability of condoms
- ◆ Access (cost, supply)
- ◆ More method-mix in FP would be needed
- ◆ Socio-economic status (affordability of dual protection/protocols for service delivery that limit a woman to only one contraceptive method)
- ◆ Resources – at individual, provider and national level – funding for HIV prevention being cut
- ◆ Female condoms – expensive and unavailable

“Hardly. While the recommendation is clear, the changes in service delivery protocol or messages for providers is not at all clear.”

“I’m lucky because of my access, but others in my community have to deal with lack of variety of contraceptive options and “locked-up” contraception. I think about youth especially who have economic hurdles already...in accessing contraception, most have to deal with stigma, bias and judgment.”

2. Information and communication

- ◆ Risk perception
- ◆ Consistent messaging in both FP and HIV services
- ◆ Recommendations are too scientific
- ◆ Mixed / contradictory messages
- ◆ Risk of women giving up use of hormonal contraceptives, thereby exposing themselves to risk of unintended pregnancy

“The statement in the WHO guidelines that “women using prog-only inject. contrac. should be strongly advised to also always use condoms” sends a mixed message - shouldn’t all women at risk for HIV be strongly advised to use condoms? [...] I would think that there needs to be education for medical providers/outreach workers to help explain the issue, but I think explaining the “new” WHO recommendations will not be easy - because they don’t really say anything.”

“The problem with “high risk” is that most people who are infected do not view themselves at ANY risk, much less “high risk”.”

“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?”

“Since we should be promoting condom for all women at risk of HIV or living with HIV my concern is that by concentrating on a particular group of DMPA users the message of dual use may be diminished for the wider community.”

3. Gender / stigma and discrimination / socio-cultural barriers

- ◆ Women targeted for FP, but men make the decisions, or FP providers coerce them
- ◆ Education, information, counselling – needs to be tailored to women in different situations
- ◆ Men in control of condom use – challenge to ‘enforce’ use
- ◆ Women use implants because it is convenient and gives them control over conception
- ◆ Women not always empowered to make and enact choices
- ◆ Insistence on condom use can put women at risk of conflict or violence within relationship
- ◆ Stigma and discrimination (higher for young women)
- ◆ Religion as barrier to condom use

“People need to be educated and empowered to make these decisions for themselves, to protect their own sexual health.”

“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.”

“As an HIV+ woman, I find it hurtful that the recommendations would say that the purpose of contraception is to prevent mother-to-child transmission, but not mention that it's also to prevent unwanted pregnancy. Am I only a vector?”

What would be needed to implement these recommendations?

“A dream...men and women, boys and girls take responsibility for action and care about the person we share body fluids with... Programmes that holistically look at barriers to safer sex attitudes and behavior.”

1. Full information and utilizing multiple communication channels

- ◆ Awareness, sensitisation and training among family planning, HIV, and other health providers – including outreach workers – to give clear, simple messages on both contraception *and* HIV prevention tailored for service users in different geographic locations and contexts, including clarification of subjective, ambiguous and potentially stigmatising terms such as “high risk”
- ◆ Critical literacy among service users and key populations.
- ◆ Involve men in communications around family planning *and* HIV prevention – particularly in destigmatising and changing attitudes around condom use
- ◆ Use of multi-media, peer education, community and school-based comprehensive sexuality education
- ◆ Monitoring of information flow

“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. So often, people are afraid to ask questions for fear of getting it wrong, for fear of being frowned at for not knowing.”

“Stop listing things as women at “high risk”. All women are at risk and this leads to varied interpretations of what constitutes risk.”

“We need to be more client-centered and find out what the client knows, feels and thinks about the issues being discussed. Exploring the real life experiences that, in this case women, have in regard to condom use is so much more helpful and realistic than just chanting, over and over and over again, ALWAYS use a condom. No wonder we have turned off so many of our clients . . . and prevention comes off as tired and out of touch.”

2. Access and advancing real choice

- ◆ Integrated HIV and FP services
- ◆ More contraceptive choice; increased commodity availability and security for all family planning methods, including a secure male and female condom supply at low or no cost
- ◆ Increase / secure access to and availability of ARVs
- ◆ New FP technologies
- ◆ Access to FP and HIV testing and treatment for young people without parental consent (and related policy review / reform)

“Better, easy to use and discrete female condoms.”

“Access to both barriers and hormonal contraception, as well as to education about both. Supplementary education on negotiation strategies that are cultural, regional, and gender specific would also be necessary.”

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

3. Policy, programming, and strengthening women’s agency

- ◆ Women’s empowerment
- ◆ Health systems strengthening at policy and programme level
- ◆ Evidence / research / science
- ◆ Clearer guidelines and protocols for providers (based on evidence)
- ◆ Building the capacity of networks and groups of women from key populations and living with HIV to demand user non-stigmatising integrated services and hold service providers to account
- ◆ Funding and monitoring systems that track and reward integrated services

“Countries must adopt country-wide policies on comprehensive sexuality education, they must also work to dismantle laws and policies that limit women’s access to sexual and reproductive health services and information.”

“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.”

“Information concerning HIV treatment and prevention needs to be more socially and culturally appropriate. Effective methods in one country may prove detrimental to a next country - spiking HIV rates because focus is not placed in key areas. Groups or organizations that are grassroots oriented should be engaged in the process to reach at risk populations. This may be done in theory but is not clearly visible on the ground.”

Additional concerns and considerations

“The care provider’s attitude towards women living with HIV seeking FP services is not friendly, they should be made to understand that WLHIV have sexual reproductive health rights.”

The concerns raised by respondents underscore the need for a holistic, integrated, and woman-centered approach to family planning and HIV prevention firmly rooted in women's sexual and reproductive health and rights, supported by rights-based policy and programming, and an enabling environment.

Other key considerations shared by respondents include:

“My concern is making certain that HIV prevention study participants, who enroll in studies whose inclusion criteria require participants to use a reliable method of contraception, receive and understand this information before they decide which contraceptive method they want to use.”

“There is no guidance on the separation of contraception and HIV prevention. Currently condoms are what is being advocated in an attempt to address both. Currently we are suggesting the reintroduction of IUDs - but we do not have the health personal or resources to provide this service. Nurses are not trained to insert IUDs as part of their training. So there is no movement.”

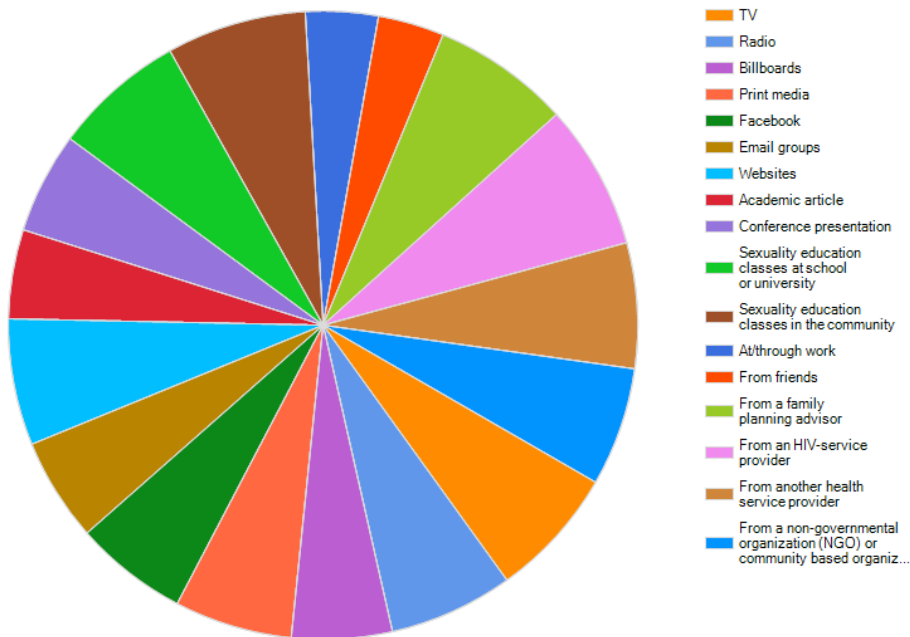
“In our setting- females with high numbers of partners/ female sex workers are usually recommended injectables (against IUDs). While ... providing injectables- the service provider should also provide condoms.”

“They [the recommendations], and the current discussion around them, entirely fail to address the massive issue of hormone use among trans (ie transgender) women worldwide. Trans women, who are consistently found to be among the highest prevalence communities for HIV infection worldwide.”

What are the channels of communication identified by community stakeholders for getting information out?

“Isn't the point of messaging that it hit a broad audience? We need to get information OUT of the normal channels and into the living rooms and vision of the average community member.”

Where would you like these messages to be available? (Please tick or check all that apply)



Russian language responses placed more emphasis on services and NGOs/CBOs as sources of information / engagement, but the response from all language groups was: “in / through as many channels as possible.”

What information would help you (or others) make decisions about contraceptive use and HIV prevention methods?

“I feel strongly that the messages need to give women the choice and that they have to communicate the uncertainties and that these are not glossed over.”

- ◆ Clear, factual statements, as far as possible informed by the evidence base
- ◆ Simple language, translated into local languages
- ◆ Messages tailored to local context, including:
 - Cultural appropriateness
 - Age appropriateness (for example to be used in schools)
 - Specific populations
 - Men as partners
 - Women living with HIV
 - Emphasizing individual choice
- ◆ HIV prevention messages
- ◆ The risks of HIV acquisition and the benefits of using condoms
- ◆ What makes a person “high risk”?

- ◆ The risk of unintended pregnancy and the benefits of using contraception
- ◆ The range, properties, efficacy and side-effects of all available contraceptives, including whether or not they protect from HIV and other STIs, and any associated links with enhanced risk of HIV acquisition
- ◆ Explain what is dual protection
- ◆ Hormonal contraception does not prevent the transmission of HIV
- ◆ Where to access condoms and contraceptives – especially free or at low cost
- ◆ Where to access further information (including advice to consult doctor or family planning provider)
- ◆ Where to access VCT and testing for other STIs
- ◆ Messages should aim to debunk myths around HIV transmission, and condom use, and reduce stigma and discrimination against people living with HIV
- ◆ Positive messages that promote condoms as smart, fun and sexy, easy to use, and beneficial to both partners – and provide guidance on condom use and negotiation. Real men use condoms, etc.
- ◆ Messages should be gender sensitive, promote women’s rights – including the sexual and reproductive rights of all women – and raise awareness of violence against women, and cultural constraints that expose women to risks of unintended pregnancy and HIV.

“For those of us who already have HIV, it's important to know: a) how to prevent unwanted pregnancy b) which methods might be harmful to my overall health c) which methods are safest for my partner d) how to prevent perinatal transmission should I choose to become pregnant (and that this is possible!).”

“I would like the messages to indicate that the WHO and other service providers are working diligently to resolve the lack of quality research into this area. However, I am not sure that this is true. What new research initiatives are coming out of this - I haven't heard.”

Methodology and approach

Over a five-week period, we:

- Initiated and facilitated a collaborative process with regional and global partners, emphasizing women living with HIV
- Consulted broadly to develop a survey and community dialogue guide in four languages, English, Spanish, French, and Russian
 - Available online via survey monkey
 - Disseminated through listserves
 - Supported by regional focal points who distributed it through their networks, facilitated participation by women who lack internet access,

and consulted in the analysis of survey responses to ensure findings reflect regional / community priorities

- Analysed findings in three languages to identify priorities, questions, and areas for greater information

Principles informing the work:

- To meaningfully include and consult women in all our diversity, including young women and women living with HIV
- To promote full information, knowledge, and understanding

Limitations to note include:

- Constrained timeline
- Internet access as barrier to participation
- Response largely by community advocates, service providers, and professional women
- Findings shared are based on a preliminary analysis focused on key themes and issues consistent across respondents

Scope of representation and participation:

English Language (250): USA, UK, Jamaica, South Africa, Kenya, Uganda, Rwanda, Algeria, Australia, Namibia, Germany, Indonesia, Malawi, New Zealand, Netherlands, St Lucia

Russian language (61): Russia, Ukraine, Kazakhstan, Tajikistan, Kyrgyzstan, Lithuania, Moldova (Transnistria)

Spanish language (50): Colombia, Portugal, Honduras, Mexico, Argentina, Peru, Guatemala, USA, El Salvador, Uruguay, Brazil, Chile

French language (7): Mauritania, Tunisia, DRC

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 Central Africa

ICW West Africa

Jamaican Community of Women Living with HIV

Namibia Women's Health Network
Sexual Health and Rights Initiative, South Africa
We-CARE+
WAPN+
WISH Associates, South Africa

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For more information, please contact ATHENA project team leader Tyler Crone (tyler.crone@gmail.com) or visit the ATHENA website (<http://www.athenanetwork.org>).

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