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# NATIONAL CANCER REGISTRY PROGRAMME

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(Indian Council of Medical Research)  
Bangalore

August 2005

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 patterns in the country.

*PRINTED IN INDIA*

*Published by the Coordinating Unit, National Cancer Registry Programme (ICMR), Bangalore 560094*

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# NATIONAL CANCER REGISTRY PROGRAMME

## *Indian Council of Medical Research*

### Two-year Report of the Hospital Based Cancer Registries

1999 - 2000

*Prepared by*

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# FORWARD

This two year report of the hospital based cancer registries under the National Cancer Registry Programme (NCRP) for the years 1999 - 2000 is the result of work carried out by the five Hospital Based Cancer Registries located at the respective institutions in different parts of the country.

The broad purpose of a Hospital Based Cancer Registry (HBCR) is to assess and evaluate cancer patient care in the concerned hospital. Besides, the HBCR gives a picture of the magnitude and patterns of cancer in a given hospital and contributes to the population based cancer registry in the geographic area. Information about types of cancers and types of treatment helps in planning the facilities required in the respective hospital, thereby facilitating health services research. The HBCR is also well suited for undertaking epidemiological research.

The HBCRs under the 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 Registry and in more recent years provided data to the project on 'Development of an Atlas of Cancer in India'. In addition, they have conducted several case control studies.

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. These institutions have evolved strategies for patient follow-up. In the coming years, the results of these studies is expected to give a picture of stage and treatment based survival at a national level and more importantly in the Indian context. This would pave the way for initiating multi-centric clinical trials with the HBCR as the backbone.

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.



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3 August 2005

# ACKNOWLEDGEMENTS

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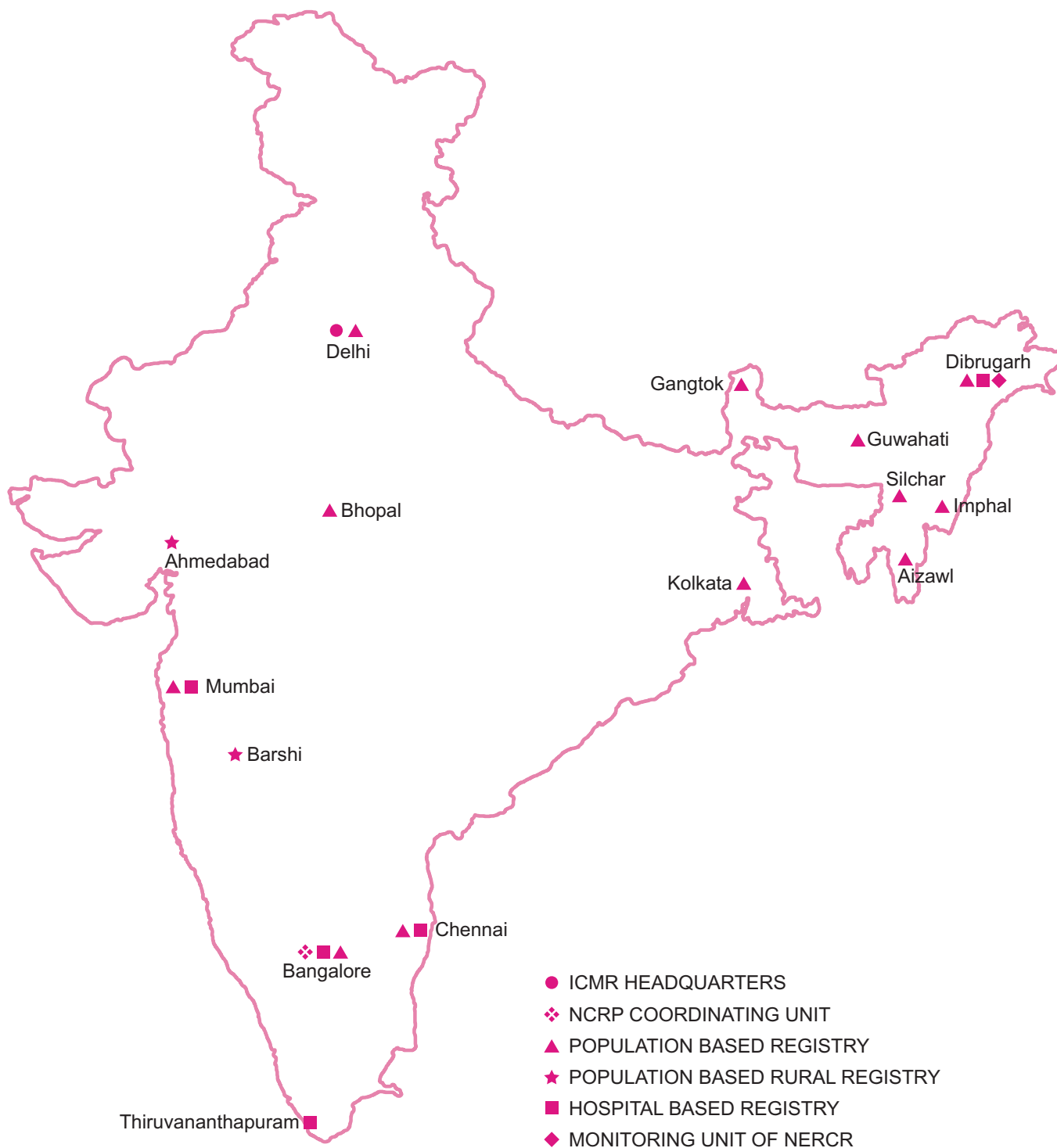
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# NATIONAL CANCER REGISTRY PROGRAMME

(Indian Council of Medical Research)



# National Cancer Registry Programme

The Indian Council of Medical Research initiated the National Cancer Registry Programme (NCRP) in 1981 and commenced a network of cancer registries across the country that started functioning from January 1982. Three hospital based cancer registries (HBCR) were commenced at Assam Medical College, Dibrugarh; Regional Cancer Centre, Trivandrum; and Post Graduate Institute of Medical Education and Research, Chandigarh. In order to extend the assessment of cancer patient care, HBCRs were also started in 1984 at Kidwai Memorial Institute of Oncology, Bangalore; Cancer Institute (WIA), Chennai and Tata Memorial Hospital, Mumbai.

More recently, the HBCRs have embarked on 'Patterns of Cancer Patient Care and Survival Studies' in cancer cervix, cancer breast and head and neck cancers. Several other institutions not in the NCRP network are also collaborating in this multi-centric project. A common agreed patient information form has been developed for each of the sites, incorporating among other things, details of clinical stage, different aspects of types of treatment and meticulous recording of follow-up information. A manual for completing the forms has also been developed.

Data collection also commenced from 1 January 1982 in the population based cancer registries (PBCRs) at Bangalore, Chennai and Mumbai. From 1986 two more urban population based cancer registries were started in Delhi and Bhopal. For the first time a population based rural cancer registry was also started by the ICMR during the subsequent year (1987) in Barshi in the state of Maharashtra. PBCRs to cover the population of Ahmedabad rural district and Kolkata Municipal Corporation have started functioning from 1 January 2004 and 1 January 2005 respectively.

Under the auspices of the World Health Organization a project on "Development of an Atlas of Cancer in India" was commenced in 2001. The two-year report for 2001 and 2002 provided many interesting findings. As a fall out of this a North-Eastern Regional Cancer Registry (NERCR) has been commenced in six areas at Guwahati, Dibrugarh and Silchar in Assam, Aizawl in Mizoram, Imphal in Manipur and Gangtok in Sikkim. These registries have started collation of information on cancer cases from 1 January 2003. A project on developing a cancer atlas especially for the North East states (specifically to include the other four states of Arunachal Pradesh, Meghalaya, Nagaland, Tripura and other areas of Assam not included under the NERCR) has also been initiated. Role of tobacco and pesticides in the occurrence of cancer in these areas is also being investigated.

The NCRP is a long-term activity of the Indian Council of Medical Research. The programme is one of the many major activities of the Division of Non-Communicable Diseases and an Officer-in-charge coordinates it. The Programme is assisted by Steering and Monitoring Committees to help oversee and guide its functioning. A workshop followed by a review meeting is held annually. The Principal Investigators and staff of the registries present data and participate in the discussions. In recent years representatives of other functioning PBCRs that are not in the NCRP Network also participate. Over the years, the National Cancer Registry Programme (NCRP) of the ICMR has laid a strong foundation to build on for cancer research. The entire activity of the NCRP and the projects under it are directed, monitored and executed (including conduct of workshops and coordination of the Annual Review Meetings and workshops) by the Coordinating Unit of the NCRP located at Bangalore.

The NCRP is gradually fulfilling many of the objectives with which it was commenced. These include:

1. Generation of reliable data on the magnitude and patterns of cancer - this would be based on morbidity

and mortality information in different regions of the country according to sex, age and residence of the patient, anatomical site of cancer and proportion of histological type or microscopic confirmation for each site; pattern of different types of cancer according to relative proportions or ratios in various population sub-groups such as religion, language spoken, educational status; clinical stage of disease when patients come to hospital for treatment and where possible the nature of treatment received and outcome;

2. Undertaking epidemiologic research, such as case control or cohort studies based on observations of registry data;
3. Providing data base for developing appropriate strategies to aid in National Cancer Control Programme;
4. Developing human resource in cancer registration and epidemiology.

Cancer registration in India is active. Staff of registries visit hospitals on routine basis and scrutinise the records in various departments that include pathology, radiology, radiotherapy, in-patient wards and out-patient clinics to elicit the desired information on reported cancer cases in a "core proforma" that has been standardised for all cancer registries in India. The hospitals include the main cancer hospitals, other general hospitals in both the government and private sector. Besides pathology laboratories that routinely report cancer cases are also visited. Death certificates are also scrutinised from the municipal corporation units. Every attempt is made by registries to register all cancer patients in the registration area who are resident (at least one year) in the area in all hospitals and copy all death certificates in which cancer is mentioned.

Certain basic checks of data especially those related to duplicate verification and matching with mortality records are carried out by the individual registries. After this, the data is sent to the Coordinating Unit for subjecting the data to various range, consistency and unlikely combinations including a further round of possible duplicate listing. The list of cases with the items of patient information, that require verification are sent to the respective registries by the Coordinating Unit. Individual registries go through the records/reports of such cases and wherever necessary discuss with the concerned clinician or the pathologist. On receiving the clarifications the Coordinating Unit prepares the detailed tabulations by five-year age group, site and sex including rates. The individual registries use these tables to prepare the registry's annual report. The Coordinating Unit collates the data and tables to prepare the consolidated report of that year.

During the annual workshop, the various aspects of working of the registry, problematic cases, use of coding and discussion on medical terminology, statistical and epidemiologic methods are discussed. About 2-3 senior and junior staff from each registry, participate in the workshop.

Apart from the above the Coordinating Unit undertakes and coordinates epidemiologic and other research studies including those to ensure that the quality of data is of a high standard and that coverage of cancer cases in the registry area is as complete as possible. More recently an on-line check programme has been developed. This will enable individual registries to conduct quality checks of their data on the web-site.

Over the years, staff from registries under the NCRP, have benefited from both short and long term training fellowships in established institutions abroad. This has helped them and the registries to develop into departments of epidemiology and undertake several studies on their own and contribute to several research publications in indexed journals.

# Two-year Report of the Hospital Based Cancer Registries: 1999-2000

*An Assessment of the Burden and Care of Cancer Patients*

## INTRODUCTION AND SUMMARY OF THE REPORT

**Objectives of Hospital Based Cancer Registries (HBCRs) (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 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 agreed common core proforma. The information in this form mainly consists of patient identifying information, demographic facts, details of diagnosis including method of diagnosis, the clinical stage of the disease and the broad type of treatment instituted. Attempts are made to collect particulars of follow-up as well but this has been difficult and in the absence of follow-up of the majority of cases registered by the HBCR, obtaining stage and treatment based survival has not been possible.

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 are carried out. Once data is finalized in correspondence with the individual registries, annexure tables are generated and reports prepared.

The two year (1999-2000) 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 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.

### Checks on Data

Several range, consistency and duplicate checks are carried out at the Coordinating Unit. These include all the checks based on the IARC publication (Parkin et al, 1994) on 'Comparability and Quality Control in Cancer Registration'. Some checks on certain additional items of patient information including those concerning clinical stage and treatment are also done. Detailed guidelines of each of the items in the core form and related aspects are covered in the coding manual specifically for HBCRs. Registry staff follow these guidelines while completing the core form and checks of data are entirely based on these guidelines.

The summary of checks that were carried out include:

1. **Range checks:** By this is meant that the numeric codes provided should be valid and be in conformity with the key to the codes (for example the code for sex should only be 1 or 2 and not any other number or character).
2. **Consistency checks:** By this is meant, that, while relating the codes of two variables there should be a meaningful or possible logical relationship. For example a patient with a code for prostate cancer can have a code only for male and cannot have the code for female. Similarly, the date of diagnosis should precede the date of commencement of treatment and cannot come after that.
3. **Duplicate checks** based on registration number, name, age, sex and ICD-10 are also carried out.

### ICD-9 vs ICD-10

The tabulations in this report are according to the International Classification of Disease and Related Health Problems, 10th Revision (ICD-10), whereas the previous reports were based on ICD-9. This may be kept in mind while comparing the data of individual sites with the previous reports as some minor differences could be due to this changeover.

The broad purpose of this Two Year (1999-2000) report of the HBCRs is to look into some of their functions outlined above. 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 PBCR of the area. HBCRs have also conducted several case control studies. However, in terms of assessing patient care - for various reasons, follow-up in a routine way has been difficult under Indian conditions. Therefore, the NCRP through the HBCRs has commenced a study on patterns of care and survival in cancer of the breast, cervix and head & neck cancers, so that greater focussed attention could be paid to clinical aspects and management.

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. 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 of 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.

Chapters 8-14 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.

Chapter 15 deals with the relative proportions of histological types of cancer for certain specific sites.

Chapter 16 summarises the relative proportion of cases according to educational status, religion and language spoken.

# HOSPITAL BASED CANCER REGISTRY

## Tata Memorial Hospital, Mumbai

**Dr. K. A. Dinshaw**, D.M.R.T. (Lond), F.R.C.R. (Lond),: Director & Principal Investigator

**Mr. D. N. Rao**, M.Sc., Co-Investigator, Head, Division of Epidemiology & Biostatistics

**Dr. B. Ganesh**, Epidemiologist, Division of Epidemiology & Biostatistics

### INTRODUCTION

The Tata Memorial Centre (TMC) comprises Tata Memorial Hospital (TMH) and ACTREC (Advanced Centre for Treatment Research and Education in Cancer). The Cancer Research Institute (CRI) has now become the basic research wing of ACTREC. This Centre is a grant-in-aid institution under the administrative control of the Department of Atomic Energy, Government of India. The main activities of the centre is diagnosis, treatment and research in cancer as well as training and education to provide the highest standard of patient care.

This report briefly outlines the hospital facilities available for patient care and working of the Hospital Based Cancer Registry during the period 1999-2000.

### TATA MEMORIAL HOSPITAL

The TMH is a comprehensive Cancer Centre with the state of art equipments for diagnosis and treatment and patients from different states in India and abroad attend this hospital. On an average 1000 patients attend this hospital every day. The hospital had 440 in patient beds available for patient care.

The hospital consists of Departments of Surgical Oncology, Medical Oncology, Radiation Oncology, Radio-diagnosis, Pathology, Cytology, Biochemistry and Laboratory Medicine. The Department of Radio-diagnosis is equipped with the latest equipments like CAT Scan, MRI, X-ray machines (1000 mA, 500 mA,), Mammography, Orthopantograph X-ray and Ultrasonography machines for the diagnosis of cancer. The supportive care facilities for cancer patients like Physiotherapy, Ostomy Clinic, Occupational Therapy and Transfusion Medicine are also available. Over 500 patients attend the hospital for radiation treatment on a daily basis.

The hospital initiated the Bone Marrow Transplantation (BMT) programme in 1982 and 23 patients underwent BMT in the year 2000.

The Department of Microbiology has been actively involved in setting up a dedicated system for handling the hospital's infectious waste system. A surveillance system is being set up to monitor post-operative wound infections and also control of infections in the Intensive Care Unit (ICU).

The Department of Preventive Oncology conducts lectures and audiovisual presentations educating

children on the ill effects of tobacco at 28 schools and colleges. The department also arranges poster exhibitions, lectures, workshops etc. on the ill effects of tobacco and Cancer Awareness programmes at 19 different locations for students as well as for general public.

The First Rural Outreach programme for early diagnosis and treatment started by the Centre at Barshi is continued by the Nargis Dutt Memorial Cancer Hospital (Aswini Cancer Research and Relief Society), Barshi with the support of the TMC.

The Clinical Research Secretariat (CRS) which was started in 1997 assists clinical researchers in data management, data analysis and other aspects of research projects. The CRS has offered infra-structural facilities for conducting randomised trials, and prospective clinical research studies.

A Department of Atomic Energy Clinical Trials Centre (DAE CTC) has been established at TMH to initiate clinicians in the concept of scientific and evidence based medicine and also to address burning medical and epidemiological questions essential in this part of the world.

The TMH Tissue Bank - the largest tissue bank in India supplies safe and reliable tissue for human transplantation and it is only one of its kind in processing and distributing multiple types of tissues. Over 900 allografts were produced and utilised so far.

The department of Rehabilitation Services established the Rehabilitation Research Centre (RRC), at the Dr. Earnest Borges Home, Bandra in the year 1998. It offered all types of prosthesis and orthosis and activities of daily living devices specially designed for cancer patients.

The hospital has been actively involved in implementing an "integrated & on-line" Information System for (i) Patient Administration comprising of OPD Registration, Appointments, Follow-up, Admission-Discharge-Transfer System for in-patients, Billing and Receipt system, etc (ii) Inventory Control System for Purchase, Stores, and Dispensary. This software makes use of Visual Basic as a GUI based front-end & DB2/400 on AS/400 as the back-end database.

Specialised software such as DIS (Diagnostic Information System) RIS (Radiological Information System) were incorporated in the Hospital Information System (HIS) and most of the diagnostic reports were available for on line retrieval.

Telemedicine and telepathology have provided an opportunity for TMH to get connected with international and national centres like Guwahati in the north east and rural cancer centres in the interior of Maharashtra at Barshi and Chiplun along the west coast. This would allow exchange of thoughts, distance bearing, transfer of technology and meaningful collaboration between individual clinicians.

A Touch-Screen facility was set up in the hospital which was inaugurated by Dr. R Chidambaram. It provides information about the hospital, on cancer, on prevention and other related information etc. It was estimated that in the first 5 months about 80,000 visitors have utilized this facility.

TMH is a post-graduate teaching centre, affiliated to the University of Mumbai, National Board of Examinations, New Delhi and Maharashtra University of Health Sciences, Nasik. The Post-graduates courses (M.D.) in Pathology, Radiodiagnosis, Radiotherapy, Anaesthesia (DA), (DMRD) Radiodiagnosis, and (DMRT) Radiotherapy are available and over 50 students were registered during the year 1999-2000.

The Tata Memorial Centre is a recognised training centre by national and international organisations such as WHO, UICC and IAEA. WHO/IAEA Fellows are provided training in various fields. In an ongoing program on Continuing Education in Oncology, trainees are registered for courses such as (i) Oncology Training Program for Doctors (ii) G.I. Endoscopy (iii) Medical Oncology/Clinical Oncology (iv) Radiotherapy & Radiodiagnosis Training Course (v) Oncology Nursing Training Course (vi) Diagnostic Cytology Training Course (vii) Certificate Course in Enterostomal Therapy and (viii) Apprenticeship in Pathology Department.

Observers from all over India, SAARC countries and other parts of the world visit the institution to update their knowledge and share their experiences.

Recognition from University of Mumbai was received for the conduct of MD in Immunoheamatology and Blood Transfusion.

## **CANCER REGISTRY**

Cancer Registry maintains cancer related information such as site of disease, histological classification, clinical extent of disease and primary treatment since 1941. Over 1,100 patients were diagnosed as cancer cases in 1941, since then there has been increase in patients attendance and at present over 25,000 new patients get registered and over 15,000 patients are diagnosed as cancer annually.

The Population Based Cancer Registry (PBCR) for Greater Bombay was started in the year 1964 and TMH Cancer Registry has been the important source for getting information on resident cancer cases. As TMH is a well recognized institution, patients from other states of India and abroad attend for expert medical care and opinion. Thus this HBCR has become an important source to identify resident cancer cases of PBCR's like Bhopal, Delhi, Chennai and Barshi in NCRP network.

The Cancer Registry operations were computerised in 1985. The new computer was installed and commissioned IBM AS/400 Server, which makes use of OS/400 as operating system, DB2/400 as the RDBMS. This server is based on Client Server architecture and has replaced old ND 550 system (NORSK DATA). The Software is Visual Basic front-end tool and DB2/400 as a back-end database available on AS/400 and is planned to be 'On - Line' system.

The standard international code such as International Classification of Disease for Oncology (ICD-0-ii, ICD-III, ICD-9, TNM (WHO) are used to classify the disease (topography & morphology), clinical extent of disease etc. and codes for demographic variables are also being used. The registry has started using ICD10 for 1999 & 2000 cancer cases. As cancer is not a notifiable disease, information about patient's health status is obtained through active follow-up of patients mostly by postal inquiry.

The Cancer Registry brings out comprehensive annual reports on cancer statistics covering various aspects of cancer management and care. End Results Reports on head & neck cancer and breast cancer are published periodically. Epidemiological studies and case-control studies are carried out to identify high risk and associated factors for common cancers like head & neck, oesophagus and breast cancers and the results are published in Indian and International Journals.

Staff from other hospitals are given training in cancer registry techniques and over 20 personnel have been given training so far. Cancer Registry staff also attend various workshops on cancer registry operations and are trained well in various aspect of cancer registration.

# HOSPITAL BASED CANCER REGISTRY

## Kidwai Memorial Institute of Oncology, Bangalore

**Dr. Bapsy Padmanabhan**, Principal Investigator & Director

**Dr. P.S.Prabhakaran**, Former Principal Investigator & Director

**Dr. K.Ramachandra Reddy**, Co-principal Investigator & Prof. & Head

**Dr. C.Ramesh**, Associate Prof.

**Mr. K.Mani**, Lecturer

Department of Epidemiology and Biostatistics

Kidwai Memorial Institute of Oncology (KMIO) is a Comprehensive and Regional Centre for Cancer Research and Treatment in Karnataka. The Institute has all the state of art facilities for the 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 and a radiology department has achieved a bed strength of 429 apart from the Dharmashala, a unique project of its kind in the country which provides accommodation to about 250 ambulatory patients with 250 of their attendants. These patients and attendants at the Dharmashala are provided with free food through perpetual free feeding endowment donation scheme.

As community outreach programme, the mobile cancer education and detection unit (Department of Community Oncology) organizes cancer detection and education camps in rural, semi urban areas of Karnataka and in the neighbouring areas of other states with support from voluntary organizations. KMIO as an apex body for the 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 of oncology. KMIO is running super speciality courses in M.Ch (Surgical Oncology) and DM (Medical Oncology), Post-graduate courses in MD Radiotherapy, Nuclear Medicine and Radiation Physics apart from Undergraduate courses in B.Sc. Medical Technology (Laboratory / Radiotherapy / Radio Diagnosis). These courses are affiliated to Rajiv Gandhi University of Health Sciences.

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

The KMIO is a well equipped Comprehensive Cancer Centre consisting of the departments of Surgical Oncology (General, Head & Neck, Oral, Gynaecologic), Radiotherapy, Medical Oncology, Paediatrics, Radiodiagnosis, Pathology, Biochemistry, Blood transfusion & Immuno Haematology, Microbiology,



Cytogenetics, Nuclear Medicine, Radiation Physics, Anaesthetics & Pain relief, Epidemiology & Biostatistics, Community Oncology, Social Welfare & Public relations, Library and information centre, Administration & supportive care facilities for cancer patients like Physiotherapy, Ostomy clinic, Occupational therapy, are also available.

KMIO being a referral cancer centre, about 70% of the patients are referred by various medical institutions and private practitioners. The Institute has established two Peripheral Cancer Centres at Mandya & Gulbarga with a main intention of reducing the distance of travel of cancer patients from far places to KMIO and to provide cancer treatment facilities at the nearest places as far as possible so that, it also reduces the load on KMIO. During the period 1999-2000 a total number of 24211 new patients were registered of which 14,498 cases were confirmed to have cancer. About 18% of the patients registered annually are from the adjacent states. On an average about 50 new cases are registered every day and 650 follow-up patients come for regular treatment. The Institute offers all modalities of cancer directed treatment - Surgery, RT, CT, Hormone therapy and Pain Relief through a multi-disciplinary team approach.

Of the total number of confirmed cancers of 14498, the proportion of cancers in females were higher and accounted for 56% (8065 cases) of the total cancers compared to 44% (6433 cases) in males.

Among males, cancer of the pharynx (ICD - CO9, C10, C12, C13 & C14) is continued to be the first predominant site of cancer (14%) followed by oral cavity (COO-CO6) (12%), oesophagus(9.4%), stomach (7%) and lung (6.9%). Among females, cancer of the cervix is the most common cancer with 32% of the total female cancer followed by breast(14.5%), oral cavity(12%), oesophagus(5.9%) and ovary (4.5%). Tobacco related cancer sites accounted for 46.5% of the total cancers in males and 22.1% in females. Together in both sexes, the tobacco related cancer sites accounted for 33% of the total cancers.

Paediatric (0-14 years) cancers formed about 4.5% of the total cancers with a slight prepondence in boys (6.02%) compared to girls (3.24%). Leukaemias and Lymphomas were the commonest sites of cancers in paediatric age-group.

#### **Other staff of Hospital Based Cancer Registry of the Dept. of Epidemiology & Biostatistics**

Mr. D.J.Jayaram	:	Sr. Investigator / Scientific Assistant
Mr. C. Shivanna	:	Asst. Social Scientist (On deputation to Community Oncology)
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 Community Oncology)
Mr. A. Subramani	:	Coding Clerk
Mrs. A.K.Jyothi	:	Stenographer
Mr. B.M.Gangaiah	:	Data Entry Operator
Mr. Mahadevaiah	:	Literate Attender



# HOSPITAL BASED CANCER REGISTRY

## Cancer Institute (WIA), Adyar, Chennai

**Dr. V. Shanta**, Principal Investigator, HBCR & Executive Chairman, Cancer Institute (WIA)

**Dr. R. Swaminathan**, Co-Investigator, HBCR & Senior Bio-Statistician,  
Division of Epidemiology & Cancer Registry

**Mrs. R. Rama**, Statistical Assistant, Division of Epidemiology & Cancer Registry

The Cancer Institute (W.I.A.), in Chennai, is the first comprehensive cancer care centre to be established in South India and the second in India. It is recognized as a Regional Cancer Centre by the Ministry of Health & Family Welfare, Government of India with state of the art facilities for cancer diagnosis, treatment and research. It is an autonomous non-profit institution with a bed strength of 423; more than 50% of the patients are boarded, lodged and treated at free of cost. The institute is primarily research oriented and is recognized by the University of Madras, Anna University and The Tamil Nadu Dr. M.G.R. Medical University for doctoral and super speciality degrees. The proportion (%) of patients attending the Institute from southern states of India : Tamil Nadu-68%, Andhra Pradesh-26% and Kerala-2%. Over 240 patients (new patients and follow-up cases) are seen at the Institute per day and these figures are increasing over the years. The three leading site of cancers among males are Oral Cavity (UICC), Oropharynx(UICC) and Oesophagus. In females Cervix, Breast and Oral Cavity (UICC) are the leading sites. In paediatric age group, all Leukemias and all Lymphomas are the predominant cancers.

The Hospital Based Cancer Registry has been functioning since the inception of the Institute in 1955. Data collection on the lines of ICMR started on 1st January 1984. All new cases attending the Institute are interviewed during registration and the required data are abstracted from the records using a standard proforma. The coded proforma are then scrutinized by the Medical Officer and Statistician. Data are then computerized. The validity and consistency checks for unlikely combinations of age, sex, site and morphology and other factors are carried out using in-house computer programs. In addition to these the IARC quality control programs are also used to validate the data. The cleaned data are then sent to the ICMR coordinating unit. Exercises on re-abstraction and coding on a random sample of cases are done regularly and presented in national level registry meetings.

Lifetime follow up of the cancer cases is generally felt difficult in India. With great efforts, we have evolved methods to overcome the problems in the follow up of cases treated at the Institute. An address

form consisting of a minimum of seven addresses of patients and their relatives / friends / referring physician is maintained to help in follow up. Reply paid cards are sent to all patients who do not report for check up on the due date. House visits / telephone enquiries are made by the field investigators to find out the vital status of the treated patients who had given a contact address in Chennai and its neighborhood. If there is no response from any of the addresses given by the patients from outside Chennai, letters are written to the Village Headman, referring doctors, President / Secretary of local service organization like the Lion, Rotary etc. for tracing the patient. The help of the cured patients from the area, who are currently on regular follow up is also sought for this purpose. We also provide concession for travel by bus, rail and air to the patient coming for treatment / follow up and an accompanying person. The completeness of follow up at three years from diagnosis is more than 80%.

Reports on the activities of hospital cancer registry are published regularly on annual / biennial basis. We have been organizing workshops on "Techniques for early detection of cancer" for the medical officers in Tamilnadu. This is one registry that has provided long-term cancer survival rates and trends for selected cancers over the period spanning four decades from 1958-1977. We had conducted cases control studies to determine the risk factors of several cancers, cohort studies on cancer patients for occurrence of second cancers and survival studies to elicit the prognostic factors. The results of these studies have been published in reports and international journals. The registry is actively involved in the Clinical trials being carried out at the institute in the form of sample size estimation, randomization of cases and rendering assistance in the analysis.

# HOSPITAL BASED CANCER REGISTRY

## Regional Cancer Centre, Thiruvananthapuram

**Dr. B.Rajan**, Principal Investigator & Director (From December 2003)

**Dr. M. Krishnan Nair**, Principal Investigator (Till November 2003)

**Dr. Aleyamma Mathew**, Associate Professor of Epidemiology & Clinical Research

### REGIONAL CANCER CENTRE

Regional Cancer Centre, Thiruvananthapuram, continues to keep high standards in patient management, research, teaching, training and development activities. The Centre caters to patients from all over the state of Kerala, from the neighboring states of Tamil Nadu and Karnataka and also from neighboring countries. The Centre has in-patient beds strength of 420.

Annually more than 10,000 new patients, with 95,000 follow-up visits and more than 2,00,000 non cancer patients report to the centre for various investigations and treatment. During the last five years, there has been 25% increase in the registration of both cancer and non cancer cases. The Centre conducts cancer control programmes covering the entire state by way of cancer awareness classes, screening camps and other public and professional educations programmes.

### Hospital Based Cancer Registry

The Hospital-Based Cancer Registry (HBCR), at the Regional Cancer Centre(RCC) Thiruvananthapuram provided the data of cancer patients reporting to the RCC, Thiruvananthapuram for the year 1999 and 2000.

The registry data entry is made online using an in-house web based software "rccintranet.org". The demographic details are collected by the social investigators and entered into the computer at the time of new patient registration and transferred to the NCRP core-proforma. The data transfer avoids the manual documentation of the first part (demographic details) of the NCRP core-proforma. The second part (diagnostic, treatment and follow-up details) is entered using the above web based software after retrieving case-sheets from the medical records division.

The HBCR maintains a follow-up system for all cancer patients. Generally all follow-up visits are through prior appointments. In-house software has been developed for appointment scheduling of patients.

Date and disease status for each follow-up visit are entered regularly.

The topography and morphology of various cancers are coded using the third edition of International Classification of Diseases for Oncology (ICD-O-3) and the International Classification of Diseases (ICD-10).

To ensure whether valid codes are entered, a series of range check as well as consistency checks and duplicates verification are done using in-house software. After necessary editing, the data are sent to the coordinating unit of national cancer registry programme in an electronic format for further checking on various range, consistency, unlikely combinations and duplicates. Necessary corrections are done based on the error list of cases sent by the coordinating unit and reports generated. The registry records around 8000 cancer cases annually.

On-line computerization of cancer registration has helped to improve the timely submission and quality of data and facilitate the access and application of data. Further, the medical documentation of case records in electronic form by the HBCR staff has helped clinicians and other researchers to obtain the necessary information. The two population based registries located in Thiruvananthapuram and Karunagappally have largely utilized the HBCR data.

The personnel of the registry are actively conducting several epidemiologic and clinical research programmes, which have helped to bring extramurally funded research programmes and publication of a number of scientific papers in peer-reviewed journals.

The official newsletter of the National Cancer Registry Programme of India, 'CRAB' has been published by the HBCR, Thiruvananthapuram.

#### **Other staff of Hospital Based Cancer Registry, Thiruvananthapuram**

Ms. Padmakumari G.	:	Lecturer in Statistics
Ms. Anitha Nayar	:	Social Investigator Gr. I
Ms. Jalaja Kumari V	:	Clerk Gr. I
Ms. Asha N.M	:	Clerk

# HOSPITAL BASED CANCER REGISTRY

## Assam Medical College, Dibrugarh

**Dr T.R. Borbora**, Principal Investigator

**Dr. (Mrs) N. Choudhury**, Principal Investigator (upto 30.9.2004)

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**Dr. (Ms). R. Akhtar**, Research Officer

Hospital Based Cancer Registry, Dibrugarh which had commenced in February, 1982 as a sequel to the recommendation of the NCRP Task Force of the ICMR has completed this year, its 22 successful years.

A systematic method for case finding, abstracting and processing are key to a successful registry programme. In a cancer hospital these can be achieved without much effort, but in a general hospital set-up achieving these objectives is a Herculean task. There are 23 OPD clinics and cancer patients may attend any clinic on any day depending on the signs and symptoms. The registry workers visit these clinics as per a prepared roster based on the patient and the information flow of certain clinics like ENT, OBG, Surgery, Medicine etc. Cancer patients attending other clinics are identified by scrutinizing the OPD cards retrieved from the central OPD counter and are noted down for subsequent matching with the admitted cases.

The central OPD counter preserves the OPD cards received from different OPD clinics at the end of the day. The Medical Records Department (MRD) of the hospital stores the records of only inpatients in a folder. The case files are not stored systematically according to MRD No. or wards. Identification and retrieval of a cancer case from a heap of files of all types of inpatients pose difficult problems. To ease the problems arrangements have been made with the MRD to transfer the case files of cancer patients to the registry office which are then indexed and arranged systematically for smooth and prompt retrieval.

During 1989-1990 the number of new cancer patients recorded at HBCR, Dibrugarh were 2397, compared to only 1533 cases registered a decade later during 1999-2000. There has been 36% reduction in cancer registration during the decade, whereas there has been around 52% increase during that decade in RCC, Thiruvananthapuram. This only signifies the difference in patient and information flow between a general hospital and an RCC or specialized cancer hospital. Qualitatively also the information on method of diagnosis, extent of disease and treatment modalities may not conform to the state of the art followed by an RCC or a specialised cancer hospital. In a general hospital each clinician usually sees and treats patients separately.

A hospital cancer registry must undertake certain essential supplementary activities like follow-up, survival and evaluation of patient care for some specific cancer sites. But because of the inherent problems

like inadequate case numbers and lack of follow-up information for the sites under review, it was not possible to undertake these activities.

Dibrugarh registry is one of the participating Centres in the WHO sponsored national programme on 'Development of an Atlas of Cancer in India'. The cancer data for the years 2001 and 2002 have already been dispatched to the coordinating unit and 2003 data are being entered in the core proformae.

The registry has also been entrusted to run a project on PBCR for Dibrugarh district comprising an area of 3381 Sq. Km with a population of 1172056 as per 2001 census. The project was initiated in March, 2003 as a part of North East Regional Cancer Registry. The cancer incidence data for the year 2003 was presented at the ARM held at Cancer Institute, Chennai. The data for the year 2004 (upto September) are being processed for presentation in the next ARM. Efforts have been made to optimize the case-finding procedures by sustained liaisoning with all the health centres and diagnostic laboratories of the district. Three camps have been conducted in 2004 in different strategic parts of the district for mobilizing the public awareness on the aims and objectives of the ongoing project and early detection of the disease.

#### **Other staff of Hospital Based Cancer Registry, Dibrugarh**

Mrs. P. Dutta	:	Medical Record Officer
Mrs. S. Ahmed	:	Social Investigator
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Mr. K. Saikia	:	Clerk
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Mr. S. R. Nath	:	Clerk
Mrs. R. Begum	:	Clerk
Mrs. J. Sonowal	:	Coding Clerk
Mr. P. Deuri	:	Typist
Mr. P.P. Saikia	:	Computer Operator (PBCR)
Mr. R. Dutta	:	Investigator (PBCR)
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**NATIONAL  
CANCER REGISTRY  
PROGRAMME**

**Indian Council of Medical Research**