

Buthelezi, S. (2008). Giving trial participants a voice! Experiences from the mdp301 clinical trial site in the umkhanyakude district of northern kwazulu natal. *Microbicides 2008*. Delhi.

Issues: The Africa Centre PRO2000 clinical trial received negative press after the closure of the Cellulose Sulphate trial in January 2007. The most notable headline referred to trial participants as "guinea pigs". As a result, participants expressed a desire to share their experiences of being in the trial. It was therefore decided to hold a participant event in August 2007. The study staff identified a former and current participant from each of the 3 study sites to serve as a participant stakeholder group.

Description: The participant stakeholders formally met four times during July and August to assist in planning the event, but also recruited other participants to assist and had many meetings in their homes to prepare for the event. The participants defined the logistical arrangements, and some of the agenda by arranging to perform a theatre-sketch, song and dance. They also defined the awards and types of prizes to be given to participants and male partners. The husband of a stakeholder asked to be able to present on condom use. The stakeholders were instrumental in promoting the event, which ended up attracting 476 participants (64% of enrolled women) and 94 male partners. In the performances the participants showed their experiences of the trial, including issues relating to the benefits of HIV testing, the fact of not knowing if PRO2000 is effective, the importance of attending scheduled visits and accurately reporting sexual behaviour, sexual experience of the gel, reasons for not sharing gel, partner opposition and infidelity, and the importance of using condoms.

Conclusion: Trial sites have a responsibility to protect the confidentiality of participants, but also provide a safe platform on which participants can express their views of trial participation and gel use if they want to do so. Participant events are an effective platform to provide this opportunity.