MY ROLE AS A STUDY COORDINATOR IN A CASE CONTROL RESEARCH IN WESTERN KENYA REGION:

My name is Pamela Akinyi Were; I am a Registered Community Health Nurse, I am also trained in Oncology and Palliative Care. I am currently working for Epidemiology of Burkitts Lymphoma in East African Children and Minors (EMBLEM).

EMBLEM is a case control study that is being conducted across the 3 East African countries i.e. Kenya, Uganda and Tanzania. It has a research arm, education and care component for patients with Burkitts Lymphoma. It is funded by the National Institute of Health (NIH) and National Cancer Institute (NCI) under Intramural programs. There are 6 sites in East Africa. In Uganda, the study sites are in Northern and North Western Uganda, based at Gulu and Kuluva. In Tanzania, the study is being conducted in the Mwanza and Mara regions with study sites at Bugando medical Centre and Shirati Hospital respectively. In Kenya, the study is conducted in Western and Nyanza provinces with study sites at Webuye and Homabay District Hospitals under Ministry of Health. The EMBLEM Kenya research team is composed of overall Principal Investigator who is based at the United States of America (USA), Co-Principal Investigator, Co-Investigators, Study Coordinator, Technical Supervisor, Laboratory Technologists, Nurses, Research Assistants and Data manager. In this team, I am the Study Coordinator (SC).

Western Kenya region has a population of about 20 million. Health structures, just like in any Low and Middle income countries (LMIC) are few and not adequately equipped. The Moi Teaching & Referral Hospital (MTRH), situated in the Western Kenya Region is one of the two national referral hospitals in the country. Other health facilities Provincial hospitals (Level 5) and District hospitals (Level 4). MTRH serves the Western Kenya Region and is home for several research projects. Most of these researches have sponsors who are based in the developed countries while the grants are managed locally through a Research and Sponsored Project Office (RSPO) based at Moi University and MTRH.

As a Study Coordinator, I have dual functions, research and administrative. My research roles are to maintain accurate and current Standard Operating Procedures (SOP's). My day today activities include managing and supervising case management and control work follow that includes spotting, consenting, questionnaire administration and biological sample collection and processing, storage, and shipment. In providing technical leadership for the field team, I plan workflow, Monitoring and facilitating interaction between EMBLEM staff, host site, and collaborators, Keeping abreast of research in the field and maintaining cooperative relationships within the research, academic and other research institutions in the country. I am also involved in managing the Project plan. This includes time, cost, quality and human resource management plan. Key tasks associated with this responsibility are developing and maintaining a detailed project work schedule for all study sites, align the schedule to the budget and priorities.

Implementation of EMBLEM Study has been full of challenges since the sites that are being used for enrollment had not been used for cancer treatment in the past and are very far from the administrative site of EMBLEM. The infrastructure was not well developed to meet the required standards for research and therefore, EMBLEM had to establish the necessary infrastructure to meet the requirements of a
Multi-country and multi-site research. As a Coordinator, my major function has been to ensure that all players are focused on this (Moi University, EMBLEM, Provincial Health management teams, District Health management team, and communities where research is being done).

This has succeeded and research and care are ongoing however with recurrent challenges of accessibility of the research sites by participants. Measures in place have included Continued Medical Education (CME), teleconference and phone calls.

Special needs have also been realized in recruiting needy patients, some of whom are not able to afford even the minimum investigations and treatment.

Nurses play a vital role in research programs as evidenced by various global researches that are currently in place. Factors limiting nurses from involvement in research include hierarchy of power among disciplines, scarce resources, few mentors and underfunding of nursing research.

In order for nurses to get more involved in research, their capacity should be built in the following areas: Proposal and grant writing in a way that meets the international standards, research mentorship, peer reviewing and manuscript preparation for publication.