

**NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH**  
**NATIONAL CANCER REGISTRY PROGRAMME**  
*Indian Council of Medical Research*

**Three-Year Report of  
Population Based Cancer Registries  
2012-2014**

*Incidence, Distribution, Trends in Incidence Rates  
and  
Projections of Burden of Cancer*

*(Report of 27 PBCRs in India)*

**Bengaluru, India**

*March 2016*

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The publications of NCDIR-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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# NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

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\* Thiruvananthapuram District is referred as Thi'puram District in the tables and figures

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# FOREWORD



सत्यमेव जयते

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The consolidated report of the twenty seven Population Based Cancer Registries (PBCRs) 2012-2014 is the second report of PBCRs since the establishment of the permanent institute - National Centre for Disease Informatics and Research (NCDIR) in 2011. It provides insight into the data collected from all the PBCRs under the National Cancer Registry Programme (NCRP) for the years 2012-2014.

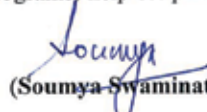
The hallmark of these consolidated reports of PBCRs is that, each new report incorporates data from newer registries thus bringing in information on cancer profiles from newer terrains of the country. This time three new registries namely, Naharlagun and Pasighat PBCRs from the North Eastern state of Arunachal Pradesh and Patiala PBCR from the state of Punjab have contributed data.

The international comparison of cancer rates with the Indian registries and cancer trends for the data collected from six oldest PBCRs would be of interest for all readers.

The staff working in the PBCRs have put in a lot of hard work to abstract, collate, verify and transmit the data to NCDIR. Likewise, the team at NCDIR has made good efforts to ensure that the data reported is of international standards. The number of institutions that make available their data to each PBCR especially in the metros has gone up manifold and their contribution is gratefully acknowledged.

NCRP has always propagated the use of information technology to support, improve, and enhance the management and exchange of electronic data in cancer surveillance and it is reaping the dividends now.

It would be extremely rewarding to all the people involved in this exercise if the information presented is used for planning and evaluation of cancer control programs, help set priorities for allocating health resources and promotion of future research.

  
(Soumya Swaminathan)

“It is more important to know what sort of person has a disease than to know what sort of disease a person has.”

*Hippocrates*

\* \* \*

“We look for medicine to be an orderly field of knowledge and procedure. But it is not. It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line. There is science in what we do, yes, but also habit, intuition, and sometimes plain old guessing. The gap between what we know and what we aim for persists. And this gap complicates everything we do.”

*Atul Gawande,  
Complications: A Surgeon’s Notes on an Imperfect Science*

\* \* \*

It is a capital mistake to theorize before one has data. Insensibly one begins to twist facts to suit theories, instead of theories to suit facts.

*Sir Arthur Conan Doyle*

\* \* \*

That which today calls itself science gives us more and more information, and indigestible glut of information, and less and less understanding.

*Edward Abbey*

\* \* \*

“Be sceptical, ask questions, demand proof. Demand evidence. Don’t take anything for granted. But here’s the thing: When you get a proof, you need to accept the proof. And we’re not that good at doing that.”

*Michael Specter*

\* \* \*

“Whenever you read a cancer booklet or website or whatever, they always list depression among the side effects of cancer. But, in fact, depression is not a side effect of cancer. Depression is a side effect of dying.”

*John Green, The Fault in Our Stars*

# Three-Year Report of Population Based Cancer Registries 2012-2014\*

## 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 consolidated PBCR report for 2012-2014 is based on the analysis of the data from 27<sup>#</sup> PBCRs including three new ones (Naharlagun and Pasighat from Arunachal Pradesh and Patiala from Punjab). Reports of two other PBCRs – Hyderabad and Ahmedabad Rural have not been included here although some description of their work has been mentioned. The coverage is less than 10% of the population of India. Nonetheless, it reflects the cancer profile of the country fairly well owing to representation of registries from different parts of the country.

### Core Focus

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

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. The incidence rates by each PBCR are given in Chapter 1.

\*# Refer to note on page 26

Chapter 2 describes the leading sites of cancer in different PBCRs. Among males, cancers of lung, mouth, oesophagus and stomach are the leading sites across most of the registries. Lung cancer is the leading site in Bangalore, Chennai, Delhi, Mumbai, Manipur, Aurangabad, Kolkata, Kollam, Thiruvananthapuram and Tripura. Mouth is the leading site of cancer in Barshi Rural, Barshi Expanded, Bhopal, Ahmedabad Urban, Nagpur, Pune and Wardha. Cancer of the oesophagus is the leading site in the registries in the state of Assam, Meghalaya and Patiala. Stomach is the leading site in Sikkim, Mizoram and the two registries in Arunachal Pradesh namely, Naharlagun and Pasighat while cancer of the nasopharynx is the leading site in Nagaland.

Among females, cancer of the breast is the leading site of cancer in 19 registry areas. Cancer of the cervix uteri is the leading site in 6 registry areas viz., Barshi Rural, Barshi Expanded, Mizoram, Tripura, Nagaland and Pasighat PBCRs. Cancer of the oesophagus led the list of cancers in Meghalaya. Stomach was the leading site in Naharlagun PBCR.

Chapter 3 gives the proportion of cancers associated with the use of tobacco. East Khasi Hills district of Meghalaya had the highest relative proportion with 69.5% and 45.0% for males and females respectively. Excluding the north east PBCRs, the highest proportion of TRC was observed in Ahmedabad Urban PBCR for both males (56.3%) and females (19.8%).

Chapter 4 deals with cancers in childhood. Among boys, the proportion of cancers in childhood relative to cancers of all ages varied from 0.7% in Nagaland PBCR to 5.4% in Delhi PBCR. Among girls, it ranged from 0.5% in East Khasi Hills District of Meghalaya to 3.5% in Naharlagun excluding Papumpare district.

Chapter 5 gives the number and proportion of different methods of diagnosis and Chapter 6 deals with cancer mortality.

Chapter 7 provides a comparison of cancer incidence and patterns in 27 PBCRs along with 7 sub areas (districts or combination of districts) within the states of Manipur, Mizoram, Meghalaya and Arunachal Pradesh. The site-wise AARs of the three newest PBCRs viz., Pasighat, Naharlagun and Patiala have also been compared with the other PBCRs. Papumpare District under Naharlagun PBCR of Arunachal Pradesh had the highest AAR in cancers of the stomach and liver for males and stomach, cervix uteri, ovary and thyroid for females in comparison to all other Indian PBCRs. Pasighat PBCR had high AARs in stomach, liver (males), cervical and ovarian cancers. Patiala PBCR had high AARs in breast, brain NS (males) and oesophageal cancers. ***Since this data is being reported for the first time from these PBCRs, it needs to be viewed with some caution as in the initial years of registry operation there could be some degree of over/under reporting and the fact that Pasighat PBCR has reported small numbers in some sites of cancer.***

Chapter 8 compares the AARs of Indian PBCRs with the International rates. East Khasi Hills district of Meghalaya had the highest AAR in cancers of the tongue and hypopharynx in males. Among females,

Bhopal showed the highest AAR in cancer of the tongue whereas Kamrup Urban District showed the highest AAR in cancer of the hypopharynx.

Chapter 9 on Data Quality and Indices of Reliability concentrates on critical parameters to assess the standards of the data collected and submitted by the cancer registries that require regular scrutiny and audits. The registries can evaluate their data to reduce the percentage of unknown and unspecified variables (age, duration of stay & sub sites), percentage of unspecified histology in microscopically verified cases and DCO%. The tables on M/I% ratio and contribution of the main sources of registration are two additional parameters to assess the quality of the data. One way to overcome the problems if any, would be to perform re-abstraction of a sample of cases from time to time.

Chapter 10 gives the trends over time for all sites and on selected sites of cancer followed by projection of the burden of cancer.

### **The Drive of Informatics**

Innovation of different software application at NCDIR-NCRP has driven the cancer registration in India to a great extent and the benefits are being realized. PBCRDM 2.1 software runs the quality checks, matching and duplicate check in order to make the data clean and valid. An additional Phonetics software is also used in PBCR only to capture the similar sounding duplicate names, spelt differently. Development of bulk deletion software has made the task of duplicate deletion much easier by deleting huge number of duplicates in very less span of time with almost no effort. An All Cause Mortality import application enables import of all deaths (cancerous and non-cancerous) submitted by the registries in varied format to match with the incidence data and trace the Death Certificate Notifications thus improving the M:I ratio. An application for generation of PBCR Book Report assists to generate the tables in the requisite format post finalization of each registry's data.

### **Thrust Areas for Research, Programme Planning and Policy Making**

There are several other anatomical sites of cancer (as documented in previous reports) that continue to be a challenge in terms of aetiology and control. Cancers of the mouth, lung, stomach, oesophagus, cervix uteri and breast continue to remain a major public health threat. Interesting geographical variation in patterns of cancer within the same country calls for a region specific research and planning of control programmes. Investigation into various possible risk factors particular to the areas of high incidence is imperative.

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.

# NATIONAL CANCER REGISTRY PROGRAMME

The National Cancer Registry Programme (NCRP)\* has been in existence since 1982 with the coordinating unit becoming a permanent institute (National Centre for Disease Informatics and Research (NCDIR)) of the Indian Council of Medical Research in 2011. As before, this centre is a crucial repository of data 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 to rectify the errors. Thereby, data quality is ensured. The software technology has the ability to handle large data sets for scientific research including evaluation of patient care.

The network of the NCRP is given in map figure adjoining this write-up.

PBCRs provide a lead to set priorities for cancer research and identify target sites – both anatomic and geographic, for cancer control measures. 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 and training.

There are 29 PBCRs under NCRP. Older PBCRs especially Bangalore, Bhopal, Chennai, Delhi, Mumbai and Barshi Rural have faced innumerable challenges and have employed registry specific strategies to mitigate the problems. Newer PBCRs and the most recent ones are trying to emulate and learn from the older ones to sustain and flourish. Indian 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.

Rapid reporting is often required from the cancer registries. However, for cancer registries, a trade-off must be recognized between data timeliness and the extent to which the data are complete. The timeliness depends on the rapidity with which the registry can collect, process and report sufficiently complete and accurate data. The PBCRs using PBCRDM 2.1 application can subject the data captured by them to different levels of checking, quality control, duplicate checks and matching. The application provides all the features necessary for a registry to complete its task. This will give more power and control to the registry in validating the quality of the data even before it is submitted to NCRP.

In recent years, the software applications developed by NCDIR have further evolved and so has the data submission methodology and overall support. The PBCRs are either using the PBCRDM 2.1 software applications installed at their institute or they have been using the web based application to enter process and submit the data to NCRP. Some PBCRs have been generating the summary tables and annexure tabulations online as soon as the data has been finalized by NCRP. Hospitals that have access to IT infrastructure can use the oncology modules for pathology, radiotherapy, medical oncology and surgical

*\*The term NCRP is used many times in this report to signify the tasks being executed at the NCDIR, Bengaluru.*

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. It is urged that the PBCRs take active interest in advocating the advantages of using these modules. Relevant data from the Hospital Based software application and the oncology modules transmitted by the hospitals through web based portals can be routed to the Population Based Cancer Registry 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). However, the mortality data were not considered for publication. This is mainly because of the inaccurate certification of cause of death. The mortality-to-incidence ratio (M:I) is an important indicator that is widely used – for example, in CI 5 – to identify possible incompleteness. It is a comparison of the number of deaths, obtained from a source independent of the registry (usually, the vital statistics department) and the number of new cases of a specific cancer registered in the same time period. The present endeavour of the Indian PBCRs would be to improve the quality of data to international standards.

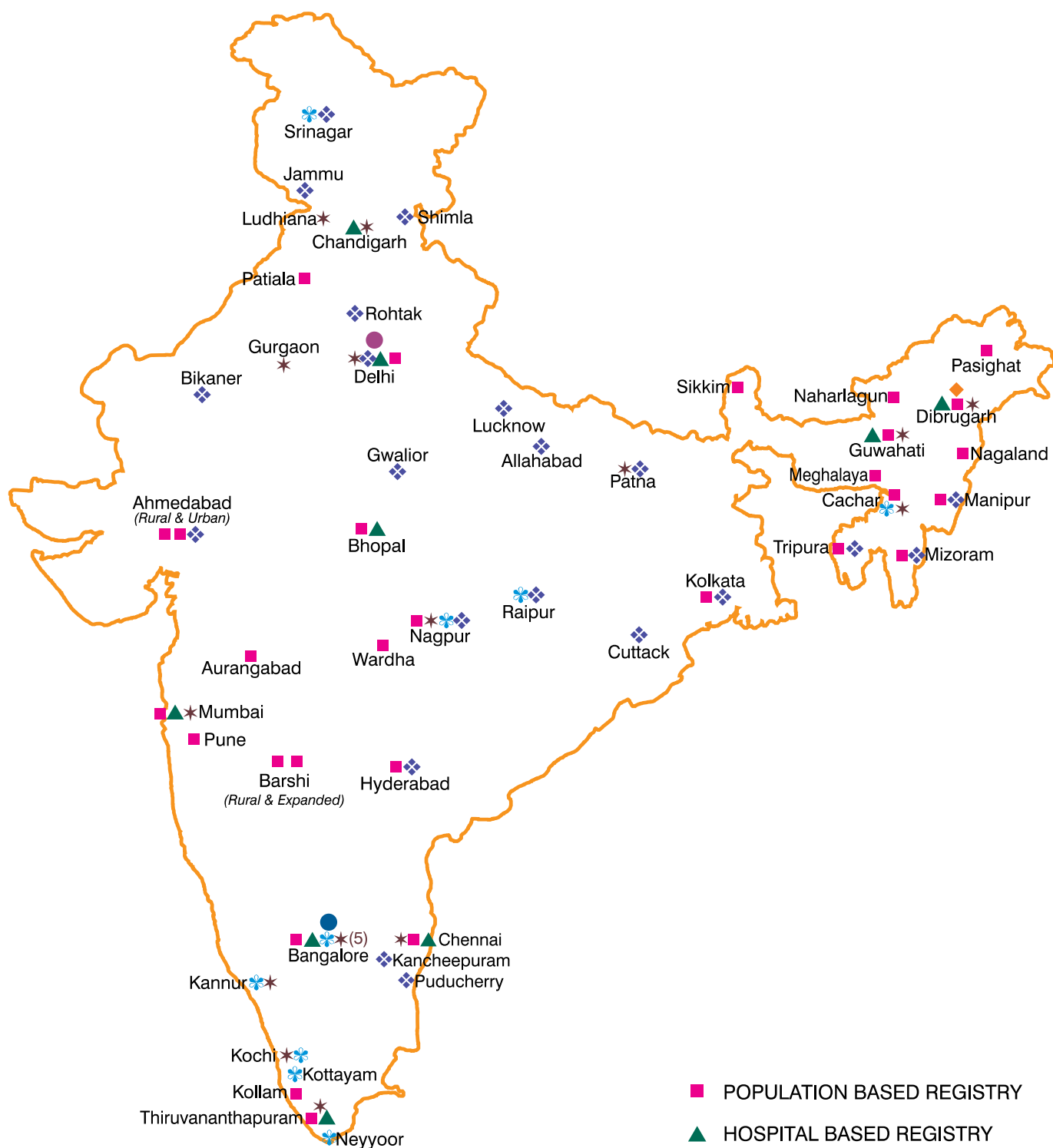
To improve the M:I ratio, ten registries have been providing the All cause mortality data in electronic form to NCRP. The same is being formatted, coded, checked and imported at NCRP to run the matches with the incidence. Thus Death Certificate Notifications are being traced back by the registries to improve the coverage both in incidence and mortality data.

National Centre for Disease Informatics and Research (NCDIR) in the last one year has strengthened its human resource by recruiting new permanent staff. The scientific staff constitutes 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 held regularly to keep itself abreast with 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.

# NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

## NATIONAL CANCER REGISTRY PROGRAMME

(Indian Council of Medical Research)



● ICMR HEADQUARTERS

● NCDIR-NCRP

◆ MONITORING UNIT, NORTH EAST PBCRs

■ POPULATION BASED REGISTRY

▲ HOSPITAL BASED REGISTRY

★ PATTERNS OF CARE AND SURVIVAL STUDIES

❄ CENTRES USING HBCRDM SOFTWARE

◆ HBCR IN REGIONAL CANCER CENTRES