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 undervalued 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 research 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- 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, Uganda LGBTI 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.

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


September 17, 2008: A VAC stakeholder dialogue on PrEP research—Participants included: civil society groups along with representatives from National AIDS Society-Services, Makerere University Institute of Public Health, Uganda National Health Research Organization.

August 4, 2009: Pre-launch meetings with key participants for 14 September high-level stakeholder meeting—Participants included: Uganda AIDS Commission, Makerere University, Uganda Council of Science and Technology, Uganda National Health Research Organization.

August 7, 2009: Civil society dialogue on PrEP research—Civil society participants from 17 September meeting present civil society input for the 14 September high-level stakeholder meeting.

August 11, 2009: High-level stakeholder’s dialogue on PrEP—Panel discussions by representatives from UNAIDS, NGOs, and participants from 14 September high-level stakeholder meeting with session on how to move forward in light of the PrEP results.

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

National Engagement on PrEP Research in Kenya—Advance planning to support stakeholder consultation.

December 12, 2008: Civil society capacity building session on HIV prevention research—Participants included representatives from KEMRI, Makerere University, National AIDS Control Program, Makerere University, Ministry of Health, Makerere University, National AIDS Control Program, Makerere University, Ministry of Health.

December 19, 2008: Focus Group Discussion on PrEP—Participants included representatives from试用版

December 19, 2008: Focus Group Discussion on PrEP—Participants included representatives from KEMRI, Makerere University, National AIDS Control Program, Ministry of Health, and others.


For more information

About AVAC

Founded 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 epidemic.

For more information about PrEP and other elements of AVAC’s work visit www.avac.org

Conclusion

Feedback from participants indicated that consultation in advance of trial results has helped build a sense of ownership 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.