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NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

Consolidated Report of
Population Based Cancer Registries
2004-2005

Incidence and Distribution of Cancer

Bangalore, India
December 2008
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-10).
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Cooperating hospitals, nursing homes and other medical institutions;
All other Population and Hospital Based Cancer Registries;
Members of Steering Committee;
Members of Monitoring Committee;
Staff of Division of NCD, ICMR, New Delhi;
Staff of Coordinating Unit, NCRP, Bangalore.
I am happy to write this foreword for the consolidated report of National Cancer Registry Programme. This consolidated report covers data accrued over a two-year period (01 Jan 2004 to 31 Dec 2005) and is the outcome of the efforts of Population Based Cancer Registries under the National Cancer Registry Programme (NCRP) of the Council. It includes the information sent by the well-established older registries as well as that of relatively newer registries of North East, the registry covering Ahmedabad rural district and Kolkata PBCR. This is a significant step towards nationwide coverage of systematic data collection.

The PBCR reports are considered as standard work of reference for describing incidence rates and patterns of cancer in the country. It serves as an important tool for target-oriented approach for cancer control programmes. This increases the importance of this evidence-based report. The obvious differences in the incidence patterns of cancer in different parts of the country have been brought to notice by the sustained efforts of these registries.

The optimal use of ever expanding field of information technology towards data collation and correction has given visible results. The time period between the calendar year of data collection and report publication has been shortened. The basic information provided by registries can be easily obtained in the form of systematic tables using computer applications.

The information regarding magnitude and pattern of cancer can be the basis of population based epidemiological studies. I am sure that researchers, clinicians, health administrators and epidemiologists would benefit with this report.

The coordination and management of the data received along with publication of this report is the result of the mammoth effort made by staff of these registries as well as that of the Coordinating Unit of the NCRP. They deserve a special appreciation for their dedicated work which has enabled this successful completion of more than two decades of data collection.

Dr. V. M. Katoch
Secretary, Department of Health Research &
Director General, ICMR
INTRODUCTION

The National Cancer Registry Programme (NCRP) was established under the Indian Council of Medical Research (ICMR) in 1981 with the definitive aim of assessing incidence and distribution of cancer in the country. Three Hospital Based Cancer Registries (HBCR) and three Population Based Cancer Registries (PBCR) commenced data collection on 01 Jan 1982. Over the years, the registry network has expanded so as to have twenty three (23) PBCRs under the NCRP network. This also included registries developed for examining special exposures like Bhopal PBCR. This was a significant attempt to register as many cases as possible in their respective geographic area. The WHO project on “Development of an Atlas of Cancer in India” provided some hitherto unknown information on the incidence and patterns of cancer in the North East. Based on the leads obtained, the ICMR commenced PBCRs in four of the eight North Eastern states in 2003, and from January 2009 in three additional states of the North East. The advent and optimal use of information technology in capturing and transmitting information, has eased the effort and reduced the time taken in processing while also significantly improving the quality of data.

The information collected by PBCRs serves as a database of cancer cases for several epidemiological studies. Meticulous planning, cooperation of local medical institutions, dedicated and committed personnel and adequate funding are the pre-requisites to establish registries in different areas of the country. The feasibility and futuristic planning required in establishing these newer registries is a mammoth effort undertaken by the Coordinating Unit of the NCRP located at Bangalore. The Coordinating Unit has paid a special emphasis on the quality of data along with its completeness and validity. Various quality checks are carried out on the data in keeping with the international data quality indices.

The present report is a culmination of sustained efforts made by the cancer registries and the NCRP. It covers the data accrued from a period of 01 January 2004 to 31 December 2005 by the six older and two newer PBCRs under the NCRP network. The report of the six PBCRs in the North East has been separately published. However, the overall comparison of the data is given in Chapter 6.

The ICMR has also commenced a number of multi-institutional research studies based on the cancer incidence data. The present report would serve as a reliable data resource in the conduct of these studies. The results of the study would find application and would also pave the way for planning and implementation of control measures in a scientific way.

Dr. Bela Shah
Head, Division of Non-Communicable Diseases, ICMR
McLennan has defined cancer registration as a process of continuing systematic collection of data on the occurrence and characteristics of reportable neoplasms (McLennan et al, 1978). Broadly there are two types of cancer registries. One is the Population Based (PBCR) and the other is a Hospital Based Cancer Registry. Registries could also be developed for a special purpose in relation to specific exposures, or, they could also be established for a specific anatomical site like Bone Tumour and Lymphoma registries. Registries could also specifically cater to a particular age group as for children or for the elderly.

The basic thrust of a PBCR is cancer in the community. PBCRs provide information on cancer incidence and mortality in a defined population and for a particular time period. They also provide information on variation in incidence or mortality over time and with follow up, population based cancer survival rates.

To initiate, establish and sustain population based cancer registries as per international norms requires meticulous planning, cooperation of medical institutions in the area, dedicated and committed personnel and adequate funding. Generally, there are several sources of registration for a PBCR from where staff of registries, collect information on cancer cases. These include pathology reports, medical records, radiology and radiotherapy departments and death certificates. 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 completeness as well as good quality cancer registration.

Cancer is not as yet a reportable disease in India. Therefore, methodology of data collection by the PBCRs is active, in that, registry staff make visits to various sources of registration to collect information on cancers recorded in the respective institutions. The advent of computing technology is gradually changing the method of working of cancer registries in India.

Studying the magnitude and patterns of cancer helps in determining clues to the cause of cancer and undertake studies in disease aetiology. 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 PBCRs constitute a base for carrying out scientific investigations in cancer aetiology. The population based design provides considerable strength and makes the results of both case control and cohort studies, extremely valid.
Cancer registration is a means to a purpose and not a purpose in itself. It is necessary in all settings, more so in the setting of a developing country like India.

The previous consolidated report of the PBCRs published in December 2006 covered data of the years 2001, 2002 and 2003 for the older registries at Bangalore, Barshi, Bhopal, Chennai, Delhi and Mumbai and 2004 data for the registry covering Ahmedabad district other than Ahmedabad urban. The present report covers the data of the above registries plus that of Kolkata Metropolitan Corporation. This report covers the data for the years 2004 and 2005 for the older PBCRs and 2005 data for the PBCR at Kolkata.

Chapter 1 gives an idea of the cancer incidence in the areas covered by the respective PBCRs. Cancer incidence rate is generally expressed as an age adjusted or age standardized rate (according to world standard population) per 100,000 persons for an anatomical site. In males, the incidence rate (AAR) varied from 49.2 from rural PBCR at Barshi to 219.5 in the National capital territory. Among females, the AAR varied from 43.1 in Ahmedabad district to 120.8 in Bangalore. The possibility of person developing cancer during the life time is also provided in chapter 1. Among the urban population whether male or female, for the 0 – 74 age group one in eight or 10 people have a life time risk of developing cancer.

Chapter 2 provides picture of the leading sites of cancer in different PBCRs. Cancer of the stomach continues to be the leading site of cancer among males in Bangalore as well as Chennai though the latter competes with lung as a leading site. The Metros at Delhi, Mumbai and Kolkata have recorded cancer of the lung as a leading site. Cancer of the lung is closely followed by cancer of the prostate in these places. Among females, cancer of the breast has replaced cancer of the cervix in all the registries except Barshi. Lung cancer in women in Delhi, Mumbai, Bangalore and even in Barshi as an important point to be noted.

Chapter 3 gives salient information on cancers associated with the use of tobacco. The proportion of Tobacco Related Cancers (TRCs) among males varies from 33.4% in Bangalore to 50.6 in Ahmedabad. Among females, the relative proportion varies from 10.7 in Delhi to 15.2 in both Chennai and Bangalore. The fact that cancer of the lung in women constitutes a considerable proportion of the sites among TRCs as important.

Chapter 4 deals with the basis of diagnosis of cancer. The relative proportion of different methods of diagnosis of cancer viz., microscopic, imaging, clinical etc. along with cases with DCO as the basis of diagnosis are given.

Chapter 5 gives an account of the 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 and more recently
Bhopal have made extra efforts to enlist deaths due to all causes and trace back these deaths to elicit cause.

Chapter 6 provides a comparison of cancer incidence and patterns in all PBCRs including those in the North East. Higher incidence rates are found especially in Mizoram state and Kamrup Urban District. Apart from the sites of cancer associated with the use of tobacco, the AAR of cancer of the stomach in Aizawl district is several fold higher in both males and females compared to the older registries at Chennai and Bangalore. Likewise, cancer of the oesophagus also shows a similar picture for not only Mizoram state but also for PBCRs at Assam state and Sikkim. Cancer of the Gallbladder among females continues to be the higher in both Kamrup Urban District and Imphal West district than that seen in Delhi. Like cancer of the stomach, cancer of the lung in both males and females is several fold higher than that recorded in the main land cancer registries.

The authenticity of the data depends on its quality, and with reference to the PBCRs, 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 7. The Coordinating Unit has now developed an on-line check programme that can be carried out by the registries through the NCRP website (ncrpindia.org).

The details individual registry write up and annexure tabulations are provided in Part II of the report. The annexure tabulation for numbers and rate (incidence and mortality) are provided for both the years 2004 and 2005 separately and in combination.

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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 with the objectives of

1. Generating 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. Undertaking epidemiologic research, such as case control or cohort studies based on observations of registry data;

3. Providing 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 training programmes 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 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, the latter to determine the effect of Methyl Isocynate gas exposure on the occurrence of cancer. For the first time a population based rural cancer registry was started in 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. One more population based rural cancer registry was commenced from 1 January 2003 to cover Ahmedabad rural district. From 1 February 2005 the urban PBCR of Kolkata was included in the NCRP network to cover Kolkata Municipal Corporation. 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 coordinates it. The Programme is assisted by Steering and Monitoring Committees that meet 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. This meeting is preceded by a workshop, where the various aspects of working of the registry, problematic cases, use of coding, medical terminology, statistical and epidemiologic methods are taught and discussed. About 2-3 senior and junior staff from each of the registries under the NCRP, participate in the workshop.

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. Coding of the disease is done according to International Classification of Diseases (WHO, ICD-10). This facilitates comparison of our data with that from registries across the world. In addition, to facilitate the detailed histologic studies, coding is also done according to International Classification of Disease for Oncology (WHO, 3rd Edition 2002). 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 same area, from all hospitals and from 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 checks 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 performs tabulations to prepare the consolidated report of that year.

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.