

Field Epidemiology Training Program

Cancer Curriculum: Principles of Cancer Registries

Case Study:

**Establishment and maintenance of
a cancer registry in Uganda**

FACILITATOR GUIDE



Overview

Participants will apply what they learned in Module 3: *Principles of Cancer Registries* to the establishment and maintenance of the cancer registry in Uganda. Participants will work in small groups as instructed by the Facilitator.

Objectives

- Review the history of the population-based cancer registry in Uganda.
- Participants will work through necessary information, and key decision points that contributed to the success of the registry.
- Make the case for the establishment of a cancer registry.

Scenario

You work in the Ministry of Health in your country, where until recently the primary focus of all programs has been the prevention and control of infectious diseases such as malaria, tuberculosis, and HIV. However, the Minister of Health knows that the burden of non-communicable diseases (NCDs), including cancer, is rising disproportionately among lower income countries and populations. The Minister of Health in your country (and your boss) is forward thinking and knows that something must be done to curb the impending NCD epidemic. Specifically, the Minister is interested in understanding and addressing the cancer burden in your country. As a result, you have been asked to investigate how other lower income countries have been able to establish successful population-based cancer registries. Through research, you learn that Uganda had the first population-based cancer registry in tropical Africa. The registry was established in 1951 at the Makerere Medical School under Prof. J.N.P.Davies. Your role is to understand the history of the registry, how it was conceptualized and established, and what factors have contributed to the continued success of the registry. You will use this information to provide suggestions to your Minister of Health on the approach that could be taken on establishing a population-based cancer registry in your country. If you believe that a population-based cancer registry is not possible, given the current situation, then make the case for the establishment of a hospital-based cancer registry.

Instructions

We have 90 minutes to work through this case. Read the background material on the Uganda Cancer Registry (provided in your guide). Work in groups to answer the questions in this document. Read the required background material on the Uganda Cancer Registry.

Required readings for the related to the Uganda Cancer Registry include:

- Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. *Brit Med J* 2:439-445, 1958. Read pages 439-441 (<http://pubmedcentralcanada.ca/pmcc/articles/PMC2026071/pdf/brmedj03064-0043.pdf>).
- Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. *Int J Cancer*. 2014 Jul 15;135(2):432-9. Read pages 432-433 (<http://onlinelibrary.wiley.com/doi/10.1002/ijc.28661/full>).

Optional readings:

- Davies JN, Knowleden J, Wilson BA. Incidence rates of cancer in Kyandando County, Uganda, 1954-1960. *J National Cancer Inst* 35(5): 789-821, 1965. Read pages 789-94.
- Templeton AC, Hutt MS. Distribution of tumours in Uganda. *Recent Results Cancer Res*. 1973;41:1-22. Read pages 1-13.

Part I: Understanding the History

Your first step is to understand the history of the cancer registry in Uganda. *[Add sufficient detail on the history to answer the question.]*

1. What were the essential items and resources needed to establish the Ugandan Cancer Registry in 1951? (Read: Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. Brit Med J 2:439-445, 1958. Read pages 439-441)
 - In 1951 the Faculty of Medicine of Makerere College set up a Cancer Research Committee to study the incidence of cancer in the local population.
 - Good longstanding relationships between the staffs in the Kampala hospitals open the possibility of cancer registration.
 - Staff of the Mulago hospital agreed to cooperate in an effort to register all cases of cancer seen at the hospital.
 - Understanding patient volume:
 - A pilot survey was conducted to determine the number of cancer patients by carefully reviewing the outpatient departments.
 - Discovery that patients in whom the clinicians suspected cancer were almost always admitted to the hospital forthwith for a more careful assessment in the wards than was possible in the crowded outpatient departments.
 - Concluding that inpatient registry would include all cancer patients coming to the hospital.
2. How did the Ugandan Cancer Registry evolve over time and what were key items/resources needed at different time points? (Read: Davies JN, Wilson BA, Knowleden J: Cancer in Kampala. A survey in an underdeveloped country. Brit Med J 2:439-445, 1958. Read pages 439-441)
 - Identify cancer-patient volume: Retrospective survey of the hospital records for the years 1952-3, to identify between in-patients all cancer patients coming to the Kampala hospitals.
 - Identify potential for errors: The survey revealed several deficiencies concerning patient information such as missing information about sex, age, tribe, and address; also these details could not be checked with the patients or relatives.
 - The appointment of a Cancer Registrar (B.A.W.) in 1954, with the help of the British Empire Cancer Campaign.
 - Defined roles for the registrar and established procedures for the registration of cases:
 - The duties of the cancer registrar were: regular visits of all the wards and out-patient departments of all the hospitals to obtain the required information and to ensure complete reporting.
 - Clinicians notify cases to the registrar either directly or through sisters, nurses, or orderlies.
 - Clinicians were asked to complete a card giving details on persons seen only as outpatients and not immediately admitted to the wards. This procedure is necessary for follow-ups.
 - The cancer registrar regularly visited all the wards and diagnostic departments of all the hospitals and registered all cases notified by the staff.
 - The cancer registrar notified the social worker of all suspect patients; these were interviewed, and detailed information obtained from them and from relatives.

- The homes of those seen only as outpatients were visited by the social worker as quickly as possible and the homes those of other cancer patients were visited systematically.
 - The clinical details of registered cases are obtained from the notes in the relevant departments
 - Completeness of registration is ensured by regular scrutiny of the histology department records, operation registers, and hospital in-patient records, and of reports submitted by the x-ray department on all tumors seen by them, admission books, ward registers, autopsy reports and medicolegal autopsy
 - Appointment of an African social worker (1956)
 - Directed by the registrar, the social worker interviews out-patients at their homes.
 - Age, sex, tribe, and address (including site, village, county chief's name, type and construction of house, nearest important objects, and how to get to the patient's home) are recorded using an elaborate form. Other contact information is also recorded, such as names and addresses of relatives, children, friends, and the name of the person who looks after the patient when ill at home. This information is used for patient follow-up.
 - Patient's address was used to define whether the patient was a resident of Kyadondo.
 - Defined the variables to be collected by the registry: (1) personal details-name, age, sex, tribe, residence, next of kin, etc.; (2) registration details-hospital, year of registration, hospital number, registry number, ward, clinician, department, etc. ; (3) clinical details and reports; (4) final diagnosis. Every case reported to the registry is recorded in the master register, and the information is also placed on a specially printed analysis card. Microscopical sections, either from biopsy or necropsy, are filed in the registry.
 - Defined which cases to register: Cases were registered only if there was satisfactory evidence of a malignant neoplastic process. If histological diagnosis was not available, the clinical notes were individually reviewed by the Cancer Research Committee (physicians, surgeons, gynecologists, and a radiologist, as well as pathologists).
 - In addition to well-recognized malignant tumors the register includes leukaemias, Hodgkin's disease, adamantinomas, mixed salivary tumors, dermoid tumors, meningiomas, recurring fibromas, Kaposi sarcomas, and developmental tumors of the ovary.
3. What actions were taken for data quality control? (Read "Materials and Methods": Wabinga HR, Namboozee S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. *Int J Cancer*. 2014 Jul 15;135(2):432-9)
- Patient and tumor information are abstracted using notification forms, entered into the registry database using CanReg.
 - Data quality controls are conducted with CanReg: consistency and validity checks, and search for duplicates.
 - Use a systematic coding approach: Tumour topography and morphology were coded according to the 2nd edition of the ICD-O. Data is then converted to ICD-10.
4. What important conclusions do you draw from the incidence data from the Ugandan Cancer Registry? (See Table 1 and Figures 2-4: Wabinga HR, Namboozee S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. *Int J Cancer*. 2014 Jul 15;135(2):432-9)
- Rates of several cancers have been increasing in both sexes:

- For men, prostate cancer, esophageal cancer, nasopharyngeal cancer, non-Hodgkin lymphoma, and leukemia.
 - For women, breast cancer, large bowel (i.e., colon) cancer, lung cancer, liver cancer, and leukemia.
 - For both sexes, rates of cancers of the eye have increased.
 - Declines in cancers rates in men seen for: penile cancer, and bladder cancer.
 - Cervical cancer, the most frequent cancer of women, has increase over the period (1.8% per year), although the rates appear to have declined in the last 4 years.
 - Kaposi sarcoma (KS), a HIV-related cancer, has declined in men until about 2002, and continued relatively constant thereafter. In women, KS has been declining since 2000.
 - Other HIV-related cancers—non-Hodgkin lymphoma of younger adults, and squamous cell carcinoma of conjunctiva—have shown major increases in incidence, although the former (NHL) has shown a small decline in incidence in the most recent 2 years.
5. In what ways would you expect those data to have been used in Uganda to guide health policy? (based on answers from the previous question #3)
- The data from the 2014 paper revealed several trends that have implications for cancer control:
 - Increases in incidence of cancers associated with a “western” lifestyle (breast, prostate, large bowel, lung) are not accompanied by major declines in the cancers traditionally associated with East Africa (oesophageal cancer) or other infection-related cancers (stomach, liver, cervix).
 - Some of these cancers can be caused by a variety of known risk factors, many of them preventable: smoking, excessive alcohol consumption, obesity and physical inactivity, and infections (H. pylori, HPV, and hepatitis B and C viruses).
 - Cancer control activities may be focused on early detection, early diagnosis and treatment, for example cervical and breast cancer.
 - Data from the registry may be use for evaluation of screening programs and access to healthcare.
 - The increasing rates of some cancers suggest increased need for treatment services that those patients will require.

Learning points:

- *Identify essential items/resources needed to establish the registry*
- *Recognize the challenges to maintaining and sustaining a cancer registry*
- *Interpret information on cancer incidence and mortality*

Part II: Developing an Approach

Your second step is to think through the steps of establishing and then maintaining a cancer registry.

[NOTE: This section will focus on the key elements of establishing a cancer registry that were learned over the course as well as the experiences of the Kampala cancer registry.]

1. Although the requirements for a cancer registry depend on the local circumstances with respect to the level of development of medical services (diagnostic, therapeutic, and palliative) for cancer patients, the size and geographical dispersion of the population, and the resources, there are several key aspects that must be met. When planning a registry, it is desirable to (list as many key factors as you can):
 - a. Articulate the purpose of the registry
 - b. Who will take professional responsibility for the registry with other stakeholders and supervising the staff (e.g. Director)?
 - c. Who are the medical specialists concerned with the diagnosis and treatment of cancer (pathologists and radiation, medical, and surgical oncologists)?
 - d. Who are the potential key stakeholders?
 - e. Where is the registry going to be located?
 - f. What is the target population (population coverage)?
 - g. What are the population-denominators (reliable census data)?
 - h. What is the prevalence of cancer in the area?
 - i. What sources of information are available and accessible within the area where cancer patients are diagnosed and cared for?
 - j. Decide what type of registry is feasible (e.g. hospital-based, population-based).
 - k. What methods of data collection will be used (active, passive, mixed)?
 - l. Which variables will be collected?
 - m. Develop a Registry Manual which must include procedures for data registration and coding, and procedures for data quality and assurance.
 - n. Other important factors are: training, equipment, office space, funding, legal basis and confidentiality.

2. Use GLOBOCAN estimates (<http://globocan.iarc.fr>) to obtain information about the burden of cancer in your country, including:
 - a. Overall cancer incidence and mortality rates
 - b. Figure illustrating the top 10 types cancer diagnosis and cancer deaths in men and women
 - c. Projected increase of cancer incidence and mortality by the year 2035
 - d. From the "Data Sources and Methods" tab, obtain the information about data availability for the estimation of incidence and mortality rates in your country

Learning points:

- Name the necessary elements for establishing and maintaining a cancer registry
- Obtain cancer statistics using international databases (GLOBOCAN)

Part III: Making the Case

Your third and final step is to make a strong case for the establishment of a cancer registry to the Minister of Health. You need to convince the Minister of Health that your approach will lead to the establishment of a sustainable cancer registry in your country.

1. Using the GLOBOCAN information obtained in Part II question 2:
 - a. Briefly describe the burden of cancer in your country (2a, 2b)
 - b. Comment on the expected increase/decrease of cancer (2c)
 - c. Comment on the quality of the GLOBOCAN data to justify the need of a cancer registry given that what is known about the burden of cancer is based on estimations from available data (2d). Note: some countries do not have incidence and/or mortality data available.
2. Describe the current cancer control plan of your country.
3. Briefly justify the importance of a cancer registry in cancer control (e.g. focus efforts and limited resources for cancer control activities, need to know who is affected, where, type of cancer, stage at diagnosis).
4. Explain how you plan to involve key players in cancer control in backing the progress and ensuring the sustainability of the registry (think back on the answers to Part I, and Part II question 1).
5. Describe the involvement of non-governmental organizations (NGOs) for cancer control (if any).
6. Given the cost of cancer registration, explain that adequate budget is needed as expenses tend to increase as time goes by.
7. Justify the need of governmental support for the establishment and maintenance of the cancer registry.

Learning points:

- *Apply the principles of cancer registration*
- *Communicate the necessary elements of a cancer registry*
- *Interpret cancer statistics using GLOBOCAN estimates*