Community engagement with microbicide clinical trials: case study of CS3 trial

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Identified community communication mechanism for the CS3 trial closure

- GCM ↔ AMAG ↔ National coalition bodies/partners ↔ communities

- Recognised constituted relation by the global community of advocates

- These represented the voices of the interested stakeholders
Identified missing link

- CABs/similar structures ↔ trial participants

- Both voices remained unheard in the discussions yet both voices were critical as they were those directly related to the trial

- Both communities’ have no communication link with the body of stakeholders. Only communication linkage is with the trial site

http://www.nhvmag.org
- While the body of stakeholders handled information dissemination well, the absence of the voices of those directly related with the trial (CABs and trial participants) constituted a gap.

- This needs to be addressed— not only for crisis management/prevention and conflict resolutions but also to help address myths and misconceptions about trials. Until these voices start to be heard the issue of trial participants being used as guinea pigs would continue.
Study participants’ voices....

1. The ethical concerns: It is not for trial team to encourage study participants to participate in discussions about the trial. However, it is the responsibility of the trial team via the community relation staff to empower the trial participants with enough information to be able to discuss publicly about what they are involved with.

2. Engagement of study participants in public discuss about the trial should be voluntary and not initiated by the study team. As members of the general community they can be readily identified. However, being empowered through their engagement in the trial, they can then engage in public discuss and debates around the trial.
Recommendation

Education efforts for the study participants engaged in clinical trials should also be focused at empowering them to speak publicly about the trials. This should be an identified secondary endpoint for community engagement efforts in microbicide clinical trials.

Facilitate this by discussing about the trial study participants as opportunities (formal and informal) show up.