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DEVELOPMENT OF AN ATLAS OF CANCER IN INDIA

First All India Report: 2001-2002

*Information Technology in Medicine –
Measuring Burden of Disease*

DEVELOPMENT OF AN ATLAS OF CANCER IN INDIA

**A Project of the National Cancer Registry Programme
(Indian Council of Medical Research)
Supported by the World Health Organization**



First All India Report: 2001-2002

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April 2004

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Cover: Districtwise Map of the Distribution of Breast Cancer in Females.

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FOREWORD

Measuring accurate estimates of the burden of disease in a developing country is challenging. There are several reasons for this. Some of them have to do with the documentation of medical records and discharge summaries, methods of referral and follow-up and the system of registration and certification of cause of death. Specific disease registers are perhaps the answer.

The Indian Council of Medical Research initiated a network of cancer registries across the country under the National Cancer Registry Programme (NCRP) in 1981. The objective was essentially to generate reliable data on the magnitude and patterns of cancer and undertake epidemiological and cancer control research. The registries mainly cover selected urban centres and one rural pocket. Under the auspices of the World Health Organization a project on "Development of an Atlas of Cancer in India" was commenced in January 2001.

The main emphasis of this report is on patterns and minimum incidence rates of cancer over several districts. The incidence rates on important selected sites of cancer are compared with that of the established population based cancer registries under the NCRP. Summary report on individual centres is also given. Overall, the presentation provides a glimpse of similarities and variation in types of cancer in different regions of India. This comprehensive account is a big step forward in covering more areas not covered by the registries under the NCRP. Continued and sustained active participation by existing and additional newer centres will augment this process.

This report covers data accrued over a two-year period (1 January 2001 to 31 December 2002) and over 100 centres (including the functioning cancer registries) have contributed and collaborated in the project. The unique feature of this exercise has been the practical application of electronic information technology in medicine. Centres have transmitted core information on cancers, through the internet on to a web-site to the Coordinating Unit of NCRP. The report is therefore a singular example of utilising advances in Information Technology for creating a ready database for research. The potential for using the data and the Information Technology system as a tool for research is enormous.

It is hoped that this first nationwide report will serve as a ready reference manual to describe incidence rates and patterns of cancer. The information provided is exhaustive, nonetheless made simple and clear to the average reader and scientist alike. To collate data, make checks on the same, generate tabulations and prepare a timely report, so as to meet international standards is no easy task. The collaborating centres and the Coordinating Unit of NCRP and their staff deserve all the appreciation for the stupendous effort.

The monetary support provided by the WHO - Government of India is gratefully acknowledged.



Prof. N. K. Ganguly,
Director General, ICMR

5 April 2004

There is nothing more difficult to take in hand or more perilous to conduct or more uncertain in its success than to take the lead in the introduction of a new order of things.

Machiavelli (1469-1527)
Italian Author & Statesman

P R E F A C E

This report on the project on "Development of An Atlas of Cancer in India" is unique in many ways. The internet as a medium of communication has been used to capture data on cancer. Several centers throughout the country have participated in this project and made use of electronic information technology in an extremely effective way. The successful working of this project as evidenced by this report marks an important milestone in gathering disease related information in a coordinated way and gives scope for similar application for other diseases. The concept and design are extremely meaningful as information has been received in a very cost effective way and the results achieved in a remarkably short time. The National Cancer Registry Programme of the Indian Council of Medical Research and its team of collaborators deserve all the praise for the tremendous effort.

Apart from creating a system, the results itself have brought a whole set of new findings which hitherto was unknown. To mention a few-some of the districts in the country have the highest incidence rate in the world of sites of cancer associated with use of tobacco. These include cancer of the mouth in Wardha district of Maharashtra, Kanniyakumari district of Tamil Nadu, in Kollam and Thiruvananthapuram districts of Kerala and in Pondicherry. Aizawl district in Mizoram State has highest incidence rate of Tongue, Hypopharyngeal and Oesophageal cancer in males. Cancer of the Gall Bladder in females has the highest incidence in Chandigarh and in Manipur (Imphal East and West districts). There seems to be a belt of very high incidence penile cancer in North East Tamil Nadu and Pondicherry. Similarly a belt of oral cavity cancer is seen across Gujarat. There are many such fresh findings that have come to light in this exciting scientific report.

This comprehensive document in two volumes opens the door for cancer research in all its dimensions be it administrative and control, basic and laboratory or field and clinic.



30 April 2004

J.V.R Prasada Rao
Health Secretary
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ABOUT THE PROJECT

Cancer is responsible for about 20% of all deaths in the industrialized countries and 10% in the developing ones. The epidemiological and demographic transition is likely to increase the cancer burden in developing countries, including India. Information about the frequency and patterns of cancer is an essential pre-requisite for undertaking cancer control programmes.

The National Cancer Registry Programme of the Indian Council of Medical Research has a network of population-based cancer registry programmes in India and has been providing information on cancer incidence in India. However, this information has been limited to urban areas. The Government of India and WHO collaborative programme for the biennium 2001-2002 has supported the National Cancer Registry Programme of the ICMR to develop an 'Atlas of Cancer in India'.

This technical report provides an analysis of over 2,00,000 cancer cases in India collected during a two-year period from 105 centres. The district has been taken as a unit to obtain incidence rates of cancer. The minimum age-adjusted incidence rates based on microscopically diagnosed cases have been calculated for the districts. The same has also been calculated for the Population Based Cancer Registries under the National Cancer Registry Programme of India. Besides describing the pattern of cancer in the 82 districts that have minimum rates above the lowest seen in population based registries, the incidence rates of individual specific sites are compared with the incidence rates of the population registries.

Several districts have been found to have very high rates of cancer, which are above that of the highest incidence rates reported elsewhere from the world. These include sites of cancer associated with the use of tobacco, cancer of the stomach, gall bladder and penile cancer, to name a few.

This information that has been generated needs to be used for developing a comprehensive cancer control programme at the district level. The majority of cancers are tobacco related and hence are amenable for primary prevention. We hope that this information will be made available to various categories of personnel who are involved in cancer control activities.

We would like to place on record our appreciation for the National Cancer Registry Programme of the ICMR and all the participating centers for the good work and the successful completion of the project.

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The prime person responsible for the sanction of this project was Dr Ravi Rangachari, then Chief of the Indo-Foreign Cell of ICMR. He was instrumental in making the crucial efforts at the Ministry of Health and the WHO to get the project cleared. Dr Nandakumar expresses his profound gratitude to him. This helpfulness has been sustained, by the present Chief of the Indo-Foreign Cell - Prof. S.C. Sehgal and his deputies - Dr Mukesh Kumar and Dr Harpreet Sandhu.

The project and report was made possible because of the funds provided by the WHO through the Ministry of Health, Government of India. Funds were provided for the main project and also for the regional and All India Workshops which were essential to the success of the project. The authors extend hearty thanks to Dr Jerzy Leowski, Regional Advisor, Noncommunicable Disease Surveillance at the South East Asia Regional Office of WHO and Dr Cherian Varghese, National Professional Officer, WR-India Office of WHO for their active participation in the workshops and giving the impetus to the participants for active collaboration.

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The Heads of Collaborating Centres, the Principal Investigators, Co-Principal Investigators and other concerned faculty have contributed overwhelmingly towards the success of the project. Their active participation in the workshops and their motivation and tireless efforts in sending data promptly has been of great help in bringing out a timely report. The authors record their appreciation.

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The staff of the Coordinating Unit of NCRP has worked as a team in bringing out this report and the Chief Principal Investigator expresses his gratitude to them. Dr Ramachandra Reddy and Dr Kumaraswamy have taken keen interest in doing the proof reading yet again and we thank them profusely.

This short report tries to tell how much and what type of cancer is occurring where in at least some parts of the country so as to attempt and seek answers to the more complex questions of the how and why of cancer and what needs to be done.

DEVELOPMENT OF AN ATLAS OF CANCER IN INDIA

First All India Report: 2001 - 2002

Executive Summary

The present account on the project on "Development of an Atlas of Cancer in India" is the First All India Report covering the calendar years 2001 and 2002. Under this project, a cost-effective design and plan using advances in modern electronic information technology, was conceived, to collate and process relevant data on cancer. This was mainly to have an idea of patterns of cancer in several other parts of the country not covered by the registries under the National Cancer Registry Programme (NCRP) of the Indian Council of Medical Research (ICMR). Wherever possible, it was also envisaged to calculate estimates of cancer incidence.

Knowledge of patterns of cancer is important to know what type of cancer is occurring where and if possible how much and to what extent. Only this will provide a background to search answers to questions related to causation of cancer, a baseline for undertaking, monitoring and evaluation of cancer control measures, and an environment for administering optimum care and measuring outcome.

The data that has been collated by the NCRP over the years has shown that over 80-85% of registered cases of cancer has a microscopic diagnosis. Making a microscopic diagnosis of cancer is the domain of the pathologist. Accordingly, the basic principle of working in this study, was to have the department of pathology (in medical colleges and hospitals) as the focal point of capture of information on cancer cases. However, several clinicians working in oncology have actively collaborated.

Accordingly, all medical colleges (both the Principals and Heads of the Departments of Pathology) throughout the country were contacted for their interest to collaborate in the two-year project. Those who responded were supplied with core forms for collecting basic information (mainly patient identification details including area of living, and site and morphology of tumour) and provided guidelines for collecting this information on all malignant cases reported in the department of pathology from 1 January 2001. Visits were made to these potential collaborating centres and on the spot instructions given. During the visits their need for support was assessed and depending on the infrastructure and average number of malignancies reported per annum, facilities for computer and internet connectivity and data collation provided. Intense training workshops in the four regions of the country were held. Principles of cancer registration, data collation, transmission and fundamentals of epidemiology constituted the thrust areas of training at the workshops. The workshops and visits contributed a great deal to the success of the project.

The Internet was identified as the primary communication medium for collecting the data. Internet as a device for data collection on patient information was a unique concept being tried for the first time (in India and to the best of our knowledge anywhere else in the world) under the project. Collaborating centres

were given an individual login-ID and password with detailed instructions on entering the core patient information and steps for onward transmission. The data so transmitted was downloaded periodically at the Coordinating Unit of the NCRP. Data was also received through floppy disks and photocopies of completed forms. Several detailed checks were done on the data so as to meet international standards. Where needed, clarification was sought from individual centres. A variety of duplicate checks to ensure that no case was counted twice were also carried out. Strict inclusion criteria were adopted.

The regular accepted measures by cancer registries for analysis, tabulation and estimation of incidence rates were followed. In all there were a total of 2,17,174 cases for the two-year period (1 January 2001 to 31 December 2002) from 105 centres including the cancer registries under the NCRP and other functioning cancer registries. The district was taken as a unit for calculation of incidence rates. The advantage of using the district as a unit, was that these are reasonably well demarcated geographic areas where the five year age group population is available from the Census of India Publications. Thus the age adjusted incidence rates (that is normally used for calculation and comparison of incidence rates) per 100,000 population were calculated for each district. The district wise incidence rates were compared with the incidence rates of the regular Population Based Cancer Registries (PBCRs) under the NCRP. Since the registry at Barshi is the only rural registry and most of the 593 districts in the country are predominantly rural, the incidence rate at Barshi (36.2 /100,000 in males) was taken as the cut-off level to look at patterns of cancer in different districts. There were 82 districts that had incidence rates above this level. The incidence rates and patterns of the leading sites of cancer in many of these districts revealed several new features.

For all sites of cancer put together, in males, there were ten districts that had incidence rates higher than that of Delhi, which had the highest rate among the PBCRs under NCRP. The corresponding number of districts in females was four. Similarly, in most of the individual anatomical sites of cancer there were several districts for each site that showed higher incidence rates than that of the urban PBCRs for that specific site.

The relatively higher incidence of several sites of cancer especially cancer of the stomach and cancers associated with the use of tobacco in both men and women, in many districts of the North Eastern states were important new features in this report. The high incidence of cancer of the cervix in women and penile cancer in men in the northern districts of Tamil Nadu were remarkable. The cancer registry in Delhi has been recording a high incidence of gall bladder cancer in women. That there could be several other areas with equally or even higher incidence of this cancer in women is notable. The other finding of interest includes the relatively higher incidence of cancer of the thyroid in women from the southern tip of India along the Kerala and Karnataka coasts to Goa. This study has revealed some more though less specific observations for further investigations.

A massive exercise such as this project on developing an atlas for cancer in a vast country like India with varied types of populations, differing literary and socio-economic status has its limitations. First, the coverage of information on cancer cases was far from complete. There were several almost entirely uncovered states like Bihar, U.P., Jharkhand and Chattisgarh and only partial coverage of other states. Even within the specific local area of the collaborating centres, no active effort was made by all centres to collect information on microscopically diagnosed cancers reported in the neighbourhood hospitals/laboratories that are not part of the study. The second major limitation was in using minimal age adjusted incidence rates as a

surrogate measure of calculating incidence rates. Normally, for a population based cancer registry, cancers diagnosed by means other than microscopic, viz., clinical, radiological, endoscopy, etc are included as a cancer case. In addition, death records are scrutinised for cancer as an underlying or antecedent cause of death. Such cases are matched with incident cases and the unmatched cases are considered as 'Death Certificate Only'. A PBCR includes such cases and all cases together provide numbers for calculation of incidence rates. This study was designed only to collect information on microscopically diagnosed cancers. Despite these limitations, the incidence rates used in this study was found to be a fairly dependable cost effective measure of incidence and patterns of cancer in diverse districts of the country.

Apart from the observance of several new patterns of cancer in many areas, the major outcome of this project has been the successful application of electronic information technology in the field of medicine in an extremely cost-effective way (at approximately Rs 24 per case). If well augmented, it could pave the way for extensive usage and opening the field of health informatics.

Sustained support on a long-term basis with scope for considerable expansion would be required for setting up a composite database through what may be called a National Electronic Surveillance System for Cancer. That then would constitute a sound platform for quality research in cancer in all its dimensions. This could be for observing incidence and patterns across a wide spectrum of populations, evolving analytic studies in molecular epidemiology to seek clues in cancer aetiology, looking at patterns of cancer patient care and survival so as to regulate management and, last but by no means the least for monitoring and evaluation of cancer control measures.

Corrigendum

The estimated population of Villupuram(males) and Thanjavur(males and females) districts of Tamil Nadu State were found to be incorrect in the printed report. These populations have been corrected in this CD-report and also on the web-site (www.canceratlasindia.org) with consequent changes in the incidence rates of cancer in these two districts (Villupuram, males and Thanjavur, males & females). All figures of populations and rates have been corrected in tables, figures and text of the report (in CD and web-site). However, the detailed description of the Thanjavur district is retained in the report, though the revised incidence rate of this district is lower than the threshold incidence rate of 36.2/100,000. Readers and researchers are requested to keep this in mind. The error is regretted.