NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research
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Consolidated Report of
Population Based Cancer Registries
2001-2004

Incidence and Distribution of Cancer

Bangalore, India
December 2006
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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The present consolidated report of the population based cancer registries (PBCRs) is the outcome of efforts made by registries under the National Cancer Registry Programme (NCRP) of the Council. This report besides including the data from the older PBCRs at Bangalore, Barshi, Bhopal, Chennai, Delhi and Mumbai also includes information on the newer PBCRs of the North East and the rural registry covering Ahmedabad rural district.

The reports of NCRP have over a period of time become the standard work of reference not only within our country but abroad as well. Besides providing information on what type of cancer is occurring where and what is the magnitude, these reports have contributed a base for deciding priorities in cancer control programmes in India. In particular, this report has compared the incidence patterns of cancer across thirteen population based cancer registries indicating striking differences. The need for shifting focus on specific cancer control in different regions of the country is obvious from this account.

The NCRP has contributed to systematic scientific data collection for over twenty years. The time consuming process of collation and correction of data has been shortened with advancement of information technology. This in turn has reduced the time between the calendar year of data and year of report publication.

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

The registries and all their team members deserve special thanks for their dedicated work and providing quality data which enabled the successful completion of this report.

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Director General, ICMR
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Principal Investigators and Staff of Population Based Cancer Registries;

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Members of Monitoring Committee;

Staff of Division of NCD, ICMR;

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Prof K. Ramachandra Reddy for final proof reading.
Dr N. Anantha (1936-2006) was one of those who did the specialty training in radiotherapy, when the discipline's independent status was not yet clearly established in India. He used to fondly narrate his humble background, and medical education from Mysore University (MBBS, 1963). He had then moved to northern India, did D.M.R.E. from Lucknow University (1967) and immediately after that pursued MD in Radiotherapy at J.K.Cancer Institute, Kanpur. Dr. Anantha got his post-graduate training at Kanpur under the famous and erudite Professor J.K.Haldar (founder and father figure of the Association of Radiation Oncologists of India (AROI)), obtaining MD in 1969. This training was greatly influential in shaping his career. He returned to join the Karnataka state medical service in early 1970s and was subsequently selected for the teaching cadre. Except for a few years spent under the Ministry of Health, Iran, (1976-1980), Dr. Anantha spent his lifetime in his home state of Karnataka.

Kidwai Memorial Institute of Oncology (KMIO) was the first comprehensive cancer centre established by the Karnataka government. Dr. Anantha joined as the Professor and Head of Radiotherapy in 1980 in the formative years of this institute and it was one of the first centres to gain the status of Regional Cancer Centre (under Government of India's National Cancer Control Programme). The department of Radiotherapy at KMIO was headed by him till his retirement in 1996. The facilities and patient care practices in this department have received wide recognitions from the medical community and public over the years. The post-graduation courses (MD and diploma in Radiotherapy) at KMIO were started in late 1980s under Bangalore University. Dr. Anantha was actively involved in patient care and teaching and the department attracted faculty and students from various parts of India. Despite the large patient burden from several states of southern India, good quality with interdisciplinary management were maintained. Dr. Anantha rose higher in administrative positions, becoming the Medical Superintendent in 1982 and subsequently was appointed Director of KMIO in 1990.He guided the institute till his retirement in 1996. He had the professional discipline to manage his time well between the administrative and professional responsibilities. He would walk into the ward for morning rounds, attend to patients in the out-patient and join the department's teaching programme routinely. It was easy to engage him in a conversation, and he would lament how 'raagi mudda' as a breakfast menu has vanished from Kannadiga homes!

Dr. Anantha had a productive career, visited Europe and USA on fellowships and training, authored more than 50 scientific articles, lectured widely and conducted the national conferences of AROI, Indian Society of Oncology, several workshops on the National Cancer Control Programme and the Annual Review Meetings of the NCRP. He was a member of several scientific bodies, including Bangalore University, Indian Institute of Science and Karnataka state Council for Science and Technology. He received several awards and honours in his career, to name just two of those laurels: Karnataka Rajyotsava award and Dr. T.B.Patel award from Gujarat Cancer Society. After his retirement, Dr. Anantha worked as Professor of Radiotherapy at M.S. Ramaiah Medical College, Bangalore from 1998 to 2003, again setting up a new department. He placed good emphasis on physical fitness, athletics and lawn tennis. He used to walk from one building to another of KMIO at a good pace, leaving behind many young residents breathless!

It was my good fortune to start the academic career as a faculty under Dr. Anantha, and to many like me in India and abroad, he was a mentor with a humble heart. He is survived by his wife and one son, who is an engineer settled in USA.
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. Developing 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, 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 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. This meeting is preceded by a workshop. 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.

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 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 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 perform 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.
Cancer registration is the process of continuing, systematic collection of data on the occurrence and characteristics of reportable neoplasms (McLennan et al, 1978). Cancer registries could be Hospital based (HBCR) or population based (PBCR) or developed with a special purpose of examining specific exposures like the Bhopal PBCR. They could also be related to specific anatomical sites like bone tumour registry or morphology like lymphoma registry or a particular age group like childhood cancer registry.

The main objective of a cancer registry is to collect and classify information on all cancer cases in order to produce information on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer on the community. PBCR records all new cases in a defined population (most frequently a geographical area) with the emphasis on epidemiology and public health. The basic purpose of PBCR is to provide information on cancer incidence and mortality, time trends of these rates, variations in patterns and population based cancer survival rates.

To initiate, establish and sustain PBCR as per international norms requires meticulous planning, cooperation of medical institutions in the area, dedicated and committed personnel and adequate funding.

PBCR forms a platform for carrying out research investigations on cancer aetiology through various epidemiological studies. The sources of registration from where registry staff collects information include pathology reports, medical records, radiology and radiotherapy departments, through death certificates and others. For a complete as well as good quality cancer registration, the requisites would include - availability of updated investigations/diagnostic facilities, well organised medical records coding according to the International Classification of Diseases (WHO) and efficient death registration system.

In India cancer is not a notifiable disease and the methodology of data collection by registries is active. Registry staff regularly and periodically visits various sources of registration to actively pursue and collect information on cancers reported and interview the patients or representatives whenever possible. The registry staff abstracts the data from various sources of registration and feed them into specified core proforma. There is a gradual transformation in the working of registries in India with advancement in computing technology.

The previous consolidated report of PBCRs was published in 2005 was of the two years data of 1999-2000 of the five urban (Bangalore, Bhopal, Chennai, Delhi and Mumbai) and one rural (Barshi) population based cancer registry. The present report covers (a) the data of the six registries - Bangalore, Bhopal, Chennai, Delhi, Mumbai, Barshi for the years 2001-2003, (b) the six PBCRs (Aizawl District, Dibrugarh District, Kamrup Urban District, Silchar Town, Imphal West District, Sikkim State) in the North East with the data of 2003-2004 and (c) that of the Ahmedabad PBCR covering Ahmedabad District (other than...
Ahmedabad Urban) for the year 2004. The report seeks to emphasise the 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 PBCRs are small (about 3%) compared to the vastness of India and its population, they give a fair idea of the cancer problem especially in urban centers in the country. This report is the culmination of sustained efforts made by the cancer registries.

Chapter 1 gives an idea of the cancer incidence in the registry areas. Cancer incidence rate is generally expressed as Age adjusted rate (AAR) or age standardised incidence rate (according to world standard population) per 100,000 persons. For all anatomical sites in urban males the AAR varied from 68 to 114.9 and in females from 92.1 to 116.5 excepting Ahmedabad with AAR of 39.8.

Unlike the earlier years incidence rates in rural registry of Barshi was lower only in males which is 43.8 but not so in case of females where a lower AAR was seen in Ahmedabad (39.8).

Chapter 2 provides a picture of leading sites of cancer in different PBCRs. 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 leading site in Chennai and Bangalore. Cancer of the stomach in males continues to be the leading site of cancer in southern registries. In women, cancers of cervix and breast, together accounted for 40.01% to 47.28% of cancers in urban women and over 53.3% of cancers in the rural registry in Barshi. Lymphoreticular malignancies as a group are a very important set of neoplasms. They comprise of around 10% of malignant neoplasms, have a potential for cure and are of interest in terms of etiology and epidemiology.

Chapter 3 gives the salient statistics of cancers associated with use of tobacco. These sites of cancer account for 34.67% to 50.34% of all cancers in males and 10.08% to 16.78% of all cancers in females.

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 Death Certificates Only as the basis of diagnosis are given.

Chapter 5 gives an account of mortality data. There are certain limitations in the collection of mortality data. These include the system of registration of death and certification of cause of death. Though in urban centers 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 lacking. Because of this, there are difficulties in having a clear and complete picture of cancer morbidity. However, traditionally Mumbai has developed a relatively better system mainly because of the earlier Coroner's act. Chennai and Bhopal registries have made extra efforts to enlist deaths due to all causes and trace back these deaths to elicit cause.

A comparison of cancer incidence and patterns of all PBCRs including those in the North East under NCRP is done in Chapter 6. Higher incidence rates are found especially in Mizoram and Kamrup Urban District. Apart from the sites of cancer associated with use of tobacco, the AAR of cancer of stomach in both males (AAR: 50.6 in males and 23.3 in females) and females in Mizoram was many times higher than...
that recorded in Chennai (AAR : 10.8 in males and 5.4 in females) and Bangalore (AAR: 8.8 in males and 4.9 in females).

Cancer of the nasopharynx was uniformly high in six of the eight North East registry areas than that seen in the PBCRs commenced in the earlier years. Delhi PBCR has consistently reported a consistently high incidence of cancer of the gall bladder in women. Kamrup Urban District showed a marginally higher incidence rate than that in Delhi.

The AARs of common sites of cancer in women viz, cervix, breast and ovary are comparable or lower than that seen in the established registries. Among the TRCs, the most common site of cancer that was several times higher than that of the highest AAR documented by older PBCRs was, cancer of the lung, in women (42.2/100,000 in Aizawl district verses 3.0/100,000in Delhi). This singular characteristic as well as the incidence and patterns seen in the north east PBCRs reconfirm the results reported from the study on Development of an Atlas of cancer in India (NCRP, 2004 a, b ; Nandakumar et al, 2005).

The authenticity of data depends upon 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 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 with 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.(www.ncrpindia.org).

Chapter 8 enlists the definitions and statistical methods followed.

The detailed individual registry write up and annexure tabulations are provided in Part II of the report. The annexure tabulation for numbers and rates (incidence and mortality) are provided for the years 2001, 2002 and 2003 separately and in combination.

The present report covers

(a) the data of the six registries - Bangalore, Bhopal, Chennai, Delhi, Mumbai, Barshi for the years 2001-2003;

(b) the six PBCRs (Aizawl District, Dibrugarh District, Kamrup Urban District, Silchar Town, Imphal West District, Sikkim State) in the North East with the data of 2003-2004;

(c) that of the Ahmedabad PBCR covering Ahmedabad District (other than Ahmedabad Urban) for the year 2004. However, in the figures this is indicated only as ‘Ahmedabad’.

The population covered by the registry area of Ahmedabad district can be defined as the population of Ahmedabad district excluding the population of three urban areas of Vejalpur, Gatlodia and Ahmedabad city. Ahmedabad district rural PBCR is essentially planned as a rural registry. However, certain urban pockets in the rural district are also included in view of the difficulties in isolating both numerator (cancer cases) and denominator (population by five year age group).