

# Engaging Communities in Africa in Clinical Trials

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# Why Do We Need Community Involvement?



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# Doing Good and Doing Well

- Ethical principle of **beneficence**.
- **Maximize benefits and minimizes risks** for participants and for host communities.
- **Minimize exposure to controversy** and risk of disruption.
- Increase the **transparency and accountability** of the research to the community.
- **Improve quality of trials**, participant retention, adherence and accurate self-reporting: ensuring trial procedures are acceptable to participants and other decision-makers.
- Strengthen **local capacity** and infrastructure.

# Case Study: Cambodia Tenofovir Study

- **2003: Preparations begin for the conduct of a tenofovir PrEP study among sex workers in Phnom Penh**
- Many miscommunications and misunderstandings between community groups and researchers
- Protests at the International AIDS Conference, Bangkok
- Press release by activist groups denounce trial
- Media storm & negative reaction from Cambodia PM
- **2004: Trial halted by Cambodia government**



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# Challenges

- Defining community & who decides
- Rumors & misperceptions
- Communication: Talking past each other
- Lack of resources / Competing priorities
- Lack of sharing/coordination across networks & fields



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# Community Involvement Strategies

- Community advisory structures (CABs, CAGs, CACs, participant representatives)
- Community preparedness
- Community mappings
- Radio & local media
- Dramas and community events
- Network community working groups
- Cross-network community involvement community of practice (CoP)



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- *Why is so much blood taken?*

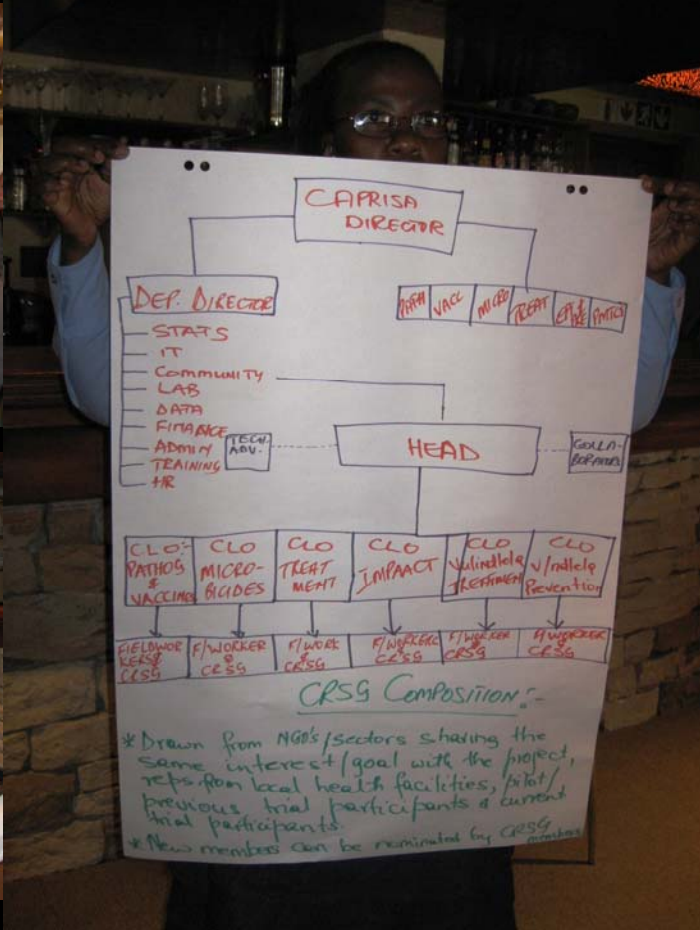
- *What do you do with the left over blood?*

- *Are the needles safe/clean?*



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# The Community of Practice (CoP)



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# Aims of the CoP

- Share experiences and challenges
- Dialogue on important issues related to community engagement
- Foster a culture of sharing and collective problem solving within the field
- Creates a level playing field where all experiences & information are valued



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# Lessons Learned

- Establish norms for community engagement
- CABs have limitations
- Adequate funding
- Early involvement
- Open dialogue
- Community perceptions & acceptance are vital for eventual introduction
- Document evidence-based approaches
- Acknowledge power imbalances & engage in capacity building



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“No one wins when a trial is stopped for non-scientific reasons. But the only way to prevent this is to invest the time and resources needed to build the kind of mutual trust on which collaborative partnerships can be based.”

- Anna Forbes & Sanushka Mudaliar

*Preventing Prevention Trial Failures: A Case Study and Lessons for Future Trials from the 2004 Tenofovir Trial in Cambodia*



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