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Strengthen Cancer Surveillance in Sri Lanka by Implementing Cancer Registry Informatics to Enhance Cancer Registry Data Accuracy, Completeness, and Timeliness

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Abstract

Cancer surveillance is a process of systematic, continuous collection, storage, analysis, interpretation and dissemination of epidemiological information on cancer cases occurring in a particular geographic area. The process of cancer surveillance is also called 'cancer registration'. A system to conduct cancer registration is called 'cancer registry'. The purpose of the project is to implement cancer registry informatics to enhance electronic cancer registry reporting activities that take advantage of emerging health information technology. The expected function of the application is to strengthen the cancer registry data accuracy, completeness, and timeliness. The goals to be achieved are: determine the incidence of cancers with respect to geographic, demographic characteristics; monitor trends and patterns of cancer incidences over time; identify high-risk populations; provide data for epidemiological studies and prioritize health resource allocations.

Keywords:

Registries, Data Collection, Health Information Systems

Introduction

National Cancer Control Programme (NCCP) of Sri Lanka was established in 1980 based on the recommendations made by World Health Organization. NCCP is the national focal point for prevention and control of cancers in the country. The institution is responsible for policy, advocacy, monitoring and evaluation of prevention and control of cancers, conducting surveillance of cancers and facilitating research related to cancer.

Cancer Burden in Sri Lanka

A total of 13,635 new cancer cases had been diagnosed in 2007 [1]. Out of 13,635 new cases, 6,356 were males and 7,279 were females. In 2007 the overall crude cancer incidence rate (CR) was 68.0 per 100,000 population. There were 16,888 new cases diagnosed in 2009 with a CR of 82.6 [2]. In 1985 there were 5,012 new cases with a crude cancer incidence rate (CR) of 31.6 [1]. It is obvious that cancer prevalence is gradually increasing in Sri Lanka. This increase may be due to several reasons [3]. Since a considerable number of government and private health care institutions have started diagnosis and treatment of cancer patients, collection of data from these institutions and statistics related to cancer deaths from death registrars have become absolutely essential to include all these data to fulfill the four quality indicators recommended by the International Agency for Research on Cancer (IARC). They are comparability, completeness, validity and timeliness of information [4].

Importance of Cancer Surveillance

Cancer surveillance provides a quantitative portrait of cancer and its determinants in a defined population. It helps epidemiologists in descriptive studies and analytical studies on cancer [5]. Knowledge of trends in the incidence of cancer over geographical areas may be used for the projection of future incidence rates, case loads, and the need for treatment facilities. It contributes to the management of cancer care programmes to ensure that all patients with a given cancer are given the state-of-the-art diagnosis and treatment.

In cancer surveillance, cancer registries are definitive and unique resources for measuring the cancer burden in a community.

Cancer Registries and Cancer Registration

Cancer registry is a fundamental tool to controlling cancers in a given country. The cancer registry is the office or institution which attempts to collect, store, analyze and interpret data on persons with cancer and cancer registration is defined as the process of continuing systematic collection of data on the occurrences and characteristics of cancer with the purpose of helping assess and control malignancies in the community [6,7]. Cancer registries are an essential part of a complete cancer control program and help in finding etiological factors of cancers primary, secondary and tertiary prevention and monitoring [8,9].

There are three types of cancer registries available globally based on characteristics, purpose, and utility in cancer control. They are:

a) Hospital-based cancer registry (HBCR) [8,9]

b) Pathology-based Cancer Registry [8,9]

c) Population-based cancer registry (PBCR). Cancer information is collected systematically on all reportable neoplasms occurring in a geographically-defined population from multiple sources. These registries have a unique role in planning and evaluating cancer control programs [8,9].

Cancer Surveillance Informatics

The definition of public health informatics is given as the systematic application of information and computer science and technology to public health practice, research, and learning. It is a subdomain of the biomedical or health informatics [10].

Likewise, it is justifiable to use the same terminology in the cancer surveillance informatics domain. Therefore, it deals with the resources, devices, and methods to optimize the acquisition, storage, retrieval and use of information in cancer surveillance practices, research and learning [11].

The tools used in the domain include computers, information and communication systems, clinical guidelines, and formal medical terminologies [11]. Thus, using emerging technology to incorporate automated process and electronic data exchange in cancer surveillance business is an efficient, fast and cost-effective way to obtain quality, accurate and complete cancer registry data as it increases data accuracy, completeness, timeliness, and comparability. It also minimizes manual handling of documents and manual processing of information.

The National Cancer Control Programme (NCCP) has been monitoring trends of cancer since 1985 and has been publishing the national cancer incidence data. Presently, the National Cancer Control Programme collects data (Figure 1) from case-finding sources including,

a) Nine provincial cancer treatment centers. These include Oncology units (9) and oncological surgery units (9). These provincial cancer treatment centers are located in 9 provinces.

b) Sixty-seven Histopathology and Hematology laboratories.

c) Twenty-five Oral and maxillofacial units.

d) Fifteen Government hospitals with specialist care, well woman clinics in Colombo district.

e) Five private sector hospitals and pathology laboratories located in Colombo district. Received data from 05 sources.

f) 42 death registrars' offices located in Colombo district.

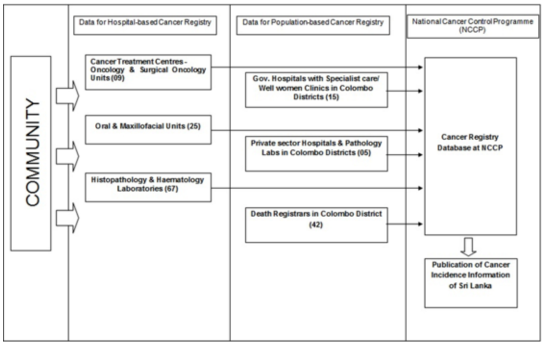


Figure 1. Current cancer registry data flow

Therefore, intended users of the database are the same institutions mentioned above. The current process of cancer registry data gathering from provincial cancer treatment centers as stated above is through an electronic application that was developed by NCCP and installed in a stand-alone desktop computer in each provincial cancer treatment center. The user export data as an excel spreadsheet, which is then sent to the NCCP quarterly. Data received from reminder case-finding sources are based on both paper-based and excel spreadsheets. Data received are then fed into another open source application called CanReg5 [12] for consistency check.

However, with the existing data collection method, the gap between diagnosis of cancer and the availability of data for analysis is significant. As a result, the publication of cancer registry data may reflect information about patients diagnosed more than a couple of years ago. In order to evaluate and react more effectively to trends, there is the need for availability of data on time. Data redundancy is also reported as the same patient attends two clinics in different provinces in the same month. It directly affects the quality, and reliability of data. The issues that are encountered in data gathering process have to be rectified through communication and information technology. Using information technology (IT) in order to shorten all phases of cancer registration process is well documented [13]. Thus, using emerging technology to incorporate automated process and electronic data exchange in cancer surveillance business is an efficient, fast and cost-effective way to obtain quality, accurate and complete cancer registry data as it increases data accuracy, completeness, timeliness, and comparability.

Methods

A web-based cancer registry information management system called Sri Lanka Cancer Registry (SLCR) was designed, developed, and implemented to maintain all reportable cancer cases using web 2.0 technology, open-source software, and mobile technology. Open-source license products were used to decrease the cost for the technical platform and also as a defining factor in terms of profitability. Although there is no clear-cut definition, the term web 2.0 suggests an upgraded and updated version of the web [14]. Web 2.0 is associated with web development and design. It facilitates interactive information sharing, user-centered design, and collaboration on the World Wide Web[13]. The web 2.0 is able to integrate different sources for a real-time cancer registry. The java technology is used as the tool for the web development process. Java is an object-oriented sever-sided programming language and is more suitable for both web and desktop application development and is enabled to write more secure programs [15]. The server is a Linux-based operating system with the Apache as the webserver. The database system for storing information is MySQL, which is multithreaded and multi-user database management system with more than 10 million installations [16]. It is distributed under a GNU General Public License (GPL) and hence has no running cost. The community involvement makes the software development progress to be steady [17]. MySQL can run over 20 operating systems including Linux-based and Windows. Its performance, scalability, and security system have made the system to be used by many large companies world-wide [17].

The software architecture of the Database Management System (DBMS) is client-server architecture. The client-server architecture is considered because this architecture has several advantages (Figure 2).

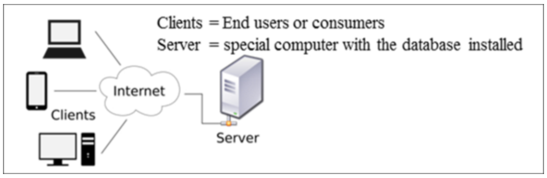


Figure 2. Client-server architecture model

a) Centralization: All the information is stored in a server. Clients can access the database over an authorized access. Every authorized client is given the opportunity to access information via the desktop or laptop interface and tools like spreadsheets. PowerPoint presentations can be used to deal with data with the help of database and application servers resident on the network to produce meaningful information.

b) Scalability: The server where the data are stored can be repaired, replaced, upgraded or relocated while the client or the end users remain unaware and unaffected by that change.

c) Availability: As the server is always turned on, data can be accessed at any time throughout the day and throughout the year.

d) Prevent from data losing: As data is stored on a server it is easy to make a backup. In case of data corruption or data loss, it can be recovered easily and efficiently from backup.

e) Security: Data can be better secured from unauthorized access by defining the permissions at the time of the setup of the server.

There are two models of client-server architecture namely, two-tier and three-tier architecture. From these two options, two-tier architecture is selected for the development of DBMS because it has several advantages over three-tier architecture.

a) Two-tier architecture is easy to maintain.

b) Modification of the database is relatively easy.

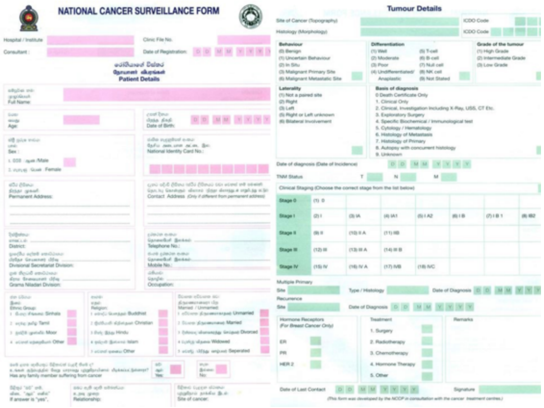
c) Communication between the end user and the database is faster.

d) Development cost is much less than the three-tier architecture.

e) Two-tier architecture is less complex than the three-tier architecture.

The mobile app is used to gather data from death registrars' offices located in Colombo district, Government hospitals with specialist care, well woman clinics in Colombo district, private sector hospitals and pathology laboratories located in Colombo district. As the minimum dataset essential for the cancer registry is collected from these institutions, using of mobile technology is more convenient for them. This method of data collection is greatly supported by the fact that more than 23 million mobile connections exist in 2015 [18]. This figure exceeds the population of Sri Lanka [19].

The process of data collection procedure begins with abstracting data from case-finding sources to a summary sheet, which is designed following several rounds of discussions with stakeholders in order to satisfy their needs yet preserving standard coding and classification procedures and definitions for the population-based cancer registry [21]. It consists of two sections. Section I is related to personal identification and demographic data and is supposed to be completed by the nursing officer of the relevant oncology unit. Furthermore, she can further ascertain data when the patient attends oncology clinic. Section II is related to tumor details and is supposed to be completed by a clinician in relevant oncology unit except ICD-O3 coding. Section II is mostly composed of coded data fields. Just putting the code number in the relevant field is all that is needed. It is expected to improve efficacy on data reporting by releasing extra burden for busy oncology clinicians engaged in registry activities to some extent. Thus the abstracted data in the summary sheet are then transferred to the electronic system by a Data Entry Operator (DEO) through system's web interface. Figure 3 shows the summary sheet to be used for feeding data to the system.



NATIONAL CANCER SURVEILLANCE FORM

Hospital / Institute
Consultant :
Clinic File No.
Date of Registration: D D M M Y Y Y Y

Patient Details

Full Name:
Age:
Date of Birth: D D M M Y Y Y Y
Sex:
1. Male
2. Female
National Identity Card No.:
Permanent Address:
Contact Address (Only if different from permanent address)
District:
Divisional Secretariat Division:
Grama Niladari Division:
Telephone No.:
Mobile No.:
Occupation:

Ethnic Group:
1. Sinhala
2. Tamil
3. Moor
4. Other

Religion:
1. Buddhist
2. Christian
3. Hindu
4. Islam
5. Other

Married / Unmarried:
1. Unmarried
2. Married
3. Divorced
4. Widowed
5. Seperated

Has any family member suffering from cancer
Yes
No
If answer is "yes",
Relationship:
Site of cancer:

Tumour Details

Site of Cancer (Topography) ICDO Code
Histology (Morphology) ICDO Code

Behaviour
(0) Benign
(1) Uncertain Behaviour
(2) In Situ
(3) Malignant Primary Site
(6) Malignant Metastatic Site

Differentiation
(1) Well
(2) Moderate
(3) Poor
(4) Undifferentiated/ Anaplastic
(5) T-cell
(6) B-cell
(7) Null cell
(8) NK cell
(9) Not Stated

Grade of the tumour
(1) High Grade
(2) Intermediate Grade
(3) Low Grade

Laterality
(1) Not a paired site
(2) Right
(3) Left
(5) Right or Left unknown
(6) Bilateral Involvement

Basis of diagnosis
0 Death Certificate Only
1. Clinical Only
2. Clinical, Investigation including X-Ray, USS, CT Etc.
3. Exploratory Surgery
4. Specific Biochemical / Immunological test
5. Cytology / Hematology
6. Histology of Metastasis
7. Histology of Primary
8. Autopsy with concurrent histology
9. Unknown

Date of diagnosis (Date of Incidence) D D M M Y Y Y Y

TNM Status T N M

Clinical Staging (Choose the correct stage from the list below)

Stage 0	(1) 0						
Stage I	(2) I	(3) IA	(4) IA1	(5) I A2	(6) I B	(7) I B 1	(8) IB2
Stage II	(9) II	(10) II A	(11) IIB				
Stage III	(12) III	(13) III A	(14) III B				
Stage IV	(15) IV	(16) IV A	(17) IVB	(18) IVC			

Multiple Primary
Site Type / Histology Date of Diagnosis D D M M Y Y Y Y
Recurrence
Site Date of Diagnosis D D M M Y Y Y Y

Hormone Receptors (For Breast Cancer Only)
ER
PR
HER 2

Treatment
1. Surgery
2. Radiotherapy
3. Chemotherapy
4. Hormone Therapy
5. Other

Remarks

Date of Last Contact D D M M Y Y Y Y
Signature

(This form was developed by the NCCP in consultation with the cancer treatment centres)

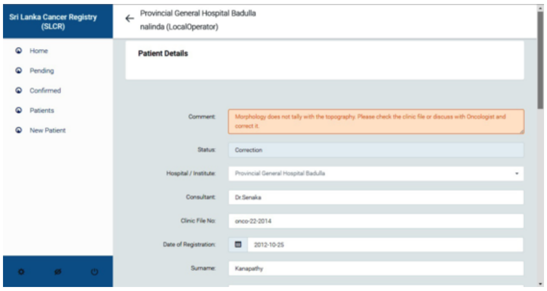
Figure 3. Summary sheets

Results

The intended results to be expected by implementing cancer registry informatics is to enhance cancer registry data completeness, accuracy (or validity), and timeliness as well as comparability. A cancer registry of the modern era is a medical registry and fulfill the standards defined by Drolet and Johnson [22]. The standard explained five features. Data from multiple sources are combined to create an aggregate set of data called mergeable data (M). data such collected are standardized data set (D), in that the same set of characteristics is collected for each patient in the dataset according to the defined set of rules (R). Furthermore, patients in the registry have a unique identifier in order to follow up over time (O), and this helps to assess the occurrence of specific outcomes of interest (k) [22]. It is expected that the new system will fulfilll the criteria of a modern cancer registry.

As the value of any cancer registry relies on the underlying quality of its data and quality control procedures it has in place, the Cancer Incidence in Five Continents (C15) assesses three dimensions of quality to enable the comparison of cancer incidence rate across different population worldwide [23] They are completeness, comparability, and validity (or accuracy). Completeness is defined as the degree to which all diagnosed neoplasms within a registry's catchment population are included in the registry database [23]. The indices of completeness are grouped into historical data, the proportion of cases microscopically verified (MV%), the mortality-to-incidence (M:I) ratio and death certificate method. Historical data are essential to find out the stability of incidence rates over time, to compare with incidence rates in different populations, to prepare age-specific incidence curves and childhood incidence rates [23]. Therefore the system is designed to include case-finding sources that are currently available with the facility for future expansion. The proportion of cases microscopically verified (MV%) is the percentage of cases that were diagnosed on the basis of microscopic verification of a tissue specimen [23]. This includes histologically, cytologically and haematologically confirmed specimens. As the system is able to integrate those data from relevant laboratories further strengthening the completeness. The cause for death due to cancer in death certificates plays a significant role in the completeness of the registry. It helps to track down the cases not captured by other registration procedures. On the other hand, it also helps to find out Mortality-to-Incidence (M:I) ratio. It is an important indicator of completeness [23] where it compares the number of death due to a specific type of cancer over a specific period of time with the number of new cases of that type of cancer registered during the same period [23]. The M:I ratio that is higher than expected raise the suspicion of completeness in that registry. As the data from death registrars' offices are integrated into the system for PBCR not only enhance the completeness but helps in evaluating the quality of the registry.

Data quality is equal to the completeness of data and its accuracy (or validity)[21]. According to the International Standards Organization (ISO) data quality as "the totality of features and characteristics of an entity that bears on its ability to satisfy stated and imply needs" [23]. In the context of a cancer registry, it is defined as the proportion of cases in a dataset recorded as having a given characteristics that truly has that attribute [23]. Accurate or quality data is essential to compare data between registries within a single registry over time and within a single registry with respect to a specific subset of cases [23]. The proposed web-based system accomplishes data accuracy in several ways. The coding standards for neoplasms are maintained using the third edition of the International Classification for Oncology third edition (ICD-O-3) [24]. It provides standardized system for coding the anatomical site of primary tumor (Topography), and its histological type (Morphology) usually obtained from pathology report, its behavior (malignant, benign, in situ, or of uncertain behavior), grade (the extent of the differentiation of the tumor) and the basis of the diagnosis (the method of diagnosis used) [23]. Thus the NCCP act as the database administrator and registry staff review each record in the system carefully and verify ICD-O code against topography, morphology, and behavior and also against sex and age. Coding of neoplasms are done only by them and not the duty of the institution where data have been obtained. If data inconsistency found between demographic data and tumor data in a particular record, For example, retinoblastoma is a malignant disease of the retina, exclusively found in young children. If the record shows the morphology as retinoblastoma but the patient's age as 45 years with the tumor behavior as benign or in another record topography has been recorded as prostate carcinoma for a female patient, then the DEO of the respective data center can be notified through the system by NCCP (registry staff). Then DEO of a particular data center is able to communicate with the clinician in order to rectify them accordingly. Figure 4 shows flagging system

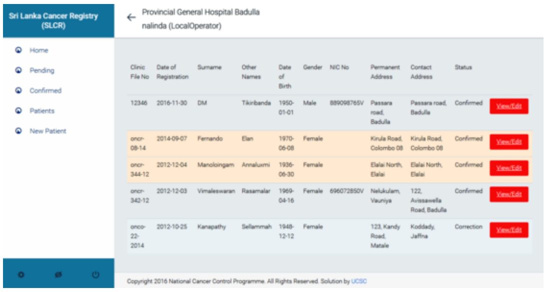


Provincial General Hospital Badulla
nalinda (LocalOperator)

Patient Details

Comment: Morphology does not tally with the topography. Please check the clinic file or discuss with Oncologist and correct it.
Status: Correction
Hospital / Institute: Provincial General Hospital Badulla
Consultant: Dr.Senaka
Clinic File No: onco-22-2014
Date of Registration: 2012-10-25
Surname: Kanapathy

Figure 4. Flagging system with example synthetic patient data.



Provincial General Hospital Badulla
nalinda (LocalOperator)

Clinic File No	Date of Registration	Surname	Other Names	Date of Birth	Gender	NIC No	Permanent Address	Contact Address	Status	
12346	2016-11-30	DM	Tikiribanda	1950-01-01	Male	889098765V	Passara road, Badulla	Passara road, Badulla	Confirmed	View/Edit
oncr-08-14	2014-09-07	Fernando	Elan	1970-06-08	Female		Kirula Road, Colombo 08	Kirula Road, Colombo 08	Confirmed	View/Edit
oncr-344-12	2012-12-04	Manoloingam	Annaluxmi	1936-06-30	Female		Elalai North, Elalai	Elalai North, Elalai	Confirmed	View/Edit
oncr-342-12	2012-12-03	Vimaleswaran	Rasamalar	1969-04-16	Female	696072850V	Nelukulam, Vauniya	122, Avissawella Road, Badulla	Confirmed	View/Edit
onco-22-2014	2012-10-25	Kanapathy	Sellammah	1948-12-12	Female		123, Kandy Road, Matale	Koddady, Jaffna	Correction	View/Edit

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Figure 5. Confirmed data with example synthetic patient data

Thus, the system assists in maintaining data consistency as well as timeliness as the data can be viewed as soon as they are included in the system and ability to correct them as soon as possible. The stand-alone databases currently used to collect data in case-finding sources are unable to fulfill such advantages. Once confirmed by the NCCP a record as a completed record, it is shown as confirmed record in the system (Figure5: image showing confirmed data).

Discussion

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Conclusion

The web-based application will ensure timely availability of information and it will provide accurate, complete and timely registry data to the stakeholders such as health policy makers, researchers, clinicians, and the general population.

Acknowledgments

International Agency for Research on Cancer (IARC), Health Informatics Society of Sri Lanka (HISSL)

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