

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH

NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

**Consolidated Report of
Hospital Based Cancer Registries
2012-2014**

An Assessment of the Burden and Care of Cancer Patients

Bengaluru, India

March 2016

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March 2016

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

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).

The members of RAP on Cancer of NCDIR recommended during the meeting held on 14-15 October 2014 that all HBCRs should be renamed with the names of the institutions (as the data is truly that of the respective institution) and not the cities they are housed. Accordingly, in this report the HBCRs have been renamed with the name of the respective institution.

This report for the years 2012-2014 is printed as per the recommendations of the meeting of Research Area Panel (RAP) on Cancer under NCDIR held on 16 February 2016. 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 2014 mark with the use of Information Technology. As and when the other HBCRs send in the 2014 data, the tables etc of the respective HBCRs will be updated and the same will be incorporated in the web-version of the report.

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** This HBCR Report of 2012-14 does not have any data of the HBCR of Regional Cancer Centres under DOHFW, MOHFW funding. These will be included in the 2015-16 report. However, three Regional Cancer Centres (1. Sher-I-Kashmir Institute of Medical Sciences, Srinagar; 2. Regional Cancer Centre, Pt. J.N.M. Medical College & Dr. Bhim Rao Ambedkar Memorial Hospital, Raipur; 3. RST Regional Cancer Hospital Cancer Relief Society, Nagpur) had commenced sending us data using HBCRDM package before commencement of funding and as they have provided at least two years complete data, these centres' report and tables are included in the report.*

FOREWORD



सत्यमेव जयते

डा. सौम्या स्वामीनाथन

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स्वास्थ्य एवं परिवार कल्याण मंत्रालय

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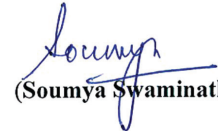
New Delhi-110 029 (INDIA)

The Hospital Based Cancer Registries (HBCRs) provide important information related to efficacy of hospital practices in the management of cancer patients. Knowledge about treatment efficacy 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 this area.

This Consolidated Report of the HBCRs under National Cancer Registry Programme (NCRP) – National Centre for Disease Informatics and Research (NCDIR) for the years 2012-2014, is the result of work carried out by not only the eight Hospital Based Cancer Registries (HBCRs) but also by another nine hospitals that used the Hospital Based Cancer Registry Data Management(HBCRDM) software developed by NCRP-NCDIR, without any additional resources from NCDIR.

The electronic capture of data with online quality checks made the data collection faster and the gap between the calendar year of data and calendar year of report is reduced. The quality of the data has considerably improved with this measure. In recent years NCRP has developed independent modules for pathology, radiation, medical and surgical oncology. These modules are linked to the HBCR-DM software ensuring ease of capturing quality real time data.

Since the report consists of government and private hospital registries, one can make out the patterns of treatment given in different types of hospital settings. This report should serve as a guide to the treating oncologists, clinical researchers and health administrators to examine different aspects of cancer management and problems specific to our country. The staff of the registries and the NCDIR team deserve appreciation for the effort in abstraction, collection analysis and preparation of the report.


(Soumya Swaminathan)

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.

As of March 2016, there are 29 HBCRs (including all Regional Cancer Centres). Web based HBCR data entry software has been provided to 103 hospitals which are potential HBCRs. Patterns of Care and Survival Studies (POCSS) are ongoing in 32 hospitals for three sites of cancer viz., Cervix, Breast and Head & Neck. The Cancer Atlas project for the state of Punjab has collected the data from that region and the report (for years 2012-13) for Punjab State has since been published (www.canceratlaspunjab.org).

Hospital Based Cancer Registry Database Management (HBCRDM)

The main objective of HBCRDM software is to capture the cancer patient's identifying, diagnostic and treatment information registered in the hospital. 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 on data 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
- Generation of Detailed Tables/Charts by overall or each anatomical sites of cancer
 - ✓ Magnitude of Cancer Patients
 - ✓ Leading Anatomical Sites of Cancer
 - ✓ Basis of Diagnosis
 - ✓ Broad Groups of Treatment
 - ✓ Clinical Extent / Stage of Disease

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

Pathology:

- Auto Entry of Codes of International Classification of Diseases
- Auto code conversion from ICD-O-3 to ICD10 classification
- WHO Histological Classification
- Cross References on same patient or other cases with same Diagnosis
- Correlation with Clinical Parameters

Hospital Services:

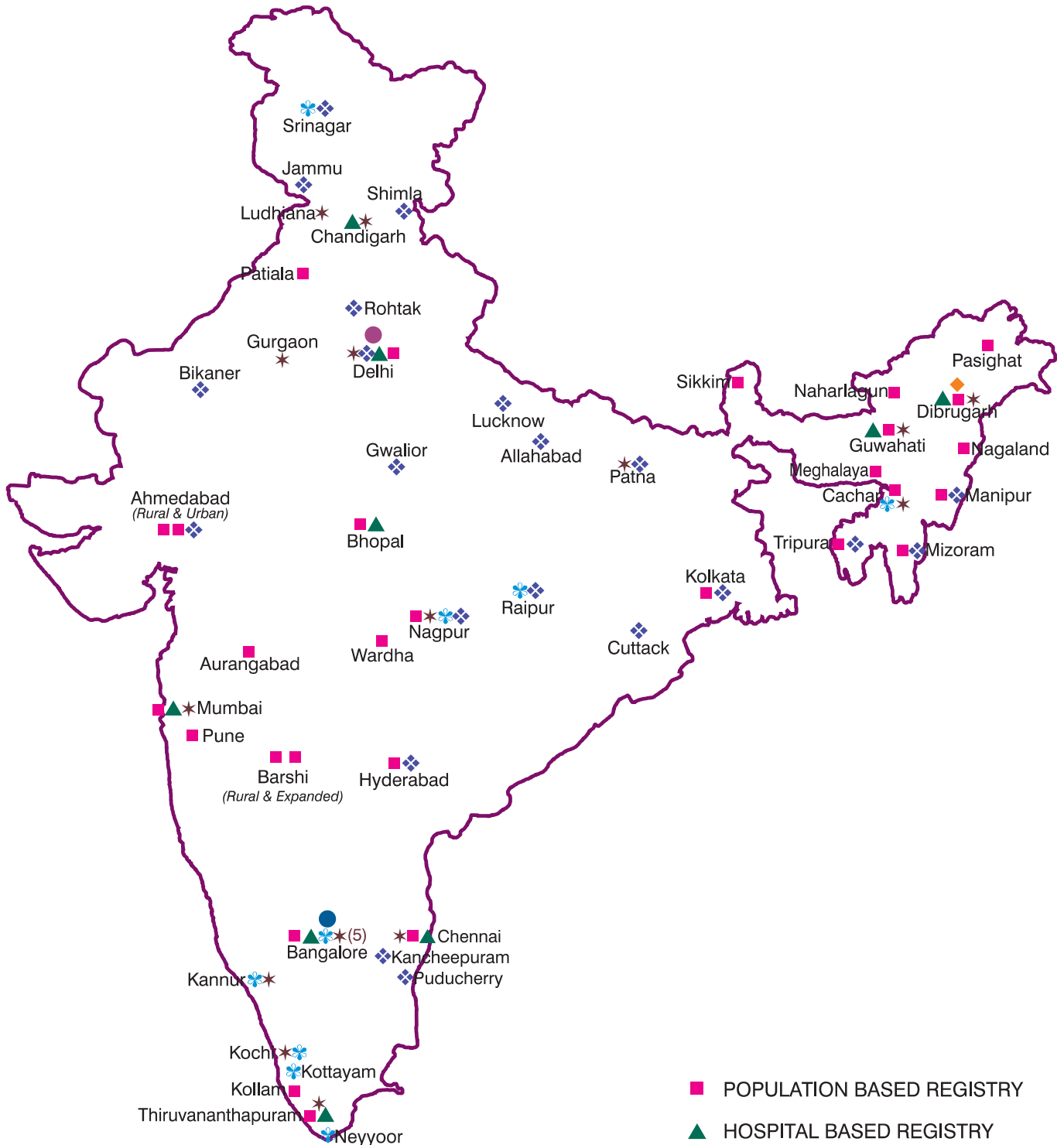
- Provide a variety of information to plan, monitor, evaluate clinical services vis-a-vis costs.

The process of integration of HBCR and Patterns of Care and Survival Studies (POCSS) is a continuation of NCRP software improvisation which is the most recent activity undertaken. The features of integrated HBCR-POCSS software are highlighted below:

- Avoid data duplication and reduce data entry time
- Avoid Data Mismatch
- 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.

NCRP has stepped into the development of independent modules for pathology, radiotherapy, surgical and medical oncology for their routine work. All the modules are inter-linked with HBCR-POCSS software, hence without any additional effort the complete information of patients could be obtained.

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



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● 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

Three-Year Consolidated Report of the Hospital Based Cancer Registries: 2012-2014

Summary

Hospital Based Cancer Registries are concerned with recording of information on the cancer patients seen in a particular hospital (Isabel dos Santos Silva et al., 1999). Data collection is done by standardised common core form for all the registries which mainly consists of patient identifying and demographic information, details of diagnosis, the clinical stage of disease and the broad type of treatment.

Objectives of Hospital Based Cancer Registries (HBCRs) have been defined as follows (MacLennan et al., 1978; Young J.L., 1991):

1. General:

- 1.1 Assess patient care;
- 1.2 Participate in Clinical Research to evaluate therapy;
- 1.3 Provide an idea of the patterns of cancer in the area;
- 1.4 Help plan hospital facilities.

2. Specific:

- 2.1 Contribute to active follow-up of the cancer patient;
- 2.2 Describe length and quality of survival in relation to anatomical site, clinical stage and treatment;
- 2.3 Contribute to the Population Based Cancer Registries (PBCRs) in the given area;
- 2.4 Undertake epidemiological research through short-term case control studies;
- 2.5 Show time trends in proportion of early to late stages at time of diagnosis;
- 2.6 Help assess quality of hospital care and cancer services in covered area.

This report of eight Hospital Based Cancer Registries (HBCR) includes the data of a HBCR from Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, New Delhi that has commenced working and been included under the NCRP network since the publication of last report for the years 2007-2011.

The three year (2012-2014) report includes data from:

- I Eight earlier HBCRs (i.e., in centres already in NCRP network)
- II Nine newer HBCRs that have contributed data without financial assistance using HBCR-DM software.

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 been further examined in the context of number of patients registered in a particular year and number diagnosed earlier. The chapter gives the relative frequencies of the leading sites of cancer overall and in broad age groups.

Chapter 2 deals with different types of cancers in childhood in terms of relative proportions, sex ratio, leading sites etc.

Chapter 3 explains the impact of the use of tobacco in the causation of cancer in terms of overall proportions as well as in accordance to individual anatomical site of cancer known to be related to any form of tobacco consumption. For planning of tobacco control activity across the country, this baseline information is of immense importance. Though, not in a defined population it gives a fair picture of the overall problem of tobacco related cancer in the country.

The basis of diagnosis in Chapter 4 is an index of the reliability of diagnosis. It describes the proportion of different broad and detailed methods of diagnosis used as the most valid basis for cancer detection. Broad methods are classified into microscopic, all imaging techniques, clinical and others. Microscopic diagnosis includes histology, cytology and haematology components with respect to primary or metastatic sites as applicable.

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

The proportion of patients presenting in different clinical extents of disease before treatment 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 health education and screening programmes in the area will be reflected in the changes in proportions of stage at presentation of relevant sites of cancer.

Chapter 7 shows 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 relative proportions have been tabulated both overall and as per different clinical extent of disease. The figures reflect quite fairly the different modalities of treatment pursued in a given institution.

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

Chapter 9 deals with the relative proportions of histological types of cancer for certain specific sites.

Chapter 10 summarises the relative proportion of cases according to education, marital status, religion and language spoken.

Chapter 11 Data Quality and Indices of Reliability.

Chapter 12 shows trends in number of certain cancer cases (such as tobacco related cancer, cancer of breast, cervix and prostate) and of different cancer directed treatment types for five old HBCRs over a period of almost 30 years.

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 11. 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 are 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.

I Earlier Hospital Based Cancer Registries (HBCRs)

- 01 Tata Memorial Hospital, Mumbai (TMH)
- 02 Kidwai Memorial Institute of Oncology, Bangalore (KMIO)
- 03 Cancer Institute (WIA), Chennai (CI (WIA))
- 04 Regional Cancer Centre, Thiruvananthapuram (RCC - TVM)
- 05 Assam Medical College & Hospital, Dibrugarh (AMC)
- 06 Dr. B. Borooah Cancer Institute, Guwahati (BBCI)
- 07 Post Graduate Institute of Medical Education & Research, Chandigarh (PGIMER)
- 08 Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, AIIMS, New Delhi (BRAIRCH)

II Newer HBCRs that have used HBCR-DM Software without Financial Assistance

- 01 Amrita Institute of Medical Sciences & Research Centre, Kochi (AIMSRC)
- 02 Sher-I-Kashmir Institute of Medical Sciences, Srinagar (SKIMS)
- 03 Malabar Cancer Centre, Kannur (MCC)
- 04 Cachar Cancer Hospital & Research Centre, Silchar (CCH)
- 05 Vydehi Institute of Medical Sciences & Research Centre, Bangalore (VIMS)
- 06 Regional Cancer Centre, Raipur (RCC - Raipur)
- 07 International Cancer Centre, Neyyoor (ICC)
- 08 RST Regional Cancer Hospital, Cancer Relief Society, Nagpur (RCC - Nagpur)
- 09 Caritas Cancer Institute - Caritas Hospital, Kottayam, Kerala (CCICH)

III Regional Cancer Centres that have Commenced HBCRs Based on Funds Provided by MOHFW

- 01 Acharya Harihar Regional Cancer Centre, Cuttack
- 02 Acharya Tulsi Regional Cancer Treatment and Research Institute, Bikaner
- 03 Cancer Hospital & Research Institute, Gwalior
- 04 Chittaranjan National Cancer Institute, Kolkata
- 05 Government Medical College, Jammu
- 06 Govt. Arignar Anna Memorial Cancer Hospital & Research Institute, RCC, Kanchipuram
- 07 Indira Gandhi Institute of Medical Sciences, Patna
- 08 JIPMER, Regional Cancer Centre, Puducherry
- 09 Mizoram State Cancer Institute (Civil Hospital), Aizawl
- 10 MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad
- 11 Pt. B.D. Sharma Post Graduate Institute of Medical Sciences, Rohtak
- 12 Regional Cancer Centre, Indira Gandhi Medical College, Shimla
- 13 Regional Cancer Centre, Kamala Nehru Memorial Hospital, Allahabad
- 14 Regional Cancer Centre, Agartala
- 15 Regional Cancer Centre, Raipur
- 16 Regional Institute of Medical Sciences, Imphal
- 17 RST Regional Cancer Hospital, Cancer Relief Society, Nagpur
- 18 Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
- 19 Sher-I-Kashmir Institute of Medical Sciences, Srinagar
- 20 The Gujarat Cancer & Research Institute, Ahmedabad

Data of centres under I and II above have been included in this report. The centres in III have commenced their HBCRs and their data would be ready for the next report.