

Developing Good Participatory Practice Guidelines in HIV Prevention Trials

Summary of the Core Group meeting in London UK, 27-28 September 2006

The success of HIV prevention trials depends on robust, mutually-respectful relationships between researchers and involved individuals and communities. Without these effective partnerships, HIV prevention trials can and will founder. The highly politicised halting of pre-exposure prophylaxis trial sites in 2004-2005 are a vivid demonstration of the degree to which communication misunderstandings and ineffective engagement between communities and researchers can affect the outcome of HIV prevention trials. With these issues in mind, the UNAIDS Secretariat assisted by the AIDS Vaccine Advocacy Coalition convened a meeting on 27-28 September 2006 in London UK to initiate the process of developing Good Participatory Practice Guidelines in HIV Prevention Trials. Participants were 16 persons from research advocacy groups, research networks, research sponsors and activist non-governmental organisations (representing Africa, Latin America and Asia), the World Health Organization, and UNAIDS.

Presentations and discussions at the meeting created a common understanding of processes, outcomes and thinking to date, along with needs and possible mechanisms to respond to these, in the context of creating effective partnerships for HIV prevention trials. Common agreement was reached on the key elements to be included in a workable, liveable guidance document that would lay out basic standards for community engagement, and provide systematic ways of evaluating whether an HIV prevention trial has succeeded in effectively engaging community before, during and after a trial is completed. The document would provide a new framework for participatory processes that are meaningful, sustainable, and that can benefit the response to HIV by achieving the goals of both the research enterprise and the communities in which a trial takes place.

Participants were unanimous that the framework would not provide specific answers for each site and each context, but it could provide the foundation for locally-driven processes which could address critical questions and issues. There was also unanimity on the need for an extensive consultation process to review, pilot test, and validate the Good Participatory Practice guidance document.

Participants drew up a plan for implementing the decisions of the meeting. Before December 2006 a draft of the GPP guidelines will be produced and, simultaneously, there will be a mapping of stakeholders who will review and validate the document. A broad consultation to inform the final GPP guidelines will be undertaken by end of March 2007 followed by pilot testing. The consultation process may include a variety of methods including solicitations of reviews of the guidelines by key research and civil society organisations and networks, web posting for general comments, and face to face workshops during other meetings and conferences planned for 2007. It is anticipated that by the end of December 2007 there will be publication and web posting of the guidelines to support implementation and roll-out.