

Emily Nyariki, PhD Student,

MA- Population Studies University of Nairobi

Bachelor of Arts (Sociology and Religion) University of Nairobi

Study Title: Volunteers' perceptions and experiences of clinical research participation in Kenya:
Case study of KAVI volunteers

Supervisors:

Prof Joyce Olenja, School of Public Health, University of Nairobi

Dr Robert Read Lorway, Department of Community Health, University of Manitoba

Dr Sabina Wakasiaka, School of Nursing, University of Nairobi

Prof Omu Anzala, Director KAVI-ICR; Dept. Medical Microbiology, University of Nairobi

Abstract

Background

The conduct of clinical research faces unique challenges that compromise optimal recruitment of volunteers into studies. In Kenya, at Kenya AIDS Vaccine Initiative-KAVI, where a number of clinical research studies are being conducted, data from the recruitment sites reveal that eligible volunteers fail to turn up for actual enrollment even after providing consent to participate. Questions regarding volunteers' knowledge, understanding, and attitudes towards clinical research and how their experiences of participation affect their decision making have been raised. According to Kost G R et al., (2011) understanding participants' perceptions of their research experiences provides valuable measure of ethical treatment, yet no validated instruments exist to measure these experiences.

Study Objective

This study aims at exploring volunteers' perceptions and experiences and their potential impact on decision making to participate in clinical research participation. Specifically the study will seek to: describe the characteristics of individuals who participate in clinical research; examine individuals' perceptions towards clinical research participation; document volunteers' experiences at various stages of trial participation and their potential impact decision making to participate identify factors that enhance and /or constrain clinical research participation experience and explore similarities and differences of participation experiences among volunteers in the Kenya AIDS Vaccine Initiative (KAVI) studies

Methods

A mixed methods design will be employed to examine how volunteers' experiences and perceptions of research participation are likely to impact on their willingness and decision making to participate. Sequential transformative strategy will be adopted for data collection where a survey questionnaire will be administered to 350 participants to be drawn from past and on-going KAVI clinical trials. 42 IDIs will be conducted with participants purposively selected from the 350 participants and 8 KIIs from clinical staff. An embedded mixed methods data analysis approach will be applied using SPSS Version 13.0 and Nvivo Version 2.0.

Expected Outcomes

It is anticipated that findings from this study will inform the design of future clinical research studies, in order to enhance volunteer experiences of participation, and research literacy among local communities and volunteer recruitment and retention in clinical research. It is further anticipated that understanding factors that hinder potential volunteers from participating in clinical research will aid in identifying potential recruitment strategies and information packaging.