

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

**Consolidated Report of
Hospital Based Cancer Registries
2007-2011**

An Assessment of the Burden and Care of Cancer Patients

Bangalore, India

September 2013

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(Indian Council of Medical Research)
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September 2013

Hospital Based Cancer Registries provided individual core data. Quality Control checks, tabulations and statistical analysis were done at the NCDIR-NCRP, Bangalore.

The publications of NCDIR-NCRP are intended to contribute to the dissemination of authentic information on cancer patterns in the country.

This report for the years 2007-2011 is printed as per the recommendations of the combined meeting of the Research Area Panel (RAP) on Cancer under NCDIR and Steering Committee of NCRP held on 27 April 2012. Keeping in mind the above recommendations, the coordination team at NCDIR, planned and made efforts to help as many HBCRs as possible to meet the 2011 mark with the use of Information Technology. As and when the other HBCRs send in the 2011 data, the tables etc of the respective HBCRs will be updated and the same will be incorporated in the web-version of the report.

Bearing in mind the need for reducing the gap between the calendar year of data and year of report publication, the report of 2012-13 is planned to be got ready during the latter half of 2014. All HBCRs are encouraged to perform real-time data abstraction and entry of the cases so as to enjoy the full power and potential of the software in cleaning and finalizing the data and thereby facilitating early release of the 2012-13 report.

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NATIONAL CANCER REGISTRY PROGRAMME

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<i>Dibrugarh</i>	<i>267-293</i>
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* Thiruvananthapuram is referred as Thi'puram in the tables and figures.

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Staff of NCDIR-NCRP, Bangalore.

“From inability to let well alone; From too much zeal for the new and contempt for the old; From putting knowledge before wisdom, science before art, and cleverness before common sense; From treating patients as cases, and From making the cure of the disease more grievous than the endurance of the same, Good Lord, deliver us”

- Sir Robert Hutchinsinon

FOREWORD



I am pleased to write this foreword on this consolidated report for the years 2007-2011 of seven Hospital Based Cancer Registries (HBCRs). It is the result of work carried out by the registries located at the respective institutions in different parts of the country.

The HBCRs have over the years given an assessment of the magnitude and patterns of cancer in the region being catered by the centre/registry. They have also contributed to the Population Based Cancer Registry. The prime function of HBCRs is to know the patterns of cancer patient care and the outcome. Standardised recording of diagnosis and clinical staging, with clear uniform guidelines for treatment especially under Indian conditions is a big challenge. Regular systematic follow-up of patients for clinical assessment of status of disease in order to judge efficacy or otherwise of treatment is a major concern.

The HBCRs have, helped to know these aspects with reference to patient management of the respective institute, which would not have been possible, but for the presence of the HBCRs. The presence of HBCRs has considerably improved the upkeep of patient medical records in a more scientific manner.

It is hoped that this report will serve as a guide to the treating oncologist, researchers and health administrators to deal with the problem of cancer in different parts of our country.

The coordination and management of the data is the result of considerable effort put in by the staff of the individual HBCRs and that of the ICMR at the National Centre for Disease Informatics, Bangalore. I appreciate the dedicated work of all of them in bringing out this publication.



Dr V. M. Katoch

Secretary, Department of Health Research &
Director General, ICMR

PREFACE



This consolidated report of Hospital Based Cancer Registries (HBCR) under National Cancer Registry Programme (NCRP) for the years 2007-2011, is the result of work carried out by the seven Hospital Based Cancer Registries (HBCRs) located at institutions in different parts of the country.

The broad purpose of a HBCR is to assess and evaluate cancer patient care in the concerned hospital. Information about types of cancer and types of treatment helps in planning the facilities required in the respective hospital, thereby facilitating health services research. Information on short and long term survival of patients according to different patient characteristics and treatment modalities lead to streamlining of management practices and helps in the development of hypothesis for future research in the area.

In bringing about an assessment of the magnitude and care of cancer patients, the need for systematic recording of clinical information is critical. The challenges in recording the same and obtaining follow-up details on a regular and sustained basis for evaluation of outcome of treatment are emphasized. This area needs considerable strengthening by the institutions.

The NCRP has commenced through the HBCRs, a detailed systematic study on 'Patterns of Cancer Patient Care and Survival' in three important sites of cancer, viz., cancer cervix, cancer breast and head and neck cancers. The collaborating centres have evolved strategies for patient follow-up. The results of these studies would give an assessment of stage and treatment based survival at a national level and more importantly in the Indian context paving the way for initiating multi-centric clinical trials with the HBCR as the backbone.

A very high percentage of clinically spread disease is seen when the patients first attend for treatment leading to poor survival. This emphasizes the importance and need of early detection and organizing palliative care and pain relief clinics.

It is hoped that this report will encourage other cancer centres throughout the country to establish their own HBCRs and commence patterns of care studies. The registries and their staff deserve appreciation for the efforts they have put in for collection and analysis of data on continuing basis and for the preparation of this report.

Dr G.K. Rath

Professor, Dept. of Radiation Oncology and Chief
DR.BRAIRCH, AIIMS, New Delhi
Chairperson, SAC of NCDIR and RAP-C &
Steering Committee, NCRP

National Cancer Registry Programme

The Coordinating Unit of the National Cancer Registry Programme (NCRP) which is now the new permanent institute of ICMR – National Centre for Disease Informatics and Research, has been functioning at Bangalore since 1991. The NCRP itself started in 1982 with three Population Based Cancer Registries (PBCRs) and three Hospital Based Cancer Registries (HBCRs). NCRP developed a unique concept of an Atlas of Cancer in India (Nandakumar *et al*, 2005) covering several regions in the country by use of internet for data collection for the year 2001-2002 thus mapping the patterns of cancer region-wise. The outcome of this activity was extensive use of information technology in subsequent activities of NCRP and the commencement of newer registries and commencement of Patterns of Care and Survival Studies (POCSS). As of September 2013, there are 28 PBCRs and 7 HBCRs. Web based HBCR data entry software has been provided to hospitals which are potential HBCRs. With the development of software modules, 55 centres have started using the Hospital Based Cancer Registry Data Management Programme. These centres have contributed data on over 66,000 cases of cancer. In addition, NCRP has 17 hospitals (including the 7 HBCRs) collaborating in the Patterns of Care and Survival Studies (POCSS) for three sites of cancer namely, Cervix, Breast and Head & Neck. The Cancer Atlas project for the state of Punjab has been initiated to collect cancer data from that region. The network of the NCRP is depicted in the map.

With the creation of the new permanent centre, National Centre for Disease Informatics and Research, other diseases namely, diabetes, CVD and stroke have also been included. It intends to plan and facilitate programmes on patterns of patient care and survival in diabetes, CVD and stroke in the not too distant future.

Further details of the working and activities of the NCRP are available in earlier reports (NCRP, 2009; NCRP, 2013) and on the website www.ncrpindia.org. The role of information technology and the more recent activities undertaken vis-à-vis HBCRs are highlighted below.

Hospital Based Cancer Registry Database Management

The project on 'Hospital Based Cancer Registry Data Management under Translational Research' was started as a part of Translational Research with setting up of Hospital Based Cancer Registries with the use of Data Management software (HBCRDM-SW) developed by the team of software professionals at National Cancer Registry Programme for use by cancer centres, individual oncologists or pathologists involved in oncology.

The HBCR-DM-SW is designed with an option of having features of pathology, radiotherapy, medical oncology and surgical oncology. Several upgrades of this programme are on the anvil, which includes integration with a given centre's Hospital Information System or Medical Records. Unlike other software programmes this one has been developed with academic and scientific content and output.

The software programme initially developed as an offline application and later on evolved into an online application. The centres have been transformed from offline to online application depending on the practicability

of internet facility. As of September 2013, 55 centres including the Regional Cancer Centres (12 Nos.) have registered for use of this software application. Centres have been provided with the login ID, password and the printed core forms. The centres are collecting and transmitting the data. Quality check report could be generated by the centres as well by the NCRP. Updates and corrections of the data can be performed online.

Main Features and Highlights

General:

- Sophisticated State of the Art Data Entry that has been Rigorously Tested.
 - ✓ International Standard Checks on Data Quality at both Data Entry and Subsequent Processing
 - ✓ Off-line and On-line Versions
- Generation of Detailed Tables/Charts/Graphs (as in printed report of HBCR) on:
 - ✓ Magnitude of Cancer Patients
 - ✓ Leading Anatomical Sites of Cancer
 - ✓ Basis of Diagnosis
 - ✓ Broad Groups of Treatment
 - ✓ Clinical Extent/Stage of Disease

All of the above by: Department/Unit/Specialist/Any defined time period/New or Old patients

Clinical:

- Treatment Procedures: Number of Surgeries/Radiotherapy or Chemotherapy courses
- Patient Appointment Scheduler
- Waiting time
- Ready List of Patients due for Treatment
- Follow-up Alerts
- Survival by Clinical Stage, Type of Treatment, Anatomical Site etc

Pathology:

- Auto Entry of Codes of International Classification of Diseases
- WHO Histological Classification
- Cross References on same Patient or other cases with same Diagnosis
- Correlation with Clinical Parameters

Hospital Services:

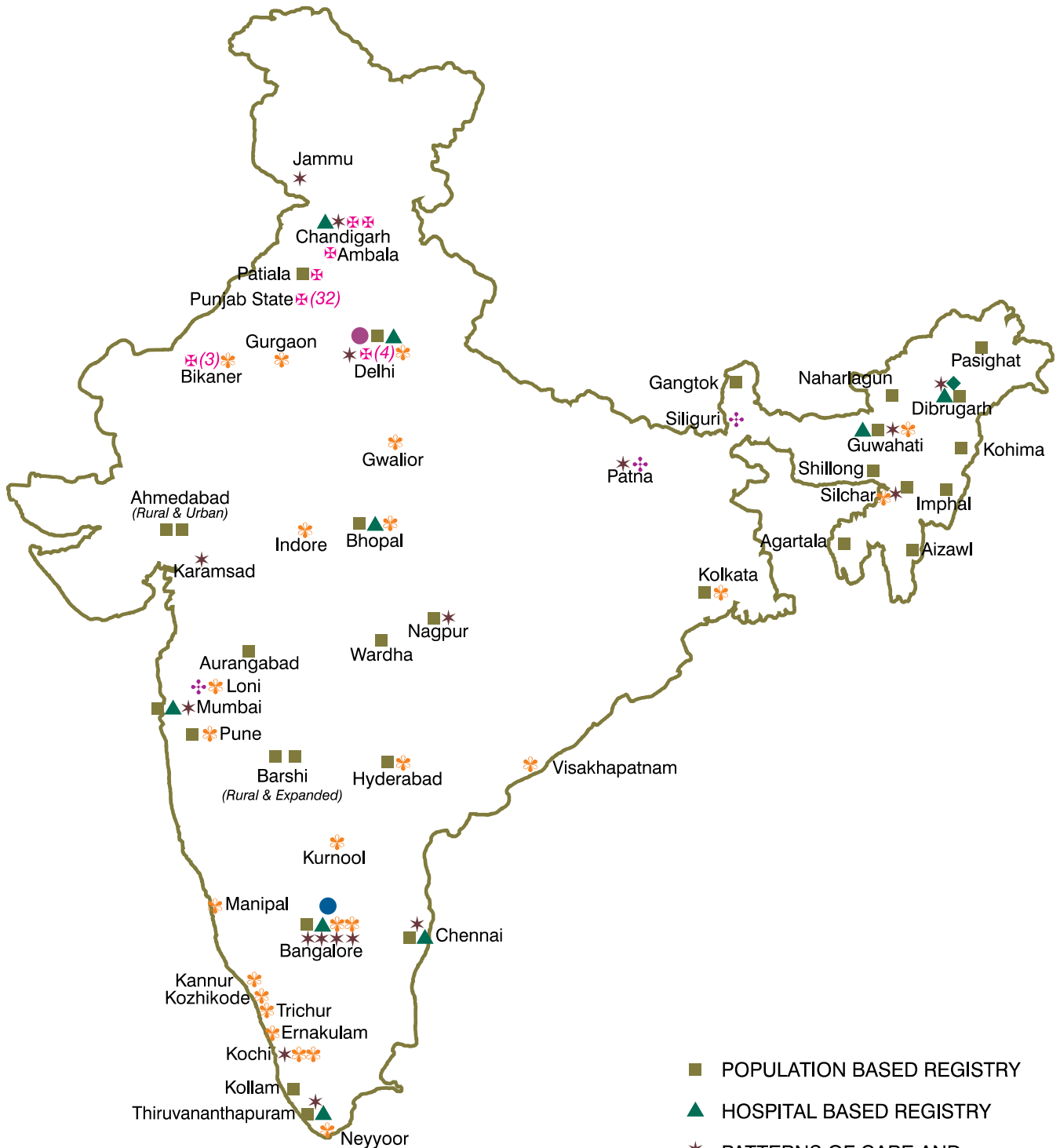
- Provide a variety of information to plan, monitor, evaluate clinical services vis-à-vis costs

Apart from developing software applications, the technical team undertakes the following activities:

- i. Data maintenance of online and offline databases, backups, restore and recovery.
- ii. Provides suggestions on system configurations and network issues.
- iii. Deployment and installations, version releases, patches deployment with bug rectifications;
- iv. Remote support to centres using monitoring and remote control tools.

Although NCRP has established that information technology is here to stay, the key lies in software development being a continuous process of improvisation especially in cancer epidemiology.

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH NATIONAL CANCER REGISTRY PROGRAMME - NETWORK (Indian Council of Medical Research)



- ICMR HEADQUARTERS
- NCDIR-NCRP COORDINATING UNIT
- MONITORING UNIT, N.E. PBCRs
- POPULATION BASED REGISTRY
- HOSPITAL BASED REGISTRY
- PATTERNS OF CARE AND SURVIVAL STUDIES
- CENTRES USING HBCRDM SOFTWARE
- CANCER ATLAS - PUNJAB STATE

Five-Year Consolidated Report of the Hospital Based Cancer Registries: 2007-2011

SUMMARY

The Objectives of Hospital Based Cancer Registries (HBCRs) have been detailed out in an earlier report of the NCRP (NCRP, 2001) including principles and ICD coding (Young, JL, 1991; WHO, 1994, 2000).

This report of seven Hospital based cancer registries (HBCR) includes the data of two new HBCRs (Dr. B. Borooah Cancer Institute, Guwahati and Postgraduate Institute of Medical Education and Research, Chandigarh) that have commenced working and contributed data to this report. Thus, the five year (2007-2011) report of the seven HBCRs is the contribution of data from the following hospitals, namely,

1. Tata Memorial Hospital, Mumbai
2. Kidwai Memorial Institute of Oncology, Bangalore
3. Cancer Institute, Adyar, Chennai
4. Regional Cancer Centre, Thiruvananthapuram
5. Assam Medical College, Dibrugarh
6. Dr B. Borooah Cancer Institute, Guwahati
7. Postgraduate Institute of Medical Education and Research, Chandigarh

A brief outline of the purpose and ways of interpreting each of the chapters and some areas where additional information should be gathered in order to get a more complete picture is indicated below.

Chapter 1 gives a picture of the overall magnitude of cancers diagnosed at the respective centres. This has to be further examined in the context of number of patients registered and number who were diagnosed earlier. The chapter gives the relative frequencies of the leading sites of cancer in broad age groups.

Chapter 2 deals with different types of cancers in childhood.

Chapter 3 indicates the impact of the use of tobacco in the causation of cancer both in proportions and anatomical site of cancer in planning tobacco control activity across the country this baseline is most important. Though, not in a defined population it gives a fair picture of the problem of cancer associated with the use of tobacco.

The basis of diagnosis in Chapter 4 is one index of the reliability of diagnosis. It indicates the proportion of methods of diagnosis used in cancer cases which are classified into microscopic, all imaging techniques, clinical and others. Microscopic diagnosis that includes histology, cytology and haematology constitutes the basis for establishing a diagnosis of cancer.

Chapter 5 gives an overview of the proportion of patients presenting in various conditions of diagnoses and treatment. It emphasizes the need for distinguishing patients who have been treated elsewhere and those treated only at the reporting hospital/institution.

The proportion of patients presenting in different clinical extents of disease is shown in Chapter 6. Clinical extent of disease at presentation of cancer is directly related to the type and effectiveness of treatment. This is one of the most important baseline indicators for initiating cancer control activity in the area and the success of any education and early detection programmes in the area will be reflected in changes in proportions of stage at presentation of relevant sites of cancer.

Chapter 7 gives the details of different types of treatment at the reporting institution. This is for patients who have not received treatment earlier. The types of treatment and their proportions have been tabulated. The types of treatment and their relative proportions give an idea of the forms of treatment pursued in a given institution.

Chapter 8 gives the proportion of the patients who have not received or not accepted treatment, incomplete treatment and treatment status unknown. The chapter gives the relative frequency of the clinical extent of disease for this of group of patients.

Chapter 9 deals with the study on individual sites of Head and Neck Cancers. This includes cancers of Tongue, Mouth, Nasopharynx, Other Pharynx and Larynx.

Chapter 10 deals with the study on cancers in Female Breast.

Chapter 11 deals with the study on cancer Cervix.

Chapter 12 deals with the relative proportions of histological types of cancer for certain specific sites.

Chapter 13 summarises the relative proportion of cases according to education, marital status, religion and language spoken.

Quality of Data

The accuracy of the data depends on its quality, timeliness in data abstraction in a given hospital and is comprehensively covered in Chapter 14. The quality of data from each registry will undergo vigorous checks during data entry and subsequently. Efforts are made by both the individual HBCRs and the coordinators at NCDIR to ensure that the data reported is as correct and as complete as possible. In more recent years the HBCRDM software application programme has greatly helped in enhancing the speed of data submission and its quality.

Use of Electronic Information Technology

Software programmes developed in-house have contributed to a great extent in improving the quality and coverage. Data that is keyed is checked as per international norms. In hospital based cancer registry setup, the core form is mainly divided into three portions namely, Patient Identifying Information, Diagnostic Details and Details of Stage & Treatment which requires recalling the patient record more than one time to complete the form. In order to facilitate the above, partial saving of a record has been provided.



Dr A. Nandakumar

Director-in-Charge