

Descriptive Paper that Compares the Cancer Registry in Sri Lanka with Australia

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A National Cancer Registry is an information system designed to collect, store, and manage data about cancer patients. Registries play a critical role in cancer surveillance and provide in efforts to reduce the cancer burden. Surveillance data can also be used for cancer research and to plan and evaluate cancer prevention and control interventions.

Cancer registries are data information systems that manage and analyze data on cancer patients and survivors. Cancer registries are maintained to ensure that health officials have accurate and timely information on cancer incidence, under care, and survivorship.

The Journey towards Developing a Cancer Registry in Sri Lanka

The National Cancer Control Programme of Sri Lanka was established in 1980 and initiated a Hospital Based Cancer Registry in 1985 starting cancer surveillance activities with the contribution of three hospitals (Apeksha Hospital Maharagama, Teaching Hospital Karapitiya, and General Hospital Kandy). The first publication was in 1990 for data from 1985. In 2000 data had obtained from 4 treatment centers including Teaching Hospital Anuradhapura.

In addition to the hospital data collection in 2000, initiated a collection of data from pathology laboratories. In 2001-2005 data were obtained from five treatment centers and Provincial General Hospital, Badulla was included. In 2006 data were obtained from six treatment centers including Teaching Hospital Jaffna and also data were obtained from 6 Oral and Maxillofacial (OMF) units.

In 2007 data were obtained from 7 treatment centers, Teaching Hospital Kurunegala was included, and data were included only from histopathology laboratories. In 2009 data were obtained from 9 treatment centers including Teaching Hospital Rathnapura and the Ministry of Health.

In 2019 cancer data was collected from 24 cancer treatment centers. And also, data was obtained from 16 histopathology laboratories, 22 hematology laboratories, and 3 oral pathology laboratories. In addition, data were obtained from 25 OMF centers.

Cancer Registry Information System in Sri Lanka

National Cancer Control Programme (NCCP) maintains the National Cancer Registry of Sri Lanka and the Population-Based Cancer Registry (PBCR) for the capital district of Colombo which are the official sources of cancer incidence data for the country. Population-Based Cancer Registry of Colombo district gets cancer data from pathology labs, cancer treatment centers, hospitals, OMF units and death registries in the district.

The process of cancer registration and data flow is summarized below

1. At the point of diagnosis
 - Histopathology laboratories-about 70
 - Hematology laboratories-about 35
 - Oral Pathology laboratories 3

The data collection instrument will be National Cancer Surveillance Form (H 1256) and the data collection mode will be a paper-based/simple excel sheet. The frequency of sending to NCCP is monthly.

2. At the point of treatment
 - Cancer treatment centers- 25
 - Oral and Maxillofacial units-about 30
 - Other units – i.e., Gastro-Intestinal (GI) Units, Hepato Biliary Units, etc.

Data Collection Instrument Cancer Return Form 1 (H 1290) and the data collection mode Cancer Register 5 software/paper-based. The frequency of sending to NCCP is 6 months after registration.

3. Point of registration of deaths
 - Divisional Death Registrars (Colombo district only). Data Collection Instrument will be Cancer Return Form – 3 and the data collection mode is paper-based. The frequency of sending to NCCP is monthly.

Central Cancer Registry database maintained at the NCCP. The country's cancer incidence data and producing a report from the National Cancer Registry will be analyzed here. Filtering patients with permanent addresses in the Colombo district and data analysis and producing a report on PBCR Colombo will be also done here.

The National Cancer Registry contains information on the so-

ocio-demographic characteristics of cancer patients, cancer site/cell type, staging of cancer, information about the patients' hospital stay and the name of the patient's treating doctor and the place of treatment. Information about the number of cancer cases and deaths from each cancer is also registered there.

The Journey towards Developing a Cancer Registry in Queensland, Australia

The Queensland Cancer Registry (QCR), Australia maintains a register of all cases of cancer diagnosed in Queensland since 1982 (excluding basal and squamous cell carcinomas) and now it operates under the Public Health Act (PHA) 2005, where notification of cancer is a statutory requirement. The QCR is one of the largest Population-Based Cancer Registries (PBCR) in Australia and is a unique data resource with a comprehensive set of cancer data elements that provide an accurate picture of the impact of cancer, its nature and the extent of cancer throughout Queensland, Australia.

General information collected about patients with cancer in Queensland in the QCR is as follows;

- Name and address
- Date of birth
- Country of birth
- Cancer site and cell type
- Medicare number
- Marital status
- Aboriginal and Torres Strait Islander descent
- Information about the patient's hospital stay
- Where the patient was treated and their doctor

Queensland Cancer Register is housed in a secured office only accessible by Cancer Alliance Queensland staff and approved visitors. Individuals can apply for access to documents held by the Queensland Government under the Right to Information Act 2009. The information Privacy Act 2009, details privacy principles and allows clients to apply for access and amendment of personal information.

The Cancer Alliance Queensland on behalf of Metro South Hospital and Health Service manages the operation of the Register/s for the Queensland Department of Health and provided ample opportunity for following activities;

- Monitor the number of new cancer cases and deaths from cancer in Queensland
- Assist in planning for the care of cancer patients in Queensland
- Monitor and evaluate the quality of cancer treatment and the outcomes of cancer care
- Provide data for research to determine the cause of cancer and to improve the quality of cancer services
- Contribute to national monitoring of cancer cases and cancer deaths
- Develop education programmes to educate our community on the risks of cancer

Cancer Registry Information System in Queensland, Australia More than 90% of cancer notifications are now being received electronically. Notification of cancer is a statutory requirement for all public and private hospitals, nursing homes and pathology services throughout Queensland, Australia and specifications for different types of notifiers (i.e. public hospitals, private hospitals, public/private pathology laboratories and public and private nursing homes) submitting electronic can-

cer notifications are mildly varied from each other. Data on all persons who die of cancer or cancer patients, who die of other diseases are abstracted from the mortality files of the Registrar of Births, Deaths and Marriages and linked to hospital and pathology data.

More than 60% of cancer notifications are from pathology, which is a major contributor to the validity of cancer incidence. The pathology report is, in the majority of cases, the initial identification of a cancer patient, making the pathology report a key data source. Receiving pathology information electronically makes a significant impact on; improving the timeliness of cancer reporting, the manual handling currently required to process the cancer data, and missing pathology cancer notifications.

Since early 2002, the register has been receiving data electronically on a monthly basis from all public hospitals in Queensland. Notifying cancer electronically is also available for private hospitals. However, some private hospitals are utilized different electronic systems and each system has unique functionality and specifications for notifying cancer Registry in Queensland, Australia.

Small private hospitals don't have the functionality to send cancer notifications electronically but can notify on the standard paper notification form, rather than in the electronic format. The hard copy of the cancer notification can be downloaded free from the QCR Notification form and sent to QCR@health.qld.gov.au. Information about the number of cancer cases and deaths from cancer is registered in the QCR.

Each request for data access is assessed by the data custodian against legislation and privacy laws. These procedures are in place to protect personal information recorded in the register from breaches of privacy as well as ensure ethical integrity and scientific merit of proposals seeking data access. QCCAT has developed a sophisticated data collection application known as QOOL-R. QOOL-R electronically collects and collates information for the QCR. All information sent to the register is kept strictly confidential and held under tight security.

One advantage of the Queensland, Australia cancer registry is invitations are directly sent to clients for some routine cancer screening programmes by the National Cancer Screening registry (i.e., breast cancer screening, cervical cancer screening and bowel cancer screening) and sending a reminder letter to anyone who doesn't complete their screening test within 6 weeks of receiving it.

In addition, it will send reminders to the people with positive results for their follow-up test This ensures that the programme is consistent with the National Health and Medical Research Council (NHMRC) clinical guidelines recommend routine screening for a specific age. On the other way, Sri Lankan cervical cancer screening routine invitations are done by Public Health Midwives (PHMM) through the field-eligible couple register and there is no direct invitation system through the National Cancer registry.

In conclusion, Cancer Registry and Cancer Registry Information System in Sri Lanka is much similar to the Cancer Registry and Cancer Registry Information System in Queensland, Australia.

In Sri Lanka mainly the data collection mode is paper-based, while in Queensland, Australia more than 90% of notifications are done electronically. So far, no application similar to QOOL-R in Queensland was developed in Sri Lanka to collect

and collates information electronically for the Sri Lankan cancer registry. In addition, there is an opportunity to contact the National Cancer Screening Registry by clients and update their contact details online in Queensland, Australia.