

# Siriraj Cancer Registry Method

**Kulwantip Neovakul, M.Sc.**

*Siriraj Cancer Center, Faculty of Medicine Siriraj Hospital, Mahidol University, Bangkok 10700, Thailand.*

**Siriraj Med J 2006; 58: 1057-1060**

**E-journal: <http://www.sirirajmedj.com>**

## **P**urpose of the cancer registry

The purpose of cancer registration in Siriraj Hospital is to help assess and control the impact of malignancy in the community. Siriraj Hospital registry has primarily been concerned with the improvement of the care for cancer patients seen in the hospital and with evaluations of treatments.

This hospital-based registry has also been concerned with cancer patients in the hospital and to assess the dimensions of cancer problems as well the number of diagnosis per year and relative frequency of cancer by site. This will contribute to show the time, trends in ratio of early and late stage at the time of diagnosis, and patient care in active follow-up, describes the length and quality of survival related to the site, stage and treatment. It also contributes to professional education, clinical research in the evaluation of therapy and identifies group of high and low relative frequency of certain cancers. The other important contribution of our hospital-based cancer registry is to help in assess the quality of hospital care and cancer services in the hospital as well as to help in planning the hospital facilities.

Those who are interested in a particular form of malignant neoplasm may set up special or ad hoc tumor registries, such as those for breast cancer, colon cancer, or lung cancer, etc. Unlike the comprehensive cancer registration, they are generally conceived as short-term programs.

## **Planning of cancer registration**

In the planning of cancer registration, we have been in discussion with members of the medical profession, and the possible benefits in the management of cancer patients. In practice, our registry is run by a core of full-time staff with some part-timers. We begin with simply and to consider first the basic needs of a cancer patient information system, the flow of information within the hospital, the kind of information routinely available and the completeness of information required by the cancer registry.

The advisory committee is important during the planning stage in order to facilitate establishment of a registry. The advisory committee helps to facilitate access to relevant data such as medical records, pathological records, and death certificates as well as improve and approve access to registry data by the medical profession and appropriate research workers, and also approve reports of the cancer registry prior to their publication.

Siriraj cancer registry began in the X-ray Department in 2471BE (AD 1928) it had one advisory medical doctor

and one part-time nurse working together. It was set up in the X-ray Department after the Department was donated a 230 kv therapeutic X-ray machine of 16,000.00 bath by His Royal Highness Prince Chulchakrapongs.

At present, the cancer registry has 30 medical doctors from various service departments as members of the advisory committee in which one medical doctor serves as a full time staff member and 6 clerks. The personnel of our registry can be divided into two groups: medical and technical. The medical staff includes a medical director and various consultants from all clinical departments in the hospital. The technical staff includes a registrar who is responsible for operation registry, including supervisory staff, preparation of reports and evaluation of the results. The record clerks and statistical clerks who are concerned with coding patient information and processing tumor records. In our registry, record clerks also do coding, data verification and data entry into the data bank.

As for the equipment, from our start in 2471 BE (AD 1928) we had no equipment. We recorded our cancer information into our summary cards and then collected them for analysis in a wooden cabinet. At present, we have all basic needs for our works. These include a room with normal office equipment such as desks, chairs, telephones, desktop computers, not to mention documental archive, and space for files.

## **Patient information need for registration**

The information needed by a cancer registry is directly related to its functions. Our hospital registry is primarily concerned with the cancer cases in the hospital. The minimal information for any cancer registry are summarized into three categories, namely:

### **1 Personal identification:**

Name:  
Sex:  
Age:  
Date of birth:

### **2 Demographic:**

Address:  
Ethnicity:

### **3 Tumor:**

Site (topography):  
Histology (morphology):  
Incidence date:  
Most valid diagnosis:

The number of items of information has subsequently been enlarged by adding further items from the core. We know that each additional item of information collected

increases the cost of registration. Thus, for each item of the registry added, we ask our self: “Do we need it?” rather than: “Would we like to have it?”

As one can see the item of minimal information described comprises of two groups, concerning the patient and the tumor. The first consists of personal identification together with some demographic information, while the second, the site, histology, incidence date and most valid basis of diagnosis of cancer.

### Sources of patient information

Our sources of information for hospital registry are found in the Outpatient and Inpatient Departments and in the Department of Laboratory. The main source is the Department of Medical Records.

The basic requirement for hospital cancer registry is a functioning Department of Medical Records. There should be a medical record for each patient, containing all relevant aspects of diagnosis and treatment. Such records are kept in a single Department of Medical Records. In some hospitals, however, each specialized service may keep its own records, thus increases the difficulty in registration process.

The pathology service is the most important source of information, since it examines the tissue that permits prediction of whether or not a tumor is likely to behave in a malignant fashion. The file of pathology service usually contains the most complete information on the histopatho-

logical nature of the neoplasm.

The Department of Radiotherapy usually treats a large number of cancer patients, and precise information is kept based on the type of treatment, mode of application and dosage. Such a service was formed the nucleus of our cancer center in the beginning of the cancer registry center.

The Outpatient Department also treats a large number of cancer patients in various specialized services. Many of such patients are found out by means of pathology report which the pathology studies were performed elsewhere; they are also required to be registered into hospital registry.

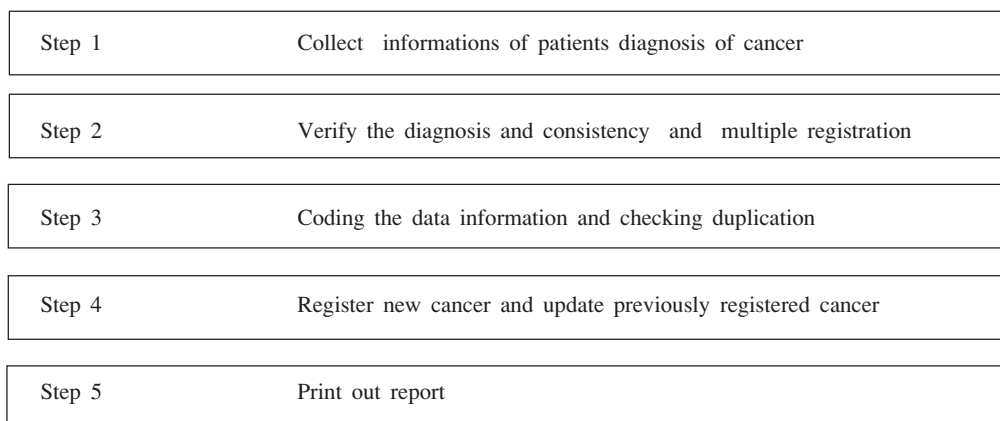
The other specialized services include Surgery, Gynecology, Obstetrics, Paediatrics, Orthopaedics, Urology, Dermatology, Neurology, Ophthalmology, Oto-rhino-laryngology, Endocrinology, Haematology, Biochemistry and Immunology. All these services can encounter cancer cases. The information of these cancer patients can be collected and registered into the hospital registry.

The identification of all cancer cases is essential to ensure the completeness of the coverage. In order to identify all reportable cases, the registry staff of all departments should check the information on cancer patients regularly and report to the cancer registry service. The cancer registry services have a cancer registry abstract form which is a summary of information on a cancer patient, including their tumor. This abstract form is completed by the registry staff of the center. An example of a cancer registry abstract form is given below.

| SIRIRAJ CANCER CENTER                                                                                                                                                                                                                                                    |  |                |  |              |  |              |  |                |  |                 |  |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|----------------|--|--------------|--|--------------|--|----------------|--|-----------------|--|
| DATE.....                                                                                                                                                                                                                                                                |  | HN .....       |  | SN .....     |  | RT _NO ..... |  | POSTCODE ..... |  |                 |  |
| NAME.....                                                                                                                                                                                                                                                                |  |                |  |              |  | SURNAME..... |  |                |  |                 |  |
| ID.....                                                                                                                                                                                                                                                                  |  | AGE.....       |  | SEX.....     |  | SMDW.....    |  | RACE.....      |  | RELIG.....      |  |
| OCCUP.....                                                                                                                                                                                                                                                               |  | BDATE.....     |  |              |  |              |  |                |  |                 |  |
| ADDRESS.....                                                                                                                                                                                                                                                             |  |                |  |              |  |              |  | MOO.....       |  |                 |  |
| TUMBOL.....                                                                                                                                                                                                                                                              |  |                |  | AMPUR.....   |  |              |  | CHANGVAT.....  |  |                 |  |
| ACODE .....                                                                                                                                                                                                                                                              |  |                |  |              |  |              |  |                |  |                 |  |
| DIAG.....                                                                                                                                                                                                                                                                |  |                |  | SITE.....    |  |              |  | DCODE .....    |  |                 |  |
| PATHO.....                                                                                                                                                                                                                                                               |  |                |  | GRADE.....   |  | GROSS.....   |  | SIZE.....      |  | PCODE .....     |  |
| INVASION.....                                                                                                                                                                                                                                                            |  |                |  | NODE.....    |  | METAS.....   |  | TNM.....       |  | STAGE .....     |  |
| TREAT_SU....                                                                                                                                                                                                                                                             |  | TREAT_RT... .. |  | TREAT_CT ... |  | TREAT_HO ... |  | TREAT_IM ...   |  | TREAT_OTHER ... |  |
| TREAT_UNK ...                                                                                                                                                                                                                                                            |  |                |  |              |  |              |  |                |  |                 |  |
| LASTSEEN .....                                                                                                                                                                                                                                                           |  |                |  | STATUS ..... |  |              |  | COMMENT .....  |  |                 |  |
| Occupation : 1 = farming, 2 = fishing, 3 = housewife, 4 = business, 5 = officer, 6 = employee, 7 = priest, 8 = labour, 9 = unoccup, 0 = unknown<br>Race : 1 = Thai, 2 = Chinese, 3 = others, 0 = unknown<br>Religious : 1 = Buddhist, 2 = Islam, 3 = others, 0 = unknown |  |                |  |              |  |              |  |                |  |                 |  |

### Data management

Data management can be divided into 5 steps as shown in the diagram



**Step 1** With co-operation of various service departments by notifying or supplying information of patients diagnosed of cancer either confirmed or not to the cancer center. The cancer center will thoroughly check the medical records of the patients for correct diagnosis.

Review medical record of provision diagnosis of cancer from various service departments

If confirm ..... accept

If not confirm ..... reject

If not yet final ..... hold for final diagnosis

**Step 2** After inspection for completeness and consistency of document coming to the registry. If accepted, the next step is to decide if they relate to a person or tumor previously registered. If not, the cancer is accepted for coding.

If accept

-Inspection for completeness of the require information.....If not complete.....hold

-Inspection for the consistency of diagnosis with sex, with age, with site, and with histology

if inconsistency.....hold and verify for the correct diagnosis

-Check for multiple registration from several service department if yes ..., cancel the duplicate

-Accept for coding the information

**Step 3** Coding the information into abstract form

In the coding of information the non-medical terms are coded by a clerk, the medical terms are coded by a medical doctor or the registrar. After abstracting and coding, an independent checking is made to ensure that all the necessary terms and correct codes have been entered into their appropriate places.

Coding begins when there are no apparent errors or inconsistency in the data. It must be realized that it may be necessary to re-code during the updating of the information.

Multiple registrations may be discovered at any stage in registry operation from identification of new patients and tumors. When duplication is discovered, all existing documents for the case must be drawn together in order to update one tumor record and cancel the others.

The registry will reject cases that give clinical diagnosis of a cancer but the histology report after examining the lesion denies this diagnosis.

Coding the data information

-Non medical term code by clerk

-Medical term code by medical doctor or registrar

**Step 4** Input information data into the databank

Input data

- Input the information from abstract form into databank by clerk

#### **Step 5** Output report

Reporting of data collected is one of the most important functions of registry. A report from the registry is prepared with guidance of a physician in order to assure proper content and balance. Registry reports are distributed to all members of the medical staff. The reports are also made available to the administrators and to the allied health professional in the hospital who may benefit from the information.

Every year since 1969, the Cancer Registry Center of Siriraj Hospital has printed out annual cancer registry report. It also prints out summary reports of the hospital based on cancer registries between 1990-1999 and summary reports of cancer registry between 2000-2004. All these reports are distributed to the administrators and to all service departments in Siriraj Hospital, and to Ministry of Public Health as well as all cancer centers throughout the country.

The Cancer Registry Center has been reporting the outcomes of some interesting cancers treated at Siriraj Hospital by active follow-up, these are: Follow - up reports of liver cancer, lung cancer, nasopharynx cancer. Several interesting cancers are being processed the follow-up results; these are cancer of the oesophagus, tongue, tonsils, pyriform sinus and cervix.