

# National Cancer Registry Programme

The Indian Council of Medical Research initiated a network of cancer registries across the country under the National Cancer Registry Programme (NCRP) in December 1981. This move followed the recognition that there was an urgent need for strengthening the existing cancer registries and organization of new cancer registries in different regions of the country.

## **The programme was commenced with the following objectives:**

1. To generate reliable data on the magnitude and patterns of cancer - this would be based on morbidity and mortality rates in different regions of the country including incidence rates according to sex, age and residence of the patient, anatomical site of cancer and proportion of histological type or microscopic confirmation for each site; pattern of different types of cancer according to relative proportions or ratios in various population sub-groups such as religion, language spoken, educational status; clinical stage of disease when patients come to hospital for treatment and where possible the nature of treatment received and outcome;
2. To undertake epidemiological studies in the form of case control or cohort studies based on observations of registry data;
3. Provide research base for developing appropriate strategies to aid in National Cancer Control Programme; this would be in the form of planning, monitoring and evaluation of activities under this programme;
4. Develop human resource in cancer registration and epidemiology.

Data collection commenced from 1 January 1982 in the population based cancer registries at Bangalore, Chennai and Mumbai, and in the Hospital Based Cancer Registries at Chandigarh, Dibrugarh and Thiruvananthapuram. From 1986 two more urban population based cancer registries were started in Delhi and Bhopal. For the first time a population based rural cancer registry was also started by the ICMR during the subsequent year (1987) in Barshi in the state of Maharashtra.

In order to extend the assessment of cancer patient care, Hospital Based Cancer Registries were also started at Bangalore, Chennai and Mumbai in 1984.

The NCRP is a long-term activity of the Indian Council of Medical Research. The programme is one of the many major activities of the Division of Non-Communicable Diseases. The Chief of the Division is the Director of the Programme with a Project officer who coordinates the activities through the Coordinating Unit. Dr Usha K. Luthra who was the then Chief of the Division and Dr L.D. Sanghvi who was the first Project Officer were the founder members. The Programme is assisted by a Steering Committee that meets periodically to oversee and guide its functioning. A review meeting is held annually where the Principal Investigators and staff of the registries, under the NCRP, present data and participate in the discussions.

Cancer registration is active in that staff of registries visit hospitals on routine basis and scrutinise the records in various departments that include pathology, radiology, radiotherapy, in-patient wards and out-patient clinics to elicit the desired information on reported cancer cases. The hospitals include the main cancer hospitals, other general hospitals in both the government and private sector. Besides pathology laboratories that routinely report cancer cases are also visited. Death certificates are also scrutinised from the municipal corporation units. Every attempt is made by registries to register all cancer patients in the registration area who are resident (at least one year) in the area in all hospitals and copy all death certificates in which cancer is mentioned.

Cancer registries collect information on cancers reported in a prescribed format with specified guidelines and the data so collected is entered on a computer. All registries are required to register all malignant neoplasms coded as per the International Classification of Diseases for Oncology (ICD-O) with a behaviour code /3 (WHO, 1975,76). Besides identifying information and duration of stay at the permanent place of residence they also collect information on educational status, religion, language spoken, method of arriving at a final diagnosis of cancer, extent of disease at the time of diagnosis and mode of treatment(s) given up to six months of diagnosis.

Certain basic checks of data especially those related to duplicate verification and matching with mortality records are carried out by the individual registries. After this, the data is sent to the Coordinating Unit for subjecting the data to various range, consistency and unlikely combinations including a further round of possible duplicate listing. The list of cases with the items of patient information, that requires verification are sent to the respective registries by the Coordinating Unit. Individual registries go through the records/reports of such cases and wherever necessary discuss with the concerned clinician or the pathologist. On receiving the clarifications, the Coordinating Unit prepares the detailed tabulations by five-year age group, site and sex including rates. The individual registries use these tables to prepare the registry's annual report. The Coordinating Unit collates the data and tables to prepare the consolidated report of that year.

A workshop is held annually, with the objectives of discussing the various aspects of working of the registry, problematic cases, use of coding and discussion on medical terminology, statistical and epidemiological methods. About 2-3 senior and junior staff of all the registries under the NCRP, participate in the workshop.

Apart from the above the Coordinating Unit undertakes and coordinates epidemiological and other research studies including those to ensure that the quality of data is of a high standard and that coverage of cancer cases in the registry area is as complete as possible. Recently a population based cancer survey was done in selected defined divisions within the registry areas in Bangalore, Chennai and Mumbai. The results revealed that the proportion of coverage of cancer cases by the registry was 71.8% in Bangalore, 100% in Chennai and 78% in Mumbai (NCRP Report, 1999).

An inter-registry panel of pathologists was constituted to study histological features that correlate with prognosis in cancer of the breast. This was completed and the results showed that clinical extent of disease, vascular invasion and involvement of nipple/areola/skin of breast were the factors that significantly influenced survival (NCRP Report 2000).

To determine the association if any between a history of vasectomy and cancer of the prostate a multi-registry case control study is underway and collection of data on cases and controls is just complete. A case control study on cancer of the gall bladder in Delhi is also going on. The WHO is supporting a project on Development of an Atlas of Cancer in India, through networking of pathology departments of medical colleges, cancer centres and major hospitals across the country.

Over the years, staff from registries under the NCRP, have benefited from both short and long term training fellowships in established institutions abroad. This has helped them and the registries to develop into departments of epidemiology and undertake several studies on their own, and contribute to several research publications in indexed journals. The NCRP and the registries also regularly contribute to the succeeding volumes of Cancer Incidence in Five Continents published by the International Agency for Research on Cancer, which is the cancer research arm of the World Health Organization. Among the more important contributions from the registries is the exercise on population based survival in selected sites of cancer. This was published for the first time in the context of a developing country.

The detailed tabulation of the respective registries' data is given in the latter part of this report.

# HOSPITAL BASED CANCER REGISTRIES AND THEIR ROLE IN THE INDIAN CONTEXT - AN OVERVIEW

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**Objectives of Hospital Based Cancer Registries (HBCRs) have been as follows (MacLennan *et al*, 1978; Young JL, 1991):**

**1. GENERAL:**

- 1.1 Assess patient care;
- 1.2 Participate in clinical research to evaluate therapy;
- 1.3 Provide an idea of the patterns of cancer in the area;
- 1.4 Help plan hospital facilities.

**2. SPECIFIC:**

- 2.1 Contribute to active follow-up of the cancer patient;
- 2.2 Describe length and quality of survival in relation to anatomical site, clinical stage and treatment;
- 2.3 Contribute to the Population Based Cancer Registries (PBCRs) in the given area;
- 2.4 Undertake epidemiological research through short-term case control studies;
- 2.5 Show time trends in proportion of early to late stages at time of diagnosis;
- 2.6 Help assess quality of hospital care and cancer services in covered area.

The HBCRs have over the years given an assessment of the magnitude and patterns of cancer in the region being catered by the centre/registry. They have also contributed to the PBCR of the area. HBCRs have also conducted several case control studies. However, in terms of assessing patient care - follow-up by registries has been difficult and in the absence of follow-up of the majority of cases registered by the HBCR, obtaining clinical stage and treatment based survival has not been possible.

## **Assessment of Magnitude of Problem**

A general way of assessing the dimension of the cancer problem in a given cancer hospital/centre is the number of cancer diagnoses per year in the concerned hospital. This gives one measure of the quantum of patients attending that hospital.

In the Indian context, there is a need to suffix this 'quantum' with several additional aspects.

Though the cancer hospitals/centres may cater exclusively to cancer patients, all patients registered and investigated are not proved to have cancer. Thus, patients are referred to the cancer centre on only a clinical suspicion 'to rule out malignancy' as well as on a radiological or cytological suspicion 'to confirm malignancy'. Thus, the number or 'quantum' of patients who eventually are proved not to have cancer as well as those patients who do not have malignancy as on date, but need to be followed up have also to be considered as magnitude of work (in terms of clinical work-up and number of investigations) by the centre.

Still other patients who have had a biopsy diagnosis may be referred for any further investigations if required, followed by treatment. Patients who have undergone partial or complete treatment would also be referred for further treatment, which may include pain relief and palliation. Finally, for various reasons, patients diagnosed as cancer in the cancer hospital may or may not undergo the required treatment.

Therefore, the number of new cancer cases recorded in a hospital cancer registry in India is just one measure of the patient load of the cancer centre. Other measures would be the number of diagnostic procedures done and number of types of treatment given.

Besides the above, previously diagnosed and/or treated patients would attend the centre for further investigations/treatment.

### **Role in Assessing Patient Care**

The primary concern of the hospital registry is the cancer patient in the hospital (Maclennan *et al*, 1978). Patient follow-up and compliance are two critical factors in evaluation of patient care (Nandakumar A., 1993). Therefore, in the Indian context, the assessment has to be by both direct and indirect means.

#### **Direct means**

A hospital registry can contribute to assessment, monitoring and evaluation of patient care in several ways. A direct way of knowing this, is the length and quality of survival including disease free survival in relation to site of cancer, its stage at presentation and outcome of specific treatment measures pursued in the hospital.

#### **Indirect means**

In the absence of the above, particularly in the Indian context, indirect measures of patient care, could be:

- *The average time taken for diagnosis to be established:* this is the interval between date of initial registration (first visit to hospital) and date of final diagnosis;
- *The period that has elapsed in commencing treatment:* this is the interval between date of final diagnosis and date of commencement of cancer directed treatment;
- *Lost for Follow-up:* The number and proportion of patients who are lost at different levels or states of investigation/diagnosis; this includes patients registered and lost before completing investigations and those lost after a diagnosis of cancer but before treatment.
- *Compliance with treatment:* The number and proportion of patients who receive and those who do complete the prescribed treatment.
- *Assessment of disease and response to treatment:* Among those who have completed treatment, the number and proportion of patients who revisit for assessment of their disease and response to treatment; this would also include the proportion that have disease free survival and the length thereof.

The end-point for follow-up of a hospital registry is death of the patient. Details of cause of death are necessary for survival analysis and evaluation of treatment. The hospital cancer registry has an important role in correctly obtaining the cause of death, particularly those deaths that occur in the hospital where the registry is located. This includes the disease status at the time of death and whether death was directly due to the site of cancer in question. If this is not the case, then the exact cause of death, whether other disease or treatment related complication led to the death is stated. If the cause of death was cancer, then, the anatomic site (and sub-site when relevant) as well as the detailed microscopic diagnosis should be indicated.

### **Diagnostic Correlation and Clinical Application**

The details of diagnostic and treatment information, gathered by a hospital registry ought to be more thorough and comprehensive, than for a population based cancer registry.

Thus, the details of various methods adopted in making a final diagnosis are clearly mentioned. If more than one method of investigation has been done to arrive at a diagnosis, correlation between the methods of diagnosis is essential. For example, this could be between radiological and pathological diagnoses or even within the different radiological and/or pathological investigations, such as ultrasound versus CT scan for radiological investigations and cytology versus histopathology for pathological investigations.

Ideally, recording of the clinical extent or staging of cancer including pathological staging is standardised, complete and correct with minimal inter-observer variation. As in investigations, if more than one department has examined the patient and the patient has undergone further investigations or surgery which has resulted in change of the 'Stage' of cancer, this latter would be meticulously recorded.

The details of performance status, which provides information on the general condition of the patient before and at the end of treatment, are also clearly recorded.

Other items that are generally required in ensuring completeness of clinical information include response of disease to treatment at every follow-up. In addition, the various surgical procedures/techniques used, the radiotherapy dose, fractions, time frame, field size etc. The schedule of chemotherapy and hormone therapy wherever given, assume importance when analysis of outcome of treatment is carried out. Details of complications, if any, whether due to disease or treatment thereof contributes to proper assessment of disease free survival and quality of life.

It is important for the hospital cancer registry to know whether in diagnosing and assessment of staging, internationally accepted standardised system is being followed for that specific site. So also, the registry needs to know whether treatments instituted are protocol based or modified to apply to Indian conditions. This would be a prelude to commencing clinical trials.

### **Role in Cancer Control**

Hospital Based Cancer Registries help in assessing the quality of cancer care in the hospital, not in the region. But, as in most situations in India, if the hospital cancer registry is located in a regional cancer

centre the data does, to some extent reflect the patterns of cancer in the region as well as the impact, if any, of cancer control measures including that of treatment provided by the centre. Therefore, the hospital cancer registry should also indicate time trends in ratio of early to late stages at time of diagnosis. While this may not straightaway show the impact of prevention measures in the community, nonetheless, it would indicate the degree of awareness of the public that visit the hospital from different areas of the region. For example, a decrease in the proportion of late stage cancers of the cervix with a corresponding increase in the proportion of those with early stage does give a positive indication of cancer control measures in the region. Another function of the hospital cancer registry is its participation in clinical research to evaluate treatment protocols or in clinical trials.

### **Role in Health Services Research**

One other major contribution of the hospital registries is in Health Services Research in terms of planning hospital facilities, in assessing quality of cancer care available in the region and the contribution to professional education.

Based on the number and proportions of cases obtained through indirect means stated above, one area of health services research involves looking into factors as to why the 'optimum' care cannot be delivered, what can be done about correcting it and observing the trends in proportions over time. The cost-benefit as well as future planning is closely dependent on looking into these aspects.

### **Conduct of case-control studies**

Hospital Based Cancer Registries, especially those located in cancer centres in India, constitute a rich source of clinical material for aetiological research. Generally, in the set-up of a western country, use of data from hospital registries is associated with some biases as it need not necessarily represent any given population. However, in the Indian experience, epidemiological data collected by the hospital registries provide invaluable and reliable data for the conduct of case control studies. This is particularly so if cases and controls though from hospital registries are restricted to the local area.

As would be seen, the potential uses of a hospital cancer registry are enormous. Part of it has been possible and is reported here. Some of the other areas are being pursued by the registries and would hopefully be incorporated in subsequent reports.

***To summarise the Hospital Based Cancer Registries, over the years have helped streamline medical records in a scientific way. They have provided an assessment of magnitude and patterns of cancer in the region and have contributed to PBCRs in the given area. Hospital registries have also conducted several short-term case control studies.***

Follow-up of cancer patients has been difficult on a routine basis. Therefore, it has not been possible to assess patient outcome based on clinical stage and/or treatment. Plans are underway to conduct active follow-up for important selected sites of cancer with defined standard format of recording stage, details of treatment and studies on its outcome.

# Ten-Year Consolidated Report of the Hospital Based Cancer Registries: 1984 - 1993

## *An Assessment of the Burden and Care of Cancer Patients*

### SUMMARY OF REPORT

The Ten-Year (1984-93) Report of the Hospital Based Cancer Registries was initially started as a Five-Year report by the Technical Wing of the National Cancer Registry Programme under Dr L.D. Sanghvi at the Tata Memorial Hospital, Bombay. Subsequently Dr A. Nandakumar was appointed as Project Officer and the Technical Wing was shifted to the campus of Kidwai Memorial Institute of Oncology, Bangalore. Five more years' (1989-1993) data accrued and this has been added to constitute the present ten-year report.

***The objectives of preparing this report is in the direction of fulfilling some of the functions of Hospital Based Cancer Registries outlined above and determine the limitations that has to be overcome in the future.***

The single most important limitation is lack of information on follow-up of cancer patients. This is a major constraint, in knowing survival based on treatment and therefore in directly assessing patient care. Nonetheless, this detailed consolidated report is required to know where we stand in several other terms. These essentially include observing the magnitude of the problem in terms of patients registered, proportion of cases having a microscopic diagnosis, stage proportions and number of those treated according to different and/or combined modalities of treatment. In presenting the results of the analysis these parameters have been classified along specified and accepted lines for Hospital Based Cancer Registries, which basically is:

- a) according to those diagnosed and treated before registration at the hospital where the registry is located, and ,
- b) those who were not previously treated with or without an earlier diagnosis.

The latter are generally called the 'Analytic Cases' for the Hospital Based Cancer Registry.

While tabulating data of Hospital Based Cancer Registries, the usual practice is to include only analytic cases, that is, only those cases that have been diagnosed and/or treated in the cancer centre/hospital. This also includes cases that are considered not treatable. However, it excludes cases that were treated elsewhere and have been referred for further treatment.

This report also brings out several critical areas that are important in terms of Health Services Research, Patient Care and Clinical, Aetiological or Cancer Control Research. Some of these areas are:

- the relative proportion or percent of patients presenting at a 'Late Clinical Stage';
- the number and proportion of patients who do not receive cancer directed treatment by Clinical Stage of Disease; and

- the number and proportion of patients who receive the varied Modalities of Cancer Directed Treatment.

The report is mainly in the form of statistical tables and graphs with the corresponding text giving only the factual description. While the report has tried to analyse, compile and consolidate the data provided by the different registries in a set format, it has in no way tried to compare and therefore comment or interpret the data between or among registries. Thus, no judgement is made of the figures in the tables. This is mainly because the individual institutions where the registries are located would have their own policies in patient care and management, which is beyond the purview of this report. Individual registries, could however view their data, interpret its possible impact and observe where, if at all modifications are required in administering patient care.

The report provides several pointers to policy makers. It gives an idea of the load of cancer patients in the main cancer hospitals of the country, the proportion and sites of cancers presenting at a late stage of the disease, the resources necessary for diagnosing and treatment according to different modalities, the proportion of patients who require palliative care, and so on. The report forms a base for both policy makers and institutions to plan for the future and would give a fair idea of the optimum number of patients a cancer centre/hospital would be able to effectively handle. The report could also form the basis of working out treatment costs and hospital stay. For the registries themselves the report should be a starting point in conducting follow-up and survival studies on at least selected sites of cancer and also initiating clinical trials.

***A brief outline of the purpose and ways of interpreting each of the chapters and some areas where additional information should be gathered in order to get a more complete picture is indicated with each chapter.***

**In the text of the report, the term “patient(s)” has been used for aspects concerning diagnosis and treatment and the term “case(s)” or cancer(s)” for instance(s) of disease (cancer) in the statistical or abstract sense.**