Mapping of Clinical Trials and Their Community Engagement Approaches in Uganda; A Situational Analysis

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Background

Community engagement is an ethical imperative for instrumental and intrinsic values. This moves beyond established ethical principles and guidelines to the dynamic social and practical aspects of research ethics. Community engagement ranges from pre-trial planning activities, formative research, sensitization, and dissemination, to community partnerships. We mapped existing clinical trials; their engagement approaches and documented evidence-informed community engagement in Uganda.

Methods

This was a cross-sectional study using descriptive approaches, combining individual and focus group discussions. A desk review of 107 clinical trials conducted by 19 research institutions as per National Drug Authority clinical trial registry (2019) was done to map clinical trials and their community engagement approaches. We interviewed 19 Principal Investigators, 10 Research Ethics Committee Chairpersons, 4 Community Representatives on the RECs, 6 Community Liaison Officers, and 5 National Research Ethics regulators. Qualitative interviews were audio recorded, transcribed, coded and analyzed using a thematic-framework.

Results

We observed a number of community engagement approaches which included; Community Advisory Boards or Groups, patient groups, peer educators, project focal persons, community liaisons and engagement officers, field workers, healthcare providers, community leaders, local council chairpersons, opinion leaders, religious and cultural leaders, village elders and chiefs and Village Health Teams, District Health Officers, Ministry of Education, and school administrators. Engagement means included community dialogues, meetings, radio announcements, television and radio talk shows, barazas ‘public meetings’, and print media; telephone calls, community megaphones, public address system drives, edutainment and drama groups, continuous medical education, and home visits. Specific engagement strategies are contingent on the goals, location, study population, nature of the research and prior community involvement experience.

Conclusions

Existing local, social, administrative, civil society organizations and political structures are used to engage communities in clinical trials in Uganda. Considerations should be made in terms of power differences, socio-cultural, economic, and structural dynamics in the design of community engagement practices.

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