

Results for Contraceptive Choice Stakeholder Consultation: Summary Report

February 2019

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Acronym List

CCP	Johns Hopkins Center for Communication Programs
CSO	Civil society organization
GCAG	ECHO Global Community Advisory Group
DMPA	Depo-medroxyprogesterone acetate
DMPA-IM	Intra-muscular depo-medroxyprogesterone acetate
DMPA-SC	Sub-cutaneous depo-medroxyprogesterone acetate
ECHO	Evidence for Contraceptive Option and HIV Outcomes
FP	Family Planning
HIV	Human Immunodeficiency Virus
ICWEA	International Community of Women living with HIV Eastern Africa
MEC	Medical Eligibility Criteria
Net-EN	Norethisterone enanthate
PrEP	Pre-exposure prophylaxis
WHO	World Health Organization
UNFPA	United Nations Population Fund

Background

The Johns Hopkins Center for Communication Programs (CCP) conducted a landscape assessment of advocacy and communication needs both globally and at country level in light of the impending results of the Evidence for Contraceptive Option and HIV Outcomes (ECHO) trial. The ECHO trial, an open-label randomized clinical trial, was launched in 2015 to test the comparative risk of HIV acquisition among women using one of the following three contraceptive methods: DMPA (Depo Provera), LNG Implants (Jadelle) and copper intrauterine devices (IUDs). Although there have been observational studies investigating related research questions, this is the first randomized control trial that has been specifically designed to examine this matter. The trial closed in December 2018, with results expected in mid-2019.

As a part of the assessment, CCP conducted numerous in-depth interviews with stakeholders who are currently, or have in the past, engaged in work surrounding the association between hormonal contraceptives and an increased risk of acquiring HIV infection, as well as those most affected by the results, including local ministries of health. A critical component of the landscaping exercise was a stakeholder consultation to jointly determine steps that should be taken before and after the release of the ECHO trial results to ensure clear and harmonized communication around the results and to anticipate the implications for family planning and HIV programming.

The Results for Contraceptive Choice Stakeholder Consultation was co-convened by CCP and AVAC in Washington, DC from January 23rd to 24th 2019 with the following objectives and intended outcomes.

Consultation Objectives:

- Share key findings from the stakeholder assessment to date.
- Agree on critical topics for communications and advocacy at global and country level.
- Identify specific communication and advocacy audiences, activities and products required at global and country level.
- Identify priorities for country-level advocacy.
- Determine timeline for activities.

Desired Outcomes:

- Outline of a strategic action plan detailing advocacy and communication needs to prepare for the ECHO trial results, including a list of any materials or tools that may be needed both before and after the trial results are listed
- Strong coalition of committed, coordinated and engaged stakeholders.

This document provides a summary of the presentations and discussions that took place during the two-day consultation.

DAY 1

Opening and Expectations

Joanna Skinner, Senior Program Officer, CCP, opened the meeting underscoring the importance of using the ECHO trial as an opportunity to draw attention to the critical need to expand the contraceptive method mix and ensure informed choice is a priority for family planning programs. Participants shared their expectations for the meeting, with many hoping that the meeting would generate alignment on hormonal contraception and HIV (HC-HIV) advocacy and messaging between the family planning and HIV communities, identify strategies to address anticipated HC-HIV issues at the country level, and reinforce a commitment to placing the needs, preferences, and experiences of women at the center of the discussion. In his opening address, Mitchell Warren of AVAC reinforced the need to view the ECHO trial as an opportunity for the HIV and family planning communities to work collectively to prioritize expanding the method mix. AVAC currently has a draft strategy focused on planning for the initial ECHO results and is working to populate a database of key media contacts and spokespersons.

Stakeholder Interview Results

Joanna Skinner and Beth Mallalieu presented results from CCP's landscape assessment, which included interviews with 49 stakeholders representing 25 organizations, including Ministries of Health, WHO, the ECHO consortium, funders, service delivery and implementing partners, HIV and family planning advocates, and researchers. Consultations with in-country representatives and Ministries were ongoing at the time of the consultation and had not yet been included in the analysis. A full report of the landscape assessment was drafted after the consultation; key highlights were shared at the consultation. The highlights and discussion based on the presentation is captured below.

Work to date

Current HC-HIV-related work to-date includes civil society engagement and partner meetings; modeling exercises to explore potential changes in contraceptive prevalence of injectables, pregnancy and HIV outcomes; pilot projects in Tanzania to test family planning messages and counseling; journalist briefings and trainings; and some message and materials development. Organizations currently working on FP and HIV may be unaware of the work of other similar organizations, and even within organizations the HIV and family planning teams may not be closely aligned in their efforts. While a handful of activities have been initiated by key stakeholders to build research literacy and prepare for results, it is not yet clear how governments are preparing to act. Even with changes to the MEC in March 2017, there was no notable resultant changes to policy, method procurement or availability, programing, or counseling practices. Overall, there is a clear need for scenario planning at each level of stakeholder engagement, identification of country priorities, and coordination among stakeholders.

Areas of confusion

The complexity and nuance of this issue creates confusion for family planning providers, family planning clients (if they are aware and informed of it), governments, advocates, civil society, and the media. Among these groups there is confusion with regard to how best to communicate the concept of “risk”, particularly what it means for a woman to be high-risk given a woman’s risk of HIV acquisition is variable throughout her life and is often not something discussed when accessing family planning. Participants noted that “risk” can also be thought of not only as the undesired outcomes associated with using the method but also associated with foregoing the use of a contraceptive, which includes unwanted pregnancy and birth complications. Participants also brought up the point that lessons learned from public policy illustrate that framing public health prioritization as a tension between lives saved, individual’s choice and agency, and funding may not yield the intended results. Therefore, it may be less important to focus on the question of risk in terms of HIV acquisition versus maternal mortality and instead pivot the focus back to informed choice and a woman’s individual right to choose what’s best for herself.

There is some confusion about the purpose of the ECHO trial, specifically what the ECHO trial results can and cannot tell us, such as implications for DMPA-subcutaneous (Sayana Press) and NET-EN. The media briefing during the 2018 Family Planning Summit in Kigali revealed that some journalists may not understand the methodology behind randomized clinical trials therefore limiting their understanding of the study protocol and interpretation of the results. Participants suggested that this can be addressed through additional media briefings and roundtables such as those being conducted by AVAC and Population Reference Bureau. There is also a question of whether and to what extent DMPA is, in fact, the preferred method of choice where it has high prevalence of use. Prevalence may be skewed toward DMPA as a result of limited comparable options (limited availability of other methods because of a limited method mix or stock outs) or heavy promotion of DMPA.

Communication and advocacy challenges

The areas of confusion closely parallel the challenges for communication and advocacy. Those challenges include the limitations of the study in terms of being able to resolve all pending questions on this issue; defining and communicating “risk”; the lacking method mix in several contexts; certain results scenarios leading to a negative view of entire method categories and their potential to prompt broad-based and reactionary decisions for family planning programs; a lack of quality counseling and changing provider behaviors; building trust amongst stakeholders, including government, WHO, ECHO, advocates, civil society, women, and family planning counselors; enabling accurate media reporting including building the capacity of the media to understand the trial and related issues.

In addition to a lack of scenario planning at each level of stakeholder engagement, a lack of clear country priorities, and a lack of coordination among stakeholders, the level of distrust between HIV and family planning

implementers as well as the lack of a cohesive voice or demands coming from the advocacy and communications communities, creates challenges.

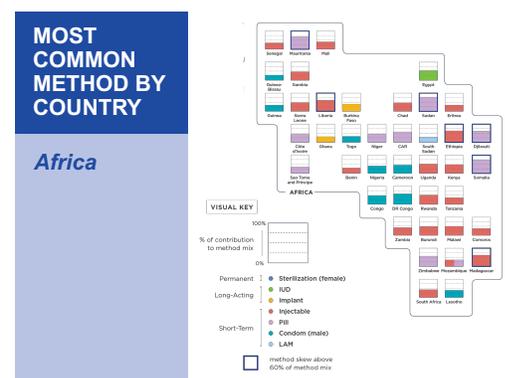
Participants also identified several challenges. First is the media’s lack of understanding of the study process or how to accurately interpret the results. Another issue raised related to communications is the tendency for dissenting voices and sensationalized stories to receive greater publicity and notice. The anticipated length of time between the release of the study results and guidance from the WHO is a period of vulnerability that opens the opportunity for negative opinions or unproductive interpretation of the results to gain attention and media coverage. A pilot study by Marie Stopes Tanzania demonstrated this, with both providers and family planning clients filling in knowledge gaps about the risk, and biological mechanism in order to better explain and understand what they were saying and hearing. There is a great deal of concern that depending on the results DMPA will be demonized or that no desired action will be taken. There may also be calls for subset analysis of the data, which is common and likely. The point was repeated that the realities of women must be placed at the center of ongoing conversations and actions taken by WHO and countries.

Civil Society Presentations

Yvette Raphael from Advocates for the Prevention of HIV in Africa (APHA) and Lilian Mworeko from the International Community of Women living with HIV Eastern Africa (ICWEA) shared ongoing work from the Civil Society Advocacy Working Group on Hormonal Contraception and HIV, including an overview of the *Taking Action Now* advocacy tool. Yvette discussed her participation in the ECHO Global Community Advisory Group (GCAG) and how it has been involved in the study to date. She also shared some of the preparations that advocates are taking to prepare for the ECHO trial results, such as planning for community dialogues and message development for different populations. They both stressed the need for ongoing engagement with civil society in every country and the importance of having women who are most impacted by these results at the forefront of all decision making.

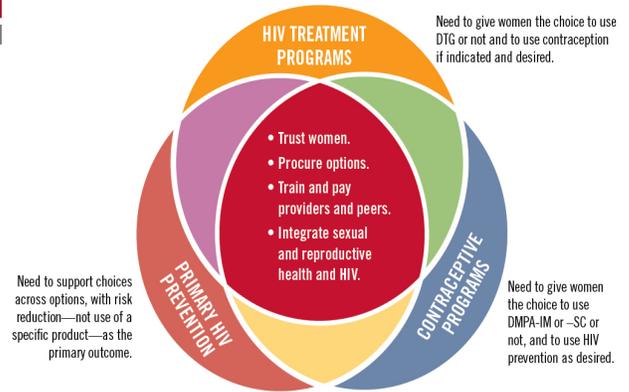
Remarks from Family Planning and HIV leaders

Tamar Abrams, Communications Director, FP2020 shared a brief presentation with an overview of FP2020 and its mandate, and a look at some of FP2020 key data on method choice and method availability. She highlighted some of the key countries that have a method skew (where one method makes up over 60% of the method mix). She also emphasized the importance of youth in both Africa and Asia – highlighting the need to consider this population – and their reproductive intentions, choices and behaviors – as we design communications around the release of the ECHO results.



Mitchell Warren, Executive Director, AVAC, gave some remarks about why this issue is a priority for the HIV community and shared some key infographics from the latest AVAC annual report that provide a useful snapshot. For example, he highlighted that putting women at the center – and promoting informed choice – is a priority for both the HIV and family planning communities – and is a point of reflection that can bring the two communities together. He also emphasized the simple formula for informed choice: procurement of a range of options; provider training, compensation and time; and implementing a human rights-based approach.

Putting Women' at the Center: Informed choice in 2018 and beyond



ECHO Trial Communication Plans

Deborah Baron represented the ECHO team to present their planned dissemination activities and clarify what the trial will and will not answer. She explained they plan to release peer-reviewed articles, press releases, deliver conference presentations, and work with the ECHO trial sites to develop communication products. Their communications will focus on the study results and addressing questions about the acceptability and potential adverse events associated with the methods included in the study, but not recommendations based on the results. Prior to the release of the results, the ECHO team has been focused on communicating the purpose of the study, the rigorous ethics protocol that has been followed, and working with trial sites to identify specific communication needs and opportunities for country-level results dissemination. Participants agreed to the importance of releasing the results in Africa and hosting coordinated country-level dissemination events. They also highlighted the need for locally-contextualized and audience specific communications collateral for various countries and audiences. Interpreting the results of the study will require a nuanced understanding of the data and study protocol, therefore there is a real risk that the implications will be misinterpreted, misrepresented, and miscommunicated. To this point, participants once again raised the issue of the importance of working closely with the media, including journalists and publishers.

The ECHO presentation generated significant discussion around pre-exposure prophylaxis (PrEP). Ms. Baron clarified that although it was not widely approved for use for women at the start of the ECHO trial, the protocol included a provision to make PrEP available to study participants as it rolled out in countries. In the later stages of the study, it was made available as part of the best prevention package available to study participants. The study used uptake tracking tools that were aligned with the national government in South Africa. This fact was followed by a lengthy discussion about expanding the current offering of PrEP to women who may be considered at high-risk but choose to use DMPA. There was a question on the feasibility of scaling up PrEP and promoting it as a solution to the concern over risk. Currently there are significant investments from PEPFAR and the Bill and Melinda Gates Foundation to learn about the potential for uptake, scaling-up, and impact of PrEP programs. However, one participant noted there may be tens of millions of women whose ability to access DMPA may be threatened by decisions following the study results. They further noted that not all of those

women will want or need to accompany their DMPA use with oral PrEP. Further, it has been difficult to get the WHO to add the guidance that PrEP for women should be included as a part of the prevention package in the MEC guidance on this topic.

Scenario Planning

Dr. Tim Mastro of the ECHO team outlined three (of many) possible results scenarios based on the study design that should be considered when planning and preparing for activities around the release of the results.

Scenario 1: Statistically significant increase in HIV risk – One of the three contraceptive methods in the study could show a statistically significant increase in HIV risk compared to other method. (A:B; B:C; A:C)

Scenario 2: Some risk shown but not statistically significant – This means that hazard ratios would hover close to the boundary of significance but not be statistically significant.

Scenario 3: No statistically significant difference.

The group expressed collective concern that if the outcome of the trial is Scenario 2 for DMPA, the results could be interpreted by some as indeterminate even though it is not statistically significant. This may also lead to calls for a follow up study given the existing observational data. If Scenario 1 confirms a statically significant increased risk of HIV acquisition with use of DMPA, some audiences, particularly those who have expressed skepticism over the heavy promotion of DMPA in southern Africa, may come to believe the level of risk was “known all along”.

Communication and Advocacy Priorities

Participants worked in groups to review a draft list of communication and advocacy priorities that arose from the landscape assessment. As a result of those discussions, the following priorities were generally agreed to be important for the work ahead:

- Utilize ECHO as an opportunity to advocate for promoting and guaranteeing informed choice for women, expanding the method mix, and expanding HIV prevention options.
- Deliver timely accurate transparent communication to stakeholders, calling out women and communities.
- Develop clear, accurate, and adaptable materials.
- Strengthen the capacity of media to reporting results accurately.
- Encourage the WHO to develop clear guidance, expediently.
- Request the WHO to involve anyone impacted by results (nurses, medical professionals, women, etc.) in their guidance development process.
- Build trust across stakeholders.
- Contextualize the issues within discussions of universal healthcare coverage.
- Call for increased investment in civil society groups to mobilize.

- Engage young women, thought leaders, researchers, and the humanitarian response community as key stakeholders.

Opportunities for Engagement

Participants identified upcoming events which are key, high-profile opportunities to discuss and plan action around this issue. These include:

- Civil Society Pre-Meeting Consultation – HC-HIV Advocacy Working Group, co-convened by AVAC and ICWEA (Lusaka, Zambia, 24-25 February 2019).
- WHO Stakeholders' Meeting on Hormonal contraception and HIV (Lusaka, Zambia, 26-28 February 2019).
- Women Deliver Conference (Vancouver, Canada, 3-6 June 2019).
- High-Level Task Force for the International Conference on Population and Development (ICPD) (Ongoing).
- Global Community Advisory Board of the AIDS Clinical Trials Group (Ongoing).
- Implementing Best Practices Knowledge Gateway (Ongoing).
- FP2020 Anglophone Africa Focal Point workshop (Ethiopia, May 2019).
- Joint FP/HIV CSO meetings in-country.

Day 2

Day two consisted of a series of small group exercises to outline communication and advocacy objectives, goals, audiences, and activities. Participants outlined the aforementioned for three time periods:

- prior to the results of the ECHO trial;
- following the release of the results but before WHO guidance is provided; and
- following the release of WHO guidance.

Participants brainstormed several activities to engage stakeholders such as governments; family planning, HIV and maternal and newborn health implementing partners and providers; women's advocates; and health journalists. Many of these activities were similar across the stakeholder groups and across the three time periods. The outputs of the small group work will be used to inform the development of a strategic plan for communication and advocacy action around the release of the ECHO trial results.

Coordination

The consultation concluded with discussion around the need for improved coordination among stakeholders working on this topic. Participants felt that there is a need to better leverage resources and competencies to

facilitate communication between ECHO, WHO, and Ministries. Partners in the room have communication, technical, advocacy and political expertise that can all be directed to achieving the priorities identified in this meeting. The momentum and urgency around the ECHO trial should be used to improve coordination and alliances between the family planning and HIV communities. While advocates and activities at the civil society level are often connected, efforts are siloed at the program level. The HIV community has a long history of grassroots advocacy and civil society action, the family planning community, and their response to this issue in particular, can benefit from those experiences. AVAC noted that it has a draft strategy focused on planning for the initial ECHO results and is working to populate a database of key media contacts and spokespersons to facilitate coordination.

Participants agreed that to advance the activities identified during the small group discussions, a small coordinating body is needed to facilitate information exchange and planning. The coordinating body would be able to follow up with partners to determine whether and what they are implementing with regard to the forthcoming strategy and check-in on their progress throughout this next 12-18-month period.

Results for Informed Choice Website

CCP shared a new resource being developed as part of the landscape assessment to support knowledge management and improved coordination around HC-HIV. The website – resultsforinformedchoice.org - hosts a collection of materials, program tools, articles, peer-reviewed literature, a timeline, and country profiles with family planning and HIV data and indicators. The resource was met with a great deal of enthusiasm and several participants remarked that this was much-needed.

Participants also noted the importance of using this resource to map materials and to identify what resources need to be updated, which resources should be adapted, and what resources are still missing. The website will be launched in February and CCP is exploring additional features to enhance its utility and the user experience.

Homepage



Closing

Participants agreed that there is an urgent need to mobilize advocacy and communication efforts to prepare for the release of the ECHO trial results and to offer support to countries to interpret the results and transform recommendations into actions. There is a need for clear guidance on what the results mean, along with advocacy and communication materials that are sensitive to the epidemiological context to assist stakeholders in taking the necessary steps to ensure women have the ability to make a full informed choice. While it is expected that the various family planning and HIV stakeholders will all communicate slightly differently around this issue given their priorities, communication efforts should be harmonized and framed around core principles. These principles include placing women at the center of her own decision making, the need to expand and guarantee the sexual and reproductive health rights of women and ensure informed choice for women. These are advocacy areas shared by both communities. Overall, for stakeholders to act on the results of the trial, communication must be timely, transparent, and contextualized.

Action Items

- All participants to share any existing activities and events that are relevant to HC-HIV via a google form to be sent out.
- CCP to complete analysis of stakeholder interviews within two weeks and share final report.
- CCP to share strategic plan and solicit feedback from consultation participants.
- Partner organizations to identify which action points from the strategic plan can be incorporated into their existing workplans and where there are gaps.
- CCP to share landscape analysis/strategic plan at upcoming WHO meeting.
- AVAC to share their draft strategy with participants.
- Interested participants are urged to join the family planning and HIV communications working groups hosted by AVAC and FP2020.
- Partners to audit their existing materials and share on the resultsforinformedchoice.org website.
- Partners to consider jointly developing an updated and consolidated package of ready-to-go materials.
- CCP to launch beta website for feedback from participants.

Annex 1: Attendee List

Result for Contraceptive Choice Stakeholder Consultation: Attendee List

Name		Organization
Saad	Abdulmumin	USAID
Tamar	Abrams	Family Planning 2020
Jennifer	Albertini	Office of the Global AIDS Coordinator
Deborah	Baron	Wits RHI
Emily	Bass	AVAC
Jvani	Cabiness	Johns Hopkins Center for Communication Programs
Ryan	Cherlin	Bill & Melinda Gates Foundation
Bergen	Cooper	Center for Health and Gender Equity
Kelly	Curran	Jhpiego
Jennifer	Drake	PATH
Elisha	Dunn-Georgiou	PAI
Anna	Forbes	AVAC
Jennie	Greaney	UNFPA
Rebecca	Husband	Population Services International
Navita	Jain	AVAC
Ida	Jooste	Internews
Chilufya	Kasanda	Treatment Advocacy and Literacy Campaign
Ricky	Lu	Jhpiego
Beth	Mallalieu	Johns Hopkins Center for Communication Programs
Nithya	Mani	USAID
Kay	Marshall	AVAC
Jennifer	Mason	USAID
Timothy	Mastro	FHI360
Jacqueline	Mwangi	AVAC
Lillian	Mworeko	International Community of women living with HIV Eastern Africa
Lisa	Noguchi	Jhpiego
Rabab	Petit	USAID
Yvette	Raphael	Advocates for the prevention of HIV in Africa (APHA)
Kathleen	Shears	ECHO Study/FHI360
Joanna	Skinner	Johns Hopkins Center for Communication Programs
Anne	Sizomu	IPPF
John	Spangler	Global Health Strategies
Lindsey	Tolliver-Miller	IPPF
Andrea	Vogt	Global Health Strategies
Mitchell	Warren	AVAC
Sarah	Whitmarsh	Advance Family Planning, Johns Hopkins University

Annex 2: Agenda

Result for Contraceptive Choice Stakeholder Consultation January 23-24, 2018 Participant Agenda

Wednesday, January 23rd

- 8:30 – 9:00** **Arrival**
Opening and Introductions
Findings from the Landscape Assessment
Resulting questions from the landscape assessment
- 11:15 –11:30** **Tea Break**
What’s happened, happening and needs to happen in Africa
FP & HIV community remarks
Plans for ECHO results communication
- 1:00 – 2:00** **Lunch**
Scenario Discussion
Introduction to draft Advocacy and Communications Framework
Framework part 1: Goals and objectives
- 3:15 – 3:30** **Tea Break**
Framework part 2: Core message
- 4:30 -4:45** Day 1 wrap up and Day 2 agenda

Thursday, January 24th

- 8:30 – 9:00** **Arrival**
Day 1 Debrief
Framework part 3: Understanding our audiences
Framework part 4: Strategic approaches and activities
- 11:00 – 11:15** **Tea Break**
Framework part 4: Continued
- 1:00 – 2:00** **Lunch**
Putting it all together
CCP next steps for stakeholder assessment
- 4:15 – 4:30** Closing Remarks