

**NATIONAL  
CANCER REGISTRY  
PROGRAMME**

**Indian Council of Medical Research**



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# NATIONAL CANCER REGISTRY PROGRAMME

## *Indian Council of Medical Research*

### Two-Year Report of the Population Based Cancer Registries

#### Incidence and Distribution of Cancer: 1997-98

*Prepared by*

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**November 2002**

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(Indian Council of Medical Research)  
Bangalore  
November 2002

Population based cancer registries provided individual core data. Quality Control checks, tabulations and statistical analysis were done at the Coordinating Unit of NCRP, Bangalore.

The publications of NCRP are intended to contribute to the dissemination of authentic information on cancer incidence by age (Five-year age groups), sex and site (ICD-9).

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# FORWARD

The two year 1997-98 report of the population based cancer registries is the result of efforts made by registries under the National Cancer Registry Programme (NCRP) of the Council. It includes data from five urban and one rural cancer registry under the NCRP. These five urban registries are located at Bangalore, Bhopal, Chennai, Delhi and Mumbai and the rural registry is at Barshi in the state of Maharashtra.

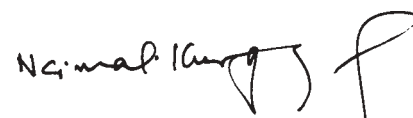
The main emphasis of this updated report is on cancer incidence and patterns of cancer. It attempts to give clues to the burden and types of cancer in these areas where the registries are located so as to present a base for studies in cancer aetiology and control. Though the geographic area and the population covered by the registries is small, compared to the vastness of the country and its huge population, the data does give a fair idea of the cancer problem in the Country. This report is the culmination of sustained efforts made by cancer registries under the NCRP. The format and the statistical tables of the previous reports have been retained.

Some similarities as well as major differences exist in the ranking of leading sites of cancer among the registries. Cancer of the stomach is a consistent leading site of cancer among males in Bangalore and Chennai, whereas it is lower down among the leading sites of cancer in Bhopal, Delhi or Mumbai. Similarly, cancer of the gall bladder is a leading site of cancer especially among women in Delhi and Bhopal, but is hardly seen in Bangalore and Chennai.

The reports of the NCRP are recognised nationally and internationally, as the standard work of reference for our Country, on the incidence of different types of cancer, their patterns and variations between regions. Such data are always important in suggesting possible aetiological factors for different cancers in knowing the severity of the problem and for determining the thrust areas in cancer control.

It is hoped that this publication will serve as a ready reference on cancer incidence in India for researchers, clinicians, health administrators and others interested in this field.

The registries and all of their staff, deserve thanks for the work they have put in and making available their data.



Prof. N. K. Ganguly,  
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# National Cancer Registry Programme

Under the National Cancer Registry Programme (NCRP), the Indian Council of Medical Research commenced a network of cancer registries across the country in December 1981.

## **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 information in different regions of the country 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 epidemiologic research, such as case control or cohort studies based on observations of registry data;
3. Provide data 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 also in the hospital based cancer registries at Chandigarh, Dibrugarh and Thiruvananthapuram. In order to extend the assessment of cancer patient care, hospital cancer registries were also started at Bangalore, Chennai and Mumbai in 1984. 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. To ensure uniformity in the data collected by different registries, code manuals separately for HBCRs (NCRP, 1987) and PBCRs (NCRP, 1987) were prepared. These code manuals are used for the data from 1st January 1986. Under the auspices of the World Health Organization, a project on "Development of an Atlas of Cancer in India" was commenced in 2001. As a fallout of this, a North Eastern Regional Cancer Registry (NERCR) has been commenced in six areas at Guwahati, Dibrugarh and Silchar in Assam, Aizawl in Mizoram, Imphal in Manipur and Gangtok in Sikkim with a Monitoring Unit at Regional Medical Research Centre, Dibrugarh. These registries have started collation of information on cancer cases from 1 January 2003. The map of India depicting the locations of the various cancer registries is shown in the adjoining page.

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 and an Officer-in-charge

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coordinates it. 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 in India is active. 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 in a “common core proforma” that has been standardised for all cancer registries in India. Proforma contains items on patient identification, socio-demographic variables, diagnostic and treatment details. Coding of the disease is done according to International Classification of Diseases (WHO, 1975). This facilitates comparison of our data at International level. In addition, to facilitate the detailed histologic studies, coding is also done according to International Classification of Disease for Oncology (WHO, 1976). 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.

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 require 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 perform tabulations 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 epidemiologic methods. About 2-3 senior and junior staff from each of the registries under the NCRP, participate in the workshop.

Apart from the above, the Coordinating Unit undertakes and coordinates epidemiologic 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.

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.

# Two-year Report of the Population Based Cancer Registries: 1997-1998

## *Incidence and Distribution of Cancer*

### INTRODUCTION AND SUMMARY OF THE REPORT

Cancer Registration is a process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms (MacLennan *et al*, 1978). Broadly there are two types of cancer registries – Population Based (PBCR) and hospital based (HBCR). Besides, there are also special purpose cancer registries in relation to specific exposure, childhood, specific anatomical site or morphology.

The primary concern of a PBCR is cancer in the community. The PBCRs provide information on cancer incidence and mortality and trends over time in the specific geographic area covered by the registry. In terms of assessing patient care, they provide overall population based cancer survival rates with reference to the community. The PBCRs constitute a base for carrying out research studies on cancer etiology through epidemiologic studies. To initiate, establish and sustain population based cancer registries as per international standards requires meticulous planning, cooperation of medical institutions in the area, dedicated and committed personnel and adequate funding. There are several sources from where staff of registries, collect information on cancer cases. These include pathology reports, medical records, radiology and radiotherapy departments and death certificates to name a few. The availability of up-dated investigation/diagnostic facilities, well maintained medical records using International Classification of Diseases together with an efficient death registration system are essential for good quality cancer registration.

The methodology of data collection by the registries in India is active in that registry staff, regularly and periodically visit various sources to actively pursue and collect information on cancers reported and interview patients wherever possible. The advent of computing technology and the age of electronic information processing have transformed working of registries in India as elsewhere in the world. This change is particularly noticed in helping duplicate checks of patient records, matching cases with death certificates and the number of range and consistency checks that can be carried out on the data.

Studying the magnitude and patterns of cancer would be the first step in determining clues to the cause of cancer and having a baseline to plan and assess control measures. Epidemiologic studies based on these help in knowing what is happening and what can be done about it. Cancer registries provide the needed information to undertake such investigations.



The previous consolidated report of the population based cancer registries published last year (2001) was of the seven-year data from 1990 to 1996 of the five urban (Bangalore, Bhopal, Chennai, Delhi and Mumbai) and one rural (Barshi) population based cancer registry. The present report covers the data of the above registries for the years 1997 and 1998. It seeks to emphasize cancer incidence and patterns of cancer in the areas covered by these registries. It attempts to give clues to the burden and patterns of cancer in these areas so as to provide a base for studies in cancer causation and its control.

Though the geographic area and population covered by the population based cancer registries under the NCRP are small compared to the vastness of India and its population, they give a fair idea of the cancer problem in the country. This report is the culmination of sustained efforts made by cancer registries under the NCRP.

Chapter 1 gives the picture of cancer incidence. Cancer incidence rate is generally expressed as age-adjusted or age-standardized (according to world standard population) incidence rate per 100,000 persons. For all anatomical sites the rates vary from 91.9 to 120.9 in urban males and 108.7 to 134.8 in urban females. Incidence rates in the rural registry of Barshi are lower. The urban incidence rates are similar to that seen in Indians in Singapore (Males: 101.5; Females: 131.7) (Parkin *et al*, 2002).

Chapter 2 deals with the leading sites of cancer in the different registries and compares with cancer incidence rates in registries in five continents. Overall, among males as in the previous report cancer of the lung is numerically the number one cancer. It is the leading site in Delhi, Mumbai and Bhopal, second and third leading site among males in Chennai and Bangalore respectively. Another site of cancer associated with the use of tobacco, namely, cancer of the oesophagus is an important leading site in both males and females. As in the reports of earlier years, cancer of the stomach in males continues to be the leading site of cancer in the southern registries of Chennai and Bangalore. In women, cancers of the cervix and breast, together account for over 40-45% of cancers in urban women and over 57% of cancers in the rural registry in Barshi. Lymphoreticular malignancies as a group are a very important set of neoplasms. They comprise over 10% of malignant neoplasms, have a potential for cure and are of interest in terms of aetiology and epidemiology.

In Chapter 3, salient statistics of two broad groups of cancers – childhood cancers and tobacco related cancers are tabulated. Childhood cancers are an important set of neoplasms as many of them have different aetiological factors and in recent years have potential for cure. The sites of cancer associated with use of tobacco account for 36 to 55% of all sites of cancer in males and 10-16% of all cancers in women.

The basis of diagnosis of cancer is one of the most important parameters in assessing the quality and completeness of the coverage of a population based cancer registry. This is discussed in Chapter 4.

Chapter 5 of the report briefly deals with mortality data. There are certain limitations in the collection of mortality data. These include the system of registration of death and certification of the cause of death. Though in urban centres all deaths are generally registered, information on exact cause of death is lacking. When cancer is mentioned as a cause, the anatomical site is not mentioned and when the site is mentioned the histology or morphology is not stated. Because of this, there are difficulties in having a clear and complete picture of cancer mortality as opposed to cancer morbidity. However, traditionally Mumbai has developed a relatively better system mainly because of the earlier Coroner's act. Chennai registry has made extra efforts to enlist deaths due to all causes and trace back these deaths to elicit cause.

The authenticity of the data depends on its quality, and with reference to the population based cancer registry, this would be both in terms of completeness of coverage of cancer cases in the geographic area as well as the reliability of the data. Registries routinely undertake various exercises to ensure that the data they collate and process is of high quality. A thorough check of data is also done before tabulation and these aspects are dealt in detail in Chapter 6.

Chapter 7 lists the definitions and statistical methods followed.

Cancer registration is a means to a purpose and not a purpose in itself. It is the forerunner of studies in descriptive epidemiology of cancer, which in turn generates specific scientific hypotheses. The registries under the NCRP have highlighted the need to undertake aetiological studies in several sites of cancer, cancer of the stomach in the south and gall bladder cancer in Delhi, to name a few.



