

Preliminary Pages

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NATIONAL CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

Consolidated Report of Hospital Based Cancer Registries 2004-2006

An Assessment of the Burden and Care of Cancer Patients

Bangalore, India

October 2009

© National Cancer Registry Programme
(Indian Council of Medical Research)
No. 557, 'Srinivasa Nilaya', 7th Main,
New BEL Road, Dollars Colony,
Bangalore - 560 094, INDIA.
Email : ncrpblr@canceratlasindia.org, ank@blr.vsnl.net.in
website : www.ncrpindia.org, www.canceratlasindia.org, www.hbccrindia.org, www.pbcrindia.org
October 2009

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

The publications of 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 CANCER REGISTRY PROGRAMME

Indian Council of Medical Research

Dr V.M. Katoch

Secretary, Department of Health Research & Director General

Division of Non-Communicable Diseases

Dr Bela Shah

Head & Sr Deputy Director General

Dr A. Nandakumar

Dy Director General (Sr Gr) &
Officer-in-Charge, NCRP

Dr Kishor Chaudhry

Dy Director General (Sr Gr)

Dr T. Ramnath

Dy Director General (Sr Gr)

Steering/Monitoring Committee

Dr G.K. Rath, New Delhi (Chairman, Steering Committee)

Dr Usha K. Luthra, New Delhi

Dr P.C. Gupta, Mumbai (Chairman, Monitoring Committee)

Dr S. Radhakrishna, Hyderabad

Dr Padam Singh, Gurgaon

Dr R.N. Visweswara, Bangalore

Dr J.P. Muliylil, Vellore

Mr P. Gangadharan, Ernakulam

Dr Kusum Verma, New Delhi

Dr Kusum Joshi, Chandigarh

Dr A.C. Kataki, Guwahati

Dr P.S.S. Sundar Rao, Bangalore (till Sept. 2007)

Dr B.D. Gupta, Chandigarh (till Sept. 2007)

Dr N.C. Misra, Lucknow (till Sept. 2007)

Hospital Based Cancer Registries at the following places

(with names of respective Principal and Co-Principal Investigators/Senior Staff) that have contributed to this report

Bangalore

: **Dr M. Vijayakumar** (from Sept. 2009)
Dr Ashok M. Shenoy (till Aug. 2009)
Dr Bapsy Padmanabhan (till Sept. 2007)

Dr K. Ramachandra Reddy

Chennai

: **Dr V. Shanta**

Dr R. Swaminathan

Mumbai

: **Dr Rajan Badwe**
Dr K.A. Dinshaw (till Nov. 2008)

Dr B. Ganesh

Thirupuram*

(*Thiruvananthapuram)

: **Dr Paul Sebastian**
Dr B. Rajan (till Oct. 2008)

Dr Aleyamma Mathew

Dibrugarh

: **Dr T.R. Borbora**
Dr D. Hazarika (till June 2007)

Dr M.S. Ali

North Eastern Regional Cancer Registry

Monitoring Unit: Dr J. Mahanta, Director, Regional Medical Research Centre (N.E.) (ICMR), Dibrugarh.

Chairman, Projects in North East Region : Prof. R.C. Mahajan, Chandigarh.

Coordinator of Special Cell : Dr M.N. Bandyopadhyay, Kolkata.

North East Population Based Cancer Registries with Names of Principal Investigators

Dibrugarh District : **Dr M.S. Ali**

Manipur State

: **Dr Y. Mohen Singh**

Kamrup Urban District : **Dr Jagannath D. Sharma**

Mizoram State

: **Dr Eric Zomawia**

Cachar District : **Dr Sekhar Chakravarty**

Sikkim State

: **Dr Yogesh Verma**

Meghalaya State : **Dr R.S. Dympep**

Nagaland (Kohima & Dimapur) : **Dr V. Khamo**

Tripura State : **Dr Gautam Majumdar**

Staff at Coordinating Unit of NCRP, Bangalore given overleaf.

Cancer Registries (with Names of Principal Investigators) Under NCRP Network

Population Based

Ahmedabad <i>(Urban & Rural)</i>	: Dr Pankaj M. Shah
Bangalore	: Dr M. Vijayakumar <i>(from Sept. 2009)</i> Dr Ashok M. Shenoy <i>(till Aug. 2009)</i> Dr Bapsy Padmanabhan <i>(till Sept. 2007)</i>
Barshi	: Dr R.A. Badwe Dr K.A. Dinshaw <i>(till Nov. 2008)</i>
Bhopal	: Dr Neelkamal Kapoor Dr V.K. Bharadwaj <i>(till March 2006)</i>
Chennai	: Dr V. Shanta
Delhi	: Dr Vinod Raina Dr Kusum Verma <i>(till Sept. 2004)</i>
Kolkata	: Dr Jaydip Biswas
Mumbai	: Dr Arun P. Kurkure
Pune, Nagpur & Aurangabad	: Dr B.B. Yeole
Kollam	: Dr Paul Sebastian
Thi'puram* <i>(*Thiruvananthapuram)</i>	: Dr Aleyamma Mathew

Hospital Based

Bangalore	: Dr M. Vijayakumar <i>(from Sept. 2009)</i> Dr Ashok M. Shenoy <i>(till Aug. 2009)</i> Dr Bapsy Padmanabhan <i>(till Sept. 2007)</i>
Chennai	: Dr V. Shanta
Mumbai	: Dr Rajan Badwe Dr K.A. Dinshaw <i>(till Nov. 2008)</i>
Thi'puram* <i>(*Thiruvananthapuram)</i>	: Dr Paul Sebastian Dr B. Rajan <i>(till Oct. 2008)</i>
Dibrugarh	: Dr T.R. Borbora Dr D. Hazarika <i>(till June 2007)</i>

Staff at Coordinating Unit of NCRP, Bangalore (including project staff)

Dr A. Nandakumar, Deputy Director General (Sr Gr) & Officer-in-Charge

Dr T. Ramnath, Deputy Director General (Sr Gr)

Dr Meesha Chaturvedi, Research Scientist - II (Med.)

F.S. Roselind, Research Scientist - III

Priyanka Das, Research Scientist - I

K.S. Vinay Urs, Research Scientist - I

K.L. Sudarshan, Programmer

Anish John, Programmer

Akanksha Tiwari, Programmer

Deenu Nadayil, Statistician

Vijay C R, Statistician

G.C. Shivayogi, Accounts Officer

G. Jayaram, Administrative Officer

N.M. Ramesha, Personal Assistant

K.R. Chandrika, Sr. Technical Assistant

C. Somasekhar, Data Entry Operator

V. Manjusha Bai, Data Entry Operator

IT Consultant :

B.S. Girish, Akshara Technologies, Bangalore.

Other Staff :

M. Rajendra, D.N. Narayana Swamy, Chandramma

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

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*Dr V. M. Katoch, Secretary, Department of Health Research &
Director General, ICMR;*

Dr Bela Shah, Head, Division of NCD, ICMR;

Principal Investigators and Staff of Hospital Based Cancer Registries;

Members of Steering Committee;

Members of Monitoring Committee;

Staff of Division of NCD, ICMR;

Staff of Coordinating Unit.

OBITUARY



Dr M. KRISHNA BHARGAVA (1927-2009)

***Former Director, Kidwai Memorial Institute of Oncology, Bangalore &
Principal Investigator, Bangalore PBCR and HBCR: 1982-1990.***

***A great teacher, strict disciplinarian and above all one of a kind
hospital and medical institution administrator.***

FOREWORD

I am happy to write the foreword on this consolidated report for the years 2004-2006 of the five Hospital Based Cancer Registries (HBCRs) located at the respective institutions in different parts of the country.

This three year report signifies the successful completion of 24 years of systematic and organized data collection by the HBCRs under the National Cancer Registry Programme (NCRP) of the Council.

The main objectives of HBCRs are to assess and evaluate patient care. The report brings into focus the complex issues involved in cancer patient care in the Indian setting. In bringing out such an assessment in terms of numbers, the report has highlighted the basic requirement of systematic and standardised recording of clinical information. Majority of patients continue to seek treatment only when the disease has reached an advanced clinical stage when curative treatment becomes difficult. Besides this, the report underscores the difficulties in obtaining follow-up details on a regular and sustained basis for evaluation of outcome of treatment.

Information about types of cancers and the different treatment modalities helps in planning the facilities required in the respective hospital, thereby facilitating health services research. HBCRs provide database for developing appropriate strategies to aid in National Cancer Control Programme.

This report will hopefully, serve as a handbook to the treating oncologist, researcher and health administrator to observe the various facets of cancer patient management and evolve institutional policies to provide more comprehensive evidence based care to the average patient.

The registries with all their team members and the Coordinating Unit of the NCRP along with its staff deserve appreciation for their dedicated work and providing quality data which enabled the successful completion of this report.



Dr V. M. Katoch
Secretary,
Department of Health Research &
Director General, ICMR

PREFACE

The Hospital Based Cancer Registries (HBCRs) under the National Cancer Registry Programme (NCRP) have, over the years, given an assessment of the magnitude and patterns of cancer in the particular region, furnished information to the Population Based Cancer Registries (PBCRs), provided data to the project on 'Development of an Atlas of Cancer in India' and in more recent years, commenced 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 advent and optimal use of electronic information technology in data checking, processing and analysis has greatly helped in significantly improving the quality of data. The Coordinating Unit has paid special emphasis on the various quality checks on the data in keeping with the international data quality indices.

It is heartening to note that several of the cancer hospitals where the HBCRs are functioning have computerized their data and the time interval between calendar year of data and calendar year of report availability is shortened. 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.

While the HBCR reports have strived to provide quality, internationally acceptable data; there are difficulties that one has to overcome to achieve this within the available infrastructure of our country. Issues such as correct assessment and recording of clinical stage, complete information on treatment given and a system to recall and reassess regression of disease or otherwise are critical. Though such details would be available in a small clinical series or for patients under the care of an individual clinician, for the HBCR as a whole, such data are not available. It is hoped that these difficulties will be overcome through the study on "Patterns of care" undertaken by the HBCRs and other institutions.

The coordination and management of the data received along with publication of this report is the result of the mammoth effort made by staff of these registries as well as that of the Coordinating Unit under the leadership of Dr A. Nandakumar, Officer-in-Charge, NCRP. They deserve a special appreciation for their dedicated work which has enabled this successful completion of more than twenty four years of data collection.



Dr Bela Shah

Head, Division of Non-Communicable Diseases, ICMR

National Cancer Registry Programme

The National Cancer Registry Programme (NCRP) was commenced by the Indian Council of Medical Research (ICMR) with a network of cancer registries across the country in December 1981. The main objectives of this Programme were: 1. To generate reliable data on the magnitude and patterns of cancer; 2. Undertake epidemiological studies based on results of registry data; 3. Help in designing, planning, monitoring and evaluation of cancer control activities under the National Cancer Control Programme (NCCP); 4. Develop training programmes in cancer registration and epidemiology.

With these objectives three Population Based Cancer Registries (PBCRs) at Bangalore, Chennai and Mumbai and three Hospital Based Cancer Registries (HBCRs) at Chandigarh, Dibrugarh and Thiruvananthapuram were commenced from 1 January 1982. The PBCRs have gradually expanded over the years and as of now there are 23 PBCRs under the NCRP network and these are illustrated in the adjoining map.

The NCRP is a long term activity of the ICMR and the office of the NCRP is located in Bangalore. It is assisted by a Steering Committee and a Monitoring Committee that meets periodically to oversee and guide its functioning. A review meeting is held annually where the Principal Investigators and staff of the registries present results and participate in the discussions. The meeting is preceded by a workshop.

Cancer registration in India is active and staff of all registries visit hospitals, pathology laboratories and all other sources of registration of cancer cases on a routine basis. Death certificates are also scrutinized from the municipal corporation units and information collected on all cases where cancer is mentioned on the death certificates.

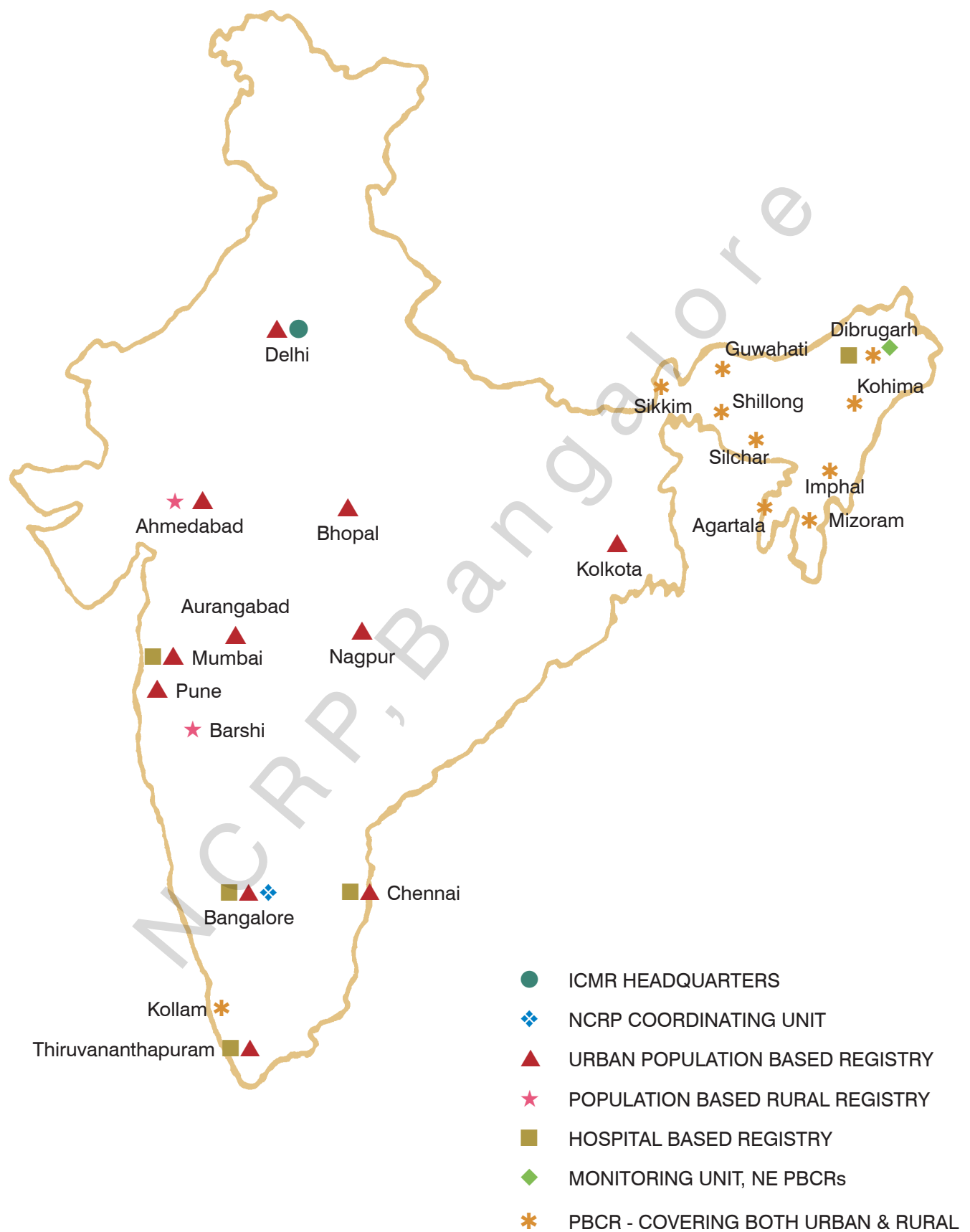
The information that is collected on a core form that is computer ready is subsequently entered in to a computer. Over the years, the registries and the office of the NCRP have used modern advances in electronic information technology to not only enter the data but also help in specific activities that involves checking of the data, verification of duplicates and matching mortality and incidence records. Electronic processing of data is now being tried out in some registries.

Data quality and completeness of coverage is a prime requisite for good cancer registration. This is ensured to the best possible extent by the NCRP.

Over the years, the staff from registries and the NCRP have benefited from both short term and long term training fellowships in established institutions in developed countries. This has helped the working of the cancer registries and also to evolve epidemiological studies. Data from the NCRP registries is regularly published in succeeding volumes of Cancer Incidence in Five Continents published by the International Agency for Research on Cancer - the cancer research arm of the World Health Organization (WHO).

NATIONAL CANCER REGISTRY PROGRAMME

(Indian Council of Medical Research)



Three-Year Consolidated Report of the Hospital Based Cancer Registries: 2004-2006

An Assessment of the Burden and Care of Cancer Patients

SUMMARY

The primary purpose of Hospital Based Cancer Registries is to contribute to patient care by providing readily accessible information on the patients with cancer, the treatment received and its results. The data is also used for clinical research and for epidemiological purposes. 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). Within the hospital, a registry is often considered to be an integral part of the hospital's cancer programme or health care delivery system.

The stated Objectives of Hospital Based Cancer Registries (HBCRs) (Maclennan *et al*, 1978; Young, J.L. 1991) are outlined below:

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 aspects of types of 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 the time of diagnosis;
- 2.6 Help assess quality of hospital care and cancer services in covered area.

Data collection is done by the individual registries using a standardised common core form. The information in this form mainly consists of patient identifying and demographic information, details of diagnosis the clinical stage of the disease and the broad type of treatment instituted.

Registries send the data to the Coordinating Unit as soft copy in MS-Excel, ASCII or other formats. These data are then converted to a uniform format at the Coordinating Unit and quality control exercises (NCRP, HBCR Report, 2007) are carried out. Once data is finalized in correspondence with the individual registries, annexure tables are generated and reports prepared.

The three year (2004-2006) report of the five HBCRs is the contribution of data from the hospitals at Tata Memorial Hospital, Mumbai; Kidwai Memorial Institute of Oncology, Bangalore; Cancer Institute-Adyar, Chennai; Regional Cancer Centre, Thiruvananthapuram and Assam Medical College, Dibrugarh. This three year report marks the successful completion of 24 years of systematic and organized data collection by these registries.

This report essentially identifies the patients who registered in these institutions and had a diagnosis of cancer. It further distinguishes those that received cancer directed treatment (CDT) or not. Those who had received prior CDT i.e., before registration at the reporting institution were considered as 'non-analytic cases'. Those who had not received prior CDT were considered as 'analytic cases'. The rationale behind such classification is simple. The main function and objective of HBCRs is to assess and evaluate patient care of that particular hospital or reporting institution. So, if a proportion of patients received some form of cancer directed treatment elsewhere, they are not expected to be reflected in the patient care of the reporting institution, even if this group had received the additional or major course of treatment at this institution. Therefore, this report deals in detail with the analysis of analytic cases.

The report is mainly in the form of statistical tables and graphs with the corresponding text giving only the factual description. While the report has tried to analyse, compile and consolidate the data provided by the different registries in a set format, it has in no way tried to compare and therefore comment or interpret the data between or among registries. Thus, no judgement is made of the figures in the tables. This is mainly because the individual institutions where the registries are located would have, their own policies in patient care and management which is beyond the purview of this report. Individual registries, could however view their data, interpret its possible meaning and observe where, if at all modifications are required in administering patient care.

The report provides several pointers to policy makers. It gives an idea of the load of cancer patients in the main cancer hospitals of the country, the proportion and sites of cancers presenting at a late stage of the disease, the resources necessary for diagnosing and treatment according to different modalities, the proportion of patients who require palliative care, and so on. The report forms a base for both policy makers and institutions to plan for the future and would give a fair idea of the optimum number of patients a cancer centre/hospital would be able to effectively handle. The report could also form the basis of working out treatment costs and hospital stay. For the registries themselves the report should be a starting point in conducting follow-up and survival studies on at least selected sites of cancer and also initiating clinical trials.

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

Chapter 9 summarises the relative proportion of cases according to educational status, religion and language spoken.

Chapters 10-16 summarize important selected sites of cancer with the comprehensive tables given in the earlier Chapters. The numbers in these tables of individual sites become more meaningful. These Chapters do not form part of the printed report, but are available on the website (www.pbcrindia.org) in electronic format.



Dr A. Nandakumar
Officer-in-Charge, NCRP

HOSPITAL BASED CANCER REGISTRY

Tata Memorial Hospital, Mumbai

Dr Rajan Badwe, Principal Investigator

Dr Ganesh B., Co-Investigator

Dr Rajesh Dikshit, Consultant Epidemiologist

Tata Memorial Hospital

The Tata Memorial Centre (TMC) comprising the Tata Memorial Hospital and the Advanced Centre for Treatment, Research and Education in Cancer (ACTREC) engaged in research, education and Comprehensive care of cancer patients is a grant-in-aid Institution and it is under the administrative control of The Department of Atomic Energy, Government of India. The ACTREC situated at Kharghar, Navi Mumbai consists of two wings - the Cancer Research Institute (CRI) relocated from Parel and the Clinical Research Centre (CRC) which will undertake basic and clinical research using GCP guidelines. The Hospital is a comprehensive cancer centre for diagnosis, treatment, education and is also a research institution with state of art technology in all areas of cancer management. The Hospital has 558 beds, 18 operation theatres and Intensive Care units. The hospital is a recognized centre for Postgraduate teaching in areas such as Surgery, Radiation Therapy, Radio-diagnosis, Pathology, Biochemistry, Radiation Physics, Cytology etc. On an average, over 1500 patients visit every day for availing various services.

Patients who seek all facilities such as diagnosis, treatment and allied facilities are registered as routine case file registrations. These patients carry unique hospital number and they are included in the cancer registry when diagnosed as cancer. Patients who require only cancer checkup are registered under care of Preventive Oncology Department and different registration numbers are allocated (PO) as long as these patients are free from cancer. For patients who require certain facilities like expert pathological opinion by submitting specimens or slides etc, or diagnostic investigations such as CT Scan, MRI, other rehabilitation facilities like breast prosthesis etc. are registered as Referral patients (RF) and a RF number is allocated to them. Some of the RF and PO registered patients eventually register as a regular case if they are diagnosed as cancer. The Hospital Cancer Registry includes only patients registered for comprehensive care where all necessary information like, date of diagnosis, method of diagnosis, clinical extent of disease, primary treatment and continuous follow-up are available.

The Cancer Registry is currently using the International Classification of Diseases 9th version and in this year all cancer cases are coded using both ICD9 and ICD10 and tables are generated using both type of codes. For histological classification, the data is coded as per ICDO III version.

Data validation

The Cancer Registry staff scrutinizes the source document for confirmed cancer cases and collect relevant information in pre-designed proforma after sufficient time has elapsed so that the information on primary treatment (normally available in about six months from the date of diagnosis). The abstracted data is then recorded in the computer. The Software developed ensures entry of valid codes thus minimizing the storage space in the registry database. In addition, special software is used to validate data for range

checks, cross checks, duplicate checks and blank checks as there are items which are to be entered without blanks in the data field. The registry data is also validated at the NCRP headquarters. To ensure quality and corrections in data, a random sampling procedure was carried where a sample of 5% of case records were scrutinized and checked with the routine recording of cases.

The infrastructure, available expertise and patient cooperation depend largely in identifying the correct diagnosis, clinical extent of disease and proper evidence based treatment and these are some of the standards required to achieve optimum patient care. Even in a Comprehensive Care Cancer Hospital there are patients diagnosed as primary unknown or secondary in some parts of the body with unknown primary etc. Such data in a Cancer Registry may provide little information for proper health care and percentage of such patients should be kept to a minimum.

Tata Memorial Hospital - Hospital Based Cancer Registry joined the NCRP Network during the year 1984 and since then the registry started submitting cancer related information to the Network. During the years 1984-2004, over 4,82,588 patients were registered in the hospital and out of which 3,13,558 patients were diagnosed as cancer cases.

Since TMH is a comprehensive Cancer hospital, patients from all parts of India and neighbouring countries like Pakistan, Bangladesh and Nepal attend for expert care and opinion. It is evident that cancer pattern remained same among males and females. The detection rate remained same whether patients attended from neighbouring areas or from far remote corners of India.

Contributors

Mr Sanjay D. Talole, Scientific Officer

Mrs T. K. Santhakumary

Mrs Sapna H. Kothare

Mrs Vidya R. Lanke

Ms Sushama L. Saoba

Ms Sandhya M. Bahire

Mrs Ashwini N. Mhatre

Mrs Amruta A. Mhatre

Mrs Sakshi V. Sawant

Mrs Snehal A. Sant (Ex-staff)

Mrs Elizabeth V. George (Ex-staff)

HOSPITAL BASED CANCER REGISTRY

**Department of Epidemiology and Bio-statistics (DEB)
Kidwai Memorial Institute of Oncology, Bangalore**

Dr M. Vijayakumar, Director-in-Charge

Dr K. Ramachandra Reddy, Professor and Head & Co-Principal Investigator

Dr C. Ramesh, Associate Professor

Introduction

Kidwai Memorial Institute of Oncology is a comprehensive and Regional Centre for Cancer Research and treatment in Karnataka. The Institute has all the state-of-the-art facilities for diagnosis and treatment of cancer and in view of this, patients from all over Karnataka as well as from the adjoining areas of neighbouring states of Andhra Pradesh, Tamil Nadu, Kerala and other regions attend this hospital. The Institute which was established in 1973 with 50 inpatient beds, a pathology laboratory and a radiology department has achieved a bed strength of 505 apart from the Dharmashala. This is a unique project in the country and has been built with support from the Bangalore Mahanagara Palike. It provides accommodation to about 250 ambulatory patients and for an equal number of their attendants. The patients and attendants are provided with free food through the perpetual free feeding Endowment donation Scheme. Another Dharmashala built with support of Infosys Foundation has general wards for poor patients and also palliative care unit.

The Mobile Cancer Education and Detection Unit (Department of Community Oncology) organizes cancer detection clinics on Wednesdays and Saturdays at the Institute. KMIO as an apex body for overall cancer control in the state, has initiated several cancer control programmes / activities at different places. The Institute has been recognized as a National Centre of Excellence. Medical and paramedical personnel from all over the country come for training in various specialities / branches on Oncology.

KMIO offers super speciality courses which are recognized by Medical Council of India. These are in Surgical Oncology (M.Ch.), Medical Oncology (D.M). It also offers postgraduate courses (MD) and Diploma courses in Radiotherapy (D.M.R.T), undergraduate courses (B.Sc.) in Allied Health Sciences (M.L.T, RD/RT & OT / AT) Anaesthesiology, Pathology and Radio diagnosis. Many Clinical / Para clinical departments offers Ph.D programmes under RGUHS.

In order to provide anti-cancer drugs at reasonably reduced prices, the Kidwai Cancer Drug Foundation Trust has been established where the costly anti cancer drugs are available at nearly 30% cheaper rates compared to market prices. Free drugs are provided to poor needy patients through Karnataka Chief Minister's Relief Fund.

The KMIO is a well equipped comprehensive cancer centre consisting of the departments of Surgical Oncology (General, Head & Neck, Oral, Gynaecology), Radiotherapy, Medical Oncology, Paediatrics, Radiodiagnosis, Pathology, Biochemistry, Blood Transfusion and Immuno Haematology, Microbiology, Cytogenetics, Nuclear Medicine, Radiation Physics, Anaesthetics and Pain Relief, Epidemiology & Biostatistics, Community Oncology, Social Welfare and Public Relations, Library & Information Centre, Administration and Supportive care facilities for cancer patients like Physiotherapy, Ostomy Clinic occupational therapy are also available.

The Hospital Based Cancer Registry has been functioning since the inception of the Institute in 1973. However, the registry was included in the network of NCRP in 1984 and supported with nominal grants from the Indian Council of Medical Research. All new cases attending at the Institute are interviewed during registration and required clinical data are abstracted later from the records using a standard proforma. The computerized data is checked for consistency for unlikely combinations of variables included using in-house computer programme.

Case control studies on breast and oesophagus have been completed and case control study on pharyngeal cancers and oral cancers are in progress. Reports on the activities of Hospital are published regularly on an annual basis. The faculty members of the Registry are actively involved in the clinical trails / research projects being carried out by the Institute apart from teaching.

The HBCR has initiated action to conduct special studies on pattern of care and survival studies on Head and Neck cancers, breast and cervical cancers as proposed by the National Cancer Registry Programme of the ICMR. KMIO being a referral cancer centre, about 70% of the patients are referred by the various medical institutions and private practitioners. During the period 2004-2006, a total number of 46,226 new patients were registered, of which 23,870 (old + new) cases were confirmed to have cancer. About 20% of the patients registered annually are from the adjacent states. On an average, about 55 new cases are registered every day and 720 follow-up patients come for regular treatment. Of the total number of confirmed cancers of 23,870 (old + new), the proportion of cancers in females were higher and counted for 54% (12,849) of the total cancer compared to 46% (11,021) in males.

Staff of Registry

Mr D. J. Jayaram	:	Sr. Investigator / Scientific Assistant
Mr C. Shivanna	:	Asst. Social Scientist
Mr V. Bhadraiah	:	Asst. Social Scientist
Mr A. V. Srinivasa Gowda	:	Asst. Social Scientist
Mr R. Lingaraju	:	Asst. Social Scientist
Mr M. K. M. Gowda	:	Asst. Social Scientist
Mrs B. J. Kumudhini	:	Asst. Social Scientist
Mr M. R. Balakrishnoji Rao	:	Asst. Social Scientist (On deputation from Comm. Oncology)
Mr K. Venkatesh	:	Statistician Assistant (On deputation from DCCP)
Mrs S. H. Sudha	:	Typist
Mr A. Subramani	:	Coding Clerk
Mr C. Kumar	:	Data Entry Operator
Mr Chinna Nayak	:	Literate Attender

HOSPITAL BASED CANCER REGISTRY

Cancer Institute (WIA), Adyar, Chennai

Dr V. Shanta, Principal Investigator

Dr R. Swaminathan, Co-Investigator

Mrs R. Rama, Statistician

The Base Institution

The Cancer Institute (W.I.A.) is the first comprehensive cancer care centre to be established in South India and is the second in India. It comprises a hospital, a research centre, a centre of preventive oncology and the Dr. Muthulakshmi College of Oncologic Sciences. It is the seat of both demographic and hospital cancer registries. The hospital has 423 beds and more than 50% of the patients are boarded, lodged and treated free of cost. Being a Regional Cancer Centre for Cancer Research and Treatment in the Ministry of Health & Family Welfare of the Government of India, this autonomous, non-profit organization draws attendances from all over the country. It offers state-of-the-art facilities for cancer diagnosis, treatment and research. The proportion (%) of patients attending the institute from Southern India in 2007 accounts for 95%: Tamil Nadu (72%), Andhra Pradesh (22%) and Kerala (1%). The research departments are recognized by the University of Madras, Anna University and the Dr. M.G.R. Medical University, for doctoral and super speciality degrees.

The Registry

The hospital cancer registry is functioning at the Cancer Institute (W.I.A.) since its inception in 1954. Data collection on the lines of ICMR started in 1984. New cases are registered using the hospital computer system and interviewed by social investigators for identification, demographic and epidemiological details. The remaining data as per ICMR Core form are abstracted from the medical records. The forms are then scrutinized by Medical Officer. The data are then entered into the computer. Computerized data are then checked by the statistician for validity and consistency using NCRP, IARC and in-house computer programs. Quality control measures include regular exercises on coding for topography and morphology and re-abstractation of cases on a random sample.

The total number of new patients (malignant and non-malignant) registered during the years 2004-2005 was 27,996. Of these, 19,098 (68%) were cancer cases with the male-female ratio of 1:1.09. The leading cancers among males are oral cavity (UICC), stomach and lung. Among females, the order is cancer of the cervix, breast and oral cavity. Breast cancer emerged at the top among those receiving cancer directed treatment at the institute.

Follow-up

The major focus of the hospital cancer registry is on the continued well-being and care of the patient. This is achieved by the life time follow-up of all treated patients. Besides the clinical follow-up of patients who are regular for check-up, an efficient active follow-up system is inherent in the functioning of the registry to get information on the vital status of all treated patients comprising postal, telephone and

house visit enquiries. Assistance is also sought from government servants (like postal personnel, village administrative personnel, etc.), medical practitioners, local service organizations and cured patients to get information on the vital status of treated patients. These measures have rendered it possible for the registry to publish the overall survival of top ranking cancers in all its reports as a routine. Complete follow-up information at five years from diagnosis ranged between 80 to 90% for cancer patients treated in 2000-2001 and followed through 2006.

Activities

Hospital cancer registry publishes reports on various hospital statistics periodically, besides publication of results of analytical studies in reputed journals for dissemination of information. A clinical secretariat, carved out of the registry, specializes in high resolution data collection for retrospective studies, data entry, analysis and slides for presentation for the faculty. Workshops on Cancer Registration are held for students of medical record/documentation and personnel from other hospitals. The NCRP project on Patterns of Care and Survival Studies is an offshoot of and integrated with the functioning of hospital registry. The registry assists in the conduct of several randomized clinical trials.

Staff of the Hospital Cancer Registry – ICMR

Mrs R. Rama	:	Statistician
Ms T. M. B. Bhavani	:	Social Investigator
Mrs Hepsi	:	Assistant

HOSPITAL BASED CANCER REGISTRY

Regional Cancer Centre, Thiruvananthapuram

Dr Paul Sebastian, Principal Investigator

Dr B. Rajan, Principal Investigator (*till October 2008*)

Dr Aleyamma Mathew, Additional Professor in Statistics & Epidemiology (in-charge)

The Hospital Based Cancer Registry (HBCR) of the Regional Cancer Centre (RCC), Thiruvananthapuram started in 1982 under the network of Indian Council of Medical Research (ICMR). Initially the HBCR collected information on cancer patients attending RCC and Medical College Hospitals. All the above hospitals are located in the same campus. Since 1997, the medical college hospitals were de-linked from the HBCR, and the registry is restricted to patients from RCC only.

The registry has made significant achievements in data abstraction in the last 10 years. The data abstraction and retrieval has been made online via intranet "rccintranet.org" with easy data management. This is the first paperless registry in the country. The demographic details are collected by the social investigators and entered into the computer at the time of new patient registration at RCC and transferred to the national cancer registry core-form of ICMR. The data transfer avoids manual documentation of the first part (demographic details) of the ICMR core-form. The second part (diagnostic, treatment and follow-up) is entered using the above software after retrieving case-sheets from the medical records division.

Using the above in-house software, the variables in the core form are selected from a selection box in the hypertext mark up language (HTML) form. The selection box contains all the codes along with their descriptions for each variable. This helps to avoid mistakes beyond the range of values for each variable. The selection box corresponding to the variables topography and morphology contains the third edition of International Classification of Diseases for Oncology (ICD-O-3) and the tenth revision of International Statistical Classification of Diseases (ICD-10). The electronic data entry and processing has greatly enhanced the quality of data. Before the computerization, there used to be a three-year delay for completing data abstraction. Now the delay is less than one year even after the patient registration is increased to nearly 3-fold.

Since its inception in 1982 (n=3596), the HBCR has been recorded increasing number of cancer cases and in 2006 (n=9441) this is 163% more than in 1982. In 2006, the percentage increases of the leading five cancers in males are 216% for lung cancer (n=187 in 1982 and n=591 in 2006), 159% for tongue cancer (n=135 in 1982 and n=350 in 2006), 43% for mouth cancers (n=315 in 1982 and n=450 in 2006), 908% for leukaemia (n=38 in 1982 and n=383 in 2006) and 306% for lymphoma (n=70 in 1982 and n=284 in 2006) compared to the patient registration in 1982. The corresponding percentage increases of the leading five cancers in females are 18% for cervix uteri cancer (n=400 in 1982 and n=473 in 2006), 466% for breast cancer (n=245 in 1982 and n=1386 in 2006), 221% for ovarian cancer (n=68 in 1982 and n=218 in 2006), 960% for thyroid cancer (n=48 in 1982 and n=509 in 2006), 191% for tongue cancer (n=47 in 1982 and n=137 in 2006) and 34% for mouth cancers (n=176 in 1982 and n=236 in 2006).

During the year 2006 (after 25 years since the inception of HBCR), 9441 (males: 4834; females: 4607) patients with cancer were recorded in the HBCR of the RCC, Thiruvananthapuram. The mean age at diagnosis was 54 years in males and 49 years in females. Children (0-14 years) constituted 4% and 62% were in the age group 35-64 years. The ten leading cancer sites altogether contributed to 69% of all cancers in males and 81% of all cancers in females. Cancer of the oral cavity (17.0%) was the leading site among males followed by lung (12.2%). Among females, cancer of the breast (30.1%) was the leading site followed by cancer of the thyroid gland (11.0%). The third and fourth common cancers were leukaemia (8.0%) and lymphoma (6.0%) in males and cervix cancer (10.3%) and oral cancers (8.4%) in females.

Other ongoing programmes utilizing HBCR data

1. Cancer Registry, Thiruvananthapuram Taluk

The Population Based Cancer Registry (PBCR), Thiruvananthapuram under the network of the National Cancer Registry Programme of ICMR aims to obtain the annual incidence and mortality rates as well as community based survival probability for each type of cancer. The Thiruvananthapuram taluk [Thiruvananthapuram corporation (urban population) as well as the rural area in the taluk] with a population of approximately 1.12 million (population from 2001 census) is the registry area. There are approximately 60 government and private hospitals, and pathology laboratories located in the taluk other than the RCC, Thiruvananthapuram. 'Active' case finding methodology is used by visiting the above hospitals and laboratories and record the necessary information using a standard format.

Seventy five percent of the PBCR, Thiruvananthapuram data is obtained from the HBCR, Thiruvananthapuram.

2. District Cancer Registry, Thiruvananthapuram

The Government of India has identified RCC as the Nodal Agency for implementing District Cancer Control Programme in Thiruvananthapuram district. In order to evaluate the programme in terms of cancer incidence, mortality and staging, a cancer registry is started in the district along with the control programmes. The district cancer registry, Thiruvananthapuram aims to record all cancer cases arising among residents in the district and analyze the outcome. The registry covers an area of 2192 sq. kms with a population of 32 lakhs of which 34% are urban population (2001 census of India). The registry has adopted an active case finding methodology by collecting data mainly from the RCC, Medical College Hospital (MCH), Thiruvananthapuram, Sree Chitra Thirunal hospital, Thiruvananthapuram located in the same campus of MCH and a few major private hospitals where cancer patients are treated in the district of Thiruvananthapuram. Additionally, death information on cancer patients from the above area is collected from the Thiruvananthapuram Corporation and the 78 panchayats (vital statistics offices) in the district. The programme has been started since 2005.

Seventy percent of the Thiruvananthapuram district cancer registry data is obtained from the HBCR, Thiruvananthapuram.

3. Rural Cancer Registry, Thiruvananthapuram

The registry provides annual data on cancer incidence and mortality covering a population of nearly 5 lakhs in a rural population in Thiruvananthapuram district. The rural area consists of three community development blocks (CD): Kazhakuttom, Chirayinkil and Thiruvananthapuram rural. The registration system was started in 1994 and the data compilation began retrospectively for the period starting from 1st January

1991. The data for the past two 5-year periods such as 1993-1997 and 1998-2002 have been published in the Volumes 8 and 9 of the Cancer Incidence in Five Continents, IARC, WHO respectively. Finnish Cancer Society is supporting the registry.

Seventy percent of the Thiruvananthapuram district cancer registry data is obtained from the HBCR, Thiruvananthapuram.

4. District Cancer Registry, Kollam

The district cancer registry, Kollam, aims to record all cancer cases arising among residents in the district and analyze the outcome. The registry covers an area of 2490 sq. kms with a population of 26 lakhs of which 82% are rural population (2001 census of India). Similar to the above registry, data is collected based on an active case finding methodology by visiting the major hospitals, laboratories and death registration offices in the entire district and record the necessary information. Additionally, information on cancer patients from the above area whom will be reported at the Regional Cancer Centre (RCC), Thiruvananthapuram and Medical College Hospitals at Thiruvananthapuram, Alappuzha and Kottayam is also collected. The annual cancer incidence and mortality rates will be estimated and detailed report will be submitted in the next year.

Fifty percent of the Kollam district cancer registry data is obtained from the HBCR, Thiruvananthapuram.

5. Cancer Control Programme, Thiruvananthapuram Corporation

Cancer awareness classes and cancer detection camps in the above area are conducted regularly. Cervical cancer screening is conducted regularly in a peripheral government hospital in Thiruvananthapuram Corporation. The programme is evaluated based on the cancer registry data.

6. Pattern of Care and Survival of Head & Neck, Breast and Cervix Cancer

HBCR, Thiruvananthapuram is one of the collaborating centres for the ICMR initiated network of pattern of care and survival studies on cancer cervix, breast and head & neck cancers. The main objective of the study is to assess the pattern of care and survival of breast, cervix, head and neck cancer patients reporting at the Regional Cancer Centre, Thiruvananthapuram. Details diagnostic, stage and treatment and follow-up details are abstracted using the site-specific proforma for the above type of cancers from the patient medical records. Currently a total of 4050 female breast cancer (n=1234), cervix cancer (n=691) and head & neck (n=2125) cancer cases are abstracted and computerized using the specifically designed 'Patient Information Form'.

7. Feasibility study for a Prospect Dietary Cohort- Part C

Part C of the above study aims to evaluate the follow-up and end-point ascertainment to establish a large prospective cohort in Thiruvananthapuram district to assess diet and other exposures in the etiology of cancers and other chronic diseases. More specifically, the feasibility study aims to evaluate Thiruvananthapuram cancer registry coverage, to determine whether supplementary activities are required to optimize case ascertainment, to assess the reliability of information provided by the cancer patients/proxy and to determine whether there is a differential disease ascertainment by socioeconomic status. A total of 750 cancer cases were obtained from the HBCR database and information collected through house-visit using a structured questionnaire and is compared with the cancer registry database.

8. Time trend analysis of Cancer Registry data (1989-2008)

Time-trend analysis aims to study the change in cancer incidence by age and type of residence (urban/rural) for the various type of cancers in Thiruvananthapuram, to predict cancer cases for Kerala for future period, to estimate the burden of cancers in terms of potential years of life lost due to pre-mature mortality and to estimate economic implications of cancers in Kerala.

9. Utilization of HBCR data for other programmes

The HBCR has interactive programmes with other divisions of RCC. This has led to wide utilization of the registry database for a variety of analyses resulting in several scientific publications.

10. Epidemiologic studies

i) A prospective life-style and dietary cohort study in Thiruvananthapuram, Kerala, India

The study aims to establish a large prospective cohort in India to assess diet and other exposures in the etiology of cancers and other chronic diseases. The study will ultimately cover approximately 250,000 populations from Thiruvananthapuram district using questionnaire data collection and bio-specimens. Currently conducting a pilot study to assess the feasibility of establishing a large cohort in India with objectives of Evaluation of conducting chronic disease and diet research in India (Part A) (n=2400) and detailed characterization of the Indian diet (n=600 a sub-set of 2400 from Part A).

ii) Case-control study of bladder & kidney cancers

This is a hospital-based case-control study investigating the role of risk factors such as tobacco smoking, alcohol consumption, occupation, obesity, hypertension and other factors such as fluid intake, analgesics consumption, fruits and vegetables consumption etc. on the risk of developing bladder and kidney cancers. Cases include new patients with a histologically confirmed diagnosis of bladder and kidney cancers reported at the Regional Cancer Centre (RCC), and at the Medical College Hospital (MCH), Thiruvananthapuram. All cases are interviewed after the initial diagnosis by a trained interviewer who will obtain information on their risk factor information. This information is obtained using a standardized pre-tested questionnaire. Age (+/- 5 years) and gender matched controls are recruited from visitors reporting at RCC or MCH and similar interview is conducted. The same interviewers are used for both cases and controls.

iii) Nutritional factors and risk of breast cancer: a case-control study

The study objective is to investigate the role of nutritional factors such as a) Total fat and its subtypes, b) Protein, c) Fiber and its subtypes, d) Vitamins and minerals, on the risk of breast cancer. Study design: Hospital based case-control study. The study is ongoing at the Regional Cancer Centre (RCC), Thiruvananthapuram. Study design: Hospital based case-control study. Cases are women with histologically confirmed incident primary breast cancer. The controls are subjects who did not have cancer and accompanied cancer patients other than those with breast cancer attending the same cancer hospital during the same time period, and matched to cases by age (+ 5 years) and residence from the state of Kerala. Collection of dietary information is based on a locally adapted diet history questionnaire, designed with the aid of dietary recall information obtained in the pilot stage of the study.

- iv) Supervision of PhD programmes – Five students who have registered under the Kerala University are undergoing doctoral programmes.
- v) List of indexed publications during the last three years

Binukumar B, Mathew A. Dietary fat and risk of breast cancer. *World Journal of Surgical Oncology*, 2005, 3:45-58.

Mathew A and Rajan B. Epidemiology of cancer and prevention of cancer in India. In Marsh RW and Samuel J (editors). *The essentials of clinical oncology*, Jaypee Brothers Medical Publishers (P) Ltd., Haryana (2005).

Balaram P, Krishnan SM, James S, Cheriyan VT, Thankappan ST, Mathew A. Epstein-Barr Virus down regulates expression of DNA-double strand break repair proteins in nasopharyngeal cancer. *Gene therapy and Molecular Biology* Vol 10, 123-132 (2006).

Rastogi T, Devesa S, Mangtani P, Mathew A, Cooper N, Kao R and Sinha R. Cancer incidence rates among South Asians in four geographic regions: India, Singapore, UK and US. *Int J of Epidemiology* 1-13 (2007).

Mathew A, Gajalakshmi V, Rajan B, Kanimozhi V, Brennan P, Mathew BS and Boffetta P. Pattern of anthropometric factors among urban and rural women in South India and the risk of breast cancer: a multicentric case-control study, *British Journal of Cancer*, 99:207-213 (2008).

Mathew A, Gajalakshmi V, Rajan B, Kanimozhi V, Brennan P, Binukumar B, Boffetta P. Physical activity level among urban and rural women in South India and the risk of breast cancer: a case-control study. *European Journal of Cancer Prevention* (2008).

Jose S, George PS, Mathew A. Assessment of confounding and interaction using the Mantel-Haenszel risk estimation method. *Asian Pacific J Cancer Prev*, 9:323-326 (2008).

Iype EM, Sebastian, Mathew A, Balagopal PG, Varghese BT, Thomas S. The role of selective neck dissection (I-III) in the treatment of node negative (N0) neck in oral cancer. *Oral Oncology* (2008).

Gajalakshmi V, Mathew A, Brennan P, Rajan B, Kanimozhi V, Rai RR, Mathews A, Mathew BS, Boffetta P. Breastfeeding and breast cancer risk in India: a multicenter case-control study. *Int J Cancer* (2008).

List of other staff working for the registry

Dr Kalavathy M.C.	:	Assistant Professor in Epidemiology
Ms Padmakumari Amma G.	:	Lecturer in Bio-statistics
Dr Preethi Sara George	:	Lecturer in Bio-statistics
Ms Anita Nayar	:	Social Investigator, Sr. Grade
Ms Asha N.M.	:	Clerk

HOSPITAL BASED CANCER REGISTRY

Assam Medical College, Dibrugarh

Dr U. C. Sharmah, Director of Medical Education, Assam

Dr T. R. Borborah, Principal cum Chief Supdt. & Principal Investigator

Dr M. S. Ali, Office-in-Charge

Dr (Ms) R. Akhtar, Research Officer

The HBCR at Assam Medical College Hospital, Dibrugarh started in 1982 under the network National Cancer Registry Programme (NCRP) of Indian Council of Medical Research (ICMR). The base institution is a tertiary general hospital and therefore, lacks the required infrastructure of a comprehensive cancer centre. Because of this, compared with other HBCRs under NCRP, the number of cancer patients attending the hospital over the years have been relatively low. Over a period of 26 years, the registry has been able to generate and project authentic data on the burden, pattern and stages at presentation of cancer patients in the hospital.

The registry has successfully completed two epidemiological case-control studies during 1988-91 on cancer pharynx and cancer oesophagus and identified a number of potential risk factors particularly associated with the practices of the indigenous populations.

Several popular articles on the pattern, causative factors of common cancers, high risk group etc. have been published both in English and vernacular languages in the regional newspapers for the awareness of both the medical personnel and common population.

The registry staff has presented several scientific papers in various national and international conference, seminars and meetings and has also published articles in indexed journals. Staff has participated as resource persons in several WHO, NCRP and UGC sponsored workshops.

The registry database has been widely used for a variety of analysis resulting in several scientific publications both by the P.G. students and clinicians of the institute. Moreover the registry has been extending expertise and guidance to a large number of P.G. students in the matter of planning, designing and statistical analysis.

Two candidates have already obtained their Ph.D. degrees by utilizing the expertise and data of HBCR and another one is about to submit his thesis for Ph.D. under Dibrugarh University. In a big way HBCR, Dibrugarh is very much involved in human resource development in cancer epidemiology.

HBCR, Dibrugarh is one of the collaborating centres of the ICMR initiated project on patterns of care and survival studies on cancer cervix, female breast and head & neck cancers. The data collection from

patients with the above specific sites was started from 1 January, 2007. Till August, 2008, a total of 186 cases of head and neck, 65 breasts and 55 cancer cervixes have been abstracted using the specifically designed 'Patient Information Form'. These patients are being followed-up and transmitted on-line to the Coordinating Unit, Bangalore.

Other Staff of the Hospital Based Cancer Registry, Dibrugarh:

Mrs P. Dutta	:	Medical Record Officer
Mrs S. Ahmed	:	Social Investigator
Mrs S. Neog	:	Social Investigator
Sri K. Saikia	:	Clerk (Sr. Gr)
Mrs I. Baruah	:	Clerk (Sr. Gr)
Sri S. R. Nath	:	Clerk
Mrs R. Begum	:	Clerk
Mrs J. Sonowal	:	Clerk
Sri P. Deuri	:	Typist
Sri B. Mech	:	Helper