Special Communication

Cancer Registration in Low-Resourced Settings: Practice and Recommendations

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SUMMARY

A Cancer Registry is an information system designed for the collection, storage, management, and analysis of data on persons with cancer, usually covering a defined population. Cancer registration is the process of continual, systematic collection of data on the occurrence and characteristics of cancers with the purpose of helping to assess and control the impact of cancer on the community. Compilation of worldwide standardised cancer rates allows the identification of countries and regions where particular tumour types are most common. Such differences usually reflect exposure to distinct causative environmental factors. In addition to providing data on the distribution of cancer disease, descriptive epidemiology provides the basis for prevention, health service planning and resource allocation. The purpose of this paper is to discuss the design and implementation of a population-based cancer registry in resource limited settings. The discussion is based on our experience in Ghana.

Keywords: Ghana; Developing countries; Registries; Africa; Epidemiology; Cancer

INTRODUCTION

Countries require cancer surveillance programmes to collect and analyze data on the scale of the cancer burden. These are urgently needed in Africa as cancer data sources are scarce. Data can help to evaluate the impact of prevention, early detection/ screening, treatment and palliative care programmes. Reducing Ghana's cancer burden is a crucial priority that involves many different professional groups including physicians, researchers, epidemiologists, public health planners, nurses, legislators and medical students. All however require and rely on cancer data in order to best tackle cancer. Cancer registries can provide this type of data and are valuable research tools for those interested in the etiology, diagnosis, and treatment of cancer. Cancer data may also point to environmental risk factors or high risk behaviors, so preventive measures can be taken to reduce the number of cancer cases and resulting deaths. Local and national cancer agencies and cancer control programs can also use registry data from defined areas to make important public health decisions that maximize the effectiveness of limited public health funds, such as the implementation of screening programs. Lifetime follow-up is another important aspect of the cancer registry. Patient follow-up serves as a reminder to physicians and patients to schedule regular clinical examinations and provides accurate survival information. Compilation of worldwide standardised [1] cancer rates allows the identification of countries and regions where particular tumour types are most common. In brief, the importance of cancer registries lies in the fact that they collect accurate and complete cancer data that can be used for cancer control and epidemiological research, public health program planning, and patient care improvement.

Ultimately, all of these activities reduce the burden of cancer. The two common cancer registry types are departmental based cancer registry and population based cancer registry.

DEPARTMENTAL BASED CANCER REGISTRY

The National Center for Radiotherapy and Nuclear Medicine – an Oncology Directorate (OD) of the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana, initiated a departmental-based cancer registry just after its commencement of operations in 2004, using analytic case finding reportability. This reports cancer cases diagnosed and treated at the reporting facility.

The success of the registry compelled the World Health Organisation (WHO) International Agency for Research on Cancer (IARC) to train a cancer registrar (first author) on several occasions to help establish a population-based cancer registry in the country to provide meaningful data for healthcare planning, implementation of intervention programs and development of a national cancer control program which Ghana currently does not have.

POPULATION-BASED CANCER REGISTRY (PBCR)

PBCR records information on cancer patients occurring in a given population (most frequently a defined geography) with an emphasis on epidemiology and public health. The aim is to produce statistics on cancer occurrence; incidence, survival and mortality and also to support research and cancer control programs. Unlike hospital-based cancer registries (HBCR) which focus on individuals and are used for treatment, evaluation and administrative purposes, PBCR focuses on populations and helps to act as a driver for policy development and program evaluation as recommended by WHO.

The following are the preliminary steps in setting up PBCRs: (1) define population size; (2) obtain denominators from official census data (age-specifics); (3) define variables and datasets; (4) define sources of information; (5) establish method of data collection - passive or active, analytic or non-analytic; (6) decide on mode of data collection - electronic versus paper recording; (7) establish quality control procedures; (8) establish administrative framework; (9) establish a legal framework for registration.

DEFINING POPULATION SIZE

In our case, Kumasi has been the first region to have a PBCR (Figure 1). The feasibility and gradual implementation of the Kumasi Cancer Registry (KCR) has compelled us to strategically replicate the design in additional geographical areas of the country. The PBCR is now being further extended to cover the geography of the Ashanti Region of Ghana.

OBTAINING DENOMINATORS FROM OFFICIAL CENSUS DATA

This is an important step for a PBCR. However, we are yet to resolve issues with census data ourselves. Ghana is working on population census and we hope to get accurate statistics in due course. We are currently focusing on data collection.

DEFINING VARIABLES AND DATASETS

The basis of criteria for cancer incidence in five continents are all included in the PBCR. We use the International Classification of Diseases for Oncology, Third Edition (ICD-O-3) coding scheme. The ICD-O is designed to promote international comparability in the collection, processing, classification, and presentation of cancer statistics. ICD-O is the conventional way to translate a medical diagnosis and text into standard codes. This includes providing a format for reporting cancer diagnosis and causes of death on the death certificate. The reported conditions are then translated into medical codes through use of the classification structure and the selection and modification rules contained in the applicable revision of the ICD-O, published by WHO. These coding rules improve the usefulness of cancer statistics by giving preference to certain categories, by consolidating conditions, and by systematically selecting a single cause of death from a reported sequence of conditions. The datasets used for registration cover the following items: patient demographics, tumour data, source of data collection, and follow-up details (Tables 1-4).

DEFINING SOURCES OF INFORMATION

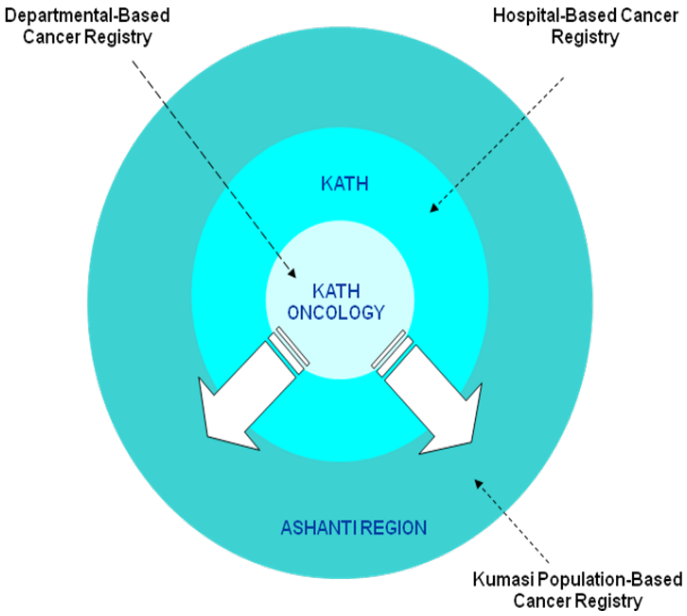

Figure 1. Strategic Structure of Kumasi Population-Based Cancer Registry

Casefinding is the system used to locate every new case of cancer that comes from the area covered by the registry. The identification of all cancer cases is essential to ensure completeness of coverage; therefore cancer cases should be available to the cancer registry databases. Examples of casefinding sources include hospital inpatient departments like oncology, haematology; pathology departments; hospices; and death certificates (Tables 5-6).

In our situation the cancer registry started from the OD - which could be considered as part of a HBCR, and later projected to cover other departments of the hospital thereby making it a HBCR except that only cases within the defined geography were abstracted. The registry is yet to capture cases from other health facilities within the Ashanti Region. The teaching hospital where the registry is located is a tertiary teaching hospital and serves as a referral center for almost all cancer cases diagnosed. OD also serves the middle and northern sectors of the country.

ESTABLISHING METHOD OF DATA COLLECTION - PASSIVE OR ACTIVE, ANALYTIC OR NON-ANALYTIC

The three ways in which cancer cases are found and reported are: (1) Active, where registry staff go out to collect cancer data; (2) Passive, where cancer cases are reported to the registry; and (3) a combination of active and passive.

The cancer registry must be complete in terms of the extent to which all the incident cancer cases occurring in the target population are included in the registry database. If the degree of completeness of registration is low, the rates will be underestimated and there is a possibility of unknown bias. The use of all possible sources is the ideal and the concept of sources and percentage each source contributes to the database must be specified.

KCR currently uses a combination of active and passive analytic case reporting. An analytic cancer case is defined as a case that is diagnosed and treated at the reporting facility; whereas a non-analytic case is diagnosed and treated before admission to reporting facility.

DECIDING ON MODE OF DATA COLLECTION - ELECTRONIC VERSUS PAPER RECORDING

The mode of data collection is an essential part of cancer registration. Our registry uses both hard (paper) and soft copies of notification forms for data management. The cancer data is abstracted on a paper cancer notification form-which is normally done at the casefinding facility. The abstracted data is then coded (mostly done at the cancer registry office) and later entered into an electronic database. Old cases are abstracted and the data updated periodically when new information is available during follow up of cases.

Ideally, notification forms are usually filed after indexing with a cancer registration identification number and stored in a secure room under lock with no unauthorized access. Only registry personnel have access to the electronic database and filing systems. Alternatively, the notification form could be scanned and stored electronically and then shredded as employed in some developed settings.

In short, the registration order is as follows: (1) Abstract; (2) Code; and (3) Record

ABSTRACTION

Abstract is the summary of a medical record for a specific cancer patient. The abstract relates the events leading to the diagnosis of cancer through initial treatment of the identified cancer.

An abstract primarily contains four parts: (1) Demographic; (2) Tumour; (3) Facility/Source: and (4) Follow-up

Table 1. Patient Demographic Data Items

Item	Description
[CANREG ID]	CanReg ID is a unique nine-digit number allocated automatically by the computer during data storage. First four digits represent year. If a patient has more than one tumour, each tumour is given the same CanReg ID by specifying it at the multiple primary section of the program. These primary tumours can be distinguished by primary site, morphology and incident date.
[FIRST NAME]	The patient's first name at the time of registration. Fifteen digits maximum.
[SURNAME]	The patient's surname or family name at the time of registration. Fifteen digits maximum.
[OTHER NAME]	Other name or surname of a female at birth. Initials, abbreviations and nicknames should only be used if the full name is not known. Fifteen digits maximum
[SEX]	Sex is the gender of the patient. If there is no clear evidence as to the patient's sex in the hospital notes, sex should be recorded as unknown; (1) Male, (2) Female, (9) Unknown.
[AGE]	Age is the age at incident of cancer. Age is not a function of time of abstraction. Age is very vital in the analysis of incidence rates.
[DATE OF BIRTH]	The patient's date of birth. It is a key item in cancer data analysis. It enables age at diagnosis to be established for epidemiological and survival analyses. The date of birth is also used to check the central database at the registry for duplications and for cross-referencing purposes. The date field is in a format of DDMMYYYY.
[ETHNICITY]	The ethnic category of the patient as specified by the patient.
[PLACE OF RESIDENCE]	The aim here is to record the patient's usual address at the time of diagnosis with a registrable condition, not any subsequent condition. It is normally a city, town or a village. This field assists epidemiological studies by establishing linkages to an exposure, etc. Address is the usual residence of the patient. Address is essential to identifying residents and non-residents, thus defining an inclusion and exclusion criteria of a case for the registry.
[DISTRICT]	District is the administrative area of the registry population coverage where the place of residence of the patient is located. Districts normally have official census data which is very useful for distributions and measurements of rates.
[OCCUPATION]	The patient's usual occupation. Details of a patient's occupation are recorded for use in epidemiological studies of the influence of social and environmental factors on cancer incidence and survival. The patient's main lifetime occupation is the one most likely to affect the probability of developing or surviving cancer. Good reliable data on main lifetime occupation can be very difficult to collect as patients may have retired or recently changed occupation because of declining health, etc.

A complete abstract contains both text and codes. The text summarizes the cancer patient medical experience and the codes collapse the text into assigned data fields. It is highly recommended that the abstractor or cancer registrar records the text section of the abstract first. Coding should be done from the recorded text.

The abstractor or cancer registrar must have knowledge of: Registry operations; Medical knowledge of cancer (diagnosis and treatment); Knowledge of anatomy; Understand medical terminologies used by clinicians, radiologists, oncologists, surgeons and pathologists; General characteristics of cancer i.e. the ability to identify and code treatment, topography, morphology, behaviour, grade and staging; How cancer spreads to organs and tissues; and How lymphatic system of major organs drain.

Complete and accurate abstract depends on the knowledge and experience of the abstractor, therefore the abstractor's work should be reviewed.

The order of cancer abstraction is as follows: (1)

Table 2: Tumour Data Items

Item	Description
[INCIDENT DATE]	The incident date is the day, month and year the tumour was first diagnosed, whether clinically or microscopically confirmed. It is the date when the cancer was confirmed by the best of the diagnostic tests performed. Incident date is the base for calculating incidence rates, outcome and survival. The date field is in a format of DDMMYYYY.
[BASIS OF DIAGNOSIS]	This field records the eligibility of the tumour for registration and allows derivation of the degree of certainty of diagnosis. Basis of diagnosis records the best method used to confirm the presence of the cancer being reported. It is therefore an indicator of data quality, with microscopic histological verification being viewed as the 'gold standard' for diagnosis. The suggested codes are hierarchal, so that the higher number represents the more valid basis and should thus be used for this purpose. This permits calculation of the number of notifications per case, number of sources per case, and the number of death certificate notifications.
[TOPOGRAPHY]	Topography is the detailed **primary site** of the body where the cancer originated. It is the most important item of data collection. Four-digit ICD-O (3) coding is used and can be referred from the appendices of the ICD-O (3) manual.
[MORPHOLOGY]	The cell type(s) of the malignant disease. Although the topography of the primary tumour is essential, the morphology is an index of the confidence of the diagnosis. The morphology is related to the prognosis and is used to determine the incidence of tumours of different histology and behaviour for epidemiological analysis.
[BEHAVIOUR]	Behaviour is how the tumour behaves. Most benign neoplasms are not life threatening and not registrable. If morphology is coded using ICD-O the fifth digit of the morphology code expresses the behaviour of the tumour. There are certain identifiable stages in the growth of a malignant neoplasm which are represented by behaviour codes. The stage of development of the tumour at the time of diagnosis reflects its clinical behaviour and it is therefore extremely important in establishing the likely prognosis for the patient.
[GRADE]	Grade is how aggressive the tumour is – a measure of how far the tumour is likely to spread. Pathologic testing determines the grade or degree of differentiation of the tumour.
[STAGE]	Stage is how far the tumour has grown and infiltrated other tissues at the time of diagnosis. SEER Summary stage is used as a shorthand or notation to describe the extent of disease. Stage at first diagnosis of the tumour is used to determine treatment, estimate prognosis, to plan and evaluate cancer screening and prevention programs, standardise groupings, and to evaluate and compare results.
[TNM STAGING]	This is the international staging classification published and maintained by the International Union Against Cancer (UICC). The UICC TNM classification used to describe the stage of the tumour and should only be recorded if it is given in the clinical notes or pathology report.

Pathology report; (2) Surgical report; (3) Radiology report; (4) Medical record report

In some registries, national or local legislation determine which, how and when cancer cases will be reported. In order to collect data that are comparable among registries, standards are needed and registry procedures need to be consistent (when defining): Residents and non-residents; Reference data; Diagnostic confirmation; Multiple primaries; and Staging.

All abstractors need to know the standards and definitions that pertain to the registry. The purpose of these standards is to increase the accuracy, quality and comparability of data and its utility.

CODING

After data abstraction with a data notification form, cancer sites are coded for topography (primary sites), morphology (cell type), grade (cancer aggression) and behaviour (tumour behaviour) according to the International Classification of Diseases for

Table 3: Source of Data Collection

[HOSPITAL/PATHOLOGY]	**The main cancer center for which the patient is receiving care or cancer was diagnosed.**
[HOSPITAL/PATHOLOGY NUMBER]	The local number by which the patient is known at a hospital or pathology lab. This may be hospital site specific i.e. there may be different hospital numbers collected for the patient at different points in the pathway.
[UNIT]	A subsection of the main cancer center for which the patient is receiving care or cancer diagnosed.
[LABORATORY NUMBER]	The local number by which the patient is known at this hospital/pathology lab. This may be hospital site specific i.e. there may be different hospital numbers collected for the patient at different points in the pathway.
[TREATMENT]	Type of treatment regimen/modality administered to the patient -with an intention to treat or palliate. The aims to record the first planned treatment given to the patient. **Treatment** is categorized, and demands either **Yes** or **No** as code.

Table 4: Follow-Up Details

[DATE OF LAST CONTACT]	The date of last contact is the day, month and year the patient was last contacted. The date field is in a format of DDMMYYYY. Unknown date of last contact is represented by 99999999.
[PRESENT STATUS]	Vital status of the patient at the time of registration. Survival time is the time between cancer diagnosis and 1. Death if occurred 2. Date when follow-up perform otherwise.
[CAUSE OF DEATH]	Cause of death if patient died from other complications.
[DATE OF DEATH]	The date of death is the day, month and year of cancer case first diagnosed at autopsy which was unsuspected during life. The date field is in a format of DDMMYYYY. Unknown date of death is represented by 99999999.
[AUTOPSY]	Indicates confirmation from autopsy if present status is death.

Oncology.

Geographic location of case addresses are also coded using a list of towns and villages of districts in the Ashanti Region where the KCR covers, using custom developed standard codes featured in the CanReg4 electronic software. These addresses are editable in the "Dictionary" of CanReg4.

STORAGE

Once the data has been coded, it is captured into an electronic database. The registry uses CanReg4 (an acronym for Cancer Registry software version 4), a customized database software designed by the International Agency for Research on Cancer (IARC) for storing cancer data. It is developed and distributed by International Association of Cancer Registries (IACR) in close collaboration with IARC. CanReg4 can be used to code, store, analyze and generate cancer reports for local and international use.

The software requires the use of passwords to allow different levels for users to access, modify or analyse the data. It incorporates data entry, editing, import, export, analysis and backup facilities. It features a search engine used to track down duplicate records and multiple primaries using a probability matching, and consistency checking for impossible or rare cases.

In much more developed settings like the Thames Cancer Registry in the UK, complex software developed by an independent vendor providing detailed characteristics on data items are used. Additionally Picture Archiving and Communication

Table 5: Casefinding

Facility Name: xxxxxxx
Year: xxxx
Expected No. Of Cases: xxx

Case Finding Source	Available (Yes/No)	Reviewed (Yes/No)	Comments
Oncology			
Pathology			
Cytology			
Hematology			
Surgery			
Dermatology			
Gynecology			
Radiology			
Medical Records			
Internal Medicine			
Pediatrics			
Patient Interview			
Clinics			
Hospice			
Death Certificates			

System (PACS), Heath Episode Statistics (HES) and Geographical Information System Software (GIS) etc, are employed from data entry through reporting. Flagging and automated online notification systems are also used where cancer information is securely shared among various facilities and registries over the internet.

CanReg4 on the other hand provides a "one-size-fit-all" cancer data management. It is best suited for countries starting new cancer registries because of its simplicity, flexibility and ease of use. It does however, require official population data and geographical details of area of coverage to establish reports on incidence of cancer.

ESTABLISHING QUALITY CONTROL PROCEDURES

Quality control is the mechanism by which the quality of data can be assessed. To ensure data validity, KCR performs routine checks for accuracy using CanReg4 Edits feature. The registry supervisor performs data quality checks after routine data storage. It is recommended that the Backup file is routinely updated and stored under strict security protected against loss, fire and interference with other files. The following recommendations should guide cancer registry managers:

Data Collection: Cancer notification forms should be locked away immediately after case abstraction. Data abstracted should not be disclosed to other parties other than the data source and the registry. Notification forms should not be left in a place where an unauthorised person might have access. It is highly recommended that data actively collected should be kept under lock and key preferably in a lockable case until they reach the registry.

Access To And Storage Of Data: Cancer notification forms should be locked away and limited access only to authorised persons. Identifiable information is never taken outside the registry. If at all taken out, this is only by the registry manager and strict measures to protect data should be adhered to. Access to the datasets by staff should be at different levels and is controlled by the use of pin codes. Each staff member should adhere to his/her level of access. Only the registry manager has the authority to make changes to the datasets. Information on a paper should be shredded into small pieces before being disposed into a paper bin.

Use And Release Of Data: Matters regarding the release of confidential data should be referred to the registry director. No information should be provided to medical funds, insurance companies, pension schemes, etc. Data sent abroad for international publication should not permit individual identification. A registry code number may be used which should not permit personal identification. Annual reports should be prepared in tabular form or graphs or histograms making individual identification impossible.

ESTABLISHING ADMINISTRATIVE FRAMEWORK

This is yet to be established in our situation, but casefinding facility managers are all considered as

Table 6: Casefinding Sources

Case Finding Source	Year 1	Year 2	...	Year N	Year N+1
Oncology					
Pathology					
Cytology					
Hematology					
Surgery					
Dermatology					
Gynecology					
Radiology					
Medical Records					
Internal Medicine					
Pediatrics					
Clinics					
Death Certificate					
Total Cases					

administrators and are given the privilege to request for information and also contribute to future decision making of the management of the registry.

The cost of running cancer registries increases with time. However a well planned strategic budget should be allocated to allow sustainability, continuity and publications. PBCRs should be simple to present all the essential and mandatory variables, flexible and must be subject to change (ICDO codes and software updates), representative and resourceful in health policy planning, epidemiology and basic research. Cancer Registry budget depends on: (1) size of the population; (2) number of data sources; (3) passive or active data collection; (4) Number of variables to be recorded; (3) number and type of staff – registrars, epidemiologists, etc; (4) equipment; (5) projects and publications.

CANCER REGISTRARS

Cancer registrars are the data management experts who collect cancer data from a variety of sources and report the resulting cancer statistics to various healthcare professionals and agencies.

Cancer registrars' work goes far beyond simply collecting and analysing cancer data. In order to accomplish the goal of preventing and controlling cancer, they also work closely with physicians, administrators, researchers, and health care planners to provide support for cancer program development, ensure compliance of reporting standards, and serve as a valuable resource for cancer information. Cancer registrars should access: local health facilities; available medical care to the population; all sources of information on cancer diagnosis; cooperation and support of medical community; and Support from policy makers and other stakeholders

ESTABLISHING A LEGAL FRAMEWORK FOR REGISTRATION

This is yet to be established in our situation. Data notification is currently voluntary.

But to ensure effective operations and sustainability of the registry, policies and protocols must be developed in order to protect the privacy of individuals while at the same time maximizing the completeness and accuracy of the information reported. A reasonable balance between the protection of privacy and the enhanced use of information for the betterment of the population is needed.

CONCLUSION

The Kumasi PBCR is in the interim being used to evaluate treatment and outcomes; and to assist public health and screening intervention programmes in collaboration with other departments of the teaching hospital. It is worth noting that not all of the steps required to set up a PBCR are completed. Administrative and legal frameworks are yet to be established as cancer notification is voluntary; but as a Chinese proverb goes "keep doing and you will improve as you do".

With standardised and consistent definitions being put in place, data from several registries would be comparable and can be aggregated for an effective central registry which can then act as a driver for policy development and program evaluation for the urgent need of a National Cancer Control Program in Ghana. Cancer registration is a 'pillar' of cancer control programs. [2-3.]

competing conflicts of interest

FOOTNOTES

Conflicts of interest: The authors declare no

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