

**NATIONAL
CANCER REGISTRY
PROGRAMME**

Indian Council of Medical Research

NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

**Population Based Cancer Registries
under
North Eastern Regional Cancer Registry**

FIRST REPORT : 2003 - 2004

Incidence and Distribution of Cancer

Bangalore, India

September 2006

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September 2006

PRINTED IN INDIA

Published by the Coordinating Unit, National Cancer Registry Programme (ICMR), Bangalore 560094

Cover: Map depicting the eight states of the North East with shaded portions indicating the areas covered by the cancer registries.

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FORWARD

The two year 2003-2004 report of the six Population Based Cancer Registries (PBCRs) from the four states (Assam, Manipur, Mizoram and Sikkim) of the north-east is the first report from that region.

The report gives an idea of the incidence and patterns of cancer in these north eastern states. The incidence rates of leading sites of cancer are compared with that of the other PBCRs under the National Cancer Registry Programme (NCRP). Both the rates and patterns are strikingly different. Overall, the report provides a glimpse of the variations in types of cancer in this part of the country.

For the first time, the NCRP is providing the incidence rates and patterns of cancer for an entire population of two states and for whole districts in three others.

The reports of the 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 generated research questions and constituted a base for deciding priorities in cancer control programmes in India.

It is hoped, that, this report will serve as a tool for aetiological cancer research on one hand and instituting site specific cancer control measures on the other.

The Principal Investigators and Staff of the north east registries have made extraordinary efforts to collect valid scientific data along international standards. They and the monitoring unit at RMRC, Dibrugarh and the NCRP at Bangalore deserve all the appreciation for this immense effort.



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ACKNOWLEDGEMENTS

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Prof K. Ramachandra Reddy for final proof reading.

Population Based Cancer Registries under North Eastern Regional Cancer Registry

First Report : 2003 - 2004

Executive Summary

This first report of the six population based cancer registries (PBCRs) of the North Eastern region is for the two year period 1 Jan 2003 to 31 December 2004. The registries are located in four states namely, Assam, Manipur, Mizoram and Sikkim. The state of Assam has three population based cancer registries comprising Dibrugarh district, Kamrup Urban district and Silchar town. In the state of Manipur, the area covered is of one main district, namely, Imphal West district. The PBCRs at Aizawl and Gangtok encompass the entire states of Mizoram and Sikkim respectively, thereby, giving a picture of cancer for these states as a whole - a distinctive aspect that has not been done earlier.

The main emphasis of this report is on cancer incidence and patterns of cancer in this part of the country. The overall aim and objective is to produce incidence data that are comparable with others under the National Cancer Registry Programme (NCRP). It attempts to give clues about the burden and patterns of cancer in these areas so as to present a base for studies in cancer aetiology and control. The data gives an overview of the cancer problem in the four states of the north east. The report is a culmination of sustained efforts made by the PBCRs of the north east.

Cancer incidence rate is generally expressed as age adjusted, or age standardized (according to world standard population) incidence rate (AAR) per 100,000 persons. In the older established registries this rate for all anatomical sites has been around 100 per 100,000, in the urban population based registries and somewhat lower in the rural registry at Barshi. The results in this report are notable, in the sense that incidence rates of well over 100 per 100,000 persons have been recorded in five of the eight registry areas identified for describing the incidence and patterns of cancer.

Chapter 1 gives a picture of cancer incidence rates and Chapter 2 summarises the leading sites of cancer. Overall, Mizoram state (AAR: 194.5 in males 155.7 in females) as a whole and Aizawl district (AAR : 277.2 in males and 231.5 in females) in particular (the latter being the main district of Mizoram) recorded the highest AAR (all sites) reported as yet from the Indian sub continent. Kamrup urban district (AAR: 177.2 in males and 154.1 in females) of Assam state follows closely in having such high incidence rates. The main anatomical site of cancer that contributed to the high incidence in males in Mizoram state was stomach cancer that accounted for almost a quarter of all cancers in that sex. This was followed by cancer of lung, oesophagus and hypopharynx that constituted over another quarter of all cancers.

Among females in Mizoram, apart from stomach cancer, lung cancer was the leading site comprising nearly 14% of all cancers in women.

In the registries in Assam, among males, cancer of the oesophagus was the leading site in Dibrugarh district and Kamrup Urban district and the third leading site in Silchar town. As in Mizoram lung cancer incidence rate was not only high in Imphal west district of Manipur, but, was also the leading site of cancer in both sexes. In females, it surpassed cervix and breast cancer as the leading site of cancer. Cancer of the nasopharynx was another site of cancer that recorded a high incidence.

Chapter 3 deals with the number and proportion of cancers associated with use of tobacco. In Kamrup Urban district, seven of the ten leading sites of cancer, were anatomical sites associated with the use of tobacco (IARC, 1987). In fact, this district had a high proportion of Tobacco Related Cancers (TRCs). Almost 60% of cancers in males and 28% of cancers in females were of sites associated with the use of tobacco. This high proportion of tobacco related cancers was also seen in the other two populated based cancer registries in Assam state viz, Dibrugarh district and Silchar town.

A comparison of cancer incidence and patterns with other older PBCRs (NCRP, 2006b, under publication) is done in Chapter 6. Site for site the incidence rates in the newer registries in the North East were higher and in some sites considerably so, especially in Mizoram and Kamrup Urban district. Apart from the sites of cancer associated with use of tobacco, the AAR of cancer of the 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 nasopharynx was uniformly higher 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 high incidence of cancer of the gall bladder in women. Kamrup urban district showed a marginally higher incidence rate than that at Delhi.

The AARs of the common sites of cancer in women, viz, cervix, breast and ovary are comparable or lower than that seen in the established PBCRs. Among the TRCs, the most common site of cancer, that was several times higher than the highest AAR documented by the older PBCRs was, cancer of the lung, in women (42.2 / 100,000 in Aizawl district versus 3.0 / 100,000 in Delhi). This singular characteristic as well as the other 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, 2004a,b; Nandakumar et al, 2005).

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. Some of the indicators of quality of data have been indicated in

Chapter 4 dealing with the basis of diagnosis and Chapter 5 on Mortality data. The report presented is of the first two years of operation of a PBCR. Care has been taken to ensure that all possible sources of registration of cancer cases have been identified and a search made of all cancer cases diagnosed during the two-year period in each of these sources. Likewise the date of diagnosis has been strictly followed so as not to include cases diagnosed outside the two-year period. Standard checking of data has been done as per IARC norms (Parkin et al, 1994). The results are along the lines of the cancer atlas report published earlier. Nonetheless, this is the first report furnishing the actual incidence rates of cancer in the north-east, and therefore a degree of prudence may be necessary in interpreting and drawing conclusions.

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 generate specific scientific hypotheses. The cancer registry is central to any rational programme on cancer control (Muir, C.S., 1985). The results of this report have set priorities for cancer research and identified target sites for cancer control measures. For example, cancer of the stomach in Mizoram is both a priority for research and a target for early detection. Similarly, cancer of the gall bladder, nasopharyngeal cancer, thyroid cancer and myeloid leukemia, to name a few, are anatomical sites of cancer, for which, aetiological studies need to be undertaken. There also appears a need to have an extended and explicit programme of cancer control for the north east, not only because of the high incidence of certain cancers, but also because, of the distinct patterns of cancer seen here, than that observed in the rest of the country.

National Cancer Registry Programme

National Cancer Registry Programme (NCRP) was commenced by the Indian Council of Medical Research (ICMR) with a network of cancer registries across the country in December 1981. The main objectives of this Programme were:

1. To generate reliable data on the magnitude and patterns of cancer.
2. Undertake epidemiological studies based on results of registry data.
3. Help in designing, planning, monitoring and evaluation of cancer control activities under the National Cancer Control Programme (NCCP).
4. Develop training programmes in cancer registration and epidemiology.

With these objectives three population based cancer registries (PBCRs) at Bangalore, Chennai and Mumbai and three hospital based cancer registries (HBCRs) at Chandigarh, Dibrugarh and Thiruvananthapuram were commenced from 1 January 1982. The PBCRs have gradually expanded over the years and as of now there are 14 PBCRs under the NCRP network and these are illustrated in the adjoining map. The North East Regional Cancer Registry (NERCR) which was a fall out of the project on Development of an Atlas of Cancer in India, has six PBCRs in four states with a monitoring unit at Regional Medical Research Centre, Dibrugarh. These registries have started accessing data from 1 January 2003 and the present report is first of its kind from this region, for the years 2003 and 2004.

The NCRP is a long term activity of the ICMR. The office is located in Bangalore. It is assisted by a Steering committee and a Monitoring 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 present results and participate in the discussions. The meeting is preceded by a workshop.

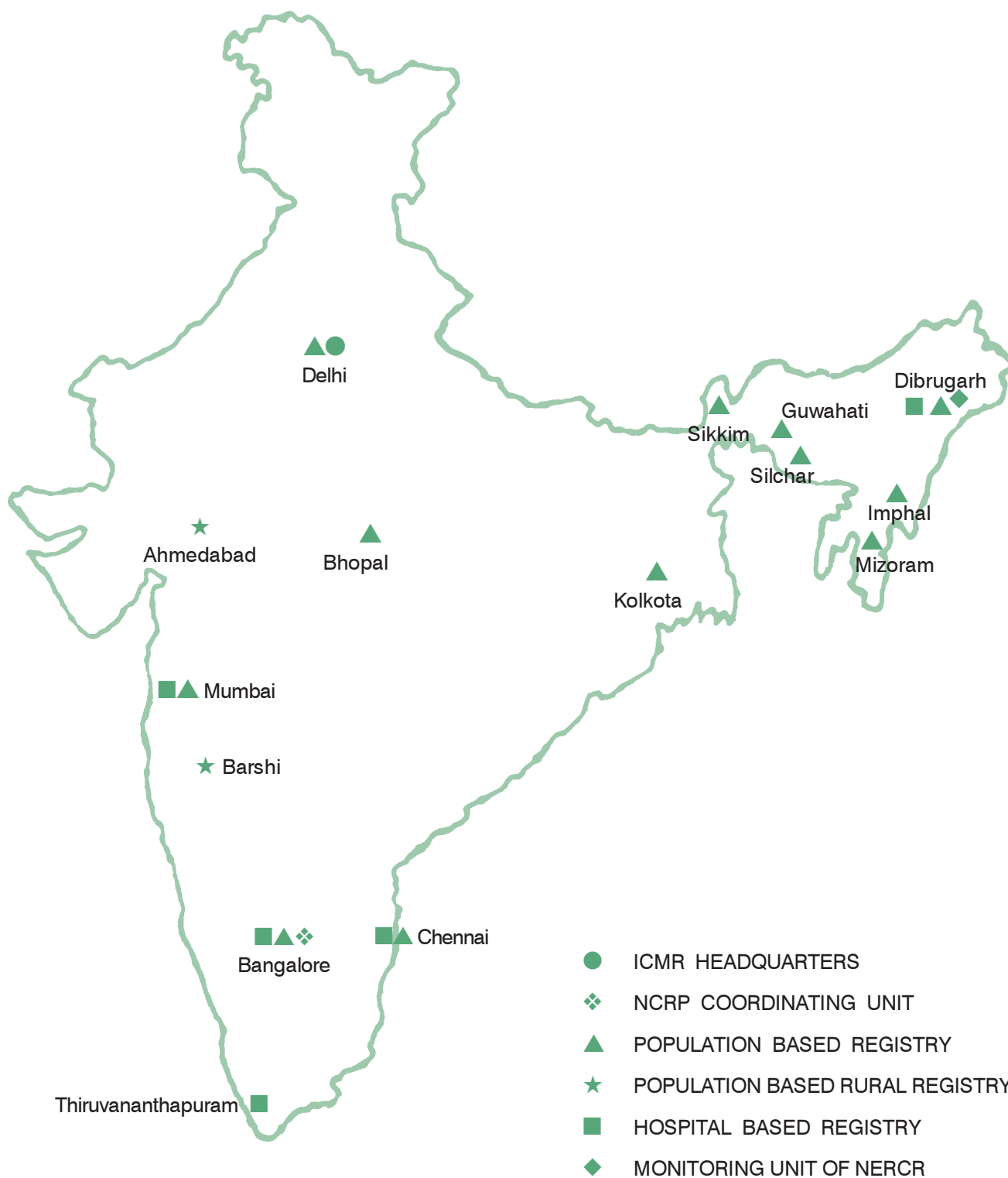
Cancer registration in India is active and staff of all registries visit hospitals, pathology laboratories and all other sources of registration of cancer cases on a routine basis. Death certificates are also scrutinized from the municipal corporation units and information collected on all cases where cancer is mentioned on the death certificates.

The information that is collected on a core form that is computer ready is subsequently entered on to a computer. Over the years the registries and the office of the NCRP have used modern advances in electronic information technology to not only enter the data but also help in specific activities that involves checking of the data, verification of duplicates and matching mortality and incidence records.

Data quality and completeness of coverage is a prime requisite for good cancer registration. This is ensured to the best possible extent by the NCRP.

NATIONAL CANCER REGISTRY PROGRAMME

(Indian Council of Medical Research)



Over the years, the staff from registries and the NCRP have benefited from both short term and long term training fellowships in established institutions in developed countries. This has helped the working of the cancer registries and also to evolve epidemiological studies. Data from the NCRP registries is regularly published in succeeding volumes of Cancer Incidence in Five Continents published by the International Agency for Research on Cancer - the cancer research arm of the World Health Organization (WHO).

The population for the areas covered by the registries for each of the years 2003 and 2004 has been estimated based on the 1991 and 2001 census population provided by the office of the Registrar General and Census Commissioner of India. The difference distribution method was used to calculate the five yearly age distribution of the population for the years.

North East Population based cancer registries provided core information on cancer patients in their respective registry areas. 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).

Monitoring Unit of North Eastern Regional Cancer Registry, Regional Medical Research Centre for North-East, Dibrugarh, Assam

Unique cancer pattern in different states of North Eastern Region observed by treating physicians and the result of the project “Development of An Atlas of Cancer in India” under National Cancer Registry Programme, Indian Council of Medical Research (ICMR), prompted ICMR setting up of Population Based Cancer Registries in these states. As a sequel Northeast Regional Cancer Registry (NERCR) project was started in January 2003 in four states. Regional Medical Research Centre for Northeast (RMRC-NE), Dibrugarh, was designated as the monitoring unit for these registries. The six population based cancer registries (PBCR) in the northeastern part of India covers the following areas with a population of:

1. Assam State:
 - i. Dibrugarh District (Population-12,21,101)
 - ii. Kamrup Urban district (Population-9,80,249)
 - iii. Silchar town (Population-17,6,550)
2. Manipur state: Imphal West district (Population-4,61,081)
3. Mizoram state: Entire Mizoram state (Population-15,40,252)
4. Sikkim state: Entire state of Sikkim (Population-5,78,252)

The Programme was commenced as an ad-hoc project of ICMR for initial 3 years, (now extended to another 2 years period) with the following objectives:

Major objectives:

1. To generate reliable data on the magnitude and patterns of cancer based on morbidity and mortality information in different states of North Eastern Region of India
2. To undertake epidemiological 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.

Minor Objectives:

1. To understand the correlation between sex, age and geographical location of the patient, anatomical site of cancer and proportion of histological type or microscopic confirmation for each site;
2. To understand pattern of different types of cancer according to relative proportions or ratios in various population sub-groups of the north eastern states according to 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;
3. To help in planning, monitoring and evaluation of activities under the Programme;

4. Develop human resource in cancer registration and epidemiology.

The staff of the Monitoring unit of NERCR have performed the following activities:

1. Principal Investigator of the monitoring unit i.e. Director of RMRC-NE, Dibrugarh, coordinates all the functions of the registries of the NEPBRCR. A Steering Committee that meets periodically along with NCRP to oversee and guide its functioning assist the Programme. A review meeting is held annually, where the Principal Investigators and staff of the registries under the NERCR, present data and participate in the discussions.
2. Active registration is done as a part of Cancer registration. Staff of registries visit hospitals routinely and scrutinize 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”. Coding of the disease is done according to International Classification of Diseases (ICD-10). This facilitates comparison of data at International level. The hospitals include the main cancer hospitals, other general hospitals in both the government and private sector. Besides the hospitals, the investigators also visit private laboratories with histology and cytology facilities and the X-ray clinics. Death certificates from the municipal corporation also forms the part of the information. 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.
3. 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 Monitoring Unit and NCRP office for range, consistency and unlikely combinations checks. A further round of possible duplicate listing and checking of the coding is done. The lists of cases with the items of patient information that requires verification are sent to the respective registries. Individual registries go through the records/reports of such cases and send the feedback.
4. The investigators and staff of Monitoring Unit visit different PBCRs at different time and hold discussion on various aspects of working of the registry, problematic cases, use of coding and discussion on medical terminology, statistical and epidemiologic methods.
5. Apart from the above, the Monitoring Unit undertakes and coordinates epidemiologic and other research studies, include 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.
6. Finally reports are sent to NCRP office at Bangalore for further check, verification and compilation.
7. Monitoring unit keeps a constant touch with NCRP office at Bangalore for guidance, help and training of staff at different level.