

Taking it to the Streets: Engaging in-country stakeholders to plan for possible PrEP implementation

Emily Bass, Mitchell Warren, Deirdre Grant, Lori Miller

AVAC: Global Advocacy for HIV Prevention

Background

It is critical to engage a range of stakeholders in advance of the release of data from large-scale trials of new HIV prevention strategies. If stakeholders feel they have been underinformed or underinvolved while research is ongoing, they may be less receptive to acting on the results—i.e., moving forward with implementation, identifying appropriate follow-up activities, or supporting researchers as they explain results that have not shown a protective effect or even negative findings. In the best-case scenario, where there is a clear positive result, having an informed and engaged group of national-level stakeholders aware of and prepared for the result increases the chances that the country will identify and implement next steps relevant for its context. There are a range of preparatory activities that can take place before a research result is known. Furthermore, if the result shows no effect or presents a safety concern, having an informed group of national stakeholders can help to minimize any misinformation that may emerge.

National stakeholder engagement is different from the types of activities undertaken to prepare for and conduct a study in specific locations—although some groups may be involved in both trial-specific outreach and broader stakeholder engagement. One of the main differences is that, in this process, stakeholders are asked to provide input and guidance on steps that can happen in the short- mid- and long-term to prepare for the results from an ongoing study. The stakeholders receive information about the topic—e.g., PrEP research overall—and are asked to lend their expertise to planning for a result that shows a positive effect, a negative effect, or no effect.

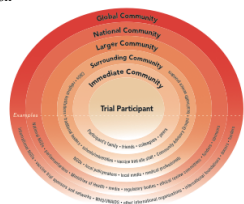
Key steps include:

- Providing information about the prevention strategy and ongoing or planned studies
- Asking questions
- Getting feedback and answers
- Acting on next steps
- Providing updates

Who needs to be engaged?

Members of key stakeholder groups whose input will be critical to implementation of PrEP if it shows effectiveness in trials and is moved into the implementation phase including:

- Civil society (people living with HIV/AIDS, women's groups, human rights advocates, treatment and health consumer rights groups)
- Communities and community leaders in areas where research is taking place
- Health care providers including doctors, nurses, counselors and others
- Parliamentarians
- Policy makers
- Ministry of Health

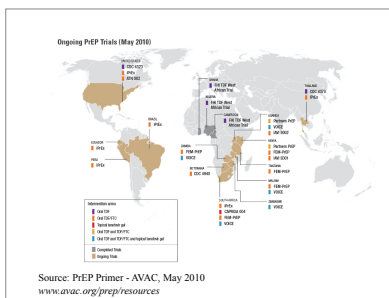


Methods

Beginning in 2008, AVAC has worked with in-country partners in Kenya and Uganda to implement a systematic engagement process to help prepare key community and national stakeholders for PrEP results.

Key steps include:

- **Identify national partners in leadership roles to take ownership of the process of preparing for PrEP results—research trial teams and sponsors are key resources but do not drive the process.** In Uganda, the Uganda AIDS Commission sponsored the high-level stakeholder meeting with support from AVAC, UVRU-IAVI and Partners in Prevention. In Kenya, the National AIDS Coordinating Committee (NACC), hosted a discussion on PrEP. AVAC and KEMRI worked together to support this dialogue by preparing civil society and other key audiences to participate.
- **Connect and coordinate.** This process is most successful if all of the various prevention research trials are aware of and have the opportunity to contribute to the agendas, presentations and messages on an ongoing basis. PrEP research is part of a larger HIV prevention “universe”—and results from any PrEP study or any other trial can affect ongoing work. Informing partners of planned activities and outcomes is critical.
- **Brief key stakeholders in advance of large meetings and provide regular updates as the process goes on.** Large stakeholder meetings are excellent venues for generating consensus, voicing and responding to concerns. However, it is also critical to meet with specific groups in other forums. Civil society groups may need additional research literacy training, more basic presentations, or a “safe space” in which to generate their specific concerns. National regulatory authorities, parliamentarians, ministry of health officials will all have specific questions—meeting with them in advance of large meetings can address and identify.
- **Follow-up on expressed needs:** Every country's context is different—and there are different issues by region, community, trial site and so on. No single strategy will work in all cases. Feedback is critical.



Source: PrEP Primer - AVAC, May 2010
www.avac.org/prep/resources

Results

The initial consultations have identified short- and long-term needs as each country prepares for results, including gaps in general PrEP knowledge, consideration of implementation issues, cost effectiveness modeling, and need for national policies.

Key Stakeholder Meetings

National Engagement on PrEP Research in Uganda: Select activities to date*

September 17, 2008: Civil society pre-briefing on PrEP research - Participants included: International HIV/AIDS Alliance, Society of Women and AIDS in Africa, HEPS (Health Empowerment organization), Straight Talk Uganda, Youth AIDS Coalition and CAB/CAG members from HIV vaccine, microbicide and PrEP studies in Uganda.

September 17, 2009: Stakeholder dialogue on PrEP research - Participants included: civil society groups along with representatives from trial teams of HIV vaccine and microbicide trials, Uganda AIDS Commission, Uganda National Council of Science and Technology, Office of the President, PATH, Makerere University Institute of Public Health, Uganda National Health Research Organization

August 5-8, 2009: Pre-meeting briefings with key participants for 10 August high-level stakeholder meeting - Participants included: National Drug Authority, Uganda Council of Science and Technology, Mildmay Uganda, Infectious Disease Institute, AIDS Control Program, Ministry of Health

August 7, 2009: Civil society dialogue on PrEP research - Civil society participants from 17 September meeting generate civil society input for the 10 August high-level stakeholder dialogue

August 10, 2009: High-level stakeholder's dialogue on PrEP - Panel observations by representatives from UNCSST, NDA, and participants included Hon MP chair of standing committee on HIV/AIDS, members of HIV prevention research teams in country (vaccine, microbicide, PrEP), Presidential Advisor on HIV/AIDS and others

October 1, 2009: Briefing of Ministry of Health AIDS Control Program

National Engagement on PrEP Research in Kenya: Select activities to date.

December 14, 2008: Civil society capacity building session on HIV prevention research - Participants included representatives from KANCO, Health Rights Action Forum, Doucandani Couples Association-Kenya, Men Mobilized Against AIDS Kenya, Kenya Network of Women Living with HIV/AIDS, WOFAK, Bar Hostess Empowerment Program, Nairobi Pastors Tackling HIV/AIDS, Global Campaign for Microbicides, and CAB/CAG members and community liaison officers from HIV prevention research sites throughout Kenya

December 15, 2008: Focus Group Discussion on PrEP and implications for Women

December 15-16, 2008: Kenya HIV Prevention Research Stakeholders Meeting - Panels and presentations by full range of HIV prevention research stakeholders including NCST, PPD, KEMRI, IRH members, representatives from male circumcision, microbicide, vaccine and PrEP research projects, civil society and others.

October 9, 2009: Civil society dialogue on PrEP research - Participants included: representatives from KANCO, Health Action International, Gay and Lesbian Coalition Kenya, FIDA, KALN, HERRAF, LICASI, Bar Hostess Empowerment Program, WOFAK, Global Campaign for Microbicides and CAB/CAG members and community liaison officers from PrEP sites throughout Kenya

November 23, 2009: Follow-up civil society dialogue on PrEP research - participants included interested stakeholders from 9 October meeting with goal of developing civil society input for 30 November NACC session on PrEP

November 30, 2009: NACC Meeting on PrEP

*This is a select list focused on non-trial-specific activities. It does not include a wide range of essential broader stakeholder engagement activities that have been initiated and carried out by sites and trial teams throughout the country.

Conclusion

Feedback from participants indicated that consultation in advance of trial results has helped build a sense of ownership of and engagement with the research endeavor. In each setting, participants have identified questions, priorities and action steps that can be addressed to improve the environment in which results will be released. It is valuable to provide a separate forum for civil society to learn and develop opinions in advance of any broader stakeholder meeting. This approach must be replicated in other countries where PrEP trials are ongoing and planned.

For more information

About AVAC

Funded in 1995, AVAC is a non-profit, community- and consumer-based organization that uses public education, policy analysis, advocacy, and community mobilization to accelerate the ethical development and global delivery of new HIV prevention options as part of a comprehensive response to the global pandemic.

To find out more about PrEP and other elements of AVAC's work visit www.avac.org