

The role of the media in HIV prevention trials

Positive and negative experiences from Tanzania and elsewhere

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HIV and AIDS statistics remind us that safe and effective HIV prevention methods such as microbicides, vaccines, genital herpes suppression medicines and use of antiretrovirals as pre-exposure prophylaxis are urgently needed to reduce HIV infections. Before these can be produced, their safety and efficacy need to be established through clinical trials. Currently many of these approaches are being tested, requiring more than 80,000 participants worldwide to participate. Yet recruiting volunteers to participate is a serious challenge that slows down efforts of coming up with new HIV prevention methods in the near future.

The media are an essential and powerful tool in educating and mobilizing communities and are particularly valuable in promoting participation in HIV clinical trials. Many people trust the media – whatever is written or broadcasted is regarded as absolute truth. Accessibility and availability of the media to most communities are some other factors that place them in a good position to mobilize potential trial participants. The Kilimanjaro Reproductive Health Programme (KRHP) has used radio in Northern Tanzania to reach and educate prospective participants of HIV prevention clinical trials conducted by the programme. These trials include microbicides and genital herpes suppression studies among HIV discordant couples. Our approach showed to be very useful as both trial participants and their communities are now better informed about these trials through the media. Accurate reporting skills built through involvement of KRHP researchers in the production and presentation of radio programmes facilitated credibility and trust between our researchers, trial participants and journalists, leading to increased participation in the trials.

However, sometimes the media can erode gains made through HIV clinical trials, especially by reporting about the efforts inaccurately and superficially. Evidently, this leads to wrong decisions among trial participants, the public and policy makers, thereby discouraging volunteers to continue participating in trials, or policy makers halting trials or adopting policies that jeopardize them. A



notable example is the case of the 2004 Tenofovir trial. This trial was underway in Cameroon and was almost taking off in Cambodia, Ghana, Malawi and Nigeria. Activists called for its discontinuation by claiming that it violated human rights and research ethics like unavailability of long-term provision of care and treatment for trial participants who become infected with HIV during the trial.

The media reported widely about the Tenofovir controversy. A study conducted by McMaster University to determine the impact of the media in the failure of the Tenofovir trial to take off revealed that out of the 37 articles on the issue, 18 did not identify their primary source of information and only eight reported to have interviewed either researchers or trial participants.¹ Surprisingly, only one article was considered to be objective by carrying views of both trial investigators and those opposing the trials. Consequently, the

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government of Cameroon halted the trial which by then had recruited 400 participants. Cambodia, Nigeria, Ghana and Malawi followed suit and cancelled plans to start trials. As a result of this development, recruitment and participation of volunteers in similar trials with injecting drug users in Thailand and men who have sex with men in the USA and Peru were severely affected.

Inaccurate reporting

Recently, CONRAD discontinued its trials of microbicide candidate *Ushercell* gel, after discovering that instead of preventing HIV infection in women who used the product, it seemed to increase risk of infection.² Following this development, Family Health International also stopped a trial of the same gel in Nigeria as a precaution. These developments were widely reported, with most of the reports carrying inaccuracies. For example, in South Africa, the media referred to trial participants as guinea pigs while journalists in Tanzania confused microbicides with antiretrovirals.

What scientists and journalists could and should do:

- Scientists should design approaches to involve journalists during both 'good' and 'controversial' moments. In collaboration with local organizations, they could conduct short trainings for journalists covering basic knowledge on HIV/AIDS and clinical trials with emphasis on research ethics and the drug development process.
- Scientists should equip themselves with skills on how to deal with the media.
- Journalists could join Community Advisory Boards in research settings.
- Research sites should have media and communication protocols in place that specify who should talk to the media. They should also allocate time for consultation with health reporters.
- Scientists should be involved in developing media programmes that educate and inform communities about ongoing and future trials.
- Activists and people living with HIV in trial catchment areas should be involved in community mobilization.
- Media houses should realize the importance of employing health journalists and if it is not possible, to provide in-house training on health reporting.
- Whenever there is inaccurate reporting, both scientists and the media should work together to communicate the accurate information to the public.
- Editors should provide room for both scientists and journalists to give their views on research.

Generally, there is little understanding by journalists about the number, types and functions of microbicides studies that are underway in different countries. Journalists also lack knowledge

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about the current development stages of the products under trial, and some do not even know that they are not on the market yet. Headlines appearing in the print media following the halting of the UsherCell trials were discouraging; stigmatizing participants, if not threatening people not to participate in HIV clinical trials. As a result, recruitment and retention of trial participants became a challenge in various sites in Africa, including in Tanzania.

In another example of inaccurate reporting, BBC Kiswahili Service interviewed a trial participant in one of AMREF's trials of microbicide candidate *Pro 2000* in Mwanza, Tanzania. During the interview, the reporter informed the woman that the World Health Organization had banned the use of this gel worldwide. The reporter went on to ask another woman whether or not she

was going to notify other women not to use the gel anymore. Being a credible and powerful channel within the region, the BBC's report threatened to affect recruitment and retention of trial participants in Mwanza and other KRHP's trials in Moshi, if we had not taken urgent measures to portray a true picture of the situation. We organized a press conference and education sessions about microbicides for journalists based in the programme area. We also developed reading materials in the local language to clarify issues about the trial which had been misreported by the media.

Vicious circle

It should be noted that trials are not only discontinued as a result of failure, but can also be stopped prematurely because an interim analysis shows that a life-saving drug or technology is that effective that it is deemed unethical to deny people its use. Notable examples are the male circumcision trials conducted in 2005 and 2006 in Kenya, South Africa and Uganda, which were stopped prematurely due to consistent evidence of effectiveness.

Most journalists lack background knowledge in science, which leads to inability to comprehend the clinical trials procedures. On the other hand, there is an unwillingness by scientists to cooperate with the media, based on fear or suspicion fed by past and present experiences of inaccurate reporting. Sometimes, researchers fear losing control when they are interviewed. This leads to a vicious circle of inaccurate reporting. Media could be an important stakeholder in promoting the research agenda for the benefit of communities. However, it is necessary to equip them with appropriate knowledge and skills about complicated scientific ethics and procedures. In tackling HIV and AIDS, researchers and the media have a common goal of fighting the same enemy with two different weapons. ■

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1. E. Mills, B. Rachlis, P. Wu et al., Media reporting of Tenofovir trials in Cambodia and Cameroon. *BMC International Health and Human Rights*, 2005, 5 (6): <http://www.biomedcentral.com/1472-698X/5/6>
2. *UsherCell* is a gel for women to insert in the vagina or anus one hour before having sex to prevent HIV infection. The objective of the trial was to establish its effectiveness. The study was conducted in Benin, India, South Africa and Uganda.