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About NCDIR - NCRP

The National Cancer Registry Programme (NCRP) has been in existence since 1982. The coordinating unit of this programme at Bengaluru was upgraded into a permanent institute, National Centre for Disease Informatics and Research (NCDIR) under Indian Council of Medical Research in 2011. This centre has been a crucial repository of data collected from the collaborating cancer registries located in medical colleges/institutions and hospitals throughout India. The use of Information technology to collate the patient information enforces data standards, instant identification of errors and opportunities for immediate action.

NCRP functions through Population and Hospital Based Cancer Registries (PBCR and HBCR) across different states in India. A PBCR captures information on cancer cases from different health establishments for individuals residing in the catchment area of that PBCR for at least last one year irrespective of place of diagnosis or treatment whereas HBCR captures cases registered in that particular hospital irrespective of place of residence.

NCRP has been generating valid estimates on burden, pattern and trends of cancer in different parts of the country addressing geographical and ethnic variation in pathogenesis of cancer. NCRP provides a direction to cancer component of National Program on Cancer, Diabetes, Cardiovascular disease and Stroke (NPCDCS) for planning prevention programme, establishing treatment facilities, allocating resources and assessing the impact of specific activities such as screening, awareness generation etc.

There are 29 PBCRs under NCRP out of which 11 are in the 8 states of North East (Assam -3, Arunachal Pradesh -2, 1 each in Manipur, Mizoram, Meghalaya, Nagaland, Tripura and Sikkim). There are 29 HBCRs under NCRP network out of which 5 are in the North East Region. ie. Dibrugarh, Guwahati, Aizawl, Imphal, Agartala.

The PBCRs face several adverse conditions and to name a few, cancer is not yet a notifiable disease in our country, the mortality registration system has its own pitfalls and hospitals do not cooperate

at all times. Hence, instituting a PBCR is only a means to an end and not an end in itself. NCRP has been continuously devising different approaches to provide timely assistance and keep the registries afloat. The limitation in the mortality data by the registries under NCDIR- NCRP is mainly refers to incompleteness of the number of cancer deaths which in turn is due to incomplete or incorrect certification of cause of death.

In recent years, the software applications developed by NCDIR have further evolved and so has the data submission methodology and overall support. Hospitals that have access to IT infrastructure can use the oncology modules for pathology, radiotherapy, medical oncology and surgical oncology developed by NCDIR to register information on patients as part of their routine work. These are available online free of cost for all the interested hospitals and laboratories. This would reduce the effort and time spent in visiting these sources to collect the data.

The incidence data from 11 out of 18 PBCRs of India have been published in Cancer Incidence in Five Continents (CI 5) Vol X published by International Association of Cancer Registries (IARC-WHO).

National Centre for Disease Informatics and Research (NCDIR) employs scientific staff constituting of medical scientists, computer science scientists, statistical scientists and technical assistants. This institute has immense potential as professionals belonging to several streams are working under the same roof. Training programmes, workshops and meetings are conducted regularly to keep the staff abreast with the new knowledge and the progress made by the centres. Additionally, it has undertaken tasks in data formatting, checking and submission of data to several international studies on behalf of the registries.

Foreword



सत्यमेव जयते
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The ICMR-NCDIR has been running the National Cancer Registry Program (NCRP) at several sites in the country since 1982, providing robust data on cancer burden, trends and outcomes through its 29 Population Based and 29 Hospital Based Cancer registries. The coverage of NCRP in the 8 States of North East has been very comprehensive and hence the data is of very high quality. It is an outcome of a partnership and hard work of investigators in all the States of North East.

I am pleased to note that ICMR-NCDIR has prepared a report of the cancer registries of the North East to highlight the magnitude of the cancer burden so as to drive appropriate policy measures, programmatic implementation and advocacy for greater efforts to undertake comprehensive cancer prevention and control initiatives. It also provides an impetus to strengthen research and interaction with public health efforts to address the burden of cancer. This would help in generation of awareness amongst stakeholders as well as development of evidence based policies for cancer management and prevention in the NE.

I hope that this report is disseminated widely to all stakeholders so that the high burden of cancers in the North East can be dealt with effectively. I wish this endeavor all success.


(Soumya Swaminathan)

Preface



NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH NATIONAL CANCER REGISTRY PROGRAMME

(INDIAN COUNCIL OF MEDICAL RESEARCH)

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The ICMR-NCDIR National Cancer Registry Program (NCRP) has developed a strong network of population and hospital based cancer registries in the north east states of India collecting and reporting high quality cancer data. Accordingly, the cancer burden reported is high with unique features and distribution across the region. The efforts have been guided by Secretary Department of Health Research & Director General, ICMR, ICMR-NCDIR Scientific Advisory Committee and Research Area Panel on Cancer and the tireless work of the investigators in the registries.

It is thus appropriate that a focused approach to address the burden of cancer be initiated. ICMR-NCDIR has prepared this special report “**A Report on Cancer Burden in North Eastern States of India**” highlighting the key pooled cancer scenario as well as state wise problem of cancer. Briefly, the leading sites of cancers, trends wherever available, treatment related information, status of risk factors and exposures for causing cancer and health systems preparedness to tackle cancers is alluded to. At the end of each chapter there are advocacy points and take home messages for initiating action.

The report shall be useful in creating awareness about cancer scenario amongst the key stakeholders in a brief and lucid manner and stimulate thoughts of undertaking appropriate research and evidence driven policies and programs for cancer control.

(Prashant Mathur)

Message

Dr. G. K. Rath, M.D.

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It gives me immense pleasure to note that the NCDIR, Bangalore is bringing out a report on incidence and patterns of cancer in North Eastern States. The earlier reports published in 2006 and 2008 covered the registries only from four states Assam, Manipur, Mizoram and Sikkim and now this present report covers entire eight states of North Eastern India.

For the first time besides providing types of cancer occurrence in this region it also provides ethnicity variation which is immensely interesting.

I hope that this report will serve as the base for aetiological studies on cancer apart from instituting region specific cancer control measures.

I take this opportunity to congratulate the principal investigators and all staff of north eastern cancer registries who had put their hard work for collection of data from various sources without whom this is impossible.

I also congratulate Dr. Prashant Mathur and all staff of NCDIR, Bangalore for their tireless effort to bring out this report of international standard.



(G.K. Rath)

Acknowledgement

It gives us immense pleasure to bring out a special report of ICMR – NCDIR, National Cancer Registry Programme on Cancer in North Eastern States of India.

We hereby acknowledge the guidance and support of Dr. Soumya Swaminathan, Secretary DHR and DG ICMR for the National Cancer Registry Programme and providing a platform to prepare a report of this kind.

We sincerely acknowledge all the Principal Investigators and Co – Principal Investigators of the North Eastern States for their consistent efforts over the years in strengthening cancer registration activities.

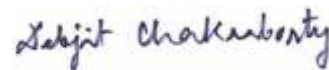
We heartily acknowledge the encouragement and enthusiasm of Dr. Prashant Mathur, Director, ICMR-NCDIR to take this initiative and put an effort to bring out this report.

The mammoth task of running a cancer registry is accomplished only by the sincere and coordinated hard work of all registry staff which include Medical Research Officer, Computer Programmer, Social Investigators and Data Entry Operators. Their contribution is very critical in preparation of this report.

Moreover, we would like to thank our Scientific Advisory Committee and Research Area Panel members on Cancer for guiding continuously on effective implementation of the National Cancer Registry Programme. Their inputs in every aspects of work is very pivotal. This achievement of NCRP in North East has been duly facilitated by the Division of NCD, ICMR New Delhi and ICMR-Regional Medical Research Centre, North East, Dibrugarh.

We acknowledge Dr. A. Nandakumar, former Director- in Charge, ICMR-NCDIR who has laid the foundation of this report by setting PBCRs and HBCRs in North Eastern States decades ago.

Last but not the least, we appreciate the hard work of our scientific, technical and administrative colleagues (Mrs. F. S. Roselind, Dr. Sukanya R, Dr. Meesha Chaturvedi, Mr. K Vaitheeswaran, Mr. Sudarshan K.L., Sathish Kumar K., Mr. Monesh B Vishwakarma, Mr. Stephen S. and others) at ICMR- NCDIR to prepare this high quality report in a such a short period.



Dr. Debjit Chakraborty

(Scientist- B, ICMR- NCDIR)



Mrs. Priyanka Das

(Scientist- C, ICMR- NCDIR)

Summary

More than thirty years journey of National Cancer Registry Programme (NCRP) has not only led to its enrichment and expansion into different parts of the country but also culminated in the establishment of a permanent institute of Indian Council of Medical Research (ICMR) namely National Centre for Disease Informatics and Research which has a very high potential of leading the public health informatics as well as research particularly on cancer and other non-communicable diseases in a developing country like India.

Population Based Cancer Registries (PBCRs) have always remained the corner stone of NCRP particularly from the public health point of view. Perhaps PBCR is the only source which provides authentic data on incidence and mortality of cancer in various parts of the nation for a defined period. As heredity and environment remain the two major determinants of cancer, understanding of wide geopathological variation in a country like India is almost imperative in order to address the problem of cancer. Here lies the importance of PBCR data.

This report on the cancer burden of North eastern states is based on the analysis of the data from 11 PBCRs including two new ones (Naharlagun and Pasighat from Arunachal Pradesh). The coverage of population based cancer registries is around 35% of the population of North Eastern states. Nonetheless, it reflects the cancer profile of the region fairly well owing to representation of all the eight states of North East partially or completely.

Core Focus

Cancer incidence rate is generally expressed as Age Adjusted Incidence Rate (AAR) per 100,000 populations in order to ensure comparability between different states and nations having varied population profile with respect to age groups.

This report provides pooled analysis of cancer problem in the North East in comparison to Rest of India. Higher incidence, low survival, lower detection of localized cases, different cancer pattern etc were

observed in North Eastern states which needs to be adequately addressed.

Among males, Aizawl District in Mizoram state shows the highest AAR followed by Papumpare District under Naharlagun PBCR in Arunachal Pradesh. The order is reversed in females, with Papumpare District recording the highest AAR followed by Aizawl District.

State wise analysis will provide specific cancer profile of each states where we can observe an interstate heterogeneity in terms of leading sites, proportion of tobacco related cancer, trend of cancer incidence etc. Additionally, the chapters will include an overall situational analysis of demography, cancer related risk factors, health system and health practices including mortality reporting status of each state. This will provide a multidimensional and holistic view of cancer problem and possible intervention point within each state. This information will facilitate State Health officials and policy makers to develop roadmap for public health programme implementation and evidence to policy translation for cancer as well as other non-communicable disease risk factors.

Thrust Areas for Research, Programme Planning and Policy Making

The unique cancer profile of the north eastern region is characterized by predominance of cancer of upper digestive tract particularly Oesophagus, Stomach, Hypopharynx etc. Cancer of Nasopharynx and cancer of Gall bladder in Nagaland and Kamrup urban district of Assam respectively show highest incidence among all PBCRs in India. Cancers of the Mouth, Lung, Cervix Uteri and Breast continue to remain a major public health threat. In Dibrugarh district of Assam there is high proportion of Breast cancer although the population is predominantly rural. Burden of various risk factors such as tobacco, alcohol etc was very high compounded by lower participation rates in cancer screening programmes.

All these findings require multidisciplinary and multidimensional research for addressing and mitigating the cancer problem in the North East which may be accomplished by a region specific and state specific endeavors. The purpose of this report is to provide a direction to all stakeholders to plan such initiatives.

Awareness generation and availability of efficient screening programme should be two sides of the same coin for early detection and treatment particularly for the sites where these can play a major role to improve the prognosis. Basic information on cancer may be made available to patients attending hospitals with any symptoms as an opportunity for health education. Women attending health facility for any reproductive health issues could be informed about self-examination for Breast cancer and preventive measures for both Cervical and Breast cancers.