

Engaging the African Community

AFRICA – a continent of contrasts and diversity. From the desert regions in the North, through the equatorial rainforests, down to the savannas of the South, the continent continues to intrigue and attract people from all over the world. But the contrast and diversity doesn't end with the climate – the continent suffers from both emerging and emerged world diseases; there are broad socio-economic differences both within and between countries and a diverse population.

However, the thread of “ubuntu” (uu – BUUN-too) is strongly woven across the fabric of African society. It is an African philosophy that defines our interconnectedness, our common humanity and the responsibility we have to one another and that we do not exist in isolation¹.

Due to the nature of its endemic diseases, Africa is most suited for clinical research in HIV, TB and malaria². Communities affected by these conditions are faced with many challenges – access to health education, access to health care, social stigma and economic sequelae.

Companies and organisations wishing to conduct clinical research in Africa are faced with many challenges too – knowledge of the ethical and regulatory frameworks in the different countries, accessing experienced clinical research sites, paucity of health resources and recruiting and retaining participants on clinical trials.

Key to the success of many clinical research interventions in Africa is the engagement of the community. This engagement can take various forms – the establishment of CAGs/CABs (Community Advisory Groups / Community Advisory Boards)^{3,4}, using existing community based organisations or non-profit groups to disseminate information, and/or the use of media such as community radio, community events and drama groups⁵. The African people have a more informal and relaxed way of living and speaking which manifests in singing, dancing, laughing, painting, and sculpturing (Broodryk, 2006:4)⁶, and it therefore behoves a sponsor to familiarise themselves with the community in which they will be conducting the research before initiating the intervention. Not all African countries are the same, and many strategies used in other regions will be ineffectual in Africa.

Too often community engagement may be perceived as an activity to boost recruitment and retain study participants rather than as an opportunity to build successful partnerships, foster trust between the parties and provide health education and relevant research. The engagement serves as a bridge between the community and the research site.

Examples of successful interactions follow.

Working with initial focus groups, sponsors can discuss the feasibility and acceptability of a proposed research intervention. This approach was used in the BAN study in Lilongwe, Malawi⁷. Based on interactions with the community over a period of 3 months, the study protocol was modified to achieve cultural acceptability while maintaining the study objectives. Without these interactions several significant areas would have gone undetected and may have jeopardised the implementation of the trial.

Research units such as the HIV Prevention Unit (HPRU) of the Medical Research Council (MRC) in Durban, South Africa, have developed various health education programmes for the community which extend beyond their clinical research interventions⁸. Community members are also educated on the various research protocols and related procedures, provided with updates on research progress and the importance of adhering to study requirements.

The Netefatso study sought to enrol sero-discordant couples, with the HIV positive partner also infected with HSV-2⁹ from 2005. At the time the study started, Botswana did not routinely offer Couples HIV Counselling and Testing (CHCT) as part of the national testing program. The Netefatso team conducted a series of talks at various forums on the necessity of CHCT as opposed to individual testing, with the message “Your Partner’s HIV status is not necessarily always yours”. The intervention was well received and CHCT now forms part of the national testing program.

There are many more examples of successful interactions such as these, and many research sites across Africa have established strong links with their communities.

Community engagement is also used to debunk myths and negative rumours which may circulate in a community and derail the clinical research intervention¹⁰. A retrospective study conducted in Zambia with mothers whose children were enrolled in a malnutrition study, showed that their concerns reflected their historical, socio-economic and cultural influences. Their concerns are not unique to Zambia and focussed on fear of stigmatisation – there is a preponderance of HIV studies in Africa, so there is a perception in the community that anyone enrolled on a study must be HIV-positive; that supplements were inferior and would result in the worsening of the child’s condition; and witchcraft. By proactively identifying and addressing these concerns ahead of study start, researchers will begin to build an open relationship of mutual trust with the community. Researchers must be prepared to discuss concerns with “significant others” and not just research participants. Inclusion also fosters community ownership and support. It is important that relevant social conventions and protocols are observed as many African societies are both hierarchical and patriarchal, and the support of community leaders is necessary if the research is to take place¹¹. It is

important to remember that consent from community leaders does not replace individual informed consent.

Let us not forget that there are ancillary benefits to participating in clinical research and receiving health education that may not be readily available in the broader community. In a study conducted in Soweto, South Africa in 2008 amongst women who had participated in a microbicide feasibility study, the central finding was the sense of empowerment felt by the women in terms of the critical role of repeated, voluntary counselling and testing, knowledge of their HIV status, and a heightened awareness of sexual and reproductive health in reshaping their approaches to sexual relationships and AIDS in spite of living in a culture that has come to fear, deny or ignore AIDS (Stadler JJ, et al, *Social Science and Medicine* 2008, vol 66, issue 1:189-200).

The Mma Bana study in Botswana sought to determine the optimal HAART regimen to prevent mother to child transmission among 700 HIV-infected breastfeeding women in Botswana¹². Participants became advocates for the trial as they perceived one of the major benefits to be that they could breastfeed their baby, thereby escaping HIV stigma associated with formula feeding. The results of the study have been incorporated into the WHO 2010 guidelines.

In summary, the benefits of community engagement are:

- The opportunity to provide additional healthcare education and outreach programmes to benefit the community
- Partnerships with communities can strengthen national health campaigns and also contribute to an understanding, acceptance and support of appropriate research within the community
- Knowing in advance if there are any socio-economic, cultural issues and/or logistic issues that may affect the conduct of your research intervention
- Pro-actively addressing community concerns that may negatively impact on the conduct of the research intervention
- Development and translation of appropriate research materials, such as informed consents and patient information pamphlets – dialects and jargon differ across regions and some words or concepts cannot be translated directly from English.

The potential drawback to community engagement is:

- Sponsors need to factor additional time and budget into their planning activities, but the benefit of inclusivity and community engagement will offset this initial discomfort.

In the words of a distinguished South African, Nelson Mandela, “A traveller through a country would stop at a village and he didn't have to ask for food or for water. Once he stops, the people give him food, entertain him. That is one aspect of Ubuntu, but it will have various aspects. Ubuntu does not mean that people should not enrich themselves. The question therefore is: Are you going to do so in order to enable the community around you to be able to improve?”¹³

References:

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